

2014 Annual Report



Mission and Vision

The National Osteoporosis Foundation (NOF) is the leading health organization dedicated to preventing osteoporosis and broken bones, promoting strong bones for life and reducing human suffering through programs of public and clinician awareness, education, advocacy and research.

Established in 1984, NOF is the nation's only organization solely dedicated to osteoporosis and bone health. Our goal is to educate the public and health professionals on ways to prevent, diagnose and treat osteoporosis.

As we celebrate our 30th anniversary and honor the significant strides that have been made in raising awareness of osteoporosis and the importance of bone health, we also look ahead to the work that still needs to be accomplished in order to curb the increased incidence of osteoporosis among our aging population. With fracture prevention now at the core of everything we do, we're working to advance a new model of coordinated care that works across hospitals, medical offices and multiple medical specialties to ensure that those who fracture receive appropriate osteoporosis testing, diagnosis, treatment, and ongoing support.

With the support of our partners and donors, we will continue advocating for medical research to better diagnose and treat osteoporosis; educating and training healthcare providers on the importance of fracture risk assessment and prevention; and raising public awareness to help people of all ages build healthy bones that will last a lifetime.

Letter from the President and Chairman

2014 marked a year of great change and progress for the National Osteoporosis Foundation. As we celebrated our 30th anniversary and honored three decades of progress in the fight against osteoporosis, we also focused on the work that still needs to be accomplished. The advances we've made since NOF's founding are great–osteoporosis is now part of the national healthcare agenda, we have worked with other healthcare organizations to educate those at risk and have worked to develop effective treatments that are proven to reduce the risk of fracture.

Despite our progress over the past 30 years, challenges remain. Perhaps the challenge that is most impactful is the unprecedented increase in longevity over the past 50 years that has not been accompanied by any strategy to prevent age-related bone loss. As a result, it is estimated that by the year 2025 osteoporosis will cause approximately three million broken bones annually and cost the healthcare system \$25 billion per year. In response to this changing landscape of bone health, NOF has made the decision to refocus our efforts on the identification of those individuals at greatest risk for fracture and the development of evaluation and treatment strategies to reduce the number of fractures Americans suffer every year. Although we are early in this effort of refocusing, this strategy is beginning to bear fruit—we are making major strides to intervene and change the course of this disease.

Our current efforts are built on much research and development by those who have come before us. Over the past 30 years, researchers have developed methods such as bone densitometry and other technology to identify and quantify fracture risk; have identified the major bone signaling pathways, discoveries that have been translated into new and more effective therapies to prevent fractures; a better understanding of the role of nutrients, minerals and vitamins to maximize bone health; and the important role of exercise in optimizing bone health at all ages. NOF has been at the forefront of efforts to develop and educate the public about these exciting discoveries.

We have also worked to understand and educate the public about the benefits and risks of osteoporosis therapy. Identifying the unexpected adverse effects of some therapies was a powerful driver in our need to refocus NOF's efforts on those individuals at highest risk for fracture. For this population, the benefits of therapy far outweigh any perceived or real risk—if you have had an osteoporotic fracture there is little doubt that your risk of a second, and potentially more serious, fracture is greater than any risk of pharmacologic therapy.

This subtle shift in NOF goals—from preventing **osteoporosis** to preventing **fractures** has energized the Foundation and has given us a clearly defined set of goals that we are pursuing with our partners in the bone community with enthusiasm and focus. The vehicle for these efforts has been the creation of the National Bone Health Alliance (NBHA)—a collaborative effort of public, nongovernmental and private organizations who have chosen to work together to advance the single goal of reducing fractures in those individuals at highest risk. NBHA, working under NOF and American Society for Bone and Mineral Research leadership, has chosen to use the fracture liaison service (FLS) model—a broad-based, best-practice model recognized as the key to reducing the post-fracture care gap of patients who are treated and released after a broken bone without being tested for osteoporosisto identify and treat patients at highest risk. Pilot projects have validated this approach in our healthcare system and NBHA/NOF is working closely with several partners to interdigitate this approach with the growing focus on quality health care delivery mandated by the Affordable Care Act. Most importantly, this effort has given us the worthy and measureable goal of reducing fractures, which a spectrum of public and private organizations has rallied around.

Surrounding this singular focus is a number of other important questions and initiatives that contribute to the success of the primary goal to prevent fractures. Members of NOF are working diligently to develop better criteria to identify those at greatest risk for fracture, better understand the role of nutrients, minerals and vitamins in bone health, and create a simpler message that will resonate with and motivate individuals at highest risk to pursue evaluation and treatment. It is not enough that we develop these strategies—it is also important that we translate these discoveries into a single message that can be understood by the entire population. We have recruited individuals with talent and skill in these areas to NOF and its Board of Directors. We will, of course, continue to provide support and information to patients, caregivers and the public, while sharing the most current and clinically-relevant information with physicians and healthcare providers.

This important shift in NOF goals is now launched. What differentiates our current focus from that of an earlier era is the establishment of a clear set of outcomes that are finite and measureable. We are committed to these goals for a period of at least five more years at which time we will assess our progress and make course adjustments and, if necessary, completely revise our approach.

In the pages that follow, you'll hear more about NOF's commitment to fracture prevention as well as the organization's important achievements of 2014. We realize reaching our goals is only possible with your continued support and are grateful for all you do to help further our mission. On behalf of NOF, we thank the NOF Board of Trustees, staff, members, partners, donors and volunteers whose support has made our work possible.

Sincerely,



Koby + Dage

Robert F. Gagel, M.D. President



Judy a. Black

Judy A. Black Chair

Letter from the Executive Director and CEO

This year, as we looked back and celebrated how far we've come since the organization was founded in 1984, we also used it as an opportunity to focus our efforts around a single, unifying goal of protecting Americans from the pain, disability and loss of independence millions suffer every year as the result of broken bones.

Osteoporosis causes two million broken bones every year in the U.S., yet more than 70 percent of older women who fracture are never tested or treated for osteoporosis and we know that if left untreated, patients who break a bone are twice as likely to break another.

The solution to changing the 70 percent care gap in existence today is the widespread implementation of Fracture Liaison Service (FLS) programs. That's why we continued working to implement our comprehensive Fracture Prevention Initiative throughout the year, providing the training tools and resources healthcare professionals need to spark widespread implementation of FLS programs across the country.

For the first time, our 2014 Interdisciplinary Symposium on Osteoporosis (ISO14) included an FLS Model of Care Training and Certificate Program which explored the most important economic and health system challenges to the widespread implementation of the FLS model of care. Upon completion of ISO14, we awarded nearly 100 FLS Certificates of Completion to our inaugural class.

In addition to training healthcare professionals, we also remain committed to educating the public on the simple steps they can take to prevent broken bones. This May for National Osteoporosis Month, we continued the **Break Free from Osteoporosis** initiative encouraging everyone to get to know their risk factors and make lifestyle changes to protect against broken bones.

Despite our efforts, we know that the number of people with osteoporosis continues to rise rapidly. Our updated prevalence data released this year estimates a total of 54 million U.S. adults, representing more than one-half of the total U.S. adult population over 50, is currently affected by osteoporosis and low bone mass. As we look ahead to the challenges that remain, we hope you share our confidence that NOF is armed with 30 years of experience and we are more dedicated than ever to changing the course of this disease.

Thank you for your continued involvement. All of our success is because of the remarkable support we enjoy from our donors, volunteers and partners. Together we can overcome the challenges ahead to prevent broken bones and end the pain and suffering that they cause millions of Americans.

Sincerely,



Amy Porter Executive Director and CEO





30 Years in Review

The National Osteoporosis Foundation's founding dates back to April 1984 when the National Institutes of Health (NIH) held a Consensus Development Conference on Osteoporosis with a conference panel led by William A. Peck, M.D., who was serving as Simon Professor at the Washington University School of Medicine and Physician-in-Chief of The Jewish Hospital of St. Louis. The consensus panel included medical representatives from the fields of orthopedics, endocrinology, gynecology, rheumatology, epidemiology, nutrition, biochemistry and family medicine, as well as the general public. The panel considered current scientific knowledge on osteoporosis and agreed on answers to several key questions.

A well attended press briefing was held at the conclusion of the NIH Consensus Conference. As a result of the widespread media coverage announcing the consensus panel's findings, major academic health centers nationwide received thousands of calls from patients and physicians alike who asked for more information on optimum approaches to the prevention and treatment of osteoporosis.

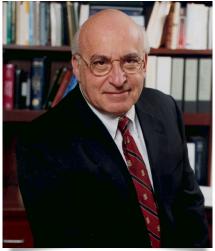
This widespread interest in osteoporosis led Dr. Peck, a past president of the American Society of Bone and Mineral Research, to call a meeting of leading osteoporosis researchers to discuss the overwhelming public and professional interest in the disease and to offer a strategy for responding to it. The meeting led to the establishment of The Osteoporosis Foundation, a national nonprofit voluntary health organization solely dedicated to osteoporosis and bone health. Founded in December 1984, the organization was renamed the National Osteoporosis Foundation (NOF) in 1985.

About NOF's Founding Chairman, William A. Peck

Born on September 28, 1933, in New Britain, Connecticut, William A. Peck graduated with honors in Biomedical Sciences from Harvard College in 1955, earning a John Harvard Scholarship. He then

graduated from the University of Rochester School of Medicine (M.D. 1960, Dsc, Honorary, 2000),completed two years of residency (Internal Medicine) and one year of fellowship (Metabolism) at Barnes Hospital (1960–1963) and served for two years as a clinical associate at the National Institutes of Health (Arthritis and Metabolic Diseases), Diplomate, the National Board of Medical Examiners and the American Board of Internal Medicine.

He returned to the University of Rochester (Strong Memorial Hospital) as Chief Medical Resident, and subsequently held appointments as Assistant Professor, Associate Professor and Professor of Medicine and Biochemistry, and Head of the Division of Endocrinology.



In 1976, Peck was appointed the John E. and Adaline Simon Professor of Medicine and co-chairman of the Department of Medicine at Washington University, and Physician-in-Chief at the Jewish Hospital of St. Louis.

From 1989 to 2003, he served as Dean of Washington University School of Medicine and Vice Chancellor for Medical Affairs (Executive Vice Chancellor for Medical Affairs from 1993), and President of the Washington University Medical Center. In 2003, Dr. Peck was named Director, Center for Health Policy and Alan A. and Edith L. Wolff Distinguished Professor of Medicine at Washington University.

Dr. Peck's academic activities include original investigations in bone and mineral metabolism (100 scientific publications), extensive clinical teaching and patient care experience. His major scientific contributions include the first method for studying directly the structure, function and growth of bone cells, demonstration of mechanisms whereby hormones regulate bone cell function, and examination of causes of osteoporosis.

In addition to serving as NOF's founding president, Dr. Peck has served on editorial boards of multiple journals; on numerous National and International medical and scientific panels; and on advisory boards of major pharmaceutical companies.

Dr. Peck's long list of honors include an NIH Career Program Award; Diplomate, National Board of Medical Examiners; Lederle Medical Faculty Award; Diplomate, American Board of Internal Medicine; NIH Research Career Program Award; Who's Who in America; Clinical Teacher of the Year Award, Washington University; Commissioner's Special Citation, Food and Drug Administration among many others.

He has appeared as a scientific spokesperson on national and local media (including McNeil Lehrer Report, Good Morning America and CBS Morning News) and chaired many National and International conferences and symposia.

1984 -

NIH holds a Consensus Development Conference on Osteoporosis in April to consider current scientific knowledge and answer several key questions about osteoporosis. The resulting widespread interest in osteoporosis leads to the formation of The Osteoporosis Foundation in December.

1986 -

NOF begins operation in Washington, D.C.

1992 -

NOF successfully advocates for the passage of the "1992 Revitalization Act," authorizing NIH to establish an information clearinghouse for osteoporosis and related bone diseases, which becomes the NIH Osteoporosis and Related Bone Diseases-National Resource Center.

1994 -

NOF holds the first International Symposium on Osteoporosis (ISO), bringing together a faculty of internationally-renowned experts to share the latest information and research on bone health and osteoporosis prevention, diagnosis and treatment with hundreds of healthcare professionals. ISO is the only scientific meeting in the United States to focus on osteoporosis and bone health across the lifespan.

-• 1985

The Osteoporosis Foundation changes its name to the National Osteoporosis Foundation. Congress passes federal legislation designating the first National Osteoporosis Prevention Week in May.

NOF develops and disseminates materials for the week and continues coordinating efforts to support National Osteoporosis Month, recognized each May.

-• 1990

NOF, in partnership with the International Osteoporosis Foundation, begins publishing *Osteoporosis International*, a monthly scientific journal dedicated to the diagnosis, treatment and management of osteoporosis.

• 1993

NOF creates and begins promoting the adoption of model state laws for osteoporosis prevention and treatment education programs and coverage of bone mineral density testing. More than 30 states have since passed these laws.

-• 1995

NOF publishes its first prevalence report, revealing that 44 million women and men age 50 and older in the U.S. have or are at risk for developing osteoporosis due to low bone density.

1998 -

NOF publishes the first clinical practice guidelines for osteoporosis. The Medicare Bone Mass Measurement Coverage Standardization Act goes into effect, giving women and men age 70 and older who are at risk for osteoporosis access to bone density testing.

2001 -

The U.S. Preventative Services Task Force releases a recommendation that follows NOF guidelines and recommends women aged 65+ have a bone density test.

2004 -

U.S. Surgeon General, Vice Admiral Richard H. Carmona, M.D., M.P.H., F.A.C.S., releases *Bone Health and Osteoporosis: A Report of the Surgeon General*, calling for the nation to recognize the challenges of osteoporosis prevention, diagnosis and treatment. NOF successfully advocates for federal funding for osteoporosis research as part of the National Coalition for Osteoporosis and Related Bone Diseases. At NIH, osteoporosis research funding increases to more than \$190 million and at the U.S. Department of Defense, osteoporosis research is funded through two programs.

2007 -

NOF and the Society for Women's Health Research hold a briefing on Capitol Hill to inform lawmakers about recent advances in the prevention and treatment of osteoporosis. Actress Sally Field, an osteoporosis patient and advocate, speaks at the briefing and encourages women to protect themselves against fractures.

~ 2000

NOF leads efforts to include an "osteoporosis section" in Healthy People 2010, the nation's blueprint for public health policy and programs.

<mark>⊸ 200</mark>2

NOF publishes America's Bone Health: The State of Osteoporosis and Low Bone Mass In Our Nation as an update to its first prevalence report. The report reveals that by the year 2010, an estimated 52 million people age 50 and older will have osteoporosis or low bone mass.

<mark>⊸ 2005</mark>

NOF's efforts are significant in helping to increase federal funding for osteoporosis research from \$5 million in 1986 to more than \$191 million in 2005.

2008 -

In February, NOF releases its *Clinician's Guide to Prevention and Treatment of Osteoporosis* to help U.S. healthcare providers make better prevention and treatment decisions and assess fracture risk for patients with low bone mass or osteoporosis.

In June, the National Coalition for Osteoporosis and Related Bone Diseases, a coalition comprising of leaders of four national bone organizations (NOF, American Society of Bone Mineral Research, the Osteogenesis Imperfecta Foundation and the Paget Foundation) meet in Washington, D.C. for a national summit to develop a coordinated national action plan to promote bone health.

2010 -

NOF serves as a founding partner of the National Bone Health Alliance (NBHA), a public-private partnership established in response to the U.S. Surgeon General's Report on Bone Health and Osteoporosis (released October 2004) and recommendations from the 2008 Summit for a National Action Plan.

NOF announces its comprehensive Fracture Prevention Initiative to help bring about the widespread implementation of the Fracture Liaison Service (FLS) model of care.

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In January, the National Action Plan for Bone Health: Recommendations from the Summit for a National Action Plan for Bone Health was published as a direct outcome of the June 2008 National Action Plan for Bone Health.

-• 2013

Renamed the Interdisciplinary Symposium on Osteoporosis to reflect the diverse team of healthcare professionals required to effectively manage and treat osteoporosis, NOF holds its annual meeting in Chicago from April 18-21. The meeting drew hundreds of diverse healthcare professionals for an opportunity to network, collaborate and learn the most effective ways of preventing, treating and diagnosing osteoporosis.

Also in April, NOF released an update to its prevalence data revealing an estimated 10.2 million adults in the U.S. have osteoporosis and another 43.4 million have low bone mass. This means 54 million U.S. adults, representing 50 percent of the U.S. adult population over 50, are at risk of breaking a bone and should be concerned about their bone health. In response, NOF launches **Break Free from Osteoporosis,** a national awareness campaign calling on the public to learn about their risk factors for osteoporosis and make the lifestyle changes needed to protect against it.

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AWARENESS

Every 20 seconds, someone in America breaks a bone due to osteoporosis, but only about 30 percent of those who break bones are tested or treated for osteoporosis. At NOF, we're committed to closing this care gap by encouraging everyone age 50 and older who breaks a bone to ask their doctor for a bone density test.

Through our nationwide network of support groups and online support community with more than 20,000 participating members, we're connecting people to raise awareness for the two million broken bones caused by osteoporosis every year and spreading the word that a few simple lifestyle changes can make a big difference in protecting against broken bones.

Break Free from Osteoporosis

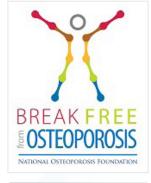
In May for National Osteoporosis Month, NOF continued its successful *Break Free from Osteoporosis* initiative, once again calling on the public to get to know their risk factors for osteoporosis and take action to protect against broken bones. As part of the campaign, NOF hosted a free webinar on the role of nutrition on bone health. Hundreds of attendees participated in the live webinar and walked away with tips to help them identify nutrients that are important to bone health, shop for foods with bone healthy ingredients and understand the specific role calcium and vitamin D play in bone health.

NOF's Bone Health Ambassador, Barbara Hannah Grufferman once again played a significant role in spreading messages on the importance of bone health during National Osteoporosis Month. Her weekly AARP.com video series and regular *Huffington Post* columns reached millions of adults age 50 and older with diet and exercise tips to help them stay healthy, active and strong as they age.

Focus on Fracture Prevention

This year, NOF implemented its first comprehensive Fracture Prevention Initiative in partnership with the National Bone Health Alliance (NBHA). Together, the partner organizations provide a broad-based, best-practice model of care to reduce the nearly 70 percent post-fracture care gap of patients who fracture, but are never tested or treated for osteoporosis.

Health systems abroad and select health care providers in the U.S. have created programs to identify patients after a fracture and ensure appropriate management through a Fracture Liaison Service (FLS). Recognizing FLS programs as the solution to reducing the two million bone breaks caused by osteoporosis each year, the initiative aims to spark widespread implementation of FLS programs across the country.





Barbara Hannah Grufferman

NOF's 2014 Interdisciplinary Symposium on Osteoporosis introduced a new curriculum to help healthcare professionals implement an FLS program, a systematic approach to secondary fracture prevention, at their institution. NOF's Fracture Prevention Initiative also included a webinar series and accompanying educational materials to educate healthcare professionals and consumers on the potential for FLS programs to reduce repeat fractures and improve bone health in America.

Expanding Our Reach

As a result of these initiatives and an effort to change the conversation from osteoporosis to fracture prevention through ongoing media outreach, 2014 marked a new high for NOF's media reach. Throughout the year, top national media outlets and women's magazines, including AARP.com, Everyday Health, *Huffington Post, New York Times, Reuters Health, Wall Street Journal* and more covered osteoporosis and echoed our call to action for men and women of all ages to build strong bones. In total, nearly 5,000 articles ran in 2014 mentioning the National Osteoporosis Foundation, resulting in more than 675 million media impressions.



NOF.org, our most valuable channel for communicating directly with

osteoporosis patients, caregivers and the public, also attracted record setting traffic with monthly visitors to the site increasing from an average of 70,000 per month in 2013 to nearly 110,000 per month throughout 2014.

Our NOF online support community, hosted by Inspire, offers patients and caregivers a place to turn for peer-to-peer support and continues to grow. We started 2014 with 15,000 active members and reached more than 20,000 active members by year's end. Special thanks to our volunteer moderators, Sandi Elkin, Pamela Flores, Susie Hathaway, and Lawrence Jankowski, who actively engage in conversations with community members to make sure their questions and concerns are addressed. We're thrilled to see our online community growing everyday.



Susie Hathaway



Sandi Elkin



Lawrence Jankowski



Pamela Flores

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EDUCATION

At NOF, our goal is to prevent fractures and ensure that those who fracture receive the best and most appropriate clinical care and support available to prevent repeat fractures. We're encouraging healthcare professionals to focus on fracture risk assessment and prevention and are providing training, tools and resources to help those interested implement Fracture Liaison Service programs to effectively treat post-fracture patients.

Through its professional educational initiatives, NOF provides the latest osteoporosis research and clinical information to help healthcare professionals advance their practices and ultimately improve patient care. The information provided through our annual Interdisciplinary Symposium on Osteoporosis, as well as our print and online resources, journals, e-newsletters and webinars, helps ensure that the team of health professionals involved with diagnosing and treating those at high risk for fracture have the information they need to make informed clinical decisions.

Interdisciplinary Symposium on Osteoporosis 2014 (ISO14): Patient Centered Care – Developing Successful Bone Health Teams

Focused on the theme "Patient Centered Care–Developing Successful Bone Health Teams," ISO14 was held in New Orleans from April 23–26 and was one of NOF's most successful meetings to date.

For the first time, the meeting featured a new training and certificate program for the Fracture Liaison Service model of care, a coordinated preventive care model that operates under the supervision of a bone health specialist and collaborates with the patient's primary care physician. The comprehensive FLS curriculum was designed to help doctors, nurse practitioners, physician assistants, registered nurses and other healthcare professionals navigate the complicated coordination of care across hospitals, medical offices and multiple medical specialties to ensure that fracture patients receive appropriate osteoporosis testing, diagnosis, treatment and ongoing support after they leave the hospital.

As part of the new FLS curriculum, ISO14 began with a pre-conference symposium covering FLS basics, database issues and practice concerns. A hands-on skills-building workshop and 13 plenaries and sessions were also included in the meeting's FLS track. More than 200 people participated in the FLS pre-conference and nearly 100



participants completed the entire track and received a Certificate of Completion for acquiring the skills to address the most important business and structural challenges to improving patient outcomes through coordinated care programs.

ISO14 also featured a session on bone health lessons from space featuring Nicole Stott, an Astronaut with the National Aeronautics and Space Administration (NASA); CME credit, sessions and networking opportunities to benefit all medical disciplines and specialties involved in treating patients with and at-risk for osteoporosis and broken bones; and plenary, workshop and breakout sessions exploring the most important economic and health system challenges to the widespread implementation of the FLS model of care.



Professional Publications

In 2014, NOF released an updated version of its *Clinician's Guide to Prevention and Treatment of Osteoporosis*, which includes updated guidance on vertebral fracture assessment and the use of biochemical markers of bone turnover, as well as updated information on calcium, vitamin D and medications. This useful guide is a must-have to inform clinical decision-making to manage the diagnosis and treatment of men and women at high risk for fractures and in June of 2014 Osteoporosis *International* published the Guide online in its entirety.

The *Clinician's Guide* is also available as an app, allowing healthcare professionals to access the latest clinical decision making information directly from their iPhones or iPads.

Interest in and subscriptions to NOF's scientific journal, *Osteoporosis International*, a joint initiative between NOF and the International Osteoporosis Foundation (IOF) also continued growing in 2014. The international, multidisciplinary journal provides a forum for communications and idea exchange on the diagnosis, prevention, treatment and management of osteoporosis and other metabolic bone disease.

The Osteoporosis: Clinical Updates online series offers cutting-edge information and pragmatic strategies clinicians may apply in clinical practice to improve their osteoporosis patient care. Current issues are available for continuing education credit. During 2014, five case-based issues were presented covering these topics: Rehabilitation of Patients with Fragility-Related Fractures; US FDA-Approved Drugs for Osteoporosis; Vitamin D and Bone Health; Osteoporosis and Chronic Kidney Disease; and Osteoporosis in Children and Adolescents.

Research

NOF supports research to examine the latest clinical controversies and provide accurate and reliable information to health professionals and the public. In 2014, NOF released updated prevalence data estimating that a total of 54 million U.S. adults age 50 and older are affected by osteoporosis and low bone mass. Published in the *Journal of Bone and Mineral Research*, the study, "The Recent Prevalence of Osteoporosis and Low Bone Mass in the United States Based on Bone Mineral Density at the Femoral Neck or Lumbar Spine," includes the number of adults age 50 and over from the institutionalized and non-institutionalized population affected by osteoporosis and low bone mass and is an update to the prevalence data NOF released in 2013. Revealing that 10.2 million adults have osteoporosis and another 43.4 million have low bone mass, more than one-half of the total U.S. adult population over age 50 is currently affected.

The updated prevalence data represents the most comprehensive and up-to-date information available to describe the total number of U.S. adults with osteoporosis and low bone mass.

The data is one of the first to look at the burden of osteoporosis using NOF's criteria for diagnosing osteoporosis based on bone mineral density at the hip or spine, offering a baseline number of those with osteoporosis and low bone mass against which we can measure our progress going forward.

The study found that osteoporosis and low bone mass are very common conditions and while most of the individuals with or at-risk for osteoporosis are Caucasian women, a substantial number of men and women from other racial and ethnic groups also suffer from osteoporosis and low bone mass.

The data also includes a state-by-state breakdown showing that states with increasingly high populations of retirement age adults as well as those with growing Hispanic populations have the highest prevalence of osteoporosis. California, Florida, Texas and New York currently have and are projected to have the highest number of individuals with osteoporosis or low bone mass, while Washington, DC, Wyoming, Alaska and North Dakota have the lowest number of individuals with osteoporosis or low bone mass.

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PARTNERSHIPS

NOF partners with like-minded health organizations to extend its reach and elevate osteoporosis and bone health to issues of national concern. The best example of this collaboration is the National Bone Health Alliance (NBHA), a public-private partnership NOF co-founded in 2011. With 55 non-profit, private and government organizational participants at the end of 2014, NBHA brings together the expertise and resources of its participating members to collectively promote bone health and prevent disease; improve diagnosis and treatment of bone disease; and enhance bone research surveillance and evaluation.

NBHA 20/20 Vision: Reducing fractures 20 percent by the year 2020

With strong support from NOF, its founding partner, NBHA is making strides toward reaching its 20/20 Vision of reducing fractures caused by osteoporosis 20 percent by the year 2020. One of NBHA's primary initiatives is a variety of efforts to foster widespread implementation of the fracture liaison service (FLS) model of post-fracture care coordination. FLS is a tested and effective way to improve patient outcomes and decrease healthcare costs. FLS programs are widely viewed as the key to closing the 70 percent care gap of those who fracture, but are never tested or treated for osteoporosis.

To spark widespread implementation of the FLS model of care, NBHA launched Fracture Prevention CENTRAL, a publicly accessible online resource to help healthcare professionals and administrators implement a coordinator-based, post-fracture FLS model of care to reduce secondary fractures and the associated costs while increasing patient outcomes. NBHA compiled materials from a number of



successful domestic and international post-fracture care programs and highlights the work of leading FLS programs, including the American Orthopaedic Association's *Own the Bone* program, Kaiser Permanente and Geisinger Health System. The site launched in March of 2013 and by the end of 2014, Fracture Prevention CENTRAL had attracted nearly 2,500 subscribers who registered on the site to access the free resources and materials it offers.

Fracture Prevention CENTRAL has also hosted a dozen webinars featuring the nation's top FLS experts presenting on topics to guide interested sites through the steps to make the business case to support launching a secondary fracture prevention program and begin implementing an FLS program of their own. The webinar series, offered as live presentations and later for on demand viewing, attracted more than 2,000 participants.

Fracture Liaison Service Demonstration Project

In early 2014, NBHA launched a cloud-based Fracture Liaison Service Demonstration Project (FLS Demonstration) in partnership with NOF and CECity.com, Inc. (CECity) to provide participating hospitals with the FLS model of care and CECity's cloud-based *MedConcert®* platform, to assess the hospitals' adoption and implementation of a fracture liaison service across their communities.

Funded by Merck and Co., Inc., the FLS Demonstration Project is designed to demonstrate the ability to scale FLS programs for implementation in the community setting, while measuring the impact on patient care. The study includes targeting the 70 percent care gap of older Americans who suffer bone breaks, but are not tested or treated for osteoporosis.

The three demonstration sites selected to participate are: Alegent Creighton Health, Omaha, NE [site lead: Robert Recker, MD]; Medstar Georgetown University Hospital, Washington, DC [site lead: Andrea Singer, MD]; and UPMC, Pittsburgh, PA [site lead: Susan Greenspan, MD]. The demonstration project will assess the three demonstration sites' adoption and implementation of a FLS across their communities and measure improvement in performance around selected quality measures.

The study will run through mid-2015 within the three initial sites selected to participate. The Bone Health Collaborative partners expect to publish results of the project by the end of 2015.

NBHA, NOF and CECity Launch a CMS-Approved Osteoporosis Qualified Clinical Data Quality Improvement Registry

In the fall of 2014, NBHA and NOF partnered to launch an Osteoporosis Quality Improvement Registry (QIR), developed in collaboration with CECity, Inc., as a Qualified Clinical Data Registry (QCDR) for the Centers for Medicare & Medicaid Services (CMS) Physician Quality Reporting System (PQRS) in the 2014 program year.

The Osteoporosis QIR is the only osteoporosis disease-focused QCDR and is designed to measure and report on health care quality and patient outcomes. The measures present in the 2014 QCDR provide healthcare professionals with a way to satisfy increased reporting requirements for PQRS through meaningful, relevant quality improvement activities related to osteoporosis.

A key advantage of participating in PQRS through the Osteoporosis QIR is that CMS has permitted the use of not only PQRS-approved measures, but also new measures that are non-PQRS measures. This provides the opportunity to develop and deploy new performance measures through the Osteoporosis QIR that the profession believes best represent how quality should be measured based on specialty, practice setting, or other criteria. Eligible providers may then use the new measures by participating in the Osteoporosis QIR to compare their performance to their peers; and benchmark their performance against measures that matter to their practice, for purposes of quality improvement, or for value based payment and public reporting.

NBHA and NOF encouraged all partner society and individual members to consider being a part of the NBHA/NOF Osteoporosis QCDR.

2Million2Many

To bring widespread attention to the two million broken bones caused by osteoporosis in the U.S. every year, NBHA launched the *2Million2Many* national awareness campaign in 2012 and continued campaign efforts throughout 2014. The campaign aims to elevate osteoporosis to an issue of national concern and issues a clear and simple call to action for healthcare professionals and consumers alike: *if it's 50+ fracture, request a test.* The visual centerpiece of the campaign, "Cast Mountain," is a 12-ft. tall and 12-ft. wide installation built of casts to represent the 5,500 bone breaks that occur in the U.S. in just one day due to osteoporosis.

To celebrate World Osteoporosis Day, Eli Lilly hosted Cast Mountain at their headquarters in Indianapolis for the



month of October. In addition to displaying the visual centerpiece of NBHA's 2Million2Many campaign, Eli Lilly employees received educational information on the two million fractures caused by osteoporosis every year and were encouraged to request a bone density test for anyone over age 50 who breaks a bone.

Bone Turnover Marker Standardization Project

Bone turnover markers (BTMs) have been recognized as useful tools in clinical practice, but have some technical issues that have limited their use to date. To address these issues, among the NBHA's major efforts is the implementation of a number of complementary activities around the harmonization and standardization of the use of these markers.

In 2014, NBHA began executing two bone turnover marker efforts:

- Drug Holiday Study: Despite recent Food and Drug Administration guidance that, for many individuals, a break from the use of anti-osteoporosis medications known as bisphosphonates might be considered after four to five years of continuous use, there is no specific guidance for clinicians regarding which patients should be considered for a drug holiday and for what duration. Therefore, this project will determine the utility of using bone turnover markers to establish the effect a drug holiday has on bone turnover for patients that have been on continuous bisphosphonate therapy for five years or more.
- Common/Consistent Normative Reference Population Database: This project will establish a common reference population database for both young normal and older normal post-menopausal women and young normal and older normal men to enable greater consistency in results and facilitate trust in biomarker use in the clinical management of patients.

Rare Bone Disease Workshop

NBHA and the Rare Bone Disease Patient Network, with support of the American Society for Bone and Mineral Research (ASBMR) and the U.S. Bone and Joint Initiative, sponsored a rare bone disease

workshop, *Mechanistic and Therapeutic Insights into Skeletal Biology Learned from the Study of Rare Bone Diseases* on September 11, 2014 in Houston, Texas. Over 225 attended this workshop, which was held the day before the ASBMR Annual Meeting and focused on lessons learned from the study of rare bone diseases that have advanced science and influenced the treatment of both common and rare bone diseases. In addition to the formal presentations, 20 young investigator awards were given to encourage participation and posters at the meeting and 63 posters were presented at the workshop. Proceedings from the workshop were published in Bone and BoneKEy.

Clinical Diagnosis of Osteoporosis Working Group

NBHA convened a working group of 17 academic experts to explore the circumstances upon which a post-menopausal female or older male patient who has suffered from a hip, vertebral or other fracture might be considered to have osteoporosis with or without the current criterion of a bone mineral density test t-score of -2.5 or lower. This working group has reached consensus and published its recommendations in the May 2014 issue of *Osteoporosis International*. To date, NBHA has secured nine non-profit and specialty society endorsements supporting this newly expanded clinical basis for diagnosing osteoporosis.

2014 | PROGRAM HIGHLIGHTS

PHILANTHROPY

We Need You. For the past 30 years, NOF has relied on the support from diversified sources, including individuals, foundations, government sources and corporations to sustain and enhance our efforts to prevent osteoporosis and build strong bones for life. Together we've been a successful team in the fight against osteoporosis, but we all have a role to play in tackling the remaining challenges and working to reduce the two million bone breaks caused by osteoporosis every year.

While some of the funds NOF receives may be restricted to specific projects, NOF maintains its independence and objectivity in accordance with the National Health Council's guiding principles. NOF does not endorse any particular product, service or point of view, but does inform the public about all FDA-approved therapies, as well as the availability of other appropriate products and services as part of its educational responsibility to the public and healthcare professionals.

NOF is in full compliance with the Good Operating Practices Standards of the National Health Council and has been awarded the Independent Charities Seal of Excellence.

We thank our generous donors listed below, whose gifts have made a significant difference in the fight against osteoporosis. We realize reaching our goals of preventing osteoporosis and broken bones is only possible if we all work together and are grateful for all you do to support NOF.

Lifetime Giving

NOF recognizes the following individuals for their generous lifetime support of \$100,000 or more. Through their dedication and lifelong support, these individuals have empowered others to live long and full lives on their own terms.

Ms. Betty M. Ahlers[#] Virginia S. Bergmann[#] Florence Blazek[#] Sylvia Blechman[#] Ms. Winifred L. Brown[#] Mr. and Mrs. Gary L. Bryant Mrs. Margaret E. Carl[#] Mr. David M. Cole[#] Ms. Irene P. Fuller[#] Adelaide[#] and Lawrence[#] Gerrity Mary S. Hansen[‡] Charlotte Jones-Kopence[‡] Mrs. Ethel LeFrak[‡] Mrs. Annalisa Maddy[‡] Ms. Lillie Mae McPhetridge[‡] Ms. Ida Miller[‡] Ms. Anne M. Miller[‡] Ms. Jean Ricardi[‡] Dena S. Sachs[‡] Mr. George B. Smith[‡]

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The Paul G. Rogers Circle of Champions

Recognizing individuals and families who, like NOF's founding chairman, the Honorable Paul G. Rogers, are advocates for a healthy America. The giving circle recognizes those who share Mr. Rogers' tradition of action and advocacy to promote bone health and osteoporosis prevention through annual gifts totaling \$5,000 or more. Gifts may be designated to specific program areas of donor interest or given to support NOF's mission and the Honorable Paul G. Rogers' vision of preventing osteoporosis and broken bones and promoting strong bones for life.

2014 Circle Members

Judy A.* and Charles Black Robert F. Gagel, M.D.* and Margo A. Cox, M.D. Ms. Barbara Hannah Grufferman* C. Berdon* and Rolanette Lawrence Jane and Munir Saltoun Ms. Carrie Wetherington

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NOF thanks those who contributed \$5,000 or more between November 2006 and December 2007 to form the Paul G. Rogers Champion Circle.

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Enduring Friends

NOF recognizes the following individuals for their generous contributions for the past 20 years or more. Through their continued dedication and support, these individuals have helped others build, maintain and protect their health for a lifetime of independence.

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Ms. Rosanne M. Weiss Mr. Solomon M. Weiss Mr. and Mrs. David P. Welsch Miss Meredith A. Whelan Commander and Mrs. Albert G. Wickham Ms. Muriel L. Wilhelm Mr. Robert E. Wilson Ms. Judy Wydick

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NOF honors those who have directed their support to help others build, maintain and protect their bone health through a planned gift to the organization.

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Annual Giving

NOF thanks all of our contributors for their generous gifts over the past year. You have helped sustain and enhance our core programs and moved us closer to our goal of helping all Americans achieve healthy bones for life. With your support, we are working to change the course of osteoporosis to prevent fractures before they happen; sparing millions of Americans from the pain, disability and loss of independence that fractures cause.

Healthy Bones for Life Annual Contribution Society *Individuals*

Protectors of Bone: \$25,000 or more

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\$499-\$250

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\$100,000 and above

Amgen, USA CECity.com, Inc. Lilly Merck & Co., Inc. Pfizer Inc.

\$25,000 - \$99,999

DePuy Synthes Health Monitor Network Pharmavite Roche Diagnostics Corporation

\$5,000 - \$24,999

American Frozen Food Institute Anonymous Best of Everything Media Inc. The Endocrine Society Fidelity Charitable Gift Fund Hologic Inc. Immunodiagnostic Systems Limited **IMA** Foundation Lane Labs USA Inc. Medimaps Group Medtronic, Inc. The Merck Foundation Mission Pharmacal Osteogenesis Imperfecta Foundation Pharmaceutical Research and Manufacturers of America Sectra Dorothy D. Smith Charitable Foundation Sunsweet Growers. Inc. Teuteberg Inc Ultragenyx Pharmaceutical Inc.

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* NOF Trustee [‡] deceased

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The NOF Corporate Advisory Roundtable is a high-level working group with a strategic and programmatic focus on promoting bone health and identifying the factors impacting patient access to osteoporosis information and medical care. Members of CAR work with NOF to identify gaps in patient access to information on osteoporosis prevention, detection and treatment and opportunities to better train and educate health professionals to advance the level of care available for osteoporosis patients.

Members of NOF's 2014 Corporate Advisory Roundtable include:

AgNovos Healthcare Alliance for Potato Research and Education Amgen Bayer Healthcare - Consumer Care CE City Data Centrum Communications, Inc. dba Health Monitor Network Eli Lilly and Company FoodCare, Inc. Hologic Impactwear Inspire Lane Labs USA, Inc. Medi Maps Medtronic Mission Pharmacal Optasia Medical, Inc. Pfizer Pharmavite Regenerative Technologies Corporation (Juvent) **Roche Diagnostics**

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2014 FINANCIALS

NATIONAL OSTEOPOROSIS FOUNDATION

STATEMENT OF FINANCIAL POSITION December 31, 2014

ASSETS

CURRENT ASSETS	
Cash and cash equivalents	\$ 1,429,989
Accounts receivable	83,952
Grants, contributions and contract receivable	532,850
Investments	2,748,922
Prepaid expenses	108,458
Inventory	 23,878
TOTAL CURRENT ASSETS	 4,928,049
PROPERTY, at cost, net	 14,839
NONCURRENT ASSETS	
Contribution receivable	89,668
Investments	 180,012
TOTAL NONCURRENT ASSETS	 269,680
TOTAL ASSETS	\$ 5,212,568
TOTAL ASSETS LIABILITIES AND NET ASSETS	\$ 5,212,568
	\$ 5,212,568
LIABILITIES AND NET ASSETS CURRENT LIABILITIES	\$ 5,212,568
LIABILITIES AND NET ASSETS	
LIABILITIES AND NET ASSETS CURRENT LIABILITIES Accounts payable and accrued expenses	344,340
LIABILITIES AND NET ASSETS CURRENT LIABILITIES Accounts payable and accrued expenses Deferred revenue	344,340 152,340
LIABILITIES AND NET ASSETS CURRENT LIABILITIES Accounts payable and accrued expenses Deferred revenue Deferred rent	344,340 152,340 19,191
LIABILITIES AND NET ASSETS CURRENT LIABILITIES Accounts payable and accrued expenses Deferred revenue Deferred rent TOTAL LIABILITIES	344,340 152,340 19,191
LIABILITIES AND NET ASSETS CURRENT LIABILITIES Accounts payable and accrued expenses Deferred revenue Deferred rent TOTAL LIABILITIES NET ASSETS	344,340 152,340 19,191 515,871
LIABILITIES AND NET ASSETS CURRENT LIABILITIES Accounts payable and accrued expenses Deferred revenue Deferred rent TOTAL LIABILITIES NET ASSETS Unrestricted	344,340 152,340 19,191 515,871 3,261,283

2014 | Annual Report

NATIONAL OSTEOPOROSIS FOUNDATION

STATEMENT OF ACTIVITIES Year ended December 31, 2014

SUPPORT AND REVENUE	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Grants and contributions	\$ 1,018,574	\$ 947,551	\$ -	\$ 1,966,125
Bayer settlement	1,354,019	-	÷ -	1,354,019
Contract revenue	176,542	-	-	176,542
Investment income	114,073	-	-	114,073
Membership dues	60,598	266,965	-	327,563
Royalties and consulting income	267,038	-	-	267,038
International Symposium on Osteoporosis	246,505	263,250	-	509,755
Legacies and bequests	246,825	266,751	-	513,576
Publications sales	23,069	-	-	23,069
Donated services and materials	11,909	-	-	11,909
Miscellaneous income	10,756	-	-	10,756
Net assets released from restrictions:				
Satisfaction of program restrictions	1,192,440	(1,192,440)		
TOTAL SUPPORT AND REVENUE	4,722,348	552,077		5,274,425
EXPENSES				
Program Services				
National Bone Health Alliance	1,192,306	-	-	1,192,306
Professional education	908,837	-	-	908,837
Patient education	149,624	-	-	149,624
Communication	278,637	-	-	278,637
Membership	107,344	-	-	107,344
Research	167,580	-	-	167,580
Public policy	42,523			42,523
Total program services	2,846,851			2,846,851
Supporting Services				
Fundraising	733,120	-	-	733,120
Management and general	450,563			450,563
Total supporting services	1,183,683		<u> </u>	1,183,683
TOTAL EXPENSES	4,030,534		<u> </u>	4,030,534
CHANGE IN NET ASSETS	691,814	552,077	-	1,243,891
NET ASSETS, beginning of year, restated	2,569,469	703,325	180,012	3,452,806
NET ASSETS, end of year	\$ 3,261,283	\$ 1,255,402	\$ 180,012	\$ 4,696,697

