Bone and Joint DECADE AMERICA

Newsletter

Published for Friends of the Decade

VOLUME 4, ISSUE I April 2002

President Signs BJD Proclamation

Rosemont, IL (March 27, 2002) -- President Bush has issued a proclamation designating the years 2002-2011 as National Bone and Joint Decade.

"I call upon the people of the United States to observe the Decade with appropriate programs and activities; and I call upon the medical community to pursue research in this important area," the President states in the proclamation.

"National Bone and Joint Decade, 2002-2011, envisions a series of international initiatives among physicians, health professionals, patients and communities, working together to raise awareness about musculoskeletal disorders and promoting research and development into therapies, preventative measures and cures for these disorders. Advances in the prevention, diagnosis, treatment and research of musculoskeletal conditions will greatly enhance the quality of life of our aging population."

The President recognized the efforts of federal agencies such as the National Institutes of Health, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, as well as in industry and private professional and voluntary agencies engaged in research in this area.

"Thanks to the hard work of these dedicated researchers, we have made great progress in understanding and treating musculoskeletal disorders," the President says. "I commend their efforts and encourage them to pursue diligently further research that will help those suffering from these disorders."

The full text of the proclamation is found in the Federal Register March 26, 2002, and at the White House Web site at http://www.whitehouse.gov/news/releases/2002/03/20020325-5.html.

"This is a tremendous boost to our ongoing efforts to reduce the burden that musculoskeletal conditions place on society," said Stuart L. Weinstein, MD, from Iowa City, IA. Weinstein is chair of the National Action Network for the Bone and Joint Decade in the United States.

"The economic impact has been estimated at more than a quarter of a trillion dollars each year, and the human impact is equally enormous. The musculoskeletal system gives us support and the power to move. When things go wrong, people are in pain and their lives become limited. The goal of the Bone and Joint Decade in the U.S. is to keep people moving, to enjoy fuller lives."

The National Action Network of the Bone and Joint Decade in the United States is made up of 59 patient and physician health care organizations, and is led by a Steering Committee. Efforts are now focused on building projects and activities that will ultimately reduce that burden.

"The Decade will emphasize education, prevention and research, and we intend to help empower patients to participate in decisions about their musculoskeletal care," said Weinstein.

"Worldwide, 38 national governments have endorsed the Decade, and more than 750 organizations, health ministries, medical groups and journals have signed the declaration of support," he continued. "With the world's aging population, musculoskeletal conditions will increase, so our program of education and research will have an impact around the world."

The global Web site for the Decade is www.boneandjointdecade.org and the U.S. site is www.boneandjointdecade.org/us.

The U.S. Web site details why the Decade is important and itemizes the burden of disease data.

(continued on page 2)

Inside this issue:

Web Site Offers Support	2
10 Ways to Spread the Word	3
National Consensus Conference	3
Nominations Sought for Honors	3
Message from the US BJD Chair	4
About Us	4
Contact Us	4

Web Site Offers Support, Peace of Mind

An elderly couple is lying in bed one morning after a good night's sleep. The husband grasps his wife's hand.

"Don't touch me!" she insists.

"Why not?"

"Because I'm dead."

Confused, the husband asks, "What are you talking about? We're both lying here in bed together and talking to one another."

The wife replies, "No, I'm definitely dead."

Her husband insists, "You're not dead. What in the world makes you think you're dead?"

His wife answers, "I know I'm dead, because I woke up this morning and nothing hurts."

By sharing humor that is, unfortunately, all too easy to relate to and important information on hip replacement surgery, the members of Totally Hip have forged a unique bond, made possible by modern technology.

Totallyhip.org, created by Linda May-Bowser, is an online support group for individuals with hip and joint problems. What began as a single sub-page of the "Bowser Family Web site" has grown into a comprehensive network of message boards, photos, personal stories and educational resources.

"The sole objective of the Web site is to help calm the fears of others in need of support and offer information regarding their hip problems," said May-Bowser. "I started the site while recovering from my second hip surgery in December of 1996," she continued. "I ran out of things to post about my family and decided to write a page about my surgery. After six other hip patients e-mailed me, we decided to call ourselves a support group."

Five years and many informative pages, links and message boards later, the Totallyhip.org Web site counter is nearing the 450,000 mark, thanks primarily to word-of-mouth publicity.

"In the beginning, I tried to keep a count of the number of site members, but it didn't take long to realize that would be an impossible task," said May-Bowser. "That number is well into the thousands."

A visit to Totallyhip.org will yield a wealth of information from first-hand accounts of surgery, to recommended reading lists, to message boards for doctor referrals, supportive messages and even sharing jokes.

The majority of site visitors are patients with hip problems who have benefited from Linda's personal story, as well as the reassurance of other site members. These users continually contribute to the growth of the site by submitting stories and tips for coping with joint replacement to support others facing the surgery.

Although keeping up with the ever-growing site can be time consuming, for May-Bowser it's a labor of love that is easier and more rewarding every day. She realized the most tangible reward a couple of years ago when her outdated computer showed signs of slowing. Totallyhip.org members came to the rescue. In only six short weeks, she received enough donations to fund a new computer, monitor and programs to keep the site up and running.

"It was a true miracle!" she said. "I never realized I'd be able to touch so many lives from the little computer in the corner of my bedroom."

For more information, visit www.totallyhip.org.

TMJ Association to Sponsor Meeting

The TMJ Association is sponsoring a scientific meeting on temporomandibular joint diseases and disorders entitled "Joint and Muscle Dysfunction of the Temporomandibular Joint." The event will take place May 6-8, 2002 at the Federation of American Societies for Experimental Biology (FASEB) Conference Center in Bethesda, Maryland.

For additional meeting details, please visit www.tmj.org.

Bush Proclaims 2002-2011 National Bone and Joint Decade

(continued from page 1)

"The U.S. steering committee, leading the U.S. National Action Network, have recently created the United States Bone and Joint Decade, Inc., a not-for-profit corporation to move this work forward."

Organizations forming part of the Bone and Joint Decade in the United States and represented on the Steering Committee include the American Academy of Orthopaedic Surgeons, American Academy of Physical Medicine and Rehabilitation, American Chiropractic Association, American College of Rheumatology, American College of Rheumatology Research and Education Foundation, American Osteopathic Association, American Physical Therapy Association, American Society for Bone and Mineral Research, Arthritis Foundation, National Athletic Trainers' Association, National Osteoporosis Foundation, Orthopaedic Research and Education Foundation, Pediatric Orthopaedic Society of North America, Shriners Hospitals for Children, and United Cerebral Palsy Research Foundation.

10 Ways to spread the word … *grease those joints!*

The Bone and Joint Decade provides an opportunity to advance many of our organizational goals. Here are 10 ways you can help spread the word to your own members, clients or other target publics.

1. Print the BJD logo in publications, on brochures, on letterhead, or meeting banners.
2. Include a BJD logo slide in audio/ visual presentations.
3. Wear a BJD button.
4. Hand out BJD buttons to members, visitors, patients, and colleagues.
5. Publish short BJD updates in your association or company publications.

Increased public awareness of the burden of bone and joint diseases on American society is a primary goal of the Bone and Joint Decade.
Do your part!

6. Include a link from your Web site to the BJD Web site: www.boneandjointdecade.org/us
7. Explain on your Web site what the Bone and Joint Decade means to your organization.
8. Ask BJD to provide a link from its Web site to yours, if there is not one already.
9. Request the BJD logo be printed on reports and materials of your organization's projects and activities that relate to the goals of the BJD. (E-mail usbjd@usbjd.org)
10. Add ***Support the Bone and Joint Decade!*** to the signature line of your E-mail messages.

and here's an 11th for good measure –

11. Request time at your next company staff meet for a short presentation to personnel on BJD.

National Consensus Conference Aims to Improve Care

By Mark Wieting

With the realization that hip fractures constitute a public health crisis, 11 national organizations convened the "National Consensus Conference on Improving the Continuum of Care for Patients with Hip Fractures." As part of the internationally-recognized Bone and Joint Decade, the conference sought solutions to the morbidity, mortality and loss of independence faced by patients with hip fracture, and to make recommendations for improving the continuum of care, from pre-hospital care, acute hospital care, rehabilitation and return to independent living. More than 40 organizations attended the conference in May 2001. The recommendations focused on four important themes: improving the communication among providers during the continuum of care; advocating reimbursement for the most appropriate care providers during the patient's care and recovery; prevention education that reduces the number of fractures in the elderly and educates providers about the special needs of the person at risk for fracture; and research investigations leading to evidence-based, multi-disciplinary clinical pathways to optimize care and patient outcomes.

For further information, please visit http://www.aaos.org/wordhtml/press/sciwrit/01oupd1.htm.

Mark Wieting is vice president of education programs for the American Academy of Orthopaedic Surgeons.

Nominations Sought for International Honors

The Bone and Joint Decade International Steering Committee is issuing a call for nominations for two international programs.

The first program, the 2nd Annual Bone and Joint Decade International Awards, will be presented at an awards banquet during the upcoming Annual Network Coordinators' Meeting in Rio de Janeiro, September 12-14. Awards will be presented to the organization, National Action Network, and individual who have made the greatest accomplishments toward the mission of the Decade. Nominations must be received by August 1, 2002.

Nominations are also being sought for the Bone and Joint Decade Ambassadors program, which is designed to recognize global and national thought leaders in the musculoskeletal patient and health professional communities to promote the Decade's mission within their disciplines and countries.

Nominations may be submitted at any time, but the Nominating Committee will make its selections to be announced at the September Annual Meeting. They encourage all interested parties to submit Ambassador nominations at the same time as the International Awards.

For nomination forms, please visit http://www.boneandjointdecade.org/news/

Message from the Chairman

Carpe Diem!

On March 25, President Bush signed a proclamation designating the years 2002-2011, as the National Bone and Joint Decade (BJD). The presidential proclamation was the culmination of several years' hard work and persistence by many individuals. The actual proclamation of the Decade now gives us the imprimatur under which all of our future projects will operate.

This endorsement comes at a critical time in our history. The "ball is now squarely in our court" to make the goals of the Decade a reality. We must develop mechanisms to actively engage the membership of our organizations into the BJD and its activities. We need to make sure that our memberships are informed about the Decade and its goals. We need to expand our national case statement and take it to our constituents and convince them that the Decade deserves their support. We must engage them in BJD activities all the while looking to work closely with our partner organizations on the national, regional and local level. For the BJD to be successful, it must be a grass roots effort within and among our organizations.

The key to success of the Bone and Joint Decade is the development of new collaborative partnerships aimed at achieving the goals of the Decade. These collaborations between patient advocacy groups, musculoskeletal associations, care providers, researchers and industry through the National Action Network (NAN) will not only achieve the Decade's goals but will also help each individual member organization more effectively accomplish their own organizational goals.

As each NAN member organization reviews its current programs and looks to develop new programs, it must continually ask the question: Will this new or existing initiative help achieve the goals of the U.S. BJD? If so, is there a way we can partner with one or more of the NAN members to accomplish this initiative more effectively?

"Silos" of information within organizations must be broken down in order to share knowledge and effort across a wider field. The members of the NAN must continually look to work more closely together with other organizations across the NAN. We must also look to develop these collaborative relationships on the regional and local level. In this fashion each organization will more effectively represent its constituencies while at the same time helping to achieve the goals of the U.S. Bone and Joint Decade. We must also look to expand the NAN to all interested and supportive organizations. They should be encouraged to join our ranks and work to achieve our common goals.

Ladies and Gentlemen: with the Presidential proclamation, the Decade has truly begun; we must seize the day.

Stuart L. Weinstein, MD
Chair, U.S. National Action Network of the Bone and Joint Decade

stuart-weinstein@uiowa.edu

CONTACT US

The U.S. *Bone and Joint Decade Newsletter* serves as a means of communication between the members of the National Action Network (NAN) and other affiliated organizations. To submit a story idea or an article, or if you have comments, please contact:

Larry Commons
214.637.6282 Ext. 119

Rachael Cole
214.637.6282 Ext. 116

U.S. Bone and Joint Decade Office
Toby King - 847.384.4010
tobyking@usbjd.org

Late-Breaking News

We're delighted to report that, as we went to press, Wyeth-Ayerst Pharmaceuticals and Smith & Nephew had signed on as sponsors of the U.S. Bone and Joint Decade!

ABOUT US

The Bone and Joint Decade (BJD) is an independent, global nonprofit organization whose mission is to improve the health-related quality of life for people affected by musculoskeletal disorders worldwide.

It is the umbrella organization by which more than 46 National Action Networks and more than 750 professional medical societies, patient advocacy groups, governments, companies, research institutions and publications partner to effect change by: (1) Raising awareness of the growing burden of musculoskeletal disorders on society; (2) Empowering patients to participate in their own care; (3) Promoting cost-effective prevention and treatment; and (4) Advancing understanding of musculoskeletal disorders through research to improve prevention and treatment.

We're on the Web!

www.boneandjointdecade.org/us