

U.S. Bone and Joint Decade holds Capitol Hill meeting

The U.S. Bone and Joint Decade on July 15 sponsored the first of several planned luncheons on Capitol Hill to raise awareness of musculoskeletal diseases and conditions in the United States.

The event, sponsored by Senator Diane Feinstein (D-CA) and Representatives Shelley Moore Capito (R-WV) and Louise Slaughter (D-NY), focused on advances in prevention, research and treatment of osteoporosis. More than 50 congressional staff attended the luncheon, as well as Allan Noonan, MD, special advisor to the office of the U.S. Surgeon General.

Regis O'Keefe, MD, PhD, president of the USBJD, chaired the session.

Deborah T. Gold, PhD, associate research professor of medical sociology at Duke University Medicine Center, spoke about the unexpected consequences of osteoporosis.

Linda Harrigan, a patient diagnosed with osteoporosis in 1986, provided a personal view of the illness. Harrigan has become an outspoken advocate for the disease, working to raise awareness and patient involvement.



Joan McGowan, PhD, chief, Musculoskeletal Diseases Branch, NIAMS, with Allan S. Noonan, MD, MPH, Special Advisor to the Office of the Surgeon General

Joan McGowan, PhD, chief, Musculoskeletal Diseases Branch of the National Institute of Arthritis and Musculoskeletal and Skin Disease, discussed the progress and promise of research. Summarizing actions that must follow, along with the need for fair appropriations, was Clifford Rosen, MD, immediate past president of the American Society for Bone and Mineral Research.

Dr. Gold explained that forty-four million Americans have or are at serious risk of osteoporosis, with over a million and a half new fractures occurring annually. Osteoporosis, she said, is a serious threat to American public health.

A recent Roper survey conducted for the National Osteoporosis Foundation found that nearly half of women believe that they probably or definitely will not develop osteoporosis. This may explain why people, not seeing osteoporosis as a personal threat, do not engage in prevention behaviors: taking calcium and vitamin D, doing weight-bearing and strength-training exercise, avoiding poor health habits such as smoking and having a bone density test at the onset of menopause.

The American public needs to hear several messages to convince them that the risk of osteoporosis is personal, said Dr. Gold. Although Caucasian and Asian women are at slightly higher risk, Americans of all ethnic origins can develop osteoporosis. Twenty percent of those with or at risk of osteoporosis are male. More than two million men have osteoporosis, and 80,000 will break a hip in the next year. One-third of men with hip fractures will be dead within 12 months of fracture. Although increasing age heightens its risk,



Senator Susan M. Collins (R-ME) with Clifford Rosen, MD

osteoporosis can occur in people of all ages. Young adults with eating disorders, middle-aged women who experience early menopause and all older adults are at risk. Yet Americans still don't believe that they themselves will lose bone.

Many people with osteoporosis find that they can no longer work and therefore experience financial problems while also losing their social roles. Depression is a serious psychological outcome of osteoporosis, but health care professionals rarely screen for it. People with osteoporosis also have distorted perceptions of themselves because of the deformity and functional limitations they experience.

Direct medical costs of treating osteoporosis, currently \$17 billion annually, will skyrocket with the aging of the American population. There will be more hip fractures and more people needing nursing home care for them.

To help Americans realize that osteoporosis is a personal threat to nearly every American, we can encourage our legislators to provide additional research dollars for

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NEWS FROM PARTICIPATING ORGANIZATIONS

National Awareness Week - October 12 - 20, 2004

How will your association raise awareness?

The USBJD is eager to know what participating organizations have planned for National Awareness Week 2004 (October 12-20).

Please let us know by September 15 how your organization will celebrate NAW. This can include special events; local community talks; Decade references in magazines, newsletter and other printed materials; or any other project your group is undertaking to improve public awareness of muscu-

loskeletal health conditions and patient education. Submissions should be sent to Toby King at TobyKing@usbjd.org.

The USBJD wishes to extend a special thank you to Abbott Laboratories and Gelita Health Initiative for making special contributions to National Awareness Week. Any other corporations wishing to help support NAW are asked to e-mail King at the address above.

Pediatric communications coalition formed

To increase Decade exposure and to get important information to parents of children who might be impacted by musculoskeletal conditions, a Pediatric Coalition has been created by the Communications and Education Committee.

The members of the subcommittee will project a unified message to gain media attention and increase public awareness of pediatric issues.

The first item on the coalition's agenda is a campaign during National Awareness Week.

The national media blitz is expected to include a week-long series on a national news program, a week-long radio series and a syndicated print series. The focus will be on school days missed due to injury and

illness. Each organization will be featured every day of the week.

Many coalition members have agreed to produce testimonial ads centered around this topic (see USBJD Web site for example). The ads will be placed in various magazines.

As a first step, members are each compiling a page of information about their specific issue's impact on missed school days.

In addition to the national media campaign, a more grassroots approach - including community events, local press releases, etc. - is being planned.

Look for more information on this emerging group in future issues of the *USBJD Newsletter*.

USBJD welcomes new Participating Members

AAOS - Corporate Advisory Council
 American Orthopaedic Foot & Ankle Society
 American Spinal Injury Association
 Association of Academic Physiatrists
 Auxiliary to the American Osteopathic Association
 National University of Health Sciences
 Palmer College of Chiropractic

Calendar of Events

September

1-4 SRS Annual Meeting
 9-12 ACRM Annual Joint Conference
 11-14 AAHKS

October

1-5 ASBMR Annual Meeting
 7-10 AAPM&R Annual meeting
 7-10 OTA Scientific Meeting
 9-13 AAP Annual Meeting
 10-13 ORS Annual Meeting
12-20 Bone and Joint Decade National Awareness Week 2004
 13-16 EOA Annual Meeting
 14-17 ASES Biennial w/AAOS
 16-21 ARHP Annual Meeting
 16-21 ACR Annual Meeting
 26-30 NASS Annual Meeting
 26-30 AANS Annual Meeting

November

5-7 AAHKS Annual Meeting
 7-11 AOA Annual Convention
 11-14 ABJS Workshop
 22-23 NOF Annual Regional Meeting

More online at: www.usbjd.org
 then go to Activities, Calendar of Events

Bone Run Walk 'n Roll event promotes Decade

The Association of Academic Physiatrists, along with the New Jersey Rehabilitation Foundation, is encouraging rehabilitation centers to host Bone Run Walk 'n Roll events in their communities. And, in support of the Decade, they're using the USBJD logo on their promotional materials and using the event as their contribution to National Awareness Week 2004.

The Bone Run Walk 'n Roll consists of a one- to four-mile walk, 5K run and 5K

Follow the AAP and NJRF's lead...use annual and new events to help promote the Decade in your community.

wheelchair race. Some rehabilitation centers choose to host health fairs in conjunction with the athletic events.

Bone Runs will be held the Sunday before Halloween. All revenue generated from the event will be split 50-50 between the center and the NJRF (who will share their portion with the AAP). The AAP will use funds to

support educational activities and the NJRF will use the funds to continue development of the Bone Run program and support the needs of those with physical disabilities.

The NJRF has developed a "how to" race manual, online materials and has staff ready provide assistance to anyone interested in hosting a Bone Run event in his/her community. Contact Robert Manestrina at 856-696-7100 for more information.

NATIONAL NEWS

Most women 45+ fail to recognize personal risk

Survey from NOF and AoA highlights need to raise awareness

Even though the majority of women aged 45 and older have at least two risk factors for osteoporosis, only 15 percent of those women not diagnosed by a doctor believe they are at risk for the disease, according to a recent survey conducted by Roper Public Affairs and Media on behalf of the National Osteoporosis Foundation.

The survey tested women's knowledge of osteoporosis, the actions they take to keep bones healthy, their overall concerns about aging, the information sources they rely on and their perception of personal risk of developing osteoporosis. The survey was funded as part of a grant that NOF received from the U.S. Department of Health and Human Services, Administration on Aging.

"Women need to know their health risk for osteoporosis and what they can do to prevent the disease," said Josefina Carbonell, assistant secretary for aging. "While we know that effective prevention, diagnosis and treatment strategies exist for osteoporosis, many women have not taken

action. At AoA, we want to reverse this trend. We want women empowered on this issue and we want them taking action to prevent this debilitating disease," she added.

Women Express Little Concern About Risk of Bone Loss

"Women do not perceive themselves to be personally at risk for osteoporosis, even though one in two women aged 50 and older will experience an osteoporosis-related fracture in their lifetime. Women aged 45 and older may be aware of osteoporosis, but do not relate that awareness to their own personal risk," said Judith Cranford, NOF executive director.

"We need to bridge the gap between perception and reality that is underscored by this survey, and encourage women to assess their personal risk and take the preventative steps that can help them to protect their bones including speaking to their health care professional," said Bess Dawson-Hughes, MD, president, NOF.

The survey also found:

- Only 62 percent said they were "very or somewhat concerned" about their risk of bone loss.
- More than four out of ten women said they do not talk to their doctor about osteoporosis or keeping their bones healthy.
- Nearly four in ten have not had a bone density test.

Women and men can reduce their personal risk of osteoporosis and fracture by following NOF's five steps to bone health at the right.

NOF's Five Steps to Bone Health and Osteoporosis Prevention

1. Get your daily recommended amounts of calcium and vitamin D
2. Engage in regular weight-bearing exercise
3. Avoid smoking and excessive alcohol
4. Talk to your doctor about bone health
5. Have a bone density test and take medication when appropriate

Flight for a Cure underway

Pilots Dr. Edwin Galkin and retired Eastern Airline Captain Richard Sollner set off July 3 on the trip of a lifetime - a flight around the world. This is no ordinary trip. The duo will fly 27,500 miles over a six week period in a single engine Cessna 210 Centurion. And they're doing it all in the name of awareness.

The *Flight for a Cure* will help raise awareness of Fibrodysplasia Ossificans Progressiva, a debilitating disease that replaces healthy muscles with bone. Galkin and Sollner hope to raise funds for FOP each mile of the trip they fly. They will also be raising awareness of the Decade. To follow the pilots' flight path, go to www.aroundtheworldagain.com.

To make donations to this exciting project, visit www.ifopa.org.

The New Jersey governor's Office of Volunteerism awarded Gary Whyte the Governor's Volunteer Award for 2004 for his advocacy efforts on behalf of Fibrodysplasia Ossificans Progressiva. (See article in April 2004 USBJD Newsletter)

NIH offers new health resources

The National Institutes of Health recently expanded its offerings to give physicians, patients and the general public greater access to health-related information. A National Resource Center and an expanded health information Web site were designed to link users to a variety of valuable tools and guidelines.

The National Resource Center

The Resource Center collects information about available materials and current programs and support services for metabolic bone diseases. It disseminates that information through publications, online services, professional and patient meetings and other outreach. The diseases addressed by

the Center include osteoporosis, Paget's disease of bone, osteogenesis imperfecta, primary hyperparathyroidism and other disorders of bone and mineral metabolism.

The Center is dedicated to increasing awareness, knowledge and understanding of metabolic bone disease for the public, especially at-risk populations such as Hispanic and Asian women, adolescents and men. It does this through injury response assistance, new material development and information dissemination.

For more information on the National Resource Center, go to www.osteoo.org, or call 1-800-624-BONE.

Online Health Information Web Site

The NIH recently launched an expanded Web site that provides links to a wide range of health information, including highlights of popular topics, cutting-edge scientific research and interactive features. The new site, a clearinghouse for valuable data from the more than two dozen institutes and centers that comprise the NIH, has three new feature sections - *Healthy Lifestyles*, *Research in Action* and *Now Online*. It also boasts an interactive *Take a Quiz* section where users can go to measure their knowledge of topics such as osteoporosis, cancer prevention and heart disease.

The Web site is at <http://health.nih.gov>.

CONDITIONS

Unexpected Consequences of Osteoporosis

By Deborah T. Gold, PhD

In 2004, osteoporosis is nearly a household word in the United States. When we hear it, we think of fragile skeletons; of older white women who are bent over and have humps on their backs; of hip fractures; and of nursing homes. We think of these negative physical consequences, yet few Americans understand the total impact of this disease on people of different races, ethnic backgrounds and both genders, and we do not understand that the worst outcomes associated with osteoporosis are not the broken bones, the canes and walkers, or the nursing home stays. The other "unexpected" outcomes diminish the quality of life of all who have fragile bones.

Forty-four million Americans have or are at serious risk of osteoporosis, with over a million and a half new fractures occurring annually. How does that compare with the prevalence of other diseases? About 13 million Americans have coronary heart disease, with 7,800,000 having a heart attack annually. About 4,800,000 strokes occur every year, as do 217,000 new cases of breast cancer. Although most of us believe that breast cancer is the deadliest threat to our health, more women will die this year from hip-fracture related causes than from breast cancer. Osteoporosis is a serious threat to American public health.

And yet, even in light of these large numbers, Americans do not embrace osteoporosis as a genuine health risk for themselves and their family members. This is true even for postmenopausal women, the age and gender group at highest risk for osteoporosis. A recent Roper survey done for the National Osteoporosis Foundation found that, although 61% of the women in the general public are concerned about the risk of bone loss, nearly half of us believe that we probably or definitely will not develop osteoporosis ourselves.

Because we do not see osteoporosis as a personal threat, most of us are not engaging in behaviors to prevent osteoporosis: taking calcium and vitamin D; doing weight-bearing and strength-training exercise; avoiding poor health habits such as smok-

ing; and having a bone density test at the menopause. These behaviors can reduce the risk of osteoporosis, yet we ignore them.

Perhaps Americans do not embrace osteoporosis because they believe it is an inevitable consequence of aging. Surely we have all seen older adults with good posture. If bone density loss were a natural part of aging, no one would escape it. But osteoporosis is a disease that does not develop in everyone. Now that we can diagnose loss of bone with a simple bone density measurement, and we have several FDA-approved medications for its prevention and treatment, no one should have to live with osteoporosis and its downward spiral. Yet many of us ignore our bone health and write off preventive behaviors as worthless. We will continue to do so until we are convinced that osteoporosis can happen to us.

The American public needs to hear several messages if we are to believe that osteoporosis is relevant to us. First, nearly every American is at some risk of osteoporosis. The National Osteoporosis Risk

"Osteoporosis may be a silent disease, but we cannot afford to be silent about it."

**Judith Cranford,
Executive Director
of the National
Osteoporosis
Foundation**

Assessment study measured bone density in over 200,000 women and showed that while Asian and Caucasian women are at increased risk, members of all racial groups can and do develop osteoporosis. In addition the National Osteoporosis Prevalence Report indicates that 20% of those with or at risk of osteoporosis are male. Of the over two million men who have osteoporosis, 80,000 will break a hip in the next year. And one-third of men with hip fractures will be dead

within 12 months of fracture. Finally, although increasing age heightens its risk, osteoporosis can occur in people of all ages. Young adults with eating disorders or who have taken corticosteroid therapy for a long time; middle-aged women who have had their ovaries removed or experienced early menopause; and older adults in general are all at risk. Yet Americans still don't believe that they will lose bone.

"We must encourage Americans to realize that their bones are not exempt from osteoporosis and that prevention is a far better option than treatment."

What happens if they do lose bone? What happens to individuals whose bone density is so low that they fracture when they sneeze, cough or twist while reaching? The

physical consequences of spinal fractures are highly visible. As spinal fractures occur, the body bends forward, and the rib cage rests on the pelvis. Breathing is compromised because lungs are compressed and eating enough is problematic when the stomach is compressed among other internal organs. The abdomen protrudes, not because of excess weight but because the new posture forces internal organs to push forward. Loss of more than an inch in height is not uncommon. And when back muscles and ligaments try to hold the body upright (a job the spine used to do), people with osteoporosis experience chronic back pain.

These are the visible outcomes of osteoporosis and fractures. But there are many invisible outcomes as well. People with osteoporosis find that they can no longer work and therefore experience financial problems while also losing their social roles. Social isolation may occur because many social outlets require long periods of standing or sitting. And they may not be able to pick up their grandchildren or do routine activities around the house for fear of fracture.

The psychological or emotional outcomes of osteoporosis can be even more devastating. Most people experience anxiety when they have their first fracture or are initially diagnosed with osteoporosis. Disease-specific anxiety forces many to give up social activities during which fractures may occur. Such activities include moderate exercise, dancing, playing golf or tennis and driving long distances. Giving them up can reduce fracture risk, but sometimes even the most diligent efforts do not prevent other fractures. As additional fractures occur, anxiety transforms into depression. Depression is a serious mental health problem for older adults in general and is a major threat to the well-being of those with osteoporosis. Several research studies have now shown a strong association between bone density loss and depression, but health care professionals rarely screen for depression when they are treating their patients. The real tragedy is that we have

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CONDITIONS

USBJD offers osteoporosis condition kit to raise awareness

In an effort to raise awareness of osteoporosis, one of the five focal conditions of the Decade, the USBJD recently released its first condition kit, which focuses on the disease.

Osteoporosis is a chronic disorder that predisposes individuals to fractures with minimal or no trauma. Approximately ten million Americans have osteoporosis and about 34 million additional men and women are at an increased risk of developing osteoporotic fractures because of low bone mass. This is 55% of people over the age of 50. Of the ten million people with osteoporosis, eight million are women and two million are men.

The number of fractures due to osteoporosis occurring annually in the US is:

300,000 hip fractures
700,000 vertebral fractures
250,000 wrist fractures
300,000 fractures at other sites

From the
National Osteoporosis Foundation

Fracture Rates

Most women enter menopause in good general health. Yet, it is at this time that bone loss begins and can eventually lead to fractures at some time in the future. One in three women will have an osteoporotic vertebral compression fracture by age 65

and a hip fracture by age 85. Overall, the lifetime risk of any osteoporotic fracture is approximately 40% for women and 25% for men.

Mortality and Morbidity

The 12-month mortality rate for complications of osteoporotic hip fractures in women is about 25%, which exceeds that for ovari-

an and uterine cancer combined. Increased mortality also results from vertebral fractures. Every vertebral and hip fracture carries with it a decrease in the quality of life for the individual. Vertebral compression fractures result in loss of height, persistent pain, spinal deformity, involvement of visceral organs, psychosocial issue and a loss of self-esteem. Thus, the decreased quality of life and loss of independence are common complications of women and men with osteoporotic fractures.

Cost

Annual direct expenditure for care of

patients with osteoporotic fractures exceeds \$17 billion dollars (2001) and is predicted to double by 2025. Ninety percent of the expenditures of osteoporosis are related to the costs of treating the fractures. Currently, only ten percent is being spent on prevention and treatment of established osteoporosis to prevent additional fractures.

The USBJD Condition Kit

The condition kit includes information on the scope of the disease; causes of skeletal fragility; diagnosis of osteoporosis; treatment and prevention; and future research directions and areas of discovery. To get your free copy, go to www.usbjd.org/rd/index.cfm?osteoporosis.

Other resources

Those interested in learning more about osteoporosis are encouraged to visit the National Osteoporosis Foundation Web site at www.nof.org and the NIH Osteoporosis and Related Bone Diseases National Resource Center site at www.osteoporosis.gov. Both Web sites provide valuable information for patients of the disease, physicians and the general public.

Education critical in battle against osteoporosis...From page 4

effective treatments for depression, but we are not very good at diagnosing and treating it in people with fragile bones.

A final unexpected consequence of osteoporosis relates to how individuals perceive themselves. Most women base their self-esteem on two personal characteristics. The first is what they do, whether that is being a lawyer, a homemaker, a teacher or a physician. The second is how they look. Osteoporosis robs women of their self-esteem. It deforms them, it debilitates them and it disables them. If we continue to ignore the threat of weak bones by avoiding prevention and treatment options, we can expect to see self-esteem diminish in women. Men with osteoporosis do not escape this threat either. Remember that they have what is commonly considered a health problem only for little old ladies. Imagine the impact of that on how they view themselves. Masculinity is measured by physical strength and endurance. Osteoporosis can diminish both.

The aging of the American population almost certainly guarantees that osteoporosis will be a much more prevalent disease

in the future. This increased prevalence assures us that the direct medical costs of osteoporosis - estimated at \$14 billion annually now - will skyrocket. We will have more hip fractures and more people needing nursing home care for them; we will also need a number of health care professionals to treat them.

What can we do to help Americans realize that osteoporosis is a personal threat to nearly each and every one of them? We can educate them, beginning in grade school, and encourage them to drink milk, eat dairy products and exercise. We can support accurate media coverage of studies of osteoporosis and the people who suffer from it. We can encourage our senators and representatives to support legislation to provide additional research dollars for bone disease. Some excellent studies of osteoporosis and its treatments have been done since 1995 when the FDA approved the first medication for osteoporosis. Yet some other research areas have been stagnant. Studies focused on the unexpected consequences I mentioned earlier - social isolation, behavioral issues, depression, chronic pain - need NIH support. This research in

socio-behavioral issues is absolutely critical. Only a few, relatively small-scale studies have examined the impact of these unexpected consequences. Although we do know that they have a powerfully negative impact on quality of life, we need to learn how to help osteoporosis sufferers live with and minimize the effects of this disease.

Osteoporosis research, education and health care must increase. We must encourage Americans to realize that their bones are not exempt from osteoporosis and that prevention is a far better option than treatment. The battle against bone loss and fractures will not be an easy one, but we are capable of winning it. As Judith Cranford, executive director of the National Osteoporosis Foundation, said at the Surgeon General's Workshop on Osteoporosis and Bone Health, "Osteoporosis may be a silent disease, but we cannot afford to be silent about it." All of us must work together to make osteoporosis extinct.

PROJECT UPDATES

USBJD subcommittees continue work on projects to support the Decade

Advocacy

The Decade has been asked to support the Arthritis Prevention, Control and Cure Act, 2004, sponsored by Senators Bond and Kennedy. This is currently under review, but it is likely the USBJD will sign on.

The USBJD Advocacy and Research committees jointly organized the Capitol Hill meeting, reported on page one.

The Advocacy Committee is soliciting states to issue special proclamations to promote bone and joint health activities, especially by local communities, during National Awareness Week 2004.

The Decade has produced an information sheet for all organizations to include in their lobby effort information kits.

Communications



A new USBJD display has been designed and is being produced. The eye-catching display (pictured at left) will be sent to meetings around the country to help raise Decade awareness.

The proposed USBJD display

The third of several testimonial advertisements has been developed, featuring Andrew Cole, MD, and a patient who experienced a back injury. The Decade hopes to produce 25-30 of these advertisements for distribution to various media outlets.

Testimonial ads can be downloaded directly from the Web site at www.usbjd.org/rd/index.cfm?Materials. Participating organizations and journals are welcomed to reproduce them.

Public Education

The importance of reaching out to the general public has led the USBJD to create a Public Education Committee. The group's initial meeting was held in May. Its priorities will be upgrading the public education and informational aspects of the Web site, development of the Protect Your Bones program of presentations to high schools (see below), working with the National Association of Chain Drug Stores to develop more information sheets for pharmacists and with AAA on road safety educational materials for their members.

The *Protect Your Bones* campaign continues to move forward. This is an opportunity for more people to become involved in the Decade and pass along the important message of bone health. During this year's National Awareness Week, a presentation will be given to freshmen at Cleveland-area high schools. Other ideas of integrating this program with the Decade are being explored.

Research

Project 100 is an initiative to address the lack of formalized training of the musculoskeletal system in allopathic medical schools. The Association of American Medical Colleges has established an expert panel to develop guidelines for medical schools. Rheumatologist Dennis Boulware, MD, will chair the panel, which will meet in September.

A letter has been sent to all Decade participating organizations inviting them to name a representative to the Question-Writing Task Force under the National Board of Medical Examiners. A number of organizations have already responded, but all relevant organizations are asked to do so as this is how the NBME will assess true interest in the development of a shelf test on musculoskeletal education.

Musculoskeletal Medicine, a textbook published by the AAOS and reviewed by the AAP, is being promoted to medical schools and health care professionals across the country. Cornell University and the State of Ohio medical schools recently adopted the book.

Seventy medical schools have now signed declarations of support for the Decade. USBJD Board members are working to obtain support of the other 57 schools.

Condition Kit on Osteoporosis was published in July-See article on page 5.

USBJD Board members meet in Atlanta

The USBJD held its annual Board meeting June 2 in Atlanta. Regis O'Keefe, PhD, president of the USBJD, presided over the meeting that was hosted by the American College of Rheumatology.

Financial report and fund-raising

Wolf & Company, LLP completed its 2003 audit of the USBJD. The audit indicates that the Decade is financially solvent, expenses are appropriately controlled and there has been an increase in net assets. The organization is handling its business efficiently and is poised to continue at this level.

Global Decade

Edward Harris, MD, a US member of the Decade's International Steering Committee, reported on worldwide Decade activities

and encouraged members to visit the international Web site (www.bjd.org). He outlined the purpose of the burden of disease report and the musculoskeletal curriculum project and noted that criteria for nominating ambassadors now permits NANs to submit entries.

Bruce Browner, MD, a US member of the International Steering Committee, was noted for having been a catalyst in the United Nations decision to raise the profile of road safety.

Patient Advocacy

Dr. O'Keefe expressed a need for increasing patient involvement in the Decade. Meeting attendees then heard from representatives from several associations.

Jack Klippel, MD, president and CEO of the Arthritis Foundation, provided an outline of the history, structure and current priorities of the Foundation. At present, the Foundation is very involved in a variety of public policy issues, including the passage of the *Arthritis Prevention, Control and Cure Act 2004*, sponsored by Senators Bond and Kennedy. The legislation emphasizes the importance of public health, coordination of the activities of federal agencies involved with arthritis and increased attention to the needs of children with arthritis.

The Foundation is also focusing on public health. In terms of interaction with the Decade, Dr. Klippel highlighted spreading awareness and public health activities, as well as his own involvement with the

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USBJD Board meets

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Decade's Young Investigators Initiative. He encouraged the Decade to work with and involve regional AF chapters.

Charles Helmick, MD, with the Centers for Disease Control, explained how his department focuses on the arthritis component of musculoskeletal conditions. This is an area that needs more public awareness. This can be achieved, Dr. Helmick said, through increased education addressing arthritis as well as musculoskeletal problems caused by injury, occupational/repetitive behavior and birth defects.

Roberta Biegel, with the National Osteoporosis Foundation, reported on its

focus this year, a campaign entitled, *It Could Be You*. The program targets the general public, not those already suffering from osteoporosis.

Steve Smith, AAPR&R, reiterated the need for common and repeated messages. The Decade, he told attendees, needs to focus on core activities in 2004 as momentum is building.

This discussion prompted the board to commit to revisiting the strategic plan to bring it up-to date. In particular, the board wishes to define global issues, select specific issues to focus on in order to increase public awareness and to reach out to the general public.

Road Safety

Mark Rosenberg, MD, presented a summary of the progress of the Decade's road safety awareness initiatives, explaining that it was the catalyst in getting the United Nations to put road safety on its General Assembly agenda and how the World Health Organization came to make this important issue the theme for World Health Day 2004.

Dr. Rosenberg urged the USBJD to support calls for legislation enabling federal agencies to share information about road safety with other countries, and to support the *Institute of Medicine Road Impact Study*.

The next meeting of the USBJD Board of Directors is scheduled for September.

Capitol Hill meeting addresses osteoporosis...From page 1

bone disease and for osteoporosis education, said Dr. Gold. Many studies of osteoporosis medications have been done. But other research has been ignored in areas such as social isolation, depression and chronic pain. Socio-behavioral research on osteoporosis is absolutely critical.

For Linda Harrigan, living with osteoporosis means being constantly conscious of her diet, taking supplements and undertaking moderate exercise. Osteoporosis may have been worsened after she became a cancer patient. When osteoporosis was diagnosed, she contacted the National Osteoporosis Foundation to learn as much as possible about the condition. Getting the word out by speaking to family and friends, policy makers and legislators is the most important way to lower the level of prevalence.

Most Americans will not escape a musculoskeletal condition, said Dr. McGowan, and bone and joint disorders can truly take the life out of living. The National Institutes of Health, a part of the Department of Health and Human Services, focuses on research that is not conducted in the private sector but is essential for fostering new treatments and approaches to understanding musculoskeletal disease. A large part of the NIH budget is spent on fundamental and basic bone research - how cells and tissues function and then the translation of that research to solve clinical problems.

Another important aspect of government-funded research is epidemiology, the study of the natural history of diseases. These studies follow hundreds of thousands of individuals over decades to understand what puts individuals at risk for disease and what preventive measures may reduce the

burden of disease. NIH also conducts clinical trials in areas, such as nutrition and physical activity, that are unlikely to lead to new products or patents and therefore not targeted by private companies.

Another very important mission for NIH and other HHS agencies is to make sure that the public benefits from the fruits of research. One such outreach effort is being conducted by the Office of the Surgeon General. The *Surgeon General's Report on Bone Health and Osteoporosis* is scheduled for release this fall. This report is an example of the different kinds of activities going on during the Bone and Joint Decade to promote public knowledge and understanding of the impact of musculoskeletal diseases and to bring "evidence into action."

Dr. Rosen, director of the Maine Center for Osteoporosis Research and Education, St. Joseph Hospital, said the National Institutes of Health is the mechanism to translate basic and clinical research into clinical practice. Congressional leaders need to know more about the effects of osteoporosis on Americans, and to encourage more appropriations for research. Many advances have been made, he said, but there is a lot more to do. It is only in the last few years that the medical community has realized the important level of incidence of osteoporosis in men, that the human skeleton remodels itself every ten years and that the disease affects not just old people but children and young adults as well.

NIH studies have contributed to x-ray diagnosis, therapies, block bone breakdown and recent advances in parathyroid therapy that help bone reform. NIH is now studying

combination drug therapy. Comparing the 1967 Surgeon General's report on smoking, and how it led to a much higher level education on the effects of smoking, Dr. Rosen said this is what is needed to tackle the increasing prevalence of osteoporosis. More needs to be known about how people fall and what they can do to avoid or lessen the impact of falls and about Vitamin D, obesity and bone health.

The USBJD's first Condition Kit, which focuses on Osteoporosis, was distributed at the Capitol Hill meeting. This kit, developed by the USBJD Research Committee, is the first in a series designed to provide the public and policy makers with an overview of the current state of osteoporosis in the United States and of recent and future directions in research. This kit was written by Edward Puzas, PhD, and reviewed by the National Osteoporosis Foundation and the American Society for Bone and Mineral Research.

On the same day as the Capitol Hill meeting, the *Wall Street Journal* published a report on the state of osteoporosis with quotes from the National Osteoporosis Foundation and Clifford Rosen, MD, speaker at the meeting, and one of the Decade's Condition Kit reviewers.

Roberta Biegel of the National Osteoporosis Foundation and David Lovett of the AAOS' Washington office provided expert guidance for the event and organized the congressional invitations, arrangements and logistical support.

FROM THE PRESIDENT

Advocacy Efforts Key to Decade's Success

As members of the Bone and Joint Decade we are committed to advancing musculoskeletal research and education, and improving patient care. Through professional organizations, including medical, nursing, rehabilitation, pharmaceutical and orthopaedic device communities, and through patient advocacy groups, we confront the burden of musculoskeletal disease on a daily basis. Furthermore, most of us experience musculoskeletal disease personally, or through association with affected family members and friends.

This issue of the newsletter highlights Advocacy. Through advocacy we educate other health professionals, the public, and legislative leaders to raise awareness of the burden of musculoskeletal diseases. These efforts are critical to the success of the decade, since it is only through general awareness and the resulting support that we will make advances in the understanding and care of musculoskeletal diseases.

It is our hope that the recent Capitol Hill Seminar, focusing on the importance of osteoporosis, will be the first of a series of seminars. The National Osteoporosis Foundation and the American Academy of Orthopaedic Surgery took leadership roles in the planning and execution of the event. A debt of gratitude is owed these organizations, and more importantly, we hope that they will serve as role models for our other members. The Bone and Joint Decade opens endless possibilities for all of us to spread our respective messages.

Another means of communicating our messages is through the development and use of the Bone and Joint Decade display, a project under development by the Communications/Education Committee. This display will have 10 back-lit panels and will provide a focal point for educational activities. Information contained on the panels can be modified and updated. The display will be available to our members at

national and regional meetings, advocacy events, and other activities. It is our intention that the display will become a recognizable part of the decade.

As national awareness week approaches (October 12-20), it is clear that there are numerous opportunities to advocate for musculoskeletal disease. I encourage our member organizations to use the Decade to advance each of their causes. Our organizations and their goals are the Decade, and together we will improve musculoskeletal care in the United States.

Sincerely,



Regis O'Keefe, MD, PhD

New Associate Members

Sapphire Level

Gelita Health Initiative
Smith & Nephew Orthopaedics*

Topaz Level

Genzyme Biosurgery, Inc.
Wyeth*

Onyx Level

Genzyme, Biosurgery, Inc.
Natural Bio Care
Stryker Corporation

*Raised membership level

About the Newsletter

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:

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