## 2017 ANNUAL REPORT





Elevating Osteoporosis on America's Healthcare Agenda



### **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,

For more than 30 years, the National Osteoporosis Foundation (NOF) has been committed to raising awareness for osteoporosis and the importance of bone health, as well as 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 reduce the two million fractures caused by osteoporosis every year and protect the 54 million U.S. adults at risk for osteoporosis by ensuring that adults age 50 and over who break a bone receive appropriate osteoporosis testing, diagnosis, treatment and ongoing support. In the U.S. today, ten million adults are already estimated to have the disease and almost 44 million are estimated to have low bone mass, placing them at increased risk for fracture.

On behalf of NOF, we're thankful for your generosity and support of our mission. With your help, we've made substantial progress toward reaching our goals of reducing the number of fractures caused by osteoporosis and improving the lives of those affected by this disease.

As we look back on the past year, we are pleased to report that we know there are effective testing and treatment options available to help patients recognize and reduce their risk for fractures. With your help, we are working to change current health care policies to allow greater access to bone density tests and ensure patients at highest risk for fractures have access to treatment options.

We still have challenges ahead to increase access to bone density testing and to reverse the negative reputation of osteoporosis therapy, but we are making progress and are charting a course for deeper engagement in the future.

In the pages that follow, you'll hear more about NOF's important achievements of 2017. Reaching our goals will only be 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,



Judy a. Black

Judy A. Black Chairman of the Board



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

# Break Free from Osteoporosis

#### **Greetings!**

2017 was a year of change for the National Osteoporosis Foundation. Amy Porter, the organization's Executive Director and CEO, let the board of trustees know that after seven years of service she was ready for a change. Engaged and interested in the healthcare environment, she wasn't quite ready for full retirement, but eager to spend more time with her beloved husband, John Porter, and her precious grandchildren.

We'd like to pause and celebrate Amy and her service. In 2010, Amy became the CEO and Executive Director of the National Osteoporosis Foundation (NOF). In her role, she was the primary spokesperson to all stakeholder groups. She was responsible for overseeing strategic planning, operations, and administration of the organization. Additional duties included identifying and developing educational and research priorities, enhancing the NOF image and enriching all levels of engagement with patients, caregivers, physicians and the public.

In Amy's first year at NOF, she established the National Bone Health Alliance (NBHA) based on the Biomarkers Consortium model developed at FNIH. Under NOF's management, the NBHA became a successful consortium of over fifty-member organizations joining together to advance research, advocacy and education in osteoporosis and rare bone diseases, and to promote bone health.

We wish Amy well as she embarks on a new professional journey as the Executive Director of the McKnight Brain Research Foundation. The MBRF promotes research and investigation of the brain that underlie the neurobiology of memory with clinical relevance to the problems of cognitive decline and age-related memory loss.

The National Osteoporosis Foundation expresses its deep and sincere appreciation to Amy for her friendship, service, steadfast support and encouragement of the Foundation in support of its mission.

#### Yours in purpose and progress,



Ef gromp.

Elizabeth Thompson Chief Executive Officer

# **54 MILLION AMERICANS AT RISK**

# **Osteoporosis is Common.**<sup>1</sup>



ARE AT RISK OF BREAKING A BONE AND SHOULD BE CONCERNED ABOUT BONE HEALTH



44 MILLION WITH LOW BONE DENSITY



A woman's risk of fracture is EQUAL to her COMBINED RISK OF BREAST, UTERINE AND OVARIAN CANCER. A man is MORE LIKELY to break a bone due to osteoporosis than he is to get PROSTATE CANCER.<sup>2</sup>

# **Osteoporosis is serious, even deadly.**<sup>3</sup>

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."



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

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.

EACH YEAR IN THE U.S., FRACTURES CAUSED BY OSTEOPOROSIS RESULT IN MORE THAN



**400,000** hospital admissions

**2.5 million** medical office visits 180,000 nursing home admissions

# Osteoporosis is Costly.<sup>4</sup>

## \$19 billion ANNUALLY

the cost of OSTEOPOROSIS-RELATED bone breaks to patients, their families and the healthcare system

# \$25.3 billion

BY **2025** experts predict that osteoporosis will be responsible for THREE MILLION FRACTURES resulting in \$25.3 billion in costs.



# WE SPEND ABOUT \$400,000 PER PATIENT, PER YEAR, ON HIP-RELATED FRACTURE CARE

That amount doesn't include the extra costs that go into moving from a home to assisted living, increased costs for physical therapy, increased costs for assisted living devices to help move around to perform activities of daily living, or the significant costs of wound care and pressure ulcers.

# **Osteoporosis is treatable and sometimes preventable.**<sup>5</sup>



# **80% NOT TESTED OR TREATED**

The disease is responsible for an estimated two million broken bones per year, yet nearly 80 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

- Wright NC, et al. JBMR doi:10.1002/jbmr2269 | Lindsay et al. Osteoporos 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.
- 3 Singer A, et al. Mayo Clin Proc. 2015;90:53-62
- 4 Burge R, et al. (2007) J Bone Miner Res 22:465 | Weaver et al. J Manag Care Spec Pharm. 2017;23(4):461-71.
- 5 Klotzbuecher CM, et al. J Bone Miner Res. 2000;15:721.

2 American Cancer Society

### RESEARCH

Bone turnover markers (BTMs) have been recognized as useful tools in clinical practice, but have some short- and long-term fluctuations related to biology and technical variability that have limited their clinical use to date. Among the contributors to the variation in BTM results include analytical methods (e.g., calibration), sample handling (e.g., sample collection) and laboratory performance (e.g., sample analysis). To address these issues, among the NOF's major efforts is the implementation of a number of complementary activities around the harmonization and standardization of the use of these markers that includes the participation of leading academic experts, the diagnostic and pharmaceutical industries, federal government representatives (from the Centers for Disease Control and Prevention, National Institute for Standards and Technology and U.S. Food and Drug Administration) and a number of both commercial and academic laboratories.

The following investigator-initiated studies are part of NOF's Bone Turnover Marker Standardization Initiative Project:

- Inter-Laboratory Comparison Study
- Patient Sample Collection Procedure Standardization Project
- Reference Population Database
- Drug Holiday Study

### **NOF PROGRAM FUNDING IN 2017**

# Program Fundraising – \$665,922 [16%] PROGRAMS – \$3,363,849 [80%]

Program Management \$184,287 [4%]

NOF's program funding demonstrates impact and strong return on investment.

### PATIENT AWARENESS, EDUCATION AND SUPPORT

NOF helps to ensure that no patient, family member or caregiver feels alone or overwhelmed by the diagnosis of osteoporosis or the effects of the disease. To support those with osteoporosis or looking to learn more about the disease, NOF offers:

- A network of small Support Groups where those affected by osteoporosis can learn more about osteoporosis and how to live with the disease directly from those in similar situations.
- An Online Support Community (http://www.inspire. com/groups/national-osteoporosis-foundation) with more than 40,000 participating members offering peer-to-peer support and advice.



• **NOF.org**, our website offering educational information about osteoporosis, strategies about how to live with the condition and ways connect with others for support and to make a difference in the fight against osteoporosis.

# Number of unique visitors average: 116,000 PER MONTH

• In 2017, NOF launched its new Spanish-language website, www.huesosanos.org. The Spanish-language website features the same expert information provided on NOF's English-language website. NOF's most recent prevalence report showed that 2.5 million Mexican-Americans suffer from osteoporosis and low bone mass. The impact of osteoporosis on the Hispanic population nationwide in general, is likely far greater.

# **PROGRAM HIGHLIGHTS**

### NOF IN THE MEDIA

Raising Patient Awareness 2017 total media impressions = 750 million 2017 total media placements = nearly 6,000

In 2017, 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 2017 media highlights.

- Build Your Bones with These 3 Delicious Snacks
  Parade Magazine
- <u>Know Your Bones and How to Take Care of Them</u> at 40 Prevention.com
- New Osteoporosis Guidelines, Treatment Offer Options Chicago Tribune
- <u>10 Things You Didn't Know about Your Bones</u> (and why you should) *Huffington Post*
- <u>Six Reasons to Love Jogging After 50</u> Next Avenue
- NOF introduced the Jumping Jack Challenge— NOF's *Break Free from Osteoporosis* is an awareness and educational initiative that launched in 2015 to help the public learn more about building bone strength and preventing fractures. As part of *Break Free from Osteoporosis*, in 2017, the Jumping Jack Challenge asked participants to film themselves or their family or friends doing 10 jumping jacks in less than 10 seconds, and then post the video to social media— helping to raise awareness and support research in bone health.

## SPECIALIZED OSTEOPOROSIS TRAINING TO ADVANCE KNOWLEDGE AND PRACTICE

- In 2017, NOF awarded 1771 CME credit hours to advance clinician expertise in the field of bone health.
- Fracture Liaison Service (FLS) Model of Care training program for healthcare professionals—FLS programs coordinate post-fracture care through a FLS coordinator (a nurse practitioner, physicians' assistant, nurse or other health professional) who ensures that individuals who suffer a fracture receive appropriate diagnosis, treatment and support. NOF is the educational partner for training FLS coordinators and helping healthcare professionals to establish an FLS program.
- Clinical Osteoporosis 2017 (CO17) Orlando, Florida—NOF and the International Society for Clinical Densitometry (ISCD) offered 27 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.



### MEDICAL DISCIPLINES REPRESENTED AT CO17

### NOF IN ACTION THROUGH ADVOCACY

In early 2017, NOF sent a letter to Members of Congress that was signed by 307 federal and state-based organizations urging them not to revoke the Medicare Part D Non-Interference Clause. Subsequently, NOF led a Protect Medicare Part D (PMPD) Working Group to keep abreast of any pending legislation that would impact seniors' access to medications.

In addition, NOF commissioned research into what the medication landscape would look like for osteoporosis patients if a national formulary were created to address rising costs. The results were dismal. With limited medications currently available for osteoporosis patients, only three would be included on a formulary (similar to the current VA formulary). Of those medications not included in the formulary, 90% of osteoporosis patients likely use them at some point in their care pathway. Thus, NOF concluded that a national formulary would be detrimental to access to treatment for osteoporosis patients. NOF continues to advocate for lower out-of-pocket costs and access to all available treatments for osteoporosis patients.

As leader of the Fracture Prevention Coalition, NOF has partnered with other leading organizations in the field to support legislation that would increase reimbursement rates for bone density test (DXA) conducted in clinical settings. After a decade-long decline in hip fractures in the U.S., the number is on the rise again, coinciding with a drop in the reimbursement rates for DXA and thousands fewer healthcare professionals now providing bone density tests at their practice.



# 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 2017, NOF's sources of support included the following:

Individuals: NOF's many generous individual donors gave more than \$1,102,000, approximately 23% of total annual revenue.

Pharmaceutical Companies: pharmaceutical company funds accounted for 20% 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 \$644,000, or approximately 14% of annual revenue.

**Other Organizations:** support from other organizations, including family foundations and other nonprofits, accounted for \$758,000, or approximately 16% 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 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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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.

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# **FINANCIAL STATEMENTS**

#### NATIONAL OSTEOPOROSIS FOUNDATION

#### STATEMENT OF FINANCIAL POSITION

#### December 31, 2017 (with comparative information as of December 31, 2016)

ASSETS

	2017	2016						
CURRENT ASSETS Cash Accounts receivable Contributions receivable Prepaid expenses Inventory	\$ 1,579,813 33,655 137,998 113,561 8,097	\$ 1,506,979 25 373,806 105,072 6,736						
TOTAL CURRENT ASSETS	1,873,124	1,992,618						
PROPERTY, at cost, net	15,584	29,280						
OTHER ASSETS Contribution receivable, net of current Investments	89,668 3,515,621	89,668 3,104,776						
TOTAL OTHER ASSETS	3,605,289	3,194,444						
TOTAL ASSETS	\$ 5,493,997	\$ 5,216,342						
LIABILITIES AND NET ASSETS								
CURRENTLIABILITIES Accounts payable and accrued expenses Deferred revenue	\$ 185,186 92,999	\$    293,929 440,580						
TOTAL CURRENT LIABILITIES	278,185	734,509						
OTHER LIABILITIES Deferred rent	149,310	145,446						
TOTAL LIABILITIES	427,495	879,955						
NET ASSETS Without donor restrictions With donor restrictions	3,842,302 1,224,200	3,090,102 1,246,285						
TOTAL NET ASSETS	5,066,502	4,336,387						
TOTAL LIABILITIES AND NET ASSETS	\$ 5,493,997	\$ 5,216,342						

#### NATIONAL OSTEOPOROSIS FOUNDATION

#### STATEMENT OF ACTIVITIES

### Year Ended December 31, 2017 (with summarized comparative information for the year ended December 31, 2016)

	2017				2016	
		Without		With		Summarized
SUPPORT AND REVENUE	Dono	r Restrictions	Dono	r Restrictions	Total	Total
Grants and contributions	\$	1,270,635	\$	1,278,436	\$ 2,549,071	\$ 1,435,806
Contract revenue		-		-	-	15,000
Investment income		411,561		2,351	413,912	160,221
Membership dues		82,925		271,265	354,190	392,325
Royalties and consulting income		380,505		-	380,505	358,487
Interdisciplinary Symposium on						
Osteoporosis		390,450		-	390,450	426,906
Legacies and bequests		444,941		-	444,941	436,303
Publications sales		148,808		-	148,808	79,825
Donated services and materials		2,321		-	2,321	34,069
Miscellaneous income		6,949		-	6,949	1,383
Net assets released from restrictions:						
Satisfaction of program restrictions		1,574,137		(1,574,137)	-	
TOTAL SUPPORT AND REVENUE		4,713,232		(22,085)	4,691,147	3,340,325
EXPENSES						
Program Services						
National Bone Health Alliance		1,228,053		-	1,228,053	1,172,613
Professional education		1,082,839		-	1,082,839	880,812
Patient education		286,791		-	286,791	207,164
Communication		283,249		-	283,249	311,464
Membership		106,045		-	106,045	82,050
Research		9,331		-	9,331	185,856
Advocacy		367,541		-	367,541	169,270
Total program services		3,363,849			3,363,849	3,009,229
Supporting Services						
Fundraising		665,922		-	665,922	583,086
Management and general		184,287			184,287	78,913
Total supporting services		850,209			850,209	661,999
TOTAL EXPENSES		4,214,058			4,214,058	3,671,228
CHANGE IN NET ASSETS BEFORE						
COMBINATION WITH PAGETS DISEASE FOUNDATION		499,174		(22,085)	477,089	(330,903)
ASSETS RECEIVED IN COMBINATION WITH PAGETS DISEASE FOUNDATION		253,026			253,026	<u> </u>
CHANGE IN NET ASSETS		752,200		(22,085)	730,115	(330,903)
NET ASSETS, beginning of year		3,090,102		1,246,285	4,336,387	4,667,290
NET ASSETS, end of year	\$	3,842,302	\$	1,224,200	\$ 5,066,502	\$ 4,336,387

### 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