

RAISING AWARENESS TO STRENGTHEN BONE HEALTH

2018 ANNUAL REPORT





OUR MISSION

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.

Dear Friends of the National Osteoporosis Foundation,

Greetings! What an honor it has been to join this remarkable community, to learn from the leaders, to hear the poignant patient stories that move all of us to do more, and to join in celebration around the areas of progress we are achieving together.

At NOF, we're keenly aware that the leadership and actions of the collective is important. With that said, there are a few special people who have truly left an indelible mark on our progress and our purpose. Please join me in celebrating and honoring the leadership, service, and dynamic contributions of our outgoing board chair, Judy Black. Many of you know that Judy realized early on how important it would be to develop an advocacy strategy. Thanks to her vision, the Surgeon General's Report on Bone Health was created and it was used as the foundation for the research and advocacy activities needed to advance the field. She came back to NOF and helped us set our new dynamic strategy and was responsible for recruiting a new cadre of board leaders who will stand with us and see her vision to fruition. Serving with Judy helped define purpose, volunteer leadership investment, and the importance of putting patients first in a movement. What a privilege it has been to serve with her! The greatest tribute we can pay to Judy, and all of those who have invested dearly in this mission, is to continue to push for progress.

Grounded in the legacy of advocacy Judy Black created for NOF, in 2018 we established the National Bone Health Policy Institute—an effort that will harness the power and best thinking of our advocates, physicians and researchers, communicators, regulators, economists and strategists. Our work through the Policy Institute ensures that the policy initiatives that impact bone health from access to reimbursement are covered and will work with the needs of our patient community and give our physicians the full spectrum of treatments and medicines needed to provide the best care for our patient population.

In the following pages, you will learn more about NOF's important 2018 achievements that lay the groundwork to implement this big idea and create true change—ensuring that adults age 50 and over who break a bone receive appropriate osteoporosis testing, diagnosis, treatment and ongoing support.

We are grateful for your generosity and support of our mission. Osteoporosis is a disease that is still stigmatized and silent, causing suffering and life-altering loss of mobility. With your help, we've made significant progress towards changing current health care policies to allow greater access to bone density tests and appropriate treatment options.

We still have a lot of work to do. Osteoporosis is responsible for an estimated 2 million broken bones per year, yet nearly 84% of older Americans who suffer bone breaks are not tested or treated for osteoporosis. And, 50% of repeat fractures could be avoided with cost-effective and well-tolerated treatments.

On behalf of NOF, we thank the NOF Board of Trustees, staff, members, partners, donors, and volunteers, whose support has made our work possible, and whose strong commitment will help us realize true change to strengthen America's bone health.



Ef gromp-

Elizabeth Thompson Chief Executive Officer



Susan buenspan

President Susan Greenspan, M.D.

OSTEOPOROSIS BY THE NUMBERS

The time is NOW to diagnose and treat this silent killer responsible for 2 million fractures and \$52B in societal costs in 2018.

Osteoporosis is Common.¹



Osteoporosis is serious, even deadly.²

EACH YEAR IN THE U.S., APPROXIMATELY 300,000 HIP FRACTURES OCCUR

Approximately **75,000** Americans who experience a hip fracture die in the year following the fracture.

Another **75,000** Americans move from the hosipital to a nursing home and never return "home."



The remaining 150,000 Americans

never regain their previous function. Six months after a hip fracture, only 15 percent of patients can walk across a room unaided.

Osteoporosis is treatable, if not preventable.³

84% NOT TESTED OR TREATED



The disease is responsible for an estimated two million broken bones per year, yet nearly 84 percent of older Americans who suffer bone breaks are not tested or treated for osteoporosis.

50% OF REPEAT FRACTURES COULD BE AVOIDED

with cost-effective and well-tolerated treatments

Osteoporosis is Costly.³

\$95 billion

\$52 billion IN 2018

The cost of OSTEOPOROSIS-RELATED bone breaks to patients, their families and the healthcare system. BY **2040** Experts predict that osteoporosis will be responsible for over 3.2 MILLION fractures annually over the

next 22 years.

SUMMARY: Policy-driven increases in diagnosis and treatment of at-risk women could substantially decrease the clinical burden, with increases in treatment preventing up to 6.1 million fractures over the next 22 years. At the same time, efficient methods of case finding leading to higher treatment rates could reduce payer costs by \$21B and total societal costs by \$44B over the same period.

1 Wright NC, et al. JBMR doi:10.1002/jbmr2269 | Lindsay et al. Osteoporosis Int. 2005;16:78-85. Wright et al. J Bone Miner Res. 2014;29(11):2520-6.Burge et al. J Bone Miner Res. 2007;22(3):465-75.

² Singer A, et al. Mayo Clinic Proc. 2015;90:53-62

³ Lewiecki, Harmon, doi: 10.1002/jbm4.10192

PATIENT JOURNEY

PATHWAYS TO PREVENTION (P2P) WORKSHOP

2018 National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

NOF Board of Trustees member and author, Barbara Hannah Grufferman, is passionate about both healthy aging and osteoporosis education. Barbara delivered a compelling presentation characterizing the patient perspective to P2P's audience of leading medical experts in the bone health field at the October 30, 2018, workshop, Appropriate Use of Drug Therapies for Osteoporotic Fracture Prevention.





NOF Board of Trustees members, Kenneth G. Saag M.D., Felicia Cosman, M.D. (both standing center) and Barbara Hannah Grufferman (far right) participate in the 2018 NIAMS Pathways to Prevention Workshop.

RESEARCH TO REALITY: IMPROVING PATIENTS' QUALITY OF LIFE

Susan Recker and her husband Dr. Robert Recker, who are both approaching 80 years old, spent much of their lives researching treatments for osteoporosis. Susan was just out of college in 1961 when she started working as a medical technologist at the



Metabolic Research Unit in Omaha, Nebraska, known today as the Osteoporosis Research Center of Creighton University. Fast forward to the mid-90s. Susan's husband, Bob, was now the Center's director and faced with the challenge of running a promising but underfunded study of a family with greater than normal bone density. He asked Susan to volunteer as project manager for the High Bone Mass Study. Over the course of two years, Susan found over two hundred members of this family, coordinated DXAs and blood for DNA evaluation on each of them. This pioneering effort-without fundinghas advanced knowledge and helped pave the way for pharmaceutical research and development.

As NOF's Support Group Leader, Susan's tireless volunteerism is fueled by the suffering caused osteoporosis and she continues to positively impact patients and their ability to live their best lives.

PATIENT EDUCATION AND SUPPORT

NOF's osteoporosis support and discussion communities bring patients and caregivers together to share information about bone density, fractures, osteopenia and more.

NOF SUPPORT GROUPS- BUILDING STRENGTH TOGETHER®

With thanks to volunteers located across the United States, NOF facilitates small, local support groups for patients to learn more about osteoporosis and how to live with the disease from others in similar situations. In 2018, NOF facilitated 35 support groups serving thousands of people across the country.

NOF ONLINE SUPPORT AND DISCUSSION COMMUNITY HOSTED BY INSPIRE

NOF's Inspire Community is a free resource and an important way that 48,000 people can connect online with others who understand the patient journey.





UPDATED NOF BRANDING FOCUSES ON PATIENTS AND AWARENESS



Protect your ability to live your best life.



While osteoporosis is common, it is not part of normal aging. One in two women and up to one in four men over age 50 will break a bone due to osteoporosis.

Talk to your healthcare provider about your risk for osteoporosis and ways you can protect your bones for healthy, active aging.

Visit *NOF.org* to learn more about how you can **STAY BONE STRONG.**

In 2018, NOF's brand evolved with a refreshed visual identity and new focus on why bone health is vitally important. *Protect your ability* to play, travel, explore, enjoy and ultimately, to live your best life. People over the age of 50 need a clear path to risk reduction, diagnosis and treatment for osteoporosis to reduce suffering. NOF's updated brand supports our mission to educate and raise awareness about bone health and ways to stay bone strong.

RAISING AWARENESS

NOF IN THE MEDIA

Raising Patient Awareness

2018 total media impressions = 250 million 2018 total media mentions = 248,000 2018 total media placements = over 3,100

In 2018, NOF's earned media helped raise patient awareness about osteoporosis and strengthen NOF's position as the authority on bone health. The following links share a selection of NOF's 2018 media highlights:

Your Lifetime Health Checkup Roadmap

New York Times, October 11, 2018 "The National Osteoporosis Foundation takes an even more proactive stance. It recommends that all men 70 or older get their bone density checked regardless of whether they have any risk factors or not."



Ehe New York

Aimes

Reader's Digest, August 1, 2018 "According to the American National Osteoporosis Foundation, adults under 50 need 400 to 800 IU of vitamin D daily and adults 50 and older need 800 to 1,000 IU. If you're

not getting enough vitamin D naturally, from the sun, supplementation can be essential. Talk to your doctor about your specific needs based on where you live, what time of year it is, and which vitamin D-rich foods you eat."

Wider Use Of Osteoporosis Drug Could Prevent Bone Fractures In More Elderly Women NPR, October 1, 2018

"This could prevent a lot of fractures,"

says Dr. Ethel Siris, who is on the board of trustees of the National Osteoporosis Foundation. "And preventing fractures in people in this age range not only prevents a lot of suffering but also saves a lot of money."

Women's Health Is About More Than Pap Smears

And Mammograms

Scary Mommy, November 2, 2018 "So what is osteoporosis? According to the National Osteoporosis Foundation, it is "a



bone disease that occurs when the body loses too much bone, makes too little bone, or both."

Osteoporosis in Men: Undertreated and Overlooked

US News & World Report, October 17, 2018 *"Whereas 1 in 2 women will break a bone during their lifetime due to osteoporosis,*

one U.S.News

according to the National Osteoporosis Foundation, 1 in 4 men will have an osteoporosis-related broken bone."

NOF.ORG AND HUESOSANOS.ORG

NOF's website is a leading comprehensive resource for educational information about osteoporosis in both English and Spanish languages.

2018 realized 1.7 million new web users



ADVOCACY

BUILDING GRASSROOTS SUPPORT THROUGH STRONG VOICES FOR STRONG BONES®

The National Osteoporosis Foundation is the voice for issues dealing with osteoporosis and bone health. For 35 years, NOF has been committed to preventing broken bones and osteoporosis through education, advocacy and research. We advocate for awareness, research, patients, and professionals. As part of these advocacy efforts, NOF utilizes VoterVoice, an automated platform allowing supporters to be connect with their elected officials.

NOF helped to spearhead a coordinated grassroots campaign in support of federal legislation to restore funding for bone density testing

Through the VoterVoice platform, we generated almost 6,300 emails to members of the US House and Senate urging support for HR 2693 and S. 283. Osteoporosis champions shared their personal stories to reinforce the message that action is needed now to protect access to DXA testing.

In 2018, over 1,400 new advocates engaged in our grassroots efforts and 1,400 members of the US house and 100 members of the US Senate were contacted about DXA. This year, we also incorporated social media into our efforts, tagging key legislative sponsors and spreading our message.



Through Voter Voice, supporters are alerted to the issue, matched to their correct elected officials, and guided through the message sending process in just seconds.

RECOGNIZING NOF'S AMBASSADORS LEADERSHIP COUNCIL WITH GRATITUDE

An NOF Ambassador is a well-informed, passionate, and often persuasive individual who cares deeply



about those who suffer from osteoporosis. Ambassadors are adept at making an impact and sparking positive change in their field, sector or community. The role of an Ambassador is to advise NOF leadership and to help make inroads in the medical, business and philanthropic sectors within their communities. Involvement is tailored to each Ambassador's areas of interest, availability and expertise.

ADVOCATING FOR BONE HEALTH AT EVERY AGE

Kavita Patel, PT, DPT is a Physical Therapist Advanced Clinical Specialist and Lead for Bone Health Special Interest Group at Kessler Rehabilitation Center in Clifton, NJ, and serves on NOF's Ambassadors Leadership Council. Dr. Patel has been busy spreading the news about



the importance of bone health and osteoporosis screening throughout the Kessler system and in her community. Through clinical skill labs, WebEx webinars and patient forums, Dr. Patel has shared information about assessing bone health while patients are rehabbing, nutrition and bone health, and fracture prevention. She has inspired members of the Kessler Ortho team to participate in NOF's Fracture Liaison Service (FLS) model of care Certificate Program, and she's been an advocate for promoting nutrition and exercise in young people to help them reach Peak Bone Mass.

ADVANCING OSTEOPOROSIS KNOWLEDGE AND PRACTICE FOR HEALTHCARE PROFESSIONALS

INTERDISCIPLINARY SYMPOSIUM ON OSTEOPOROSIS 2018 (ISO18)- NEW ORLEANS, LA



ISO18 offered 30 sessions in addition to networking opportunities to benefit all medical disciplines and specialties involved in testing and treating patients with and at risk for osteoporosis and fractures.

NOF launched the Fracture Liaison Service (FLS) Model of Care Training

and Certificate of Completion at the ISO conference in 2014. The FLS Training and Certificate of Completion explores the most important economic and health system challenges to the widespread implementation of the FLS model of care, covering topics such as the impact of healthcare reform; challenges and barriers in clinical care; and strategies for organizing, staffing and structuring a successful FLS program.

Under the leadership of NOF Trustee, Andrea Singer, MD, FACP, CCD, NOF launched the Fracture Liaison Service (FLS) Advanced Course Model of Care Training and Certificate of Completion in New Orleans, May 16, 2018 at our Interdisciplinary Symposium on Osteoporosis (ISO). This course explored more practice-based clinical questions such as: comorbid conditions and osteoporosis; opioid use and osteoporosis; case-study and treatment selection case reviews; drug coverage issues and resources for providers and patients; and an interactive panel discussion. Recognizing that we have cohorts with four or more years of basic knowledge from previous trainings, the FLS Advanced Course Training is specifically developed for those who have already completed the FLS Certificate. The FLS Advanced Course Training emphasizes the importance of patient tracking, medication approvals, use of registries, and growing your FLS program.

2018 ISO Attendees by Speciality/Industry



CONTINUING MEDICAL EDUCATION

The National Osteoporosis Foundation is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians and is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

In 2018, NOF awarded 521 MORE CME credit hours



PHILANTHROPY

SOURCES OF SUPPORT

To accomplish our mission of preventing osteoporosis and broken bones, NOF accepts support from a variety of sources, including individuals, foundations, government sources, and corporations.

In 2018, NOF's sources of support included the following:

- Individuals: NOF's many generous individual donors gave nearly \$1,900,000, approximately 46% of total annual revenue.
- Pharmaceutical Companies: pharmaceutical company funds accounted for 26% of annual revenue.
- Other Corporate: corporations support NOF's mission through sponsorships, corporate gifts, educational grants, employee matching programs, in-kind contributions, and more. Corporate support accounted for \$640,000, or approximately 15% of annual revenue.
- Other Organizations: support from other organizations, including family foundations and other nonprofits, accounted for \$140,000, or approximately 3% of annual revenue.

THE PAUL G. ROGERS CIRCLE OF CHAMPIONS

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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To accomplish its mission, NOF accepts support from a wide breadth of diversified sources, including individuals, foundations, government sources and corporations.

While some of these funds 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 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.

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.

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FINANCIAL STATEMENTS

NATIONAL OSTEOPOROSIS FOUNDATION

STATEMENT OF FINANCIAL POSITION

December 31, 2018 (with comparative totals as of December 31, 2017)

	2018		2017	
Assets				
Current assets				
Cash and cash equivalents	\$ 2,783,127	\$	1,579,813	
Accounts receivable	24,893		33,655	
Contributions and bequests receivable	729,651		137,998	
Prepaid expenses	86,248		113,561	
Inventory	 79,215		8,097	
Total current assets	 3,703,134		1,873,124	
Property and equipment, at cost, net	 10,359		15,584	
Other assets				
Contribution receivable, net of current	-		89,668	
Investments	 3,242,862		3,515,621	
Total other assets	 3,242,862		3,605,289	
Total assets	\$ 6,956,355	\$	5,493,997	
Liabilities And Net Assets				
Current liabilities				
Accounts payable and accrued expenses	\$ 221,126	\$	132,136	
Deferred revenue	 1,438,845		92,999	
Total current liabilities	1,659,971		225,135	
Other liabilities				
Obligations under charitable gift annuities	95,700		53,050	
Deferred rent	149,402		149,310	
Total liabilities	 1,905,073		427,495	
Net assets				
Without donor restrictions	3,863,930		3,842,302	
With donor restrictions	1,187,352		1,224,200	
Total net assets	 5,051,282		5,066,502	
Total liabilities and net assets	\$ 6,956,355	\$	5,493,997	

NATIONAL OSTEOPOROSIS FOUNDATION

STATEMENT OF ACTIVITIES

Year Ended December 31, 2018 (with comparative totals for the year ended December 31, 2017))

	2018			
	Without Donor With Donor		2017	
	Restrictions	Restrictions	Total	Total
Support and revenue				
Grant and contributions	\$ 829,495	\$ 1,381,030	2,210,525	\$ 2,549,071
Membership dues	67,596	35,700	103,296	354,190
Royalties and consulting income	413,622	-	413,622	380,505
Interdisciplinary Symposium on				
Osteoporosis	427,523	-	427,523	390,450
Legacies and bequests	1,102,564	-	1,102,564	444,941
Publication sales	92,868	-	92,868	148,808
Donated services and materials	6,488	-	6,488	2,321
Miscellaneous income	23,680	_	23,680	6,949
Net investment income (loss)	(250,860)	1,247	(249,613)	413,912
Net assets release d from restrictions		,		,
Satisfaction of program restrictions	1,454,825	(1,454,825)		
Total support and revenue	4,167,801	(36,848)	4,130,953	4,691,147
Expenses				
Program services				
National Bone Health Alliance (NBHA)	618,402	-	618,402	1,228,053
Patient Education	400,388	-	400,388	286,791
Professional Education	1,046,641	-	1,046,641	1,082,839
Advocacy	495,270	-	495,270	367,541
Communications	254,629	-	254,629	283,249
Membership	78,573	_	78,573	106,045
Research	58,197	-	58,197	9,331
Total program services	2,952,100		2,952,100	3,363,849
	2,752,100		2,752,100	5,505,047
Supporting services	002.075		002.055	665.000
Fundraising	803,077	-	803,077	665,922
Management and general	390,996		390,996	184,287
Total supporting expenses	1,194,073		1,194,073	850,209
Total expenses	4,146,173		4,146,173	4,214,058
Change in net assets before combination with Pagets Disease Foundation	21,628	(36,848)	(15,220)	477,089
Assets received in combination with				
Pagets Disease Foundation	-	-	-	253,026
rugeto Discuse roundation				
Change in net assets	21,628	(36,848)	(15,220)	730,115
Net assets				
Beginning of year	3,842,302	1,224,200	5,066,502	4,336,387
End of year	\$ 3,863,930	\$ 1,187,352	\$ 5,051,282	\$ 5,066,502

ABOUT THE NATIONAL OSTEOPOROSIS FOUNDATION (NOF)

Established in 1984, the National Osteoporosis Foundation is the nation's leading health organization dedicated to preventing osteoporosis and broken bones, promoting strong bones for life and reducing human suffering through programs of awareness, education, advocacy and research. NOF works to improve patient care and support for those who have broken bones due to osteoporosis. NOF is the nation's only health organization solely dedicated to osteoporosis and bone health.



National Osteoporosis Foundation 251 18th Street South, Suite 630 Arlington, VA 22202 www.nof.org