



BJD GLOBAL NETWORK CONFERENCE: A BRIEF



For the first time in history, a broad-based gathering of musculoskeletal organizations met in the United States. Some 329 delegates from 56

countries attended the annual Bone and Joint Decade Global Network Conference and Patient Advocacy Meeting October 21-24, 2009, in Washington, D.C.

More than 100 Senators, Congressional Leaders and Ambassadors served on the host committee for the conference that brought together musculoskeletal healthcare professionals, patients and patient advocates as well as representatives of BJD National Action Networks plus more than 40 USBJD participating organizations, many represented by their leadership.



Nancy Lane, MD, Stuart Weinstein, MD and Lars Lidgren, MD, PhD

Nancy Lane, MD, and Stuart Weinstein, MD, co-chaired the organizing committee for the high-profile conference, an event hosted by the USBJD and its major undertaking in 2009.

The conference's two primary goals were to raise awareness and advocate for musculoskeletal health, as well as to focus on a future built on the momentum created by the Bone and Joint Decade. Sessions ranged from patient advocacy seminars to

experts discussing advances in prevention, care management, and research, and what now needs to be addressed.

Patient advocacy efforts began on the first day of the conference with a seminar attended by some 80 patients and patient advocates who gathered to discuss how to build advocacy campaigns and develop messages designed to change health priorities.

The next day, healthcare professionals joined patients and patient advocates on Capitol Hill for an authentic advocacy experience. But first, there were training sessions focused on the afternoon's congressional and embassy visits. Key messages delegates were to present in meetings were the need to:

- 1) Increase awareness of the burden of musculoskeletal disease
- 2) Improve access to healthcare
- 3) Increase funding for research, prevention and rehabilitation programs

Congressmen **Charlie Melancon** (D-LA) and **Dave Camp** (R-MI) spoke to participants, as



Senator John Barrasso, MD (R-WY)



Senator Chuck Grassley (R-IA)

BEYOND THE DECADE: A NEW FUTURE

The Decade will continue. So will many of its programs. But after 2010, the global initiative will have a new name.

That was the consensus at the Bone and Joint Decade Global Network Conference (BJD09) in October in Washington, D.C. That plan was further endorsed in December by the USBJD Board members who unanimously agreed that the USBJD should continue beyond 2011.

The Board concurred that an organization that brings together the variety of disciplines concerned with musculoskeletal health, patients and patient advocates, has been and will continue to be particularly beneficial. The Board's challenge now? Develop a business plan based on issues identified by the Strategic Planning Specialty Groups prior to the BJD09 conference. Executive Summaries of this work can be viewed in the conference program (see page 49 on) available online at www.usbjd.org/rd/?BJD09.

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did Former Assistant Surgeon General of the United States, Rear Admiral **Susan Blumenthal, MD.**

At lunch, Senators **John Barrasso, MD** (R-WY) and **Chuck Grassley** (R-IA) addressed delegates. At an afternoon session of *Experts in Arthritis* sponsored by **Congresswoman Anna Eshoo** (D-CA), she spoke to attendees, after which a panel of healthcare professionals answered questions on arthritis from some 100 patients. "The Capitol Hill visits were very timely, given the ongoing debate on health care reform," said USBJD President **Joshua J. Jacobs, MD.** "We stressed the patients' need for access to specialty care, raised the awareness of the burden of musculoskeletal disease, and stressed that investments in research can mitigate the impact of that burden in the future."

The conference was officially opened that evening at a reception offered by the Canadian Embassy, with **Guy Saint-Jacques**, Deputy Head of Mission; **Colin Carrie, MP**, Canadian Parliamentary Secretary for Health; and **Lars Lidgren, MD, PhD**, chair, BJD International Steering Committee.



Guy Saint-Jacques, Stuart Weinstein, MD, Colin Carrie, MP

The world's leading experts in musculoskeletal disease gathered for the conference's third day, speaking on advances in research, prevention and care management developments over the last 10 years, as well as mapping the outlook for future advances. Topics ranged from osteoarthritis, and inflammatory conditions, to back pain, bone health and osteoporosis, and trauma.

Other sessions focused on:

- How advances in treating military casualties lead to civilian applications
- Rehabilitation of victims of last year's earthquake in Sichuan, China
- How the Ponseti International Association used the Decade and online patient networks to expand global awareness of and training in the Ponseti method for treating clubfoot
- How to advance the health policy agenda for musculoskeletal conditions



CPT Raymond O'Donnell, USA



Joshua J. Jacobs, MD

"We had real luminaries in their respective fields," said Dr. Jacobs, "and their presentations of current issues were at a very high level. The conference exceeded my expectations — it was a real shining moment for the USBJD."

The conference also involved strategic planning beyond the Decade. In an exercise led by Dr. Jacobs and **John H. Klippel, MD**, President and CEO, Arthritis Foundation, six multidisciplinary groups of experts from the U.S. and around the world had spent months before the October conference identifying issues, setting priorities for lowering the burden of musculoskeletal disease and developing plans to address each. In the conference's facilitated sessions, delegates worked by condition specialty area to review the groups' draft documents and develop priorities in six areas: arthritis, bone health and osteoporosis, pediatric musculoskeletal conditions, spinal disorders and back pain, trauma and injury, and research.

The day's efforts were capped by an evening of awards and recognition, with **Stephen I. Katz, MD, PhD**, director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, headlining the event. His keynote speech reviewed the Decade's progress and spoke of directions in research.

Dr. Katz spoke of the USBJD's Young Investigator program, which mentors young researchers in multiple disciplines, helping



Stephen I. Katz, MD, PhD

them improve their research strategies and grant applications. "It has clearly been a success," he said, citing the \$35 million in research grants the program has generated so far. Dr. Katz also urged conference participants to collaborate on all these efforts within the U.S. as well as at the global level. For the burden of musculoskeletal disease in the U.S., he said, has been estimated at \$849 billion per year in 2004.



Nicolas Walsh, MD, member of the BJD International Steering Committee, presented awards. **James Waddell, MD**, of Bone and Joint Canada was recognized for achievements by its network in raising awareness and improving access to care through effective musculoskeletal management programs. **Chris Bossley, MD**, (New Zealand), **Professor John Hart** (Australia), **Mr. Toby King** (USA), **Marcos Musafir, MD**, (Brazil), **Ms. Ntombifuthi Pearl Seboya** (South Africa), and **Margaret Smith, PhD**, (Australia) were made BJD Ambassadors for their dedication and achievements in furthering the cause of the Decade. Dr. Jacobs accepted the BJD 2009 International Video Award on behalf of the American Academy of



Nicolas Walsh, MD, Ms. Ntombifuthi Pearl Seboya

Orthopaedic Surgeons for its animated television public service announcement, *"Joints Don't Jump"*.

Finally, in creating a roadmap for the Decade's future, delegates worked in groups by the world's regions to develop a priority issue to be addressed for their region. Group leaders are revising drafts of their original executive summaries which will be edited, then published.

"We set the stage for the next decade," said conference co-chair Dr. Weinstein, "by having strategic planning sessions in the six main topical areas then developing world regional planning sessions. These sessions included all the stakeholders: patients, advocates, healthcare providers, researchers and more."

"As the Decade concludes in 2010," he said, except in the U.S., where it will conclude in 2011, "leaders of the global initiative now have a roadmap for the future."

The conference drew to a close with **Jill Zarin**, of Bravo TV's "The Real Housewives

of New York City," who spoke about her efforts to raise awareness of arthritis on behalf of her daughter and stepson both of whom have forms of the disease, as well as the need to attract more high-profile personalities to do the same.

Armin Kuder, member of the BJD International Steering Committee, outlined plans for the reorganization of the Decade's structure following 2010. He explained it will largely involve a change in the way the international steering committee is formed and run, and proposals for establishing regional committees where there is a need.

Dr. Lidgren concluded the conference with a presentation on next year's BJD Global Network Conference, which will be held September 10-11, 2010, in Lund, Sweden.

In-depth reports for several conference sessions follow this brief summary, and video-recordings of many sessions can be viewed at <http://tinyurl.com/bjdvideos>.

BEYOND THE DECADE: A NEW FUTURE

(continued from page 1)

The Board will decide which USBJD existing programs should continue in light of the organization's mission and issues identified by the planning groups. These include:

- The *Burden of Musculoskeletal Diseases in the United States: Prevalence, Societal and Economic Cost*. A fundamental tool for raising awareness and advocating for bone and joint conditions, the book is also an important resource for investigators.
- Young Investigators Initiative (YII). Thanks to the program, YII participants have already won \$35 million in research funding. The YII committee suggests 4 to 5 more years of effort to establish a strong pipeline of clinician scientists studying musculoskeletal diseases.
- Public-education programs: *Fit to a T* on bone health/osteoporosis and *Experts in Arthritis* are reaching thousands of Americans.
- Project 100: The program to increase instruction of musculoskeletal medicine in medical schools reports that less than 50 percent of schools offered instruction or a clerkship in 2002. Today, nearly 80 percent do.

In the works: The USBJD needs a new name to reflect its new reality and purpose — a group of musculoskeletal-concerned organizations — and to remove "decade" from its title. Among the names considered: Bone and Joint Alliance/Coalition/Network. Bone and Joint USA. Suggestions are welcome.

PATIENT ADVOCACY MEETING

BUILDING A CAMPAIGN: Wednesday, October 21



Patients and patient advocate participants

The seminar's title was "Changing Health Priorities." Throughout the day, 80 patients and patient advocates concentrated on learning to build a campaign and develop strategies for getting their messages across. So with a welcome by **Armin Kuder**, member of the BJD International Steering Committee, and introductions from program organizers **Amye Leong** and **Sara Martin**, the group got down to work.

Create fireworks, Ms. Leong urged. "It's [often] not visibly obvious that you have a musculoskeletal disorder, and there are not enough trained people to treat bone and joint disorders," she said, so patient advocacy is "about creating fireworks, about igniting the information and resources in order to live a full life."

USBJD MISSION

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

How do you do it? “This is all about how to influence situations and agendas, how to craft a message that tells a compelling story,” said **Brian Tjugum** and **John Lotspiech** facilitators with Weber Shandwick. “And it’s about providing outcomes and data to support messages.”

Exercises and interactions designed to show how advocacy works around the world, including the importance of building relationships and alliances, filled the day’s agenda.

Public affairs and advocacy are about aligning agendas, Mr. Lotspiech emphasized. Legislators need to know what you want him or her to do, backed by compelling reasons and data. That may mean explaining cost versus benefit or how a request equates with reducing costs. Or it may mean comparing the prevalence or cost of a musculoskeletal condition with that of other diseases.

A well-formed plan should also include alliances with people or organizations, as well as concerned or affected parties, to further your agenda. Since policy makers can change with different administrations, it’s crucial to build a range of relationships and alliances. Approaching advocacy in a systematic way and sticking to it is the key to an effective effort, he said, citing several case studies.

Fit for Work is a program Weber Shandwick developed for European legislators in Brussels. Another effort, presented by **Chris Bossley MD**, explained how the development of data on burden of disease was used to support a request to the New Zealand government to change health priorities. And **Marios Kouloumas** spoke about efforts by European League Against Rheumatism’s standing committee, People With Arthritis/Rheumatism in Europe (PARE).



Chris Bossley, MD

Challenged by Tjugum and Lotspiech to come up with six advocacy issues considered most important, delegates cited:

- 1) Educating healthcare professionals in the diagnosis and treatment of musculoskeletal diseases
- 2) Changing the paradigm from correction to prevention
- 3) Advancing research
- 4) Expanding access to the best treatment options
- 5) Improving early intervention of children and education
- 6) Making musculoskeletal disease a health priority

It was then delegates set to work developing a plan to address each issue, particularly an overriding concern with educating healthcare professionals. A look at several:

Educating healthcare professionals: Primary care physicians were identified as the main target since getting an early and correct diagnosis allows patients to begin appropriate treatment as soon as possible.

The group’s message: Early identification of diagnoses will reduce unnecessary visits, improve patient satisfaction and psychological conditions, as well as reduce work absenteeism and the burden on families. The benefits: It’s cost-effective for the patient, physician and employer since it requires less medications, less visits and less absenteeism from work. **The proposal:** Create post-training courses and target professional bodies, medical boards or councils, students, government and pharmaceutical companies as well as medical schools where courses would take place.

Correction-to-prevention: The group suggested a shift in funding priorities. They determined that if 90 percent of research dollars are now being spent on correction and 10 percent on prevention, then the ratio ought to be adjusted with 70 percent on research and 30 percent on prevention. **The proposal:** Encouraging patients and doctors to work together to advocate for more research to find evidence-based pathways. They also proposed the CDC and NIH fund a demonstration project.

Advancing research: Numbers to build evidence are crucial. **The proposal:** The group determined that registries and data models, such as the one presented by New Zealand, as a means to prove cost versus benefit.

One element addressed: It was clear from the groups’ work that global applications of the strategies would vary with each country.

Build a grassroots campaign based on a simple, focused objective was the message delivered by **Amy Melnick**, Chief Public Policy Officer, Arthritis Foundation. “Policy makers respond to cost-savings and cost-effectiveness requests,” she reminded delegates, then detailed the expenditure discrepancies between burden and research for musculoskeletal diseases compared with other disease groups.



Amy Melnick

Ms. Melnick outlined the key elements of an advocacy program.

- Work from a simple, focused objective
- Tie it to data and an evidence base
- Align your agenda with your target and form alliances
- Know your stakeholders
- Deliver a compelling story that is both rational and emotional.

To begin a grassroots effort, Ms. Melnick said, involves direct interaction with your elected officials, spontaneous letters and local constituency visits and articles in the local newspaper. It’s one’s duty and right to speak out especially when representing others with the same or similar conditions, she said. To drive home her point, she cited late Speaker of the House Tip O’Neil who once said “All politics is local” and filmmaker Woody Allen who said, “Eighty percent of success is showing up.”

Asked if there is data to prove arthritis leads to a higher incidence of other diseases, Ms. Melnick said the Arthritis

Foundation has such information. She said data show that 50 percent of people with heart disease and diabetes, for example, also have arthritis compared to 20 percent in the general population. So when talking about arthritis, she said, it is important to also talk about heart conditions or diabetes.

The meeting's presentations were recorded and can be viewed at www.tinyurl.com/bjdvideos.

ADVOCACY IN ACTION ON CAPITOL HILL: Thursday, October 22

Nearly 200 patients, patient advocates and healthcare professionals gathered for Advocacy Day on Capitol Hill. Congressmen **Charlie Melancon** (D-LA) and **Dave Camp** (R-MI) as well as Former Assistant Surgeon General of the United States, Rear Admiral **Susan Blumenthal, MD**, addressed the group which then



Congressman Charlie Melancon (D-LA)



Congressman Dave Camp (R-MI)



Rear Admiral Susan Blumenthal, MD

trained for their afternoon visits with members of Congress.

It was, as one participant put it, an “experience that will be with the patients we brought for the rest of their lives.”

It was also, as conference co-chair **Stuart Weinstein, MD**, said in the day’s opening remarks, “the chance to say why we need more research dollars and why we need more prevention activities based on the significant burden of disease.

“Awareness is a theme of this conference, and the main purpose of the conference is advocacy,” he said. “We each have our own individual issues, but today we are working as a team. Patients — and we’re all patients — you are the human face of musculoskeletal conditions. You have a compelling story to tell. But we need to weave those messages into the mission of the Bone and Joint Decade. For it is always important to put ‘I’ behind ‘you’. It’s ‘we.’ We are a team building momentum for the global Bone and Joint Decade, not just our individual causes.”

Health-care reform and its impact on access to care in rural communities were the focus of Representative Melancon’s speech, as well as the challenge of attracting primary care physicians to rural areas for lower pay.

Advocacy, prevention and innovation in health care, were highlighted by Representative Camp when he talked about Congress’ efforts at healthcare reform. “We need to get prevention in healthcare and permit Medicare to innovate,” he said. At present “you need an advocate when you visit the healthcare system.”

Congress is trying to make it more affordable, get more people covered and coordinating care, though Medicare’s current configuration currently doesn’t permit that. And while bringing costs down is very important, he said, it doesn’t mean we cannot continue to support research and that when pursuing advocacy efforts, remember that Washington, D.C. is very much a face-to-face business.

“You heard it from the members of congress,” said **Amy Melnick**, Chief Public Policy Officer, Arthritis Foundation, “Being here is the most important thing you can do.”

Melnick and **Christopher Kush**, author of *The One-Hour Activist*, then worked with delegates to review their advocacy messages prior to meetings with congressional leaders. Three talking points that delegates needed to get

across, said Melnick: Musculoskeletal conditions are costly, common and disabling.

Arthritis is the leading cause of disability in the U.S., she said, the most frequent reason for seeing a doctor and taking a day off work. Sixty-two percent of all bankruptcies are due to bills for medical care; almost 50 percent of home foreclosures are due to the costs of medical care. More than 20 million chronically ill adults (1 in 4) in 2007 went without medical care, she added, and more than half went without a prescription medication because of cost concerns.

The next step? Fine tuning those messages since laundry lists of requests rarely play well in Congress. Government affairs representatives for several Decade organizations had worked together to narrow the focus. The messages:

- 1) Increase awareness of the burden of musculoskeletal disease
- 2) Increase access to healthcare
- 3) Increase funding for research, prevention and rehabilitation programs

“All our meetings today are going to be leading to the same thing,” said Mr. Kush, leading a training exercise. “Members of Congress are going to ask what you want them to do. We have to be clear with our messages.”

Mr. Kush introduced delegates to the “hook, line, sinker technique,” a valuable method for getting your message across when time is limited, as it often is for congressional visits. The “hook,” he said, involves telling who you are, where you come from; the “line” uses a statistic and logical argument — or telling the story of what brought you to the meeting. And the “sinker”? That’s “the ask,” the message that has to be the same for everyone. To demonstrate the technique, patient advocates **Joseph O’Brien, Sara Olsen, and**



Sara Olsen, patient advocate

Martin Egbert “visited” Mr. Kush, who played the role of a congressional leader. First confirming where the visitor is from is essential since geography is important to Congressional leaders. Follow that with why you are there, and then what you want them to do. “Caring is not enough, they have to do something,” Mr. Kush said. “Don’t go off message. Stay on message.”

Global health challenges and the strengthening of health systems were addressed by Rear Admiral **Susan Blumenthal, MD**, who also spoke about key principles behind health-care reform and what needs to be done, cost containment and quality improvement.

Senators John Barrasso, MD (R-WY), and **Chuck Grassley (R-IA)** addressed participants at lunch. In discussing healthcare reform Sen. Grassley said “No Medicare beneficiary with arthritis should lose access to their physician because of the unintended consequences of healthcare reform.”

While delegates made congressional visits throughout the afternoon, 100 patients and their families attended the seminar *Experts in Arthritis*, sponsored and introduced by **Congresswoman Anna Eshoo (D-CA)**. Led by **John Klippel, MD**, President and CEO, Arthritis Foundation, and emceed by **Amye Leong, MBA**, a panel of seven leading expert healthcare professionals answered their questions on advances in treatment, care management, and the outlook for research. Panelists included **David Borenstein, MD, FACP, FACR (USA)**, **Mieke Hazes, MD, PhD (The Netherlands)**, **John Klippel, MD (USA)**, **Girish Mody, MBChB, MD (South Africa)**, **Carol Oatis, PT, PhD (USA)**, **David Pisetsky, MD, PhD (USA)**, **Christy Sandborg, MD (USA)**.



Congresswoman Anna Eshoo (D-CA)

A success? “This was a great experience. Advocacy Day was phenomenal,” said **Joseph O’Brien**, of the Scoliosis Research Foundation. “This experience will be with the patients we brought for the rest of their lives.” Said **Christy Sandborg, MD**, “Preparation for Advocacy Day was excellent. I have done this many times before – this was the best ever.”



Christy Sandborg, MD

Most of the morning presentations were recorded and can be viewed at www.tinyurl.com/bjdvideos.

PLENARY SESSIONS: Friday, October 23

The global burden of musculoskeletal disease, its vast range of conditions and its impact on setting healthcare priorities for the coming years, dominated the remarks by **Anthony Woolf, MBBS, FRCP**, to more than 300 delegates attending the opening of the plenary sessions.



Anthony Woolf, MBBS, FRCP

Musculoskeletal conditions rank highest in studies of chronic diseases and their effect on quality of life, said Woolf, a BJD International Steering Committee member who has researched the diseases’ global burden.

Understanding the current status of the wide range of musculoskeletal conditions and co-morbidities, coupled with the urgency for action, set the tone for presentations by global experts in osteoarthritis, inflammatory conditions, back pain, bone health and osteoporosis, and trauma, who spoke about the burden of disease, advances in research,

prevention and care management developments over the last ten years, as well as opportunities for the future.

How advances in treating military casualties can lead to civilian applications, and the story of rehabilitation of victims of last year’s Sichuan earthquake in China, were presented, as well as a case study on how the Ponseti International Association used the Decade, the Internet and family networks to expand awareness of their efforts around the world.

Dr. Woolf, in speaking on the issue of the burden of the disease, noted that aging is a factor, but data also shows significant impairment of activities in the working population. He talked about age and gender differences of those affected by certain conditions; for example, women are more commonly affected by OA and RA. And he spoke of conditions caused by soft tissue, the effects of trauma, and co-morbidities which are often unrecognized.

And while some increases may be due to people living longer and some decreases may be due to modern technologies such as joint replacement, not all trends are positive. If some trends are an indication of the work we have to do — a 25-year old woman today spends four times as much time watching TV as exercising, and obese children will become obese adults — there is a lot of work ahead.

The message needs to be what can be achieved, said Dr. Woolf, and how do we set our priorities for action over the next few years.

OSTEOARTHRITIS

Osteoarthritis affects more people than any other musculoskeletal condition, said **Linda Sandell, PhD**, session leader for the osteoarthritis panel, and needs to be diagnosed long before joint replacement. She cited Dr. Virginia Kraus, who she says



Linda Sandell, PhD

believed total joint replacement of “OA is a heart attack of the joint,” which some are now calling a “joint death.”

Considering there were 600,000 “joint deaths” in the U.S. in 2002 (94 percent because of OA), compared with 451,326 coronary heart deaths in 2004, the focus has to be on how we identify the onset of OA compared with how the onset of other diseases are identified. Better diagnostics, MRI diagnostics and biomarkers provide some new methods. And we need to push radiographic diagnosis at the time of joint failure back towards onset when we can look at it molecularly, a point underlined by **Steve Abramson, MD**, in a later presentation on future directions.



Steve Abramson, MD

Joanne Jordan, MD, MPH, another panelist, pointed out that 27 million Americans had OA in 2005, up from 21 million in 1995. OA is the highest cause of work loss. And it is frequently co-morbid with diabetes and heart disease, which makes it much harder for people with those conditions to adhere to prescribed exercise regimens. These diseases may be much less prevalent than OA, but receive more attention and more research dollars.



Joanne Jordan, MD, MPH

Risk factors, including genetics, aging, obesity, joint injury, occupation and diet, all have an impact. Most importantly, increased OA due to aging and obesity

will have significant impact on direct and indirect costs.

The time for prevention is now, emphasized **David Hunter, MD**, because we know the risk factors and several of them (obesity and injury) are modifiable. Our increasingly obese populations present challenges, both from a policy perspective as well as clinically. The U.S. Surgeon General sees it as one of the most important mandates of their position.



David Hunter, MD

There is an opportunity for synergy with diabetes, heart disease, hypertension and other metabolic syndromes, he said. The numbers tell the story: Of 125 million Americans with chronic diseases, it is estimated that 48 percent have at least one co-morbidity; 62 percent of persons 65 years of age and over have two or more chronic illnesses. For those with OA, 65 percent are overweight or obese, 40 percent have hypertension, and 15 percent have diabetes.

These co-morbidities compound management challenges and are frequently ignored in current management approaches. If we can tackle obesity together, he said, we can prevent about 80 percent of percent of osteoarthritis.

There needs to be a shift from symptomatic treatment to a focus on prevention and disease progression. There are opportunities for non-pharmacologic modalities in managing the disease, but they are not being used as much as they could be. There have been lots of recent guidelines with merit about how best to manage OA, but like many other conditions there is little if any relation between what is advocated in a guideline and what is actually practiced.

We know what needs to be done, he said, but at this point there is little action.

There's a need to forge ahead on alternatives to joint replacement, said Dr. Abramson. “Look back 100 years. I would argue, that

absent total joint replacement, we haven't made a significant impact on treatment of OA,” he said. “As the curves get worse, what are we going to do to bend the curve, to do better and get ahead of the curve?”

He urged that in the next Decade, we move towards a better understanding of OA phenotypes, better biochemical markers, genetic understanding and advances in MIT and strategies for tissue repair. We need, he said, to understand molecular mechanisms at earlier stages of disease onset.

We need, he concluded, safer more effective analgesia, genetic and biochemical determination of risk for progression, functional imaging studies of disease activity, molecular targeting for early intervention, microsurgical intervention and cellular tissue repair.

INFLAMMATORY CONDITIONS

Early diagnosis of inflammatory forms of arthritis is the direction that healthcare needs to take, now that improved treatments and strategies exist, according to members of the panel chaired by **David Pisetsky, MD, PhD**.



David Pisetsky, MD, PhD

Because effective treatments and treatment strategies are available to reduce inflammation and stop disease progression, **Mieke Hazes, MD, PhD**, emphasized, it's essential to seek earlier diagnoses.

Rheumatoid arthritis (RA), a multi-systemic disease, is the most prevalent of the inflammatory forms of arthritis presented by the panel. This disease affects 23.7 million people worldwide (WHO, 2004), according to **Michael Ward, MD, MPH**, with incidence increasing with age.





Work disability occurs in 21 to 71 percent of patients after 10 years of disease duration. Mortality ratios are 22 to 69 percent higher among RA patients than controls. Dr. Ward also provided figures for juvenile idiopathic arthritis, spondyloarthritis and gout.



Michael Ward, MD, MPH

Because we understand the pathogenesis of RA better now, said **Clifton Bingham, MD**, we have moved to a point where we can intervene to treat the disease and induce remission. Involved with ACR and EULAR efforts to establish criteria to diagnose RA so it can be detected in its very early stages, Bingham has tried working with primary care physicians to enable earlier detection since cardiovascular disease, malignancy, infection, fatigue and anemia are now recognized co-morbidities. Equally important: It is now recognized that there is an association between RA and cigarette smoking.



Clifton Bingham, MD

The longstanding “Go low, start slow” theory, said Dr. Bingham, has now been changed to early aggressive treatment regimes. Thought leaders have moved from the gradual use of agents to a paradigm based on prompt treatment using objective measures of disease activity to achieve a state of remission as early in disease as possible. Early therapy is key

to improved outcomes, including helping people return to the workforce sooner. Among the issues that need to be addressed is a critical shortage of pediatric rheumatologists. Also ongoing is research that centers on risk/benefit and cost/efficacy analysis.

Dr. Pisetsky cited a decade of unprecedented growth and success in the treatment of inflammatory arthritis, with remission rates in RA approaching 50 percent. But current approaches are very costly and raise questions about long-term safety and efficacy. Access to treatment can be limited because of cost and restrictions on use. These issues lead to the question about better defining and maintaining remission. Dr. Pisetsky also noted there are still a significant number of patients not in remission with current treatments.

One of the advances in this area is called theranostics, a new strategy that seeks to design the best therapy from the hundreds of ways to treat RA and other inflammatory diseases. In fact, a systems approach to medicine needs healthcare providers to look at strategies in a fundamentally different way. But to confirm this strategy’s effectiveness, you need to look at large populations, including those with co-morbidities.

“The only way we’re going to find out, for inflammatory diseases, what is the best approach is to begin to look in the real world as opposed to the clinical trial setting,” said Dr. Pisetsky, “and begin to get an effective strategy for use of these agents. To develop systems approach, we need cooperation. We need to train people to think in different ways.”

BACK PAIN

On average 4 to 5 percent of all healthcare visits in the U.S. are for back pain, said **Gunnar Andersson, MD, PhD**, as he presented back and neck pain prevalence figures. But these figures are understated, he said. He cited several factors that support this: While



Gunnar Andersson, MD, PhD

total prevalence has not shown a significant increase, the number of physician visits has. More than any other condition, people report low back and neck pain limits their ability to walk or work. Spine procedures have increased gradually in the U.S. And spinal fusion is now the most common inpatient procedure in the U.S. and has been gradually increasing over the last nine years. More disturbing? The cost has increased dramatically in the same period, mainly due to use of more devices and biological factors.

Edward Yelin, MD compared characteristics of persons with spine conditions and cost with those of other musculoskeletal conditions and the U.S. population as a whole, and the effect on the overall economy. The proportion of people reporting spine conditions increased by 19 percent between two 3-year periods (1996-98 and 2002-04) while the population increased 7 percent in those same periods. By comparison, patients reporting non-spine



Edward Yelin, MD

conditions increased by only 13 percent (or 15 percent for all musculoskeletal conditions). Of those with spine conditions, 78 percent were 18-64 years of age, prime working ages, compared with 61.7 percent for non-spine-related conditions. The largest increase in the cost of treating spine care between the two periods was for prescriptions, which nearly doubled in both number and cost of prescriptions. Spine costs between the two periods increased 49 percent to treat spine conditions, compared with 38 percent for non-spine musculoskeletal conditions or 42 percent for all musculoskeletal conditions. There was also a significant increase in annual growth of the number of non-MD visits.

To put this in perspective, Dr. Yelin noted that direct costs of musculoskeletal diseases represented 4.4 percent of U.S. GDP by the second period, an increase of 33 percent over the six-year period. Spine conditions represented 1.7 percent, up 42 percent over the period, and non-spine conditions 2.5 percent, a 19 percent increase.

In terms of earnings losses, spine problems cause less absenteeism. Dr. Yelin summarized by combining direct and indirect costs, which show that spine conditions account for 2% of GDP, mostly direct costs, non-spine just over 5 percent, and all musculoskeletal conditions nearly 8% of GDP.

Boyd Buser, DO, FACOFP, reported that 50 to 69 percent of back pain patients use complementary and alternative medicine (CAM). Manual therapies are increasingly used to treat the spine, typically practiced by osteopaths, chiropractors and physical therapists. The evidence base needs further development, he said, and further regulation is needed for appropriate use and patient safety. Guidelines are being produced by several world bodies, including the WHO.



Boyd Buser, DO, FACOFP

Scott Boden, MD, set the stage for the future by first presenting challenges still faced today. They include detecting the source of pain, evaluating treatments

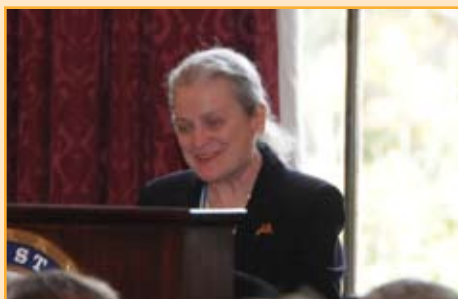


Scott Boden, MD

and the effect of psychosocial factors. Expect further development of two innovations: minimally invasive surgery and bone graft substitutes. He spoke about opportunities and drawbacks to spine fusion, motion preservation and gene therapy. Future opportunities, he said, lie in improved diagnostics, evidence-based testing on non-operative treatments, long-term comparisons of fusion versus motion preservation, and biologic solutions to prevent, delay or reverse age-related disc changes.

BONE HEALTH AND OSTEOPOROSIS

Focusing on global epidemiology and the challenge of osteoporosis, **Ethel Siris, MD**, drew attention to the fracture as the sentinel event in osteoporosis and the need for a standard of care.



Ethel Siris, MD

Some 200 million women worldwide are thought to suffer from osteoporosis, she said, 8 million women in the U.S. alone, and 2 million men. Another 34 million are thought to have low bone mass. Yet a diagnosis of osteoporosis or vertebral fracture is made by fewer than 2 percent of primary care physicians, and only around one third are given drug therapy despite the fact that good treatments are available.

A bone density test? Only 20 percent of U.S. patients who should have one are getting it. Other figures Dr. Siris presented should be of concern to all: 20 percent of people suffering from a hip fracture will die within one year. 30 percent will have a permanent disability. 40 percent will be unable to walk independently. And 80 percent will be unable to carry out at least one independent activity of daily living.

These statistics need not be the case. "We can actually do quite a bit to prevent a fracture from taking place," she said. "There's a gap between what we know and what we're doing.

"We should know better," she added. "We have the science, we have the understanding, we know what's wrong, we know how many people fracture, we know what it costs, we have ways of addressing it, and there's a gap between what we know and what we're doing."

For example, she said, relatively few individuals follow the recommendations related to the amounts of physical activity, calcium and vitamin D that are needed to maintain bone health. Several studies suggest that awareness of risk factors is low and when medical treatment is prescribed, adherence is terrible, reducing the opportunity to reduce the burden of fractures.

The cost of treatment is substantial, \$12-\$18 billion a year. Those with osteoporosis and low bone mass in the U.S. are expected to grow from 43.7 million in 2002 to 52.4 million in 2010, and to 61.4 million in 2020. Worldwide, the problem is not much better. In 1950, there were 1.66 million hip fractures; in 2050 it is projected that number will jump to 6.26 million.

The biggest problem today, Dr. Siris said, is a lack of awareness of bone disease by the public and health care professionals, both of whom do not understand the magnitude of the problem or the ways in which bone disease can be prevented and treated.

It's also about congenital or acquired disorders of the bone such as Paget's disease, and osteogenesis imperfecta. They affect substantial numbers of people but physicians are often unaware of the clinical manifestations or means of diagnosing, treating, preventing timely introduction of management of the disease. In fact, physicians frequently fail to diagnose and treat osteoporosis even in patients who have suffered a fracture.

"Let me say loudly," she said, "a fracture is a sentinel event, and coordination between those who repair fractures and those who manage the patient to prevent the next fracture is a critical need.

"If you fail to do the right thing for your patient," she said, "you're a bad doctor."

Future directions in osteoporosis were presented by **Sundeep Khosla, MD**, who cited better identification of patients who



Sundeep Khosla, MD

could use pharmacological therapy, new approaches to bone loss, the need to customize treatment plus which drugs to use and when.

While DXA is the key for diagnosing osteoporosis, he said, it does have limitations. There are currently in vivo techniques available to assess bone structure, including Central QCT, high resolution peripheral QCT and MRI, which provide important information on changes in bone structure and show promise.

There is also great potential in formation stimulating drugs and an enormous amount of interest in the bone field in Wnt signaling. The study of the effects of inhibiting the SOST protein holds tremendous promise for the future as a new approach to reverse bone loss. With a host of available drugs now, the questions are which drug when, what combinations, in what sequence, and for what duration as well as whether or not there should be drug holidays.

A global perspective was provided by **Kristina Åkesson, MD, PhD**, who highlighted the disparity in aging trends around the world as well as prevention and treatment needs. This, in turn, reinforced the need for sub-regional approaches, preventative care systems to be accepted and practiced, plus better fracture management without forgetting



Kristina Åkesson, MD, PhD

that a vast increase in people over age 65 is expected by 2025.

TRAUMA

In the last few years road traffic deaths rank number one and have surpassed deaths from HIV in the 15-29 year age group, said **Bruce Browner, MD**, who provided an overview of the burden of traumatic conditions.



Bruce Browner, MD

In a WHO survey of 178 countries published in June 2009, 1.27 million deaths per year due to vehicle crashes were reported. And 91 percent of road deaths occur in countries with only 48 percent of the world's registered vehicles. The U.S. is the third highest country with road deaths.

A WHO report predicts that road traffic crashes, currently in 9th place and a leading cause of disability adjusted life years, will move to 3rd place by 2020 and hold a similar position until 2030. Many people killed and injured are of working age. The financial impact is approximately \$500 billion. The annual loss (\$100 million) in developing countries is twice that of all the accumulated development assistance they have received.

Prevention still has a long way to go, he said, with many countries still without alcohol limits and enforced helmet and seat belt use. "We have to care more. We have to react the same way we have with disasters like the tsunami or Hurricane Katrina in the U.S.," Dr. Browner said. "There is a real parallel between those with HIV/AIDS and road traffic injuries. We waited too long with AIDS, let it get out of control."

Ambassador Al-Hinai explained how the Decade was instrumental in bringing road safety to the attention of the United Nations. Now, there is a movement and in February 2010, the UN announced the next decade "A Decade of Action on Road Safety." A baseline of reports on road safety has been developed during the past decade, and more will come at upcoming

global conferences including the first ministerial meeting in Moscow. Overall there is a need for political will, he said.

Nancy Carter-Foster of the U.S. State Department highlighted the importance of governments as facilitators in correcting infrastructure and increasing cooperation among countries.



Nancy Carter-Foster

The devastating earthquake in Sichuan, China, mobilized the orthopaedic community to rehabilitate victims in a project titled "Stand Tall." **Kai-Ming Chan, MD**, presented a heartrending video of the determination and progress of earthquake victims as a result of the "Stand Tall" program. The video and news of the program can be viewed at www.standtallchina.org.



Kai-Ming Chan, MD

PATIENT ADVOCACY: A Success Story

Using the Decade as a springboard, the power of the Internet and parental/patient networking resulted in a patient advocacy movement that changed the world of club foot treatment, said **José Morcuende, MD**.

The number of physicians and allied healthcare workers throughout the world trained in the use of the Ponseti method to treat clubfoot has significantly grown over the last seven years, he said, and the Ponseti International Association has become a hub of information and knowl-



José Morcuende, MD

edge exchange between patient families and trained healthcare providers.

ADVANCING AN AGENDA: MSK and health policy

Where is the wisdom in health care? That's what **James Weinstein, DO, MS**, asked in opening the session on how to advance the health policy agenda for musculoskeletal conditions.



James Weinstein, DO, MS

He listed a litany of issues: Poor quality of health care, a rising number of uninsured, spiraling costs, patient and societal expectations, the business of health care, the politicization of health care, loss of physician autonomy/specialization, and legal problems.

The U.S. GNP is currently at \$12 trillion and projected to grow at 3 percent per year, while healthcare is costing \$2.7 trillion and projected to rise by 7 percent per year. The dilemma, he said, is that the specific aims of healthcare reform are not clear enough. There is inadequate evidence on treatments and their effectiveness. The public incorrectly assumes that more health care is better, and there are flawed incentives for payers, providers and patients leading to rewards for volume, not value.

Adding to the confusion is a tremendous disparity in how health care is given, he said. Such variations cause potential

problems, particularly in health care, he said, then spoke about the variation in the cost and delivery of procedures by different institutions. And he spoke of care that is important but often not delivered, and care that is delivered but is often not important.

In talking about disparities in spending on healthcare, Dr. Weinstein stated that there can be a three-fold difference in the cost of similar procedures across the country. And mortality is actually higher in regions where the intensity of care is higher.

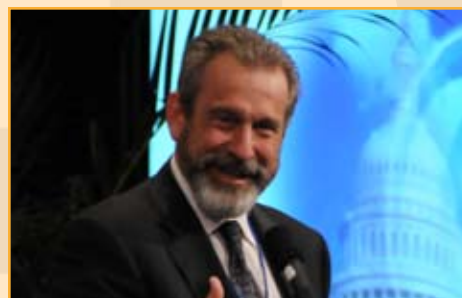
In other words, he said, patients are at greater risk of dying in regions where the healthcare system delivers more supply-sensitive care. He referred to Atul Gawande's article in *The New Yorker* in which he compared care provided in McAllen and El Paso, Texas. For a patient in the United States, geography is destiny, he said, with no better outcome.

Currently, low-cost regions, where providers are relatively efficient, are subsidizing relatively inefficient providers in high-cost regions. Outcomes tend to be better and costs lowered, he said, when patients participate in decisions about their care through "informed choice", rather than informed consent.

"There's very little measurement in health care. We're flying the healthcare airplane without instruments," he said. "Most of us can't tell you how our practice [is doing] and what our patients outcomes are. I don't think that's acceptable moving into the future."

BEYOND THE DECADE: Friday, October 23

Mapping a road to the future was the focus of Beyond the Decade sessions opened by **Joseph Zuckerman, MD**, president of the American Academy of Orthopaedic Surgeons. "The Decade's going to officially end, but the problems don't end with that," he said. Highlighting the accomplishments that have already been made possible by bringing all stakeholders together, he said, "The work



Joseph Zuckerman, MD



that takes place today will be instrumental in developing what happens over the next Decade."

The focal point of the day's efforts: ensure musculoskeletal disease and disabilities get the attention they need now and into the future.

"We now get to work," said Dr. Joshua Jacobs, USBJD President. "Today has been phenomenal. We understand where the gaps are and the knowledge. We're going to build on this base of knowledge of where the gaps are. Now we're going to ask each and every one of you to help us plan for what's going to happen beyond the Decade."

"We've created some tremendous momentum with the programs we've established, but there's much to be done. The future is going to be decided by what we decide," he said, explaining six groups would concentrate on strategic areas: the burden of disease, public and professional education, prevention, intervention, research plus the cross-cutting themes of advocacy and diversity.

Brian Tjugum and John Lotspiech of Weber Shandwick facilitated the strategic planning sessions in which delegates worked by condition specialty area then world region, reviewing issues working groups had identified prior to the conference. Their working documents are included in the Program Agenda which can

be viewed at www.usbjd.org/rd/?bjd09 (see pages 49-171).

Specialty working groups covered:

- arthritis
- bone health and osteoporosis
- pediatric musculoskeletal conditions
- research
- spinal disorders and low back pain
- trauma and injury

ARTHRITIS GROUP

A robust document prepared by the arthritis specialty group prior to the conference was largely endorsed at the session which was chaired by **Christy Sandborg, MD, Eric Gall, MD, and Anthony Woolf, MBBS, FRCP**. Their challenge? Addressing the differences in issues between the U.S., developed and less-developed countries.

Promoting awareness to address the lack of understanding about opportunities for prevention and treatment is a primary goal and a message that needs to reach the public, patients and policy-makers, as well as professional and non-professional organizations. It is vital that more patients become involved. Action items were identified.

Priorities include access to care and work force issues. More has to be done to increase interest in the rheumatology and pediatric rheumatology specialties as a way of addressing shortages, with the USBJD a valuable resource.

Also discussed: Increasing the emphasis on prevention, early diagnosis and treatments that exist but are not well known; employing a “pull” strategy that could create patient demand; establishing guidelines. Increased research needs to be more in line with the burden of disease, especially in the areas of



epidemiology, outcomes and comparative effectiveness.

Combining the efforts of BJD organizations coupled with an international coordinating organization, the group concluded, would ensure sustainability, the sharing of resources and cost reductions.

BONE HEALTH AND OSTEOPOROSIS

The pivotal role fractures play was addressed by the session chaired by **Steven Goldring, MD**, assisted by **Ann Elderkin, PA** and **Kristina Åkesson, MD, PhD**. While four priorities were identified in the pre-conference document, three primary challenges were pinpointed by the group. They are:

- a) Preventing secondary fractures. All providers need to recognize an initial fracture as a sentinel event and act together to provide treatment and follow-up.
- b) Providing accurate data that is localized to geographical areas.
- c) Elevating consumer awareness of risk factors for men and women.

By 2020, systems should be in place so that a fracture would initiate a pathway of care, adapted for different countries. Logistics for the continuum of care, outcomes measurement, and making bone health a healthcare priority, need to be developed. The U.S. now has a good basic structure with which to move forward.



Delegates were told that the U.S. National Action Plan on Bone Health and Osteoporosis has formed a Steering Committee and four priority working groups.

- 1) *Best Practices in Systems-Based Interventions to Reduce the Burden of Fractures* will be the subject of a 2010 meeting.
- 2) The Bone Coalition (ASBMR, NOF, Paget Foundation, IOF, AAOS) had the Bone Health Promotion and Research Act introduced into Congress in October. It is an authorization bill, requesting the establishment of a National Bone Health Program at the Centers for Disease Control and Prevention, an Osteoporosis and Related Bone Disease Advisory Committee, expanded research activities at the National Institutes of Health, and grants and cooperative agreements for the collection, analysis and reporting of data on osteoporosis and related bone diseases. A Congressional briefing was held in May on the National Action Plan.
- 3) A task force of organizations is working to get DXA language included in healthcare reform legislation.
- 4) A survey of public health departments will be undertaken to assess their current resources.

PEDIATRIC MUSCULOSKELETAL DISEASES

Healthy Lifestyles is the centerpiece of efforts at the session chaired by **Paul Caskey, MD, Paul Esposito, MD, and Peter Brooks, MD**, a priority developed in the pre-conference work. Numerous groups are already working on this, but



Christy Sandborg, MD, Eric Gall, MD, and Anthony Woolf, MBBS, FRCP



coordination is crucial to avoid duplicating effort.

For infectious diseases, developing uniform guidelines is the major goal. For chronic diseases, the focus should be on diet, supplements and exercise with a tie-in to the healthy-lifestyle discussion. For specific disorders, standards of treatment (such as those for the Ponseti Method for clubfoot) are needed and there is support for developing registries of specific disorders.

The value of involving patient advocates worldwide can be very influential in these efforts.

RESEARCH

Charged with looking at the broad spectrum of research (not specific conditions) the session chaired by **David Burr, PhD**, and **Jane Aubin, PhD** focused on three points:



David Burr, PhD



- The need to translate information about basic research into clinical research, in part through comparative effectiveness studies, and linking this to health-care delivery and advocacy, as well as considering the importance of research into rare disorders.
- Training graduate students and postdoctoral fellows, as well as making research part of the educational process so more students are attracted into research. A lack of stable funding was noted; materials should be developed with global usability.
- Advocacy, with increased public awareness a large component.

On steps that can be taken in the U.S., the following was determined: Begin creating networks of consortia, cut across basic, clinical and translational areas to generate informational transfer; emphasize musculoskeletal research earlier in schools; assess outcomes by developing metrics to define clinical impact and the likely results of increased research funding.

SPINAL DISORDERS AND BACK PAIN

Developing bone and joint guidelines for managing spinal disorders (including deformity) that are multidisciplinary and patient-centered, plus establishing an infrastructure for multidisciplinary collaboration on research



and education was the focus at this session, chaired by **Sigurd Berven, MD**, and **Nicolas Walsh, MD**. Goals identified prior to the conference, they felt, were too ambitious.

In their discussions participants also identified the importance of obtaining burden of disease data; agreement on definitions; developing outcomes measures on spine care; how to help globally where little spine care is available, perhaps by distance learning.

TRAUMA AND INJURY

Chaired by **Andy Pollak, MD**, and assisted by **Eric Farrell, MD**, the overriding priorities of the group were identified as road traffic crashes, and more research into the prevention and treatment of fragility fractures and improving outcomes. Road traffic crashes have been a BJD priority and will continue to be addressed. Extremity war injuries, and



Andy Pollak, MD



Eric Farrell, MD

repetitive use disorders, had also been identified by the working group prior to the conference.

Beyond the Decade Follow-up

At the December Board meeting, group chairs reported to the USBJD Board and are currently revising the Executive Summaries based on discussions at the conference. They will be published as a single paper. In the coming months, groups will be invited to continue the winnowing process to select the top priority issues that the USBJD will focus on moving forward.



The USBJD thanks Mark Wieting and Eric Gall, MD, who took many of the conference photographs in this newsletter.

MEMBER NEWS

Moving is the Best Medicine

The Arthritis Foundation and the Centers for Disease Control and Prevention (CDC) have announced the National Public Health Agenda for Osteoarthritis, a major initiative to reduce the impact of osteoarthritis on Americans. In conjunction with the announcement, the Arthritis Foundation, the Ad Council and the American College of Rheumatology have launched a new national public awareness campaign "Fight Arthritis Pain" showing those living with osteoarthritis how "moving is the best medicine".



One in five adults in the United States (46 million people) has arthritis; an estimated 67 million will be affected by 2030.

A combination of inactivity, obesity, injury and the aging of Americans, the prevalence of osteoarthritis is expected to escalate the severe health and economic effects of this disease.

"Now is the time that we as a nation must invest our resources in the prevention of osteoarthritis," said **John H. Klippel, MD**, President and CEO of the Arthritis Foundation. "This Agenda and the new public awareness campaign will dispel the myth that osteoarthritis is an inevitable part of aging."

The multi-media campaign directs Americans to visit a new website, www.fightarthritispain.org, which features a risk assessment tool for osteoarthritis, movement tracker, live news feed, community forums and blogs, program and event locator, as well as campaign materials.

Pediatric Musculoskeletal Medicine CME Courses

The American Academy of Pediatrics is offering two opportunities for Pediatric Musculoskeletal Medicine CME study.

ONLINE Pediatric Musculoskeletal Medicine: Differential Diagnosis and Assessment of a Limping Child runs from Oct 20, 2009 to Oct

20, 2012. Register at www.pedialink.org/cme/mskdd.

ONSITE Practical Pediatrics CME Musculoskeletal Medicine Course, Sept 3-5, 2010 (Labor Day Weekend) in Washington, DC. Early Bird Rates until Aug 6, 2010. Register online at www.pedialink.org/cmefinder or call 866/843-2271.

New Executive Director and CEO Announced for National Osteoporosis Foundation

The National Osteoporosis Foundation (NOF) has named **Amy McGuire Porter** the new Executive Director and CEO of the Foundation. Ms. Porter joins NOF with more than 20 years experience in the nonprofit sector. Porter's most recent position was as Executive Director of the Foundation for the National Institutes of Health. She has played key roles in executive, communications and development positions, working to further the missions of many forward thinking and visible institutions in the D.C. area.



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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:

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