



Bone and Joint Decade Global Network Conference

October 21-24, 2009

We are pleased to announce plans for the Bone and Joint Decade Global Network Conference, to be held October 21-24, 2009, at the JW Marriott in Washington, DC, and hosted by the USBJD.

Official patient, health care professional, and specialty society representatives from about 60 countries will be attending.

Invitations for the President, Chief Staff Officer, and Decade representative to attend have been extended to all USBJD participating organizations, and a number have already confirmed their participation.



This conference represents the first time in history such a broad-based assemblage of musculoskeletal organizations will meet in the United States.

USBJD MISSION

To promote and facilitate collaboration among the public, patients, and organizations to improve bone and joint health through education, research and advocacy.

The primary goals of the conference are

- to raise awareness and advocate for musculoskeletal health
- to develop a roadmap for the future to build on the momentum created by the Bone and Joint Decade.

USBJD Participating Organizations

How can you and your organization participate?

1. Encourage your President, Chief Staff Officer, and BJD representative to attend the conference.
2. Your representatives are invited to join their colleagues from other musculoskeletal specialty societies and patients in meetings with congressional leaders on Capitol Hill.
3. Sponsor and arrange for a patient to join the Patient Advocacy Seminar and visits to Capitol Hill.
4. Let us know in which Strategic Planning Specialty Group(s) your organization would like to participate. The goal of the sessions is to identify issues and opportunities for collaboration by the musculoskeletal community to raise awareness and advocate for musculoskeletal health over the next few years. Issues and proposed actions are to complement the existing programs and plans of organizations uniquely concerned with each specialty within the community. The results will be presented by the session leader at the plenary leadership session where, along with other specialty leaders, a musculoskeletal community-wide roadmap will be developed to advocate for musculoskeletal health in the future and beyond the Decade, building on the foundations and momentum that has been created. The groups will work over the

coming months by email and teleconference to identify the issues and opportunities for collaboration, and formulate a basic plan to be discussed and finalized at the meeting itself.

GROUPS:

- ▶ BONE HEALTH AND OSTEOPOROSIS
- ▶ PEDIATRIC MUSCULOSKELETAL DISEASE
- ▶ SPINAL DISORDERS AND LOW BACK PAIN
- ▶ ARTHRITIS
- ▶ RESEARCH
- ▶ TRAUMA AND INJURY

Publication of an enduring document on the outcomes of the meeting in leading specialty journals is planned.

Email tobyking@usbjd.org to let him know your area(s) of interest. He will put you in touch with session leaders and send you a copy of the framework for these sessions.

5. Your organization's leadership will be invited to participate in meetings with senior administration officials. Please encourage and support their participation.
6. This conference represents a considerable undertaking by the USBJD. We invite USBJD participating organizations, associate members, other organizations and individuals to make a contribution or offer a grant towards covering costs. For information on levels of support and how to contribute, please contact tobyking@usbjd.org, and ask for a Prospectus.

PROGRAM OVERVIEW



The program consists of a two-day Patient Advocacy Meeting, October 21-22, and the Global Network Conference, October 23-24, a two-day

education and strategic planning meeting for health care providers, patients, patient advocates, government officials, and industry. The meeting will highlight the significant burden of disease posed by musculoskeletal conditions and discuss why raising awareness and engaging in advocacy are important means to advance prevention and treatment.

During the afternoon and evening of Thursday, October 22, the program will focus on raising awareness of musculoskeletal conditions on Capitol Hill for U.S. delegates, including patients and the leadership of USBJD participating organizations. Arrangements will be made for international delegates to meet with officials from their own embassies, and then to join the U.S. delegates on Capitol Hill. Meetings with senior administration officials concerned with health policy and research, congressional leaders, and officials of foreign embassies are planned.

Join us in the most significant gathering of the United States Bone and Joint Decade and the leadership of its participating organizations as we welcome the representatives of Bone and Joint Decade

National Action Networks from around the world.



BACKGROUND

The Bone and Joint Decade

The Bone and Joint Decade is an international collaborative movement sanctioned by the United Nations/World Health Organization. Its mission is to improve the quality of life for people with musculoskeletal conditions and to advance the understanding, prevention and treatment of these conditions. Today 63 national governments and more than 750 patient advocacy and health professional organizations endorse this effort.

Officially proclaimed by the U.S. President, the United States Bone and Joint Decade (USBJD) 2002-2011 has been endorsed by all 50 States and more than one hundred national health care professional, patient and public organizations, all 125 U.S. medical schools and many colleges of medicine.

The goal of the United States Bone and Joint Decade is to improve bone and joint health by enhancing collaborative efforts among individuals and organizations in order to raise awareness of the growing burden of musculoskeletal disorders on society, to promote wellness and prevent musculoskeletal disease, and to advance research that will lead to improvements in prevention, diagnosis and treatment.



ATTENDEES

- Bone and Joint Decade delegates from the more than 60 country National Action Networks (health care providers, patients, patient advocates, government officials)
- Leaders from health care provider and patient organizations in the U.S. involved in education, research and advocacy
- Members of Congress and health policy officials
- Scientific Leaders from the U.S. National Institutes of Health and major medical centers
- Patient Advocates

Bone and Joint Decade Participating Countries include:

Algeria, Argentina, Australia, Austria, Bangladesh, Belgium, Bolivia, Bosnia and Herzegovina, Brazil, Bulgaria, Burma, Canada, Chile, China, Colombia, Republic of the Congo, Costa Rica, Croatia, Cuba, Cyprus, Czech Republic, Denmark, Dominican Republic, Ecuador, El Salvador, Egypt, Estonia, Finland, France, Georgia, Germany, Greece, Guatemala, Haiti, Honduras, Hong Kong SAR, Hungary, Iceland, India, Indonesia, Iran, Ireland, Israel, Italy, Japan, Jordan, Kenya, Kuwait, Latvia, Lebanon, Lithuania, Macedonia, Malaysia, Mauritania, Mexico, Morocco, Netherlands, Netherland Antilles, New Zealand, Nicaragua, Nigeria, North African Region, Norway, Oman, Pakistan, Panama, Peru, Philippines, Poland, Portugal, Puerto Rico, Qatar, Romania, Russia, Saudi Arabia, Singapore, Slovakia, Slovenia, South Africa, South Korea, Spain, Sweden, Switzerland, Chinese Taipei, Tanzania, Thailand, Tunisia, Turkey, United Arab Emirates, United Kingdom, Uruguay, United States of America, The Vatican, Venezuela, Vietnam, and Zimbabwe.

ORGANIZING COMMITTEE

Co-Chairs

Nancy Lane, M.D.
Stuart L. Weinstein, M.D.

Members

Peter B. Ajluni, D.O.
John P. Dormans, M.D.
Edward D. Harris, Jr., M.D.
Joshua J. Jacobs, M.D.

Kenneth J. Koval, M.D.
Toby King, C.A.E.
Armin U. Kuder, Esq.
Joan A. McGowan, Ph.D.
J. Edward Puzas, Ph.D.
Barry S. Smith, M.D.
Kimberly Templeton, M.D.
Peggy Trossen
Hillary Weldon

Contact Information

United States Bone and Joint Decade, NFP
6300 N. River Road
Rosemont, Illinois 60018, USA
Phone: 847.384.4009/4010
Fax: 847.823.1822
Email: usbjd@usbjd.org
www.usbjd.org

PRELIMINARY PROGRAM DETAIL**Patient Advocacy Meeting – October 21-22**

- Tues., Oct. 20 Evening reception
- Wed., Oct. 21 Workshops on patient advocacy
Visits to research laboratories
Evening dinner and reception
- Thurs., Oct. 22 Workshops on patient advocacy
U.S. delegate visit to Capitol Hill
International delegates meet with embassy delegations
Capitol Hill evening reception/dinner (with participants arriving for Global Network Conference)

Global Network Conference - October 22-24**Thursday, October 22**

- 1700 Reception and Dinner on Capitol Hill for all participants

Friday, October 23

- 0800 – 0830 Welcome
- Prof. Lars Lidgren, Chair, International Steering Committee, Bone and Joint Decade
 - Stuart Weinstein, MD, and Nancy Lane, MD, Conference Co-Chairs
- 0830 – 0845 The urgency of addressing the burden of musculoskeletal disease – Prof. Anthony Woolf
- The major conditions, geographical differences, societal impact, projection of inaction
- 0845 – 0930 Osteoarthritis (Session leader – Linda Sandell, PhD):
- Burden of disease impact and trend line
 - Research, prevention and care management developments during the Decade
 - Opportunities
- 0930 – 0945 Break
- 0945 – 1030 Inflammatory Conditions (Session leader – David Pisetsky, MD):
- Burden of disease impact and trend line
 - Research, prevention and care management developments during the Decade
 - Opportunities
- 1030 – 1115 Back Pain (Session leader – Gunnar Andersson, MD):
- Burden of disease impact and trend line
 - Research, prevention and care management developments during the Decade
 - Opportunities
- 1115 – 1200 Osteoporosis (Session leader – TBC):
- Burden of disease impact and trend line
 - Research, prevention and care management developments during the Decade
 - Opportunities

Friday, October 23 (continued)

- 1200 Lunch: Guest speaker
- 1330 – 1415 Trauma (Session leader – Bruce Browner, MD):
- Burden of disease impact and trend line
 - Research, prevention and care management developments during the Decade
 - Opportunities
- 1415 – 1445 Bone and Joint Decade Success Story: Club foot treatment – Ponseti International Association model of success of patient advocacy movement.
- 1445 – 1500 Break
- 1500 – 1600 How do we advance the Health Policy agenda for musculoskeletal conditions?
James Weinstein, DO, MS Director, The Dartmouth Institute for Health Policy and Clinical Practice
- Advancing public policy agenda
 - Disparities in care
 - Shared decision making.
- 1600 - 1730 Strategic Planning - Specialty Group Breakout Meetings
- Arthritis
 - Bone Health and Osteoporosis
 - Pediatric Musculoskeletal Disease
 - Research
 - Spinal Disorders and Low Back Pain
 - Trauma and Injury
- 1800 Reception/Dinner

Saturday, October 24

- 0830 - 0900 Prof. Lars Lidgren
- 0900 - 1000 Strategic Planning Leadership Session – Developing a Roadmap for Advancing Musculoskeletal Health
- Participating Organization leaders present conclusions of specialty group strategic planning sessions and create a roadmap document for the future, identifying opportunities and actions that combine efforts to raise the profile of musculoskeletal health and advocate for prevention, diagnosis, treatment and research to lower the burden of disease.*
- 1000 – 1015 Break
- 1015 – 1130 Strategic Planning Breakouts
- By World Geographic Region (North America, Latin America, Europe, Africa, Middle East, Asia & Pacific): Discussion of plans to transition the Decade beyond 2010/2011.*
- 1200 Noon Lunch – Guest speaker
- 1300 – 1700 Bone and Joint Decade International Reports and New Business
- 1800 Dinner

IMPACT STATEMENT

Musculoskeletal conditions are reported by U.S. citizens more than any other health condition. It is estimated that these conditions occur in nearly one in two persons over the age of 18 or about 48% of the U.S. population. These conditions are also the most common cause of severe long-term pain and physical disability around the world affecting hundreds of millions of people (Burden of Major Musculoskeletal Conditions, Woolf & Pfleger, *WHO Bulletin* 2003; 81: 646-56). Musculoskeletal conditions include back pain, arthritis, traumatic injuries, osteoporosis, and childhood conditions. Osteoarthritis is ranked fourth across the globe as a cause for years lived with disability. The prevalence of musculoskeletal conditions are predicted to increase greatly across the globe due to increasing life expectancy, changes in risk factors, and availability of appropriate prevention measures unless actions are taken now.

Musculoskeletal conditions can lead to significant disability, resulting in lost productivity and a substantial impact on

quality of life. In 2004, the estimated total cost of treatment and lost wages associated with musculoskeletal diseases in the U.S. alone was \$849 billion, equal to 7.7 percent of the gross domestic product (GDP). In spite of this high cost, funding for research to reduce the pain and suffering created by these conditions is currently less than 2 percent of the National Institutes of Health budget each year. In 2011, "Baby Boomers" will become beneficiaries of Medicare, and the economic and societal cost of bone and joint health is expected to begin an escalation that will endure for decades.

In response to these staggering statistics in all continents and the need to improve the quality of life for these individuals, the global initiative of the Bone and Joint Decade 2000-2010 (2002-2011 in the U.S.) was formally launched at the World Health Organization headquarters in Geneva, Switzerland in 2000. Today, sixty-three (63) national governments and more than 750 patient advocacy and health professional organizations endorse this effort. To further advance the goals of the Decade, more than 60 countries have formed National Action Networks (NAN).

Meeting Goals: Awareness and Advocacy, The Cornerstones to Medical Advances in Musculoskeletal Diseases

This meeting brings together the representatives from each of the countries that have formed National Action Networks, as well as the leadership of the organizations that make up the U.S. Bone and Joint Decade National Action Network.

The Bone and Joint Decade is approaching the completion of Phase 1, the founding of a movement to raise awareness and to better educate professionals and the public about musculoskeletal health, and to increase research that will lead to improved diagnosis and treatment.

As the Decade prepares for Phase 2, this meeting will emphasize the progress made in the formative years of the Decade and advances in the prevention and effective management of musculoskeletal conditions, engage participants as advocates and to better understand the role of advocacy in advancing the mission of the Global Bone and Joint Decade, and most importantly to begin the strategic planning for the future.

Thanks to Supporters

We thank the following organizations which have pledged support for the conference.

Gold

Bone and Joint Decade – International Steering Committee

Silver

American Academy of Orthopaedic Surgeons - Council on Education
American Board of Orthopaedic Surgery

Bronze

American College of Rheumatology
American Orthopaedic Society for Sports Medicine
American Osteopathic Association
American Physical Therapy Association
American Shoulder and Elbow Surgeons
American Society for Bone and Mineral Research
National Osteoporosis Foundation

Orthopaedic Research Society
Rush University Medical Center
Scoliosis Research Society
University of Rochester Medical Center

Individual/Personal Contributions

Bill and Hillary Weldon

Program Activities and Items

Arthritis Foundation (Delegate bags)
University of Kansas Medical Center

To pledge a financial contribution, please contact Toby King at phone 847-384-4010.



U.S. Bone and Joint Decade

The USBJD Newsletter serves as a means of communication for participating organizations, their members, and other affiliated organizations. To submit a story idea or an article, please contact:

U.S. Bone and Joint Decade
6300 N. River Road
Rosemont, IL 60018
Ph 847-384-4010 • Fax 847-823-1822
usbjd@usbjd.org
www.usbjd.org

© 2009, United States Bone and Joint Decade, NFP

New Board Member Kathy Kuntzman

Newly named to represent the National Osteoporosis Foundation on the USBJD Board, Kathy Kuntzman has over 30 years of medical association management experience, including 15 years at the vice president level at the American Medical Association. Her most recent position at the AMA was Vice President of Health Policy. She managed AMA field operations for the county, state and national medical specialty societies, as well as constituent services for medical students, resident and young physicians, and other special interest groups. She has also worked at major medical organizations including the American College of Surgeons and the Chicago Heart Association.



Her areas of expertise include the facilitation of relations between medical societies, management of member segments, and health policy development. Ms. Kuntzman has served on the American Association of Medical Society Executives Board. She serves on the Roosevelt University College of Arts and Sciences Advisory Board and is also Secretary of the National Osteoporosis Foundation.

Ms. Kuntzman holds a Bachelor of Arts degree from Blackburn College, Carlinville, IL, in Elementary Education and English. She also has a Master's in Public Administration from Roosevelt University, Chicago, IL.

National Action Plan for Bone Health

In June 2008, more than 150 individuals representing an array of stakeholders concerned about bone health met in Washington, DC, to develop an action plan and agenda to advance bone health promotion and disease prevention.

The National Coalition for Osteoporosis and Related Bone Diseases, which includes the American Society for Bone and Mineral Research, National Osteoporosis Foundation, Osteogenesis Imperfecta Foundation, and the Paget Foundation, convened the meeting. The USBJD was represented on the Planning Committee. Several USBJD participating organizations were represented at the Summit. The USBJD itself was represented by Edward Puzas, PhD, President, Nancy Lane, MD, immediate Past-President, and Toby King, Executive Director.

Meeting participants built on the findings and recommendations of the 2004 Surgeon General's Report on Bone Health and Osteoporosis and on lessons learned from the development and implementation of the European Action Plan for Osteoporosis. Participants also discussed current bone health activities and initiatives and they considered the latest scientific advances, policy concerns and findings regarding bone health awareness, education and practice. The discussions generated numerous concerns, ideas and suggestions, which participants used to devise recommended steps for advancing bone health in our nation.

The National Action Plan for Bone Health is a direct result of their work, and is a testament to the widespread commitment to making the issues and importance of bone health a national health priority.

Summit participants condensed dozens of ideas into specific steps for improving the nation's bone health. For the action plan, the recommendations were grouped into four priority areas:

1. Develop a bone health alliance
2. Promote bone health and prevent disease
3. Improve diagnosis and treatment
4. Enhance research, surveillance, and evaluation

Each of these four priority areas includes several action steps to be taken by the bone health community. Next steps for the action plan include seeking more input and guidance from stakeholder groups, with a focus on determining more specifically how to accomplish these steps, and who will take responsibility for doing so.

To download a copy of the plan, visit www.nof.org/professionals/National_Action_Plan.htm

A Synopsis of the 1st Advances in Rare Bone Diseases Scientific Conference

*Michael J. Econs, MD, and
Craig B. Langman, MD, Meeting Co-Chairs*

The 1st Advances in Rare Bone Disease meeting was held from October 23-24 in the Natcher Center on the NIH campus. Faculty from academic health centers, and representatives from patient support groups and foundations, the NIH and the FDA and industry were invited to attend. The meeting was organized by the United States Bone and Joint Decade and the Rare Bone Disease Patient Network. The overarching hypothesis of the meeting was that this unique grouping of individuals and organizations interested in rare bone diseases would be able to create new opportunities and understanding through common themes, but with specific applications to the unique diseases and conditions represented at the meeting. A measurable outcome for the meeting was to not only assess the current state of understanding for a given disease, but to determine the next steps in developing therapies for these disorders.

We were pleased to have the meeting begin with welcoming remarks from Dr. Stephen Katz and Dr. Ronald Margolis, representing NIAMS and NIDDK, respectively. These institutes have been instrumental in providing support to many of the rare bone diseases discussed at the meeting, including FOP, the hypophosphatemic rachitic disorders, hypophosphatasia, and the osteopetroses. Basic and translational research has progressed to partnering with industry to devise very promising treatments, two of which are now in clinical trials for hypophosphatasia and XLH, and others that are likely to be in trials in the next few years.

The format of the meeting had presentations of four plenary lectures of the highest quality science outside of traditional bone biology, but with applicability to problems encountered within rare bone diseases. We provide a brief précis of those presentations below. Following the outstanding learning experience provided by these preeminent plenary lecture scientists, we had brief presentations by

outstanding junior scientists representing each of the component diseases of the meeting. Each was chosen by the meeting organizers with consultation from the Program Committee. These presentations helped to update all attendees about the current state of the science for each disease as well as showcase work done by some of the best young investigators in the world. This work is summarized in the meeting abstracts (on BoneKEy). At the lunch and dinner venues, which were important parts of the meeting, we had lectures from our federal agency and industry partners. A key goal of the meeting was to not only assess the current state of knowledge, but to outline the various pathways to develop therapies for these disorders. Representatives from NIH, the FDA, and industry made important presentations. Dr. Steve Groft, Director, Office of Rare Diseases, outlined mechanisms by which the Office of Rare Diseases serves to assist patient support groups and investigators. Dr. Matthew Thomas of the FDA outlined the process for getting a disease designated an “orphan disease” and presented information that is critical to getting approval for a new therapy or device for a rare disease. He also outlined potential future developments in this area. Dr. Edward Kaye from Genzyme, Inc. focused his presentation on the critical issue of academic and industry partnerships for rare diseases, a very necessary component for therapeutic advances that arise from the basic work of our scientists involved in rare bone diseases.

The first day closed with *state-of-the-art presentations* by three well-recognized bone scientists, Dr. Bjorn Olsen, Dr. Gerard Karsenty, and Dr. Lynda Bonewald, representing areas of bone development, neural control of bone formation, and the role of the osteocyte, respectively (the presentations are noted in the Abstracts for the meeting).

Plenary Lecture Summaries: Dr. Jeffrey Kelly discussed the emerging field of *proteostasis*, or the maintenance of protein folding in health and disease. This network acts beyond the intrinsic properties of protein structure, which supports its quaternary folding patterns through the extrinsic forces of the proteostasis network. The proteostasis network may play an important role in disorders,

such as Alzheimer’s disease, where protein aggregation is likely important in the pathogenesis (too much protein folding) and loss of function diseases associated with excessive mutant protein misfolding and degradation, such as primary hyperoxaluria type I/oxalosis. Dr. Kelly also discussed approaches to treating diseases of the proteostasis network with small molecule proteostasis regulators, some of which are approved pharmaceuticals at present, and which enhance proper folding of mutant proteins through signaling pathways that control the proteostasis network. As an example a therapeutic approach to osteogenesis imperfecta was given as a target of successful modulation of the proteostasis network.

Dr. Eddy Rubin described work by his group and others to identify *tissue specific enhancers*, which are regulators of spatiotemporal gene expression. Work to date has identified over 500 putative elements and demonstrated that at least 200 of them function as tissue-specific enhancers that effect gene expression. Moreover, over the next few years, his group plans to identify several thousand enhancers. Such work will have important implications for rare bone disorders as we seek to understand phenotypic variability among patients who have the same genetic basis for a disease.

Dr. Garry Cutting used Cystic Fibrosis as an example of *complexity in Mendelian disorders*. Most “single gene” genetic disorders display phenotypic variability that may be unrelated to variation in the disease causing gene. For example, approximately 50% of Cystic Fibrosis patients are homozygous for the D508 mutation. However, within this group, patients have extremely variable disease severity. Twin studies implicate both modifier genes and environmental exposure as playing a substantial role in this variability. Dr. Cutting reviewed approaches and recent successes from the Cystic Fibrosis Modifier Gene Consortium. These studies have identified TGFβ1 as a genetic modifier and have established second hand smoke as a key environmental exposure. This work represents the next frontier in Mendelian genetics and a potential approach for many genetic rare bone diseases.

Dr. Samuel Stupp presented the rationale and several applications for the formation and delivery of self-assembling bio-nanostructures to human disease. Such structures allow precise, often repetitive delivery of growth factors, supporting frameworks, and critical enzymes to groups of cells, a given organ,

or even to the whole body through the bloodstream, in order to correct genetic and structural defects. Dr. Stupp provided examples that included regeneration of axonal structures in neural cord injury and fracture healing.

Following the daytime presentations on October 23, attendees divided themselves into *disease-specific sessions*. Members of these groups consisted of patients, members of the patient support groups and foundations, industry representatives, and clinical and basic researchers. Each group was asked to address the question “what is needed to move your disease area to where it needs to go?” Specifically, what basic and clinical research is needed to assist in the development of new therapies? These groups then reported their findings on the second day of the meeting. These individual disease-based meetings pointed out the vast diversity in the state of knowledge among the rare bone diseases, and could be divided into three groupings. The first group of diseases was represented by diseases where there was 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.

Our third grouping, however, is not so fortunate in that many of the cases have an incomplete picture of the disease manifestations and there is little to no information about their pathogenesis. With little knowledge about the disease and even less about the pathogenesis, the hope for development of therapy is limited, at best. Of note, the single biggest predictor of which category a disease fell into was whether there was a dedicated research group working on the disease and, in the case of emerging therapies, if those groups partnered successfully with industry.

Another critical need that arose for those diseases in one of the first two groupings was the absence of sufficient clinical research to advance drug testing, should it be available. As but one example, there is no generally accepted severity score for X-linked hypophosphatemic rickets and absence of such a way to grade and monitor its severity may hamper Phase 2

and Phase 3 trials of new investigational therapies. This becomes even more apparent when considering diseases for which much less is known. In several breakout groups, participants felt that a patient registry with detailed clinical information was critical to gaining the phenotypic information that is required to better to push the field forward. Realistically, without a reasonably complete understanding of disease manifestations it will be difficult to pursue further research with either animal models or in vitro studies. Additionally, for some disorders, such as melorheostosis (OMIM 155950), it is not clear in all cases as to whether the disease is a genetic or environmentally induced disorder. Development of patient registries may be another area for collaboration between academic physician scientists and patient support groups/foundations. Patient groups may be able to mobilize patients to participate in clinical research studies. Additionally, they may be able to provide critical early funding of registries. It will be important for these groups to work with the NIH Office of Rare Diseases, which has substantial experience in initiating registries for rare diseases, to ensure that the registries are set up to maximize their usefulness to researchers.

On some level the distinction between rare and common disease is somewhat 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 FGF23. Further research has established that FGF23 is a hormone that controls normal phosphate and vitamin D metabolism and that 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. Other examples include research on osteopetrosis, which has enlightened osteoclast biology and work in familial Pagets disease, which has provided insight into the RANK, RANKL, OPG system. Thus, it may be very important to have representative investigators at forums where more common bone disorders are discussed.

The 1st meeting on Advances in Rare Bone Diseases thus represented a partnership of exploration, discourse, and discovery between academic scientists, industry, government and patient groups. We learned of new science outside of traditional bone research that may be very useful, of the current best bone research into processes common to those rare diseases, of the creative aspects of our junior investigators for the diseases, and of the many arenas, both federal and through industry-partnerships, for pathways to drug discovery and development. We learned of the mutual needs for dialogue between patient groups and scientists and how important patient support groups are to the successful development of new therapies not only in providing access to potential study subjects, but in informing both industry and academic researchers what the needs of patients with the disease really are. The attendees left with renewed vigor and capacity to influence the course of research into rare bone diseases. In the future it will be important to have regular Advances in Rare Bone Diseases meetings to highlight those successes, and provide a forum for new, creative venues for understanding mechanisms of disease, and achievement of novel diagnostics and therapeutics.

Experts in Arthritis

Around 200 patients from the Bay area attended Experts in Arthritis: *A Meeting of World-Renowned Health Care Professionals and Researchers For Patients and Their Families* which took place Sunday, October 26, 2008, at the San Francisco Marriott Hotel, during the annual scientific meeting of the American College of Rheumatology.

Jointly organized by the Arthritis Foundation and its Northern California chapter, USBJD, American College of Rheumatology, and American Academy of Pediatrics, participants pointed to the quality of information provided and opportunity for exchange. World renowned experts participated with presentations, as moderators or as panelists in breakout sessions on osteoarthritis, rheumatoid arthritis, and juvenile arthritis.

J. Edward Puzas, PhD, USBJD President and David Fox, MD, President, American College of Rheumatology welcomed participants. Jack Klippel, MD, President and CEO of the Arthritis Foundation moderated the seminar. The plenary session featured Roland Chang, MD, and Amye Leong who explained the importance of

advocacy and encouraged patients and caregivers to become active advocates. Breakout sessions afterwards kept the doctors on their toes with a stream of questions from patients and care givers. Panelists included Neal Birnbaum, MD, Ruben Burgos-Vargas, MD, Stanley B. Cohen, MD, Mieke Hazes, MD, PhD, Maura D. Iversen, DPT, MPH, ScD, Tore K. Kvien, MD, Christy Sandborg, MD, Janalee Taylor, MSN, RN, CNP, Anthony D. Woolf, MBBS, FRCP.

Special thanks for the success of this event are offered to Deborah Jackson, Arthritis Foundation Northern California Chapter, Association of Rheumatology Health Professionals, a division of the ACR, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Philip Le Vasseur – Public Radio Talk Show Host, The Art of Peace, KCSB 91.9 FM.

NBME Musculoskeletal Subject Examination

Using a content outline developed by National Board of Medical Examiners (NBME) staff members in collaboration with a musculoskeletal task force comprised of basic science and clinical faculty from several medical schools, a web-based exam comprised of 75 basic and clinical science items now exists. For more information on the MSK musculoskeletal examination, contact Judith Miller (jmiller@nbme.org).

Thanks!

The USBJD thanks the following sponsors for their generous support of the Decade:



Public Education

Public education provides a vehicle to unite professionals, patients, policy makers and the general public and to promote and facilitate collaboration to improve bone and joint health. USBJD Public Education initiatives afford rich opportunities to partner with other organizations in an effort to form coalitions committed to ensuring continued focus on prevention, treatment and rehabilitation of musculoskeletal conditions throughout the decade and beyond. The focus of the USBJD Public Education committee is to develop programs and initiatives which are sustainable and that will be adopted by partners as part of ongoing educational initiatives.

Fit to a T

More than eighty sessions of *Fit to a T*, the USBJD's public education program on bone health and osteoporosis, were held in 2008, bringing the total number of sessions held to more than 200. Many of the sessions result from our partnerships with the American Association of Occupational Health Nurses, Arthritis Foundation, Business and Professional Women/USA, National Association of Commissions for Women, and the Public Library Association. Members of the American Osteopathic Academy of Orthopedics, American Physical Therapy Association, and the National Association of Orthopaedic Nurses have come forward to present many of these sessions.

A recent addition to program material is *Boning Up*, a publication of the National Osteoporosis Foundation. In 2009 *Fit to a T* will be receiving a fresh coat of paint.

For information on the program, and how to schedule a session, visit www.fit2t.org.



Members of the Red Hat Society in Asheville, NC, receive *Fit to a T* presented by Susan Reece, RN, BSN, CRRN

Young Investigators Initiative – \$20,987,401 in approved grants

Forty seven participants in the USBJD and BJD Canada's Young Investigator Initiative program now report \$20,987,401 in approved funding as a result of their participation in the program.

To learn more about the program and how to apply, please visit www.usbjd.org/rd/?YII.

More than one hundred young investigators have been accepted into the program covering anatomy, chiropractic, dentistry, endocrinology, epidemiology, gerontology, kinesiology, orthopaedics, pathology, PM&R, physical therapy, occupational medicine, rheumatology.

The program does not provide grants, but is aimed at training promising investigators to become successfully funded. Program mentors' commitment to the program is

significant – faculty agree to work with individual participants and to mentor them until they are funded. The multi-disciplinary nature of the program is an important element as participants benefit from the exchange of cross-disciplinary knowledge and experience.

Welcome New Members and Participating Organizations

American Association of Orthopaedic Executives

The American Association of Orthopaedic Executives is an organization dedicated to providing education and resources to orthopaedic practice executives and their staff members. The AAOE is the premier orthopaedic practice management association. Its goal is to identify and provide unmatched peer-to-peer networking and to be recognized for educational excellence for orthopaedic practice executives.

Novartis

Novartis Pharmaceuticals Corporation researches, develops, manufactures and markets leading innovative prescription drugs used to treat a number of diseases and conditions, including those in the cardiovascular, metabolic, cancer, organ transplantation, central nervous system, dermatological, GI and respiratory areas. The company's mission is to improve people's lives by pioneering novel health-care solutions.

Recently the FDA approved once-yearly Reclast® Injection for treatment to increase bone mass in men with osteoporosis. Until now, Reclast®, manufactured by Novartis, has been on the market for treatment of women, and for Paget's disease of bone.

Although often viewed as a "woman's disease", osteoporosis is also an important male health concern and one in four men older than the age of 50 will experience an osteoporosis-related fracture in his lifetime. If a man experiences a hip fracture – the most serious consequence of osteoporosis – he is twice as likely as a woman to die in the following year because of complications.



Faculty and participants at the Young Investigator Fall 2008 workshop.