# Bone and Joint Decade Global Network Conference







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ORGANIZING COI	MMITTEE
Co-Chairs Nancy Lane, MD Stuart L. Weinstein, MD	Joshua J. Jacobs, MD Toby King, CAE Kenneth J. Koval, MD
Members Peter B. Ajluni, DO John P. Dormans, MD Tom W. Fullan Edward D. Harris, Jr., MD	Armin U. Kuder, Esquire J. Edward Puzas, PhD Barry S. Smith, MD Kimberly J. Templeton, MD Peggy Trossen Hillary Weldon

#### **WELCOME MESSAGES**



Dear Friends of the Bone & Joint Decade,

Next year we will reach the end of the Decade. Nevertheless, musculoskeletal disorders will continue to be important on global and national health and research agendas.

The 2009 Global Network Conference in Washington, DC, will set the background and the agenda for the future with a focus on strategy and research. It will lay the foundation for continuation of the Bone and Joint Decade programs, with special attention on those developed in individual regions and countries.

We should continue building musculoskeletal networks with an eye on the future. Sustaining such efforts through many decades to come is a crucial objective.

I thank the USBJD Network for all its support and for organizing this meeting, as well as all of you for coming to Washington.

Professor Lars Lidgren Chairman International Steering Committee The Bone and Joint Decade



Dear Delegates,

On behalf of the United States National Action Network of the International Bone and Joint Decade, we would like to extend to you a warm welcome to our Nation's Capital, Washington, DC.

It has been our privilege to serve as program chairs for this 2009 meeting of the National Action Networks.



The program's theme is *Awareness and Advocacy*. Washington, DC, provides an excellent venue for all attendees to have an advocacy experience — for our international guests, with their home country Embassy staffs and for U.S. participants, with members of Congress.

As the end of the Decade approaches, this 2009 meeting has also been organized to prepare the foundations for 2010 and beyond. We look forward to an exciting program showcasing the tremendous advances that have been achieved since the beginning of the Decade and the promises that are just beyond the horizon.

Welcome to Washington, DC, USA.

Nancy Lane, MD Conference Co-Chair Stuart L. Weinstein, MD Conference Co-Chair

#### HOST COMMITTEE

## 111th Members of Congress

Senator John Barrasso (R-Wyoming)

Senator Richard Burr (R-North Carolina)

Senator Bob Casey, Jr. (D- Pennsylvania)

Senator Tom Coburn (R-Oklahoma)

Senator Thad Cochran (R-Mississippi)

Senator Byron L. Dorgan (D-North Dakota)

Senator Charles E. Grassley (R-Iowa)

Senator Tim Johnson (D-South Dakota)

Senator John Kerry (D-Massachusetts)

Senator Barbara A. Mikulski (D-Maryland)

Senator Lisa Murkowski (R-Alaska)

Senator Patty Murray (D-Washington)

Senator Charles E. Schumer (D-New York)

Senator Jeanne Shaheen (D-New Hampshire)

Senator Roger Wicker (R-Mississippi)

Congressman Rodney Alexander (R-Louisiana)

Congressman Joe Baca (D-California)

Congressman Brian Baird (D-Washington)

Congresswoman Tammy Baldwin (D-Wisconsin)

Congresswoman Shelley Berkley (D-Nevada)

Congresswoman Judy Biggert (R-Illinois)

Congressman Robert Brady (D-Pennsylvania)

Congressman Bruce Braley (D-Iowa)

Congressman Michael C. Burgess, M.D. (R-Texas)

Congressman Anh Joseph Cao (R- Louisiana)

Congressman Michael Capuano (D-Massachusetts)

Congressman Russ Carnahan (D-Missouri)

Congresswoman Donna Christensen (D-Virgin Islands)

Congressman William Lacy Clay, Jr. (D-Missouri)

Congressman James E. Clyburn (D-South Carolina)

Congressman Howard Coble (R-North Carolina)

Congressman Gerald E. Connolly (D-Virginia)

Congressman John Conyers (D-Michigan)

Congressman Jerry F. Costello (D-Illinois) Congressman Elijah E. Cummings (D-Maryland)

Congresswoman Kathy Dahlkemper (D-Pennsylvania)

Congresswoman Diana DeGette (D-Colorado)

Congresswoman Rosa L. DeLauro (D-Connecticut)

Congressman John D. Dingell (D-Michigan)

Congressman Lloyd Doggett (D-Texas)

Congresswoman Anna G. Eshoo (D-California)

Congressman Eni F. H. Faleomavaega (D-American Samoa)

Congressman Chaka Fattah (D-Pennsylvania)

Congressman Bill Foster (D-Illinois)

Congresswoman Marcia L. Fudge (D-Ohio)

Congressman Robert W. Goodlatte (R-Virginia)

Congresswoman Kay Granger (R-Texas)

Congressman Gene Green (D-Texas)

Congressman Raúl M. Grijalva (D-Arizona)

Congressman Luis V. Gutierrez (D-Illinois)

Congressman Bob Inglis (R-South Carolina)

Congressman Walkter B. Jones (R-North Carolina)

Congresswoman Marcy Kaptur (D-Ohio)

Congressman Ron J. Kind (D-Wisconsin)

Congressman Tom Latham (R-Iowa)

Congressman Steve C. LaTourette (R-Ohio)

Congressman John Lewis (D-Georgia)

Congressman John Linder (R-Georgia)

Congressman Dave Loebsack (D-Iowa)

Congresswoman Carolyn B. Maloney (D-New York)

Congressman Kenny Marchant (R-Texas)

Congressman Eric J. Massa (D-New York)

Congresswoman Doris Matsui (D-California)

Congressman James A. McDermott (D-Washington)

Congressman Gregory Meeks (D-New York)

Congressman Brad Miller (D-North Carolina)

Congresswoman Candice Miller (R-California)

Congressman Jerrold Nadler (D-New York)

Congresswoman Eleanor Holmes Norton (D-District of Columbia)

Congressman Ed Pastor (D-Arizona)

Congressman Donald M. Payne (D-New Jersey)

Congressman Thomas E. Petri (R-Wisconsin)

Congressman Tom Price (R-Georgia)

Congressman Nick J. Rahall II (D-West Virginia)

Congressman David Phil Roe (R-Tennessee)

Congresswoman Lucille Roybal-Allard (D-California)

Congresswoman Linda Sanchez (D-California)

Congresswoman Loretta Sanchez (D-California)

Congressman Adam B. Schiff (D-California)

Congressman Aaron Schock (R-Illinois)

Congressman John M. Shimkus (R-Illinois)

Congresswoman Louise M. Slaughter (D-New York)

Congressman Fortney Pete Stark (D-California)

Congresswoman Ellen O. Tauscher (D-California)

Congressman Chris Van Hollen, Jr. (D-Maryland)

Congresswoman Maxine Waters (D-California)

Congressman Frank R. Wolf (R-Virginia)

#### **Diplomatic Community and International Health Organizations**

Sir Nigel Elton Sheinwald, Embassy of Britain The Honorable Michael Wilson, Embassy of Canada

His Excellency Väino Reinart, Embassy of Estonia

His Excellency Pekka Lintu, Embassy of Finland

His Excellency Pierre Vimont, Embassy of France

His Excellency Francisco Villagran de Leon, Embassy of Guatemala

His Excellency Bayney Ram Karran, Embassy of Guyana His Excellency Ferenc Somogyi, Embassy of the

Republic of Hungary His Excellency Hjalmar Hannesson, Embassy of Iceland

His Excellency Anthony Johnson, Embassy of Jamaica

His Excellency Audrius Bruzga, Embassy of the

Republic of Lithuania

His Excellency Arturo Sarukhan Casamitjana, Embassy of Mexico

Her Excellency Renée Jones-Bos, Embassy of the

Kingdom of The Netherlands

Her Excellency Hunaina Sultan Ahmed Al-Mughairy, Embassy of the Sultanate of Oman

His Excellency Roy Ferguson, Embassy of New Zealand His Excellency Willy C. Gaa, Embassy of the Philippines

His Excellency Robert Kupiecki, Embassy of Poland

His Excellency João de Vallera, Embassy of Portugal

His Excellency Roman Kirn, Embassy of Slovenia

His Excellency Welile Nhlapo, Embassy of the Republic of South Africa

His Excellency Jonas Hafström, Embassy of Sweden

His Excellency Habib Mansour, Embassy of Tunisia

His Excellency Nabi Sensoy, Embassy of the Republic of Turkey Dr. John P. Howe, Project HOPE

Susan Dentzer, Editor-in-Chief, Health Affairs

#### PATIENT ADVOCACY MEETING

## Wednesday, October 21 – JW Marriott Hotel

**BJD 2009 Patient Advocacy Meeting** 

Capitol Ballroom, Salon E

0800 Registration – Capitol Ballroom Foyer

0900 Welcome

Armin U. Kuder, Esquire

Member, International Steering Committee

Bone and Joint Decade

**Presentation of Themes and Practical Information** 

Amye Leong, BJD Patient Advocacy Leader & Director of Strategic

Relations

Sara Martin, BJD Communications Manager

Facilitators: Brian Tjugum and John Lotspeich

Directors, Weber Shandwick, London

1030 Break

## **How to Change Health Priorities**

• Who to contact

- Stating your case and follow-up
- When to lobby
- Coaching: Speaking about your cause to an elected official Best Practice Examples: Chris Bossley

NAN Coordinator, New Zealand

1230 Lunch – Salon D

## Mentoring & Learning by Example:

Amy Melnick, Arthritis Foundation, United States

Marios Kouloumas, PARE, Europe

Brief report:

- 1. Explanation of how the organization is structured
- 2. Discussion of how interaction with members is carried out
- 3. Update on the organization's current activities

1530 Break

1730 Close

1900 Patient Advocacy Meeting Reception and Dinner

Garden Terrace, JW Marriott Hotel

## Thursday, October 22, 2009

## **Advocacy Day on Capitol Hill**

See program below for Global Network Conference

Supported in part by grants from Novartis AG and UCB, S.A.

#### GLOBAL NETWORK CONFERENCE PROGRAM

## Thursday, October 22, 2009 - Advocacy Day on Capitol Hill

## 0715 Buses depart JW Marriott for Capitol Hill

#### 0800 Welcome Breakfast - Capitol Hill Visitors Center HVC-215

## 0830 Welcome and Briefing from Member(s) of Congress

Capitol Hill Visitors Center - HVC-215

- Congressman Dave Camp (R-MI)
- Congressman Charlie Melancon (D-LA)
- Congressman John Dingell (D-MI)

## 1000 Health Care: Opportunities and Challenges

Rear Admiral Susan Blumenthal, MD, Former Assistant Surgeon General of the United States, Director, Health and Medicine Program, Center for the Study of the Presidency and Congress, Clinical Professor, Georgetown School of Medicine

## 1200 Advocacy Day Luncheon

Russell Caucus Room, Russell Senate Office Building Keynote speakers:

- Senator Chuck Grassley (R-IA), Ranking Member, Finance Committee
- Senator John Barrasso (R-WY)
- Congressman Charles Rangel (D-NY)
   Chair, House Ways and Means Committee

## 1330 **Experts in Arthritis** - Gold Room 2168 – Rayburn House Office Building Keynote speaker:

Congresswoman Anna Eshoo (D-CA)

#### Panelists:

- David G. Borenstein, MD, FACP, FACR, United States
- Peter Brooks, MD, FRACP, FRCP Edin., FAFRM, FAFPHM, Australia
- John H. Klippel, MD, United States
- Amye Leong, MBA, France and United States
- Girish Mody, MBChB, MD, FRCP, FCP, South Africa
- Carol A. Oatis, PT, PhD, United States
- David S. Pisetsky, MD, PhD, United States
- Christy Sandborg, MD, United States

#### 1330-1730 Congressional visits – Embassy appointments

Visits and appointments as previously scheduled.

For delegates without pre-arranged visits or appointments, suggestions will be provided of places to visit on Capitol Hill and the National Mall.

## 1800 Buses depart JW Marriott for Canadian Embassy

#### 1830 Reception, Canadian Embassy

501 Pennsylvania Avenue, NW, Washington, DC Speakers:

- Colin Carrie, MP, Parliamentary Secretary for Health, Canada
- Lars Lidgren, MD, PhD, Chairman, International Steering Committee, Bone and Joint Decade, Sweden

Supported in part by a grant from Pfizer, Inc.

#### Friday, October 23 - JW Marriott Hotel

0730 – 0800 Briefing for Strategic Planning Specialty Group Leaders

State Room

0800 - 0830 BJD 2009 Global Network Conference

Capitol Ballroom

Welcome:

Lars Lidgren, MD, PhD Chairman, International Steering Committee Bone and Joint Decade Lund, Sweden

Conference Co-Chairs:

Nancy E. Lane, MD Professor of Medicine and Rheumatology Director, Center for Healthy Aging -Vice Chair for Research, Department of Medicine University of California at Davis Medical Center Sacramento, California

Stuart L. Weinstein, MD Ignacio V. Ponseti Chair Professor of Orthopaedic Surgery Department of Orthopaedic Surgery University of Iowa Hospital Iowa City, Iowa

0830 - 0845 The Urgency of Addressing the Burden of Musculoskeletal Disease

The major conditions, geographical differences, societal impact, projection of inaction

Anthony Woolf, MBBS, FRCP Professor, Duke of Cornwall Rheumatology Unit Royal Cornwall Hospital Truro, Cornwall, England

0845 Plenary Sessions on the Status of Musculoskeletal Conditions
Worldwide and Promising Opportunities That Will Reduce the
Impact

Each session will feature:

- Burden of disease impact and trend line
- Research, prevention and care management developments during the decade
- Opportunities

#### 0845 - 0930 Osteoarthritis

#### Session Chairs:

Linda J. Sandell, PhD

Professor and Director of Research Department of Orthopaedic Surgery

Professor, Department of Cell Biology and Physiology

Washington University School of Medicine

St. Louis, Missouri

Peter Brooks, MD, FRACP, FRCP *Edin,* FAFRM, FAFPHM Professor, Director, Australian Health Workforce Institute The University of Melborne/University of Queensland Australia

## Panelists: Joanne Jordan, MD, MPH

Associate Professor in the Division of Rheumatology Associate Professor of Orthopaedics, and Adjunct

Associate Professor of Epidemiology

University of North Carolina Chapel Hill, North Carolina

David Hunter, MD

Chief, Division of Research New England Baptist Hospital Boston, Massachusetts

Steven B. Abramson, MD Chair, Rheumatology

New York University Hospital for Joint Diseases

New York, New York

#### 0930 – 0945 **Break**

## 0945 – 1030 Inflammatory Conditions

#### Session Chair:

David S. Pisetsky, MD, PhD Rheumatology and Immunology

**Duke Medicine** 

Durham, North Carolina

#### **BJD International Steering Committee Liaison:**

Mieke Hazes, MD, PhD

Professor, Department of Rheumatology

Erasmus Medical Center (MC)

University Medical Center Rotterdam

The Netherlands

## Panelists: Clifton O. Bingham, III, MD

Assistant Professor of Medicine, Divisions of

Rheumatology and Allergy and Clinical Immunology Associate Director, The Johns Hopkins Arthritis Center

Johns Hopkins University Baltimore, Maryland

Michael Ward, MD, MPH Intramural Research Program National Institutes of Health Bethesda, Maryland

## 0945 Rare Bone Disease Patient Network Meeting

State Room

#### 1030 – 1115 **Back Pain**

#### **Session Chair:**

Gunnar B. J. Andersson, MD, PhD The Ronald L. DeWald, MD Professor and Chairman Emeritus Department of Orthopaedic Surgery Rush University Medical Center Chicago, Illinois

## **BJD International Steering Committee Liaison:**

Shoichi Kokubun, MD

Professor Emeritus, Tohoku University

Director, Research Center for Spine & Spinal Cord Disorders

NHO Nishitaga Hospital

Sendai, Japan

#### Panelists: Edward H. Yelin, MD

Professor of Medicine and Health Policy University of California, San Francisco

San Francisco, California

Scott Boden, MD

Director, The Emory Spine Center Professor, Orthopaedic Surgery Emory University School of Medicine

Atlanta, Georgia

Boyd R. Buser, DO, FACOFP Vice President and Dean

Pikeville College School of Osteopathic Medicine

Pikeville, Kentucky

## 1115 – 1200 **Bone Health and Osteoporosis**

#### **Session Chairs:**

Steven R. Goldring, MD

Chief Scientific Officer, Hospital for Special Surgery Professor of Medicine, Weill Cornell School of Medicine

New York, New York

Kristina Åkesson, MD, PhD

Professor of Clinical and Molecular Osteoporosis Research.

**Lund University** 

Department of Orthopaedic Surgery

Malmö University Hospital

Malmö, Sweden

## **BJD International Steering Committee Liaison:**

Ghassan Maalouf, MD Professor and Medical Director Bellevue Medical Center Beirut, Lebanon Panelists: Ethel S. Siris, MD

Madeline C. Stabile Professor of Clinical Medicine

Columbia University

Director of the Toni Stabile Osteoporosis Center

Columbia University Medical Center New York-Presbyterian/Columbia

New York, New York

Lawrence G. Raisz, MD

Board of Trustees Distinguished Professor of Medicine Emeritus, University of Connecticut Health Center Associate Director, New England Musculoskeletal Institute Farmington, Connecticut

Sundeep Khosla, MD

Dr. Francis Chucker and Nathan Landow Research Professor, Departments of Medicine and Physiology Department of Endocrinology

College of Medicine, Mayo Clinic

Rochester, Minnesota

Supported in part by a grant from The Alliance for Better Bone Health

## 1200 Young Investigator Poster Session

Capitol Ballroom Foyer

Introductory remarks from Robert H. Carter, MD, Deputy Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases

## 1215 Lunch – From the Battlefront to the Home Front

Grand Ballroom, Salon 1

#### **Keynote speakers:**

Real Admiral Thomas R. Cullison Deputy Surgeon General, Medical Corps and Vice Chief, Bureau of Medicine and Surgery U.S. Navy "Overview of the Military Medical Effort"

CPT Raymond O'Donnell, USA "Injury and Recovery: A Soldier's Experience"

Andrew N. Pollak, MD
Associate Professor and Head
Department of Orthopaedic Trauma
University of Maryland School of Medicine
Baltimore, Maryland
"How Advances in Treating Military Casualties Are
Leading to Advances in Treating Trauma in Civilian Life"

Supported in part by a grant from Smith & Nephew, Inc.

1330 – 1415 **Trauma** 

**Session Chair:** 

Bruce D. Browner, MD

Department of Orthopaedic Surgery

University of Connecticut School of Medicine

Farmington, Connecticut

**BJD International Steering Committee Liaison:** 

Marcos E. Musafir, MD Rio de Janeiro, Brazil

and World Health Organization, Geneva

Panelists: Adnan Hyder, MD, MPH, PhD

Associate Professor, International Health Deputy Director, Health Systems Program Director, International Injury Research Unit Johns Hopkins Berman Bioethics Institute

Baltimore, Maryland

Ambassador Al-Hinai United Nations New York, New York

Nancy Carter-Foster

Senior Advisor, Health Affairs U.S. Department of State

Washington, District of Columbia

1415 – 1430 Rehabilitation of Musculoskeletal Disorders – Social Integration and Engagement

**Speaker:** Kai-Ming Chan, MD

Professor, Department of Orthopaedics & Traumatology The Chinese University of Hong Kong, Prince of Wales Hospital

Hong Kong SAR, China

1430 – 1500 Patient Advocacy Success Story: Treatment of Clubfoot and the Ponseti International Association

**Speaker:** Jose Morcuende, MD

Associate Professor, Department of Orthopaedic Surgery

University of Iowa Iowa City, Iowa

1500 - 1515 **Break** 

1515 - 1600 **How Do We Advance the Health Policy Agenda for Musculoskeletal Conditions?** 

- Advancing public policy agenda
- Disparities in care
- Shared decision making

Speaker: James N. Weinstein, DO, MS

Director

The Dartmouth Institute for Health Policy and

Clinical Practice

Lebanon, New Hampshire

#### 1600 – 1730 Beyond the Decade Strategic Planning: Specialty Group Breakouts

## **Introductory Remarks**

Joseph D. Zuckerman, MD President, American Academy of Orthopaedic Surgeons

## **Beyond the Decade Strategic Planning**

Co-Chairs: Joshua J. Jacobs, MD and Jack H. Klippel, MD (Amy Melnick for Jack Klippel, MD)

#### Facilitators:

Brian Tjugum and John Lotspeich, Weber Shandwick, London

#### <u>Arthritis</u>

## **Group Leaders:**

Eric P. Gall, MD Chairman, Department of Medicine Rosalind Franklin University North Chicago, Illinois

Christy Sandborg, MD Professor and Chief, Pediatric Rheumatology Stanford University School of Medicine Lucile Salter Packard Children's Hospital Stanford, California

## **BJD International Steering Committee Liaison:**

Armin U. Kuder, Esquire Kuder, Smollar & Friedman, PC Washington, District of Columbia

#### **Bone Health and Osteoporosis**

#### **Group Leaders:**

Steven R. Goldring, MD Chief Scientific Officer, Hospital for Special Surgery Professor of Medicine, Weill Cornell School of Medicine New York, New York

Kristina Åkesson, MD, PhD

Professor of Clinical and Molecular Osteoporosis Research, Lund University Department of Orthopaedic Surgery, Malmö University Hospital Malmö. Sweden

#### **Presenters**

Ann L. Elderkin, PA Executive Director American Society for Bone and Mineral Research Washington, DC

Lawrence G. Raisz, MD Board of Trustees Distinguished Professor of Medicine Emeritus University of Connecticut Health Center Farmington, Connecticut Board of Directors, National Osteoporosis Foundation

Supported in part by a grant from Amgen, Inc.

#### Pediatric Musculoskeletal Diseases

## **Group Leaders:**

Paul Caskey, MD Chief of Staff Shriners Hospitals for Children Spokane, Washington

Paul W. Esposito, MD Professor, Orthopaedic Surgery, and Pediatrics University of Nebraska Medical Center Omaha, Nebraska

## **BJD International Steering Committee Liaisons:**

Peter Brooks, MD, FRACP, FRCP *Edin,* FAFRM, FAFPHM Professor, Director, Australian Health Workforce Institute The University of Melborne/University of Queensland Australia

Edward D. Harris Jr., MD George DeForest Barnett Professor of Medicine Stanford University School of Medicine Stanford, California

#### Research

#### **Group Leader:**

David B. Burr, PhD Professor and Chair, Department of Anatomy and Cell Biology Indiana University School of Medicine Indianapolis, Indiana

#### **BJD International Steering Committee Liaison:**

Mieke Hazes, MD, PhD Professor, Department of Rheumatology Erasmus Medical Center (MC) University Medical Center Rotterdam Rotterdam, The Netherlands

## Spinal Disorders and Low Back Pain

## **Group Leader:**

Sigurd Berven, MD Department of Orthopaedic Surgery University of California, San Francisco San Francisco, California

## **BJD International Steering Committee Liaison:**

Karsten Dreinhöfer, MD, PhD Medical Park, Le Charité Berlin, Germany

Nicolas E. Walsh, MD Professor, Department of Rehabilitation Medicine The University of Texas Health Science Center at San Antonio San Antonio, Texas

## **Trauma and Injury**

## **Group Leader:**

Andrew N. Pollak, MD
Associate Professor and Head
Department of Orthopaedic Trauma
University of Maryland School of Medicine
RA Cowley Shock Trauma Center
Baltimore, Maryland

## **BJD International Steering Committee Liaison:**

Wahid AlKharusi, MD, FRCS Ambassador, Foreign Ministry Muscat, Sultanate of Oman

Kenneth J. Koval, MD Professor Department of Orthopaedics Dartmouth Hitchcock Medical Center Lebanon, New Hampshire

## 1815 Buses depart JW Marriott for American Pharmacists Association

1900 **Reception** – American Pharmacists Association 2215 Constitution Avenue NW, Washington, DC

## **Research Directions and Opportunities for Collaboration**

Keynote speaker:

Stephen I. Katz, MD, PhD

Director

National Institute of Arthritis and Musculoskeletal and Skin Diseases National Institutes of Health

Supported in part by a grant from Eli Lilly and Company

## Saturday, October 24 – JW Marriott, Capitol Ballroom

0830 – 0850	Beyond the Decade: Advancing Musculoskeletal Health Lars Lidgren, MD, PhD, Hon. FRCS Chairman, International Steering Committee, Bone and Joint Decade Lund, Sweden
0850 – 0905	The Way Forward – Armin U. Kuder, Esquire
0905 – 0915	<b>Discussion</b> Moderators: Brian Tjugum & John Lotspeich, Weber Shandwick, London
0915 – 1045	Beyond the Decade: Strategic Planning Breakouts Developing a Global Roadmap for Advancing Musculoskeletal Health
1045 – 1100	Break
1100 – 1230	Beyond the Decade: Strategic Planning Breakouts by World Geographic Region  North America Latin America Europe Africa Middle East Asia Pacific
1230 - 1330	Lunch – Spotlight on Women's Health Care Salon 1  Jill Zarin, Cast, The Real Housewives of New York City Bravo TV, and arthritis advocate
1330 – 1400	Report back from Strategic Discussions
1430 – 1600	Bone and Joint Decade International Reports
1430 - 1445	Award Presentation
1445 – 1515	Invited Network Reports
1515 – 1530	Report on Embassy visits Professor Kristina Åkesson and Sara Martin
1530 – 1545	BJD Global Network Conference 2010 Professor Lars Lidgren
1545 – 1600	Closure Professor Lars Lidgren, MD, PhD Nancy Lane, MD, Stuart Weinstein, MD
1800	Dinner and Tour of Washington, DC

#### **Speaker Biographies**

## Steven Barry Abramson, MD

Dr. Abramson is Professor of Medicine and Pathology, Senior Vice President and Vice Dean for Education, Faculty and Academic Affairs at the NYU School of Medicine and the NYU Langone Medical Center. He is also Director of Rheumatology at the NYU School of Medicine and the NYU-Hospital for Joint Diseases. A graduate of Dartmouth College and Harvard Medical School, Dr. Abramson completed his residency at New York University Medical Center-Bellevue Hospital, where he went on to serve as a Chief Resident in Medicine, and a Fellow, and Chief Fellow, in the Division of Rheumatology.

Dr. Abramson has an international reputation in the area of arthritis, inflammation and drug treatments, with a recent focus on the role of inflammatory mediators produced by cartilage and synovial tissues. His laboratory is among five designated by the NIH to be part of the Osteoarthritis Biomarkers Network, on which Dr. Abramson serves on the Steering Committee. He has experience in both basic science and clinical research, and has published more than 200 papers on these and related topics. Moreover, he has been a leader in education, including both rheumatology and general medical education. He has served as NYU Vice Dean for Medical Education and is currently Vice Dean for Education, Faculty and Academic Affairs and Associate Dean for Clinical Research.

He is a co-editor of the journal Arthritis & Rheumatism, a former member of the Rheumatology Board of the American Board of Internal Medicine, President of the Osteoarthritis Research Society International, and is a consultant to, and former chairman of, the Arthritis Advisory Committee of the US Food and Drug Administration.

## Professor Kristina Åkesson, MD, PhD

Dr. Akesson is professor of Orthopedics at the Department of Orthopedics at Malmö University Hospital, Faculty of Medicine, Lund University, Sweden. She is a member of the Faculty board and currently chairing the appointment committee at the Faculty of Medicine. Prior appointments include faculty counselor of the clinical research post-graduate program, 2000-2006 and board member and vice-chair of the research education committee. She is a member of the Swedish Research Council review board in medicine and the Royal Physiographic Society.

Dr. Akesson graduated from Lund University, became a board certified orthopaedic surgeon and was awarded a PhD degree in medicine/orthopaedics from Lund University in 1995; a fellowship in bone metabolism research at Loma Linda University, California followed. Her clinical focus was initially joint replacement surgery, followed by osteoporosis and fragility fractures. She established the osteoporosis clinic at Malmö University Hospital. She is engaged in translational bone research to identify risk factors for osteoporosis and fracture in women.

Dr. Akesson is a founding member of the Bone and Joint Decade and member of the international steering committee, member of the International Osteoporosis Foundation committee of scientific advisors and chairing the working-group on fractures, member of the European Calcified Tissue Society Professional Practice Committee. She is cochair of the WHO Collaborating Center for Evidence-based Health Care in Musculoskeletal Disorders, Lund University, Department of Orthopedics and past board member of the Swedish Orthopedic Association. She has served as advisor to the Swedish Medical Product Agency and Board on Health and Welfare.

She is deputy member of the editorial board of Acta Orthopedica, member of European Orthopaedics and Traumatology and associate editor of BMC Geriatrics.

## **HE Ambassador Fuad Mubarak Al-Hinai**

HE Ambassador Al-Hinai was appointed by His Majesty, the Sultan of Oman as the Permanent Representative of the Sultanate of Oman to the United Nations in New York, with the rank of Ambassador Extraordinary and Plenipotentiary in August 1998. Concurrently, Ambassador Al-Hinai is Non Resident Ambassador to Colombia, Cuba and Venezuela. He also serves as the Honorary Chair of the 2nd UN Stakeholders Forum on Global Road Safety.

Before his present appointment, Ambassador Al-Hinai served since 1994 as Deputy Chief of the International Conferences and Organizations Department in Oman's Ministry of Foreign Affairs. He was Deputy Chief of the Ministry's Training Department (1992-1994). Ambassador Al-Hinai's diplomatic career includes appointments as Counselor and Charge d'Affaires at the Omani Embassy in Brunei, Darussalam from 1986 to 1992 and, from 1983 to 1984, as First Secretary at Oman's Permanent Mission to the United Nations in Geneva. From 1979 to 1982. Ambassador Al-Hinai served as First Secretary at the Oman Embassy in Cairo, Egypt.

## Wahid Ali Said AlKharusi, MD, FRCS

Until his appointment by Royal Decree as Ambassador at the Foreign Ministry of Oman and Special Advisor to the Minister of Foreign Affairs, Dr. AlKharusi was Head of Khuola Hospital in Muscat, Sultanate of Oman, President of Oman Sports Medicine and Secretary General in Asian Federation of Sports Medicine. His specialties are sports injuries and trauma. Educated in Jordan, the United Kingdom, Egypt, Germany and Switzerland, Dr. AlKharusi was the first trained and accredited Omani orthopaedic surgeon. Over the years he gradually developed orthopaedic, trauma and rehabilitation facilities in the Sultanate.

With the increasing number of casualties and deaths caused by road traffic Dr. AlKharusi took a special interest in road traffic safety. Along with other members of the Bone and Joint Decade, he advocated for the United Nations to pass five resolutions on Road Safety. He became a member of the UN Road Safety Collaboration chaired by the WHO and as the official representative from Oman. Dr. AlKharusi founded and chairs the National Association on Road Safety. He is also Secretary General of the National Association for Cancer Awareness.

#### Gunnar B. J. Andersson, MD, PhD

Dr. Andersson is the The Ronald L. DeWald, MD Professor and Chairman Emeritus of the Department of Orthopedic Surgery at Rush University Medical Center, Chicago, Illinois. Dr. Andersson was Chairman of the Department of Orthopedic Surgery from 1995 to 2008. During his tenure as Chairman he has also been the President of the Medical Staff, the Vice Dean for Surgical Sciences and Services and the Senior Vice President of Medical Affairs each for two year periods.

Dr. Andersson received his MD from the University of Göteborg, Sweden, did his residency at Sahlgren University Hospital and also obtained a PhD in medical science at the University of Göteborg in 1974. After a fellowship at the London Hospital he joined the faculty at the University of Göteborg for ten years. In 1985 he moved to the United States and Rush University Medical Center. His clinical area of interest is spine while his research interests are disc degeneration, epidemiology and occupational biomechanics.

Dr. Andersson is a past President of the Orthopaedic Research Society, the International Society for the Study of the Lumbar Spine and the American Academy of Disability Evaluating Physicians. He has been a council member of the National Institutes of Arthritis and Musculoskeletal and Skin Diseases at NIH, Chairman of the Research Committee at the American Academy of Orthopaedic Surgeons and a member of three Institute of Medicine committees.

He is a member of 15 editorial boards, a deputy editor for Spine, editor-in-chief of Contemporary Spine Surgery and an associate editor of Clinical Biomechanics. He is the author of over 250 original publications, over 150 books and book chapters and 430 abstracts.

## US Senator John Barrasso, MD (R-WY)

Senator John Barrasso was elected to the US Senate on November 4, 2008. Barrasso is known by many as Wyoming's Doctor. He has a long and recognized career in both medicine and public service.

Barrasso was first sworn in to the US Senate in June, 2007 having represented the people of Natrona County in the Wyoming State Senate for five years; he was appointed with the passing of Senator Craig Thomas. During 24 years as an orthopedic surgeon, he served as President of the Wyoming Medical Society and was named Wyoming Physician of the Year. He also served as medical director of the Wyoming Health Fairs, bringing low-cost health screening exams to people around the state.

Barrasso is known throughout Wyoming for his health messages. His public service announcements have been on TV, radio and in numerous newspapers for more than 20 years. Barrasso serves on the Energy and Natural Resources Committee, the Environment and Public Works Committee, the Indian Affairs Committee and the Senate Foreign Relations Committee.

He pioneered the "telephone town hall" which allows folks to discuss issues with him — without leaving their homes. Barrasso has also conducted more than 50 town meetings, met with thousands of constituents, and addressed hundreds of groups.

## Sigurd H. Berven, MD

Dr. Berven studied Human Biology as an undergraduate at Stanford University. He was a graduate student at University of Oxford, earning a degree in Philosophy, Politics, and Economics. He received his Doctorate in Medicine from Harvard Medical School, had further training in Pediatric Orthopaedic Surgery as Chief Resident at The Boston Children's Hospital, and graduated from the Harvard Combined Orthopaedic Residency program. After completion of his residency, he had further clinical training in spine surgery as a clinical fellow at the University of California-San Francisco (UCSF).

Dr. Berven has a strong clinical interest in pediatric and adult deformity, degenerative conditions of the spine, spinal tumors, and spinal trauma. His research in basic science includes studies of intervertebral disc regeneration and spinal cord injury. Other research interests include assessment of clinical outcomes in spinal surgery — notably assessments of perioperative care pathways — and he has worked closely with the hospitalists at UCSF in modifying

existing pathways and in contributing to resident education. He has established a database for pre-operative and post-operative general health status and disease-specific assessments for all patients undergoing spine surgery. He has studied access to healthcare in populations including Afghan refugees in Pakistan, NHS patients with osteoarthritis in the UK, and patients with degenerative spinal conditions in the US.

Dr. Berven is a frequent speaker at orthopaedic conferences and has published more than 60 articles in peer-reviewed orthopaedic journals. He has also coauthored chapters in several surgical textbooks on adult and pediatric spinal conditions and treatments.

Dr. Berven was honored to be chosen as a 2005 ABC (American, British, Canadian) Fellow of the American Orthopaedic Association. This prominent traveling fellowship in orthopaedics serves to identify future leaders of the specialty. The elite group of seven orthopaedic surgeons spent six weeks visiting hospitals throughout England and South Africa.

## Clifton O. Bingham III, MD

Dr. Bingham is an Assistant Professor of Medicine in the Divisions of Rheumatology and Allergy at the Johns Hopkins University, where he serves as the Director of Rheumatology Clinics and as Associate Director of the Johns Hopkins Arthritis Center. He received his MD from Columbia University, where he also completed his residency in Internal Medicine. He trained as a Fellow both in Rheumatology and in Allergy and Clinical Immunology at the Brigham and Women's Hospital in Boston, where he then served as attending Rheumatologist and Allergist/Immunologist at Brigham and Women's and at Massachusetts General Hospital. He was recruited to join the faculty at NYU Hospital for Joint Diseases in 1999 where he directed the rheumatology clinic at Bellevue Hospital Center. At NYU he founded and directed the Seligman Center for Advanced Therapeutics, a pioneering center which incorporated cutting edge clinical therapeutics with clinical trials and translational research in rheumatology. In 2005 he was recruited to join the faculty at Johns Hopkins University.

He has served as an investigator for clinical trials of multiple agents in early to late phases of development for rheumatoid arthritis and osteoarthritis. These have included lead investigator for the largest international study to date of a disease modifying drug for OA (KOSTAR), the NIHsponsored Glucosamine Arthritis Interventional Trial (GAIT), and lead investigator roles in more than 35 additional clinical trials for RA, OA, and other autoimmune diseases. He currently chairs working groups for the international Outcome Measures in Rheumatology Clinical Trials (OMERACT) group in developing a standardized definition of disease flares in RA, and in evaluating the efficacy and safety of intra-articular agents including gene therapy.

His current research program focuses on oral health in inflammatory arthritis, risk factors for OA progression, and defining clinical and biochemical disease phenotypes related to therapeutic responses in RA and OA. He was recently awarded an American College of Rheumatology "Within Our Reach" grant to study Periodontal Disease in patients with RA. He has been active in American College of Rheumatology and Arthritis Foundation committees and has chaired meetings, study groups, and grant review sections.

He is a board member for the Maryland Chapter of the Arthritis Foundation. He is regular reviewer for leading rheumatology journals, an associate editor for the text Clinical Care in the Rheumatic Diseases and has recently been selected as an associate editor for Arthritis and Rheumatism. He has authored more than 50 original articles, reviews, and editorials, 10 book chapters, several topics in UpToDate in Medicine, and more than 60 abstracts.

#### Scott D. Boden, MD

Dr. Boden received his BA and MD from the University of Pennsylvania and completed an Orthopaedic Residency at The George Washington University Medical Center, followed by a Spine Fellowship at Case Western Reserve University Hospitals. He is currently a tenured Professor of Orthopaedic Surgery at the Emory University School of Medicine and serves as the Director of the Emory Orthopaedics &

Spine Center. He is also the Clinical Director of the Whitesides Orthopaedic Research Laboratory and has received many awards including the Volvo Award for Low Back Pain Research (four times), The Marshal Urist Young Investigator Award, the North American Spine Society Outstanding Paper Award (seven times), and the AAOS/ORS Kappa Delta Research Award. He has received the Leon Wiltse Award for Outstanding Contributions to the field of spine surgery from the North American Spine Society.

Dr. Boden has authored more than 140 peer-reviewed articles on spine and basic science topics as well as 30 chapters and 7 textbooks. He is co-editor of Seminars in Spine Surgery, a deputy editor of SPINE, and an associate editor for Basic Science for the Journal of Bone and Joint Surgery.

Dr. Boden serves as Secretary of the American Orthopaedic Association after having served on the Executive, Finance, Membership, and Critical Issues Committees for two years as a Member-at-Large. He has served as Secretary on the Board of Directors of The Orthopaedic Research Society and The International Society for Study of the Lumbar Spine, for which he served as President in 2009, and The Eastern Orthopaedic Association of which he served as President in 2007.

Dr. Boden's basic research focus has centered on gaining an understanding of the biology of spine fusion healing and bone graft substitutes as well as the molecular control of bone formation and gene therapy applications for bone and intervertebral disc cartilage regeneration. His interests also include innovative health care delivery strategies in a managed care environment and he is Founder and Chairmen of the National Spine Network, a collaboration of 25 Spine Centers of Excellence around the US focusing on outcomes research and quality improvement. He has recently helped Emory to plan an open free-standing multidisciplinary Musculoskeletal Outpatient Center (2004) as well as an Orthopaedics & Spine Specialty Hospital (2008).

#### Peter Brooks, MD, FRACP, FRCP Edin

Professor Peter Brooks recently stepped down as Executive Dean of Health Sciences at the University of Queensland and is now Director of the Australian Health Workforce Institute — a joint venture of the University of Melbourne and the University of Queensland. He has held previous posts as Professor of Medicine at St. Vincent's Hospital, Sydney (University of New South Wales) and was the Foundation Professor of Rheumatology at the Royal North Shore Hospital and the University of Sydney. He completed his medical training at Monash University in Melbourne and then studied rheumatology under Professor Watson Buchanan in Glasgow.

Prof. Brooks is a rheumatologist with a major research interest and international expertise in the treatment and epidemiology of rheumatic diseases. He has a major interest in medical research, in particular, the linking of basic and clinical research and in internationalization and the development of postgraduate activities.

He has published widely in the treatment and outcomes in arthritis and in psychological aspects of rheumatic diseases and medical education. More recently, he has developed interests in the challenges of the health workforce of the future — how we recruit and retain current and new workers, how we develop new models of care and new ways of educating health professionals and how we imbed inter-professional learning and team care in all students. Of overriding importance is also the issue of reducing demand on the health system by improving prevention and health literacy strategies for all.

Prof. Brooks is or has been a member of a number of boards including: Council of Queensland Institute for Medical Research, Advisory Committee (arthritis and musculoskeletal disease) to the National Health Priority Action Council, Mater Medical Research Institute, Board of CONROD, Executive Committee of the International League of Associations for Rheumatology, International Steering Committee of the Bone and Joint Decade Counciller and Honorary Secretary of the Royal Australasian College of Physicians, Epworth Foundation and the Partnerships Grant's Committee of the NH&MRC.

#### Bruce D. Browner, MD

Dr. Browner is Professor and Gray-Gossling Chairman Emeritus, and Residency Program Director in the Department of Orthopaedic Surgery at the University of Connecticut Health Center in Farmington, Connecticut. He is also the Director of Orthopaedics at Hartford Hospital in Hartford, Connecticut.

Dr. Browner graduated from his orthopaedic residency at Albany Medical Center Hospital in June of 1978. His fellowship was also at Albany Medical Center in the Shock Trauma Research Unit.

Dr. Browner is beginning his fourth year on the Board of Regents with the American College of Surgeons, having been appointed to the Research and Optimal Patient Care Committee. He also serves on the Health Policy Steering Committee and its Quality Subcommittee, the Surgical Specialty Society/Emergency Workforce Summit.

A member of the American Association of Orthopaedic Surgeons, he is involved with the Trauma Call Project Team, the Council on Advocacy, and the Council on Health Policy and Practice. He is past Chairman of the AAOS International Committee. He is also on the Committee on Quality of Care and Committee on Legislation for the Connecticut State Medical Society.

He is Past President of Orthopaedic Trauma Association, a member of the American Association for the Surgery of Trauma, Association for the Advancement of Automotive Medicine, American Orthopaedic Association, Academic Orthopaedic Society, Musculoskeletal Infection Society, and Association for Safe International Road Travel.

Dr. Browner is an editor for Skeletal Trauma, the 4<sup>th</sup> edition presently underway. He is also entering his fourteenth year as editor in chief for Techniques in Orthopaedics. Professional interests include Health Policy, Emergency On-Call Workforce, and Prevention of Surgical Infections. His specialties include bone infection, problem fractures and orthopaedic trauma.

Throughout his career, Dr. Browner has received numerous local, national and

international honors and awards including The University of Connecticut's Residency Educator of the Year in June 2006 and The Connecticut Orthopaedics Society's 2003 Orthopedist of the Year. He has been chosen one of Connecticut's Top Doctors and recognized as a Top National Surgeon on more than one occasion.

## David Burr, PhD

Dr. Burr is Professor and Chair of the Department of Anatomy and Cell Biology and Professor of Orthopedic Surgery at the Indiana University School of Medicine. He holds an appointment as Professor of Biomedical Engineering (IUPUI) and a courtesy appointment as Professor of Biomedical Engineering at Purdue University. He joined the Indiana University School of Medicine faculty in 1990 to develop interdisciplinary skeletal biomechanics programs on the Indianapolis campus.

Dr. Burr received his PhD from the University of Colorado in 1977. He then spent three years as Instructor and Assistant Professor of Anatomy at the University of Kansas before joining West Virginia University in 1980 as Assistant Professor of Anatomy and Orthopedic Surgery. Dr. Burr's research activities include study of the response of bone to mechanical stimuli at the cell and tissue levels, pharmaceutical treatments for osteoporosis, cartilage repair in osteoarthrosis, and the biomechanics of stress fractures. He is the author of more than 190 research articles in the peerreviewed literature, 16 book chapters and four books on the structure, mechanics and fracture of bone.

Dr. Burr's current research activities include evaluation of the effects of pharmacologic agents used to treat osteoporosis on properties associated with quality of the bone matrix, specifically, the accumulation and repair of microdamage, changes in mineralization and alterations to the collagenous matrix. He is also involved in studying the role bisphosphonates play in vivo on osteocyte apoptosis, and the direct effects of bisphosphonates on the activity of individual osteoblasts. Related to this, he is performing studies to define the periods for primary and secondary mineralization of bone and how rates of mineralization are affected by anti-remodeling treatments. He

has been a leader in studying the role of skeletal fatigue and microdamage-mediated remodeling in bone biomechanical and physiological adaptation.

Dr. Burr has served as consultant to the US Congress Office of Technology Assessment, American Institute of Biological Sciences and NASA (for the nonhuman primate flight program, for the Phillips Primate Experiments Committee, and more recently for the Fracture Event Review Panel). He was President of the Association of Anatomy, Cell Biology and Neurobiology Chairpersons in 2001-2002. He has served on several committees for the American Association of Anatomists, including three years on its Executive Board, was Secretary-Treasurer (2004-2005), its President-Elect (2005-2007) and President (2007-2009). He served a 3-year term on the Program Committee for the Orthopaedic Research Society (ORS), finally as Program Chair (2005-2006). He served as President of the ORS in 2008-2009. In 2004, he became the Director of the Sun Valley International Workshop on Skeletal Tissue Biology. He is an associate editor for Bone, Experimental Biology and Medicine, and the J of Musculoskeletal and Neuronal Interactions, and serves on the editorial boards for three other scientific journals (J of Biomechanics, Calcified Tissue International, J of Bone and Mineral Metabolism).

## Boyd R. Buser, DO, FACOFP

Dr. Buser is Vice President and Dean of the Pikeville College School of Osteopathic Medicine in Pikeville, Kentucky, where he also holds the rank of Professor of Osteopathic Principles and Practice. He previously served as a Department Chair, Associate Dean, and Interim Dean and Vice President of the University of New England College of Osteopathic Medicine. He is a graduate of Des Moines University College of Osteopathic Medicine and is dually board certified in Osteopathic Manipulative Medicine and Family Medicine, and is a Fellow of the American College of Osteopathic Family Physicians. He is currently a member of the Board of Trustees of the American Osteopathic Association (AOA) and the Board of Directors of the Osteopathic International Alliance. He has taught extensively, both nationally and internationally in the field of

Osteopathic Manipulative Medicine. Dr. Buser is a past Chairman of the Board of the National Board of Osteopathic Medical Examiners. In 2007, he was elected by the American Medical Association Board of Trustees to a position on the Current Procedural Terminology Editorial Panel, the first osteopathic physician to be so elected. In 1995, Dr. Buser served as President of the American Academy of Osteopathy and was named Educator of the Year by the American Osteopathic Association and American Osteopathic Foundation in 1994. He twice received the Distinguished Service Award from the Maine Osteopathic Association, in 1996 and 2007. Dr. Buser is a member of the Kentucky Institute of Medicine and the Kentucky Board of Medical Licensure.

## US Congressman Dave Camp (R-MI)

Congressman Camp represents the people of the 4th Congressional District of Michigan, encompassing all or parts of 14 counties in northwest and mid-Michigan.

First elected to Congress in 1990, Camp made an "unusually rapid rise to prominence," according to the major national policy journal, Congressional Quarterly. In December of 2008, Camp's colleagues elected him to serve as the Ranking Minority Member of the Committee on Ways and Means. The committee is considered one of the most powerful in Washington, with jurisdiction over tax, tariff and trade laws, plus Medicare and Social Security. As the Ranking Member, Camp is the lead Republican on the Committee.

On Ways and Means, Camp first made his mark in 1996 by playing a crucial role in the passage of the historic welfare reform legislation. Time magazine credited Camp's activity as the "decisive breakthrough" that led to the bill's enactment.

Since then, Camp's signature issues have been: tax credits to increase the utilization of alternative fuels; lowering and simplifying tax rates for both individuals, families and American businesses; and, reforming health care to focus on wellness and prevention as well as utilizing the power of the tax code to ensure all Americans have access to quality, affordable health care.

While active on the policy front in Washington, DC, Camp has a reputation for paying close attention to the needs of his 4th Congressional District. Camp still personally signs more than 30,000 pieces of constituent mail yearly and regularly travels the sprawling district to meet personally with constituents.

As an attorney in private practice before his first election, Camp worked extensively with parents and children in the foster care system. His experiences in this field gave him the background and insight to introduce landmark Adoption and Safe Families Act of 1996, co-sponsor the Inter-country Adoption Act in 2000 and author the Adoption Promotion Act of 2003. Camp's work in this field has led to him to become one of the House's leading adoption and foster care proponents and experts.

Camp, who was born in Midland, Mich., earned his BA, magna cum laude, from Albion College in Albion, Mich., and graduated with a JD from the University of San Diego.

#### MP Colin Carrie, BSc (Hons.), DC

Dr. Carrie, a Member of Parliament, was first elected to the House of Commons of Canada in June 2004 and re-elected January 2006 and October 2008.

In November 2008, he was appointed Parliamentary Secretary to the Minister of Health by The Right Honourable Stephen Harper. Dr. Carrie served as the Parliamentary Secretary to the Minister of Industry in the 39th Parliament. Dr. Carrie is committed to ensuring that Oshawa's automotive industry remains the pride of Oshawa. When he was elected in 2004, his passion, commitment and knowledge of Oshawa's auto industry led him to create the first ever Conservative Automotive Caucus, serving as its founding chair.

As Parliamentary Secretary, he spearheaded an unprecedented study on the state of Ontario's manufacturing industries leading to the landmark report entitled "Manufacturing: "Moving Forward — Rising to the Challenge". Carrie was also instrumental in developing the federal government's Auto Action Plan.

During the 38th Parliament, Dr. Carrie served as a Member of the Standing Committee on Health. He re-introduced Bill C-420, An Act to Amend the Food and Drugs Act, and advocated for greater choice in personal health care and natural health products for Canadians.

A graduate of Oshawa's RS McLaughlin CVI, Dr. Carrie earned a bachelor's degree in kinesiology from the University of Waterloo and later graduated from the Canadian Memorial Chiropractic College as a Doctor of Chiropractic in 1989. Prior to entering Parliament, he co-owned and operated one of Durham Region's leading chiropractic and wellness clinics in Oshawa. He is a past executive member of the Durham Chiropractic Society, former chair of Spinal Health Week and former Director of the Oshawa Federal **Progressive Conservative Riding** Association. He is a strong advocate for autistic children, victims of Hepatitis-C and families affected by Fetal Alcohol Spectrum Disorder.

#### Robert H. Carter, MD

Dr. Carter, former director of the Division of Clinical Immunology and Rheumatology at the University of Alabama at Birmingham (UAB), is currently deputy director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the National Institutes of Health.

As deputy director, Dr. Carter assists NIAMS Director Stephen I. Katz, MD, PhD, in providing strong and visionary leadership to the NIAMS, an organization dedicated to a national innovative research program in diseases of bones, muscles, joints, and skin. In addition, he contributes to the NIAMS' pursuit of cutting-edge research on a broad spectrum of investigations, from basic science to clinical studies, with translational research as a particular area of interest.

Prior to this appointment, Dr. Carter was professor of medicine at UAB, served as director of the Division of Clinical Immunology and Rheumatology, and principal investigator (PI) of the NIAMS-supported UAB Rheumatic Disease Core Center and the PI of an Autoimmunity Center of Excellence supported by the NIH's National Institute of Allergy and

Infectious Diseases (NIAID). He also served as staff physician at the Birmingham Veterans Affairs Medical Center.

Dr. Carter is board certified in rheumatology and internal medicine and has an established record of exemplary career achievements in the fields of rheumatology and immunology. He and his colleagues have been leaders in contributing to the understanding of molecular regulation of B lymphocyte activation to identify targets for therapeutic control of autoantibody production. A major focus has been on signal transduction by the B cell surface molecule CD19. He and his group were expanding their focus to include target identification in human lupus and the study of B cells in the immune response of healthy individuals.

Dr. Carter holds memberships with the Association of American Physicians, the American College of Rheumatology (ACR), the American College of Physicians, the American Association of Immunologists, and the American Association for the Advancement of Science.

Dr. Carter received his bachelor's degree from Williams College in Williamstown, Massachusetts, in 1978, magna cum laude, in biology. He received his medical degree from Harvard Medical School in 1982. He trained in internal medicine at the University of Virginia Health Sciences Center in Charlottesville. In addition, he was a fellow in rheumatology and immunology at Brigham and Women's Hospital in Boston, and in molecular and clinical rheumatology at the Johns Hopkins University School of Medicine in Baltimore.

#### Paul Caskey, MD

Dr. Caskey, a Wisconsin native, has spent almost 18 years practicing full time pediatric orthopaedics at the Shriners Hospital for Children in Spokane, Washington. He completed his undergraduate and medical education at the University of Wisconsin in Madison, Wisconsin and Orthopaedic Surgery Residency at McLaren Regional Medical Center in Flint, Michigan. He is fellowship trained in pediatric orthopaedics and scoliosis at the Texas Scottish Rite Hospital in Dallas, Texas. Dr. Caskey served in the US Air Force for four years where he was a staff pediatric orthopaedic surgeon at

Wilford Hall USAF Medical Center at Lackland Air Force Base in San Antonio, Texas. He was Chief of pediatric orthopaedics at Wilford Hall USAF Medical Center from 1990 to 1992. He was appointed Assistant Chief of Staff at Shriners Hospitals for Children, Spokane, Washington, in 1992 and Chief of Staff in 2006. In addition to general pediatric orthopaedics, his special interests include spinal deformity, deformity correction and limb lengthening. He is board certified in Orthopaedic Surgery and is a member of numerous organizations including the American Academy of Orthopaedic Surgery, the Pediatric Orthopaedic Society of North America and the American Orthopaedic Association.

Dr. Caskey has academic appointments at the Uniformed Services University of the Health Sciences in Bethesda, Maryland, and the University of Washington School of Medicine in Seattle, Washington. In addition to taking care of "the children," he is actively involved in teaching orthopaedic residents the art and science of pediatric orthopaedics.

He serves on the local Institutional Review Board, the Spokane County Medical Society Grievance Committee and the American Academy of Orthopaedic Surgeons Pediatric Evaluation Subcommittee. Dr. Caskey is the Chairman of the Pediatric Orthopaedic Society of North America Bone and Joint Decade Ad Hoc Committee and is a Member of the United States Bone and Joint Decade Board. He is the author of manuscripts in referred journals, several book chapters and on-line educational material.

Professor K.M. Chan, MBBS (Hong Kong), FRCS (Edinburgh), FRCS (Glasgow), M.Ch. Orthopaedic (Liverpool), FRCS Orthopaedic (Edinburgh), FACS, FHKAM (Orthopaedics), FHKCOS, FCSHK

Prof. Kai-Ming Chan is the Chair Professor and Chief of Service at the Department of Orthopaedics and Traumatology, Prince of Wales Hospital, The Chinese University of Hong Kong. He also currently serves as the Director of the CUHK-WHO Collaborating Centre for Sports Medicine and Health Promotion, Director of the Joint Universities Sports Medicine and Rehabilitation Centre and

the Co-Director of The Hong Kong Jockey Club Sports Medicine and Health Sciences Centre. Prof. Chan received his medical degree from the University of Hong Kong in 1975.

Prof. Chan is internationally recognized for his expertise in orthopaedic sports medicine. He has authored over 200 scientific articles in peer-reviewed journals and over 53 book chapters in internationally published books, edited 25 books and produced almost 600 abstracts. His major research interests are in sports injuries and rehabilitation, arthroscopic surgery, basic science research in tendon injuries. He is also currently the co-chief editor of Journal of Orthopaedic Surgery and Research (JOSR) and Journal of Sport Medicine, Arthroscopy, Rehabilitation Therapy & Technology (SMARTT).

He is the President of the Chinese Speaking Orthopaedic Society (CSOS) and the Asia-Pacific Orthopaedic Society for Sports Medicine (APOSSM). Prof. Chan is a member of the International Steering Committee (ISC) of Bone and Joint Decade (BJD).

He was the Past President of the International Federation of Sports Medicine, Asian Federation of Sports Medicine, Hong Kong Orthopaedic Association and Hong Kong College of Orthopaedic Surgeon, and the Past treasurer of International Society of Arthroscopy, Knee Surgery and Orthopaedic Sports Medicine (ISAKOS).

Prof. Chan was honored with an Officer of (the Order of) the British Empire (OBE) for his contribution to sports medicine in 1995 and the Justice of the Peace (JP) in 2003.

## Rear Admiral Thomas R. Cullison

Rear Admiral Cullison, Medical Corps
Deputy Surgeon General, and Vice Chief,
Bureau of Medicine and Surgery, US Navy,
is a native of Plymouth, Indiana. Rear Admiral
Cullison graduated from Hanover College
and was commissioned through Officer
Candidate School in 1968. He served as a
surface line officer in USS Charles R. Ware
(DD 865), participated in riverine salvage
operations in Vietnam with Harbor
Clearance Unit 1, and was a saturation
diving officer assigned to Submarine
Development Group 1.

Cullison received his doctor of medicine degree in 1979 from Indiana University School of Medicine. Following a surgical internship and orthopedic surgery residency at Naval Medical Center San Diego he reported to Naval Hospital, Camp Pendleton in 1984, becoming Chief of Orthopedic Surgery in 1986. There he deployed as Leader of Surgical Team 7 and Commander Amphibious Task Force Surgeon. He held several positions while stationed at Naval Medical Center, San Diego from 1987-1995 including Assistant Chairman of Orthopedic Surgery, Director, Sports Medicine Service, Surgeon General Specialty Leader for Orthopedic Surgery, and Director of Surgical Services.

He served as Deputy Commander, Naval Medical Center, Portsmouth from 1995-1998, Commanding Officer, Naval Hospital Camp Lejeune from 1998-2001, Fleet Surgeon, US Pacific Fleet from 2001-2003, Command Surgeon, US Pacific Command from 2003-2004, and Medical Officer of the Marine Corps from 2004-2005. His most recent assignment was Commander, Navy Medicine East and Commander, Naval Medical Center, Portsmouth from 2005-2007.

Cullison's personal awards include: Legion of Merit with three gold stars, Bronze Star with Combat V; Defense Meritorious Service Medal; Meritorious Service Medal; Navy Commendation Medal; and Combat Action Ribbon.

His professional activities have included:
Adjunct Assistant Professor of Orthopedic
Surgery at the Uniformed Services
University of Health Sciences, Clinical
Assistant Professor of the University of
California San Diego School of Medicine,
Diplomate American College of Healthcare
Executives, Board of Councilors of the
American Academy of Orthopaedic
Surgeons, Board of Directors for the Society
of Military Orthopaedic Surgeons and Fellow
American Orthopaedic Association.

#### US Congressman John D. Dingell (D-MI)

Congressman Dingell represents Michigan's 15th Congressional District and is the Chairman Emeritus of the Committee on Energy and Commerce, one of five "exclusive" committees in the US House.

During the 111th Congress, he has the lead role in crafting national health insurance legislation that goes before this Committee and the House. On the Committee, he also works on energy and climate change issues, telecommunications and consumer protection policy, and conducts oversight and investigations. On February 11, 2009, Congressman Dingell became the longest serving Member in the history of the US House of Representatives.

Over the last five decades, Dingell has written some of the best known laws protecting health and the environment, as well as the rights of workers and consumers. One example: the 1990 Clean Air Act which is credited with cleaning up the air, while preserving American competitiveness. He fought for the passage of revolutionary legislation such as the Endangered Species Act; as well as laws that address America's most pressing needs like the Children's Health Insurance Program (CHIP) and the Mammography Quality Standards Act.

Dingell remains vigilant in his pursuit of a "Patients Bill of Rights" which will ensure patients' care is in the hands of doctors, not HMO's and insurance companies.

A conservationist and outdoorsman, and senior member on the Migratory Bird Conservation Commission, Dingell successfully passed legislation to create North America's first international wildlife refuge, protecting thousands of acres of natural habitat in Southeast Michigan and Canada.

A leader in the effort to toughen corporate accountability both before and after the Enron and WorldCom accounting scandals, Dingell has also taken the lead in exposing government waste and abuses of tax dollars, including the investigation of no-bid defense contracts in Iraq.

Dingell, born in Colorado Springs, Colorado, split much of his childhood between Detroit and Washington, DC, while his father, also named John, served as Congressman from Michigan's 15th district.

In 1944, at the age of 18, the younger Dingell joined the US Army. He rose to the rank of Second Lieutenant. Dingell finished his military service in 1946, then attended Georgetown University in Washington, DC where he studied chemistry. He continued his studies at Georgetown Law School, graduating in 1952. He then worked as a forest ranger, a prosecuting attorney for Wayne County, Michigan, and ran his own private law office. When his father passed away while still a Member of the US House of Representatives in 1955, the younger Dingell stepped up to fill the void, beginning his Capitol Hill career at the age of 29.

At the beginning of every session of Congress, Dingell introduces the national health insurance bill his father sponsored when he was a Member.

## Karsten E. Dreinhöfer, MD

Dr. Dreinhöfer is Professor of Orthopaedics at the Charité University Medicine, Berlin and Head of the Department of Orthopaedics, Medical Park Humboldtmühle, Berlin, Germany. He holds subspecialty degrees in emergency medicine, physical therapy, chiropractic therapy and social medicine. He has also graduated as an health economist (ebs) from the European Business School, Oestrich-Winkel, Germany. Dreinhöfer graduated from Medizinische Hochschule Hannover (MHH), Germany 1988. From 1985 to 1987, he was a Fellow of the German Medical Exchange Service (DAAD) at Tufts University Medical School Boston and Harvard University Medical School Boston, Massachusetts. From 1989 to 1991 he trained at the Department of Trauma Surgery, Hannover Medical School (Chairman: Prof. H. Tscherne). In 1991/92 he spent one year as a research fellow of the German Research Foundation (DFG) at the Department of Orthopedics, University Hospital Lund, Sweden (Chairman: Prof. L. Lidgren). During that period, he began working on epidemiology and prognostic factors in soft tissue sarcoma with Prof. A. Rydholm. Since 1992 he has been at the Department of Orthopaedics at the University Ulm (Chairman: Prof. W. Puhl). He was board certified in 1996 and was appointed as attending surgeon in the same year.

In 1997, he joined Johnson & Johnson Orthopaedics as the European Director of Professional Education and a member of the European Franchise Operating Committee, until he returned to his consultant position in Ulm in 1999. In the same year he graduated as a Health Economist from the European Business School. In 2002 he was appointed Deputy Head of the Department of Orthopaedics at the University Ulm. In 2009 he was appointed to become Professor of Orthopaedics at the Charité University Medicine, Berlin and Head of the Department of Orthopaedics, Medical Park Humboldtmühle, Berlin, Germany.

Dr. Dreinhöfer is Director of Development for the International Steering Committee of the Bone and Joint Decade and serves as Vice-President for the German Network of the Bone and Joint Decade.

He is a member of the Executive Board of the German Professional Association for Orthopaedics (BVO) and editor of the Orthopädie Mitteilungen and Orthinform. Dr. Dreinhöfer serves as co-opted member of the board of the European Federation of National Associations of Orthopaedics and Traumatology (EFORT) and chairman of the Health Service Research Standing Committee. In addition, he is heading the Commission for Epidemiology and Health Economy, German Orthopaedic Alliance (DGOOC and BVO) and the German Institute for Health Service Research in Orthopaedics (IVO).

He is the delegate of the German Orthopaedic Osteology Society (OGO) to the national umbrella society (DVO) and delegate of DVO and OGO to the International Osteoporosis Foundation (IOF). In addition, he is the National Coordinator Germany of the Invest in Your Bone Campaign of the IOF and was a member of the Fracture Working Group of the IOF. Dr. Dreinhoefer is founding member and treasurer of the Fragility Fracture Network. He coordinates the EuroHip Project — European Collaborative Database of Cost and Practice Pattern of Total Hip Replacement — and is editor of Eurohip — Health Technology Assessment of Hip Arthroplasty in Europe.

His clinical focus is on conservative and rehabilitative treatment of musculoskeletal conditions, especially osteoporosis, osteoarthritis and back pain.

He has written extensively on a variety of orthopaedic problems and diseases,

focussing on osteoporosis, bone and soft tissue sarcomas and hip arthroplasties as well as on epidemiology and health service research in musculoskeletal conditions. He is one of the editors of the German report on musculoskeletal conditions by the Robert-Koch-Institute focussing on Epidemiology and Health Economics.

## Ann L. Elderkin, PA

Ms. Elderkin is Executive Director of the American Society for Bone and Mineral Research (ASBMR), the world's largest professional, scientific and medical society established to bring together clinical and experimental scientists involved in the study of bone and mineral metabolism. With almost half its members from outside the US, ASBMR is proactive in shaping research and facilitating the translation of that science to health care and clinical practice worldwide.

A driving force in the development of the National Action Plan for Bone Health, the ASBMR works closely with the National Coalition for Osteoporosis and Related Bone Diseases (the Bone Coalition), comprised of ASBMR, the National Osteoporosis Foundation, the Osteogenesis Imperfecta Foundation, The Paget Foundation and the American Academy of Orthopaedic Surgeons. The Plan outlines recommended actions, responsibilities, and short- and long-term timelines for priorities and programs for health professionals, health systems and population-based approaches to promote bone health.

A leader with a reputation for making a difference in the health care industry, Elderkin has more than 25 years of experience in health care leadership positions, directing health care policy development, managing public health administrations and providing medical services as a physician assistant. Prior to joining ASBMR, Elderkin served as project director and managing editor of Bone Health and Osteoporosis: A Report of the Surgeon General, released in October 2004. She also directed projects on women's mental health and health care services.

Elderkin served in the Office of the Surgeon General of the US as a Senior Health Policy Fellow and Consultant from 2000 to 2002. From 1990 to 2000, she was director of the City of Somerville (Massachusetts) Health Department and also served as director of the City of Portland (Maine) Public Health Division.

Elderkin has received many awards for her work, including: the Surgeon General Exemplary Service Award in 2002; the American Medical Association Dr. Nathan Davis Award for Outstanding Career Public Servant at the Local Level in 1995; the American Cancer Society Making a Difference Award for Outstanding Community Service in 1995; the Massachusetts Department of Public Health Partners in Prevention Award in 1995; and the American Cancer Society Award for Extraordinary Effort and Results, recognizing leadership in tobacco-control regulations in 1992.

Elderkin has a bachelor's degree in human services from the University of Massachusetts and a Physician Associate Certificate from Yale University School of Medicine.

## US Congresswoman Anna G. Eshoo (D-CA)

Congresswoman Eshoo was first sworn in as a Member of the US House of Representatives in 1993, after serving on the San Mateo County Board of Supervisors for 10 years. For more than a decade in Congress she has defended consumers, promoted American competitiveness and innovation, fought for access to health care for families and children, and protected the environment.

Eshoo has served on the powerful House Energy and Commerce Committee since 1995 and is a member of the Subcommittee on Telecommunications and the Internet and the Subcommittee on Health. The Energy and Commerce Committee is responsible for legislation affecting Medicare, Medicaid, telecommunications, energy, the Internet, health-based environmental laws, children's health, biotechnology, high technology, water resources, bioterrorism, homeland security, interstate commerce, gun safety, consumer protection, and food and drug safety.

Eshoo was appointed to the House Permanent Select Committee on Intelligence in January 2003. In the 111th Congress, Eshoo chairs the Subcommittee on Intelligence Community Management, which focuses on policies and management challenges affecting agencies that comprise the nation's Intelligence Community.

Eshoo co-chairs the Congressional High-Tech Caucus, the E-911 Caucus and the House Medical Technology Caucus, and serves as Vice Chair of the 21st Century Health Care Caucus. She is a member of the Congressional Humanities Caucus. She has co-sponsored numerous reform bills to require more transparency and accountability in lobbying.

Last year, the House passed a bill authored by Eshoo that would invest in research and support services for the 46.3 million Americans living with arthritis. In the 110th Congress Eshoo introduced legislation that would modernize the medical records system and protect the privacy of patients. She has authored landmark legislation that has, among others, ensured that low-income women who are diagnosed with breast and cervical cancer receive treatment, and requires insurance companies to pay for reconstructive surgery for cancer patients.

In 2005, Eshoo led House Democrats in introducing The Innovation Agenda — A Commitment to Competitiveness to Keep America #1. This comprehensive policy plan was developed with leaders from the high technology, biotechnology, academic and venture capital communities. Education is a key element of the Innovation Agenda, with a national commitment to:

- Educate 100,000 new scientists, engineers, and mathematicians in the next four years;
- Create a special visa for the best and brightest international doctoral and postdoctoral scholars in science, technology, engineering and mathematics;
- Make college tuition tax-deductible for students studying math, science, technology, and engineering.

Eshoo's work has earned the approval of a wide range of organizations, including the 2006 Inaugural Congressional Award from the American Institute for Medical and Biological Engineering. In 2008 she received the "Legislator of the Year" award from the Biotechnology Industry Organization and in 2009 she received the Arthritis Foundation Leadership Award.

## Paul W. Esposito, MD, FAAOS, FAAP

Dr. Esposito is Professor of Orthopaedic Surgery and Pediatrics at the University of Nebraska College of Medicine. He received his MD from Hahnemann Medical College and Hospital, Philadelphia, Pennsylvania, completed his internship and residency in orthopaedic surgery at the US Naval Hospital, Oakland, California, and a pediatric orthopaedic fellowship at Children's Hospital Medical Center Cincinnati, Ohio. Dr. Esposito is board certified. He is a member of the Pediatric Orthopaedic Society of North America and served as Chair of the Trauma Committee. He is a member of the American Orthopaedic Association, a Fellow of the American Academy of Orthopaedic Surgeons, and a Fellow of the American Academy of Pediatrics, having served both the Section on Sports Medicine and the Section on Orthopaedics. He has served on the AAP Section on Orthopaedics Program Committee, as Scientific Program Chair, and Executive Committee member 2001-2007. He is a manuscript reviewer for the Journal of Pediatric Orthopaedics and for Pediatrics.

Dr. Esposito is President of the Medical Staff and is on the Board of Directors at Children's Hospital and Medical Center, Omaha, as well as the Board of Directors of One World Community Health Center in Omaha, Nebraska. He is the pediatric orthopaedic surgeon of the Osteogenesis Imperfecta Clinic at Children's Hospital and Medical Center, Omaha. His particular interests are children's extremity deformities, osteogenesis imperfecta, cerebral palsy, and orthopaedic aspects of congenital and developmental disorders.

## Professor Liana Euller-Ziegler, MD

Dr. Euller-Ziegler is Professor of Rheumatology & Head of the Rheumatology Department, Hospital of Nice, University of Nice in Sophia Antipolis, France. She is a member of the French Society for Rheumatology, American College of Rheumatology, and American Society for Bone & Mineral Research.

She serves as Vice President (elected by Social Leagues/patient organizations) of the European League Against Rheumatism (EULAR), General Secretary 1st Annual European Congress of Rheumatology,

EULAR'2000, Chair of the Social Leagues Program Committee, EULAR'2000 and 2001 Congress Chair, and Organizing Committee member of the Worldwide Conferences of Arthritis and Rheumatism Patient Societies organized by the Social Leagues of EULAR for 2000.

She is President of AFLAR (Associative French League Against Rheumatism) and has been involved in many areas including Editor, Journal de l'AFLAR, Chair of the AFLAR Annual Congresses, Member of working parties of the French Health Ministry (struggle against Pain, Osteoporosis), Founder Member of IAPO (International Alliance of Patient Organizations), and Coordinator of the Patient Partner Program in France.

## **Nancy Carter-Foster**

Ms. Carter-Foster is Senior Advisor for Health Affairs for the US Department of State in the office of the Deputy Assistant Secretary for Science and Health. She is responsible for identifying emerging health issues and making policy recommendations for foreign policy concerns regarding international health. Carter-Foster is the Department's liaison on the National Biosurveillance Integration System, having worked on its creation from concept to development, following 12 years of experience in infectious disease and biosurveillance issues.

Carter-Foster has served as Head of Delegation and primary US negotiator in multilateral conferences for global health issues, including the Global Fund for HIV/AIDS, TB and Malaria at its creation: for women's issues and women's health; as well as infectious diseases writ large. As US Coordinator for Population Affairs, she led the US Government preparations and was the US Head of Delegation for the Beijing Women's Conference Preparatory Meetings, and for the United Nations Preparatory meetings on Population and Development. She was US Negotiator for Population, Women's Issues and Health for the UN Conference on Environment and Development (the Rio Conference, 1992).

She is the Department's representative for obesity and international diabetes issues, and has worked on a variety of health,

trade and environmental issues, amassing in-depth knowledge and experience in policy development, program implementation and project management and oversight.

Carter-Foster chairs the Interagency Roundtable on Global Road Safety, working with domestic agencies, international and the private sector on health and transportation.

## Eric P. Gall, MD, MACP, MACR

Dr. Gall is professor & Chair, Department of Medicine, Chief Rheumatology and Allergy Division & Professor of Microbiology at the Chicago Medical School, Rosalind Franklin University of Medicine & Science. Prior to this he was Head of the Rheumatology Allergy and Immunology Section and Director of the Arthritis Center at the University of Arizona. He was educated at the University of Pennsylvania and received his training at the University of Cincinnati and again at Penn. He serves on the USBJD as Coordinator of Educational Activities. He is a Master of the American College of Rheumatology (ACR) and the American College of Physicians (as well as a Laureate). He is currently chair of the Greater Chicago Chapter of the Arthritis Foundation and serves on the national leadership council.

He has been involved for many years in funded research in educational methodology for Rheumatology and was chair of the Professional Education Committee for the Illinois Partnership on Arthritis, a Centers for Disease Control and Prevention-funded initiative. He has served for years on the ACR AV Teaching Collection and was founding chair of the Educational Products Committee and founding member of the Education Council. He is past president of the Association of Rheumatology Health Professionals, was Chair of the ACR Rehabilitation Section and served on the ACR and Arthritis Foundation National Board of Directors. He is Councilor for the Illinois Delta chapter of Alpha Omega Alpha National Medical Honor Society and serves on the National Board of Trustees.

Dr. Gall has a special interest in Synovial Pathology, Hypermobility (primary collagen) disorders and Hemophilic Arthritis as well as Medical Education and Curriculum.

#### Steven R. Goldring, MD

Dr. Steven R. Goldring is the St. Giles Chair and Chief Scientific Officer at Hospital for Special Surgery and Professor of Medicine at Weill Cornell Medical College in New York City. He previously was a Professor of Medicine at Harvard Medical School and Chief of Rheumatology at New England Baptist Hospital and Beth Israel Deaconess Medical Center, Boston, Massachusetts. After receiving his MD from Washington University School of Medicine, St. Louis, Missouri, he completed his medical residency training at Peter Bent Brigham Hospital and his rheumatology training at the Massachusetts General Hospital in Boston. His research interests focus on the cellular and molecular mechanisms involved in the regulation of physiological and pathological bone remodelling.

He is past President and Secretary-Treasurer of the American Society of Bone and Mineral Research. He previously served as the Chairman of the Orthopaedics and Musculoskeletal Study Section at the National Institutes of Health, Chairman of the Gordon Research Conference on the Molecular Biology of Bones and Teeth, Co-Chairman of the Keystone Conference on the Pathogenesis of Rheumatoid Arthritis, and Vice-Chairman of the National Institutes of Health, Consensus Development Panel on Osteoporosis.

Dr. Goldring is a co-recipient of the Klemperer Award, Carol Nachman Prize in Rheumatology and has received the Arthritis Foundation's James H. Fairclough, Jr. and Marian Ropes Awards and the Paget's Disease Foundation Research Award.

## **US Senator Charles Grassley (R-IA)**

US Senator Chuck Grassley has made his mark in Washington with his commitment to constituents, more accountable government, and common sense solutions since his election to the Senate in 1980.

Grassley cites Congress' responsibility to see that the laws it passes are faithfully executed, and for that reason carefully tracks the practices of the Internal Revenue Service, the FBI, the Food and Drug Administration, the Department of Homeland Security, the Centers for Disease Control and Prevention, the General Services Administration, the Securities and Exchange Commission, and the Centers for Medicare and Medicaid Services. He sought an investigation of fraud and abuse of Social Security disability payments, while also passing legislation to close loopholes.

Grassley watches out for the interests of the elderly, including residents in US nursing homes. As chairman of the Senate Aging Committee in the late 1990s, he exposed terrible neglect in some of the nation's 17,000 nursing homes and spurred a comprehensive effort to improve standards of care. Grassley's scrutiny of the Food and Drug Administration resulted in more information for the public about the risks of antidepressants in young people and stronger warnings and restricted uses for other drugs on the market.

Grassley champions whistleblowers in government and the private sector. He coauthored the Whistleblower Protection Act of 1989 for government workers and whistleblower amendments that Grassley sponsored during a 1986 update of the False Claims Act are the government's most effective tool against health-care fraud.

Grassley is the Ranking Member of Finance Committee which is responsible for tax policy, Social Security, Medicare, Medicaid, welfare policy, pensions, worker's compensation, and job-generating international trade. Health care policy is a top priority for Grassley, who developed the first Medicare prescription drug benefit with extra help for lower-income seniors and won approval of landmark rural health provisions to improve unfair federal formulas that had shortchanged health care delivery system in those areas.

He also works to help the disabled and working poor to afford health care coverage. Grassley won a victory in 2006 with enactment of a Grassley-Kennedy plan to allow working parents to buy into Medicaid for children with special needs.

#### Edward D. Harris, Jr., MD

Dr. Harris graduated from Dartmouth College in Hanover, New Hampshire and obtained his MD from Harvard Medical School. He remained in Boston at the Massachusetts General Hospital for training in internal medicine and rheumatology. His experience in the US Public Health Service served at the National Institutes of Health prepared him for research in connective tissue. In 1970, he joined the faculty at Dartmouth Medical School as Chief of the Connective Tissue Disease Section. His research was in the area of metalloproteinases, enzymes that destroy cartilage, tendon and bone in inflammatory joint diseases, while his clinical interests were principally in the pathophysiology, diagnosis and treatment of rheumatoid arthritis.

In 1982, he moved to Rutgers University as Chair, of the Department of Medicine at the medical school in Piscataway, New Jersey and in 1987 was appointed Chair of Medicine and the Arthur L. Bloomfield Professor at Stanford University. During his eight-year tenure there he made 80 faculty appointments and helped build a distinguished department with a clinical reputation equal to its research achievements.

He joined Bill Kelley, Shaun Ruddy, and Clement Sledge to launch the Textbook of Rheumatology, now in its ninth edition, and was heavily involved with the American College of Rheumatology, becoming its president in 1985-86. The ACR awarded him its Distinguished Investigator Award in 2006 and its highest honor, the Presidential Gold Medal, in 2007. He served five years after retirement from the Stanford faculty as Academic Secretary to the University, and now is in his 13th year as Executive Secretary of Alpha Omega Alpha Honor Medical Society and editor of its non-technical quarterly, The Pharos.

#### Professor Mieke Hazes, MD, PhD

Prof. Hazes is a graduate of Leiden University, Leiden, The Netherlands, where she obtained her medical degree in 1980. She gained a specialist degree in rheumatology in 1988 and a Rheumatology Doctorate in 1990, before undertaking her PhD, also at Leiden University.

Prof. Hazes served as Assistant Professor of Rheumatology at the University Hospital Leiden between 1986 and 1988. After this, and until 1995, she held the role of Medical Head of the specialist rehabilitationrheumatology clinic "Solo Mio" in Noordwijk, The Netherlands. During this time she was a visiting epidemiologist for the Arthritis and Rheumatism Council Epidemiology Research Unit at Manchester University in the UK.

In 1996, Prof. Hazes was appointed Head of the Out-Patient Department and Deputy Head of the Department of Rheumatology, Leiden University Hospital. She became Professor of Rheumatology and Head of the Department of Rheumatology, Erasmus University Medical Center, Rotterdam, The Netherlands in 2000.

Prof. Hazes is a member of the Dutch Societies for Rheumatology, Rheumatoid Surgery, Epidemiology, and Medical Specialists, as well as a member of the British Society of Rheumatology and the American College of Rheumatology. She is a member of the International Steering Committee of The Bone and Joint Decade 2000-2010, the subcommittee on Health and Work Participation of the National Health Council, and the Erasmus Medical Centre advisory board for medical research. In addition, she is Chair of the Erasmus Medical Centre Fund for Care and Cost Effectiveness Research as well as the Erasmus Medical Centre Research Integrity Committee.

Prof. Hazes' current research interests are diagnosis and prognosis of early arthritis, pregnancy and rheumatoid arthritis, coordinated care, and epidemiology of musculoskeletal conditions.

#### David Hunter, MD

Dr. Hunter, Chief of Research at New England Baptist Hospital and Assistant Professor at Boston University, is a rheumatologist epidemiologist. He completed a fellowship in Rheumatology at the Royal Australian College of Physicians, earned a Masters of Medical Science (Clinical Epidemiology) from the University of Newcastle, a Masters of Sports Medicine from UNSW and a doctorate from the University of Sydney. He completed his doctoral thesis on the genetics of osteoarthritis, more specifically cartilage volume.

Dr. Hunter is a member of the Australian College of Physicians, Australian Rheumatology Association, American College of Rheumatology, Orthopaedic Research Society and International Osteoarthritis Research Society. Since late 2007 he has been a board member for the Osteoarthritis Research Society. Dr. Hunter has a number of first author peer reviewed publications in highly respected international journals. The more recent publications have focused on knee osteoarthritis epidemiology. Dr Hunter has over 120 peer reviewed publications in international journals and recently completed his second book on self management strategies for the lay public. In his current work, he is investigating a number of key elements in osteoarthritis including (but not limited to) the epidemiology of patellofemoral osteoarthritis, genetic epidemiology of osteoarthritis, the role of biomarkers in understanding OA etiopathogenesis and the role of knee braces and orthotics in disease management. The quality of his research is evidenced by the fact that he received the Young Investigator of the Year Award at the Osteoarthritis Research Society International Annual Meeting in 2000.

He was recently invited on to a steering panel by the National Institutes for Health (USA) to assist in determining a 5-year plan for research funding for the Arthritis Institute (NIAMS). He is part of the review committee for osteoarthritis for the American College of Rheumatology annual scientific meeting, an advisory editor for the premier rheumatology journal Arthritis and Rheumatism, and has been involved in reviewing grants for the NIH and the Arthritis Foundation. He is the editor of the osteoarthritis module in PIER, the major continuing medical education for the American College of Physicians.

#### Adnan A. Hyder, MD, MPH, PhD

Dr. Hyder is an Associate Professor in the Department of International Health, Bloomberg School of Public Health, Johns Hopkins University. He is Director of the International Injury Research Unit and the PhD Program in Health Systems, core faculty at the Johns Hopkins Center for Injury Research & Policy and the Johns Hopkins Berman Institute of Bioethics. Dr. Hyder serves as a consultant to several international organizations including the World Health Organization in Geneva.

He has been working on injury prevention and control in developing countries, especially South Asia and Sub-Saharan Africa, for over 15 years and has published widely in the international literature. Dr. Hyder in an editor of the WHO/World Bank-World Report on Road Traffic Injuries Prevention; WHO-Guidelines for Injury Surveys; WHO/UNICEF-World Report on Child Injuries (forthcoming); and an author of the chapters on injuries and emergency care for the World Bank/WHO/UNDP/NIH/ Gates Foundation-Disease Control Priorities in Developing Countries project.

He is well known for his work on burden of disease and injury measures, for developing the healthy life year indicator, and has been researching the impact of unintentional injuries in Asia and Africa. Dr. Hyder is a founding member and current Vice Chair of the global Road Traffic Injuries Research Network and Chairman of the International Society for Child and Adolescent Injury Prevention. He is the recipient of the IRTE/Prince Michael Award for Road Safety and the American Public Health Association-International Health Section Mid-Career Award. Dr. Hyder did his M.D. from the Aga Khan University, Pakistan and obtained his MPH and PhD in Public Health from Johns Hopkins University, USA.

#### Joshua J. Jacobs, MD

Dr. Jacobs received a Bachelor of Science degree in Materials Science and Engineering from Northwestern University and graduated from the University of Illinois Medical School prior to General Surgical Training at the University of Illinois/Cook County Hospital Program, In 1987, Dr. Jacobs completed his orthopaedic training at the Combined Harvard Orthopaedic Residency Program in Boston. During his residency, he served as a Research Fellow in the H. H. Uhliq Corrosion Laboratory at the Massachusetts Institute of Technology pursuing his interests in biomaterials. Dr. Jacobs then completed a one-year fellowship in Adult Reconstructive Orthopaedic Surgery at Rush University Medical Center.

Dr. Jacobs has remained at Rush since his fellowship training and currently is Professor and Chairman of the Department of Orthopaedic Surgery at Rush. He was the Director of the Orthopaedic Residency Program (1994 to 2009) and is the current Director of the Section of Biomaterials Research. His major research focus is on the biocompatibility of permanent orthopaedic implants, particularly joint replacement devices.

Dr. Jacobs has published numerous peer-reviewed manuscripts, most of which focus on the biological consequences of material degradation from joint replacement implants. He has received several research awards including a Career Development Award from the Orthopedic Research and Education Foundation, the Otto Aufranc Award from The Hip Society, the Ann Doner Vaughan Kappa Delta Award, American Academy of Orthopaedic Surgeons/Orthopaedic Research Society, and the Mark Coventry Award from the Knee Society.

Dr. Jacobs has served on the Special Grants Review Committee of National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) and in 2005, he was appointed to the NIAMS Advisory Council recently completing his four-year term. In 2000, he was named Fellow, American Institute for Medical and Biological Engineering and elected to the International Hip Society. He is Past Chairman of the Council on Research, Quality Assessment and Technology of the American Academy of Orthopaedic Surgeons and Past President of the Orthopaedic Research Society. He is the current President of the United States Bone and Joint Decade.

## Joanne M. Jordan, MD, MPH

Dr. Jordan (AB, Cornell University; MD The Johns Hopkins Medical Institutions; MPH University of North Carolina School of Public Health) received her training in Internal Medicine and sub-specialty training in Rheumatology and Immunology at Duke University Medical Center. She joined the faculty of the Division of Rheumatology, Allergy, and Immunology at the University of North Carolina in 1987. She has directed the Multidisciplinary Clinical Research Center since 2003 and the institutional Training Grant in Arthritis and Immunology since 2002. She currently is the Chief of the Division of Rheumatology, Allergy, and

Immunology and the Director of the Thurston Arthritis Research Center.

Her clinical interests are in Osteoarthritis and the arthropathy of Hemochromatosis. Her research interests are in the epidemiology and genetics of Osteoarthritis and in genetic interaction with environmental triggers of arthritis and autoimmune diseases, particularly metal exposures. She is the founder and Director of The Johnston County Osteoarthritis Project, a long-term study designed to span decades, of osteoarthritis in African Americans and Caucasians in a rural county of North Carolina. This study has enjoyed continual funding from the Centers for Disease Control and Prevention since 1990 and from the National Institutes of Health since 1993. This study was the first of its kind to include African Americans and has provided critical information regarding biomarkers of joint metabolism in the osteoarthritis process, the co-morbidity of psychosocial conditions upon osteoarthritis outcomes and disability, and the epidemiology of osteoarthritis.

Dr. Jordan also directs the Genetics of Osteoarthritis study, a large genetic association study, and is one of the lead investigators in the Genetics of Generalized Osteoarthritis study, the largest family study of osteoarthritis in the world. She has served as consultant and collaborator to numerous research groups worldwide and is the author of approximately 100 journal articles and four book chapters.

## Stephen I. Katz, MD, PhD

Dr. Katz has been Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases since August 1995 and is also a Senior Investigator in the Dermatology Branch of the National Cancer Institute. He was born in New York in 1941 and his early years were spent in the Washington, DC, and Bethesda, Maryland areas. After attending the University of Maryland, where he graduated with honors, he graduated from the Tulane University Medical School with honors in 1966. He completed a medical internship at Los Angeles County Hospital and did his dermatology residency at the University of Miami Medical Center from 1967 to 1970. He served in the US military at Walter Reed Army Medical Center from 1970 to 1972.

From 1972 to 1974, Dr. Katz did a postdoctoral fellowship at the Royal College of Surgeons of England and obtained a PhD degree in immunology from the University of London in 1974. He then became Senior Investigator in the Dermatology Branch of the National Cancer Institute and assumed the position of Acting Chief in 1977. In 1980, he became Chief of the Branch, a position he held until 2002. In 1989, Dr. Katz also assumed the position of Marion B. Sulzberger Professor of Dermatology at the Uniformed Services University of the Health Sciences in Bethesda, Maryland, a position that he held until 1995.

Dr. Katz has focused his studies on immunology and the skin. His research has demonstrated that skin is an important component of the immune system both in its normal function and as a target in immunologically-mediated disease. In addition to studying Langerhans cells and epidermally-derived cytokines, Dr. Katz and his colleagues have added considerable new knowledge about inherited and acquired blistering skin diseases.

Dr. Katz has trained a large number of outstanding immunodermatologists in the US, Japan, Korea, and Europe. He has served many professional societies in leadership positions including as a member of the Board of Directors and President of the Society for Investigative Dermatology, on the Board of the Association of Professors of Dermatology, as Secretary-General of the 18th World Congress of Dermatology in New York in 1992, as Secretary-Treasurer of the Clinical Immunology Society, and as President of both the International League of Dermatological Societies and the International Committee of Dermatology.

Dr. Katz has also served on the editorial boards of a number of clinical and investigative dermatology journals, as well as several immunology journals. He has received many honors and awards, including the Master Dermatologist Award and the Sulzberger Lecture Award of the American Academy of Dermatology, the National Cancer Institute's Outstanding Mentor Award, the Harvey J. Bullock, Jr., EEO Award in recognition of his extraordinary leadership in scientific, programmatic, and administrative arenas,

the Excellence in Leadership Award from the Intl. Pemphigus Foundation, the "Change It" Champion Award from Parent Project Muscular Dystrophy, honorary membership in numerous international dermatological societies, and election into the Institute of Medicine of the National Academy of Sciences (USA).

He has also received the Alfred Marchionini Gold Medal, the Lifetime Achievement Award of the American Skin Association, Doctor Honoris Causa Degrees from Semmelweis University in Budapest, Hungary, Ludwig Maximilian University in Munich, Germany, and the University of Athens in Greece. He also received the Rothman Award for distinguished service to investigative cutaneous medicine and the Kligman/Frost Award, both from the Society for Investigative Dermatology. Dr. Katz has twice received the Meritorious Rank Award and has also received the Distinguished Executive Presidential Rank Award, the highest honor that can be bestowed upon a civil servant.

#### Sundeep Khosla, MD

Dr. Khosla is the Dr. Francis Chucker and Nathan Landow Research Professor of Medicine and Physiology and Associate Director for Research at the College of Medicine, Mayo Clinic. Dr. Khosla received his AB degree from Harvard College and his MD from Harvard Medical School. He was subsequently a resident in Internal Medicine and a fellow in Endocrinology at the Massachusetts General Hospital. In 1988 he moved to Mayo Clinic, where his research interests include mechanisms of postmenopausal and age-related bone loss, sex steroid regulation of bone metabolism, and osteoblast/stem cell biology.

Dr. Khosla has served as chair of the NIH SBDD Study Section and has been appointed to the Council of the National Institute on Aging from 2007-2010. He has received numerous awards and honors, including the Frederic C. Bartter Award for Clinical Investigation from the American Society for Bone and Mineral Research, the Innovation Award from the National Osteoporosis Foundation, and election to the ASCI and AAP. He has been elected President of the American Society for Bone and Mineral Research for 2010-2011. He is associate editor of the Journal of Bone and

Mineral Research and has served or is serving as a member of the editorial boards for the Journal of Clinical Investigation, Journal of Bone and Mineral Research, Journal of Clinical Endocrinology and Metabolism, Bone, and Endocrine Reviews.

## John H. Klippel, MD

Dr. Klippel is president and CEO of the Arthritis Foundation, the largest voluntary health organization serving the 46 million Americans living with the nation's numberone cause of disability. Dr. Klippel has held the position since, 2003 and under his leadership, the foundation has grown in national prominence. There are currently more than 150 local offices nationwide.

Dr. Klippel is currently spearheading a strategic plan that will lead the Arthritis Foundation through the most significant change in its 60-year history. The plan will greatly improve the organization's efficiency while ensuring continued investment in research, public policy, and the provision of evidence-based public health programs and services in communities throughout the nation. Dr. Klippel joined the Arthritis Foundation in September, 1999, as Medical Director and was the principal liaison for the organization for medical research and professional affairs with responsibility for oversight of the Foundation's research programs.

Prior to joining the Arthritis Foundation, Dr. Klippel served as Clinical Director of the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). During his professional career at the National Institutes of Health, he authored or co-authored 190 peer-reviewed publications and textbook chapters related to arthritis. He has served as editor of the Primer on the Rheumatic Diseases and the textbook Rheumatology.

Dr. Klippel earned a BA magna cum laude in chemistry and mathematics at Bowling Green State University and an MD at the University of Cincinnati College of Medicine. He completed internship and residency training in internal medicine at the Yale-New Haven Hospital and fellowship training in rheumatology at the National Institutes of Health and the University of California at San Diego.

Dr. Klippel is a member of several academic honor societies including Alpha Omega Alpha, Phi Eta Sigma, and Omicron Delta Kappa and a Fellow of the American College of Physicians and the American College of Rheumatology. His honors and awards include the Borden Research Award, the Surgeon General's Exemplary Service Award, and the Distinguished Clinical Teacher and Directors Award from the National Institutes of Health.

## Shoichi Kokubun, MD, PhD

Dr. Kokubun is Director of Research Center for Spine & Spinal Cord Disorders at NHO Nishitaga Hospital in Sendai, Japan. He was Professor and Chairman of the Department of Orthopaedic Surgery, Tohoku University School of Medicine in Sendai from 1995 to 2006. He was at the University of Hong Kong in 1974 and at University of Oxford in 1992.

His major research and clinical activities are spine and spinal cord diseases such as spinal deformities and injuries and radiculopathy and myelopathy due to degenerative pathologies. He is the author of more than 130 original publications in English including 46 papers on spine and spinal cord disorders.

In Japan, as Congress President, he held the JOA Annual Congress in 2004. Internationally, he was National Delegate to SICOT (1999-2005), Chief National Delegate to the Asia-Pacific Orthopaedic Association (APOA) (2001-2006), and Chairman of the Spine Section, APOA (2005-2008). The 2nd Triennial Congress of the International Federation of Pediatric Orthopaedic Societies (IFPOS) was a great success under his presidency in Sendai in 2001. He is participating in Bone and Joint Decade as a member of its International Steering Committee since 2003.

He has been making every effort to improve orthopaedic surgery, especially spinal surgery, in many Asian countries by visiting there or by accepting fellows to his university department and research center for their training. Because of the achievements, he has been granted an honorary professorship from Jilin University in Changchun, China, the Ho-Chi-Minh City Medal from Ho-Chi-Minh City, Vietnam, and an honorary membership from Royal College of Orthopaedic Surgeons of Thailand.

#### Ken J. Koval, MD

Dr. Koval, who was born and raised in New York City, attended Tufts University in Boston where he graduated in 1980 with a BS in Chemistry. He attended NYU School of Medicine and received his Medical Degree in 1984. He attended Beth Israel Medical Center in NYC for a one year surgical internship and the Hospital for Joint Disease in NYC for an Orthopaedic residency from which he graduated in 1989. He attended the University of South Florida in Tampa for a one year fellowship in Orthopaedic Traumatology, graduating in 1990.

Dr. Koval became the Chief of the Fracture Service at the Hospital for Joint Disease in NYC in 1990 and remained there until 2003. It was during this time period that he developed his research interests in fracture outcomes with an emphasis on fractures in the elderly. He was co-director of the geriatric hip fracture program at the Hospital for Joint Diseases, a prospective database of hip fracture patients.

Dr. Koval is currently Chief of the Orthopaedic trauma service and Professor of Orthopaedics at Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire. He has written extensively on all aspects of fracture management with an emphasis on hip fractures and fracture outcomes in the elderly. He has authored more than 250 papers and written several books. He was an American Orthopaedic Association ABC Traveling fellow in 1997 and was awarded the OREF Clinical Research Award in 2002 for his work on hip fractures.

#### Armin U. Kuder, Esquire

Mr. Kuder, of Kuder, Smollar & Friedman, P.C., Washington, DC, has been cited in "Best Lawyers in America" for over 25 years. After serving in numerous capacities at the local and national level of the Arthritis Foundation, he served six years on its Executive Committee, and two years as Chair. He became the first non-physician to be selected as a member of the International Steering Committee of the BJD.

Among his many civic activities, he has served as Chair of the Center for Marine Conservation, Washington, DC, Chair of the Board of Hyde School, Bath, Maine, and headed a Human Subjects Review Panel for the National Institutes of Health. Professional positions for the District of Columbia Bar have included serving as Chair of the Client's Security Fund, of a Hearing Committee for the Board on Professional Responsibility, and of a committee concerned with delivery of legal services to unrepresented litigants.

Mr. Kuder, a graduate of Lafayette College and Harvard Law School, served to the rank of Lieutenant Commander in the US Navy.

## Nancy Lane, MD

Dr. Lane, Past-President, United States Bone and Joint Decade (USBJD), and Chair, USBJD Young Investigators Initiative, is director of the Center for Healthy Aging, and co-director of the NIH funded BIRCWH program, and Professor of Medicine and Rheumatology at the University of California at Davis Medical Center.

Dr. Lane earned her medical degree at the University of California at San Francisco and completed a fellowship in rheumatology at Palo Alto Veterans Administration Hospital in Palo Alto, California, and Stanford University Medical Center in Stanford, California.

Dr. Lane is co-editor of Arthritis and Rheumatism. She is on the editorial board of the Journal of Bone and Mineral Research, Osteoporosis International, and Arthritis Research. She is also a consultant reviewer for numerous peer-reviewed journals, among them JAMA, Journal of Bone and Mineral Research, Annals of Internal Medicine, and Journal of Bone and Joint Surgery.

Dr. Lane is a frequent lecturer on osteoporosis and the author of hundreds of journal articles, book chapters, books, and abstracts and is fully funded NIH researcher on the epidemiology and genetics of hip OA in elderly women and men, osteoporosis and bone health.

One special area of expertise is the use of PTH for the treatment of glucocorticoid-induced osteoporosis and the genetics epidemiology of hip OA in elderly women and men.

# Amye L. Leong, MBA

Ms. Leong is an internationally-recognized arthritis health advocate, educator, author, leader and motivational speaker. She is President and CEO of Healthy Motivation, a health communications, education, advocacy and medical motivation consulting firm in Santa Barbara, California, and Paris, France.

Diagnosed with rheumatoid arthritis, osteoporosis and Sjogren's syndrome at age 18 and wheelchair-bound within 6 years, Leong drew on her personal advocacy skills to regain function and take control of her life. While undergoing 16 surgeries, including 12 joint replacements, she developed America's largest network of young adult programs for 8.3 million young people affected by rheumatic disease, is regarded as the leader of the young adult/baby boomer arthritis movement, and became a respected medical speaker and advocate.

Leong has more than 20 years experience working with industry, nonprofits and governments in patient-centered initiatives, patient advocacy, disability rights, access to care and treatment, patient partners in research, health communications, public affairs, web development, motivational speaking, direct-to-patient education programs, conflict resolution, and strategic planning. She is a popular educator and speaker to patient, clinical, research and industry audiences.

Leong received the 2001 President's Community Volunteer Award, America's highest honor for community service, at the White House from (former) President G.W. Bush. The Arthritis Foundation named her one of "America's 50 Heroes" and she is the recipient of their highest honor, the Harding Award. She carried the Olympic Torch for the Centennial Olympic Games as a Community Hero. As a member of the NIH Council of Public Representatives, she currently serves as an advisor to the US Director of the National Institutes of Health. She is the author of GET A GRIP: A Take Charge Approach to Arthritis (2002), its Spanish translation SUPÉRATE! (2004), Patient Advocacy and Arthritis in the WHO Bulletin (2004), The Complete Idiot's Guide to Arthritis (2009), and other professional articles.

She has served as BJD International Spokesperson and Director of Strategic Relations since 2000. She earned her MBA from Purdue University and her BA in Communications from the University of California, Santa Barbara.

# Professor Lars Lidgren, MD, PhD, Hon FRCS, Hon. Member AAOS

Dr. Lidgren holds the University Chair of Orthopedics and is Head of the Department of Orthopedics at the University of Lund, Sweden. An undergraduate major in statistics, he went on to medical school at Lund and graduated in 1971. His PhD thesis was "Post-operative wound infections in Orthopedic Surgery." He has been an author of more than 300 original publications, served as thesis advisor for 25 graduate students.

Dr. Lidgren has received significant honors and been president of various musculoskeletal societies. He is honorary member of several orthopedic societies. Currently he is Chairman for the Swedish National Knee Register, Director of the National Board of Health and Welfare, Musculoskeletal Competence Center, member of several Editorial Boards, Director, WHO Collaborating Centre for Evidence-Based Care in Musculoskeletal Disorders.

He initiated a Bone and Joint Decade Consensus Meeting in Lund in 1998, which led to the worldwide Bone and Joint Decade 2000-2010, officially supported by the United Nations on 13<sup>th</sup> November 1999 and launched by the WHO in January 2000. He is presently Chairman of the International Steering Committee.

# John Lotspeich

John has almost 20 years of communications experience, spanning journalism, research, in-house writing and editing, and internal and external publication production in the public and private sectors. He has specialized in global cross-cultural communication throughout his career, having produced communication materials for companies with more than

80,000 employees, and been assigned to projects in Chicago, New York, London, Paris, Delhi and Nairobi.

He has experience in the developing world (mainly sub-Saharan Africa) and work with the WHO and other international NGOs, with an emphasis on understanding the varying needs of the media in culturally diverse markets. During his public relations career he has focused on international, multi-regional communications, overseeing both global and pan-European programs for a wide range of international clients. Currently, he leads the 25-country Fit for Work program in partnership with The Work Foundation, ensuring strategic delivery across countries of an integrated public relations and government affairs program in support of improving rheumatology services across the EU and beyond. His most recent focus has been on health policy and pharmaceutical regulation, completing a secondment to Brussels, work at Westminster and has experience in numerous therapy areas including rheumatoid arthritis, HIV, cardiovascular disease, vaccinology, oncology, urology, pain, schizophrenia, malaria and global health.

# Professor Ghassan Maalouf, MD

Professor Maalouf is Professor of Clinical Orthopaedic Surgeon at the Bellevue Medical Center and the Chairman of the Musculoskeletal Disease Program. He is also the Medical Director of the Bellevue Medical Center-Lebanon. He is the founder of the Lebanese Osteoporosis Prevention Society (LOPS) of which he is currently the President. He is the founder of the Pan Arab Osteoporosis Society (PAOS) and President of its Scientific Committee.

Prof. Maalouf is a member of the International Committee for the World Health Organization (WHO) and the Department of Physical and Rehabilitation Medicine (PRM); Representative of Lebanon at the European Foundation for Orthopedic and Traumatology (EFORT); member of the Scientific Committee of EFFORT; member of the Governance Board of Bone and Joint Decade (BJD); Board member of the Osteoporosis Fracture Line (OFL); and has created many Patient and Scientific societies in the Middle East and Worldwide dealing with Osteoporosis and Fragility Fracture.

With more than 150 published articles, Prof. Maalouf's primary concern is the fight against osteoporosis and focus on the problem of fragility fractures, osteodensitometry and musculoskeletal diseases. In 2006, he received the first IOF-Presidential award for his achievements and research done in the field of osteoporosis. On behalf of IOF, he convinced Queen Rania of Jordan to become a Patron of IOF, and helped create the 206 Bone Fund (for number of bones in the body), which raised one million dollars for IOF.

In November 2008, he received the Medal of Honor of the French Orthopaedic Association (SOFCOT). He is a Partner in Lund University's WHO Collaborating Center for Evidence—Based Health Care in Musculoskeletal Disorders, October 2008. He was appointed by WHO as chairman of Osteoporosis and Fragility Fractures TAG for ICD coding.

# US Congressman Charlie Melancon (D-LA)

Congressman Melancon is currently serving his third term in Congress representing the 3rd District of Louisiana. The district covers much of South Louisiana. His top priority is helping South Louisiana recover from the devastation caused by Hurricanes Rita and Katrina. Since the storms, he has worked both at home in Louisiana and in Congress to bring much-needed federal disaster recovery money to the 3rd District.

Melancon is also working to create more jobs and economic opportunities across rural America, lower the costs of healthcare, and to provide our children the education they need to succeed. As a member of the Energy and Commerce Committee, he has an impact on a broad range of issues, including the oil and gas industry, health care, and telecommunications. He is also a member of the Committee on Budget.

Prior to his election to Congress in 2004, Melancon spent 11 years as the President and General Manger of the American Sugar Cane League where he worked to protect and grow Louisiana's sugar industry. He is also a former successful small businessman and entrepreneur.

From 1987 to 1993, Melancon served in the Louisiana Legislature. During the 1970's,

Charlie served as Executive Director of South Central Planning and Development Commission where he worked to build infrastructure and lay the groundwork for important economic development initiatives like Port Fourchon and the Louisiana Offshore Oil Port (LOOP).

A graduate of the University of Southwestern Louisiana with a degree in Agri-Business, Charlie has served as chair of the LSU Ag Development Council and as vice chair of the South Louisiana Economic Council based in Thibodaux. He is a member of the Assumption Parish Farm Bureau, the Assumption Chamber of Commerce, as well as many other civic and professional groups.

# **Amy Melnick**

Ms. Melnick is the Chief Public Policy Officer for the Arthritis Foundation in Washington, DC and leads the Foundation's public policy agenda on behalf of the 46 million Americans, including almost 300,000 children with arthritis, the nation's leading cause of disability. She represents people with arthritis before Congress and the agencies of the Department of Health and Human Services such as the National Institutes of Health, Centers for Disease Control and Preventions, and the Food and Drug Administration, among others.

Melnick began her career as Committee Staff at the US House of Representatives' Select Committee on Aging. Until June of 2007, she served as the Vice President, Health Policy for the Heart Rhythm Society, a medical specialty society for cardiologists and nurses. She attended the London School of Economics and Political Science and received her undergraduate degree (BA) from Wellesley College and her masters of public administration (MPA) from George Mason University.

Melnick works with arthritis advocates from all across the US to pass legislation beneficial to people with arthritis. This includes research and prevention funding for arthritis and improving access to medications and providers for people with arthritis.

# Jose A. Morcuende, MD, PhD

Dr. Morcuende, originally from Madrid, Spain, studied Medicine at the Universidad Autonoma de Madrid, Spain, where he also did his PhD. He moved to the United States in 1991. He is Associate Professor, Department of Orthopaedic Surgery and Rehabilitation, at the University of Iowa. His clinical practice is in Pediatric Orthopaedics and Musculoskeletal Oncology. He is Director of the Molecular Genetics Orthopaedic Laboratory at the University of Iowa, concentrating on the genetics of clubfoot, scoliosis and other children disorders.

He has more that 70 publications and has spoken in many national and international meetings. He is former Chairman of the POSNA Bone and Joint Decade Committee, member of the AAOS Bone and Joint Decade Committee and the member of the USBJD Board of Directors. He is also Director of the USBJD-Clubfoot Project and Past President of the Ponseti International Association.

# Marcos Musafir, MD

Dr. Musafir was born in Rio de Janeiro, Brazil and is an orthopedic surgeon with a specialty in sports medicine and traumatology. For eight years prior to joining WHO, he was the Head of the Trauma Center of Miguel Couto Municipal Hospital in Rio de Janeiro. At the Federal University of Rio de Janeiro, he conducted research on the impact of road trauma. He holds a Master of Orthopedics and Traumatology and an MBA from the same university. He has been a fellow in traumatology in Canada, Germany, Japan, Switzerland and the US, and lectured extensively on the topic. He is the author of the book, "Fracture Classification" and has contributed to various books and articles on trauma treatment. In 2007 he served as the 40th President of the Brazilian Orthopedic Association.

In late 2008, Dr. Musafir was invited to join the VIP team at WHO headquarters in Geneva to oversee a project on Building Partnerships for Trauma Care, which he conducts in collaboration with The Bone and Joint Decade 2000-2010. The objectives of the project are to increase attention to trauma care globally, strengthen alliances and develop and expand networks of collaborators for trauma care advocacy.

# CPT Raymond O'Donnell, USA

CPT O'Donnell was commissioned as a Second Lieutenant of Infantry in 2003 upon graduation from the University of Hawaii at Manoa. His first assignment was as an active-duty augmentee with the 100<sup>th</sup> Battalion, 442nd Infantry Regiment (Army Reserve), serving as an Anti-Tank Platoon Leader in support of OIF III, in Balad, Iraq. Following attendance at the Infantry Advanced Course at Fort Benning, Georgia, he was assigned to the 1<sup>st</sup> Brigade, 1<sup>st</sup> Infantry Division, Fort Riley, Kansas, as a Company Mentor on a Military Transition Team. In January 2007, he deployed to Afghanistan, where he saw stints as Logistics Officer, Operations Officer, and Executive Officer for a Military Transition Team in Farah Province, working with the Afghan National Security Forces in support of OEF.

In August 2007, CPT O'Donnell sustained multiple injuries as a result of a HMMV rollover mishap during a patrol in Herat, Afghanistan. He spent the next eight months as an inpatient in various medical facilities, including Walter Reed Army Medical Center, Brooke Army Medical Center, and the PolyTrauma Unit of the James A. Haley Veterans' Hospital in Tampa, Florida.

He is currently assigned to the Warrior Transition Unit at Schofield Barracks, Hawaii, where he is continuing to rehabilitate while undergoing a Medical Board at Tripler Army Medical Center. It is his goal to continue to serve as an Infantry Officer through the Continue on Active Duty program. CPT O'Donnell has completed the Infantry Officer Basic and Advanced Courses.

CPT O'Donnell's awards and decorations include the Bronze Star Medal with Oak Leaf Cluster, Army Achievement Medal, National Defense Service Medal, Afghan Campaign Medal, Iraqi Campaign Medal, Global War on Terrorism Service Medal, Army Service Ribbon, Overseas Service Ribbon, NATO Medal, Combat Infantryman Badge, Parachutist Badge, and Navy SCUBA Badge.

# David S. Pisetsky, MD, PhD

Dr. Pisetsky is Professor of Medicine and Immunology at the Duke University Medical Center. He received his BA from Harvard College in 1967 and his MD and PhD from the Albert Einstein College of Medicine 1973. After house staff training at the Yale-New Haven Hospital, he was a Clinical Associate in the Immunology Branch of the National Cancer Institute. He joined the Duke faculty in 1978 as an Assistant Professor and Chief of Rheumatology at the Durham VA Hospital, and established a program of basic and clinical research in the pathogenesis of the rheumatic diseases.

Throughout his career at Duke, Dr. Pisetsky has investigated the mechanisms of autoimmunity in systemic lupus erythematosus, focusing on the immunological properties of nuclear macromolecules. These studies led him to the discovery of the mitogenic activity of bacterial DNA. More recently, Dr. Pisetsky has been studying the role of alarmins in innate immunity, the mechanisms of inflammation in rheumatoid arthritis and the role of early treatment in inflammatory arthritis.

Dr. Pisetsky has published more than 300 papers and chapters. He has served on many editorial boards and, from 2000-2005, he was the editor of Arthritis and Rheumatism. Currently, he is the editor of The Rheumatologist, a publication of the American College of Rheumatology. In 2001, Dr. Pisetsky received the Lee C. Howley Award of the Arthritis Foundation in recognition of his studies on the immune response to DNA.

# Andrew N. Pollak, MD

Dr. Pollak is Associate Professor, Program Director and Head of the Division of Orthopaedic Trauma at the University of Maryland School of Medicine. He is also Associate Director of Trauma and Chief of the Division of Orthopaedic Traumatology at the R Adams Cowley Shock Trauma Center, Maryland's officially designated primary adult resource center for trauma care. Dr. Pollak received BS and MD degrees from Northwestern University and completed an orthopaedic surgery residency at the integrated Case Western Reserve University/ University Hospitals of Cleveland program.

In 1994 he completed a fellowship in orthopaedic trauma at the University of California Davis Medical Center. He has served in the past as Chair of the Board of Specialty Societies for the American Academy of Orthopaedic Surgeons. He currently chairs the Extremity War Injuries and Disaster Preparedness Project Team for the AAOS and for the past four years has served as Co-Chair for the annual Extremity War Injuries Conference.

Dr. Pollak is a former Commissioner for the Maryland Health Care Commission and a Past President of the Maryland Orthopaedic Association. His current responsibilities include Editor of the AAOS Orange Book Series, Medical Director of the Baltimore County Fire Department, Special Deputy US Marshal, and 2nd Vice President of the Orthopaedic Trauma Association.

# Lawrence G. Raisz, MD

Dr. Raisz is currently Board of Trustees Distinguished Professor of Medicine, Emeritus, Director of the UConn Center for Osteoporosis and Associate Director of the New England Musculoskeletal Institute at the University of Connecticut Health Center in Farmington, Connecticut. Dr. Raisz has been carrying out clinical and basic research in osteoporosis and bone metabolism for more than 40 years.

Dr. Raisz served as Scientific Editor of Bone Health and Osteoporosis: A Report of the Surgeon General. He is the vice president of the NOF Board of Trustees. He served on the NOF Scientific Advisory Board and was its Chair as well as the Chairman of the Education Committee from its inception and has been responsible for the development and production of many of the educational materials produced by NOF. He was a founder and second President of the American Society for Bone and Mineral Research (ASBMR) and the founding Editor of the Journal of Bone and Mineral Research.

Dr. Raisz has served on NIH Study Sections and advisory committees, numerous journal editorial boards and scientific advisory groups for national and international meetings on osteoporosis and metabolic bone disease. He served on the National Advisory Arthritis and Musculoskeletal and Skin Diseases Council.

He has received the William F. Neuman Award, the Shirley Hohl Service Award and the Gideon Rodan Excellence in Mentorship Award of the ASBMR, the Edwin B. Astwood Lecture Award of the Endocrine Society, an honorary degree from the University of Umea in Sweden and the Brackenridge Visiting Scholar Award from the University of Texas Health Science Center at San Antonio. He has authored more than 450 publications in the field of Osteoporosis and Bone Metabolism.

# Christy Sandborg, MD

Dr. Sandborg is Professor of Pediatrics at Stanford University School of Medicine where her research focuses on clinical studies and clinical trials in systemic onset juvenile arthritis and pediatric SLE, and access to pediatric rheumatologist expertise. She is the Director of the Division of Pediatric Rheumatology and Associate Chair of Pediatrics at Stanford School of Medicine, as well as Chief of Staff of the Lucile Packard Children's Hospital, and Director of the Child Health Research Program.

Sandborg is an internationally recognized leader in pediatric rheumatology, advocacy, education and research. She has served on many national committees, including the American Board of Pediatrics Subboard of Rheumatology, American College of Rheumatology Board of Directors and other ACR committees, local and national Arthritis Foundation in many capacities, and several NIH Special Study Sections and invited workshops. She has been a member of the scientific advisory committees of several foundations, including the Lupus Foundation of America, Arthritis Foundation Southern California Chapter, and the Lupus Clinical Trials Consortium.

Sandborg is one of the founders and immediate past-Chair of the Childhood Arthritis and Rheumatology Research Alliance, a network of pediatric rheumatologists in the US and Canada dedicated to clinical and translational research in pediatric rheumatic diseases. She has been the recipient of funding from the NIH, Arthritis Foundation, and other funding agencies, and she has mentored several pediatric rheumatology fellows and young faculty, who have received mentored career-development awards.

# Linda Sandell, PhD

Dr. Sandell's laboratory at the Washington University School of Medicine, St. Louis, Missouri, focuses on gene regulation of extracellular matrix proteins and its influence on the phenotype of cells. Of particular interest is the role of transcriptional and post-transcriptional mechanisms of regulation of protein expression in the differentiation of mesenchymal cell phenotypes such as cartilage, bone, muscle and adipose.

The Sandell laboratory has also had a long-standing interest in cellular mechanisms associated with chondrogenesis and endochondral bone formation and the discovery of new related extracellular matrix proteins and the interplay of positive and negative factors that regulate their expression. These anabolic and catabolic control mechanisms are of direct concern to the current understanding of the major cartilage disease, osteoarthritis.

Arising from an interest in cartilage, recent studies have focused on understanding the molecular basis of inhibition of angiogenesis and tumors invasion in cartilage and the application of these findings to cancer and other diseases where neo-vascularization must be inhibited.

# Ethel S. Siris, MD

Dr. Siris is the Madeline C. Stabile Professor of Clinical Medicine in the Department of Medicine, College of Physicians and Surgeons of Columbia University, and the Director of the Toni Stabile Osteoporosis Center of the Columbia University Medical Center, New York-Presbyterian Hospital, all in New York, New York. She is a graduate of Radcliffe College, Harvard University, and received her medical degree from the College of Physicians and Surgeons of Columbia University.

An endocrinologist, Siris works as a clinician, as a clinical investigator and as a medical educator, all in the area of metabolic bone diseases, including osteoporosis and Paget's disease of bone. She has worked extensively with the class of bisphosphonate compounds in these disorders as well as with selective estrogen receptor modulators (SERMS) in osteoporosis.

Dr. Siris served as the Medical Director of NORA, the National Osteoporosis Risk Assessment, a public health initiative and longitudinal study of osteoporosis that included over 200,000 postmenopausal women in the US. Most recently her research activity has focused both on risk factors for osteoporosis and treatment compliance with osteoporosis medications.

Dr. Siris is the immediate past president of the National Osteoporosis Foundation and currently serves on the Board of Trustees of both the National Osteoporosis Foundation in the US and the International Osteoporosis Foundation. She is a member and former vice chair of the Board of Directors of the Paget Foundation for Paget's Disease of Bone and Related Disorders. She has previously served on the Council of the American Society for Bone and Mineral Research and on the Endocrinologic and Metabolic Drugs Advisory Committee of the US Food and Drug Administration. She has published widely in the medical literature, is co-editor of the book, The Bone and Mineral Manual, and is a member of the editorial board of the Journal of Bone and Mineral Research.

# **Brian Tjugum**

Tjugum has 18 years of professional healthcare communications experience in the UK, Belgium, the US and developing countries. Much of his work has involved health policy activity for small and large NGOs, global private sector companies and numerous public sector agencies.

Heading up European Public Health projects for Weber Shandwick, he delivers pro bono strategic counsel to multi-national and UN organizations and currently: directs the Bill & Melinda Gates Foundation account in Europe; leads projects on non-communicable diseases for World Heart Federation; oversees NHS change management projects; runs a UK hepatitis health policy campaign; and guides a pan-European media relations and government affairs program to ensure musculoskeletal disorders remain high on policy-makers' health and employment agendas.

Six years prior, at Ogilvy PR Worldwide, he counseled public and private sector clients, launched new NGOs, collaborated with

multilateral organizations, led the research phases of a multi-year project to sensitize the public to clinical trial recruitment for an AIDS vaccine, and directed aspects of the Red Dress campaign to raise awareness of heart disease amongst women. He began his career in social marketing designing HIV prevention programs for the Academy for Educational Development, Washington, DC, and also worked at a social marketing research firm moderating focus groups on public health issues for government agencies.

Tjugum obtained a bachelor's degree from the University of Wisconsin-Madison and completed masters course work in public health at George Washington University and in marketing at University of California-Berkeley. He has published articles and contributed to book chapters on public health.

# Nicolas E. Walsh, MD

Dr. Walsh is Chairman and Distinguished Professor with tenure of the Department of Rehabilitation Medicine at The University of Texas Health Science Center at San Antonio. He was recently appointed President of the Medical-Dental Staff of University Health System for 2009-2010 and is also currently serving as the Acting Chief of Staff for the South Texas Veterans Health Care System.

Dr. Walsh is a member of the International Steering Committee of the Bone and Joint Decade: 2000-2010, a member of the International Society of PM&R, and author of many journals and book chapters. He has served as Chairman of the American Board of Physical Medicine and Rehabilitation, President of the Association of Academic Physiatrists, and as a member of the National Board of Medical Examiners. He has also served on many organizations and boards in the fields of Physical Medicine and Rehabilitation as well as Pain Medicine.

Dr. Walsh is a graduate of the University of Colorado School of Medicine in Denver, Colorado, and completed his residency at the University of Texas Health Science Center at San Antonio in the Department of Rehabilitation Medicine. He is Board Certified in both Physical Medicine and Rehabilitation and Pain Medicine. He is a

frequently invited lecturer at various professional meetings worldwide. He also serves as the Principal Investigator on several research projects at the University and VA.

# Michael Ward, MD, MPH

Dr. Ward is a rheumatologist and investigator in the Intramural Research Program, National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health.

Dr. Ward's research interests include clinical epidemiology and health outcomes of patients with rheumatic diseases, with a special interest in health disparities. He is currently an Associate Editor of Arthritis Care and Research, and former Associate Editor of Arthritis and Rheumatism and Arthritis Research and Therapy.

# James N. Weinstein, DO, MS

Dr. Weinstein is Director of The Dartmouth Institute for Health Policy and Clinical Practice, a leading health services research and educational organization studying and addressing reform of the U.S. health care system. He is also Chairman of the Department of Orthopaedics at Dartmouth Medical School and Dartmouth-Hitchcock Medical Center (DHMC), and an internationally renowned spine surgeon and researcher. He recently accepted the newlycreated position of Vice-Chair, Board of Governors, DHMC.

Dr. Weinstein has been a champion of "informed choice" among patients (as opposed to the traditional doctrine of informed consent). He founded the first Center for Shared Decision-Making in the United States, allowing patients to incorporate clinical trials evidence into decisions about their health care choices. The Spine Center at Dartmouth, which he established, has become a model for informed choice and patient-centered care, transparently presented on the web, drawing administrators and colleagues from around the world who wish to replicate the Center in their own institutions. In testimony before Congress, published research, and frequent participation in conferences, he has demonstrated the financial, patient satisfaction, and outcomes benefits of shared decision making.

A practicing spine surgeon, Dr. Weinstein is a leader in the diagnosis, treatment and study of spinal disorders. He developed the primary classification system used for treating spine tumors, now used around the world. His animal models for studying low back related symptoms have been recognized by the Bristol-Myers Career Research Award and the prestigious Kappa Delta Award. In 2006, he was only the 7<sup>th</sup> person to receive the Wiltse Lifetime Achievement Award from the International Society for the Study of the Lumbar Spine.

Dr. Weinstein's research has received more than \$37 million in federal funding. He is the Principal Investigator of the Spine Patient Outcomes Research Trial (SPORT), the largest study funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health. He also directs the NIH sponsored, Multidisciplinary Clinical Research Center in Musculoskeletal Health Care at Dartmouth and a T32 NIH training grant. He is editor-in-chief of Spine, an international, peer-reviewed, multidisciplinary journal, highly ranked in its field by Scientific Content Index. His published research numbers in the hundreds of articles. He was recently named to the editorial board of Health Affairs, the leading US policy journal.

Dr. Weinstein has served on many national and international committees, including the NCQA Spine Care Advisory Committee whose work resulted in the Back Pain Early Recognition Program; the National Quality Forum: Episodes of Care Working Group (AMI and Back Pain); and the Blue Cross Blue Shield National Advisory Board for new technologies.

He participated in the institute of Medicine's roundtable workshops covering evidence-based medicine, identifying highly effective clinical services, and shared decision making. Recently, he was nominated by the Secretary of Health and Human Services to serve a three-year term on the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Council. He is a member of the Institute of Medicine and serves the Committee of Medical Experts to Assist Social Security on Disability Issues and the Committee on Comparative Effectiveness Research Priorities.

Dr. Weinstein also serves on the American Board of Orthopedics and heads their public reporting research initiatives.

He was named the 2008 Outstanding Physician in Practice by the Care Continuum Alliance, a national organization that promotes the role of population health improvement in raising the quality of care, improving health outcomes and reducing preventable health care costs for individuals with chronic conditions and those at risk of developing chronic conditions.

Dr. Weinstein and colleagues at TDI are frequently sought after for their strategies and tactics around the national health care crisis and recently testified before the Congressional Budget Committee about NIH and health-care funding.

As Director of The Dartmouth Institute for Health Policy and Clinical Practice, he believes "knowledge informs change" and is committed to practicing and teaching this every day. The bridging of the clinical, research, and policy worlds are mirrored in his stated vision for TDI: "to achieve a patient-centered, high-quality, costeffective health care system with access and excellence for all."

# Stuart L. Weinstein, MD

Dr. Weinstein is the Ignacio V. Ponseti Chair and Professor of Orthopaedic Surgery at The University of Iowa. He received his AB Honors degree in Political Science and History from the University of Illinois in 1968. He received his medical degree (Alpha Omega Alpha) from the University of Iowa in 1972. After interning in Internal Medicine at The University of California-San Francisco, he returned to the University of Iowa for a residency in Orthopaedic Surgery. In 1976, he joined the faculty of the Department of Orthopaedic Surgery at The University of Iowa.

Dr. Weinstein is an NIH funded researcher. He has published more than 180 scientific articles in peer review journals on a wide variety of pediatric orthopaedic conditions. His research work has focused on spinal deformity in children, children's hip and foot problems, and the natural history and long-term outcome of pediatric musculoskeletal conditions. He has edited three major textbooks including The Pediatric Spine:

Principles and Practice; Lovell and Winter's Pediatric Orthopaedics and Turek's Orthopaedics.

Dr. Weinstein's many contributions to orthopaedics have been recognized by his receipt of the Bristol-Myers Squibb/Zimmer Award for Distinguished Achievement in Orthopaedic Research; The Kappa Delta /Orthopaedic Research and Education Foundation Clinical Research Award; The Russel Hibbs Award for Clinical Research given by the Scoliosis Research Society; and The Arthur H. Heune Memorial Award, given by the St. Giles Foundation and The Pediatric Orthopaedic Society of North America in recognition of outstanding research contributions to pediatric orthopaedics.

In 2005, Dr. Weinstein was the recipient of the Alfred R. Shands, Sr., MD Award, presented by the Orthopaedic Research Society and The American Orthopaedic Association. This award is presented each year to a US or Canadian citizen who has made significant contributions to orthopaedics. It recognizes the devotion of a significant portion of the professional lifetime to furthering knowledge in the fields of musculoskeletal disease.

# **Professor Anthony D. Woolf**

Prof. Woolf is Professor of Rheumatology, Institute of Health Care Research, Peninsula College of Medicine and Dentistry, Universities of Exeter and Plymouth and Consultant Rheumatologist at the Royal Cornwall Hospital, Truro, UK.

He is a clinical academic rheumatologist and his special interests are in the burden of musculoskeletal conditions, the management of musculoskeletal conditions, medical education and osteoporosis on which he has written widely. He is involved in various initiatives to raise awareness of the impact of musculoskeletal conditions and priority for education, prevention, treatment and research at a national, European and global level.

He is a founder member of the Bone and Joint Decade 2000-2010 International Steering Committee. He leads the Bone and Joint Monitor Project, a global health needs assessment that provides the evidence base for the Decade; edited the WHO Report on the Burden of Musculoskeletal conditions at the Start of the New Millennium; and coordinated the European Bone and Joint Health Strategies project. He is co-lead of the Musculoskeletal Expert Group currently revising the Global Burden of Disease and is leading the European Musculoskeletal Surveillance and Information Network — a new initiative supported by the European Community to promote a comprehensive strategy to minimize the impact of musculoskeletal conditions across Europe.

He is editor-in-chief of Best Practice and Research Clinical Rheumatology; and Past President of the European Board of Rheumatology and of the Section of Rheumatology of the UEMS.

# Ed Yelin, MD

Dr. Yelin received his doctorate from the Department of City and Regional Planning, University of California, Berkeley (1979). His undergraduate degree is from the University of Chicago (Public Affairs, 1972). Dr. Yelin's research has emphasized the health policy issues related to chronic disease, with a focus on rheumatic diseases. Dr. Yelin is perhaps best known for his work on employment among persons with arthritis and other chronic diseases.

A second major thread to his research concerns studies of the impact of changes in the health care system on persons with arthritis. Briefly, he has shown that the pre-paid group practice form of health maintenance organization provides similar kinds and amounts of care for rheumatoid arthritis and has achieved similar outcomes over as long as 11 years. However, rheumatologists, the subspecialists for arthritis, achieved significantly better outcomes than generalist physicians, and their patients use fewer resources. Recently, however, he has shown that a smaller proportion of persons in managed care environments use the biological response modifiers for rheumatoid arthritis than those in fee-forservice settings. And he has shown that the fissures between HMOs and fee-forservice appear to be wider for persons with systemic lupus erythematosus.

Dr. Yelin has also been involved in studies documenting the economic and social impacts of chronic disease and disability. Most recently he authored the chapter on health care utilization and costs in The Burden of the Musculoskeletal Diseases in the US. Dr. Yelin has recently been named the Director of the Effectiveness Center for the California Health Benefits Review Program (CHBRP). With colleagues from the University Office of the President, UC, Berkeley, and UCLA, CHBRP evaluates potential health insurance mandates for the State Legislature.

Dr. Yelin has received numerous awards for his research and, in 1999, was elected to membership in the National Academy of Social Insurance, an organization of the foremost figures in research and policy related to health care, public income programs, and disability.

# Jill Zarin, advocate

Jill Zarin is an advocate and cast member of Bravo TV's "The Real Housewives of New York City." Her daughter, Allyson Shapiro Zarin, has struggled with Spondyloarthropathy her whole life.

On the TV show, Zarin has been a spokeswoman for her daughter's struggles with arthritis in addition to being a key advocate. At the end of last season, Zarin threw a fundraiser reception that raised nearly half a million dollars for Creaky Joints.

When Zarin is not preparing Allyson for college or helping her husband Bobby run their business, Zarin Fabrics, she juggles a calendar full of charity events and galas. When her daughter traveled to France to study for the summer, Zarin quickly immersed herself working for the "Help for Orphans" charity, then gathered the other "Housewives" to help a friend with a major charity event, "People Reaching Out."

"The Real Housewives of New York City" follows six glamorous women as they balance motherhood, demanding careers and a fast-paced social calendar in the most exclusive areas of New York.

# Joseph D. Zuckerman, MD

Dr. Zuckerman is currently the President of the American Academy of Orthopaedic Surgeons. He is also Chairman of the Department of Orthopaedic Surgery at NYU Hospital for Joint Diseases and is the Walter A. L. Thompson Professor of Orthopaedic Surgery at NYU School of Medicine.

A graduate of Cornell University, he received his medical degree from the Medical College of Wisconsin where he was a member of the Alpha Omega Alpha Medical Honor Society. He completed his residency in Orthopaedic Surgery at the University of Washington Affiliated Hospitals in Seattle followed by a fellowship in Adult Reconstructive Surgery/Arthritis Research at Harvard's Brigham and Women's Hospital in Boston. He was then a Visiting Clinician in shoulder surgery at the Mayo Clinic.

Dr. Zuckerman joined the faculty of the Hospital for Joint Diseases in 1984. In 1990 he was appointed Vice-Chairman and Director of the Orthopaedic Residency program. In 1994, he was appointed Chairman of the Department of Orthopaedic Surgery and Surgeon-in-Chief. In 1997, he became Professor and Chairman of the NYU Hospital for Joint Diseases Department of Orthopaedic Surgery and initiated a merging the two departments.

Dr. Zuckerman is recognized internationally as an expert in shoulder surgery and hip and knee replacement and as an orthopaedic educator. During his tenure, he has been instrumental in developing and overseeing one of the largest and most renowned orthopaedic programs in the country, providing orthopaedic care at five different hospitals including Tisch Hospital, the Hospital for Joint Diseases (now known as NYU Hospital for Joint Diseases), Bellevue Hospital Center, the Manhattan Veteran's Administration Medical Center and Jamaica Hospital. He served as the Director of the NYUHJD Orthopaedic Surgery Residency Program, which trains over sixty residents in a five-year program from 1990-2006. This is the largest orthopaedic surgery residency program in the country.

Dr. Zuckerman has received a number of distinguished awards including the Clinical Research Award from the Orthopaedic Research and Education Foundation (OREF) and the Mel Post award from the American Shoulder and Elbow Surgeons. In 1991, the American Orthopaedic Association selected him as an American-British-Canadian Traveling Fellow. He received Teacher of the Year award from the NYUHJD orthopaedic residents on five occasions. In 2004, he was recognized as Alumnus of the Year by the Medical College of Wisconsin and in 2005 he received the Lifetime Achievement Award from the New York Chapter of the Arthritis Foundation.

Dr. Zuckerman is a spokesperson for the American Academy of Orthopaedic Surgeons and an editorial board member of several prominent orthopaedic and medical journals and a member of the Board of Trustees of the Journal of Shoulder and Elbow Surgery. He is the author or editor of 14 orthopaedic textbooks and more than 275 scientific articles.

He maintains an active role in several national organizations. He is the past President of the American Shoulder and Elbow Surgeons. He has also served as Chair of the Council on Education for the AAOS and in this position completed a sixyear term as a member of their Board of Directors.

Dr. Zuckerman's research initiatives have focused primarily in the area of outcomes research with a particular emphasis on hip fractures and shoulder surgery. In 1986, he established the Hip Fracture Research Group at HJD with the goal of increasing our understanding of the problem of hip fractures, as well as developing improved treatment programs to improve outcomes. These efforts have significantly improved our understanding of recovery from this important injury in the elderly. In 1991, he established the Shoulder Research Group which has focused on the study of fractures about the shoulder, rotator cuff problems and the treatment of shoulder arthritis. He has been active in the design of a new prosthesis used to treat glenohumeral arthritis and complex shoulder fractures.

In addition to Dr. Zuckerman's educational, research and administrative responsibilities, he maintains an active clinical practice specializing in shoulder surgery and hip and knee replacements, performing over 250 operative procedures each year.

#### YOUNG INVESTIGATOR POSTERS

Clinical research in the musculoskeletal diseases performed by young investigators is not keeping pace with the increasing burden of these diseases. Bone and Joint Decade Canada and the United States Bone and Joint Decade offer a grant mentoring program to provide early-career clinical investigators an opportunity to work with experienced researchers in our field to assist them in securing funding. The goal of the program is to increase the number of funded clinical investigators in the musculoskeletal sciences.

The young investigators displaying posters during the Global Network Conference are some of the program participants that have received funding. Of the 168 young investigators that have been accepted into the program, 61 have obtained funding for a total of \$33,713,737 since they began.

# Nancy Baker, ScD, OTR/L

- Problems & Coping Strategies Reported by Computer Users with RA
- Association Between Hand Impairment & Hand Function in RA

# Sasha Bernatsky, MD, FRCPC

• Malignancy Risk in Juvenile Idiopathic Arthritis

#### Terese Chmielewski, PT, PhD

Clinical Factors that Differ Between
Return to Sport Status Groups in
Patients with ACL Reconstruction

# Constance R. Chu, MD

- Integrating Bench to Operating Room
- Cartilage Tissue Engineering

# Megan Clowse, MD, MPH

• Diminished ovarian reserve after cyclophosphamide in women with Wegener's Granulomatosis

# Matthew B. Dobbs, MD

• Gene Discovery in Pediatric Musculoskeletal Genetics

# Mark Ehrensberger, PhD

 Titanium Electrical Polarization on Pre-osteoblasts

# Leslie R. Harrold, MD, MPH

- Patients' & Providers' Views of Gout Management: a qualitative study
- Rheumatologists' Prescribing Patterns for RA Patients with Active Disease
- Real World Utilization of Nonbiologic & Biologic Disease Modifying Anti-Rheumatic Drugs in RA: A Systematic review of the Literature

# Carolyn Hettrich, MD

 Role of Mechanical Loading in Tendon to Bone Healing

# Dina Jones, PhD., PT

 The Natural History of Physical Activity Up to Twelve Months After Primary Total Knee Arthroplasty for Osteoarthritis

# Yasser Salem, PT, PhD, NCS, PCS

 A Community-Based Group Aquatic Program for Individuals with Multiple Sclerosis

#### Carla Scanzello, MD, PhD

 Acute Meniscal Injury is Associated with Synovial Inflammation: Cellular & Molecular Characterization of Synovitis

# Chwan-Li (Leslie) Shen, BS, MS, PhD

GTP and Tai Chi for Bone Health

# Janet A. Yu-Yahiro, PhD

• The effect of a one-year exercise program on markers of bone metabolism after hip fracture.

# Veronica Wadey, BPHE, B.Ed., MD, MA, FRCSC

- Optimizing Functional Outcomes in Patients Discharged 4 Days After Total Knee Replacement-A Pilot Study
- MSK Health Innovation in Education Project

# Yejia Zhang, MD, PhD

 Fibronectin Alternative Splice Variants in the Human Intervertebral Disc BEYOND THE DECADE
STRATEGIC PLANNING

#### **BEYOND THE DECADE**

# An Introduction to the Strategic Planning Exercise and Executive Summaries

The Washington conference marks the final year of the global Bone and Joint Decade – but it is not an end, rather the end of the beginning. This makes both the conference and the following months an exceptional opportunity for us as an organization to reflect on what we have achieved, where we will go next and how to get there. Indeed, only with consensus and partnership can we be confident of ourselves and the work we do as we look to the Second Decade, after the BJD Global Network Conference to be held in Lund, Sweden, next year.

To this end, the USBJD Board in consultation and with the assistance of members of the BJD International Steering Committee, began a year ago to put in place some of the groundwork for the Washington conference that would provide attendees with the opportunity to discuss and shape the key issues and areas of focus for a Second Decade. The Board began with the insight that the Decade can certainly do more to raise awareness of bone and joint issues as well as serve as an advocate for change in musculoskeletal health. Additionally, collaboration and specific measures for the outcomes of the program we undertake would add credibility to the work we do.

Keeping this in mind, six working **Strategic Planning Specialty Groups (SPSG)** were identified which were tasked with identifying the key priority areas for specific streams of activity covering the condition areas of primary concern to the Decade, suggesting goals for these areas, and begin to think about what activities might move the Decade towards these proposed goals. The areas are: Arthritis, Bone Health and Osteoporosis, Pediatric Musculoskeletal Disease, Research, Spinal Disorders and Low Back Pain, and Trauma and Injury.

Over the past year, each group, made up of between 9 and 20 participants, led by one or two chairs, have worked via teleconference and email to create proposed outlines to be presented and discussed at the Washington conference, with a view to beginning the process of consensus on the activities of a second Bone and Joint Decade that will ultimately be prepared for the Lund conference in 2010, with a final handover presentation to the World Health Organization (WHO) in Geneva.

Over the course of Friday and Saturday, there will be three break-out sessions

- A 90-minute break-out to review the preliminary proposed outlines for each theme, discuss what the key issues are and prioritise them, and agree key objectives and outcomes
- 2. A 90-minute break-out to discuss **how** the issues can be addressed, identifying target audiences and strategies
- 3. Finally, regrouping according to world regions, in a 90-minute break-out, you will identify specific actions and a timeline for achieving them

What are we asking you to do?

- Read the executive summaries ahead of time, with particular emphasis on the group you will be joining
- Participate fully in discussions: bring ideas, challenge conventional wisdom, think strategically
- Use the break-out sessions as fodder for further discussion during the conference's networking opportunities

The Decade gratefully acknowledges Weber Shandwick for their support by allowing Brian Lotspeich and John Tjugum to act as facilitators for the Beyond the Decade sessions.

#### STRATEGIC PLANNING SPECIALTY GROUPS

# **MEMBERS**

#### **Arthritis**

Eric P. Gall, MD, MACP, MACR – Co-Leader Christy Sandborg, MD – Co-Leader Joseph A. Buckwalter, MD Najia Hajjaj-Hassouni, MD Dina Jones, PT, PhD Armin U. Kuder, Esquire Alan Morton, DO Ranit C. Shriky, BA Patience White MD, MA

# **Bone Health & Osteoporosis**

Steven R. Goldring, MD – Co-Leader Kristina Åkesson, MD, PhD – Co-Leader Roberta Biegel Ann L. Elderkin, PA Liana Euller-Ziegler, MD Timothy L. Kauffman, PT, PhD John D. Kaufman, MD Ghassan Maalouf, MD Lawrence G. Raisz, MD

#### **Pediatric**

Paul Caskey, MD - Co-Leader Paul W. Esposito, MD - Co-Leader Nuno Alegrete, MD Peter Brooks, MD, FRACP, FRCP Edin Robin Crandall, MD Howard Epps, MD Lisa M. Esposito, MS, RD, CSSD, LN Edward D. Harris, Jr., MD Lawrence (Larry) Jung, MD Joan M. Lappe, PhD, RN, FAAN Kellie Leitch, MD Michael A. Levine, MD Jose Morcuende, MD, PhD Jose R. Romero, MD, FAAP David A. Spiegel MD Laura L. Tosi, MD

#### Research

David B. Burr, PhD - Leader Jane E. Aubin, PhD Boyd R. Buser, DO, FACOFP Michael J. Econs, MD John Eisman, AO Marian T. Hannan, DSc, MPH Mieke Hazes, MD, PhD Lisa Heral, RNBA Mark L. Johnson, PhD Sundeep Khosla, MD Craig B. Langman, MD Masaki Noda, MD, PhD Graham Russell, PhD, DM, FRCP Kenneth G. Saag, MD, MSc Kimberly J. Templeton MD Kristy Weber, MD Joan A. McGowan, PhD J. Edward Puzas, PhD

# Spinal Disorders/Low Back Pain

Sigurd Berven, MD - Leader Peter B. Ajluni, DO Gunnar B. J. Andersson, MD, PhD Oheneba Boachie-Adjei, MD John P. Dormans, MD Paul Dougherty, DC Karsten Dreinhoefer, MD Michael Furman, MD Gregory E. Hicks, PT, PhD Cynthia M. Howe, RN, MSN, ONC Arvind Jayaswal, MD Barry S. Smith, MD Nicolas E. Walsh, MD

# Trauma & Injury

Andrew N. Pollak, MD - Leader Wahid Al-Kharusi, MD Peter C. Amadio, MD Kristin R. Archer, PhD, DPT Michael J. Bosse, MD Bruce D. Browner, MD Kai-Ming Chan, MD Karsten Dreinhoefer, MD Eric D. Farrell, MD Satish Goval, MD Cynthia M. Howe, RN, MSN, ONC Kenneth J. Koval, MD Ellen J. MacKenzie, PhD Jay Magaziner, PhD, MSHyq Marcos E. Musafir, MD Scott Rodeo, MD Laura L. Tosi, MD Nikhil Verma, MD Kevin R. Vincent, MD, PhD James P. Waddell, MD, FRCSC

# STRATEGIC PLANNING SPECIALTY GROUPS EXECUTIVE SUMMARIES

#### BONE AND JOINT DECADE

# **Arthritis Strategic Planning Specialty Group**

# **Executive Summary**

# Introduction

Arthritis is the most common cause of chronic disability worldwide. The past bone and joint decade has made major advances in developing programs for public education, public health, advocacy, improving research and other programs to better the lot of the millions of people who suffer from the broad range of diseases included under the term "Arthritis". The next decade is key in solidifying what has been done and in making the next step in continuing to improve the burden of people suffering from these illnesses. This document outlines the overall purpose of the planning group, the background, barriers and opportunities. Priority Area issues, goals, and objectives for addressing each Priority Area. The Arthritis Strategic Planning group identified the following principles to guide our approach. The process needs to address global issues, while highlighting differences between developed and underdeveloped countries where needed. Concepts should be simple, focusing not on what needs to be done as this will vary significantly from country to country, but what the major approaches should be with respect to developed and underdeveloped countries, providing a broad foundation for focus by each region in the future. These strategies should leverage the strengths of the BJD and collaborative organizations in each region. In addition we identify opportunities for helping one another and developing broad international programs and the pooling of resources.

Our approach is to facilitate collaboration, and identify strategies that specifically leverage the unique opportunities available through the consortium of organizations in the Bone and Joint Decade. These include professional health organizations (e.g., rheumatology, orthopedic, osteopathic, chiropractic, general medicine, nursing, physical therapy, etc.), voluntary arthritis advocacy organizations and patient/family organizations (e.g., Arthritis Foundation in US, EULAR in Europe, AFLAR in Africa, PANLAR in Asia and other national and international charitable organizations.

#### Priority Areas/Issues

- 1. Public Education
- 2. Education of Policy Makers
- 3. Access to Health Care Providers with Expertise in Arthritis
- 4. Prevention and Early Diagnosis and Prevention
- 5. Research
- 6. Sustainability for Ongoing BJD Initiatives Related to Arthritis

# Priority Area #1: Public Education

- Issue: Lack of awareness of the burden of disease and opportunities for prevention and treatment.
- Goal: Increase public awareness of arthritis related health promoting behaviors
  - **Global Objective:** BJD organizations will work to establish a public awareness process regarding arthritis health promoting behaviors in all regions/countries.

# Priority Area #2: Education of Policy Makers (Government and Non-Government)

- Issue: Lack of awareness of the burden of disease and opportunities for prevention and treatment.
- Goal: Increase policy makers' awareness that arthritis is a significant health priority
  - **Global Objective:** Increase funding for public health initiatives, professional training, research, health care system resources for arthritis care through collaborating with arthritis advocacy groups (e.g., AF, Lupus Foundation, EULAR, for developed and ILAR and member organizations for underdeveloped countries) in lobbying efforts for increasing funding for resources to address public health initiatives, professional training, research, health system resources for arthritis care.

# Priority Area #3: Access to Health Care Providers with Expertise in Arthritis

- Issue: Limited access to health care providers with expertise in arthritis results in poor outcomes
- Goal: Increase arthritis related expertise in primary care givers and specialists
  - **Global Objective**: Establish basic musculoskeletal curricula for xx% medical schools and health oriented professional schools.
    - Developed Countries: Advocate for inclusion of musculoskeletal and arthritis related curricula in all medical and professional schools through collaboration with BJD organizations and academic centers.
    - Underdeveloped Countries: Advocate for inclusion of musculoskeletal and arthritis
      related curricula in all medical schools (as first step) through collaboration with BJD
      organizations and academic centers. Evaluate the role of trained health workers
      with special training in arthritis for community health centers.
  - **Global Objective:** Develop cost effective process to disseminate arthritis specific educational tools free of cost.
    - Collaborate with BJD member organizations to create easy free or low cost dissemination strategies leveraging existing technologies (on-line, social networking, wikis) to distribute tools.
  - Global Objective: Increase arthritis specialty care giver workforce.
    - Developed and Underdeveloped Countries: Perform workforce studies in collaboration with BJD organizations, and utilize information to encourage individuals to enter arthritis related specialties.
    - *Underdeveloped Countries*: Develop health assistants with expertise in musculoskeletal health and disease to improve treatment and triage of more serious conditions.

# Priority Area #4: Prevention and Early Diagnosis and Prevention

- **Issue:** Public health policy and health care systems do not support arthritis prevention or early diagnosis and management that could improve outcomes in arthritis.
- **Goal:** Increase health care system prioritization of development and dissemination of standardized protocols and public health resources focused on improving prevention, early diagnosis and management of arthritis.
  - *Global Objective:* Develop and disseminate standardized protocols for prevention, diagnosis and management of arthritis to primary care and arthritis providers.

# Priority Area #5: Research

- **Issue:** Research in musculoskeletal disease does not reflect the burden of disease. It takes a back seat to many other health conditions which are more dramatic but less of an economic burden and /or less prevalent.
- **Goal:** Increase health care system prioritization of research through allocation of research dollars for arthritis related issues.
  - *Global Objective*: Increase research in the epidemiology, outcomes, and comparative effectiveness of treatments.

# Priority Area #6: Sustainability for Ongoing BJD Initiatives Related to Arthritis

- Issue: No infrastructure to support ongoing BJD initiatives globally.
- **Goal:** Establish international coordinating rheumatology organization to focus on arthritis related issues in both underdeveloped and developed countries.
  - **Global Objective**: Establish international coordinating organization, i.e. ILAR and its member organizations or an international BJD committee dedicated to arthritis in partnership with other relevant organizations, to focus on facilitating the BJD Arthritis Strategic Plan in developed and underdeveloped countries.

Discussion of our group along with interested parties attending the Global Bone and Joint Decade meeting will allow us to look more closely with a wider spectrum of individuals to see if there are areas that we have not anticipated or missed and to further prioritize our goals. Once this is done geographic regions will be able to further adapt these issues to their own priorities. The "Next Decade" will allow us to take the steps to assure that we are able to reduce the burden of Arthritis.

#### BONE AND JOINT DECADE

# Bone Health and Osteoporosis Strategic Planning Specialty Group

# **Executive Summary**

# Introduction

Although there have been important advances in our understanding of bone health and new methods to prevent, diagnose and treat osteoporosis and related bone diseases, these advances have not been adequately disseminated or implemented. Osteoporosis is under diagnosed and under treated worldwide, with osteoporotic fractures contributing significantly to increased morbidity and mortality, as well as rising medical costs.

To address these concerns and chart a course for the future, this document identifies four priority areas where concerted and coordinated efforts by nations of the world can make significant improvements in the prevention, diagnosis and treatment of osteoporosis and related bone diseases, as listed immediately below. Each of these correlate to the Bone and Joint Decade mission-related areas of raising awareness, advocacy, education and research.

This document outlines recommended goals and objectives for each of the Priority Areas, identifies potential barriers and facilitators, and provides a framework for establishing action items, timelines, and those responsible for priorities and programs for health professionals, health systems and population-based approaches to promote bone health. The plan outlines a global approach while recognizing that each country or region will need to tailor it to its own resources and opportunities.

# **Priority Areas/Issues**

- 1. Develop a Bone Health Alliance
- 2. Promote Bone Health and Prevent Disease
- 3. Improve Diagnosis and Treatment
- 4. Enhance Research, Surveillance, and Evaluation

# Priority Area #1: Develop a Bone Health Alliance

The first Priority Area is to develop a Bone Health Alliance that can serve as a collaborative, ongoing infrastructure to support efforts to increase awareness of bone health among the public and professionals, and to develop prevention, diagnosis and treatment approaches.

A major goal is to forge an international alliance focused on bone health issues. An organizational structure should be developed in one of the existing bone health organizations. International stakeholder organizations should be recruited to develop a shared vision, mission and priorities. Key working groups should be established to coordinate efforts in specific areas. Bone health information from government and non-governmental sources should be coordinated and made widely available. Social marketing campaigns should be strategically developed and disseminated for maximum impact. A related goal is to collaborate with organizations whose messages about healthy lifestyles dovetail with messages about improving bone health, and to foster connections with other chronic disease groups and professional organizations.

# Priority Area #2: Promote Bone Health and Prevent Disease

The second Priority Area is to promote bone health and prevent disease. Since optimizing bone health must begin early and continue throughout life, goals have been established to promote good nutrition and physical activity, as well as fracture prevention in older adults.

A key goal is to build the capacity of health care providers to focus on bone health across the lifespan, working with leading health professional organizations to help primary care providers emphasize good bone health in children and adolescents, and fracture prevention in older adults.

Health care professionals in emergency departments and orthopedic practices need to be helped to view bone fractures as a sentinel event that needs a coordinated intervention. Another goal is to promote vitamin D and calcium supplementation, with a focus on revising the adequate intake level for vitamin D. An additional goal is to promote policy change, making the prevention of osteoporosis and related fractures a governmental health care priority in all countries.

# **Priority Area #3: Improve Diagnosis and Treatment**

The third Priority Area is to improve diagnosis and treatment of osteoporosis and related bone diseases. Despite significant advances in the diagnosis and treatment of bone diseases, further research is needed. Evidence-based treatments need to be adequately covered. Importantly, there needs to be a focus on fracture as a sentinel event.

Thus, a major goal is to find better ways to diagnose disease and assess risk, to further develop existing and new tools to understand who is at risk and how best to initiate treatment and prevention. Another goal is to address issues of adequate reimbursement, or coverage of costs, for evidence-based treatments such as DXA, rehabilitation and exercise programs. An important goal is to focus on fracture as a sentinel event in bone health management, which will involve professional education, the development of bone health curricula for health professionals, and a focus on optimal fracture management including timely surgery when necessary and rehabilitation, both essential in the prevention of further falls and fractures.

# Priority Area #4: Enhance Research, Surveillance, and Evaluation.

The fourth Priority Area is to enhance research, surveillance, and evaluation. Even with optimal management, there will still be many undiagnosed patients and many fragility fractures. It will be important to continue cutting-edge research, collect and analyze data, and evaluate existing programs to highlight promising practices and translate critical findings to the field.

One of the goals is to continue and expand research now underway, and to find ways to make more effective use of existing research through the translation of knowledge into clinical practice. A second goal is to collect and analyze data to better understand who is at risk and improve prevention, diagnosis, and treatment. This will involve country or regional audits to identify gaps and opportunities in current data collection by collecting baseline data through available mechanisms. A third goal is to evaluate the effectiveness of public education programs by conducting an inventory of public education programs at all levels and conducting evaluations of programs to determine the most effective models.

# **Summary/Conclusions**

The draft strategic plan for bone health and osteoporosis will be presented and discussed at the BJD09 Global Network Conference. Input from these discussions will further shape the plan. Once consensus is reached on the plan, countries and regions will be asked to ratify the plan over the next year. At the same time, individual countries and regions with their own action plans will continue with their efforts and have new opportunities to collaborate with others working on similar initiatives. Other countries and regions might initiate new activities from the plan. It is recommended that there be a meeting at the next BJD Global Networking Conference to assess progress and establish priorities for the coming year.

#### BONE AND JOINT DECADE

# Pediatric Musculoskeletal Conditions Strategic Planning Specialty Group

# **Executive Summary**

# Introduction

The goal of the group was to identify areas with the most significant impact on the musculoskeletal health of the greatest number of children around the world. The central goal for all of the priority areas is to significantly improve the musculoskeletal health and function of children through educational activities and advocacy through the BJD and its member organizations.

The group further identified that individuals with childhood onset chronic neuromuscular and musculoskeletal disorders are increasing in number and face significant challenges in terms of access to quality medical care and significant functional barriers both as children but also as they transition to adulthood.

Additional experts from member organizations will be enlisted to further define these priority areas and the means to achieve positive change.

# **Priority Areas/Issues**

- 1. Healthy Lifestyles
- 2. Infectious Disease of the Musculoskeletal System
- 3. Trauma Prevention
- 4. Limb Deficiency in Children
- 5. Optimizing Bone, Joint and Muscle Function in Children with Chronic Neuromuscular and Musculoskeletal Disorders
- 6. Successful Transition from Pediatric to Adult Care for Persons with Childhood Onset Musculoskeletal Disorders
- 7. Specific Disorders

# **Priority Area #1: Healthy Lifestyles**

The group agreed that one of the areas with the greatest potential impact the BJD could have on the greatest number of individuals would be in the area of healthy lifestyles for children. Emphasis should be on coordination of the efforts of the member organizations toward education and advocacy so that all children reach their full musculoskeletal potential.

- **A) Impact of obesity on the musculoskeletal health of children:** This is one of the most remedial health problems of children which are increasing in frequency and in terms of intensity of burden of disease. The impact of obesity extends into adulthood with potentially grave consequences.
- **B)** Development of ideal bone mass and strength though exercise and diet: In growing children, nutrition and activity are important determinants of current and future strength and quality of bone and muscle. Lack of affordable, high quality foods, adequate calcium and vitamin D intake, and poor dietary choices interfere with the development of optimal bone mass and strength. The goal is to change attitudes, and to educate, focusing on exercise and diet.

# Priority Area #2: Infectious Disease of the Musculoskeletal System

- A) Antimicrobial resistance and morbidity is a growing problem worldwide. The incidence of complications related to bone and joint infections in pediatric patients are increasing.
- B) Despite extensive experience in the treatment of bone and joint infections in children, no uniform guidelines exist for their management as do for other conditions.

*Goal:* There is a need to optimize prevention strategies and therapeutic pathways for pediatric bone and joint infections in resource-poor environments.

# Priority Area #3: Trauma Prevention

The pediatric strategic planning group agreed that the trauma planning group should lead this effort, and that we should support, but not duplicate, their efforts.

# Priority Area #4: Limb Deficiency in Children

- A) Child limb deficiency, either acquired or congenital, is relatively uncommon but requires lifelong medical and frequently surgical services, and has a major financial, functional, and psychosocial import on these children. The cost of prosthetic services and ongoing rehabilitative services can be overwhelming, both in the developed and developing world.
- B) To live a healthy lifestyle with limb deficiency requires access to appropriate prosthetic, surgical and rehabilitative services.

*Goal:* The main goal is to advocate and educate to assure access to appropriate prosthetic, surgical, and rehabilitation services for children with either acquired or congenital limb deficiency.

# Priority Area #5: Optimizing Bone, Joint and Muscle Function in Children with Chronic Neuromuscular and Musculoskeletal Disorders

Children with chronic neuromuscular and musculoskeletal disorders face unique and special medical, physical and psycho social challenges. Children with these disorders, including chronic inflammatory diseases, as well as other congenital or acquired childhood musculoskeletal disorders can today live well into adulthood with appropriate medical treatment and support.

Goal: It is therefore critically important to develop and make available programs that can optimize bone, joint and muscle function for these children

# Priority Area #6: Successful Transition from Pediatric to Adult Care for Persons with Childhood Onset Musculoskeletal Disorders

Most children with significant or severe childhood musculoskeletal disease can today expect to live well into adulthood with appropriate medical treatment. There disorders also may worsen with age, and they may have decreased function, even as they lose access to appropriate medical care.

*Goal:* To improve the transition from pediatric to adult care and support for persons with childhood onset musculoskeletal disorders.

# Priority Area #7: Specific Disorders

A) The group agreed that we should maintain a separate priority to cover specific disorders for which the USBJD could impact outcome through targeted educational efforts and/or coordination of resources.

These include but are clearly not limited to:

- Clubfeet
- Developmental Hip Dislocation
- Slipped Capital Femoral Epiphysis
- B) The group recognizes that for rare, metabolic bone diseases, the Rare Bone Disease Patient Network is the most appropriate venue within the USBJD to pursue education and advocacy for rare but important musculoskeletal diseases.

*Goal:* One area of discussion included developing an online resource through the USBJD to coordinate an online library of resources and contacts from member organizations with interests and expertise in dealing with specific diagnosis and disorders.

# **Summary/Conclusions**

There are many priorities listed, all of which the planning group felt were important, and recognized that these priorities could not be resolved during a short meeting. However, the overarching goal of the committee was to bring attention to the most significant issues affecting the musculoskeletal health of children. If a general consensus is reached that these priorities address the concerns of the worldwide members, it is proposed that the leaders of the priority sections of the Pediatric Strategic Planning group enlist and coordinate the efforts of the member organizations and their identified experts in these priority areas to further develop a plan to achieve the goals expressed in the draft strategic planning document. This effort would include developing educational material and advocacy for achieving the goals under each priority area.

It is recognized that some of the priority areas are also being addressed by other strategic planning groups, but it was the belief of the pediatric group that it was vital that the interests of children be emphasized, recognizing that optimal growth and development is the most assured way of achieving optimal musculoskeletal health in adults.

In view of the limited resources available, the group considered several options which would be beneficial to the worldwide community of children and their care givers. One consideration is the development of a monograph outlining the presently recognized burden of musculoskeletal health, related to the priority areas, and the potential impact that the achievement of the goals and objectives outlined in the strategic planning document might have on that burden.

The USBJD website offers a venue to provide balanced educational information and links from recognized world leaders and organizations to develop evidence based standards of care, to provide consistent quality of care for children with musculoskeletal problems regardless of where the child lives.

The web site has the potential to coordinate the information from the member organizations to allow for optimal dissemination of information related to achieving improved musculoskeletal health in children.

#### BONE AND JOINT DECADE

# Research Strategic Planning Specialty Group

# **Executive Summary**

#### Introduction

The charge for the Specialty Group on Research was to bring a global perspective to the identification of important issues in musculoskeletal research, to prioritize them and to develop an action plan to achieve them, with a set of measurable outcomes to determine eventual success. The plan identifies priority issues in research that extend beyond specific musculoskeletal disease entities. It does not focus on specific musculoskeletal conditions, or specific musculoskeletal tissues, but outlines the direction of musculoskeletal research that may significantly improve musculoskeletal health over the next 5-10 years.

The central theme of the Research Strategic Plan is Knowledge Translation. The Committee viewed research as a bridge in which advances in basic science are translated to changes in public health through comparative effectiveness studies and well-designed and innovative clinical trials. Support for knowledge translation occurs through a strong training pipeline that provides qualified young investigators, and which is supported by advocacy efforts at several different levels in support of research funding. The Committee identified three Priority Areas.

# Priority Areas/Issues

- 1. Important Areas for Research
- 2. Training Programs
- 3. Public Awareness and Advocacy for Research

# Priority Area #1: Define Important Areas for Research

**Basic Research:** Musculoskeletal conditions are under-researched relative to the burden of disease at essentially every level, including basic research questions. Much of the basic research that is done in musculoskeletal systems and diseases is narrowly focused, with lack of integration across other relevant organ systems and informative disciplines. The primary goal should be to increase the quantity, quality and relevance of basic musculoskeletal research. A secondary goal is to foster translation of basic results into new products, approaches and therapies for musculoskeletal disease.

Funding for research in musculoskeletal conditions lags behind research funding for other chronic diseases. Musculoskeletal research funding at NIAMS comprises less than 2% of the NIH budget, even though chronic musculoskeletal conditions are much more prevalent. This discrepancy between research funding and prevalence of disease impairs progress in reducing the burden of musculoskeletal disease in all countries. It is exacerbated the current downturn in the economy that makes it difficult for governments to pay for research or changes to health care delivery, and also by the expense of large clinical trials which the pharmaceutical industry can no longer afford to support.

Comparative Effectiveness Research: One mechanism to facilitate translation of research to clinical practice is through comparative effectiveness studies that overcome the limitations of clinical trials and provide data on how to choose among therapeutics. Definition of critical therapeutic areas, such as evaluation of treatments for osteoporosis and osteoarthritis, can allow investigators to assess differences in effectiveness of treatments among demographic groups, particularly important when dealing with studies in a globally diverse perspective.

Clinical Research/Innovative Trial Designs: This may require more innovative clinical trial designs that move beyond randomized control trials, which in the modern environment can be prohibitive based on difficulties identifying an appropriate sample, and on cost. Identification of surrogate endpoints in some studies, and the development of more collaborative public-private partnerships will allow for the breadth and depth of expertise necessary to design, implement and analyze clinical data, and may provide greater financial support for important trials. It is also important to include patient advocacy groups in this effort.

**Translation to the Community:** This new knowledge must be translated to the patient populations it is intended to serve, and to their health care providers. Despite considerable progress in tools to diagnose musculoskeletal diseases and availability of new drugs and surgical treatments, there are significant obstacles in translating these advances into patient care. The major obstacles include access to care – even in first world countries – as well as the willingness of patients to alter lifestyle and to comply to treatment regimens. Improved access to care and better patient compliance may have the greatest effect on the overall reduction in morbidity and mortality associated with musculoskeletal conditions, and also lead to the elimination of differences in treatment based on gender, race and ethnicity.

Health Care Reform and Public Health Interventions: Ultimately, issues of patient care are dependent on satisfactory health care delivery systems. Health care reform is urgently needed to improve care for musculoskeletal diseases, ensure that care, and emphasize preventive efforts. It is anticipated that health care costs related to musculoskeletal conditions will continue to rise over the next two decades due to current demographic trends, such as aging of the population and increased prevalence of morbid obesity. The scientific evidence backs public health interventions for musculoskeletal conditions, but these interventions must be expanded globally, and utilized by the patient population. This may require greater engagement of the public health community in advocacy efforts.

Rare Musculoskeletal Diseases: In addition, greater collaboration is necessary to achieve progress in rare musculoskeletal diseases, which are often overlooked because of their lower prevalence. There are over 7000 rare diseases world-wide, and collectively they affect over 100 million people. The very nature of these diseases means that expertise in them is difficult to achieve without a coherent and coordinated network of information. Patient populations that are small in number and widely distributed geographically present unique challenges for scientists who study them. Identification and coordination of a network of information resources, regularly held forums for rare musculoskeletal diseases, and coordination of efforts to enhance and encourage research in this area may all contribute to more rapid solutions.

# **Priority Area #2: Training Programs**

Graduate and Postgraduate Education: These issues in research and health care delivery are long-term challenges, and are likely to outlive the current generation of scientists. Therefore, it is vitally important to recruit, train and support the next generation of scientists and to broaden training to become more multidisciplinary. It is important not only to attract the best minds into musculoskeletal research with appropriate incentives, but also to engage under-represented populations in training for research. This can be accomplished through bridge programs that provide partnerships with those institutions that have large populations of under-represented minorities. More stable training opportunities with shorter career tracks may remove some of the barriers that currently discourage bright young people from entering into research careers. It is also important for the musculoskeletal community to broaden its training, creating multidisciplinary research consortia that create new opportunities to recruit students into the field.

Physician and Physician Scientist Training: The disincentives for entering a research career are particularly striking for physician-scientists, causing great concern over the shrinking pool of medically-trained scientists in the current medical system. Socioeconomic and political changes in medicine have resulted in increased financial pressures on hospitals and physicians which can negatively affect the physician's and hospital/medical center's interest in pursuing research activities. One benefit of physician-scientists involved in translational and basic research is that they bring a clear sense of problems that need to be solved to improve care of patients. The absence of a strong physician presence in laboratory work creates the possibility of a rift between those on the bench and those at the bedside and detracts from research that easily translates to patient care and improved health.

Currently there is no formal curriculum for training students and physicians in the concepts of basic and translational musculoskeletal research. In addition there is not a continuous focus on research through all educational levels (medical school, residency, fellowship). As the amount of available data about the musculoskeletal system increases, there is a vast amount of information that physicians need to understand. This requires active participation and oversight on the part of the educators and engagement on the part of students and physician trainees. Ideally, physician training in research should occur at all levels of education from medical school through fellowship; this should be the immediate goal as curricula change in response to recent mandates from organizations accrediting medical training.

International Considerations: On the International level, differences between countries in educational structures, educational goals, resources and community involvement make solutions to scientist training and education unique to that country. Therefore, one key issue is the extent to which educational materials developed within one environment will be translatable to another, particularly where resources available to support them differ. Such materials must be sufficiently flexible to be readily modifiable and applicable to all environments. Thus the major objective is the development of improved medical and allied health professional curricula that are translatable internationally across different environments and structures of medical education. These curricula should be adaptable, to address conditions more common in certain areas, while recognizing the social and cultural impact on health.

# Priority Area #3: Raise Public Awareness and Promote Advocacy for Research

Advocacy can occur at various levels, but ultimately involves dissemination of information to both the public, as well as to governmental legislative agencies and the private sector. There is a large gap in knowledge among the general public about matters of bone health which may eventually affect the success of public health interventions. Ultimately, in a public responsible for its own health, improved public education about the causes and prevention of musculoskeletal disease and trauma, and the role played by behaviour and life-style choices is critical. Even with such education, the public, legislators and health care providers may have no way to sort through the available information on bone health to sort anecdote from fact. Partnerships with various media sources should be enhanced to provide resources and materials that can be disseminated to the widest possible populations.

Legislative authority too often places obstacles in the path of solutions to these problems. Dwindling pharmaceutical company support, in part the result of increasingly prohibitive regulatory oversight, has negatively impacted bone health research and limited partnerships. Partnerships between industry and bone health focused organizations and researchers should be promoted and action plans developed that focus on legislation and regulatory oversight that enables the conduct of clinical trials that are safe, efficient and yet reasonable to perform. Opportunities to establish partnerships with industry and university based researchers should be facilitated and coordinated at various local, regional, national and international levels.

# **Summary/Conclusions - Next Steps**

Bone diseases represent a major financial burden to our health care system. Inadequate support internationally for bone related research is a major threat to the health and well-being of the world's population as it severely compromises our ability to make the research advances that will lead to new drugs and paradigms to treat and cure these diseases. A world-wide effort is needed to advocate for adequate funding for musculoskeletal research, and potential new sources of funding need to be identified and developed to support musculoskeletal research funding. Agencies within international health-oriented agencies, such as the World Health Organization and the United Nations should be enlisted to contribute to this effort.

But progress is hampered by more than adequate funding. It is delayed by barriers that prevent interaction among the various constituent groups, whether they be basic and clinical scientists, scientists and health care providers, or health care providers and their patients who must work within a particular health care delivery and reimbursement system. Expansion of training opportunities to broaden the training experience, make it accessible to new populations and to make it more internationally flexible and translatable will enhance this communication among groups and provide for progress into the future. These initiatives will involve public education through the media and individual public health care providers, but also will require public-private partnerships. Ultimately, issues addressed in this plan extend beyond the boundaries of any one country. International agencies, such as the WHO and the U.N., that are well positioned to coordinate global initiatives, should be lobbied to specifically address the actions identified within this plan in each of the priority areas.

#### BONE AND JOINT DECADE

# Spinal Disorders and Low Back Pain Strategic Planning Specialty Group

# **Executive Summary**

# Introduction

Spinal disorders and low back pain have an important impact on health-related quality and cost of healthcare across the globe. The prevalence and impact of specific disorders, including degenerative, injury-related, traumatic, and infections, is variable between different countries and healthcare economies. This document is intended to identify priority issues that are important for raising international awareness, for promoting advocacy in public policy and healthcare funding, and for future collaborative research and educational programs that are intended to improve our management and care for patients with disorders of the spine and low back pain.

The central theme of the Strategic Planning Group for Spinal Disorders and Low Back Pain is to improve education and awareness about the impact of spinal disorders on health and quality of life worldwide. The measurement of the impact of disease, and the value of care using specific health status instruments that can be applied internationally is an important goal. The prioritization of research and new technologies for care should be defined by the burden of specific disorders, and the opportunity to improve quality of life with improvements in access to care and methods of care.

The purpose of the Specialty Group Strategic Planning Session for Spinal Disoders and Low Back Pain is to address the priority issues identified, and to define a roadmap that will guide action of national and international organizations in the next decade with an emphasis on the goals of raising awareness, advocacy, education and research.

# Priority Areas/Issues

- 1. Defining the Burden of Disease
- 2. Specific Disorders of the Spine
- 3. Introduction of Technologies and Devices in the Treatment of Spinal Disorders
- 4. Identification of areas for spine-related research and for international collaboration

# Priority Area #1: Defining the Burden of Disease

Spinal disorders and low back pain are significant public health problems that affect millions of people each year. Low back pain is the most common reason for a patient to visit a physician. There is growing evidence that there are significant costs and functional limitations associated with spinal dysfunction. Defining the burden of spinal disorders and low back pain requires consideration of incidence and prevalence of disorders, and evaluation of the impact of disorders on health-related quality of life, economic productivity, and direct and indirect costs of care.

By fully understanding the negative impact of spinal dysfunction on the individual and society as a whole, we will be able to emphasize the message that spinal disorders and low back pain should be considered as high priority areas of research and advocacy for the future.

The specific goals for this issue are to discuss how we measure impact of disease in terms of direct and indirect cost, and quality of life. A strategic plan will involve developing a consensus for how to measure impact of spinal disorders and the impact and value of care.

# **Priority Area #2: Specific Disorders of the Spine**

Identification of specific conditions that require an increased awareness and an increase in activity internationally is important to direct and guide efforts to improve spinal health internationally. The conditions identified are spinal disorders that present the greatest burden to health internationally, and spinal conditions that have the greatest potential for a change in incidence and impact through preventative strategies and existing treatment modalities.

The purpose is to identify specific spinal disorders that warrant attention, international awareness and research focus. Identification of priority disorders will serve to focus future clinical resources, research efforts and collaboration on areas that are most significant clinically and that have the most potential for change.

Areas for discussion include:

- 1. Traumatic injuries of the spine
- 2. Infection affecting the spine
- 3. Developmental and degenerative conditions of the spine

Goals for this issue include the development of multidisciplinary collaborations between physicians and healthcare providers caring for these disorders, and of an infrastructure for informational exchange regarding education, research and outcomes.

# Priority Area #3: Introduction of Technologies and Devices in the treatment of spinal disorders

Technologies directed toward the diagnosis and treatment of disorders of the spine have contributed significantly and importantly to the management of spinal disorders and low back pain. Important technologies include diagnostic modalities and treatment technologies. The distribution and utilization of technologies are characterized by significant variability. The cost of technologies is an important expense in health care, and a significant reason for the disproportionate rise in costs for management of spinal disorders. It is therefore imperative that the discussion about the utilization of these technologies evaluate the best allocation and utilization of resources to evaluate and treat disorders of the spine.

This issue's goal is to develop a systematic approach for the assessment and definition of value of new and current technologies, and to define an appropriate utilization rate and distribution of technologies. Discussion will include methods and infrastructure required for comparative effectiveness research, and defining the cost and value of different modalities of care.

# Priority Area #4: Identification of areas for spine-related research and for international collaboration

Clinical and basic science research are fundamental to the pursuit of evidence-based changes in our management of disorders of the spine. Current research funding and implementation is structured to promote parallel silos rather than interdependent collaborative networks. There are significant economies of scale that may result from an organized approach to scientific investigation. Identifying priority areas for clinical and basic research, and collaborating broadly in the pursuit of these investigations is an important goal of the next decade of spine-related research.

Research into clinical comparative effectiveness and into basic science approaches to diagnosis and care may have a significant impact of the cost-effective practice of managing patients with disorders of the spine. Development of collaborative networks working toward a common goal can accelerate the rate and productivity of research in spinal disorders. The goals of this section are to develop a consensus on priorities for future research, and to define opportunities for collaboration in the pursuit of funding, and in the pursuit of basic science and clinical research.

# **Summary/Conclusions**

Disorders of the spine and low back pain are an important priority in musculoskeletal health. A strategic plan for the next decade is intended to guide the development of multidisciplinary collaborations and the establishment of an infrastructure for clinical and basic science data collection. Goals for the next decade may include the establishment of a Global Congress for Spinal Disorders, the development of a shared voice or platform for spine health advocacy and education, the organization of research collaborations that will improve access to competitive funding sources, and the development of a shared database for measuring health status and the outcomes of care from multiple disciplines and places.

#### BONE AND JOINT DECADE

# Trauma and Injury Strategic Planning Specialty Group

# **Executive Summary**

#### Introduction

Trauma is the leading cause of death and disability in the United States for persons under the age of 55 and a leading cause of morbidity and mortality for young people throughout the world. While improvement in musculoskeletal trauma care in general through research and advancement in treatment capabilities would therefore yield substantial benefit globally, the trauma and injury strategic planning specialty group has proposed four distinct subtopics within the overall category of trauma and injury where focused effort through collaborative programs to raise awareness and advocate for resources for education and research has a great chance to improve care and limit disability.

In selecting these subtopics, a goal of the group was to include challenges of interest to a great number of the Decade's constituent members in order to maximize the relevance of the document and therefore increase the potential opportunities for collaborative efforts to achieve increased awareness of musculoskeletal trauma as a relevant condition warranting increased public attention.

A central focus of the trauma and injury subtopic analyses was that while prevention strategies will likely achieve great efficacy, prevention alone is unlikely to eliminate these areas of concern. Thus research directed at developing and defining effective evidence-based treatment methodologies remains important. In determining the degree to which the burden of injury for each subtopic varies across geopolitical regions, defining educational and treatment infrastructure needs becomes possible.

Overall, topics were selected for inclusion when burden of disease was identified as substantial, when gaps in knowledge limited the ability of clinicians to develop and implement effective treatment strategies, when treatment resources, both human and technological were lacking, and when increased public awareness through advocacy and education offered opportunity to correct these problems.

# Priority Areas/Issues

- 1. Fragility Fractures
- 2. Road Traffic Crashes
- 3. Extremity War Injuries
- 4. Repetitive Use Disorders

# **Priority Area #1: Fragility Fractures**

Key Considerations: Hip fractures are the most devastating of all fragility fractures in terms of both morbidity and mortality with medical care costs in the US alone exceeding \$15 billion annually; their incidence is expected to double within the next 40 years. While primary prevention is being addressed by other groups, secondary prevention after initial fracture must be an important component of any educational and treatment strategy developed for physicians and surgeons charged with management of these injuries.

Proposed Goals and Objectives: Goals should be to improve long-term survival after fragility fracture, to improve function and to institute secondary prevention. This can be accomplished through development and implementation of evidence-based protocols that address challenges associated with treatment across the continuum of care spanning from acute management to rehabilitation and secondary prevention. Education about the scope of the problem and advocacy for increased research and treatment funding will be necessary in order to achieve improvement in care.

Potential Collaborations: A broad range of advocacy groups represent potential partners in the effort to raise awareness of fragility fracture as a public health challenge warranting increased attention. These include geriatric medical care groups, endocrinology groups, and primary care groups in addition to orthopaedic surgeons. Other organizations with traditional interest in promoting the well-being of the elderly who are disproportionately affected by fragility fracture such as the AARP might also be important partners.

# Priority Area #2: Road Traffic Crashes

Key Considerations: Worldwide, road traffic crashes (RTC) account for approximately 1.4 million deaths and between 20 and 50 million injuries/disabilities each year. Lower and middle income countries appear to be disproportionately affected. This is related to decreased transportation safety and poor access overall to trauma care. Musculoskeletal trauma care lags further behind resuscitative capabilities in many places because of the need for additional human and technical resources in order to treat these conditions.

Proposed Goals and Objectives: While prevention efforts offer the possibility of dramatically limiting morbidity and mortality from RTC worldwide, these efforts cannot eliminate the problem. Furthermore, many patients who suffer death or disability from trauma could have been helped by access to effective trauma care systems. Thus improvement in trauma care delivery systems worldwide must be a core component of any program. This can be accomplished by working with and within organizations charged with oversight and improvement in trauma care systems worldwide to improve trauma treatment capacity, improve educational programs and define strategies for improving surgical care globally.

Potential Collaborations: Efforts to improve musculoskeletal trauma care are inseparable from those to address overall trauma care and similar to those necessary to ensure access to basic surgical care needs. Thus the American College of Surgeons, the American Association for the Surgery of Trauma and worldwide surgical organizations must be key partners in this endeavor. In addition, the needs of children are paramount as they are disproportionately affected. Thus pediatric organizations must be enlisted to help. Globally, efforts are necessary to increase the recognition of RTC as a worldwide threat within the World Health Organization, the United Nations and other organizations with an interest and responsibility for promotion of health and safety globally.

# Priority Area #3: Extremity war injuries (EWI)

Key Considerations: Extremity injuries are the most common of all injury types associated with modern combat. Advances in protective equipment combined with improvements in resuscitative care have led to more survivors of war injury with more severe high-energy extremity injury. Extremity injury has represented the greatest single source of inpatient medical care expense for the United States military during the Global War on Terror and the greatest anticipated source of long-term disability expense. In developing countries exposed to armed conflict, additional challenges include land-mine injuries effecting the civilian population.

Proposed Goals and Objectives: Improved care for EWI will require a better understanding of the burden of injury which can best be obtained by funding and development of better data collection tools. Such tools will also likely lead to improved understanding of the role and effectiveness of body armor which can in turn lead to development of efforts aimed at prevention. Additional resources are necessary to improve care for common complications including heterotopic ossification and infection and to better understand how to prevent them.

Potential Collaborations: The American Academy of Orthopaedic Surgeons, the Orthopaedic Trauma Association, the Society of Military Orthopaedic Surgeons, and the Orthopaedic Research Society have played important leadership roles to date in advocating for increased EWI research funding.

With additional focus on the burden of injury associated with civilian land mine injuries which have similar treatment challenges and complication profiles, additional international groups may be interested in becoming advocacy partners including the International Committee of the Red Cross, the North Atlantic Treaty Organization, the United Nations and others charged with operation of medical care facilities within war zones internationally

# **Priority Area #4: Repetitive Use Disorders**

Key Considerations: Repetitive use disorders (RUD) are work-related musculoskeletal disorders (WMSD) that result from excessive micro-trauma and represent an increasing source of substantial cost and threat to quality-of-life in many countries, in some cases representing as many as 60% of all occupational illnesses. Reported geographic variations in disease incidence are substantial but may be partially related to variation in methods of data collection. Costs include lost work days, wages and tax revenue in addition to individual clinical morbidity. Regardless of the estimate used, the problem is large both in health and economic terms.

Proposed Goals and Objectives: Improved surveillance and development of standardized definitions of will help better understand the burden of disease. Improved understanding of risk-factors through improved surveillance can lead to development of prevention strategies. Development of evidence-based treatment strategies is necessary for a variety of WMSD.

#### Potential Collaborations:

Better collaboration between insurers, employers, unions, private business, community organizations and government groups can improve comparability of systems, instruments, diagnostic tools and definitions. Internationally, the World Health Organization and the European Commission have infrastructure and interest in the topic. Further education and advocacy will help increase research support to improve surveillance systems, disease definitions and initiation of comparative effectiveness studies necessary to develop evidence based treatment guidelines.

# STRATEGIC PLANNING SPECIALTY GROUPS FULL VERSIONS OF DRAFT PLANS FOR DISCUSSION

### ARTHRITIS STRATEGIC PLANNING SPECIALTY GROUP

#### Introduction

This document outlines the overall purpose of the planning group, background, barriers and opportunities. Priority Area issues, strategies, goals and objectives for addressing these Priority Area issues. The Arthritis Strategic Planning group identified the following principles to guide our approach. The process needs to address global issues, while highlighting differences between developed and underdeveloped countries where needed. Concepts should be simple, focusing not on what needs to be done as this will vary significantly from country to country, but what the major approaches should be with respect to developed and underdeveloped countries, providing a broad foundation for focus by each region in the future. These strategies should leverage the strengths of the BJD and collaborative organizations in each region as well as frame a format for international co-operation.

**Purpose:** The overarching goal is to reduce the burden of musculoskeletal diseases due to arthritis in the population (e.g., strategies should include worldwide and be able to be adapted in both developed and underdeveloped countries.

**Burden of Disease:** Worldwide, arthritis (up 100 different varieties with osteoarthritis the most common, is one of the common cause of disability. Osteoarthritis accounts for 52% and 61% of the global burden of musculoskeletal disease in underdeveloped and developed countries respectively, and is increasing as the population ages. The prevalence of rheumatoid arthritis is 1-3% worldwide, while gout, HLA B27 spondyloarthropathies are globally distributed, certain populations are more susceptible. In developed countries JIA (Juvenile Idiopathic Arthritis) is the most common cause of acquired disability in children, but the burden in underdeveloped countries is not known. Infectious arthritis, including Tuberculosis, bacterial, and HIV related arthropathies, is more prevalent in underdeveloped countries, as is reactive arthritis. Lessening the burden of disease due to arthritis will likely require different approaches for different types of arthritis, as well as different approaches for similar types of arthritis in different regions of the world.

## There are many preventative, diagnostic and treatment opportunities that are now available to alleviate the burden of disease:

- Effective approaches to mitigating the burden of disease and disability exist for all types of arthritis, but vary by the type of arthritis and the availability of resources locally and regionally. Even in affluent regions there is much disparity in the delivery of and access to diagnosis and treatment.
- Primary prevention with healthy lifestyle education and early detection of disease will have the greatest impact across all populations and regions
- Advanced medical and surgical approaches for established disease exist but are limited by resources

**Priority Areas for strategies to reduce of burden disease:** Our approach is to facilitate collaboration, and to identify strategies that specifically leverage the unique opportunities available through the consortium of organizations in the Bone and Joint Decade. These include professional health-care organizations (e.g., rheumatology, orthopedic, osteopathic, chiropractic, primary care medicine, nursing, physical therapy, etc.), voluntary arthritis advocacy organizations and patient and family organizations (e.g., Arthritis Foundation in US, EULAR in Europe, AFLAR in Africa, PANLAR in Asia and other national and international charitable organizations.

## **Priority Areas**

- Public Education
- Education of Policy Makers (Government and Non-Government)
- Access to Health Care Providers with Expertise in Arthritis
- Prevention and Early Diagnosis and Prevention
- Research
- Sustainability for Ongoing BJD Initiatives Related to Arthritis

#### I. PRIORITY AREA #1: PUBLIC EDUCATION:

**a) Issue:** There is a lack of awareness of the burden of disease and opportunities for prevention and treatment.

## b) GOAL: increase public awareness of arthritis related health promoting behaviors

i) **Global Objective:** BJD organizations will work to establish a public awareness process regarding arthritis health promoting behaviors in all regions/countries

## (1) Developed Countries Action Items

- (i) Identify key regional and national public institutions and organizations to be targeted for raising awareness regarding the benefits of arthritis prevention, early diagnosis and treatment
- (ii) Identify key regional and national nonprofit arthritis related professional organizations and voluntary patient and family advocacy organizations to help with awareness of arthritis prevention, early diagnosis and treatment (e.g., ILAR organizations, Arthritis Foundation (US), Arthritis Society (Canada))
- (iii) Facilitate identified regional and national public institutions, nonprofit arthritis related professional organizations and voluntary patient and family advocacy organizations in increasing awareness regarding the importance of positive health behaviors in preventing or ameliorative the burden of arthritis (e.g., obesity prevention, smoking cessation, regular exercise, healthy diet)

## (1) Underdeveloped Countries Action Items

- (i) Identify key regional and national public institutions and organizations to be targeted for raising awareness regarding the benefits of arthritis prevention, early diagnosis and treatment
- (ii) Identify key regional and national nonprofit health (and if present arthritis) related professional organizations and voluntary patient and family advocacy organizations to help with awareness of arthritis prevention, early diagnosis and treatment (e.g., WHO, ILAR organizations, health related NGO Non Government Organizations such as the Peace Corps, etc.)
- (iii) Facilitate identified regional and national public institutions, nonprofit arthritis related professional organizations and voluntary patient and family advocacy organizations in increasing awareness regarding the importance of positive health behaviors in preventing or ameliorative the burden of arthritis (e.g., obesity prevention, smoking cessation, regular exercise, healthy diet)

## e) Barriers:

- a) Lack of awareness of arthritis as a major disease leads to inadequate resource allocation
- b) High costs of interventions once disease is established

## f) Facilitators

- a) Understanding that arthritis as a significant contributor to disability
- b) Understanding that primary prevention (health promoting behaviors), early detection and treatment are effective in decreasing potential disability.
- c) Understanding of the role of the patient and family in arthritis self management and specific health promoting behaviors
- g) *Time Line:* I.b.i.1.(i) Year 1; I.b.i.1.(ii) Year 1-2; I.b.i.1.(iii) Year 2-5; I.b.i.2.(i) Year 1; I.b.i.2.(ii) Year 1-2; I.b.i.2.(iii) Year 2-5

## f) Outcome Measures

- i) Data available for all countries and regions before and after intervention (Establish targets for each effort and region)
- ii) Countries that include musculoskeletal health in their public health programs
- iii) Increased funding by public and private institutions for awareness

## II. PRIORITY AREA # 2: EDUCATION OF POLICY MAKERS (GOVERNMENT AND NON- GOVERNMENT)

**a) Issue:** There is a lack of awareness of the burden of disease and opportunities for prevention and treatment.

## b) GOAL: increase policy makers' awareness that arthritis is a significant health priority

- i) *Global Objective:* Increase funding for public health initiatives, professional training, research, health care system resources for arthritis care
  - (1) Developed Countries Action Items
    - (i) Collaborate with arthritis advocacy groups (eg., AF, Lupus Foundation, EULAR, etc) in lobbying efforts for increasing funding for resources to address public health initiatives, professional training, research, health care system resources for arthritis care
  - (2) Underdeveloped Countries Action Items
    - (i) Collaborate with international arthritis advocacy groups (eg., ILAR and member organizations) in lobbying efforts for increasing funding for resources to address public health initiatives, professional training, research, health care system resources for arthritis care

## c) Barriers:

- i) Lack of awareness of arthritis as a major disease leads to inadequate resource allocation
- ii) High costs of interventions once disease diagnosis or risk is established
- iii) Significant geographic and geopolitical differences contribute to burden of disease due to variation in health care systems

## d) Facilitators

- i) Understanding that arthritis as a significant contributor to disability
- ii) Understanding that public health measures (health promoting behaviors), and early detection and treatment are effective in decreasing potential disability.
- e) Time Line: Year 1-5

## f) Outcome Measures:

- i) Available data for all countries and regions before and after intervention. Establish goals in each region'
- ii) Countries that include musculoskeletal health in their public health programs
- iii) Increased funding by public and private institutions for awareness

## III. PRIORITY AREA #3: ACCESS TO HEALTH CARE PROVIDERS WITH EXPERTISE IN ARTHRITIS

**a) Issue:** Limited access to health care providers with expertise in arthritis results in poor outcomes

## b) GOAL: Increase arthritis related expertise in primary care givers and specialists

- i) *Global Objective*: Establish basic musculoskeletal curricula for all medical schools and health oriented professional schools
  - (1) Developed Countries Action Items
    - (i) Understand current musculoskeletal curricular opportunities and barriers to inclusion of such a curriculum in medical and other health care professional schools (Surveys)
    - (ii) Collaborate with BJD member organizations to develop musculoskeletal curricula for medical and other health care professional schools and to better utilize those available.
    - (iii) Collaborate with other musculoskeletal disease organizations to engage medical school and other health care professional schools faculty organizations and individual faculties in medical schools to participate in field testing of standardized test questions and advocate for including musculoskeletal disease in curricula
    - (iv) Encourage certification exams to develop questions emphasizing curricular principles.
  - (2) Underdeveloped Countries Action Items
    - (i) Understand current musculoskeletal curricular opportunities and barriers to inclusion in medical and other health professional schools
    - (ii) Collaborate with BJD member organizations to develop musculoskeletal curricula for medical and other health care professional schools
    - (iii) Develop and initiate approach to engage medical schools and their faculties in including robust musculoskeletal elements into curriculum (next phase will be other professional schools)
    - (iv) Evaluate the role of trained health workers with special training in arthritis for community health centers
- ii) Global Objective: Develop cost effective process to disseminate arthritis specific educational tools free of cost
  - (1) Developed Countries Specific Action Items
    - (i) Collaborate with BJD member organizations to create easy free or low cost dissemination strategies leveraging existing technologies (on-line, social networking, wikis) to distribute tools.
    - (ii) Collaborate with BJD member organizations to facilitate creating new tools where gaps exist
  - (2) Underdeveloped Countries Specific Action Items
    - (i) Collaborate with BJD member organizations to create easy free or low cost dissemination strategies leveraging existing technologies (on-line, social networking, wikis) to distribute tools.
    - (ii) Collaborate with BJD member organizations to facilitate creating new tools where gaps exist

## iii) Global Objective: Increase arthritis specialty care giver workforce

- (1) Developed Countries Action Items
  - (i) Collaborate with BJD member organizations to perform workforce studies in arthritis related specialty and primary care areas
  - (ii) Utilize workforce information to increase awareness of the need to focus on encouraging individuals to enter arthritis related specialties

## (2) Underdeveloped Countries Action Items

- (i) Collaborate with WHO and other BJD organizations to develop plans for understanding workforce needs in different countries and regions, matching to burden of disease.
- (ii) Utilize workforce information to increase awareness of the need to focus on encouraging individuals to enter arthritis related specialties and practice in country of origin
- (iii) Develop health assistants with expertise in musculoskeletal health and disease to improve treatment and triage of more serious conditions
- (iv) Develop programs to encourage retention of experts in the field.

## c) Barriers

- i) Workforce issues in both developed and underdeveloped countries.
  - (1) In developed countries, there are not enough providers entering rheumatology and related fields especially to care for the increasing numbers of aging individuals affected and the aging workforce.
  - (2) In underdeveloped countries, the situation is more challenging with a severe loss of subspecialists leaving the area leaving extremely few rheumatologists or orthopedists in clinical practice in certain regions. There is also a lack of appropriately trained allied health professionals.

## d) Facilitators:

- i) Development of recommendations for appropriate access in diverse environments and regions (e.g., developed vs. underdeveloped countries, urban vs. rural, international, diverse health care financing models, diverse cultural norms relating to health care beliefs, etc)
  - (1) Clarification of roles and appropriate utilization of specialist health care provider (rheumatologist, orthopedist, PT & OT specialists in arthritis, podiatrist, nurse practitioner and PA etc.)
  - (2) Enhancement of the roles and recognition of the importance of primary health care providers including physicians and nurses, NP, PT, OT, PA in the care of arthritis patients

## e) Time Line:

- i) II.b.i.1.(i) Year 1; II.b.i.1.(ii) Year 3-5; II.b.i.1.(iii) Year 1-5; II.b.i.2.(i) Year 1-4; II.b.i.2.(ii) Year 3-5 II.b.i.2.(iii) Year 2-4; II.b.i.2.(iv) Year 4-5
- ii) II.b.ii.1.(i) Year 1; II.b.ii.1.(ii) Year 2-4; II.b.ii.2.(i) Year 1; II.b.ii.2.(ii) Year 2-4
- iii) II.b.iii.1.(i) Year 1-3; II.b.iii.1.(ii) Year 3-5; II.b.iii.2.(i) Year 1-3; II.b.iii.2.(ii) Year 3-5

### f) Outcome Measures:

- i) Data in all professional areas in all regions before and after implementation.
- ii) Development of curricula
- iii) Inclusion of adequate musculoskeletal disease curriculum in >80% of medical schools
- iv) ACR Primer and slide collections available to all medical professional schools free of cost or low cost depending on region
- v) Development of 3 new tools
- vi) Workforce studies in all major regions completed
- vii) Special funding opportunities for training in arthritis related specialties. Retention of providers in underdeveloped countries

### IV. PRIORITY ISSUE #4: PREVENTION AND EARLY DIAGNOSIS AND PREVENTION

- **a) Issue:** Public health policy and health care systems do not support arthritis prevention or early diagnosis and management that could improve outcomes in arthritis
- b) GOAL: Increase health care system prioritization of development and dissemination of standardized protocols and public health resources focused on improving prevention, early diagnosis and management of arthritis
  - i) Global Objective: Develop and disseminate standardized protocols for prevention, diagnosis and management of arthritis to primary care and arthritis specialty providers
    - (1) Developed Countries Action Items
      - (i) Collaborate with arthritis related BJD professional organizations to develop and disseminate evidence-based guidelines and protocols for major areas of arthritis prevention, early diagnosis and management
    - (2) Underdeveloped Countries Action Items
      - (i) Collaborate with arthritis related BJD professional organizations to disseminate guidelines and protocols arthritis prevention, early diagnosis and management and educate primary care providers regarding use

## c) Barriers:

- Lack of awareness of arthritis as a major disease leads to inadequate resource allocation
- ii) Lack of access to health care providers with expertise or education in arthritis prevention and care
- iii) Understanding the real-life clinical and health related quality of life outcomes of different interventions, predictors of severity, response, complications
- iv) High costs of interventions once disease diagnosis or risk is established
- v) Workforce issues in both developed and underdeveloped countries.
- vi) Significant geographic and geopolitical differences contribute to burden of disease due to variation in health care systems

## d) Facilitators

- i) Awareness of societal and lifestyle opportunities to limit the likelihood of development of severe aggressive disease by facilitating:
- ii) Positive health behaviors (e.g., obesity, exercise, smoking)
- iii) An active partnership between patients and providers in health care.
- iv) Awareness of the benefit of using standardized protocols for diagnosis, early treatment and referral guidelines. The protocols should be evidence-based and specific to the different types of arthritis where possible.
- v) Utilization of protocols already developed by professional societies internationally and locally as well
- e) **Time Line**: III.b.i.1.(i) Year 1-4; III.b.i.2.(i) Year 3-5

### f) Outcome Measures

 i) Development and publication and/or dissemination of protocols for care of top 5 arthritis conditions

### V. PRIORITY AREA #5: RESEARCH

**a) Issue:** Research in musculoskeletal disease does not reflect the burden of disease. It takes a back seat to many other health conditions which are more dramatic but less of an economic burden and /or less prevalent.

## b) GOAL: Increase health care system prioritization of research through allocation of research dollars for arthritis related issues

- i) *Global Objective*: Increase research in the epidemiology, outcomes, and comparative effectiveness of treatments
  - (1) Developed Countries Action Items
    - (i) Collaborate with arthritis related BJD professional organizations to promote and lobby for increased public and private research funding for arthritis in order to obtain the evidence to create the best practices in the prevention, diagnosis and treatment of arthritis
  - (2) Underdeveloped Countries Action Items
    - (i) Collaborate with arthritis related BJD professional organizations to promote public and private research funding for international collaborations

## c) Barriers:

- Lack of awareness of arthritis as a major disease leads to inadequate resource allocation
- ii) Understanding the real-life clinical and health related quality of life outcomes of different interventions, predictors of severity, response, complications
- iii) Competition with other disease groups for research dollars

## d) Opportunities/Facilitators:

- i) Creation of scientific agendas to decrease the global burden of disease due to arthritis, including regional as well as international agendas
- ii) Increase in focus on osteoarthritis prevention, early detection and treatments
- iii) Determination of the real-life clinical and health related quality of life outcomes of arthritis and the effectiveness of different interventions, the predictors of disease severity, response to treatment, and complications of treatment
- iv) Translation of discoveries to real-life situations
- v) Increase funding for research—private charitable, national & governmental, professional organizations
- vi) Coordination with BJD Research Strategic Planning Group
- vii) Coordination with regional, national and international arthritis related research organizations (private and public) to collaborate on existing research initiatives, as well as defining and developing new focus areas for research
- e) Time Line: Years 1-5

## a) Outcome Measures

i) Increased funding for arthritis research and international collaborations

## VI. PRIORITY ISSUE #6 SUSTAINABILITY FOR ONGOING BJD INITIATIVES RELATED TO ARTHRITIS

- a) Issue: There is no infrastructure to support ongoing BJD initiatives globally
- b) GOAL: Establish international coordinating rheumatology organization to focus on arthritis related issues in both underdeveloped and developed countries

- i) *Global Objective*: Establish international coordinating organization, such as ILAR and its member organizations or an international BJD committee dedicated to arthritis in partnership with other relevant organizations, to focus on facilitating the BJD Arthritis Strategic Plan in developed and underdeveloped countries
  - (1) Developed Countries Action Items
    - (a) Evaluate the best option for an international coordinating organization capable of facilitating the BJD Arthritis Strategic Plan
    - (b) Establish an international BJD committee for arthritis which may be the international coordinating organization in addition to other roles
      - (i) Enhance the commitment and engagement of ILAR member organizations to BJD arthritis related initiatives and collaboration with other BJD organizations
  - (2) Underdeveloped Countries Action Items
    - (a) Evaluate the best option for an international coordinating organization capable of facilitating the BJD Arthritis Strategic Plan
    - (b) Establish an international BJD committee for arthritis which may be the international coordinating organization in addition to other roles
      - (i) Enhance the commitment and engagement of ILAR member organizations to BJD arthritis related initiatives and collaboration with other BJD organizations

## c) Barriers:

- i) Lack of awareness of the burden of musculoskeletal diseases in general and arthritis in particular
- ii) Significant geographic and geopolitical differences contribute to burden of disease due to variation in health care systems

## d) Facilitators

- i) Increase in ongoing interest and investment by private and public institutions through clear articulation of value added by commitment and action on BJD initiatives
- ii) Understanding that advocacy is the major activity for achieving the changes identified in our strategic plan in all areas by raising these issues with the following entities:
  - (a) Governmental and legislative institutions
  - (b) Public health institutions
  - (c) Educational and training institutions
  - (d) Regulatory bodies
  - (e) Non-governmental, industrial, and private non-profit institutions
  - (f) Health care providers and professional organizations
  - (g) Voluntary health organizations
  - (h) Governmental and private research funding organizations
- e) Time Line: Year 1-3

## f) Outcome Measures:

- i) Determination of optimal structure for an international coordinating committee for arthritis
- ii) If new organization, ensure that commitment to facilitating BJD Arthritis Strategic Plan is included in By-Laws
- iii) If existing organization, such as ILAR, obtain agreement and changes in By-Laws if needed

## BONE HEALTH AND OSTEOPOROSIS STRATEGIC PLANNING SPECIALTY GROUP

## Issue 1 - Develop a Bone Health Alliance

## Goals and Objectives:

- 1. Forge an international alliance focused on bone health issues
  - a. Develop organizational structure
    - Determine where the alliance should be housed among the existing bone health organizations
    - Identify and recruit key international stakeholder organizations in:

North America

Europe

Middle East & Africa

Asia

Australia

South & Central America

- Develop shared vision/mission, charter and priorities
- b. Determine key Working Groups
  - Epidemiology/Quality of Life
  - Bone Imaging
  - Nutrition
  - Physical Activity for Prevention and Rehabilitation
  - Orthopaedics Fracture Management
  - Pathophysiology
  - Geriatric Issues fall prevention, vision, environmental
  - Surveillance of Treatment of Osteoporosis
- c. Coordinate world-wide government and non-governmental bone health-related information to:
  - Provide online and print resource of all materials available to the field and the public
  - Track and evaluate programs and policies
  - Form the basis for advocacy for research funding and improvement in public policy
- d. Strategically develop social marketing for bone health messages
  - Inventory existing programs and their effect
  - Develop and evaluate new messages and programs (including those focused on specific populations such as men, and racial and ethnic groups)
  - Integrate bone health messages within bone health organizations so that they are uniform and consistent

## 2. Collaborate with organizations whose messages about healthy lifestyles dovetail with messages about improving bone health

Foster connections with other chronic disease groups and professional organizations

- Inventory existing programs and campaigns supporting similar messages, and highlight successful programs and their sponsors
- Convene an interdisciplinary medical advisory group to agree on a key set of messages about nutrition and exercise benefits for bone health
- Develop effective messages (e.g., for "healthy lifestyles") for an array of audiences
- Work with partners to develop integrated and coordinated messages and programs, in part by building on current "hooks" such as Vitamin D and physical activity guidelines

## **Barriers and Facilitators**

- 1. Barriers Lack of dedicated staff and funding resources
- 2. Facilitators Existence of over 191 osteoporosis patient societies worldwide, many interested individuals and organizations; existence of many interested scientific and professional associations, including those for family practice, internal medicine, OB/Gyn, endocrinology, rheumatology, pediatrics and orthopedics.

## Action Items and Those Responsible/Deliverables

- 1. The NOF and IOF have many educational materials that could be used to produce new materials that could be translated and used world-wide.
- 2. The Bone Health Special Interest Group (BHSIG) of the Section on Geriatrics (SOG) within the American Physical Therapy Association (APTA) has some materials available and new ones are being developed concerning posture evaluation, intervention and exercise. Depending on the BJD committee's thoughts and direction, the BHSIG could take a lead role on this material.
- 3. The SOG has developed certification for Exercise Expert for Aging Adults (CEEAA) which includes the special population of persons with osteoporosis.

### Timeline

### **Outcome Measures**

- 1.
- 2.

## Issue 2 - Promote Bone Health and Prevent Disease

## Goals and Objectives:

## 1. Build capacity of health care providers to focus on bone health across the lifespan

Work with umbrella organizations and leadership of medical and health care professional organizations to help:

- Primary care providers pay close attention to bone health issues and emphasize the basics of good bone health during interactions with patients, from children and adolescents, to the elderly, with preventing fractures in older adults a high priority
- Health care professionals in emergency departments and orthopedic practices view bone fractures as a sentinel event and refer patients to appropriate resources and health care providers including specialists in nutrition, body mechanics, exercise, rehabilitation and geriatrics.

## 2. Promote vitamin D and calcium supplementation, with a focus on revising the adequate intake level for vitamin D

- Continue to test patients at risk for deficiency and prescribe appropriate therapeutic doses of vitamin D for those who are deficient
- Enhance provider and patient education and information concerning vitamin D (e.g., what it is, how to raise it with providers and patients, etc.)
- Assist in the development of consistent messages and recommendations regarding vitamin D intake

## 3. Promoting Policy Change

- Make the prevention of osteoporosis and related fractures a governmental health care priority in all countries, with objectives including:
  - Decrease waiting times for bone mineral density testing
  - Make a wide range of proven treatments available, including balance and mobility screening, muscular strengthening and falls intervention
  - Declare osteoporosis and bone health a healthcare priority
  - Increase number of bone mineral density scanners
  - Obtain full reimbursement for bone mineral density
- Create a Women's Leaders Roundtable around the world
- Issue white papers
- Institute an Osteoporosis and Bone Health Audit

### **Barriers and Facilitators**

- 1. Barriers -
- 2. Facilitators Efforts should be made to educate parents and teachers about the

importance of early bone health (diet and exercise).

## Action I tems and Those Responsible/Deliverables

1.	. The Bone Health Special Interest Group (BHSIG) of the Section on Geriatrics	(SOG)
	within the American Physical Therapy Association (APTA) Bone Health Special	Interest
	Group and the Balance Special Interest Group	

2.

Timeline

## **Outcome Measures**

1.

2.

## <u>Issue 3 - Improve Diagnosis and Treatment</u>

## **Goals and Objectives**

## 1. Find better ways to diagnose disease and assess risk

- Continue research to understand who is at risk and how best to initiate treatment and prevention
- Explore implementation of FRAX® as pre-screening tool and match it with prevention, risk reduction (posture, exercise, body mechanics, pulmonary function, nutrition and falls) and treatment protocols
- Find other existing tools that can be used for bone health screening, e.g. CaMos tool, Garvan algorithm, DESTINY method and flexible rule for kyphosis)
- Assess effectiveness and develop new tools
- Incorporate falls risk, postural, strength and pulmonary assessment, the latter especially for VCF

## 2. Address issues of adequate reimbursement for evidence-based treatments

(e.g., DXA, rehabilitation and exercise programs)

- Increase consumer understanding of access and quality issues around reimbursement rates
- Seek more appropriate level of funding for reimbursement of costs to increase patient access and prevent disincentives for use
- Support existing lobbying efforts

## 3. Focus on fracture as a sentinel event in bone health management

- Focus on professional education
- Develop bone health curricula for medical, nursing schools and allied health in each country
- Focus on optimal fracture management, including timely surgery when necessary and rehabilitation, both essential in the prevention of further falls and fractures

### **Barriers and Facilitators**

- 1. Barriers -
- 2. Facilitators World Confederation of Physical Therapy

## Action I tems and Those Responsible/Deliverables

- 1.
- 2.

## Timeline

## **Outcome Measures**

- 1.
- 2.

## Issue 4 -- Enhance Research, Surveillance, and Evaluation

## Goals and Objectives:

## 1. Continue and expand research now underway, and find ways to make more effective use of existing research

- Continue research at all levels (i.e. basic, clinical and translational research)
- Translate findings and developments to the field for application to treatment and care
- Conduct research to understand how clinical and pharmaceutical and nonpharmaceutical research translates into the community setting
- Conduct research to learn more about racial, socioeconomic, and gender differences in bone health and disease

## 2. Collect and analyze data to better understand who is at risk and improve prevention, diagnosis and treatment

- a. Conduct country or regional audits to identify gaps and opportunities in current data collection, reporting and evaluation
  - Analyze existing data
  - Conduct gap analysis
- b. Collect baseline data through available mechanisms for example:
  - Pharmaceutical prescriptions written for osteoporosis prevention and treatment medications (tracked by industry or pharmaceutical companies)
  - Number of DXA tests completed each year
  - Vitamin D and calcium sales (by survey or by sales)
  - Fracture rates Awareness, knowledge, beliefs and practices (public opinion surveys)
  - Postural and exercise programs; balance and mobility screening and public education before the first fracture and especially after the first fracture

## 3. Evaluate effectiveness of public education programs

- a. Conduct an inventory of public education programs at all levels
  - Include aspects such as social marketing products and ancillary materials, target audiences, key messages and themes, action steps, and the results of any evaluation measures
  - Include any major public policy or legislative measures undertaken that would support or promote the measures in the social marketing campaign
  - Conduct evaluations of existing programs to determine what works
- b. Examine effective models used for other chronic conditions (e.g., diabetes, breast cancer, substance use, HIV/AIDS) and specific populations (e.g. racial and ethnic groups, men)
  - Adapt for use with bone health
  - Work with partners to highlight effective strategies

## **Barriers and Facilitators**

Barriers Facilitators -

## Action I tems and Those Responsible/Deliverables

- 1.
- 2.

## Timeline

## **Outcome Measures**

- 1.
- 2.

### PEDIATRIC STRATEGIC PLANNING SPECIALTY GROUP

## Introduction

The Pediatric Strategic Planning Group has developed the following prioritized list after multiple phone conferences and consultations. The individual listed under the Topics and Subtopics has developed the goals and objectives, and identified barriers, facilitators and action plans for each of the priority areas. The goal of the group was to identify areas with significant impact on the musculoskeletal health of children, and which could be significantly improved through educational activities and advocacy through the BJD and its member organizations.

The group further identified that individuals with childhood onset chronic neuromuscular and musculoskeletal disorders are increasing in number and face significant challenges in terms of access to quality medical care and significant functional barriers as they transition to adulthood.

These priorities are meant as a starting point for the discussion with regard to how we might best affect research, education, and advocacy to improve the musculoskeletal health of children. This is not meant to be all inclusive; the group does not desire to be redundant with other groups within the Bone and Joint Decade, which the pediatric planning group fully supports, such as the Rare Bone Disease Patient Network and the Spine, Research, Trauma and Injury, and Arthritis Strategic Planning Specialty Groups.

Additional experts from member organizations will be enlisted to further define these priority areas and the means to achieve positive change.

### **PRIORITIES**

## **Priority #1: HEALTHY LIFESTYLES**

The group agreed that the greatest potential impact the USBJD could have would be in the area of healthy lifestyles for children. Emphasis should be on coordination of the efforts of the member organizations toward education and advocacy so that all children reach their full musculoskeletal potential.

Under Healthy Lifestyles the group further defined the subgroups and the individual responsible for completing the goals, objectives, and action plan for each subgroup. This individual will also be responsible for helping to recruit other experts, both national and international, to further refine and develop these plans of action.

- A) Impact of obesity on the musculoskeletal health of children K. Leitch, N. Alegrete, P. Esposito
- B) Development of ideal bone mass and strength though exercise and diet J. Lappe. P. Esposito, M. Levine

## Priority #2: INFECTIOUS DISEASE OF THE MUSCULOSKELETAL SYSTEM

The impact of infectious diseases on musculoskeletal health and activity
J. Romero, H. Epps

## Priority #3: TRAUMA PREVENTION

The pediatric strategic planning group agreed that the trauma planning group should lead this effort, and that we should support, but not duplicate, their efforts.

D. Spiegel, L. Tosi

## **Priority #4: LIMB DEFICIENCY IN CHILDREN**

Agreed to advocate and educate to assure access to appropriate prosthetic, surgical, and rehabilitation services for children with either acquired or congenital limb deficiency.

## Priority #5: OPTIMIZING BONE, JOINT AND MUSCLE FUNCTION IN CHILDREN WITH CHRONIC NEUROMUSCULAR AND MUSCULOSKELETAL DISORDERS

## Priority #6: SUCCESSFUL TRANSITION FROM PEDIATRIC TO ADULT CARE FOR PERSONS WITH CHILDHOOD ONSET MUSCULOSKELETAL DISORDERS

L. Jung, L Tosi, M. Levine

## **Priority #7: SPECIFIC DISORDERS**

A) The group agreed that we should maintain a separate priority to cover specific disorders for which the USBJD could impact outcome through targeted educational efforts and/or coordination of resources. These include but are clearly not limited to:

Clubfeet

Developmental Hip Dislocation

Slipped Capital Femoral Epiphysis

- B) The group recognizes that for rare, metabolic bone diseases, the Rare Bone Disease Patient Network is the most appropriate venue within the USBJD to pursue education and advocacy for rare but important musculoskeletal diseases.
- C) One area of discussion included developing an online resource through the USBJD to coordinate an online library of resources and contacts from member organizations with interests and expertise in dealing with specific diagnosis and disorders.

## Priority Area #1: Healthy Lifestyles

## Sub-Section A: Musculoskeletal Problems of Childhood Obesity

## Issue:

Obesity is *one* of the most significant remedial health problems of children in the US and throughout much of the developed and developing world. Obesity is causing an ever increasing incidence and severity of childhood musculoskeletal problems that carry over into adulthood.

### Goals:

- 1. To reduce the burden of musculoskeletal disease that will lead to lifetime limitations and disabilities through modification of attitudes and cultural behavior of both parents and children.
- 2. To educate parents, youth and children, in the importance of good nutritional habits in enhancing optimal musculoskeletal growth and development as well as optimal bone strength.
- 3. To educate parents, youth and educators of the importance of a physically active lifestyle, tailored to the abilities and gifts of the individual, not only in childhood, but throughout life.

## **Objectives:**

- 1. Gather data documenting the increasing negative effects of childhood obesity on musculoskeletal health. What is the burden in our society?
- 2. Document the societal costs of childhood obesity in terms of physical function. Emphasize segments of the population that are at most risk.
- 3. Gather data on diet and physical activity that are relevant, to specific segments of society such as ethnic, race, geographic or socio economic groups to enhance targeted intervention.
- 4. Determine the optimal means to communicate to parents, children, and community leaders how optimal diet, activity and lifestyle choices decrease the morbidity of childhood obesity.
- 5. Develop a communications and social marketing plan of action to cause community leaders and parents to actively combat the epidemic of childhood obesity. <u>Motivate celebrities to participate in campaigns to promote healthy lifestyles and adequate nutrition.</u>
- 6. Develop a plan to advocate to Congress, and other levels of governments, as well as other international governments, to create adequate legislation that leads to:

  a) assurance of adequate labeling of foods to ensure that consumers know, in plain language, the health benefits or detrimental effects of each food product sold (examples to be drawn from New York City, and the Government of Canada);
  b) limitations on the use of children in advertisements for hypercaloric foods [now illegal], c) control of the kinds of food that can be dispensed by vending machines at schools.
- 7. Utilize and support the resources in place at the federal, state and local levels to diminish the effects of childhood obesity.
- 8. Develop educational and clinical musculoskeletal resources nationally and locally to assist in education and program development.
- 9. Encourage and facilitate collaboration among industry, academic and community leaders to take action on combating obesity.

## Barriers:

- 1. Obesity is often multigenerational and long standing within families and cultural groups.
- 2. Many ethnic and lower socioeconomic groups do not have access to what they consider reasonably priced healthy foods, nor access to safe facilities for physical activities.
- 3. Even when fast food vendors attempt to market healthier options, consumers/children tend to migrate to the higher fat, higher caloric options.
- 4. There is a lack of safe play areas in many neighborhoods, a reality that inhibits unorganized childhood exercise as an alternative to sedentary activities such as video games.
- 5. Institutions such as school cafeterias continue to offer higher caloric, less healthy foods based on cost and lack of knowledge of the impact of these foods on children.

## Facilitators:

- 1. Recognition that obesity in children and adults is having a significant impact on health, productivity and quality of life.
- 2. Data is becoming available that clearly demonstrates the impact of obesity on health.
- 3. There is a clearer understanding of the financial and societal costs of obesity-related disorders, that will escalate as this generation of children becomes adults.
- 4. Government, shown these potential cost and societal savings, should be inclined to act with appropriate education and advocacy.

## **Action items:**

- 1. Form a steering committee/Task force with representatives from as many interested organizations as possible, such as the AAP, POSNA, ADA, ACSM... with the AAP in the lead in view of the obesity programs involving multiple sections and councils already demonstrating effectiveness in this area. (Consider participation of industry and community service leaders on this committee.)
- 2. Research, develop and support a working network of existing resources and organizations with a stated priority of combating obesity and invite participation and cooperation of efforts.
- 3. Develop a cohesive and complete model for data to demonstrate the deleterious effects and impact of obesity on the musculoskeletal system.
- 4. Utilize the impact and recognition of the USBJD by acting as a repository of links and information, e.g. publications, presentations and perhaps most important the internet.
- 5. Mine and formulate the available data and promulgate interest in investigation of less than optimally documented areas of concern relative to childhood obesity, such as the impact on the musculoskeletal system.
- 6. Develop a system of educational material and programs for parents and school teachers that is clear, concise and practical in collaboration with primary and secondary school educators.
- 7. Form a task force to work exclusively on determining how to gain receptivity and action by parents and children, as well as schools.
- 8. Form a government affairs group to develop an advocacy plan of action and impact.

Priority Area 1: Healthy Lifestyles

Sub-Section B: Building Strong Bones for Life through Diet, Exercise, and Attitude

Issue: Nutrition

J. Lappe, M.D., M. Levine, M.D., L. Esposito, M.S., R.D. L.N.

In growing children, nutrition and activity are important determinants of current and future strength and quality of bone and muscle. Peak bone mass is acquired during the third decade of life, and is influenced by nutrition and activity during childhood and adolescence. Recent changes in the average child's diet and decreases in physical activity represent significant threats to acquisition of optimal peak bone mass and can thereby lead to compromised bone health throughout the lifespan.

In developing nations, as well as in many areas of the developed world, reduced availability of affordable high quality and nutritious food presents similar barriers to acquisition of optimal peak bone mass. Importantly, children in the developed world are increasingly choosing diets that are based on highly processed foods that are low in nutritional value and which can impair acquisition of optimal bone mass. The costs of healthy foods are also a significant barrier in the U.S. and other developed countries.

Eating disorders that are characterized by severe restriction of calories or by excessive intake of low quality foods both constitute significant problems in the developed world. Severe overweight, as well as underweight, are both associated with defects in bone quality and bone mass. Poor nutrition and related diseases continue to be causes of morbidity and excess morbidity in the developing world. Throughout the world, inadequate intake of calcium and vitamin D is increasingly recognized as an important threat to optimal bone health. Because most people do not receive sufficient sunlight to stimulate adequate cutaneous synthesis of vitamin D, and typical diets lack significant amounts of it, vitamin D and minerals supplementation may well be required to ensure an adequate intake considered optimal for bone health.

### Goal:

To promote acquisition of optimal peak bone mass in children and adolescents throughout the United States and the world, by changing attitudes, focusing on exercise and nutrition.

### Objectives:

- 1. Increase public awareness of the importance of nutrition and physical activity in promoting healthy weight and optimal bone health in childhood.
- 2. Develop clinical practice guidelines for promotion of bone health in childhood and adolescence in conjunction with member organizations to implement guidelines.
- 3. Disseminate information to pediatricians about bone health interventions and methods of assessing children at risk for acquisition of suboptimal peak bone mass.
- 4. Increase the number of schools that offer physical activity programs.
- 5. Develop and implement bone health educational programs for children and adolescents.
- 6. Work with athletic trainers, coaches, and educators, as well as health care providers to help implement age appropriate activities.
- 7. Promote research in bone and muscle development in children.

### **Barriers:**

- 1. Entrenched attitudes in society and children towards tasty but nutritionally deficient foods.
- 2. Significant advertising by fast food industry that makes items lower in nutrition more attractive than more beneficial foods.
- 3. Displacement of vitamin-D fortified dairy products by inexpensive, nutritionally deficient soft drinks and high-calorie/sugar-added fruit drinks.
- 4. The cost of nutritionally beneficial foods frequently is in excess of lesser quality foods.
- 5. Lack of emphasis on the importance of developing peak bone mass during childhood and adolescence.
- 6. Relative lack of physical exercise in many children which inhibits bone and muscle development.
- 7. Routine physical activity is progressively decreasing in children for a variety of reasons, including few physical education programs, decreased recess time in primary schools, and concern for children's safety when playing outside, walking to school, or during unsupervised outdoor play.

## Facilitators:

- 1. Increasing public awareness of the impact of osteoporosis in adults.
- 2. Coordinated government, community, and athletic programs emphasizing the importance of nutrition in performance and health are becoming more common as the awareness of diet and exercise in developing bone and muscle mass in children is becoming more clearly recognized.
- 3. Increasing awareness of the overall health benefits of exercise and diet.

### **Action Plan:**

- 1. Support educational efforts to alter diet in the developed world for optimal bone health.
- 2. Advocate for the monitoring of diet and activity levels of competitive athletes.
- Coordinate the educational advocacy efforts of the member organizations towards optimizing diet and exercise for maximum bone and muscle growth and development.
- 4. Work with international organizations such as the WHO to assure that educational programs emphasize the importance of specific nutrients in the prevention of nutritionally related bone diseases and optimizing bone and muscle growth and development during childhood and adolescence.
- 5. Promote and disseminate research on optimizing bone health.
- 6. Support the goals of programs such as Healthy People 2010 and Powerful Bones, Powerful Girls, which are already in place.

## Priority Area #2: Infectious Diseases of the Musculoskeletal System

## Issues:

- 1) Antimicrobial resistance and morbidity is a growing problem worldwide. The common pathogens associated with pediatric bone and joint infections have developed or are developing a high prevalence of resistance to commonly used antimicrobial agents.
- 2) The incidence of complications (i.e. abscess, deep vein thrombosis, pyomyositis, sepsis, etc.) related to bone and joint infections in pediatric patients are increasing. These complications appear to be primarily related to infections due to *Staphylococcus aureus*.
- 3) Despite extensive experience in the treatment of bone and joint infections in children, no uniform guidelines exist for their management as do for other conditions (e.g. endocarditis, bacterial meningitis, skin and soft tissue infections, etc). Development of such guidelines may improve care and decrease complications associated with the treatment of pediatric bone and joint infections (i.e. catheter-related complications).
- 4) There is a need to optimize prevention strategies and therapeutic pathways for pediatric bone and joint infections in resource-poor environments.
- 5) In developing nations tuberculosis continues to be a significant health problem, contributing to the cause of many bone and joint infections. Furthermore, the management of tuberculous osteomyelitis and septic arthritis is complicated by increasing rates of resistance to the commonly used drugs used for the treatment of tuberculosis. As persons from TB endemic areas of the world migrate to regions unfamiliar with its varied clinic presentations, physicians may encounter tuberculous bone and joint infections.
- 6) Although rarely life-threatening, lymphatic filariasis causes widespread and chronic suffering and disability. It can lead to grotesquely swollen limbs; a condition known as elephantiasis. Lymphatic filariasis is an infection with the filarial worms, *Wuchereria bancrofti*, *Brugia malayi* or *B. timori*. It is estimated that >120 million people worldwide are infected with one of these three microfilariae and that >40 million infected individuals are seriously incapacitated and disfigured by the disease. These parasites are transmitted to humans through the bite of an infected mosquito and develop into adult worms in the lymphatic vessels, causing severe damage and lymphedema.

## Goals:

- 1a) Decrease the growing incidence of antibiotic resistance among pathogens commonly associated with bone and joint infections in children through education of practitioners.
- 1b) Increase the rate of obtaining appropriate clinical samples prior to onset of antibiotic treatment in order to selectively guide antibiotic therapy.
- 1c) Increase the utilization of up-to-date methodologies for the detection of pathogens associated with pediatric bone and joint infections.
- 1d) Increase the choice of appropriate empiric and definitive antibiotic therapy for the therapy of bone and joint infections in the pediatric and adolescent populations.
- 2a) Decrease the morbidity associated with musculoskeletal infection through appropriate combined multidisciplinary treatment.
- 2b) Increase research funding for efforts to identify microbial and host factors that lead to increased severity of bone and joint infections in pediatric patients.

- 3a) Develop specific guidelines for the evaluation and management of pediatric osteoarticular infections to be endorsed and accepted by orthopedists and pediatric infectious disease subspecialists caring for children.
- 4a) Validate simple and effective intravenous to oral therapeutic regimens that will permit the short-term use of intravenous therapy prior to switching oral therapy.
- 4b) Promote the use and development of vaccines that will prevent infections such as those caused by *Haemophilus Influenza* and pneumococcus.
- 5a) Improve therapy of drug resistant tuberculous bone and joint disease in developing nations and resource poor regions of the world.
- 5b) Increase awareness of bone and joint complications of *Mycobacterium tuberculosis* infections among healthcare providers caring for individuals from tuberculosis endemic regions.
- 6a) Increase public awareness of the impact of infectious disease of the musculoskeletal system worldwide, including the impact of lymphatic filariasis.
- 6b) Promote and support World Health Organization efforts for the treatment and prevention of lymphatic filariasis.

## Objectives:

- 1a) Obtain information regarding worldwide trends in resistance in both industrialized and developing nations for the common (i.e. *Staphylococcus aureus*, *Kingella kingae*, etc.) and less common (i.e. Salmonella sp.) causes of pediatric bone and joint infections.
- 1b) Educate practitioners regarding the evolving patterns and incidence of antibiotic resistance among pathogens commonly associated with bone and joint infections in children.
- 1c) Develop practice guidelines for determining the most appropriate antimicrobial agents for empiric therapy of pediatric bone and joint infections based on local antimicrobial resistance data.
- 1d) Increase the appropriate use of antibiotics and surgery to decrease the burden of disease while slowing the development of antibiotic resistance.
- 2a) Obtain information regarding worldwide trends in the incidence of complications associated with bone and joint infections in children and adolescents (i.e. abscess, deep vein thrombophlebitis, pyomyositis, etc).
- 2b) Educate practitioners regarding the growing incidence of complications associated with bone and joint infections in children and adolescents (i.e. abscess, DVT, pyomyositis, etc.).
- 2c) Educate practitioners regarding the appropriate medical and surgical management of infectious complications associated bone and joint infections in pediatric patients.
- 2d) Educate practitioners regarding the appropriate evaluation for the detection of infectious complications associated bone and joint infections in pediatric patients.
- 3a) Convene a body of experts in the treatment of pediatric bone and joint infections to include potentially orthopedists, infectious diseases specialists, radiologists and experts in diagnostic microbiology to draft guidelines for the evaluation and therapy of these conditions.

- 3b) Lobby the governing bodies of the orthopedic and infectious diseases society world-wide to adopt a guidelines for the evaluation and therapy of pediatric bone and joint infections.
- 4a) Increase clinical and basic science research funding for efforts to develop appropriate treatment protocols and the development of new, more effective antibiotics.
- 4b) Develop programs to provide prompt, effective, cost effective treatment of musculoskeletal infections in resource poor environments.
- 4c) Develop and foster programs to increase immunization against common pediatric pathogens associated with bone and joint infections.
- 5a) Provide appropriate antituberculous medications for the treatment of bone and joint infections due to drug resistant *Mycobacterium tuberculosis* in resource-poor regions of the world.
- 5b) Educate health care providers caring for immigrants from tuberculosis endemic areas regarding the role of *Mycobacterium tuberculosis* in bone and joint infections.

### **Barriers:**

- 1) Engrained habits of overuse of antibiotics.
- 2) Lack of resources and education in some areas of the world to allow for early diagnosis and treatment of bacterial bone and joint infection.
- 3) Difficulty in developing effective new antibiotics to combat the ever-increasing trends in bacterial resistance.
- 4) Lack of clinical trials validating the use of newer antimicrobials for the treatment of bacterial bone and joint infections.
- 5) Lack of collaborative efforts among multi-centered groups of orthopedists and infectious diseases subspecialists for the study of problems related to the evaluation and therapy of pediatric bone and joints infections.
- 6) Lack of collaborative efforts among orthopedists and infectious diseases subspecialists expert in the care of children with bone and joints infections to develop guidelines for the evaluation and treatment of these conditions.
- 7) Lack of simple, inexpensive and readily available methodologies for the identification of microbial agents.
- 8) Lack of simple, inexpensive and readily available methodologies for the determination of antimicrobial susceptibilities.
- 9) Lack of funding for novel research into the bacterial and host factors that contribute to the pathogenesis of pediatric bone and joint infections.
- 10) Lack of resources for vaccine programs in developing nations.
- 11) Anti-vaccine rhetoric leading to decreasing rates of immunization in certain sectors of the population.
- 12) Lack of funding to provide high cost anti-tuberculous drug to resource compromised regions of the world.

13) Lack of perception and recognition of tuberculosis as an important cause of bone and joint disease in developing nations and in individuals emigrating from those nations.

## Facilitators:

- 1) Awareness and concern of governmental agencies, health care agencies and health care providers world wide with regard to the dangers of antibiotic resistance.
- 2) Recognition of the life long burden of disease on individuals following musculoskeletal infections, especially when treatment is delayed, or suboptimal.
- 3) Efforts by the World Health Organization and other organizations for the treatment and prevention of tuberculosis in developing nations.

## **Action Items:**

- 1) Support and educational programs in conjunction with member organizations, including the development of treatment and diagnostic algorithms in treating musculoskeletal infections.
- 2) Convene a body of experts in the treatment of pediatric bone and joint infections to include potentially orthopedists, infectious diseases specialists, radiologists and experts in diagnostic microbiology to draft guidelines for the evaluation and therapy of these conditions.
- 3) Advocate governmental agencies to support the development of new, more effective antibiotics.

## Priority Area #3: Trauma Prevention

The pediatric strategic planning group agreed that the trauma planning group should lead this effort, and that we should support, but not duplicate, their efforts.

D. Spiegel, L. Tosi

### Goals:

- 1. Support a collaborative approach to improve road traffic safety that includes elements of education, prevention, and treatment spanning the spectrum from prehospital to rehabilitative and re-integrative care.
- 2. Improve trauma care delivery systems
- 3. Highlight special needs of children with regard to development and availability of educational and operational resources.

## Barriers:

**Health system deficiencies** such as fragmentation of services and gaps in the capacity to deliver services.

- 1. **Deficiencies in the capacity to deliver services** in terms of infrastructure, physical resources (supplies and equipment) and human resources for health (number, distribution, and training).
- 2. Lack of political will.
- 3. WHO and other organizations involved in promoting worldwide road-traffic safety and crash victim care have focused on **prevention rather than treatment** of the injured in the pre-hospital and hospital based settings.
- 4. **Inadequate funding** for a) advocacy efforts and b) implementation of basic health system reforms aimed at strengthening the delivery of curative services (pre-hospital and hospital based) and rehabilitation services.

## Facilitators:

- World Health Organization through it's Department of Violence and Injury
  Prevention and the Department of Essential Health Technologies (Emergency and
  Essential Surgical Care Project, Global Initiative for Emergency and Essential Surgical
  Care). Guidelines have been developed including the such as the Integrated
  Management of Emergency and Essential Surgical Care toolkit, Surgical Care at the
  District Hospital (SCDH) and the Guidelines for Essential Trauma Care and
  Prehospital Trauma Care.
- 2. **International stakeholders** with an interest in the prevention and treatment of injuries.
  - These may include governments and/or Ministries of Health, non-governmental organizations, Universities and other institutions, individuals, societies, and foundations.
- 3. **United Nations resolutions** concerning road safety (references).
- 4. "Task shifting" models to enhance delivery of services, for example the Orthopaedic Clinical Officers of Malawi
- 5. Opportunity to integrate trauma care and surgery within the overall concept of health system reforms envisioned by Primary Health Care.

### **Action Items:**

- 1. Organize a global meeting to develop a plan to implement trauma treatment standards worldwide
- 2. Support **advocacy efforts**. Fund more surgeons to become involved at high level for RTC. Increase the level of attention at leadership organizations like UN/WHO so that funding for road traffic crash and/or injury prevention and treatment is commensurate with the burden of disease. BJD to prioritize making RTC education, prevention and treatment important parts of their advocacy efforts.
- 3. Support the Global Initiative for Emergency and Essential Surgical Care, and the implementation of Emergency and Essential Surgical Care training programs.
- 4. Support for 6<sup>th</sup> UN resolution to have the next decade (2010-2020) directed at Road Traffic Safety/ Road Traffic Crashes. Make sure trauma CARE is a specific part of this resolution so that the entire effort does not become consumed with pure prevention. Insure that Surgeons are well represented on the RTC Decade
- 5. Define acceptable trauma care levels for developed and developing nations to include pre-hospital, acute care, definitive care and rehabilitative/re-integrative components
- 6. Need to develop global strategic plan to make trauma care more affordable and available
- 7. Need to convince major world organizations to include trauma treatment initiatives in addition to prevention efforts
- 8. Define better list of collaborators who do we want to bring into the process
- 9. Define action plan to get more mid-level and even low-level practitioners involved, educated and credentialed
- 10. Need situational analysis of capacity to deliver trauma care worldwide so as to develop and implement plans to help nations develop systems worldwide

## Priority Area #4: Limb Deficiency in Children

Child limb deficiency, either acquired or congenital, is relatively uncommon but requires lifelong medical and frequently surgical services, and has a major financial, functional, and psychosocial import on these children. The cost of prosthetic services and ongoing rehabilitative services can be overwhelming, both in the developed and developing world.

To live a healthy lifestyle with limb deficiency requires access to appropriate prosthetic, surgical and rehabilitative services.

## Goals:

- 1. To maximize comfort and function in children with limb deficiency.
- 2. To educate orthopedic surgeons about cost of prosthetic components versus utility for various pediatric limb deficiencies.
- 3. To educate the public about lawn mower/farm equipment safety.
- 4. To decrease the incidence of preventable acquired amputation in children.
- 5. To educate patients/parents in a reasonable unbiased fashion using evidence based literature informing them about prosthetic options.
- 6. To develop an interface with the prosthetic industry to help create more physician and payor input.
- 7. Educate the amputee and family about problems with obesity, particularly with inactive lower extremity amputees.
- 8. To promote appropriate ergonomic prosthetic components and supportive service, which can be adapted or replaced to accommodate for growth and developmental change for all children worldwide.
  - To avoid devices that are excessively complex and expensive that may interfere with function rather than assist.
  - To promote prosthetic devices that can easily be utilized in Third World countries.

## **Objectives:**

- 1. To develop educational programs and resources for orthopaedists, prosthetists, and therapists around the world to provide consistently the most appropriate devices to allow maximum function.
- 2. To disseminate the experience of centers that deal with large numbers of children with limb deficiency to assure that all are able to benefit from proven devices and therapy.
- To develop relationship between healthcare providers and the prosthetic industry to develop cost-effective devices and techniques for children regardless of where they live.
- 4. To educate parents and patients about the appropriate devices through evidence-based data to maximize function and comfort to offset the drive to obtain the most sophisticated, expensive devices.
- 5. To decrease the incidence of lawn and farm machinery amputations in children through educational programs and development of safety equipment.

- 6. To raise the awareness of the worldwide problem of mine and military explosive related amputations in children.
- 7. To develop and support appropriate adaptive athletic activity for children with limb deficiencies

## Barriers:

- 1. Prosthetic advances in new products often promoted as "best" options without evidence based research.
- 2. Because limb deficiency is relatively uncommon, there are many areas where providers are inexperienced.
- 3. Pediatric amputees may frequently find themselves excluded from healthy sport activities by a variety of factors including their level of performance, cohort and teacher perception of what their "problem" actually is.
- 4. Access to the internet and other media can mislead families and drive their desire for the latest, most complex, expensive devices, even when a simpler, more cost effective prosthesis will provide better function.
- 5. There are many areas in the developed world where insurance coverage is limited to one prosthesis total, despite the clear evidence that children require multiple prostheses to accommodate growth.
- 6. Despite educational efforts, injuries from lawnmowers and farm equipment continue to be a major cause of limb deficiency in children.
- 7. There are parts of the world where land mines are an ever present danger. The resources to rid their countries of these decades-lasting threats are severely limited.

## Facilitators:

1. Returning injured war veterans have demonstrated the ability to achieve excellent function and a physically active lifestyle with appropriate surgery, therapy, and prosthetic fitting.

### **Action Items:**

- 1. Form a task force with members of ACPOC, ORA, Amputation Coalition of America, AOPA, and leaders in the prosthetic industry to define research and education to improve appropriate access to prosthetics and therapy.
- 2. Develop a model of proper resource utilization acceptable to patients, physicians, and industry.
- 3. Advocate for patients to payers for appropriate prosthetic reimbursement, especially in the pediatric age group where frequent prosthetic changes are needed.
- 4. Gather data from limb deficient children and their families about the effects on quality of life with respect to obesity, and the lack of physical education programs.
- 5. Support efforts to develop indigenous prosthetic services to provide optimal prosthetic fitting and care worldwide.

## Priority Area #5: Optimizing Bone, Joint and Muscle Function in Children with Chronic Neuromuscular and Musculoskeletal Disorders

L. Tosi, L. Jung, M. Levine, P. Esposito

### Issue:

Children with chronic neuromuscular and musculoskeletal disorders face unique and special medical, physical and psycho social challenges. Children with these disorders, including chronic inflammatory diseases, such as juvenile idiopathic arthritis, lupus and dermatomyositis; those with congenital musculoskeletal disorders such as myelomeningocele, cerebral palsy, osteogenesis imperfecta, and arthrogryposis as well as those with post traumatic impairment, can today live well into adulthood with appropriate medical treatment and support. It is therefore critically important to develop and make available programs that can optimize bone, joint and muscle function for these children.

The importance of physical activity, in addition to adequate nutrition, medical treatment and education is increasingly being shown to have long term positive effects on health in general and in terms of musculoskeletal health and function for all children. Given the additional physical and medical burden that children with chronic musculoskeletal disorders must live with, the importance of a healthy lifestyle for these individuals is probably even more essential.

Ongoing programs of physical activity, optimized diet and appropriate medical care may decrease the deterioration in function and comfort, as well as the significant burden of care to their families and society that many children with chronic musculoskeletal conditions experience with aging and relative inactivity.

### Goal:

To optimize bone, joint and muscle function in children with chronic musculoskeletal disorders by providing opportunities for maintaining maximum comfort, function and independence in these children through careful implementation of an appropriate program of physical activity, diet, and exercise.

## **Objectives:**

- 1. Determine the obstacles that limit children with chronic musculoskeletal diseases from participating in age appropriate activities.
- 2. Determine the resources presently available to guide appropriate physical activities and physical educational programs for children with chronic musculoskeletal disease.
- Define the needs for development of curricula to maximize the benefits of physical activities in the school setting, and develop a means to safely and effectively assess the child's abilities to guide the implementation of these programs.
- 4. Expand the opportunities for children with chronic musculoskeletal disorders to participate in exercise programs.

## Barriers:

- 1. Public perception that children with physical disabilities are incapable of participation in physical activities.
- 2. Adaptive sporting activities, such as the Special Olympics, wheel chair sports, and skiing for limb deficient children do exist, but geographical and financial barriers may limit access to all appropriate children.
- 3. Limited numbers of facilities with trained personnel to assist those with special needs.
- 4. Lack of self esteem, anxiety, and peer pressure may limit the willingness of the individuals to participate in programs and activities that do exist.
- 5. Physical limitations such as chronic pain, risk of fracture and injury, and the need for potentially expensive adaptive equipment.

- 6. Certain medications, such as steroids, may increase the risk of fractures, interfere with bone strength, and contribute to difficulties with weight control.
- 7. Lack of governmental or community support for those with physical disability
- 8. Lack of a cost-benefit analysis which documents the health and cost benefits of providing children with chronic musculoskeletal conditions with healthy lifestyle alternatives

## Facilitators:

- 1. Currently existing disease-specific advocacy groups, especially member organizations of the USBJD.
- 2. Increased commitment to disabled war veterans has created a window of opportunity to enhance focus on accessibility.
- 3. Programs such as Special Olympics and Wheel chair sports activities, already are making a significant contribution, and could potentially increase their impact with the support of an organization like the USBJD and its member organizations.
- 4. Positive example and publicity generated by the example and efforts to develop an active healthy lifestyle by returning injured war veterans.

### Action Items:

- 1. Partner with advocacy organizations in articulating the importance of maintaining an active and healthy life style for children with neuromuscular disorders to national policy makers
- 2. Engage school organizations in discussions and programs that emphasize the need for children with musculoskeletal disorders to have an active and healthy lifestyle.
- 3. Develop a cost-benefit analysis of the health benefits from an active lifestyle for children with musculoskeletal conditions to assist advocacy organizations in their appeals for government and philanthropic support.
- 4. Develop, in conjunction with the appropriate PT, OT, and physical education teacher's organizations, a curriculum to assist with development of age, and disability appropriate physical activity and education to maximize the health benefits for each child.
- 5. Advocate for government and insurance industry support for alternative physical activities such as aqua therapy and hippo therapy for the appropriate child when more mainstream activities are not physically safe or possible.

## Priority #6: Successful Transition from Pediatric to Adult Care for Persons with Childhood Onset Musculoskeletal Disorders

## Issue:

Most children with chronic inflammatory diseases, (such as juvenile idiopathic arthritis, lupus and dermatomyositis), congenital musculoskeletal disorders (such as myelomeningocele, cerebral palsy, osteogenesis imperfecta and arthrogryposis) as well as children with post traumatic impairments, can today expect to live well into adulthood with appropriate medical treatment and support. This success brings new challenges to the medical community, as access to specialized medical care, exercise, education and training/work for these individuals often diminishes or even disappears as they reach adulthood. and, they enter into an unpredictable, and many times for them, frighteningly inadequate and uncoordinated health and social services system. In addition, as they age, these individuals often develop unique musculoskeletal and neurologic symptoms, such as marked bone fragility, severe pain, fatigue, and a premature decline in mobility and function. Adult medical practitioners as well as facilities ranging from gyms to hospitals, are frequently not equipped to provide environments in which these individuals can receive safe and appropriate care. Adults with childhood onset musculoskeletal disorders deserve the same level of sophisticated, cost-effective medical care and support as they received as children, and they should not be any less appreciated as members of society because they have reached an arbitrary age.

### Goal:

Improve the transition from pediatric to adult care and support for persons with childhood onset musculoskeletal disorders.

## Objectives:

- 1. Engage both policy makers and the healthcare professionals in addressing the unmet needs of individuals with childhood onset musculoskeletal disorders as they transition to adulthood.
- 2. Define the combination of services/facilities young people with childhood onset musculoskeletal disorders need to maximize their musculoskeletal health as adults and use that data to identify and address the challenges these individuals face accessing health care, therapies, and exercise facilities.
- 3. Develop outcome measures for evaluating successful transition to adult care for individuals with childhood onset musculoskeletal disorders.
- 4. Engage medical professional societies from fields such as internal medicine/ rheumatology, physical medicine, and orthopaedics etc in the process of developing evidence-based standards of care for adults with childhood onset musculoskeletal conditions.
- 5. Promote research leading to an understanding of the biological mechanisms which lead to musculoskeletal complications in the adult with a childhood onset musculoskeletal disorder.
- Identify and promote new treatments and technologies developed for patients with adults onset musculoskeletal disorders (such as stroke and osteoporosis) that may help to improve the aging process in adults with childhood onset musculoskeletal disorders.

## Barriers:

- 1. Lack of epidemiologic data delineating patient numbers, impairments, life expectancy etc of persons with childhood onset musculoskeletal disorders makes it difficult to convince policy makers that a problem exists.
- 2. Absence of cost-benefit analyses that demonstrates that improving healthcare access and supporting "wellness" initiatives in persons with childhood onset musculoskeletal disorders translates into improved health status and/or cost savings.

- 3. Lack of adequate/coordinated funding to support care of individuals with childhood onset musculoskeletal disorders.
- 4. Adult health care providers receive inadequate training about the care of adults with childhood onset musculoskeletal disorders in medical school and residency programs which leads to hesitancy and discomfort to engage in the care of these individuals.
- 5. Adolescents and young adults with childhood onset musculoskeletal disorders are frequently reluctant to engage in transition of care processes either because 1) they do not want to give up the care givers they are accustomed to or 2) because they deny their medical and physical vulnerabilities and wish to declare their medical independence.

# Facilitators:

- 1. Patient/parent advocacy organizations
- 2. Professional health care organizations devoted to the care of individuals with childhood onset musculoskeletal disorders such as the American Academy for Cerebral Palsy and Developmental Medicine, Arthritis Foundation, etc
- 3. Quality Improvement Committees from medical professional organizations
- 4. Quality improvement organizations that recognize that individuals with childhood onset neuromuscular and musculoskeletal conditions face increased risk for complications when they interface with the healthcare system

# **Action Items:**

- 1. Support the development of epidemiologic data that delineates patient numbers, impairments, life expectancy etc of persons with childhood onset musculoskeletal disorders.
- 2. Develop a cost-benefit analysis that makes the case for the investment of resources in improved care for individuals with childhood onset musculoskeletal disorders.
- 3. Encourage advocacy groups to press for increased funding for the establishment of model transition care programs.
- 4. Initiate collaboration among professional health-care organizations to develop evidence-based care standards, outcome measures, and practice guidelines to ensure that all patients with childhood onset musculoskeletal conditions receive the highest possible level of care.
- 5. Ensure that training programs for health care professionals include training on the care of adults with childhood onset musculoskeletal conditions in their curricula.
- 6. Encourage advocacy groups to press for improved access to health insurance for individuals with childhood onset musculoskeletal disorders.
- Encourage advocacy groups to form coalitions to press for government and institutional support for research funding to support the development of evidence based standards of care and outcomes measures for transition and adult care programs.

#### RESEARCH STRATEGIC PLANNING SPECIALTY GROUP

# Introduction

The leadership of the U.S. Bone and Joint Decade identified a Research Strategic Planning Committee, which was asked to develop a long-range plan for musculoskeletal research for presentation at the Global Network Conference in Washington, DC, in October, 2009. The charge for the Committee was to bring a global perspective to the identification of important issues in musculoskeletal research, to prioritize them and to develop an action plan to achieve them, with a set of measurable outcomes to determine eventual success.

This document is intended to identify priority issues in research that extend beyond specific musculoskeletal disease entities, and to consider the barriers and facilitators to progress in musculoskeletal research more broadly and with an international perspective. Consequently, this document does not focus on specific musculoskeletal conditions, or specific musculoskeletal tissues and diseases, but attempts to outline the direction of musculoskeletal research that may significantly improve musculoskeletal health over the next 5-10 years.

The central theme of the Research Strategic Plan is Knowledge Translation. In this sense, the Committee viewed research as a bridge in which advances in basic science are translated to changes in public health through comparative effectiveness studies and well-designed and innovative clinical trials. Support for knowledge translation occurs through a strong training pipeline that provides qualified young investigators, and which is supported by advocacy efforts at several different levels in support of research funding. With this background, three Priority Areas were identified: (1) Definition of Important Areas for Research; (2) Training Programs; and (3) Raising Public Awareness and Promoting Advocacy for Research.

# Priority Area #1: Define Important Areas for Research

### A. Basic Research

<u>Issues:</u> Bone and joint diseases are numerous and the most prevalent (e.g., osteoarthritis, osteoporosis) are chronic, increasing in incidence and prevalence, and common causes for visits to physicians. Yet, virtually all remain poorly understood to both professionals and the public, difficult to diagnose and to treat. As examples, the detection of early osteoarthritis depends on a vague definition and the concept of bone quality in the context of fracture risk remains undefined. Furthermore, risk factors, preventive strategies and best treatment options at various stages of progression of particular musculoskeletal diseases are complex, spanning issues of genetic predispositions and responses to sex/gender, racial/ethnic, and psychosocial determinants.

Musculoskeletal conditions are under-researched relative to the burden of disease at essentially every level, including basic research questions.

Much of the basic research that is done in musculoskeletal systems and diseases is narrowly focused, with lack of integration across other relevant organ systems and informative disciplines.

<u>Goals:</u> Primary goals of the International Bone and Joint Decade should be to increase the quantity, quality and relevance of basic musculoskeletal research. A secondary goal should be to foster translation of basic results into new products, approaches and therapies for musculoskeletal disease.

# Objectives:

- Increase interactions between internationally based investigators to foster integration of research across musculoskeletal systems and diseases.
- Increase physiological and systems biology level approaches to understanding musculoskeletal health and diseases by attracting specialists from outside the musculoskeletal community.
- Increase training in and use of informatics tools within musculoskeletal basic research
- Foster opportunities and mechanisms for national partnerships and international collaborations that increase basic research activity in and enhance synergistic approaches to musculoskeletal systems and diseases
- Increase visibility of opportunities for basic research in musculoskeletal tissues and diseases to investigators in other disciplines and trainees in all disciplines, including to those groups underrepresented in research, such as women and racial/ethnic minorities
- Accelerate translation of new basic research knowledge in musculoskeletal health and disease to new approaches, products and therapies

# Barriers and Facilitators:

#### **Barriers**

Many basic research projects in musculoskeletal tissues and diseases are reductionist, focused on individual components of each tissue and disease. This approach has provided an explosion of exciting and important new genetic, molecular, cellular, biological, and biophysical understanding of bone, cartilage, joints, muscle and soft connective tissues. However, the new knowledge acquired in one tissue or disease is often not known nor well-integrated with knowledge of other musculoskeletal tissues or diseases.

The lack of integration of information across multiple MSK tissues and diseases is exacerbated by a growing recognition of the multiple other cell and tissue types whose activities - proteomes, metabolomes, secretomes, etc - impinge on and participate in regulation of MSK tissues and organs. Vice versa, it has become clear that bone itself is an endocrine organ. In other words, beyond the integrated musculoskeletal "system" is a large network of other interacting cells and tissue types where progress is also rapid and researchers are constantly facing the need to integrate and consolidate information. There is increasing knowledge of the impact of sex on responses of musculoskeletal tissues.

Along with the fragmented character of basic research, many training programs also remain unidisciplinary with few opportunities for exposure to multidisciplinary discussions or training in systems level tools such as bioinformatics.

There is increasing recognition of the value of and opportunities for multidisciplinary and international team, center and network approaches to musculoskeletal research and training. An impediment, however, is that there are often insufficient or no funds available to seed early and exploratory exchanges of information and interest, especially over long distances.

Most undergraduate and graduate basic science curricula provide scant exposure to state-of-the-art knowledge in, importance of or future directions in, musculoskeletal systems or diseases, leading to recruitment obstacles to trainees and investigators in musculoskeletal research. There are additional recruitment issues for racial/ethnic minorities into basic science and clinical research.

Many investigators also fail to engage in multidisciplinary approaches to complex musculoskeletal diseases, often for such reasons as fear of losing momentum and funding in their specialized areas and individual projects or for lack of opportunities to interact with clinical colleagues or colleagues in other disciplines.

Many basic science researchers and their trainees have few opportunities for interactions with consumers/patients who can offer first-hand experience and ideas about research topics and outcomes relevant to them.

The relevance of particular model organisms, models, and approaches and their translatability to human musculoskeletal disease is sometimes - perhaps often - uncertain. One highly relevant example for musculoskeletal diseases: immunologists are beginning to question at a fundamental level the relevance of rodent, in particular mouse, models of the immune system and autoimmune/inflammatory responses to the human conditions, and new initiatives in enhancing accessibility to human samples and developing human models for immunology research are underway.

Many basic science research projects, including those related to musculoskeletal diseases, require and have evolved to very expensive "big science" projects, involving genome-wide screens of various sorts and requiring platforms and infrastructures that are expensive not only to obtain but also to maintain, keep current and grow (e.g., mouse models of diseases, chemical libraries and biological screens, multiple kinds of databases). Large scale bioinformatics expertise is required to maximize the research outputs from these projects and recognize the importance of pathways and relationships across single and multiple musculoskeletal tissues and diseases and across other organs and diseases.

Pressures to increase informatics/bioinformatics platforms and expertise are increasing even more rapidly as real-time systems biology/live-cell/whole organism imaging and sampling approaches increase in popularity and availability.

There is a lack of easily accessible, widely-available, widely-disseminated information on opportunities for collaborative research and access to international platforms of various sorts. This is exacerbated by extremely rapid growth in some countries where relatively recent large-scale investments have been made in basic research projects and platforms that impinge on musculoskeletal research (e.g., Singapore, Korea, China).

In many countries, stable and inflation-adjusted increases to national funding agencies that support basic research are uncertain. Many governments are also asking for more evidence of the impact of basic research of all kinds to support requests for additional and new funding in all areas of basic research. These constraints can impede research progress at a national level and hinder efforts to expand international collaborations and activities.

# **Facilitators**

There are increasing opportunities and models for national and international partnerships that minimize duplication and maximize synergy and impact of research funding programs, infrastructures and platforms. Examples come from such areas as the human genome or microbiome projects and the international consortia to link mutant mouse projects, repositories and phenotyping efforts. Examples extend to ones involving novel public-private partnerships, e.g., the Structural Genomics Consortium and the Osteoarthritis Initiative. Another example specific to musculoskeletal research are those genome-wide association analyses for osteoporosis susceptibility alleles that are funded by the European Union and other partners, and involving patient cohorts in multiple countries, eg GENOMOS (http://www.genomos.eu) and GEFOS (http://www.gefos.org/).

Bone and Joint Decade initiatives, together with increasing and world-wide recognition of the escalating socio-economic burden of disease, can help position musculoskeletal research to take advantage of new opportunities.

Informatics and bioinformatics degree programs (undergraduate and graduate) and tools (databases and data-mining algorithms and tools, including ones freely accessible via internet), although not specifically focused on musculoskeletal tissues and diseases, are increasing in number and quality.

Internationally, there is recognition of the need to foster innovative and novel approaches to complex biology and complex diseases, and many agencies are initiating or expanding programs to fund more such innovative and novel approaches.

Many national and international research societies, including ones focused on bone and joint disease, are increasing emphasis on including talks and symposia on muscle and related musculoskeletal systems as well as other more diverse basic and clinical research topics and disciplines in annual meetings and workshops. Some national and international societies are also offering opportunities for specialized workshops in novel topics related to musculoskeletal systems and disease.

The importance of developing evaluation frameworks to measure the impact of basic research is becoming more widely recognized, and good initial prototypes, some developed with international partners, are becoming available and are applicable to musculoskeletal research.

# Action Items and Timelines:

# Short term (1-5 years):

- Compile and disseminate information on available platforms and resources relevant to musculoskeletal research
- Engage in ongoing national and international discussions, such as these seeded by BJD, on novel and next generation platforms and resources that would accelerate MSK research
- Compile and disseminate information on international funding opportunities relevant to musculoskeletal research
- Expand national and international partnerships of multiple sorts (federal funding agency to agency, public-private) to increase basic research and translation opportunities in musculoskeletal disease
- Partner internationally on development of evaluation frameworks to document the impact of basic research in musculoskeletal disease
- Consider opportunities to expand public-consumer access to and involvement in musculoskeletal research
- Develop collaborations between first and third world investigators to attack problems, such as motor vehicle injuries, that have known solutions that are not currently implemented in all parts of the world.

# Long term (5-10 years):

- Demonstrate increase in innovative and multidisciplinary research in musculoskeletal systems and diseases and in models that accelerate translation to the clinic
- Demonstrate accelerated translation of basic research information to new approaches, products and therapies
- Demonstrate strong national and international collaborations among current and younger generation of basic scientists for sustainable cooperation for research and education
- Evaluate changes to basic science curricula to ascertain improvements in education in musculoskeletal tissues and research
- Assess the impact of these changes on the number of graduates entering musculoskeletal research
- Increase the number of graduates, especially women and racial/ethnic minorities, entering this field
- Demonstrate increased public awareness of the benefits of basic research in musculoskeletal health and treatment of disease

## Outcomes:

- Information about nationally- and internationally-accessible platforms and resources for musculoskeletal research are regularly distributed/featured through key societies to national and international membership.
- Demonstrated awareness of national and international funding opportunities relevant to musculoskeletal research through polls of key societies' national and international members.
- Demonstrable Increase in number of international partnerships to promote and undertake musculoskeletal research and knowledge translation of all sorts (e.g., public awareness, commercialization activities, policies)
- Increased number of new technologies and relevant models for basic musculoskeletal research
- Increased number of program announcements and funding for musculoskeletal research, especially in multidisciplinary and translational research, and between first and third world investigators
- Internationally-useful evaluation framework(s) for documentation of the outcomes and benefits of basic research in musculoskeletal disease
- Expansion of opportunities for public-consumer access to and involvement in peer review of and participation in appropriate musculoskeletal research, built upon existing successful programs and models demonstrated through public web based polls of target groups.
- Increased awareness of the opportunities for multidisciplinary research in musculoskeletal diseases among undergraduate and graduate students demonstrated through public web based polls of target groups.

# B. Comparative Effectiveness Research

<u>Issue:</u> Pre-marketing studies of drugs and biologics provide evidence of efficacy but frequently are limited by small sample size, healthy-person bias, and absence of high risk subgroups, limited follow-up time, and unrealistic compliance to therapy. Thus, many clinical trails have excellent internal validity but lack external validity or cannot be generalized. Comparative effectiveness studies seek to overcome these limitations of clinical trials and provide data on how to choose among therapeutics based on head-to-head data indicating which agents work and under what circumstances in the real world. The U.S. Institute of Medicine (IOM) has released a report trumpeting the need for comparative effectiveness research and identifying areas of priority including the further study of biological therapies in arthritis and bisphosphonates in osteoporosis.

Osteoporosis and arthritis therapeutics are important example areas where the options for prevention and treatment continue to increase but very little is known about the comparative effectiveness of emerging drugs and biologics. A limited number of head-to-head randomized controlled trials (RCTs) have focused predominantly on surrogate outcomes. For example, in osteoporosis, comparative studies of different drugs have only been designed to examine bone mineral density but not fracture outcomes. Further, safety considerations, such as emerging concerns about longer-term bisphosphonate use, have been inadequately studied in randomized designs without large enough numbers or with long enough follow-up to provide adequate risk estimates.

Pharmacoepidemiology provides rigorous methodology for observational comparative effectiveness studies and seeks to overcome many of the limitations of pre-marketing clinical trials and paves the way for rigorous observational studies among bone and joint medications.

#### Goals:

- To define critical therapeutic areas that would benefit from comparative effectiveness studies
- To perform and support high quality evidence-based clinical practice guidelines in areas related to musculoskeletal health
- To assess for differences in effectiveness of treatments between the sexes and among racial/ethnic minorities

# Objectives:

- Biological agents offer great promise in rheumatoid arthritis and other autoimmune disorders and have been associated with considerable efficacy in clinical trials.
   Studies that address how these agents compare with one another, and nonbiological (synthetic) disease modifying anti-rheumatic agents, as well as their longterm safety are needed
- A growing number of agents are now available for the prevention and treatment of osteoporosis. Studies that address how these agents compare with one another in terms or real world effectiveness and comparative safety should be carried out.
- Improved methodologies to address the limitation that clinical therapeutic decisions may influence study outcomes. These methods may include: a) use of practical clinical trials, b) new statistical methods to address confounding by indication in observational studies, c) Baysian approaches to clinical trials data analysis, analysis d) systematic reviews (also called comparative effectiveness reviews) of all available

evidence on specific musculoskeletal topics, and e) analysis of claims databases or registries to compare clinical treatments

• Develop registries to determine outcomes of key treatments related to the musculoskeletal system (ie total joint registry)

# Barriers and facilitators:

Comparative effectiveness commonly relies on observational studies of drugs, devices and biologics. These studies have a number of strengths but are limited by several types of potential biases. Confounding by indication (susceptibility bias) is a key limitation of all observational studies of therapeutics since treatment choice is not randomly assigned. Methodologies to address this limitation include traditional multivariable statistical modeling, propensity scores, and the use of instrumental variable. Organizations such as the AAOS have a process in place to develop high quality evidence-based clinical practice guidelines to assess clinical treatments. These are developed using systematic reviews and can provide data on effectiveness of current treatments and identify areas where evidence is lacking. This can lead to focused clinical research efforts in musculoskeletal medicine.

# 5. Action items and those responsible/deliverables:

Organizations within the Decade will be responsible for performing comparative effectiveness research related to musculoskeletal topics by any of the methods previously outlined, as well as identifying areas where adequate evidence does not exist to perform such research

6. Timeline: Target of 5 years.

### 7. Outcome measures:

- Change in clinical practice
- Identification of evidence-based treatment approaches to the care of patients with musculoskeletal conditions

# C. Clinical Research/Innovative Trial Designs

<u>Issue:</u> Although the randomized control trial (RCT) is considered the gold standard in research, this method is not always practical, effective, or in some instances even ethical. Careful consideration should be given to other methods of research when addressing musculoskeletal heath and quality of life issues. For example, and in view of prohibitive costs of trials there is a need for identification/acceptance of possible surrogates for fracture (e.g., FE models of bone strength, assessment of load-strength ratios) that might facilitate comparator drug trials (if not the initial efficacy studies for a new drug).

The pharmaceutical industry has played an essential role in bringing novel treatments to patients, but this is a changing scene. Traditionally the industry has engaged in the discovery of new drugs, and their subsequent development and evaluation through clinical trials, followed by their registration and commercialization. Once drugs or devices are on the market, the companies have an ongoing responsibility for further trials, and especially and increasingly for post-marketing surveillance to monitor safety. In recent years there have been remarkable successes in bringing new drugs forward for the treatment of rheumatoid arthritis (especially 'biologics') and for osteoporosis with about a dozen options now available. Likewise, devices and biologics have been introduced successfully for orthopaedic uses. In notable contrast, there has not been comparable success with drugs for osteoarthritis.

The pharmaceutical and biotech industries are major employers of biomedical scientists, clinicians and other health professionals, and a significant number of those with training in musculoskeletal sciences take up careers in industry. There is a risk that this career path may be less available in the future.

<u>Goals:</u> To support areas of clinical research which require innovative trial designs in order to improve quality of life and standards of care for patients with musculoskeletal issues.

# Objectives:

- Define 'innovative' trial designs /'innovative' research
- Identify problems in musculoskeletal health where innovative trial designs would have the greatest impact.
- Identify stakeholders and facilitators to support areas of musculoskeletal research most dependent upon innovation
- Coordinate support for innovative research that has been determined to be imperative

### Barriers and facilitators:

# **Barriers**

• The continued merging of companies means that there are fewer and fewer large pharmaceutical companies with the resources to support clinical trials. For these big companies, drug markets have to be highly profitable to generate the revenues to support R&D and shareholders' demands. For these reasons success requires drugs of 'blockbuster' status i.e. sales of >\$1 billion/year with a long patent life. Although this may be feasible for musculoskeletal disorders that affect large populations of people, it will be a disincentive to develop treatments for rare musculoskeletal disorders, and will be a disincentive to develop improved treatments for those conditions for which there already exists some treatment.

- For osteoporosis we are entering the generic era, in which effective drugs will become very cheap. Although this is a welcome development in terms of health costs and patient access to affordable medicines, it acts as a deterrent to further innovation. With the current costs of fracture end-point trials in osteoporosis costing in excess of \$500 million, it is difficult to see how any company can invest on this scale and expect to recoup revenue. This may explain why many big companies have closed their bone research programs, and are switching to other musculoskeletal areas.
- The lifetime of patents is a particular problem. Trials typically take 3-5 years after discovery and preclinical development, which significantly erodes into the overall patent life of 18-20 years. This detracts from the incentive to market new inventions, and to profit from innovation, and to fully explore all clinical uses. In practice most drugs coming to market in OP have less than 10 years of exclusivity, and may be subject to generic challenge within that period. A better system would be to guarantee a defined period of exclusivity, eg 10 or 15 years dating from the completion of trials and approval of the drug, rather than from the date of first synthesis.
- Large clinical trials are very expensive (and time consuming). In the current economic climate, funding of such large trials is less likely to be supported either by industry alone, or by government alone.
- Ethical considerations make it difficult or impossible to conduct placebo-controlled trials for conditions in which effective treatments already exist. Comparator non-inferiority trials against established drugs have limitations in ascertaining the true impact of new treatments. This also discourages patients being recruited from 'Western' countries (USA, Europe) in favor of Asia, Africa or South America, leading to concerns about the 'generalizability' of the results.

# **Facilitators**

• Collaborative partnerships that involve public-private partnerships will undoubtedly be required, both to support the trials financially, but also to acquire the breadth and depth of expertise necessary to design, implement and analyze the study. Such partnerships should include universities, industry, and government funding agencies, working in collaboration with patient advocacy groups.

# Action items and those responsible/deliverables:

- Encourage academic industrial partnerships for training and research (e.g. UK schemes supported by Research Councils)
- Perform pharmacogenomic studies to better identify subjects who might respond better
  or less well to certain treatments (e.g. PTH, RA antibody treatments) or who might
  suffer complications of therapy (e.g. femoral shaft fractures, ONJ).
- Lobby for choice in drug prescribing rather than restricting to generic options. The issue of patient's and prescriber's freedom of choice is a feature that distinguishes between different health care systems (e.g. private vs. public funded)
- Encourage FDA and other regulatory bodies to be more open to new trial designs and end points for trials (e.g. imaging in OA, OP and RA)
- Lobby to reform patent law to give innovators guaranteed periods of exclusivity

- Develop and test new technologies to assess whether these approaches (QCT with FE models, HRpQCT, MRI) add to (or can replace) DXA in terms of better identifying those individuals at risk for fracture, thereby targeting potentially expensive treatments to these individuals.
- Develop novel approaches to better understand the mechanisms of bone loss in humans, including differences between the sexes and among racial/ethnic minority groups. These would include the ability to evaluate pathways in a small number of cells from bone/bone marrow or peripheral blood samples, or to use laser capture microdissection from bone biopsies (as only two examples). From this might come new preventative/treatment approaches.
- Educate the public and media on the essential role played by industry for innovation and improving health care. Without industry there will be no new treatments.
- Similarly discourage irresponsible reporting of adverse events. All drugs/devices have safety issues, and the public need a better understanding of how to balance benefits against risk.
- Continue testing and validation of FRAX and/or alternate fracture prediction algorithms to help identify those at most risk of fracture.
- Develop and evaluate the formation of new research collaborations which support outcomes research activities.

Timeline: Target of 5 -10 years.

### Outcome measures:

- A greater number of academic-industrial partnerships in the design and implementation of clinical trials
- Development of individualized therapies/treatments for some musculoskeletal diseases
- Legislation that increases the flexibility of patient and physician choice in prescribing drugs
- Review and possible revision of current patent law to give innovators longer periods of guaranteed exclusivity
- Development of new educational programs to inform the public about balances between risk and benefit in treatment
- Continued development of FRAX, and an improvement in predictive capability for those most at risk of fracture

# D. Translation of Research to the Community

<u>Issue:</u> Despite considerable progress in tools to diagnose musculoskeletal diseases and availability of new drugs and surgical treatments, there are major gaps in translating these advances into the care of patients in the community with these disorders. These gaps fall into the following categories:

- Increasing public awareness regarding lifestyle and other non-pharmacologic measures, which are interventions that can be applied across the population
- Identifying patients at highest risk of morbidity (e.g., fracture, progression of joint disease) and those who would benefit most from pharmacological and/or surgical intervention
- For those patients who would benefit from pharmacological therapy, ensuring initiation and long-term compliance with therapy
- Ensuring timely access to joint replacement surgery for patients with advanced joint disease
- Decrease disparities in care for some racial/ethnic minority groups

<u>Goals:</u> To improve the care of patients with musculoskeletal diseases by public health measures, identification of high risk patients prior to the onset of morbidity, and improved access to therapy and long-term compliance.

# Objectives:

Improve current efforts at preventing fractures. There is considerable evidence that individuals throughout the world who experience a fragility fracture are not receiving adequate osteoporosis management, and those at risk of osteoporosis are not evaluated or treated prior to fracture. Many of these individuals go on to experience subsequent fractures, without ever being aware that they have osteoporosis. For example, in the United States, only 22% of women ≥ 67 years of age with a new fracture receive either a bone mineral density (BMD) test or prescription treatment within 6 months of their fracture, a Healthcare Effectiveness Data and Information Set (HEDIS) quality measure. There are also important sex-based disparities in osteoporosis care, with men less likely than women to receive an osteoporosis diagnosis or treatment after fracture. In addition, there are also racial/ethnic disparities in osteoporosis care, with black women much less likely than white women to receive osteoporosis prescription therapy after a fracture. In addition, the global issue of vitamin D deficiency has not been addressed. While a number of approaches have been attempted to address these issues, much additional research is needed to develop optimal methods to ensure treatment of those individuals clearly requiring osteoporosis therapy.

A related issue is the development and application of the World Health Organization's Fracture Risk Assessment Algorithm (FRAX), which is now being used widely to estimate fracture risk in various countries. Before this approach is universally accepted, further validation and calibration of this model in diverse populations, including additional studies in men, are warranted, as well as ongoing evaluation of alternate fracture prediction models to help guide therapeutic decisions.

• Rapid access to subspecialty care for patients with inflammatory joint disease. There is now considerable evidence that disease-modifying anti-rheumatic drugs are effective in reducing inflammation, joint damage, pain and other primary outcome measures in patients with rheumatoid arthritis and other inflammatory arthropathies,

and that they are most effective when started early in the course of the disease. However, despite this evidence, delays in diagnosing and initiating disease-modifying treatment are not uncommon. Since many primary care practitioners may lack the ability to recognize, diagnose, or manage rheumatoid arthritis and other inflammatory arthropathies, early referral of these patients to practitioners with expertise in rheumatology is recommended.

- rimely access of patients with advanced disease to joint replacement surgery. With progression of osteoarthritis of the hips and knees, joint replacement surgery may be necessary when non-surgical interventions fail. Done appropriately, the procedure is cost-effective and has been shown to improve health-related quality of life. There is also evidence for inequities in service, with women, older persons, and men and women of color being less likely to be offered the procedure and perhaps later in the course of the disease. However, despite the evidence that joint replacement surgery is an effective treatment for the pain and disability of osteoarthritis and is cost-effective, due to issues of access and disparities in care, the procedure appears to be under-utilized.
- Global access to services for musculoskeletal diseases. It should be noted that while the above points identify key areas for improved access to services, there is a need world-wide for broader access to services for musculoskeletal diseases, and this objective clearly needs to be pursued in parallel.

# Barriers and facilitators:

# **Barriers**

- Changing physician behavior and increasing awareness of gaps and sex and racebased disparities in care
- Restrictions on reimbursement for bone density testing, specialty care, and joint replacement may represent additional barriers
- Lack of availability of some musculoskeletal specialists in some areas of the world, especially those with a pediatric focus
- Lack of musculoskeletal education of primary care providers

### **Facilitators**

- Professional societies across the world, who could help with physician education and changing physician behavior. These organizations could also facilitate interactions with third party payers and government agencies to help with issues of reimbursement for services as well as access to specialty care, when appropriate.
- Improved patient education, to help empower patients to seek appropriate care for musculoskeletal disorders.
- Improved professional education, both for students going into primary care, as well as to expose uncommitted students to musculoskeletal disciplines, to improve the number going into these fields
- Improved culturally competent care

# Action items and those responsible/deliverables:

- Further research on approaches to increase physician awareness and modification of clinical practice patterns to meet the above goals
- Dissemination of treatment guidelines to the widest possible physician and lay audience
- Increase access to physician services
- Increase awareness of differences in care for women and some racial/ethnic minority groups
- Validate of FRAX (or alternate fracture risk prediction algorithms) as useful tools

Timeline: Target of 5 years.

Outcome measures: Outcomes are specific for each of the disease entities, for example:

- Fracture prevention: adherence to HEDIS (and/or other) quality measures, validation of FRAX or alternate fracture risk prediction algorithms.
- Inflammatory arthritis: time to early initiation of disease-modifying therapy.
- Osteoarthritis: appropriateness of timing of joint replacement surgery and prolongation of implant service-life.
- Overall reduction in morbidity and mortality associated with musculoskeletal conditions.
- Increase in the number of musculoskeletal specialists, thereby addressing to some degree access to care.
- Elimination of differences in treatment for women and some racial/ethnic minority groups.

#### E. Health Care Reform

### Issue:

Musculoskeletal disease is the leading cause of disability in the United States which translates into enormous costs to the health care system. In 2004, it was estimated that direct health care costs combined with lost wages due to musculoskeletal conditions was nearly \$850 billion. More than 25% of Americans have a musculoskeletal condition that requires medical attention.

Funding for research in musculoskeletal conditions lags behind research funding for other chronic diseases. Currently, a great discrepancy exists between the burden of musculoskeletal disease in the US and the funding dedicated to research directed toward musculoskeletal disease.

Health care reform is urgently needed to improve care for MSK diseases, ensure that care, and emphasize preventive efforts.

# Goal(s):

- Improve access to care for musculoskeletal diseases
- · Reduce the mortality and morbidity related to musculoskeletal diseases
- Reduce healthcare costs

# Objectives:

- Emphasize prevention of musculoskeletal diseases through wellness management programs
- Ensure high quality care through the expanded use of quality measures and evidence-based clinical practice guidelines, and encourage coordination and integration of care across different specialities and care settings.
- Increase funding for musculoskeletal research via both public and private agencies
- Raise public awareness and promote legislative advocacy
- Encourage broader health care reform that will not only have a positive effect on musculoskeletal health but will also positively affect many chronic conditions that impact on mobility

# Barriers and facilitators:

# Barriers:

There is a discrepancy between the burden of musculoskeletal disease in the US and the funding dedicated to research directed toward musculoskeletal disease. Musculoskeletal research funding at NIAMS comprises less than 2% of the NIH budget. The investment in musculoskeletal research lags behind other chronic conditions.

It is anticipated that health care costs related to musculoskeletal conditions will continue to rise over the next two decades due to current demographic trends, such as aging of the population and increased prevalence of morbid obesity.

There is resistance to change on the part of health care insurers because there will be economic repercussions to those businesses.

The current downturn in the economy makes it difficult for governments to pay for changes to health care insurance that may provide greater access to all, but especially to those with pre-existing conditions.

There is decreasing support from the pharmaceutical industry in part due to the expense of funding large clinical trials.

### Facilitators:

A collaboration of professional organizations involved in the US Bone and Joint Decade joined together to create 'The Burden of Musculoskeletal Disease' (BMUS, 2008) (http://boneandjointburden.org/). Using a scientific research design, BMUS measures the incidence and prevalence of musculoskeletal conditions and is able to predict trends and outline health care costs.

The development of high quality evidence-based clinical practice guidelines by professional specialty societies (<a href="http://www.aaos.org/research/guidelines/guide.asp">http://www.aaos.org/research/guidelines/guide.asp</a>) can assist in outlining best practices for physicians, ultimately leading to improved quality of care for patients.

In the U.S., an increased awareness of health care cost factors will help facilitate the current health system reform debate (US).

### **Action Items**

- Develop chronic care management programs to include musculoskeletal MSK diseases and conditions
- Propose and implement health care reform legislation that specifically includes musculoskeletal conditions
- Connect with other chronic disease groups for those diseases which may have implications for musculoskeletal complications
- Through public education, inform the public about the burden of musculoskeletal diseases to society and subgroups within the society, and encourage increased focus on interventions, treatments and health care reform
- Organizations within USBJD will be responsible for encouraging a renewed focus on musculoskeletal issues related to Health Care Reform

<u>Timeline:</u> Target 5-8 years. Evaluation of changes in health care reform should occur at 3,5, and 8 years.

# Outcome Measures:

- Decreased morbidity and mortality related to musculoskeletal conditions, due to increased access to healthcare providers with training in this area
- Maintain or reduce health care costs and costs of insurance
- Lower morbidity and mortality rates for musculoskeletal diseases, compared to 2009 rates
- Improve funding levels for musculoskeletal research to make them more consistent with funding levels for other chronic diseases, based on measures of dollars spent per affected patient

#### F. Public Health Interventions

### Issue:

While public health interventions are excellent for infectious diseases and scientific evidence backs efforts for public health interventions for musculoskeletal conditions (especially arthritis and osteoporosis, among others) the recommended public health interventions for these musculoskeletal diseases are mostly not used or emphasized as public health interventions in populations. It is important to stimulate increased public awareness regarding physical activity, diet and other lifestyle and non-pharmacologic measures as public health interventions that can be applied across the population.

# Goal(s):

- Lessen the burden of musculoskeletal MSK diseases
- Enhance prevention of musculoskeletal diseases
- Enhance educational activities that emphasize early diagnosis and treatment to slow progression
- Raise awareness of the burden of musculoskeletal conditions in the public health community

# Objectives:

• Collect and disseminate evidence of the importance of prevention of musculoskeletal conditions that provide the public health evidence showing that population changes make a difference to general health.

The evidence for a positive effect from public health interventions is excellent for infectious diseases; while the scientific evidence backs public health interventions for musculoskeletal conditions, the recommended public health interventions must be utilized

- Expand the use of recommended interventions globally to all
- Engage the public health community in advocacy efforts for research funding in musculoskeletal conditions

# **Barriers and Facilitators**

# Barriers:

- Short-term treatment interventions with no prevention aspects are the current standard for most musculoskeletal diseases, despite knowledge that prevention works and long-term interventions (e.g., weight loss for osteoarthritis) lessen the burden of disease
- Need to get away from "one exposure-one disease" thinking and embrace that
  musculoskeletal diseases and conditions are complex and chronic. Need a multifaceted response to complexity and response that would consider the interactions of
  various disease processes (e.g. obesity, diabetes and musculoskeletal disease, as
  one example) and a multi-faceted approach to changing lifestyle factors (e.g.,
  physical activity and dietary changes)
- Lack of funding and difficulties in sharing information remain major barriers to improving public health and the ability to intervene early in musculoskeletal disease

- Current health care reimbursement often ignores preventive aspects, and limited
  access to health care as well as bureaucratic issues only emphasize the difficulty in
  focusing on preventive measures
- Established behaviors and resistance to change prevent healthy practices related to physical activity and nutrition.
- There is a widespread lack of understanding in the general population about bone and joint disease and prevention strategies. Public awareness of research efforts and findings is insufficient –too much stays in the research community solely. There is a need to make publicize public health campaigns via use of television and movies. These could take the form not only of educational and public service announcements, but be embedded in entertainment such as fictional TV dramas and series that provide lay education.
- Lack of communication across differing health systems and education systems in various countries limit the knowledge and use of effective public health interventions (e.g., UK slipper exchange program to reduce falls versus lack of national (or even state-level) falls reduction programs in US)
- Lack of awareness within the public health community of the societal impact and monetary costs to both society and to individuals that is associated with musculoskeletal conditions

#### Facilitators:

- Professional societies across the world could help with public health education, public health interventions, and changing physician behavior. These organizations could also facilitate interactions with health insurance and government agencies to help with issues of reimbursement for preventive services
- Improving patient education will help to empower patients to prevent musculoskeletal conditions as well as seek appropriate care for musculoskeletal diseases
- The existence of programs within the World Health Organization and other international groups could be used to support and facilitate public health interventions and address the specific public health education program needs of a nation or region
- One could create teams where physician-scientists & researchers can effectively collaborate with state Public Health Departments and inform public health interventions at the population level as well as the individual level

# Action Items:

- Champion education programs such as Project your Bones & Joints Program from the U.S. Bone and Joint Decade
- Work within key health agencies globally (CDC, WHO, United Nations, specific health insurance companies) to employ multi-faceted programs of common interventions for multiple chronic disease outcomes (e.g., CDC program to prevent/improve knee osteoarthritis symptoms through public health programs of increasing physical activity has a positive effect not only upon musculoskeletal conditions, but also on diabetes, heart disease, and other related conditions)

- Develop methods to promote the integration of physical activity/exercise into real-life activities of daily living, removing them from just game-related activities
- Increased funding of public health infrastructure (especially in US)
- Develop and promote collaborative efforts between key public health agencies, especially focusing on early childhood interventions to increase physical activity, improve diet, and control obesity
- Tie multiple outcomes, including musculoskeletal outcomes, to funding for other major diseases (heart, cancer, diabetes)

# Timeline: Target 5-8 years

# Outcome Measures:

- Increase in population-level physical activities (as reported by CDC in US; other agencies in other countries) to promote musculoskeletal health
- Increased programs in health care agencies, providers and health insurance groups that focus on prevention and early intervention for musculoskeletal diseases
- Increased public education and access to musculoskeletal preventive efforts
- Overall reduction in rates of incidence and prevalence of musculoskeletal diseases as well as mortality associated with musculoskeletal conditions.
- Development of specific new programs that include themes on public health interventions across the population rather than solely individual treatments and only with medications
- Wider community awareness of the importance of musculoskeletal conditions leading to an increased number of public health intervention programs, increased public education programs and an ultimate global reduction in MSK disease burden.

#### G. Rare Musculoskeletal Diseases

There are over 7000 rare diseases world-wide, but collectively, they affect over 100 million people. Almost 100 rare diseases are described yearly in the medical literature. Although a global definition for rare disease remains elusive, many of the challenges encountered by the researchers, clinicians and patients who are concerned with these diseases are universal.

The very nature of rare diseases means that expertise in them is difficult to achieve without a coherent and coordinated network of information. Patient populations that are small in number and widely distributed geographically, present unique challenges for the scientists who study them. There is a great need for international research collaboration if advancements in therapies for rare diseases are to be realized. As stated by Francoise Grossetete, a French parliamentarian, "since no [EU member state] is capable of combating rare diseases on its own, access to information, diagnostics, care[giver]s, and research needs to be organized into coherent and coordinated networks---usable by all those involved---of methodologies and shared approaches at national [and international] level[s]". Rare diseases are an excellent example of this critical lack of attention, to date, despite the fact that the cumulative effects of rare bone diseases have a large cost to individuals, families/caregivers and society.

In addition to fulfilling the BJD's mission to raise awareness and advocate for musculoskeletal health, the support of research for rare musculoskeletal diseases can contribute to the broader population represented by revealing critical clues about the biological processes that underlie all musculoskeletal disorders. On some level the distinction between rare and common disease is artificial because research into rare diseases frequently benefits common diseases. There are numerous examples of research into a rare disorder enlightening the pathophysiology of a more common disorder. One of the more recent examples is research into the very rare disorder autosomal dominant hypophosphatemic rickets, which led to the identification of a factor called fibroblast growth factor 23 (FGF23). Subsequent research has established that FGF23 is a hormone that controls normal phosphate and vitamin D metabolism. FGF23 is markedly elevated in chronic kidney disease (CKD), and is emerging as its most useful biomarker for mortality related to CKD induced bone and mineral disturbances (CKD-MBD). Other examples include research on osteopetrosis, which has enlightened osteoclast biology and work in familial Pagets disease, which itself has provided insight into processes of normal bone formation and resorption (the RANK, RANKL, OPG system). Thus, it may be very important to have representative investigators interested in rare bone diseases at forums where more common bone disorders are discussed to ensure that the cross-talk provides fertilization for innovative research in both areas, using the examples above.

<u>Issues:</u> There is tremendous diversity in the state of knowledge among the rare musculoskeletal diseases. Although there has been great progress made in a few areas of rare disease research, other disease groups remain relatively untouched. The disorders can be divided into three groupings. The first group of diseases is that in which there is substantial knowledge about the disease and its pathogenesis and new therapies are starting to emerge. In the second group there is some knowledge about the disease and pathophysiology, but, as of yet, no emerging therapy. The third group includes the majority of rare diseases for which there is an incomplete picture of disease manifestations and limited information about the pathogenesis. With little knowledge about the disease and even less about the pathogenesis, the hope for development of therapy is limited, at best.

Lack of funding and difficulties in sharing information remain major barriers toward improving standards of care and the quality of life of people who suffer from rare bone diseases. Even when funding for rare disease research is made available, rare bone diseases have not been positioned to take full advantage. Success in competitive grants such as the RDCRN for rare bone diseases entails an integration of diverse groups at all levels.

<u>Goal</u>: To improve rare musculoskeletal diseases research through innovative and collaborative efforts

# Objectives:

- Support regularly held programs that involve investigators, physicians, patients and
  caregivers with their relevant interests in rare musculoskeletal diseases. This
  collaboration among stakeholders empowers scientists and gives patients hope, while
  allowing them to understand the pace of research. It provides a forum for industry
  to understand the needs and discuss limitations and advances in development of
  therapy for rare musculoskeletal diseases
- Identify and coordinate a network of information resources for rare musculoskeletal disease, e.g, facilitate data repositories or find rare disease research models that are working on a large scale that could potentially be used as a model for rare musculoskeletal conditions
- Provide a mechanism to develop the correct nosology for, natural history of, and evidence-based approach to current diagnostic and therapeutic options for rare musculoskeletal conditions
- Identify relevant resources for the advancement of research in rare musculoskeletal diseases. These resources may include: various institutes of the U.S. National Institutes of Health (NIAMS, NIDDK, NICHD) NORD (National Organization of Rare Diseases), and the newly established TREND (Therapeutics for Rare and Neglected Diseases) program, among others
- Develop an action plan for coordination of efforts of relevant resources to enhance and encourage research of rare musculoskeletal diseases.
- Enhance the pipeline of young investigators (MD and PhD) interested in performing studies in rare bone disease and increase the number of physicians interested in taking care of these patients, with the realization that there is an obligation for those with appreciable numbers of patients with a rare disease to contribute to knowledge about these diseases.
- Improve standards of care for patients with rare bone disease by establishing
  meetings which will represent each rare bone disease and bring thought leaders
  together to establish a scheme that will enhance the understanding of the variability,
  progression, identification, and natural history of the key manifestations of each
  disease, and establish tools to evaluate the long-term effectiveness and safety of
  available treatment options and support measures.

### **Barriers and Facilitators:**

#### Barriers

Logistics, limited funding, shortage of investigators, and complications that are inherent to sharing data are major barriers that will need to be addressed in order to make progress toward achieving the goals and objectives for the improvement in all areas of rare musculoskeletal disease research.

These obstacles make it impractical to expect large multi-disciplinary teams to form around a rare disease. Thus, rare disease research must use innovative strategies that overcome these obstacles and to meet the challenge of tracking a population of patients that is small in number and widely dispersed.

There is a critical shortage of investigators who have the skills necessary to move freely between basic science investigation and translational work. Physicians engaged in clinical work are losing contact with more basic work and are being directed to perform high volume clinical work to generate shrinking healthcare dollars, resulting in less time for scientific investigation.

In addition, the type of information lacking in each disease is varied. For some diseases there is a lack of knowledge about the natural history of the disease. In others lack of an animal model hinders research progress. For most there are large gaps in knowledge about the pathogenesis of the disease.

#### **Facilitators**

The Rare Bone Disease Network (RBDN) was recently formed to enhance cooperation between groups interested in diverse rare bone diseases [http://www.usbjd.org/projects/RBDPN\_op.cfm). The RBDN is an obvious choice for helping lead the complex and diverse systems that must be created and actuated for an enhanced understanding of rare bone diseases. The pharmaco- and biologics-therapy industries should become willing partners with continuation of benefits from providing therapy for rare [bone] diseases. The NIH should continue to be a strong advocate in the study of rare bone diseases.

The BJD is ideally positioned to support, coordinate, and advance the global research efforts needed for rare musculoskeletal diseases. For example, studies that are designed to answer questions about epidemiology, natural history, and treatment outcomes for a particular rare disease can be difficult to sustain, yet it is often imperative that this preliminary knowledge base be acquired so that research for that disease can advance to the next level. In addition, these types of data also lend value to existing studies. Without support for these important yet often complex research efforts, clinical and scientific advancements may be difficult.

# **Action Items:**

- Compile and disseminate information on funding opportunities relevant to rare musculoskeletal disease research
- Provide initial funding for establishment of a network with the goal of being competitive for the RDCRN grants when next available
- Increase patient- investigator interactions and establish regular forums for interaction with multiple sources including: researcher, physicians, patient advocacy groups, industry representatives and the FDA

- Increase attendance of patient advocacy groups at ASBMR, ORS, ASN, Endocrine Society, IBMS, and other similar meetings with the goal to arrange for coordinated discussions among these groups in coordinated small meetings arranged around the larger meetings
- Invite promising young investigators (both MD and PhD) to these meetings to present work relevant to rare bone diseases
- Allow patients to be present at study section meetings (as non voting members) on a trial basis
- Increase funding, including the initiation of pilot grant programs, for studies of the clinical manifestations and pathophysiology of rare musculoskeletal diseases as well as those aimed at developing new therapies
- Increase the pipeline of investigators performing research in rare musculoskeletal diseases.
- Establish innovative cross-institutional training grants and other post-doctoral award mechanisms in support of rare musculoskeletal diseases scientists in-training and in early stage faculty roles
- Place promising scientists into industry-based laboratories with directed interest in product development for rare musculoskeletal diseases
- Apply emerging technologies to rare musculoskeletal disease
- Create a comprehensive list of global resources for rare musculoskeletal diseases so that research efforts can be enhanced

# Timeline: 3-5 years

# Outcome Measures:

- Increase number of grant submissions of all types, program announcements and funding by 25% over the next five years
- Complete the infrastructure for a database of [de-identified] patients with rare musculoskeletal disease
- Measure attendance of patients and patient support group members at key major meetings. Assess the number of satellite meetings concerning rare musculoskeletal disease
- Determine if the NIH will pilot a program to allow patients to attend study section
- Record the number of patents and new drug applications for rare musculoskeletal disease

# **Priority Area #2:** Training Programs

# A. Graduate and Postgraduate Education

<u>Issues</u>: Graduate and post-graduate training replaces research scientists for the coming generation and form the pillars upon which the future of the science will rest. Besides providing the future workforce to maintain progress, younger scientists improve the progress of established labs. The trainees create vitality by moving into novel and creative areas. They also are usually more technologically savvy than their experienced mentors and drive science forward with newer techniques.

Funding for expansion, even the maintenance, of existing training programs has declined significantly in recent years. In the short term, this is a result of the current global economic climate. During this downturn, federal agencies already are directing their limited supply of funds to support existing research that is successful and that can be translated relatively quickly to clinical application rather than supporting the training of a new generation of scientists. This satisfies the short term goal for improved public health. In addition to this focus of governmental agencies, foundations that support the training of junior scientists have curtailed their activities as both their investments and new contributions have diminished. This is a significant threat to the vitality of future research as intelligent and hard-working young scientists become discouraged and move out of research into other areas of work. A short-term strategy to support research without a clear vision of the longer-term goal to maintain the pool of research scientists will ultimately damage the entire research enterprise and slow the progress of new advancements and new clinical treatments.

Musculoskeletal conditions are debilitating and expensive, but generally do not result in a high rate of mortality. As a result, musculoskeletal research is at a disadvantage in the competition for funding with other more lethal diseases. Programs in cancer, diabetes, immunology and others have a much higher profile in the public mind, even though these areas are tied to the musculoskeletal field in important ways and even though the direct costs associated with musculoskeletal disease are immense.

<u>Goals:</u> To recruit, train and support the next generation of scientists to replace the current generation, and to broaden training to become more multidisciplinary as the science becomes more multidisciplinary

# Objectives:

- Attract the best minds into musculoskeletal research. The debilitating effects of musculoskeletal conditions are immense. In the first world, conditions of aging such as arthritis and osteoporotic fracture debilitate the elderly. In the third world, those who survive to old age suffer equally but, in addition, untreated injuries to spine, joint, muscle and tendon force manual laborers into unemployment, dependence and possibly into death. Although osteoporosis and osteoarthritis may be important issues in the more developed world, musculoskeletal-related trauma due to automobile accidents and other traumatic incidents may be of greater concern in less developed nations. The broad and disproportionate impact of musculoskeletal disease on the poor and disadvantaged provides an opportunity to attract the talented and socially conscious young into training programs for basic research and public health approaches to musculoskeletal health. It would be appropriate to develop an outreach program emphasizing the disproportionate effects of these conditions on the poor to help attract these dedicated individuals.
- Attract underrepresented populations into research. "Bridges" programs (eg Bridges to the Doctorate) provide partnerships with historically black colleges and universities, and with other institutions that have large populations of URMs. These programs allow

recruitment and training of bright students with an interest in science who might otherwise be unaware of the opportunities of a career in research. However, these programs typically rely on significant support –both in time and money – that must be provided by both the host and the home institutions. This may make them less attractive than other types of training programs.

In addition, administrative supplements on existing grants, such as those currently provide by the National Institutes of Health, should be expanded and made increasingly available. Such supplements complement the research program of the advisor as well as bringing new underrepresented minorities into the field.

Other programs exist as well, and should be continued. These are vital to bringing these populations into the research arena. For example:

- Louis Stokes Alliance of Minority Partners grant from the National Science Foundation provides tutoring, mentoring, and summer research support to six minority undergraduate students each year.
- NIH T35M Training Grant (Short Term Research Training for Minority Students, HL 07802) introduces undergraduate minority students to biomedical research.
- Summer high school research apprenticeship programs
- Project SEED (Summer Experience for the Educationally Disadvantaged), a
  program co-sponsored by the American Chemical Society and Eli Lilly and Co.
  takes promising minority students from high school and places them in a
  research laboratory for an 8 week summer rotation.
- CIC-Summer Research Opportunities Program (SROP) sponsored by the Consortium on Institutional Cooperation (CIC). The CIC includes the Big Ten universities and the University of Chicago. The CIC-SROP affords departments and schools the opportunity to host intellectually talented and academically motivated minority undergraduates for a summer of intensive research.
- Concentrate on interdisciplinary training opportunities. Multidisciplinary research consortia create new opportunities to recruit students into the field of musculoskeletal research, and to coordinate several diverse fields that cross the spectrum of basic and clinical science, with engineering. New training programs must allow the development of an integrated curriculum and new recruiting strategies to attract students interested in musculoskeletal research. Although not as high profile as programs in cancer, diabetes, or immunology, musculoskeletal research can be tied to these more highly funded areas in important ways to improve the training and funding base.

To accomplish this, training will need to be broadened, and should include significant portions of genetics, molecular biology, cell biology and microbiology.

• Create stable training opportunities. The inconsistency of funding sources for trainees can hamper the continuity of training programs. For example, NIH Training Grants are renewable every five years. However, because of the competitive environment, it may still require several submissions before even a successful training program can be renewed. During this period, trainees lose their support and may be required to leave the lab or find other labs in which they can work. This disrupts their training progress, and the progress on their research. In some cases, it may even require a complete shift in the research direction.

Develop shorter career tracks. The current model for creating a first world musculoskeletal research investigator involves a training period that is too long, and which provides an uncertain future. Graduate training that can extend for 6-7 years, followed by 2-6 years of postgraduate education produces scientists who are 35-40 years old by the time they can establish their own laboratories. Moreover, because there are too few tenure-track lines available for the number of trainees, leaving eventual employment uncertain, some students may be deterred from pursuing a career in research. Others are left with uncertain futures as non-tenure track scientists dependent on "soft" money to support themselves and their families. This model is dysfunctional and failing. The failure of this model is exemplified by evidence that on average a research scientist is > 40 years of age by the time he/she receives his/her first extramural grant award and begins to establish an independent laboratory. This, in part, has led to a rapid disappearance of clinician scientists. Moreover, the age of the active research cohort is increasing, in part fueled by the attrition of students out of musculoskeletal research into career tracks that provide emotional and financial awards sooner and more reliably. Commissioning a group to investigate alternative and shorter paths into musculoskeletal research would be appropriate.

# **Barriers and Facilitators:**

#### Economic barriers

- Reduced support for training in favor of basic and applied research, especially in times of economic distress or in countries with limited programs for support of the research enterprise
- o The limited financial incentive for trainees, who will experience modest salaries at the end of a very long training program. In comparison to training programs for medical doctors, which are equivalent or even shorter than for research scientists, the cost-benefit for scientists to complete training may be insufficient

# Political barriers

- o Particularly in developing nations, there may be some pressure for bright young professionals to enter into professions which are seen as more critical for the economic and political development of the developing nation
- Some areas of research may be restricted (e.g. HIV/AIDS, stem cells). This may limit opportunities for bright young scientists who wish to enter these areas of research

# • Disciplinary Barriers

- It is important to break the barriers among basic, clinical and engineering disciplines. These ultimately limit career opportunities and slow the pace of research
- Discipline-based grants frequently have an age-restriction, limiting applications from women, especially as they are establishing their research and/or clinical careers during their child-bearing years. These age restrictions should be limited when possible

#### Facilitators:

• World Programs

- The existence of programs within international agencies such as the World Health Organization and the United Nations could act to support and facilitate training programs that can address the specific needs of an individual nation or region
- Additional Training Opportunities
  - Young investigator programs developed within professional societies, and those that already exist, can be used to facilitate training opportunities

# **Action Items:**

- Develop an outreach program to attract talented and socially conscious young scientists
- Expand "Bridges" programs through active recruiting at the high school and college levels. Enhance the attractiveness of "Bridges" programs by expanding funding and revising the responsibilities for both trainee and host institutions. Support and expand other programs that attract underrepresented minorities to research careers
- Tie musculoskeletal research to more highly funded areas such as cancer, diabetes and immunology, and establish multidisciplinary programs for training in MSK within these areas
- Compile current content and explore opportunities for expansion of topics in musculoskeletal biology in basic science curricula at undergraduate and graduate levels
- Establish greater stability in training programs by offering greater flexibility in time
  periods for such programs and by developing bridging between funding periods to
  allow trainees to complete their training even in the case of nonrenewal of the
  training grant
- Commission a group to investigate alternative *and shorter* paths into musculoskeletal research

<u>Timeline</u>: All of the action items identified could be addressed within the next 5-10 years.

# Outcome Measures:

- Global reduction in the rate of musculoskeletal injuries
- Global increase in the number of research scientists
- Increased number of students/fellows converting to tenure-track research positions
- More underrepresented minorities and women in research positions
- Increased salary potential for research scientists in academia and government
- Decreasing average age for scientists and lower average age at time of receipt of first grant
- Development of specific new training programs that are based on research themes rather than on individual disciplines

# B. Physician and Physician Scientist Training

<u>Issues</u>: There is great concern over the shrinking number of physician-scientists in the current medical system. This phenomenon is occurring across medical and surgical departments throughout the United States and presents a challenging problem. Socioeconomic and political changes in medicine have resulted in increased financial pressures on hospitals and physicians which can negatively affect the physicians' and hospital/medical center's interest in pursuing research activities. One benefit of physician-scientists involved in translational and basic research is that they bring a clear sense of problems that need to be solved to improve care of patients. The absence of a strong physician presence in laboratory work creates the possibility of a rift between those on the bench and those at the bedside and detracts from research that easily translates to patient care and improved health.

Currently there is no formal curriculum for training students and physicians in the concepts of basic and translational musculoskeletal research. In addition there is not a continuous focus on research through all educational levels (medical school, residency, fellowship). As the amount of available data about the musculoskeletal system increases, there is a vast amount of information that physicians need to understand. This requires active participation and oversight on the part of the educators and engagement on the part of students and physician trainees. Ideally, physician training in research should occur at all levels of education from medical school through fellowship; therefore, the goal should be to develop a true culture of research.

#### Goals:

- Improve the recruitment and retention of physician-scientists in musculoskeletal research
- Enhance physician training by instituting a culture of research from medical school through fellowship

# Objectives:

- Increase the number of physician-scientists entering fields related to the musculoskeletal system
- Develop a curriculum for research education in medical school, residency, and fellowship
- Promote a system of oversight and mentoring for individuals likely to follow the career path of a physician-scientist

# **Barriers and Facilitators:**

# Barriers:

- Decreased salary for the physician-scientist who must rely partially on grant funding to support his/her income as a result of decreased clinical revenue
- Increasing medical student loan amounts require longer time to pay back, often necessitating a focus on an increased salary
- Length of training (both clinical training and additional years of research training) can be discouraging
- All physicians (especially those in procedure-focused departments such as surgery)
  are under demands to increase clinical productivity and generate increased revenue
  to offset rising costs and decreasing reimbursements which decreases time for
  research
- Lack of available, appropriate mentoring by senior scientists as they are also pressed for time and focused on shrinking extramural funding opportunities

- The barriers may be magnified for female physicians starting their academic careers if they take time off to start a family
- There are often inadequate resources and structures to protect research time
- Physician training in research concepts is not uniform between academic programs and is not continuous throughout the length of training (medical school, residency, fellowship)

# Facilitators:

- Educate department chairs about the need for additional physician-scientists
- Encourage potential physician-scientists to look for training and employment opportunities in programs where basic and clinical research is highly prioritized and funded
- Provide a structured research curriculum for physicians with appropriate oversight
- Provide protected time for research free from clinical responsibilities
- Advertise and take the opportunity to engage in NIH Loan Repayment programs that reward physicians who take time off for research (http://www.lrp.nih.gov/)
- Provide appropriate financial support (ie. endowments, etc) to fund new physicianscientist faculty for the first 3 years of practice
- Focus on federal grant opportunities (K08, K12) that provide salary support for the investigator
- Provide a network of committed senior scientist mentors and role models
- Allow flexibility for female faculty to pursue a career as a physician-scientist while concurrently starting a family. Realize that the timelines for grants, awards, honors and academic promotion may need to be extended
- Recognize the importance of co-localizing scientists and physicians
- Provide research infrastructure at the Department level
- Create research teams where physician-scientists can effectively collaborate with other scientists
- Actively recruit promising MD-PhD students early in their training, including women and minorities to the field of musculoskeletal medicine and surgery
- Encourage medical student participation in research programs such as the Howard Hughes Medical Institutes.
- Increase incentives for senior faculty involvement at the NIH and other funding agencies
- Increase efforts at early education of students concerning musculoskeletal conditions and research to increase the pipeline of women and underrepresented minorities into this field

# Action items/deliverables:

- Prepare and distribute a white paper on the current problem and a list of solutions to all stakeholders in the BJD.
- A model curriculum for the training of college and medical students, residents, and fellows in the concepts of basic and translational research.

### Timeline:

White paper: 3 yearsModel curricula – 5 years

# **Outcome Measures:**

- Number of physician-scientists in the field of musculoskeletal research
  - Goal to increase number of physician-scientists entering the field 5% increase at 5 years and 10% increase at 10 years
  - b. Goal to retain physician-scientists in the field once they are trained 5% decrease in dropout rate at 5 years and 10% decrease at 10 years
- Increase in the amount of NIH funding by physician researchers in the field of musculoskeletal health (5% by 5 years and 10% at 10 years)
- Increase the number of academic programs utilizing an educational curriculum that emphasizes concepts of basic and translational research at all levels of training

# **C: International Considerations**

<u>Issues</u>: Differences between countries in educational structures, educational goals, resources and community involvement make solutions to scientist training and education unique to that country. Therefore, one key issue is the extent to which educational materials developed within one environment will be translatable to another, particularly where resources available to support them differ.

Training encompasses teaching individuals about basic biology, clinical outcomes and how they should be able to evaluate alternatives for therapy with respect to efficacy and safety. This is relevant to both prevention and treatment of osteoporosis, to early intervention in inflammatory arthritis and optimal approaches to joint replacement, including differing availability of and access to:

- New agents for the treatment of osteoporosis
- New biological agents for the treatment of inflammatory arthritis
- Surgical options, i.e. joint replacements for both rheumatoid and osteoarthritis

<u>Goals:</u> The development of educational materials that are sufficiently flexible to be readily modifiable and applicable in all environments.

### Objectives:

Training in part relates to the availability and dissemination of useful resources, both basic and clinical. Basic and clinical bone science is well-served by resources from the American Society for Bone and Mineral Research

(http://depts.washington.edu/bonebio/ASBMRed/ASBMRed.html), the European Calcified Tissue Society (http://www.ectsoc.org/courses.htm), and the International Osteoporosis Foundation (http://www.iofbonehealth.org).

Part of the clinical training must be focused on the fundamental approach in all areas of clinical care of "evidence based medicine." Randomized controlled clinical trials rather than expert opinion remain the gold standard for evidence of efficacy and safety. However longer-term real-world follow-up is an important aspect for analyses of potentially uncommon, but at the same time potentially important, adverse events.

Part of training must equip individuals to evaluate evidence of efficacy, for example, in osteoporosis therapy, and any other effects that these interventions may have on the clinical end-point (e.g. fracture, joint function, mobility, pain), but also any associated impact on adverse events, quality of life and premature mortality. Understanding of basic bone and joint biology and the efficacy and safety profiles of interventions are considered likely to impact currently poor levels of delivery for both prevention and treatment.

Thus the major objective is the development of improved medical and allied health professional curricula that are translatable internationally across different environments and structures of medical education. These curricula should be adaptable, to address conditions more common in certain areas, while recognizing the social and cultural impact on health.

# Barriers and Facilitators:

#### Barriers:

# • Educational structures and educational goals

Bone and joint diseases are considered and addressed by many different clinical areas, including but not limited to geriatrics, orthopaedics, rheumatology and endocrinology as well as primary care physicians. This diversity of responsibility is considered likely to contribute to the lack of a clear responsibility for taking preventative and therapeutic actions.

Investigation and treatment carry time and economic costs and, with many clinical groups involved, responsibility for such costs and disagreement about who should bear the burden of these costs is another barrier.

# • Resources and community involvement

Inadequate medical and allied health professional curricula in musculoskeletal conditions are a problem in all types of musculoskeletal conditions. Coupled to this is a widespread lack of understanding in the general population about bone and joint disease and prevention strategies.

There is also difficulty in introducing and monitoring adherence to therapy, unless individuals (i.e. patients and the community) are aware of its importance, and this may impact adversely on adoption of preventative modes. The chronic nature of bone and joint diseases and the long-term nature of appropriate prevention and treatment also represent major barriers.

#### Facilitators:

# • Educational structures and educational goals

There is good evidence that intervention with fracture prevention programs, particularly attached to individuals who have already suffered fractures, are effective in improving investigation and therapy. A key facilitator for this change is "local champions" as well as economic evaluations that demonstrate the cost effectiveness at a global level for such interventions (e.g. in health maintenance organizations).

Development of more appropriate medical and allied health professional school curricula that could be widely available internationally, with opportunities for modification to reflect local musculoskeletal health issues, would also facilitate an international flavor to physician training. These curricula should be adaptable, to address conditions more common in certain areas, while recognizing the social and cultural impact on health.

# • Resources and community involvement

Economic evaluations that demonstrate the cost effectiveness at a global level for such interventions (e.g. in health maintenance organizations) encourage the provision of adequate resources to treat patients as well as resources to train new basic and clinical scientists interested in these areas.

The development of stronger international relationships among the younger generation of basic and clinical scientists will allow for and accelerate sustainable cooperation in research and education. To promote this international cooperation, the development of programs that emphasize the growing awareness of the need for and implementation of programs for knowledge translation activities would enhance this global cooperation.

### Action Items:

- Calls for more educational resources to demonstrate cost effectiveness of training and community involvement for:
  - Secondary fracture prevention clinics that could be presented to national, local and private health organizations
  - o Early intervention in rheumatoid arthritis and
  - o Appropriate joint replacement in advanced osteoarthritis
- Focus training on evaluation of existing and novel therapies with respect to efficacy and safety through rigorous scientific review processes
  - Evidence on efficacy and safety of public health interventions to maintain bone health
  - Evidence on efficacy and safety of drug interventions to maintain bone health and reduce fracture risk
  - o Evidence on efficacy for early OA diagnosis and prevention
  - Evidence of improved functional outcomes with early intervention in inflammatory arthritis

Each of these action items should result in a whitepaper on these concepts.

- Outline more appropriate medical and allied health professional school curricula
- Develop facilities to support interaction of younger generation of bone and joint scientists. These should include:
  - o Exchanges during training between countries through scholarships
  - Ensuring good interactions between basic and clinical trainees at relevant scientific meetings

<u>Timelines:</u> Position papers should be available for publication and distribution to national, international and local health organizations within three years. The proposal for the development of novel medical curricula could be outlined by mid-2011. Evaluation of changes in health care curricula for each of the Action Items should occur at 3, 5 and 10 years.

# Outcome Measures:

- Publication of above reviews/position papers, and the packaging and dissemination of these for different international and national organizations
- Wider community awareness of the importance of musculoskeletal conditions and recognition of the value of public health and disease-specific interventions. This

would be based on regular community-based assessments of knowledge of the importance of these clinical conditions and the importance of basic science to improvements in care

 Demonstrate of strong international relationships among the younger generation of basic and clinical scientists for sustainable cooperation for research and education. This is measured by enumeration of scholarships available and accepted and by the number of basic-clinical meetings arranged at appropriate international (and national) scientific meetings

# Priority Area #3: Raise Public Awareness and Promote Advocacy for Research A. Education of the Public

Issue: There is a large gap in knowledge amongst the general public (and perhaps many health care providers) about matters of bone health (including but not limited to diseases such as arthritis, osteoporosis and the large number of rare bone diseases. These gaps include; 1) risk factors for developing the disease, 2) symptoms of disease, 3) approaches to and types of treatments and alternatives, 4) life-style choices that can modify the course of disease including nutrition and exercise, 5) genetic aspects of disease and 6) impact of disease on quality of life.

<u>Goal</u>: Improve public education about causes and prevention of musculoskeletal disease and trauma, and the role played by behavior (life-style choices) and genetics

# Objectives:

- Improve access to pertinent and expert information for the public and health care providers
- Promote bone and joint health at a world-wide level
- Increase research support for understanding the pathophysiology of musculoskeletal diseases

# Barriers and Facilitators:

#### Barriers:

- Many musculoskeletal conditions are not viewed by the public as lifethreatening and as such are not considered a concern that requires their attention
- Younger members of the public are generally not concerned about health issues that may arise when they are 50+ years of age.
- The General Medicine Physician and other Health Care Providers, who could be a major venue for public education, may themselves be insufficiently knowledgeable and do not have time during office visits to provide adequate patient education

# Facilitators:

- The Internet is a major source of information and can be used to create a more informed public
- The US National Action Plan for Bone Health is developing a blueprint for the United States and several aspects of that plan can be adapted for a global effort

## Action Items:

- Develop a Master Website Resource on Bone Health that contains links to existing bone organizations and other related websites
- Develop an easy to understand "Primer on Bone Heath" for dissemination of information to the general public
- Create an email list serve to broadcast skeletal health related issues to the public
- Place editorial pieces in newspapers worldwide on bone health issues
- Generate and take advantage of public speaking initiatives
- Form Advocacy Groups to promote bone health

- Promote campaigns for grassroots health literacy and advocacy
- Encourage consumer involvement in research activities
- Involve consumer representatives in the development and implementation of action plans
- Develop bone health curricula for medical and nursing schools
- Include bone health as an element in licensing and credentialing programs, and certification and recertification processes
- Encourage education on musculoskeletal topics in high schools, to address lifestyle factors that affect bone and joint health, as well as to encourage students to enter the field
- Emphasize that lifestyle changes that impact bone and joint health are similar to recommendations for other organ systems, making adherence easier

<u>Timeline</u>: All Action items should be achievable within a five year period. The last two bulleted points may take 5-10 years for full implementation.

# Outcome Measures:

- Creation of the Master Website and publication of skeletal health editorials
- Creation of Joint Advocacy Groups
- Inclusion of consumer members on peer review panels and advocacy groups
- Development of bone health sections in curricula and continuing education programs

### B. Media Involvement

<u>Issue:</u> Dissemination of the proper (expert) information relating to bone health issues is a major concern. The public (and health care providers) often have no means of sorting through the available information on bone health to ascertain "fact from fiction" or what is validated versus what is anecdotal.

<u>Goal:</u> Improve dissemination of expert opinion, and offer a means by which the public can ascertain the validity of the information

<u>Objectives:</u> Partnerships should be established with various media sources to provide resources and materials that can be disseminated to the widest possible populations. As in the National Action Plan for Bone Health (US centered initiative) develop world-wide collaborations with organizations whose messages about healthy lifestyles dovetail with messages about improving bone health.

# **Barriers and Facilitators**

#### Barriers:

- Advances in research related to bone health are not front page news as are other more high-profile diseases such as cancer or AIDS
- Advertising campaigns and other public affairs initiatives require financial resources

### Facilitators:

 A bone community "umbrella" organization is being developed by the US National Action Plan for Bone Health. This will incorporate all bone organizations world-wide and may be an effective means of keeping advances in bone health research and related issues in the media

### Action Items:

- Develop and support Faces of Osteoporosis types of initiatives that can personalize various bone diseases and draw media attention
- Recruit a spokesperson for rare musculoskeletal diseases
- Appoint an "Expert" panel for media relations to include a core of spokespersons able to dynamically communicate information on bone health
- Develop a world-wide network or "umbrella" organization focused on matters of bone health across all ages
- Identify a "Recognizable Face" Spokesperson

**Timeline**: Five years

Outcome Measures: Completion of all Action Items

# C. Legislative Advocacy

<u>Issues:</u> Bone diseases represent a major financial burden to our health care system. Inadequate support internationally for bone related research is a major threat to the health and well-being of the world's population as it severely compromises our ability to make the research advances that will lead to new drugs and paradigms to treat and cure these diseases.

### Goals:

- Improve international support for musculoskeletal research and for facilities associated with research
- Raise awareness of government agencies and legislators to the societal costs of musculoskeletal disease

<u>Objectives:</u> A world-wide effort is needed to advocate for adequate for funding for musculoskeletal research. Potential new sources of funding need to be identified and developed to support musculoskeletal research funding. Agencies within international health-oriented agencies, such as the World Health Organization and the United Nations should be enlisted to contribute to this effort.

## Barriers and Facilitators:

## Barriers:

Support for research in general at the Federal, State and local levels needs to be a high legislative priority. Often, these governmental agencies do not appreciate the value returned for the investment made in research. For them, bone health is not a national priority as are other diseases. This restricts both access to healthcare, and reimbursements for services performed. Legislators must be convinced of the societal costs associated with musculoskeletal conditions and injury

#### Facilitators:

Coordinated lobbying efforts at the global level must keep bone health at the forefront of issues being viewed with high priority by legislative bodies

# Action Items:

- Draft language for funding at various levels
- Provide surveillance on Health Care Reform Legislation
- Provide input/guidance on focus areas for funding support at various agencies (e.g. NIH, Foundations supporting musculoskeletal research, WHO, the U.N. and other agencies across the globe)
- Promote legislation that reduces barriers to training opportunities worldwide (e.g. Visa issue for foreign postdocs/students coming into the US)
- Advocate for insurance coverage for musculoskeletal-health preventive care and screenings

<u>Timeline</u>: Immediate. This should be an ongoing and continuing effort.

# Outcome Measures:

- Increased funding for bone health related research
- Improved reimbursement and inclusion of prevention programs as part of insurance coverage.

# D. Industry Partnerships

<u>Issue:</u> Dwindling pharmaceutical company support and increasingly prohibitive regulatory oversight has negatively impacted bone health research and limited partnerships.

# Goals:

Partnerships between industry and bone health focused organizations and researchers should be promoted and action plans developed that focus on legislation and regulatory oversight that enables the conduct of clinical trials that are safe, efficient and yet reasonable to perform. Opportunities to establish partnerships with industry and university based researchers should be facilitated and coordinated at various local, regional, national and international levels.

# Objectives:

- Increase investigator-industry collaboration by reducing governmental influence in the private research enterprise
- Enhance public-private partnerships that are focused on research that will translate to therapies
- Improve the image of industry support of research, especially in partnership with non-industry investigators

# Barriers and Facilitators:

#### Barriers:

 Receiving support for research from industry is viewed negatively, both within the academic community and by the public • Industry support for Continuing Education is viewed negatively (creates Physician bias, conflict of interest, etc.)

### Facilitators:

 Continuing education programs that are supported by industry but developed by a bone health organization that removes the stigma of industry-academic relationships

# Action Items:

- Promote the creation of joint industry-university initiatives through ventures similar to SBIRs
- Develop University resource networks/registries
- Advocate for legislation that promotes partnerships with industry

<u>Timeline</u>: Immediate. This should be an ongoing and continuing effort

# **Outcome Measures:**

- Increased industry-academic relationships with University investigators
- Increased support for Continuing Education Programs
- Government-sponsored incentives for industry-academic partnerships

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# SPINAL DISORDERS AND LOW BACK PAIN STRATEGIC PLANNING SPECIALTY GROUP

# **Overview**

Priority Area 1: Defining the Burden of disease Priority Area 2: Specific Disorders of the Spine

Priority Area 3: Introduction of Technologies and Devices in the treatment

of Spinal Disorders

Priority Area 4: Identification of areas for spine-related research and for

international collaboration

# Priority Area 1: Defining the Burden of Disease

#### Issue:

Spinal disorders and low back pain are significant public health problems that affect millions of people each year. Low back pain is the most common reason for a patient to visit a physician. There is growing evidence that there are significant costs and functional limitations associated with spinal dysfunction. Defining the burden of spinal disorders and low back pain requires consideration of incidence and prevalence of disorders, and evaluation of the impact of disorders on health-related quality of life, economic productivity, and direct and indirect costs of care.

#### Goals:

- 1. To measure the burden of spinal disorders and low back pain, across the age spectrum, from the individual level to the societal level.
- 2. Identification of disparities in the burden of spinal disorders and low back pain between socioeconomically and ethnically diverse cultures
- 3. To understand the financial costs of spinal disorders and low back pain to society.
- 4. To understand the value of care for disorders of the spine from a cost-utility analysis perspective.

<u>Significance of goals</u>: By fully understanding the negative impact of spinal dysfunction on the individual and society as a whole, we will be able to emphasize the message that spinal disorders and low back pain should be considered as high priority areas of research and advocacy for the future.

# Objectives:

- 1. Determine what are the optimal, age-appropriate measures (self-report and performance-based) of functional limitation and disability to be used for varying spinal disorders.
- Document the societal costs of spinal disorders and back pain in terms of quality of life. Emphasize segments of the population that are at most risk, including geriatric and pediatric populations.
- Document the societal costs of spinal disorders and back pain in terms of physical function and work capacity. Emphasize segments of the population that are at most risk, including geriatric and pediatric populations. Include measures of functional mobility.
- 4. Determine the impact of spinal disorders and back pain on mental health, physical fitness, obesity and other co-morbidities. Further, to determine how these factors might impact the outcome of care for persons with spinal disorders and back pain.

- 5. Develop and validate appropriate measures of functional limitation, disability and quality of life for specific spinal pathologies, including lumbar degenerative pathologies, trauma, infection, deformity, osteoporosis, etc.
- 6. Determine the psychological and cultural influences and effects on spinal disorders and chronic back pain.
- 7. Determine the direct and indirect costs of spinal disorders and back pain to society as compared to other medical conditions. Utilize comparative effectiveness analysis to estimate differences in burden of disease compared with other musculoskeletal and medical conditions.
- 8. Identify drivers of cost in spinal disorders and potential targets to reduce costs.
- 9. Determine country-specific priorities in terms of spinal disorders and back pain. i.e. how do spinal disorders/back pain compare to other pressing issues such as clean water and controlling the spread of infection.
- 10. Determine the value of care for disorders of the spine from a cost-utility analysis perspective (i.e. cost and quality-adjusted life year calculations).
- 11. Determine the cost of care threshold that is most cost-effective in different healthcare economies.
- 12. Collect data regarding the overall burden (i.e. cost, disability, quality of life) of spinal disorders and back pain that are relevant to specific segments of society such as ethnic, racial, geographic or socio-economic groups to enhance the development of targeted intervention.
- 13. Build upon the work of John Dormans and Gunnar Andersson on the Epidemiology of Adult Spine disorders and Spinal Deformity.

#### Barriers:

- 1. Lack of common definitions among researchers and clinicians regarding how we should define burden of disease.
- 2. Paucity of available databases with appropriate information regarding spinal disorders/back pain and healthcare utilization.
- 3. Lack of large, representative ongoing epidemiological studies (i.e. NHANES) with detailed data being collected regarding spinal dysfunction.
- 4. Difficulty in measuring the value of treatment for pediatric deformity where the goal is avoiding the consequences of deformity progression rather than treating present disease or disability.
- 5. Societal attitudes that spinal disorders and back pain are less important than other medical conditions.

# Facilitators:

- 1. Growing recognition that spinal disorders can have a significant impact on health, productivity and quality of life.
- 2. Internationally, there are multiple professional societies, representing multiple disciplines, which would share in this mission of establishing a clearer understanding of the true societal burden of spinal disorders and back pain.

# **Action items:**

- 1. Build national/international networks of musculoskeletal epidemiologists who could develop future studies that would incorporate all of the necessary information needed to measure the true burden of spinal disorders/back pain.
- 2. Search for available data sources that contain information on spinal disorders/back pain and other measures of disease burden, such as quality of life, functional limitation, and cost data.
- 3. Form a task force to lobby funding agencies (identify funding sources) to provide funding for epidemiologic and /or healthcare utilization studies relating to spinal disorders and back pain.

## Timeline:

# Year 1:

- 1. Epidemiology studies of prevalence of spinal disorders and back pain worldwide.
- 2. Establish measures of HRQOL and functional assessment that will be used to measure the impact of disease
- 3. Identify sources for data on HRQOL in patients with spinal disorders
- 4. Establish infrastructure for prospective data collection

# Year 2-5:

- 1. Ongoing prospective data collection with interim analysis
- 2. Measurement of impact of disorders on functional measures of disability
- 3. Identification of funding sources
- 4. Annual meeting of task force

Priority Area 2 – Specific Disorders of the Spine: Identification of Spinal Disorders that have the greatest impact on health and that require increased awareness and activity directed toward prevention and treatment

# I) Definition of the Issue:

Disorders of the spine have a significant and measurable impact on health-related quality of life. The burden of spinal disorders is determined by factors that include prevalence, demographics of the affected population, and effect size.

Identification of specific conditions that require an increased awareness and an increase in activity internationally is important to direct and guide efforts to improve spinal health internationally. The conditions identified are spinal disorders that present the greatest burden to health internationally, and spinal conditions that have the greatest potential for a change in incidence and impact through preventative strategies and existing treatment modalities.

# II) Goal

The purpose is to identify specific spinal disorders that warrant attention, international awareness and research focus. Identification of priority disorders will serve to focus future clinical resources, research efforts and collaboration on areas that are most significant clinically and that have the most potential for change.

# III) Objectives:

The specific spinal disorders that require international attention are identified by prevalence and impact of the disorder. The objective of the identification is to target resources to interventions that have the greatest effect and impact on global health. The conditions that we identify as priorities are:

- 1. Traumatic injuries of the spine
  - a. High energy
  - b. Repetitive stress
- 2. Infection affecting the spine
  - c. Tuberculosis
  - d. Osteomyelitis and discitis
- 3. Developmental and degenerative conditions of the spine
  - e. Pediatric deformity
  - f. Adult deformity
  - g. Degenerative conditions of the cervical and lumbar spine
    - i. Neural impairment
      - 1. Myelopathy
      - 2. Radiculopathy
    - ii. Instability
    - iii. Pain
  - h. Disorders of the Aging Spine
- Traumatic injuries of the spine include fractures, dislocations, and soft tissue injuries.
   Internationally, trauma is the most common cause of death and disability in males age 18-30. Trauma to the spine may result in spinal cord injury, functional limitations and prolonged disability. Prevention of spinal trauma, and effective treatment of traumatic injuries to the spine will have an important impact on health globally.
- 2) Infection of the spine affects patients across demographic groups. Internationally, infections including tuberculosis and pyogenic osteomyelitis have a significant impact on spinal health in causing deformity, neural compromise, pain and prolonged disability. Tuberculosis is the most common cause of death from infectious disease worldwide, and

affects one third of the world's population. Prevention, early detection and effective treatment of infections of the spine will have a positive and valuable impact on spinal disorders worldwide.

- 3) Spinal deformity is an important cause of disability in the adolescent and the adult. Scoliosis and kyphotic spinal deformity have an important impact on health status and spine function. The prevalence of lumbar scoliosis in adults has been estimated to affect over 50% of postmenopausal females. Identification of progressive deformity and treatment of early onset deformity will have an important effect on reducing the burden of scoliosis and kyphotic deformity in adults.
- 4) Degenerative conditions of the cervical and lumbar spine affect the vast majority of adults worldwide. Symptomatic degenerative spinal disorders have a point prevalence of over 30% of the population in developed nations, and a lifetime prevalence of >80% of the population. Operative and non-operative care have a significant effect on improving symptoms of pain and disability in affected patients, and are among the most cost-effective interventions in healthcare. Prevention of symptomatic degenerative changes, and effective treatment of symptomatic degenerative spinal disorders will have an important impact on spine health internationally.

# IV) Barriers:

- Access to care is an important barrier to effective treatment for many patients who
  are affected by infectious, traumatic and developmental conditions of the spine.
  Access to care includes access to a primary provider who will identify spinal disorders
  and access to a spine specialist who can provide effective non-operative and
  operative care.
- 2. Prevention is an important strategy, especially in the objectives of reducing the burden of disease from trauma and infection of the spine. Prevention requires information exchange and education. The lack of an infrastructure for information exchange internationally is an important limitation to preventative strategies.
- 3. Population-based screening for patients at risk for infection and deformity of the spine is not well-developed in most countries. Effective early treatment may prevent long-term disability.
- 4. Effective interventions for many degenerative pathologies of the spine that do not involve neural impairment of instability are not well-defined. Evidence on the efficacy of non-operative and operative care for degenerative disorders without instability or neural compromise is limited and therefore there is little evidence-based guidance to appropriate management strategies.
- 5. In developing nations, most people are pedestrians with limited access to transportation, and spinal disorders prevalent in third world populations, do hamper mobility of affected individuals with no means of transportation. There are no clearly defined non-operative (epidural) or operative (decompressive) procedures.
- 6. EMS services are unavailable in most underdeveloped and developing nations. Traumatic injury results in paraplegia and death from lack of early evaluation and on-the-scene stabilization and transfer.
- 7. Understaffed facilities and regional health care centers. Physician workforce issues and lack of qualified practitioners for spinal disorders.
- 8. Asymmetric distribution of medical resources internationally will be an obstacle to the establishment of uniform goals.

# V) Action items and facilitators for moving the Objectives Forward:

- i. Identification of stakeholders that have an interest in reducing the burden of common spinal disorders on global health. Specific stakeholders include patients, physicians who care for patients with spinal disorders, third party payers and clinical and research societies and organizations.
- ii. Development of an infrastructure for effective information exchange. Early recognition and screening for progressive spinal disorders, and identification of patients at risk for infection and progressive deformity will enable early intervention and effective treatment.
- iii. Safety standards for motor vehicles and occupational health is an important action item to reduce the burden of spinal trauma. Prioritization of road safety programs and work safe environments will have a major impact on prevention of spine trauma.
- iv. Early and effective prevention and treatment of tuberculosis will have an important impact on spine infection. Completion of antibiotic courses and identification and effective eradication of infection will help to prevent the late sequelae of disease.
- v. Collaboration between primary care physicians and spine specialists will help to improve early identification of spinal disorders and early and effective interventions.
- vi. Developing an infrastructure for spine health and fitness will reduce the burden of degenerative conditions affecting the spine. Reducing the prevalence of obesity and physical deconditioning will improve spine specific health status.
- vii. Establish funding for programs focused on effectively improving spine health and reducing the impact of degenerative spinal disorders on health status.
- viii. Ambulances and EMS programs to facilitate points of care and transfer.

# VI) Timeline:

## Years 1-3:

- 1. Improve collaboration between stakeholders through regularly scheduled conferences and meetings.
- 2. Develop a consensus of priorities for public resources and expenditures
- 3. Study efficacy of preventative strategies for degenerative disorders, trauma and infection.
- 4. Develop educational resources for patients and primary care providers
- 5. Establish sustainable funding for prospective research on treatment effectiveness

#### Years 3-5:

1. Measure outcomes of interventions by rates of disease and severity of disease

# VII) Outcome Measures:

- 1. Incidence and prevalence of specific spinal disorders
- 2. Impact of specific disorders on health-related quality of life
- 3. Presence of funding sources to support research on treatment and prevention of identified disorders
- 4. Presence of a multidisciplinary conference dedicated to treatment and prevention of identified disorders

# Priority Area #3: Introduction of Technologies and Devices in the treatment of Spinal Disorders

#### Issue:

Technologies directed toward the diagnosis and treatment of disorders of the spine have contributed significantly and importantly to the management of spinal disorders and low back pain. Important technologies include diagnostic modalities such as: imaging modalities that allow for better visualization of possible pathophysiologic mechanisms. Other testing which evaluates neurologic function including electrodiagnostic studies such as EMG/NCV, SSEP and Transcranial magnetic stimulation. Treatment technology includes both invasive procedures such as, percutaneous spinal interventions, and implantable devices. Non-invasive options include treatments such as manual therapies, exercise interventions and cognitive therapies. The distribution and utilization of technologies are characterized by significant variability. The cost of technologies is an important expense in health care, and a significant reason for the disproportionate rise in costs for management of spinal disorders. It is therefore imperative that the discussion about the utilization of these technologies evaluate the best allocation of resources to best evaluate and treat disorders of the spine.

#### Goals:

- 1. To define the technologies which contribute most significantly to health-related quality of life.
- 2. To determine a rationale distribution of technologies that will optimize access to care and prevent overutilization of resources.
- 3. Identify health care environments and population demographics that benefit most from options in technologies.
- 4. Identify technologies that should be distributed more effectively for optimal management of spinal disorders.
- 5. Direct future research toward the development of invasive and non-invasive technologies that are effective over a broad range of patients, and that have a sustainable cost internationally.
- 6. Optimize distribution of existing technologies
- 7. Critical assessment of existing and new devices and technology

# Significance of goals:

The role of technologies in the management of spinal disorders is incompletely defined. New and current technologies account for a large portion of spine care cost, and the incremental value of novel interventions, devices and diagnostic techniques is largely unproven. A systematic effort to assess and define the value of new and current technologies, and an appropriate utilization rate and distribution will have a significant impact on improving access and reducing cost of care worldwide.

# **Objectives:**

- 1. Define the value of technologies in the management of spinal disorders
  - a. Non-operative interventions
    - i. Non-invasive
      - 1. Physical modalities: Low level laser, TENS, etc...
      - 2. Manual medicine: Manipulation and mobilization
      - 3. Exercise: general and specific programs
      - 4. Behavioral therapy: cognitive behavioral therapy, relaxation
      - 5. Weight Loss/Conditioning
      - 6. Decompression
    - ii. Interventional procedures (minimally invasive)
      - 1. Diagnostic
      - 2. Therapeutic
        - a. Intradiscal technologies
          - i. Devices (polymers, biologics, etc)
          - ii. Drugs (fibrin, stem cells, etc)
          - iii. Disc Decompression
          - iv. Annular destruction (IDET, Accutherm, etc)
        - b. Medication installation
        - c. Neurodestructive (RF, phenol, etc)
        - d. Others
      - 3. Accupuncture
      - 4. Spinal Cord Stimulation
  - b. Operative Interventions
    - i. Decompression of neural elements
    - ii. Arthrodesis of the spine
    - iii. Motion preservation
- 2. Develop a systematic framework to assess the cost/benefit ratio of technologies in areas of diagnosis and management of spinal disorders.
- 3. Develop a systematic framework to assess the distribution of technologies internationally in order to correlate distribution of technologies with spine-specific health status. This will require a practical strategy for research that may work with single payer systems internationally.
- 4. Identify technologies that are underutilized and over utilized internationally, and that require improved distribution and access to care.
- 5. Support comparative effectiveness research in the assessment of new technologies compared with existing technologies
  - c. Identify appropriate outcomes- questionnaires, cost effectiveness, functional measures

#### Barriers:

- 1. Cost of technologies will limit an equitable distribution of diagnostic and therapeutic interventions
- 2. Stakeholders in new technologies will seek to maximize utilization of technologies in limited regions
- 3. Accurate data on appropriate rates of utilization limits the establishment of quidelines for utilization
- 4. Clinical outcomes data on interventions is limited for the measurement of comparative efficacy
- 5. Paucity of available databases with appropriate information regarding spinal disorders/back pain and healthcare utilization.

#### Facilitators:

- 1. Third party payors including national payors have a positive incentive to define the appropriate role of new technologies in the management of spinal disorders
- 2. Spine-specific societies and networks with an infrastructure for data collection
- 3. Industrial developers of new technologies would benefit from guidance in directing research and development resources toward technologies that would be adopted widely

# **Action items:**

- 1. Develop a map of the distribution and utilization of technologies nationally and internationally
- 2. Support a national and international database for clinical data collection that will facilitate research on comparative effectiveness for new technologies
- 3. Federal funding for the development of new technologies that are most likely to contribute to significant incremental change in quality of life, with limited increase in the cost of care
- 4. Develop evidence-based guidelines to define the reimbursement of new technologies by third party payors

# Timeline:

- Year 1: Develop infrastructure for data collection nationally and internationally (possibly working with the WHO countries with single payer system databases)
- Year 2-4: Data collection, secondary analysis of existing databases, industry-society Partnership to direct new technology development
- Year 5: Analysis of comparative effectiveness of alternative approaches using data

  Data collected from the infrastructure created.

# Priority Area #4: Identification of areas for spine-related research and for international collaboration

#### **Issue Definition:**

Clinical and basic science research are fundamental to the pursuit of evidence-based changes in our management of disorders of the spine. Current research funding and implementation is structured to promote parallel silos rather than interdependent collaborative networks. There are significant economies of scale that may result from an organized approach to scientific investigation. Identifying priority areas for clinical and basic research, and collaborating broadly in the pursuit of these investigations is an important goal of the next decade of spine-related research.

#### Goals:

- 1) Identify priority areas as defined by the burden and the impact of disease that have the most potential for improvement with directed research
- 2) Identify resources for research funding and execution
- 3) Improve the efficiency and efficacy of clinical and basic science research in spinal disorders

# Importance of Goals:

Disorders of the spine are among the most significant medical conditions affecting the population in all demographic categories. Research into clinical comparative effectiveness and into basic science approaches to diagnosis and care may have a significant impact of the cost-effective practice of managing patients with disorders of the spine. Development of collaborative networks working toward a common goal accelerate the rate and productivity of research in spinal disorders.

# **Objectives:**

- I) Identify priority areas for research:
  - ii. Basic science research initiatives
    - 1. Diagnostics
    - 2. Pharmacologics
    - 3. Stem Cells
  - iii. Clinical research initiatives
    - 1. Measurement of outcomes
      - a. Disability, Pain, cost, societal
    - 2. Multicenter data collection
    - 3. Integrating assessment of alternative approaches
      - a. Operative and non-operative database infrastructure
      - b. Comparative effectiveness
        - i. Strengths and weaknesses of research
        - ii. Systems research
        - iii. Specific modalities
        - iv. Generalizability
      - c. Measures of value
- II) Public information initiatives
  - 1. Prevention of spinal disorders
  - 2. Awareness of spinal disorders
  - 3. Advocacy for research support and patient care
  - 4. Media opportunities
- III) Plan to integrate stakeholders
  - 1. Creating comprehensive teams
  - 2. Spine specialty societies
  - 3. Industry partners
  - 4. Public/private partnerships
  - 5. Legislative advocacy

- IV) Funding Opportunities
  - 1. Identify potential payers and funding sources including third party payors and national health initiatives

## Barriers:

- 1. Existing infrastructure for research funding supports individual rather than cooperative effort
- 2. Lack of transparency regarding clinical outcomes and incentives of stakeholders
- 3. Cost of basic science and clinical research
- 4. Valuation of preventative strategies compared with treatment strategies

#### Facilitators:

- 1. Funding sources for research may recognize economies of scale in supporting collaborative research efforts
- 2. Spine-specific societies and networks treating similar disorders
- 3. Industrial developers of new technologies and regulatory requirements for marketing and distribution of new technologies

#### **Action items:**

- 1. Identify priority areas for clinical and basic science research based upon areas that have the greatest impact on spine health
- 2. Identify effective infrastructures for clinical and basic research and use existing infrastructures to model future research teams
- 3. Support a national and international database for clinical data collection that will facilitate research on comparative effectiveness for new technologies
- 4. Identify sources for funding including stakeholders such as third party payors, federal sources, and spine societies.
- 5. Create incentives for collaborative research with multiple disciplines and centers contributing to research initiatives

# Timeline:

Year 1: Identify specific priorities for clinical and basic science research

Identify stakeholders and potential sources for funding

Year 2-4: Develop multidisciplinary research teams for the pursuit of identified

priorities

Establish annual multidisciplinary clinical and research conferences

Year 5: Re-identify priorities for further clinical and basic science investigations

#### TRAUMA AND INJURY STRATEGIC PLANNING SPECIALTY GROUP

# **Overview**

Issue 1: Fragility Fractures
Issue 2: Road Traffic Crashes
Issue 3: Extremity War Injuries
Issue 4: Repetitive Use Disorders

# **Issue 1: Fragility Fractures**

Hip fracture is the most devastating of all fragility fractures with consequences for the patient, family and the health care system. In the US alone, there were 310,000 hospitalizations for hip fracture in 2007; worldwide, 1.6 million hip fractures occur annually. The number of hip fractures is expected to double within the next 40 years unless effective primary prevention efforts can be identified and implemented globally. While 80 percent of hip fractures occur in white women, approximately 20 percent of hip fractures are in men and 8 percent are in those who are non white. Risk factors for hip fracture, which need to be considered for both primary and secondary prevention are bone weakness and propensity to fall. Each of these, of course, has multiple proximal causes that need to be addressed with medical, psychosocial, environmental interventions.

The direct medical and indirect non-reimbursed costs for care of those with hip fracture exceed \$15 billion in the US. Of those who fracture, approximately 18 percent of women and 36 percent of men will die during the post fracture year, and of survivors, almost 50 percent will not regain their ability to walk independently, an essential function for performing other tasks of daily life (Magaziner et al, 2000; Hannon et al, 2001; Wehren et al, 2003). Other consequences of hip fracture include increased rates of delirium, depression and other cognitive difficulties all of which are associated with poorer functioning in the year after a fracture (Dolan et al, 2000; Gruber-Baldini et al, 2003; Magaziner, et al, 2000; Miller et al, 2009).

#### Goal

Improve outcomes by:

- 1. Increasing long-term survival, improving function in multiple areas (e.g., physical, instrumental, psychosocial).
- 2. Preventing additional fractures, through carefully targeted and well designed secondary prevention efforts and improved post fracture care starting at the time of fracture and continuing for a year or longer post fracture. (Note: Primary prevention of fractures is being addressed by the bone health and osteoporosis specialty group.)

# **Objectives**

- 1. Develop and implement globally acceptable evidence based protocols for the treatment and management of hip fractures.
- 2. Design protocols that address the specific deficits that hip fracture patients face at different times (pre-operative, peri-operative/in hospital, post hospital) following their fracture.
- 3. Ensure that protocols are designed so that they patients and providers are able to adhere to them.

- 4. Develop medical, psychosocial and rehabilitative interventions that begin at the time of fracture, before medical attention is available, and extend for a year or longer post fracture, and include expertise of multiple disciplines in developing and testing these interventions.
- 5. Develop improved approaches to prevention of secondary fractures.
- 6. Raise awareness at all levels (patients, families, providers, insurers, government and non-profit agencies) of the consequences of hip fracture and the need for significant care improvements.
- 7. Increase the federal investment in research on the treatment and management of those who have had hip fractures.
- 8. Increase funding for the treatment and care of hip fracture patients that extends to one year or longer.
- 9. Design evidence based protocols that can be implemented in individually selected clusters to meet the needs of individual patients and specific care settings, such as acute care hospitals, rehabilitation units in hospitals and nursing homes, nursing homes and at home.

# **Barriers**

- 1. Lack of awareness of potential long term cost savings and quality of life improvements that can be realized with better and longer term post fracture care.
- 2. Care in many countries, including the US, is fragmented so that no single entity takes responsibility for the longitudinal care of hip fracture patients.
- 3. Hip fracture care does not have a champion in the US Congress and other legislative bodies around the world to advocate for resources to support better evidence and implementation of best practices for secondary prevention and care to improve disability free survival.
- 4. No funded Centers of Excellence dedicated to improved research on post hip fracture care.

#### **Facilitators**

- 1. Recognition that the burden of hip fracture on the patient, family and health care system can help identify champions for new funding initiatives in federal, non-profit and philanthropic sectors targeted at developing and implementing evidence based protocols to improve survival and other outcomes from hip fracture.
- 2. Recognition that improved post fracture care and management has the potential to save money in the long term and to reduce burdens on patients, families and the health care system.

#### **Action Items**

- 1. Educate the WHO, Congress in US, and legislative bodies in other countries on the need for resources to improve evidence based treatment and management strategies for hip fracture patients.
- 2. Identify and mobilize champions, advocates and special interest groups who can draw more attention from Congress, federal funders, non-profit funders and philanthropic organizations to the need to improve funding for research and evidence based care for this patient population.
- 3. Develop the evidence needed to lobby effectively, including detailed information on the economic and psychosocial burdens of hip fracture, and the cost savings of effective intervention strategies to the health care system and the health and psychosocial benefits of effective interventions for patients and their families.
- 4. Educate medical community (including orthopaedic, internal medicine and geriatric, nursing, rehabilitation specialist, social work, psychology, others) on the need to work together, with well-integrated hand-offs, to manage the complex care of the hip fracture patient.
- 5. Petition NIH and other funders of scientific studies on the need for more basic research on the process by which hip fracture patients recover, and the need for more phase III research on the efficacy of interventions/protocols designed to improve survival and post fracture functioning in the community.
- 6. Develop funding to support networks of scientists and practitioners to pursue interdisciplinary research on development and evaluation of new protocols for the treatment and management of hip fracture patients.

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#### **Issue 2: Road Traffic Crashes**

#### Overview

Injury is a major cause of death and disability globally. Worldwide, road traffic crashes (RTC) account for approximately 1.4 million deaths and between 20 and 50 million injuries/disabilities each year. These figures are expected to increase by about 65% over the next 20 years (WHO world report RTS). Road traffic crashes are the leading cause of death among people aged 10-24 years. Road traffic crashes are predictable and preventable and should be viewed as a disease. Lower and middle income countries (LMIC) experience a disproportionate burden from RTC and trauma; approximately 2-5x higher than HIC (The Global Burden Disease study (GBD)). Mortality rates from trauma are nearly twice as high in LMIC compared to HICs. 95% of all childhood injury deaths occur in LMIC (WHO 1999). Many of these deaths are preventable and not all deaths occur instantaneously. These statistics do not include the significant morbidity and suffering that accompanies those who survive. Furthermore, the permanent burden(s) and cost due to the sequelae of these injuries is even greater.

Access to even the most basic trauma care is lacking in most LMIC. Nonexistent infrastructure such as EMS/ambulance service and even running water at hospitals is common in LMIC. The inadequacy of treatment is not limited to RTCs, but affects the entire spectrum of traumatic injuries. Funding and policy to trauma treatment is disproportionate to other global health issues. RTC prevention is well supported, both financially and politically. However, there are no major well-funded global programs to improve trauma care. Recently there has been increased concern and attention given to improving the delivery of trauma care. Significant decreases in morbidity and mortality have been documented in LMIC with relatively small increases in funding and manpower. As the new decade arrives, we should continue the prevention of RTC, however, it is imperative that we increase efforts in the treatment of those injured.

#### Goals

- 1. Improve trauma care delivery systems
- 2. Recognize the value of prevention programs
- 3. To include highlighting the special needs of children with regard to development and availability of educational and operational resources.
- 4. Develop holistic approach to road traffic safety that includes elements of education, prevention, and treatment spanning the spectrum from pre-hospital to rehabilitative and re-integrative care.

# **Objectives**

- Ensure sufficient <u>surgeons</u> involved at WHO level, UN and other international organizations so that appropriate attention is given to the trauma care of RTC victims. (Non-surgical specialists are unlikely to devote the same level of attention. The overall goal is to ensure that the level of attention at the leadership organizations like UN/WHO is proportionate to burden of disease).
- 2. BJD to prioritize making RTC education, prevention and treatment important parts of WHO portfolio of action items.
- 3. Promote emergency and surgical care of RTC victims.
- 4. Improve vesting in surgical disease overall among leaders and among infrastructure of global organizations responsible for world health.
- 5. Define acceptable trauma care levels for developed and developing nations to include pre-hospital, acute care, definitive care and rehabilitative/re-integrative components.
- 6. Develop global strategic plan to make trauma care more affordable and available.

- 7. Define trauma care as priority for large donor nations i.e. USAID, G8 Nations, FIS Foundation.
- 8. Convince major world organizations to include trauma treatment initiatives in addition to prevention efforts Viet Nam example.
- 9. Organize a global meeting to develop a plan to implement trauma treatment standards worldwide.
- 10. Define better list of collaborators who do we want to bring into the process
- 11. Define action plan to get physicians and surgeons to rural areas where trauma occurs.
- 12. Define action plan to get more mid-level and even low-level practitioners involved, educated and credentialed.
- 13. Define action plan to bring basic trauma supplies/infrastructure to LMIC countries
- 14. Define action plan to bring basic pediatric trauma supplies/infrastructure to LMIC countries
- 15. Need situational analysis of capacity to deliver trauma care worldwide so as to develop and implement plans to help nations develop systems worldwide.
- 16. Define action plan for developing trauma treatment educational programs for nonsurigcal healthcare professionals in rural districts of LMIC through apprenticeships. Will allow stabilization of trauma patients until they can be transferred to appropriate facility (eg. Oman midwife apprenticeships).
- 17. Define action plan for HIC to better organize trauma services and care and disseminate knowledge and practices to LMICs.
- 18. Define action plan for HIC to supply resources/personnel and surplus good to LMIC.

# **Barriers**

- 1. Recognize that the most basic infrastructure is severely lacking in most LMICs
- 2. WHO and other organizations involved in promoting worldwide road-traffic safety and crash victim care have focused on prevention more cost-effective. Treatment with regard to pre-hospital care and ED care is in its infancy in many areas. Need exists for development of definitive care and rehabilitative care capacity. Need to promote acceptable basic standards of trauma care and distribute these customized as necessary to individual populations and countries.
- 3. Organizational modeling within leadership agencies (i.e. WHO) has not promoted trauma care to become a greater operational priority more proportionate to burden of disease.
- 4. Lack of funding globally in WHO and specifically within trauma programs at WHO represents important barrier.
- 5. Non-affordability of trauma care in low and some middle-income nations
- 6. G8 Millennium Development Goals to prevent and reduce poverty only includes infectious disease. There is no mention of RTCs.
- 7. Insufficient allocation of budget towards adequate treatment, emergency services and surgical care in LMIC and some HIC.
- 8. Resource shortage/lack of availability
  - a. Nepal 3 days to reach hospital
- 9. Manpower shortages
  - b. Human resources brain-drain
    - i. From rural to urban areas and from low-income to higher income areas

#### **Facilitators**

- 1. UN Resolution A/62/257 Improving Global Road Safety. Recognizing that road-traffic crashes are a cause of premature mortality and loss of economic productivity that represent a major economic threat to the stability of developing nations. This should pave the way for release of resources (i.e. USAID funds) to support development of trauma care systems. Will also be important to convince funding agencies (USAID) to directly support trauma surgery initiatives rather than going through World Bank where likelihood increases of funds being diverted to prevention efforts.
- 2. Global Initiative for Emergency and Essential Surgical Care. Developed series of standards related to delivery of emergency trauma care. Implementation has resulted in successes in several areas already example of Mongolia provided.
- 3. 1<sup>st</sup> WHO Global Forum on Trauma Care Brazilian Ministry of Health, Health Secretary of Rio de Janeiro and WHO
- 4. World Health Assembly Resolution on Trauma and Emergency Care Services: WHA 60:22 Encourages countries to increase trauma care services.
- 5. First Global Ministerial Conference on Road Safety Moscow, 2009
- 6. Foundations with resources willing to dedicate them to trauma care i.e. Formula 1 Foundation Foundation Internationale for Road traffic Safety
- 7. RTC included within NCDs
- 8. Models in some developing countries of novel use of mid-level and even low-level practitioners to deliver protocol driven trauma care...."Task Shifting" i.e. Malawi model
- 9. Resurgence of primary care healthcare models opportunity to integrate trauma care as one of a series of reforms integrating surgery within the overall concept of how to run a health care system.
- 10. Resources such as, Surgical Care at the District Hospital (SCDH), WHO Integrated Management of Emergency and Essential Surgical Care toolkit, The Guidelines for Essential Trauma Care and Prehospital Trauma Care
- 11. Pediatric resources such as Youth and Road Safety.
- 12. Groups such as *SIGN project, Doctors Without Boarders, World Orthopaedic Concern, Health Volunteers Overseas, etc.*

# **Action Plan**

- 1. Support 1st WHO Global Forum on Trauma Care
- 2. Support and surgeon presence in First Global Ministerial Conference on Road Safety and ensure trauma care receives adequate attention.
- 3. More surgeon involvement at WHO RTS projects.
- 4. Implement WHO Global Initiative for Emergency and Essential Surgical Care
- 5. Support for 6<sup>th</sup> UN resolution to have the next decade (2010-2020) directed at Road Traffic Safety/ Road Traffic Crashes
  - a. Make sure trauma CARE is a specific part of this resolution so that the entire effort does not become consumed with pure prevention
  - b. Insure that Surgeons are well represented on the RTC Decade
- 6. Support and promote resources such as, Surgical Care at the District Hospital (SCDH), WHO Integrated Management of Emergency and Essential Surgical Care toolkit, The Guidelines for Essential Trauma Care and Prehospital Trauma Care
- 7. Lobby for road traffic accident care to be included in G8 Millennium Development Goals. Poverty and likelihood of being a victim of RTC is clearly and strongly

- correlated in addition to the lack of prevention and treatment in these LMIC. In LMIC, 15% of premature death is due to trauma, of which 80% is caused by RTC.
- 8. Bigger allocation of budget towards adequate treatment, emergency services and surgical care in LMIC and HIC.
- 9. Support *Make Roads Safe Report* recommending 10% of any transportation budget to be allocated to road safety, which includes medical facilities around major highways.
- 10. Support of groups dedicated to delivery of trauma care in LMIC such as SIGN project, Doctors Without Boarders, World Orthopaedic Concern, Health Volunteers Overseas, etc.

# Issue #3 - Extremity War Injuries

Extremity war injuries (EWI) have been prevalent in war besieged areas of the developing world since the beginning of the widespread use of landmines. Their presence has led to severe extremity blast injuries with resultant amputation and severe disability. In addition, EWI represent the most common type of injury sustained by US warriors in the Global War on Terror that began in 2001. Recent studies have demonstrated that EWI are also the source of the greatest acute care hospital cost and the greatest long-term disability cost for the US military. Postulated causes for the disproportionate burden of injury associated with EWI include a combination of the effectiveness of body armor in protecting the chest, abdomen and, to a lesser degree, head, and the outstanding pre-hospital resuscitative care provided in the modern military theatre of operations. This has resulted in a surviving war fighter with severe and debilitating injuries to the body regions that were unprotected and therefore exposed to blast or other combat injury, namely the extremities.

#### Goal

Improve the quality of care provided for severe high-energy EWI and therefore limit long-term disability that results from these injuries.

# **Objectives**

- Improve our understanding of the burden of EWI globally by developing and
  populating databases of injury from conflicts worldwide. In addition to helping to
  understand the need for further research and the need for treatment resource
  development, this information may help better define the relative contribution of
  body armor to the incidence of severe extremity injury in survivors.
- 2. Increase the global research effort focused on treatment of conditions typically associated with EWI including infection and osteomyelitis, segmental bone defects, heterotopic ossification, and soft-tissue regeneration.
- 3. Improve access to modern treatment techniques for extremity war injuries worldwide including acute resuscitative care, wound debridement and coverage, and definitive bony reconstruction.
- 4. Develop meaningful disease-specific outcomes measures for EWI that will facilitate meaningful comparative effectiveness research of EWI treatment modalities.
- 5. Develop and evaluate integrated systems of post acute care and rehabilitation that address both the physical and psychosocial needs of the EWI patient.
- 6. Improve worldwide access to low cost prosthetic and orthotic devices and associated services that limit disability and ensure return to meaningful activity and reintegration into society.

# **Barriers**

 Lack of awareness of the burden of disease particularly with regard to the following components remains a major impediment to increasing the societal investment in extremity war injury research: Comparative prevalence of EWI; cost of acute care for EWI; cost of long-term disability related to EWI; lack of funding for EWI from other agencies (i.e. NIH, CDC); degree to which outcomes could be improved and amputations prevented with further research; distinction between EWI research, rehabilitation research and prosthetics-orthotics research; degree to which advances made in EWI research could be applied to civilian trauma care and lead to decreased disability from road traffic accidents and other mechanisms of injury more typically encountered in civilian populations.

# **Facilitators**

• Public and U.S. Congressional concern for well being of injured warriors has raised awareness and created a climate sympathetic towards funding research into solutions for treating injuries sustained in Global War on Terror activities. This awareness and concern can be leveraged to develop programs that will lead to long-term sustainable research programs intended to improve the quality of musculoskeletal trauma care. Such sustained programs are highly justifiable based on burden of injury to civilians in peace time and to warriors in times of conflict.

# **Action Items**

- Develop EWI focused research programs within Department of Defense (DOD)
   Congressionally Directed Medical Research Programs (CDMRP) funded through
   regular and supplemental appropriations processes and focused on research priorities
   established by a consensus process and based on burden of disease as measured by
   injury prevalence, associated treatment challenges and disability propensity.
   [ongoing]
- 2. Educate Congress on need to fund these programs on an annual and ongoing basis in order to attract researchers with greatest possible scientific expertise. [ongoing]
- 3. Educate DOD and Administration officials on need and value in moving these programs into POM to increase likelihood of receiving ongoing funding. [Goal 3 years]
- Educate Congress on need to pass legislation authorizing these programs to remove earmark stigma and to improve legislative and fiscal sustainability of programs.
   [Goal – 2 years]
- 5. Educate orthopaedic community including subspecialty societies on need to respond to RFPs with well-designed, scientifically rigorous proposals in response to DOD program announcements. [ongoing]
- 6. Work with DOD to establish high-level grant-review process that ensures that funded proposals represent those most likely to result in scientifically valid, medically important, and militarily relevant results. [ongoing]
- 7. Develop a worldwide database of EWI including information about prevalence, treatment challenges and resultant disability to allow better understanding of global need for improvement in treatment. [5 years]
- 8. Improve mechanisms to facilitate the conduct of clinical research within Military hospitals.

# Issue #4 - Repetitive Use Disorders (Work-Related Musculoskeletal Disorders)

# Overview

Work-related musculoskeletal disorders (WMSD) or repetitive use disorders (RUD) are conditions that develop because of repetitive tissue microtrauma that exceeds the tissue's ability to heal itself. WMSD are widespread in many countries, with substantial costs and impact on quality of life. Reports estimate that as many as 60% of occupational illnesses involve repetitive trauma, usually of the upper extremity. The majority of injuries or illnesses are associated with lifting, pushing and pulling, computer work, and repetitive use of tools or other objects. In the United States (US), Canada, Finland, Sweden and England, musculoskeletal disorders lead to more work absenteeism or disability than any other group of diseases (1). The specific WMSD that account for a major component of the cost of workrelated illness are repetitive strain of the neck and shoulder, tendinitis, epicondylitis, handarm vibration syndrome, and carpal tunnel syndrome (2,3). Estimates from the United Kingdom indicate that 5.4 million working days are lost annually due to WMSD and the Health and Safety Executive (HSE) in Britain reports that WMSD incur annual costs of approximately I.25 billion pounds (3,4). In the Nordic countries, estimates have shown that the total expenditure for WMSD range from 0.5% to 2% of the gross national products of these countries (5,6). The European Schedule of Occupational Diseases (collected by Eurostat) has yet to provide estimates of the size and cost of WMSD at the European level, because there is no standardized system for the assessment of WSMD across or within member states (3). In the US, the median time away from work is 17 days as a result of injuries or illnesses due to repetitive motion (2). Recent US annual estimates of the direct costs associated with WMSDs range from \$13 to \$20 billion and indirect costs related to such factors as lost wages, lost productivity, and lost tax revenues must be added to the cost of compensation claims, leading to estimates as high as \$45 to \$54 billion (2). Regardless of the estimate used, the problem is large both in health and economic terms. Global efforts to address the problem of WMSD have been initiated by the National Institute for Occupational Safety and Health (NIOSH), the National Research Council (NRC) and the Institute of Medicine (IOM) in the US, the World Health Organization (WHO), and the European Commission (DGV) through the European Agency for Safety and Health at Work. Broad priority areas identified by these groups include surveillance, etiology and intervention.

# Goals

- 1. Improve worldwide surveillance of workplace hazards and WMSD through the use of valid, reliable, and cost-effective systems, instruments, and standardized definitions of WMSD and key health and non-health factors.
- 2. Improve understanding of the risk factors associated with WMSD, particularly biomechanical, psychosocial, psychological, personal and organizational factors.
- 3. Develop and evaluate new and existing intervention strategies for preventing and reducing the incidence, severity and disability associated with WMSD.

# **Objectives**

#### Surveillance:

- Develop and validate standardized definitions for WMSD and stages of the disease processes as well as key health factors, such as severity, duration, onset and character of symptoms and disorder.
- Identify existing passive and active surveillance systems and evaluate in terms of usefulness, timeliness, simplicity, predictive value and cost.
- Develop and validate evaluation and screening tools that detect and predict the onset, progression and outcome of WMSD.
- Develop methods for distinguishing behaviors of symptom magnification and malingering from behaviors associated with WMSD symptoms.

- Determine whether non-health factors (e.g. increase in temporary workers, job transfer, absenteeism, early retirement, reduced productivity) can identify jobs with elevated risk of WMSD.
- Evaluate the usefulness of data sources (national surveys, government surveys, OSHA logs, and insurance, workers' compensation, physician and hospital records) in identifying WMSD and disease patterns.
- Improve collaboration between insurers, employers, unions, private business, community organizations and government groups in order to develop comparability of systems, instruments, diagnostic tools and definitions.

# **Etiology**

- Test and refine conceptual models of WMSD development and recovery in the clinic and laboratory to help understand the link between exposures, tissue changes, physiologic responses, adaptation and disease and the multifactorial relationship between biomechanical, environmental and physiological factors.
- Develop and validate assessment tools that identify risk factors associated with WMSD.
- Identify personal, psychological, organizational and psychosocial factors associated with WMSD and subsequent time away from work and chronic pain and disability.
- Determine the impact of mental and physical (both whole body and local muscle) fatigue and presenteeism on the development and maintenance of WMSD.
- Evaluate risk factors in relation to special populations (aging, children, and workers with disability or chronic conditions). One example is to determine if childhood exposures lead to problems in adulthood.
- Evaluate the impact of lawyer involvement, workers' compensation, disability benefits, and other forms of compensation or secondary gain on recovery and return to work.
- Evaluate the use of observation compared to self-report and direct measurements in identifying and predicting WMSD.
- Develop standards for operationalizing return to work outcomes and disability for research studies.

## Intervention

- Develop evidence-based treatment (education, work hardening, wellness, ergonomics, and rehabilitation) protocols for WMSD.
- Develop and evaluate engineering interventions that reduce the intensity, frequency, and duration of external forces on muscles and supporting structures. Examples include alternative product and tool design, workspace and seating arrangements, and semi-automated/intelligent material-handling devices. Industries to specifically target include health care, warehousing, construction, maritime, agriculture, meatpacking and poultry processing.
- Develop effective behavioral interventions and environmental factor facilitators to improve use of assistive equipment, personal protective equipment, regular rest and/or stretching breaks, avoidance of hazardous activities (heavy lifting) and compliance with workplace strategies/programs.
- Develop standard outcome measures for workplace interventional studies.
- Evaluate the direct and indirect costs of workplace interventions.

### **Barriers**

- No standardized system for the assessment of WMSD.
- Lack of consistent reporting opportunities for companies, clinicians, public health agencies and ministries of health.
- Under- or over-reporting of WMSD leading to difficulty in detection and diagnosis.
- Not fully recognized as a legitimate disorder or concern in many countries until recently.
- Limited integration of workers' health into the strategies of primary health care.
- Poor communication between private businesses, government and research institutions.
- Lack of a comprehensive theoretical framework of the disability and return to work process.
- Difficulties associated with gaining access to industrial and non-industrial sites to conduct research.
- Cost of surveillance and intervention strategies lead to poor adoption and maintenance of systems and workplace programs.
- Limited data on healthy populations who have not developed WMSD despite exposure to risk factors.

#### **Facilitators**

- NIOSH funding for intramural and extramural research on WMSD and funding for educational resource centers that provide training and educational opportunities aimed at identification, prevention and treatment of WMSD.
- Infrastructure support of NIOSH, NRC, IOM, WHO and the European Commission.
- The 2001, National Occupational Research Agenda for Musculoskeletal Disorders (NORA) developed by NIOSH and the WMSD agenda developed by National Research Council and the Institute of Medicine.
- Existing surveillance systems, such as the Bureau of Labor and Statistics (BLS) and the European Schedule of Occupational Diseases.

#### **Action Items**

- Organize a series of international multidisciplinary symposiums to organize and develop 1) a comprehensive conceptualization of occupational health, disability and return to work (RTW); 2) standards for operationally defining and consistently reporting WMSD; 3) standards for operationalizing return to work and disability outcomes for epidemiologic and interventional studies; 4) a comprehensive list of WMSD hazards, exposures (force, repetition, vibration), risk factors and outcome assessment tools; 5) global priority areas and topics for research and public awareness.
- Work with journal and trade editors from a variety of disciplines to publish symposium findings and reports.
- Work with national and international associations and societies to include WMSD priority areas and topics in research grant applications and conference agendas.
- Integrate continuing education on WMSD into conferences and annual meetings. A priority target population to include primary care physicians.
- Establish WMSD interest groups within medical, biomedical, policy and social/behavioral associations or integrate the topic of WMSD into existing disability/injury interest groups.
- Establish a multidisciplinary advisory group to interpret and disseminate usable information on WMSD to Congress, state public health agencies, ministries of health, researchers (through conferences and associations) and businesses (through websites, conferences, and speaking bureaus).
- Work with NIOSH and WHO to hold an international "research symposium" for researchers, government funding agencies, public health agencies, and companies to facilitate access to worksites and funding sources.

- Work with NIOSH to coordinate funding among federal agencies (NIH, AHRQ, CDC, NSF) for WMSD priority areas and topics, emphasizing partnerships with industries and unions and interdisciplinary research teams.
- Work with NIOSH, WHO, the European Commission and other global organizations to initiate a public awareness campaign (focus on success stories, prevention of WMSD, ergonomics and wellness programs).

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**Driving Directions to House Side:** Head east on Pennsylvania Ave NW toward 13 1/2 St NW (0.2 mi). Take the 2nd right onto 12th St NW (0.2 mi). Turn left at Constitution Ave NW (0.3 mi). Take the 2nd right onto 7th St NW (0.3 mi). Turn left at Independence Ave SW. House buildings will be on your right.

Walking Directions to House Side: Head east on Pennsylvania Ave NW toward 13 1/2 St NW (0.9 mi). Continue on E Capitol Cir (0.2 mi). At the traffic circle, take the 1st exit onto South Capitol Cir SW (387 ft). Slight left to stay on South Capitol Cir SW (180 ft). At the traffic circle, take the 1st exit onto 1st Ave SW (210 ft). Turn left at South Capitol Cir SW (0.1 mi). Turn right at Capitol Driveway SW (66 ft). Turn left at Independence Ave SW. House buildings will be on your right.

**Driving/Walking Directions to Senate Side:** Head east on Pennsylvania Ave NW toward 13 1/2 St NW (0.8 mi). Turn left at Constitution Ave NW (0.6 mi). Turn left at 1st St NE. Senate office buildings will be on your left.

Metro stations: JW Marriott: - Metro Center; Senate Buildings - Union Station (Red); House Buildings - Capitol South or Federal Center SW (Blue & Orange).