



NATIONAL  
OSTEOPOROSIS  
FOUNDATION



# 2016 ANNUAL REPORT





# MISSION & 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.

With a more than 30-year history of raising awareness for osteoporosis and the importance of bone health, today NOF is also committed to curbing the increased incidence of osteoporosis among our aging population and preventing fractures among those at highest risk. With fracture prevention 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 adults age 50 and over who break a bone 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

For the past few years, NOF has been focused on identifying individuals at greatest risk for fracture and developing evaluation and treatment strategies to reduce the number of fractures Americans suffer every year. To advance this effort, we've continued working to increase adoption of the Fracture Liaison Service (FLS) model of care and have joined with other leaders in the bone health field to promote FLS as a very effective process for identifying, diagnosing and treating those at highest risk for fracture.

As we work to reduce the incidence of fracture, we're fortunate that the therapies available for osteoporosis are effective in preventing fractures and can reduce the risk of future fractures by approximately 30-70 percent. We also recognize the significant challenge we face in overcoming the fear of side effects that prevents many osteoporosis patients from starting or continuing prescribed treatment.

To better understand patient and caregiver experiences and concerns when it comes to fractures, osteoporosis diagnosis, treatment and adherence, this summer we surveyed members of our online support community, hosted by Inspire. Since osteoporosis is responsible for two million broken bones in the U.S. every year, we were not surprised to find that loss of independence (42%) and loss of mobility (25%) ranked as the leading concerns about aging among the osteoporosis patients who responded to NOF's Bone Health Index Survey.

However, we were surprised to learn that 52% of the patients who responded to the survey had broken a bone, with three being the average number of bones broken, yet 44% said they were only somewhat or not concerned about fracturing again. We found it very concerning to hear that patients who have fractured are not more concerned about fracturing again, especially when we know that a prior fracture is the most powerful predictor for sustaining an osteoporotic fracture.

Underscoring the fear of medication side effects we know exists among many patients, the survey found that 38% of those who were prescribed an osteoporosis medication said they didn't take it, most commonly citing fear of side effects from the medication as the leading factor for not taking it. And more than half of the patients who were on a medication said they stopped taking it because of the side effects they experienced (53%) or out of concern for the risk of side effects (38%).

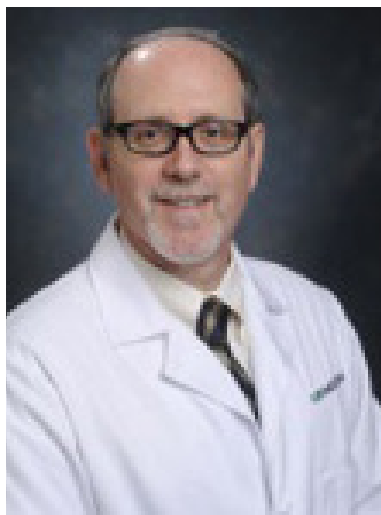
While we know that the number of fractures that are prevented with treatment far outweigh the risk of rare side effects like atypical femur fractures and osteonecrosis of the jaw, we also understand that any side effect is significant when it happens to you or someone you love.

We are taking what we've learned from the survey and working to improve the services and materials we provide to make sure patients, caregivers and healthcare professionals alike are aware of the safety and effectiveness of current treatments and are able to recognize the possible warning signs for rare side effects.

We still have challenges ahead to reverse the negative reputation of many osteoporosis therapies, but are pleased with what we've learned from the Bone Health Index Survey and look forward to leveraging these insights to inform NOF's programming and materials over the coming years.

In the pages that follow, you'll hear more about NOF's important achievements of 2016. Reaching our goals is only possible with your continued support and we 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,



A handwritten signature in black ink, appearing to read 'K. Saag'.

*Kenneth G. Saag, M.D.*  
President



A handwritten signature in black ink, appearing to read 'Judy A. Black'.

*Judy A. Black*  
Chair

## LETTER FROM THE EXECUTIVE DIRECTOR AND CEO

Over the past several years, NOF's education and research efforts have focused primarily on individuals who are at greatest risk of breaking a bone due to osteoporosis and those who have fractured already. Much is being done to reach individuals when their bone density falls very low and their chance of fracturing begins to soar.

Yet, despite years of effort by the medical community to reach those at highest risk for fracture, fewer patients now have access to screenings and many of those diagnosed refuse to take the effective and available treatments. Many people with osteoporosis still go undiagnosed and untreated.

One of the best tools we have in the field is the bone-density scan, axial dual-energy X-ray absorptiometry, called a DXA. Unlike other diseases, where we are waiting to find an accurate screening test or cure, osteoporosis is a model for disease prevention with accurate, cost effective diagnostic tools and inexpensive treatments that are effective in preventing fractures. Bone density testing is more powerful in predicting fractures than cholesterol is in predicting myocardial infarction or blood pressure in predicting stroke.

Our Bone Health Index survey found that unfortunately, a majority (60%) of those who said they broke a bone were not referred for a bone density test, such as a DXA, after they fractured to determine if osteoporosis was the underlying cause of the fracture and less than half (47%) were prescribed an osteoporosis medication for treatment, which could prove to be devastating and costly for our rapidly aging population. In 2010, Medicare paid over \$16 billion for direct costs of new fractures that year and the cost is projected to grow to over \$25 billion by 2025.

To address these challenges head-on, NOF has joined with other leaders in the bone field calling for greater access to bone density tests and for access to all treatment options for patients at highest risk for fractures. This year, we also launched the NOF Ambassadors Leadership Council, a grassroots network of passionate healthcare professionals, patients and caregivers who can help promote greater understanding and awareness of osteoporosis and advocate for access to testing, treatment and awareness. Working together with fellow bone health leaders and this passionate group of advocates, we look forward to bringing attention to the appallingly low level of testing, diagnosis and treatment and working to close the significant care gap it has created.

Coming out of our Bone Health Index Survey, we were encouraged to find that most patients and caregivers (89%) knew that proper diet and exercise, including getting the recommended daily allowance of calcium and vitamin D, is an important part of treating osteoporosis and 90% knew that osteoporosis can not be treated solely through diet and exercise.



We're happy to have such an engaged community of patients and caregivers willing to share their thoughts and experiences with us and will leverage these insights to inform our programming and materials over the coming years.

We appreciate your ongoing support and look forward to working with you to address the needs of osteoporosis patients and the physicians who treat them in the years to come.

A handwritten signature in black ink, reading "Amy Porter".

**Amy Porter**  
Executive Director and CEO



## AWARENESS

*With an estimated 54 million U.S. adults currently at risk for osteoporosis and low bone mass, more than half of the U.S. adult population over age 50 is at risk of breaking a bone and should be concerned about their bone health. At NOF, we're committed to changing the course of this disease by focusing on those at high risk for fracture and helping them make changes to maintain their lifestyle and independence.*

*Through our nationwide network of support groups and online support community with more than 30,000 participating members, we're connecting people to raise awareness for the two million broken bones caused by osteoporosis every year, encouraging anyone age 50 and older who breaks a bone to ask for an osteoporosis test and spreading the word that a few simple lifestyle changes can make a big difference in protecting against broken bones.*

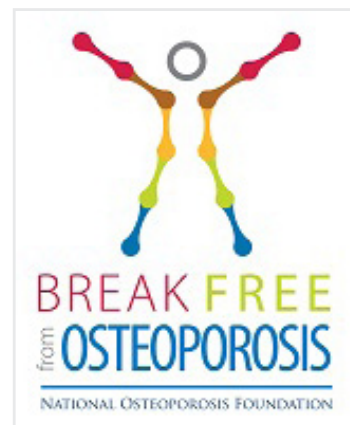
### BREAK FREE FROM OSTEOPOROSIS

In May for National Osteoporosis Month, NOF launched its new website providing a more user-friendly experience and improved navigation, allowing patients, caregivers and healthcare professionals to easily access the latest information on the prevention, diagnosis and treatment of osteoporosis.

Featuring a new "Food for Thought" online pop quiz and updated "Your Guide to a Bone Healthy Diet" brochure, the website places a greater emphasis on the important role diet plays in preventing and managing osteoporosis. The new site also includes information on the importance of clinical research.

This May, NOF also continued its successful *Break Free from Osteoporosis* initiative, offering free resources for the public and healthcare professionals, including a webinar featuring NOF Clinical Director, Dr. Andrea Singer, discussing the recently released Medicines in Development report and providing information on the current treatment options available for osteoporosis patients.

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. Underscoring her commitment to making people of all ages aware of how they can prevent osteoporosis, Barbara published weekly columns on the important role exercise plays in maintaining bone strength and encouraging readers to join her in trying new exercises in honor of National Osteoporosis Month.



**Barbara Hannah  
Grufferman**

## BONE HEALTH INDEX SURVEY

This summer, NOF surveyed members of its Inspire online support community to gain insights into their experiences and concerns regarding fractures, osteoporosis diagnosis, treatment and adherence. Among the patients who responded to NOF's Bone Health Index Survey, loss of independence (42%) and lost mobility (25%) ranked as their leading concerns about aging. Caregivers of osteoporosis patients noted they were most concerned that they would be unable to manage their patient or loved one's care (50%).

The survey also uncovered troubling findings related to patients' concern about fracturing and medication adherence. Fifty-two percent of patients said they had broken a bone, with the average number of broken bones being three, yet 44% said they were only somewhat or not concerned about fracturing again.

Thirty-eight percent of the patient respondents said they were prescribed an osteoporosis medication they didn't take. Fear of side effects from the medication was the leading reason cited for not taking the medication (79%). And more than half (51%) of patients who were on a medication said they stopped taking it most commonly because of the side effects they experienced (53%) or out of concern for the risk of side effects (38%).

Despite these concerning findings, we were encouraged to learn that most patients and caregivers (89%) knew proper diet and exercise, including getting the recommended daily allowance of calcium and vitamin D, is an important part of treating osteoporosis. And 90% knew that osteoporosis cannot be treated solely through diet and exercise.

We are thankful to have such an engaged community of patients, caregivers and people interested in learning about bone health and will use the survey findings to evaluate our current educational materials and activities as part of an ongoing effort to improve the services we provide to patients, caregivers and healthcare professionals.

## POSITIVE EFFECT OF CALCIUM INTAKE AND PHYSICAL ACTIVITY ON BONE DEVELOPMENT

### NOF PEAK BONE MASS POSITION STATEMENT

In February of 2016, NOF released a position statement providing evidence-based guidance and a national implementation strategy to help children and adolescents achieve optimal bone health, or what is known as "peak bone mass," early in life. Considered the first systematic review of its kind, researchers found strong evidence supporting a positive effect of calcium intake and physical activity on bone accumulation and growth.

The manuscript, titled "*The National Osteoporosis Foundation's Position Statement on Peak Bone Mass Development and Lifestyle Factors: A Systematic Review and Implementation Recommendations*," highlights nutrition, physical activity and lifestyle factors involved in developing optimal peak bone mass, which is typically reached in one's early 20's.

Optimizing peak bone mass and strength is a primary strategy to reducing the risk of osteoporosis and related fractures later in life. Bone mass, density and strength are all factors associated with fracture in children and adults that are largely influenced by lifestyle factors.

By releasing the Peak Bone Mass position statement, NOF's goal is to help implement a national strategy to prevent fractures and protect against osteoporosis by highlighting known nutrition and lifestyle changes that can be made to achieve peak bone mass.

## **NOF AND THE AMERICAN SOCIETY FOR PREVENTIVE CARDIOLOGY JOINT POSITION STATEMENT**

Given the ongoing confusion on the topic of calcium, NOF partnered with the American Society for Preventive Cardiology (ASPC) to determine what is known about the connection between cardiovascular disease and dietary and supplemental calcium in order to help those who treat osteoporosis patients provide clear recommendations on calcium and vitamin D intake.

NOF and ASPC convened an Expert Panel to evaluate the effects of dietary and supplemental calcium on cardiovascular disease based on the existing peer-reviewed scientific literature as of July 1, 2016. The Expert Panel considered the findings of the accompanying updated Evidence Report provided by an independent Evidence Review Team at Tufts University School of Medicine.

In October of 2016, NOF and ASPC released a joint position statement on the lack of evidence linking calcium with or without vitamin D supplementation to cardiovascular disease in generally healthy adults.

Together, NOF and ASPC adopted the position that at this time there is only “moderate” evidence that calcium with or without vitamin D intake from food or supplements has no relationship (beneficial or detrimental) to the risk of cardiovascular and cerebrovascular disease incidence, mortality, and all-cause mortality in generally healthy adults. This official position statement was adopted by the Boards of Directors of both societies as of July 2016 and published in the October 25, 2016 issue of the *Annals of Internal Medicine*.

## **ADVOCACY EFFORTS**

### **AMBASSADORS LEADERSHIP COUNCIL**

This year, NOF launched the Ambassadors Leadership Council program, forming a team of well-informed, passionate and persuasive individuals who care deeply about those who suffer from osteoporosis. NOF's Ambassadors are called upon to advise NOF leadership and help make inroads in the medical, business and philanthropic sectors within their communities. Involvement in the program is tailored to each Ambassador's areas of interest, time constraints and expertise.





Our Ambassadors are committed to learning about the challenges and opportunities in bone health and participating in a way they find comfortable and effective. From sharing their personal stories to introducing NOF to their social or professional networks, being interviewed by local and national media, or meeting with or writing to their elected officials in support of patients and caregivers, NOF's Ambassadors are adept at making an impact and sparking positive change in their field, sector or community and do so in their own personal ways.

## MEDICINES IN DEVELOPMENT REPORT

As part of a joint effort with the Pharmaceutical Research and Manufacturers of America (PhRMA), in March NOF released a report on new, innovative therapies being developed for the treatment of osteoporosis. The report, *Medicines in Development for Osteoporosis*, examines the nationwide effects of osteoporosis and explores how new medications can improve and save lives.

The new medications being developed have the potential to save lives and reverse the course of osteoporosis, giving older Americans hope, not only of greater mobility, but also of greater longevity.

Osteoporosis patients often suffer from an imbalance between the reabsorption of old bone and the formation of new bone. Due to greater understanding of this imbalance and its causes, some of the medicines in the development pipeline employ novel approaches to correct this problem.

## EXPANDING OUR REACH

As a result of NOF's awareness initiatives and an ongoing effort to change the conversation from osteoporosis to fracture prevention through year-round media outreach, 2016 was a record-setting year for NOF's media reach. Throughout the year, top national media outlets and women's magazines, including *Everyday Health*, *Huffington Post*, *New York Times*, *Prevention*, *Readers Digest*, *TIME.com*, *USA Today* and more covered osteoporosis and echoed our call to action for men and women of all ages to prevent fractures by maintaining a healthy lifestyle and taking action to protect their bones. In total, nearly 5,000 articles ran in 2016 mentioning the National Osteoporosis Foundation, resulting in more than 715 million media impressions.



## NEW WEBSITE AND E-NEWSLETTER DESIGNS

For National Osteoporosis Month this year, we unveiled a new design for NOF.org, our most valuable channel for communicating directly with osteoporosis patients, caregivers and the public. The new site design is optimized for easy navigation and provides information for patients, professionals and anyone interested in learning about osteoporosis prevention. With richer online content that is easier to navigate and share, we hope the website will be your go-to resource for the most up-to-date information on osteoporosis prevention, diagnosis and treatment.

With the third quarter issue, we also debuted a new design for our quarterly *Osteoporosis Report* e-newsletter. We hope you'll find the new, more colorful and easy to navigate design engaging and will look forward to getting the quarterly update as a great way to keep up on the latest developments in the osteoporosis field.



In 2016, we continued engaging in partnerships with like minded organizations, including the Healthy Weight Commitment Foundation, Huffington Post, Medical Fitness Network, NeedyMeds.org, and Next Avenue. Our successful partnerships help drive additional traffic to NOF.org and we're able to connect osteoporosis patients and caregivers to new resources where they can find health information, qualified fitness instructors and healthcare providers and assistance paying for medications.

### **NOF'S ONLINE COMMUNITY REACHES 30,000+ MEMBERS**

2016 was also an exciting year for NOF's Online Support Community hosted by Inspire. In October, we celebrated passing the community's 30,000 member milestone and we also welcomed a new volunteer moderator to help with the community's rapid membership growth. Our team of volunteer moderators actively engages in conversations with community members to make sure their questions and concerns are addressed and we thank them for their time and dedication to the community.

Ray Morgan joined Sandi Elkin, Pamela Flores, Susie Hathaway and Lawrence Jankowski as our newest community moderator. Ray was diagnosed with osteoporosis after falling and suffering a spine fracture at age 45. Over the next few years, his osteoporosis continued to worsen and after four additional fractures, he was no longer able to work and ended up on disability. Ray credits the help of good doctors for improving his t-scores and keeping him fracture free for the past two years. Ray joined NOF's team of volunteer moderators to try and help others with osteoporosis, especially the newly diagnosed.

NOF's online support community is free to join and participation is open to anyone concerned about their bone health, people with osteoporosis, caregivers, family members and health professionals. We're thankful to our dedicated team of online volunteer moderators and are thrilled to see our online community continuing to grow everyday.

## EDUCATION

*At NOF, our goal is to prevent fractures and ensure that those who fracture receive the best care and support available to prevent repeat fractures. We provide training, tools and resources to help healthcare professionals understand the importance of fracture prevention, especially through osteoporosis testing and treatment to protect those at highest risk. We're also working to advance the widespread implementation of Fracture Liaison Service (FLS) programs as the most effective way to treat post-fracture patients and prevent repeat fractures.*

*Through 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 healthcare professionals who diagnose and treat those at high risk for fracture have the information they need to make informed clinical decisions.*

### **INTERDISCIPLINARY SYMPOSIUM ON OSTEOPOROSIS 2016 (ISO16): AMERICA'S LEADING CLINICAL CONFERENCE ON BONE HEALTH**

ISO16 brought together medical and scientific leaders in the bone health field to identify solutions to reduce the two million broken bones caused by osteoporosis every year. ISO16 was held in Miami, Florida, from May 12-15 and was praised as one of NOF's most informative and successful meetings to date.

ISO16 featured more case-based learning, an updated FLS training and introduced Bone Health ECHO (Extension for Community Health Outcomes), a strategy of tele-mentoring FLS coordinators and healthcare professionals of all levels with the aim of reducing the osteoporosis treatment gap.

Attendees of ISO16 also heard from nationally and internationally recognized experts who presented plenaries and small group sessions on a wide range of topics, including controversies in osteoporosis treatment and care, tools for assessing fracture risk, safe exercises for people with osteoporosis, and answers to common patient questions on osteoporosis and fracture prevention.

The meeting kicked off with professional development workshops on patient education and new coding and reimbursement for osteoporosis and featured keynote speaker Sanjeev Arora, MD with Project ECHO, who presented "Improving Health in Underserved Populations through Technology," and



**SAVE THE DATE**

April 20-22, 2017

Orlando, FL  
Renaissance Orlando at SeaWorld

**NOF**  
NATIONAL OSTEOPOROSIS FOUNDATION

**ISCD**  
THE INTERNATIONAL SOCIETY FOR CLINICAL DENSITOMETRY

**CLINICAL OSTEOPOROSIS**  
2017

The poster features a city skyline at sunset reflected in water. The NOF and ISCD logos are at the top, followed by the event title and date. The location and venue are listed below.



Raisz Memorial Lecturer, Robert Neer, MD of Massachusetts General Hospital, who presented “Historical Perspectives in the Development of Anabolic Therapy.”

Attendees left ISO16 with a wealth of osteoporosis knowledge after hearing many clinical insights and multiple perspectives, all intended to improve care for osteoporosis patients and those at risk for fractures.

## COMMITMENT TO FRACTURE PREVENTION

Underscoring NOF’s commitment to fracture prevention, in August 2016, NOF and NBHA launched the 2016 version of the Osteoporosis Quality Improvement Registry. The registry is intended for all providers and specialties caring for patients with osteoporosis. For the third year in a row, the registry is approved by the Centers for Medicare & Medicaid Services (CMS) as a Qualified Clinical Data Registry (QCDR) for Eligible Professionals and Group Practice reporting Option (GPRO) practices.

The registry comprises of 46 quality measures and, with easy to use reporting, can help providers avoid penalties under quality reporting programs such as the Physician Quality Reporting System (PQRS), Value Based Modifier (VBM) and satisfaction of the Meaningful Use (MU) Specialized Registry Public Health Objective. The QIR registry can also help providers automate EHR data, track performance against benchmarks, close gaps in patient care and manage patient populations.

Also in 2016, NOF joined with the American Society for Bone and Mineral Research (ASBMR) and the National Bone Health Alliance (NBHA) to issue a call for action to address the dangers associated with not treating osteoporosis more aggressively. The statement was issued in response to an Icelandic study, Imminent Risk of Major Osteoporotic Fracture after Fracture, which found that the fracture risk for a person with osteoporosis jumps three-fold after the first fracture.

Lead author Nicholas Harvey, MD, from the University of Southampton in the United Kingdom, and his colleagues found that one year after the first major osteoporotic fracture, the risk of a second fracture tripled compared with the general study population and the risk factor was doubled even 10 years later.

NOF’s Immediate Past President, Dr. Robert F. Gagel, a Professor of Medicine with M.D. Anderson Cancer Center, said that the new information makes it more important than ever for physicians and healthcare providers to take immediate steps to evaluate and treat patients who have sustained an osteoporotic fracture. Currently only 26% of patients who sustain their first osteoporotic fracture are evaluated and treated for osteoporosis, putting large numbers of patients at risk for subsequent life altering and preventable fractures. Leaders from NOF, NBHA and ASBMR agree untreated osteoporosis is a major public health crisis that must be addressed.

## PROFESSIONAL PUBLICATIONS

Interest in and subscriptions to NOF’s scientific journal, *Osteoporosis International*, a joint initiative between NOF and the International Osteoporosis Foundation (IOF) continued growing in 2016. 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.

In February of 2016, NOF announced new and returning editorial staff for *Osteoporosis International's* North American office, including Adrienne Tewksbury, Managing Editor; Jeri Nieves, Ph.D., Helen Hayes Hospital, Senior Associate Editor; Robert Adler, M.D., McGuire Veterans Affairs Medical Center, Associate Editor; Neil Binkley, M.D., University of Wisconsin, Associate Editor; David Dempster, Ph.D., Helen Hayes Hospital, Associate Editor and E. Michael Lewiecki, M.D., New Mexico Clinical Research & Osteoporosis Center, Review Editor.

The editors joined Felicia Cosman, M.D., Medical Director of the Clinical Research Center at Helen Hayes Hospital and Professor of Medicine at Columbia University College of Physician and Surgeons, the recently announced Co-Editor-in-Chief of *Osteoporosis International*.

The editorial staff selected to lead the journal are all highly respected members of the bone research community, who share the strategic vision necessary to attract top manuscripts for publication and maintain OI's position as the most impactful clinical osteoporosis journal in the world.

## **VERTEBRAL COMPRESSION FRACTURE CAMPAIGN**

Vertebral Compression Fractures (VCF) are the most common type of osteoporotic fracture, yet approximately 2/3 go undiagnosed and treated. If untreated, VCFs can lead to serious complications, including chronic pain, decreased mobility, neurological complications and increased mortality risk. In 2016, NOF launched a campaign to raise awareness for the prevalence and severity of VCF by presenting at industry meetings and conferences, including, the Interdisciplinary Symposium on Osteoporosis (ISO) and the American Society of Bone and Mineral Research (ASBMR). In addition, NOF shared information about VCFs through email outreach, via a webinar and added detailed information to its website.

## 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 2010. With 55 organizational participants at the end of 2016, NBHA brings together the expertise and resources of its participating members, and liaisons from five federal government agencies, 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 FRACTURE 20 PERCENT BY THE YEAR 2020

Celebrating its 6th anniversary in 2016 and with NOF continuing to serve as a founding partner, NBHA is making strides toward reaching its 20/20 Vision of reducing the rate of fracture 20 percent by the year 2020. One of the organization's primary initiatives is working to foster widespread implementation of the fracture liaison service (FLS) model of care. FLS programs are widely viewed as the key to closing the 80 percent care gap of those who fracture, but are never tested or treated for osteoporosis.



**NATIONAL BONE HEALTH ALLIANCE**  
STRONG BONES AMERICA



**FRACTURE PREVENTION  
CENTRAL**

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 interested in implementing a coordinator-based, post-fracture FLS model of care to reduce secondary fractures and the associated costs while increasing patient outcomes. Three years after launching in 2013, Fracture Prevention CENTRAL has attracted more than 3,600 subscribers who registered on the site to access the free resources and materials it offers.

In 2016, NBHA focused on improving the usability of the site, adding new resources and hosting new webinars. Having sponsored more than 20 webinars to date featuring the nation's top FLS experts, the successful Fracture Prevention CENTRAL webinar series continued with six new webinars in 2016 covering topics to help interested sites make the business case for and take the steps needed to set up a successful FLS program. The bi-monthly webinar series, offered as live presentations and later for on demand viewing, has attracted more than 3,500 participants in total.

Based on feedback from site users and members of the bone health community, NBHA continued growing the content and tools available on Fracture Prevention CENTRAL throughout the year and in July 2016



debuted its fracture liaison service (FLS) return on investment (ROI) calculator on Fracture Prevention CENTRAL.

NBHA developed the FLS ROI calculator in collaboration with the Research Triangle Institute and University of Alabama- Birmingham to provide a variety of estimates of the costs (and potential cost savings) associated with the healthcare use of statistical modeling techniques following fractures. The calculator also allows for estimates tailored to specific providers, payers, managed care organizations and other stakeholders.

The initial version of the calculator applies to patients age 65 and above, while future releases will allow sites to estimate FLS impact on patients age 50 and above and quantify the impact of the transition to value-based payment models.

NBHA also continued offering its one-on-one consulting service with appointments available at NOF's Interdisciplinary Symposium in May and ASBMR's annual meeting in September. NBHA's FLS consulting service offers 1-on-1 support from leading FLS experts to individual sites seeking assistance with aspects of their FLS program. Since its launch in May 2015, more than 200 individual sites have taken advantage of the service.

## **NOF AND NBHA OSTEOPOROSIS QUALITY IMPROVEMENT REGISTRY (QIR) APPROVED BY THE CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS) AS A QUALIFIED CLINICAL DATA REGISTRY**

On August 30, 2016, NBHA and NOF launched its 2016 version of the Osteoporosis Quality Improvement Registry (QIR), which has been approved by CMS as a Qualified Clinical Data Registry (QCDR) for the past three years. As the only osteoporosis disease-focused QCDR, NBHA's QIR is designed to measure and report on health care quality and patient outcomes. A key advantage of participating in PQRS through the QIR is that CMS has permitted the use of Physician Quality Reporting System (PQRS)-approved measures, as well as non PQRS measures.

Eligible professionals participating in the QIR QCDR also benefit from avoiding costly PQRS penalties by tracking treatment results, quality of care, efficiency and patient satisfaction; auto-generated PQRS and QCDR reporting; being able to compare their results to benchmarks for diagnosis and treatment; practice and outcome comparisons and quality improvement in osteoporosis care.

The measures present in the 2016 QCDR include 46 quality measures that provide healthcare professionals with a way to satisfy increased reporting requirements for PQRS through meaningful and relevant quality improvement activities related to osteoporosis.

## 2MILLION2MANY

Recognizing the need to educate healthcare professionals and patients alike on the risks vs. benefits of osteoporosis therapy, NBHA shifted the focus of its 2Million2Many campaign in 2015 and formed a working group to develop new messages to help change current patient attitudes about treatment. Over the course of 2016, the group continued working to develop a new message platform to communicate the risk vs. benefit of osteoporosis treatment, and created 30-second PSAs featuring real life stories that detail the consequences of undiagnosed and untreated osteoporosis.

The PSAs were distributed via a national cable distribution service in the fourth quarter of 2016 and reached more than 5,000 viewers through their local cable stations.

From August – September, NBHA fielded surveys offering two different versions of the patients and caregiver targeted messages that had been developed by the working group. The surveys were sent to NOF's database of constituents in order to determine the appropriate tone and approach to take with the final messaging platform. One version tested used a very blunt and direct approach and the other used a neutral, educational tone. An invitation to participate in the surveys was distributed via e-blast to NOF's distribution list of constituents.

Survey respondents were asked to self-identify as patients or caregivers and respond to the appropriate survey. NBHA received a total of 511 responses to the surveys, with 399 patients responding and 112 caregivers responding.

Based on feedback from the patient survey, we found that taking a balanced approach to the messaging resonates best with patients. Focusing on the serious risks and consequences of osteoporosis, like loss of mobility and independence resonates well with patients, but needs to be balanced with providing a solution in an optimistic tone. We also found the patients are skeptical of any messages that position medication/treatment as the only solution and also need to strike a balance when positioning medications and treatment as the optimal solution to preventing osteoporosis and fractures.

The caregiver group preferred the direct approach to messaging on all topics, including the effectiveness of available osteoporosis treatment.

NBHA used the survey results to finalize its osteoporosis messaging platform and is working on plans to launch an updated version of the 2Million2Many campaign centered on the new messaging in 2017.

## CALL TO ACTION TO ADDRESS THE CRISIS IN OSTEOPOROSIS TREATMENT

With new evidence emerging showing that the 30-year downward trend in hip fractures in the U.S. has hit a plateau in the last few years, ASBMR called for the bone health field to work together to take action and aggressively work to reduce fracture risk in the aging population.

NBHA joined with ASBMR and 35 other organizations that pledged to intensify their current efforts and collaborate on new opportunities to increase the screening, diagnosis and treatment of high-risk individuals to prevent fractures and to partner with patients to make informed choices about osteoporosis treatment

options. The effort also includes supporting regional efforts in those areas of the world that have a need for greater health professional education and public awareness.

After the call to action was launched at ASBMR's annual meeting in September, NBHA led the process to implement a national action plan detailing how organizations in the U.S. specifically plan to address the crisis. NBHA started by creating a map of all current and planned initiatives U.S. organizations are implementing to support reducing the osteoporosis treatment gap and will coordinate efforts between participating groups to make sure activities are carried out over the following year



# 2016 PROGRAM HIGHLIGHTS

# PHILANTHROPY

*We Need You. For more than 30 years, NOF has relied on the support of a wide breadth of 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. By continuing to work together, we can tackle the remaining challenges and 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 to 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. We 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<sup>‡</sup>  
Virginia S. Bergmann<sup>‡</sup>  
Judy A.\* and Charles Black  
Florence Blazek<sup>‡</sup>  
Sylvia Blechman<sup>‡</sup>  
Ms. Winifred L. Brown<sup>‡</sup>  
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\* NOF Trustee  
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*This giving circle recognizes individuals and families who are advocates for a healthy America, like NOF's founding chairman, the Honorable Paul G. Rogers. The members 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.*

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*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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## 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 have 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

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Medtronic, Inc.

Pharmaceutical Research  
and Manufacturers of America

Roche Diagnostics Corporation

\* NOF Trustee  
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Dorothy D. Smith Charitable Foundation  
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### **\$5,000 - \$24,999**

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Sanofi Foundation for North America  
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*The NOF Corporate Advisory Roundtable (CAR) is a high-level corporate advisory body to our Board of Trustees. Our CAR members share a strategic and programmatic focus on bone health and work to address the fundamental forces that impact patient access to osteoporosis information and medical care.*

*CAR members help identify issues of common concern to NOF and companies with products and services that advance the prevention, detection and treatment of osteoporosis. Through dedicated Working Groups, CAR is addressing specific needs of the bone health field and developing targeted projects that support NOF's Mission.*

### MEMBERS OF NOF'S 2016 CORPORATE ADVISORY ROUNDTABLE INCLUDE:

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## 2016 FINANCIALS

### NATIONAL OSTEOPOROSIS FOUNDATION

#### STATEMENT OF FINANCIAL POSITION

December 31, 2016 (with comparative information as of December 31, 2015)

#### ASSETS

	2016	2015
<b>CURRENT ASSETS</b>		
Cash	\$ 1,506,979	\$ 1,490,314
Accounts receivable	25	111,014
Contributions receivable	373,806	561,890
Prepaid expenses	105,072	131,820
Inventory	6,736	9,037
<b>TOTAL CURRENT ASSETS</b>	<u>1,992,618</u>	<u>2,304,075</u>
<b>PROPERTY, at cost, net</b>	<u>29,280</u>	<u>40,905</u>
<b>OTHER ASSETS</b>		
Contribution receivable, net of current	89,668	89,668
Investments	3,104,776	2,876,090
<b>TOTAL OTHER ASSETS</b>	<u>3,194,444</u>	<u>2,965,758</u>
<b>TOTAL ASSETS</b>	<u><u>\$ 5,216,342</u></u>	<u><u>\$ 5,310,738</u></u>

#### LIABILITIES AND NET ASSETS

<b>CURRENT LIABILITIES</b>		
Accounts payable and accrued expenses	\$ 293,929	\$ 203,055
Deferred revenue	440,580	399,600
<b>TOTAL CURRENT LIABILITIES</b>	<u>734,509</u>	<u>602,655</u>
<b>OTHER LIABILITIES</b>		
Deferred rent	145,446	40,793
<b>TOTAL LIABILITIES</b>	<u>879,955</u>	<u>643,448</u>
<b>NET ASSETS</b>		
Unrestricted	3,090,102	3,454,522
Temporarily restricted	1,066,273	1,032,756
Permanently restricted	180,012	180,012
<b>TOTAL NET ASSETS</b>	<u>4,336,387</u>	<u>4,667,290</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<u><u>\$ 5,216,342</u></u>	<u><u>\$ 5,310,738</u></u>



# NATIONAL OSTEOPOROSIS FOUNDATION

## STATEMENT OF ACTIVITIES

Year ended December 31, 2016

(with summarized comparative information for the year ended December 31, 2015)

	2016				2015
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	
<b>SUPPORT AND REVENUE</b>					
Grants and contributions	\$ 756,534	\$ 679,272	\$ -	\$ 1,435,806	\$ 1,741,216
Contract revenue	15,000	-	-	15,000	97,914
Investment income (loss)	160,221	-	-	160,221	(18,753)
Membership dues	106,825	285,500	-	392,325	349,715
Royalties and consulting income	358,487	-	-	358,487	334,354
Interdisciplinary Symposium on Osteoporosis	426,906	-	-	426,906	250,153
Legacies and bequests	436,303	-	-	436,303	1,040,504
Publications sales	79,825	-	-	79,825	22,686
Donated services and materials	34,069	-	-	34,069	30,179
Miscellaneous income	1,383	-	-	1,383	3,562
Net assets released from restrictions:					
Satisfaction of program restrictions	931,255	(931,255)	-	-	-
<b>TOTAL SUPPORT AND REVENUE</b>	<b>3,306,808</b>	<b>33,517</b>	<b>-</b>	<b>3,340,325</b>	<b>3,851,530</b>
<b>EXPENSES</b>					
Program Services					
National Bone Health Alliance	1,172,613	-	-	1,172,613	1,216,038
Professional education	880,812	-	-	880,812	835,680
Patient education	207,164	-	-	207,164	173,761
Communication	311,464	-	-	311,464	372,071
Membership	82,050	-	-	82,050	116,850
Research	185,856	-	-	185,856	253,475
Advocacy	169,270	-	-	169,270	12,901
Total program services	3,009,229	-	-	3,009,229	2,980,776
Supporting Services					
Fundraising	583,086	-	-	583,086	757,313
Management and general	78,913	-	-	78,913	142,848
Total supporting services	661,999	-	-	661,999	900,161
<b>TOTAL EXPENSES</b>	<b>3,671,228</b>	<b>-</b>	<b>-</b>	<b>3,671,228</b>	<b>3,880,937</b>
<b>CHANGE IN NET ASSETS</b>	<b>(364,420)</b>	<b>33,517</b>	<b>-</b>	<b>(330,903)</b>	<b>(29,407)</b>
<b>NET ASSETS, beginning of year</b>	<b>3,454,522</b>	<b>1,032,756</b>	<b>180,012</b>	<b>4,667,290</b>	<b>4,696,697</b>
<b>NET ASSETS, end of year</b>	<b>\$ 3,090,102</b>	<b>\$ 1,066,273</b>	<b>\$ 180,012</b>	<b>\$ 4,336,387</b>	<b>\$ 4,667,290</b>



**NATIONAL OSTEOPOROSIS FOUNDATION**

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