

National Coalition for Osteoporosis And Related Bone Diseases

*American Academy of Orthopaedic Surgeons
American Society for Bone and Mineral Research*

*National Osteoporosis Foundation
Osteogenesis Imperfecta Foundation
The Paget Foundation*

Fact Sheet

Mission of the Bone Coalition and Recent Accomplishments

The National Coalition for Osteoporosis and Related Bone Diseases (Bone Coalition), organized in the early 1990s, is dedicated to increasing federal research funding for bone diseases through advocacy and education.

The Coalition successfully encouraged the federal government to create *Bone Health and Osteoporosis: A Report of the Surgeon General (2004)*. In response to the Surgeon General's Call to Action, the Coalition convened a Summit for A National Action Plan for Bone Health (2008) and published its proceedings, *Recommendations from the Summit for a National Action Plan for Bone Health*. To implement the recommendations of this report, the Coalition urges Congress to support and pass the "Bone Health Promotion and Research Act."

The Coalition members are five leading national bone disease groups, consisting of two professional societies and three national voluntary health organizations: American Academy of Orthopaedic Surgeons, American Society for Bone and Mineral Research, National Osteoporosis Foundation, Osteogenesis Imperfecta Foundation and The Paget Foundation.

Social and Economic Impact of Bone Diseases

- Musculoskeletal disorders and diseases are the leading cause of disability in the United States.
- More than 1 in 4 Americans have a musculoskeletal condition requiring medical attention.
- Annual direct and indirect costs for bone and joint health are \$849 billion – 7.7 percent of the U.S. gross domestic product.
- Musculoskeletal research currently makes up only about 1 percent of the National Institutes of Health research budget, while the burden of musculoskeletal conditions is expected to escalate in the next 10-20 years, due in part to an aging population.
- More research is urgently required to contain or lower the economic burden arising from America's musculoskeletal health needs.
- Over 10 million Americans are estimated to have osteoporosis and almost 34 million more are estimated to have low bone mass which puts them at risk for osteoporosis and fractures
- 80 percent of those affected by osteoporosis are women who are usually the primary caregivers in their families.
- Between 20,000 and 50,000 Americans have osteogenesis imperfecta, which causes brittle bones to break easily because of a problem with collagen production.
- Paget's disease of bone, the second most prevalent bone disease after osteoporosis, is a chronic skeletal disorder that may result in enlarged or deformed bones in one or more regions of the skeleton and affects people over the age of 50.

- Bone metastasis occurs in up to 80 percent of patients with myeloma, 70 percent of patients with either breast or prostate cancer, and 15 to 30 percent of patients with lung, colon, stomach, bladder, uterine, rectal, and renal cancer causing severe bone pain and pathologic fractures. Many of these patients survive for years after developing bone related complications. Therefore research to develop more and better therapies for bone complications will improve quality of life and improved survivorship for these patients.

How Has Bone Research Helped People?

Research has:

- Found that intervention reduces the incidence of future fractures, thereby improving quality of life
- Led to the development of non-invasive, accurate tests to determine bone mass to help predict future fracture risk
- Identified and demonstrated a variety of drugs that can reduce bone loss and fractures, and even build new bone
- Discovered that bisphosphonate drugs, which are commonly prescribed for osteoporosis and Paget's disease of bone, significantly reduce mortality rates among older adults by preventing fractures and other severe complications
- Led to the better understanding of calcium metabolism, so that food manufacturers have fortified numerous products with this vital nutrient
- Demonstrated the necessity for vitamin D, protein, iron, and other nutrients in building and maintaining strong bones, while also emphasizing a major public health problem of vitamin D deficiency
- Helped to understand the need for weight-bearing exercise to build and maintain bone in order to reduce fracture risk and to understand that strength-building exercise increases balance and flexibility can therefore can reduce falls
- Identified the genetic components responsible for many bone diseases, paving the way for the development of genetic approaches for diagnosis and treatment
- Decreased fracture risk and extended lifespan to normal for people with OI
- Identified drugs which improve quality of life of people whose cancer has metastasized to bone

What Challenges Still Remain?

- Increasing the promotion of better bone health and prevention of osteoporosis
- Improving the diagnosis and treatment of all bone diseases
- Enhancing bone disease research, including research on rare bone diseases
- Expanding surveillance efforts and evaluation of prevention programs for osteoporosis

Who are Coalition Participants?

American Academy of Orthopaedic Surgeons (AAOS): The preeminent provider of musculoskeletal education to orthopaedic surgeons and others worldwide, represents over 17,000 board-certified orthopaedic surgeons and researchers.

American Society for Bone and Mineral Research (ASBMR): The premier professional, scientific and medical society established to promote excellence in bone and mineral research and to facilitate

the translation of that research into clinical practice, represents nearly 4,000 physicians, basic research scientists, and clinical investigators.

National Osteoporosis Foundation (NOF): The nation's leading voluntary health organization solely dedicated to osteoporosis and bone health represents the nation's 44 million individuals with or at risk for osteoporosis and its mission is to prevent osteoporosis and related fractures, to promote lifelong bone health, to help improve the lives of those affected by osteoporosis and to find a cure through programs of awareness, advocacy, public and health professional education and research..

Osteogenesis Imperfecta Foundation (OIF): The only national voluntary health organization dedicated to improving the quality of life for people with osteogenesis imperfecta (OI) through research to find treatments and a cure, education, awareness, and mutual support.

The Paget Foundation for Paget's Disease of Bone and Related Disorders: A voluntary health agency founded in 1978 to address several disorders including Paget's disease of bone, primary hyperparathyroidism, the rare disorders fibrous dysplasia and osteopetrosis, and the complications of certain cancers of the skeleton.

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