



NATIONAL  
OSTEOPOROSIS  
FOUNDATION



# 2020 ANNUAL REPORT



# LETTER FROM THE CHIEF EXECUTIVE OFFICER AND CHAIRMAN

Dear Friends of the National Osteoporosis Foundation,

The year 2020 will certainly not be soon forgotten. We faced challenges and isolation due to the COVID-19 pandemic and NOF and its people weren't immune to these effects. We cancelled our annual Interdisciplinary Symposium on Osteoporosis (ISO), which typically attracts hundreds of healthcare professionals dedicated to osteoporosis and bone health and provides much needed revenue for our organization and we witnessed drastic changes among our industry partners, necessitating budgetary restraint. Despite these challenges we were resilient: we responded to questions from countless patients and caregivers worried about their osteoporosis; we worked diligently to educate Congress and our federal health agencies about bone health during this tumultuous health crisis; and we continued to support our healthcare providers as they worked tirelessly to provide quality care to patients with osteoporosis.

Despite the challenges our staff and Board of Trustees experienced over the past year, we remained committed to supporting our patient, caregiver, and clinical communities. We quickly modified our office procedures, changing our office and programs to virtual formats, reinvigorated our efforts to provide clinically relevant and updated information on osteoporosis and fractures and learned how to streamline diagnosis and treatment of osteoporosis while navigating national stay-at-home and telework mandates. This was difficult, but everyone rose to meet the challenge.

In the following pages, you will learn more about what we accomplished in 2020. Importantly, we discovered that we can function efficiently using a hybrid telework model, portending greater efficiency and use of resources in the future. We interacted vigorously with governmental and other agencies to advance policy initiatives focused on osteoporosis (as outlined in the report we commissioned from Milliman). We initiated a review of our "branding" that you will hear more about in the future. And this past spring, we held a successful virtual ISO. Not only is NOF alive and well, but we believe we are a better organization. Together, these efforts have helped move us closer to our goal of eradicating fractures due to osteoporosis.

The challenges we faced in 2020 brought about a renewed sense of commitment to making bone health a priority on America's health agenda and we are looking forward to a very busy and productive 2021. We also look forward to active collaboration with other organizations espousing bone health with the goal of improving quality of life for all Americans through

fracture prevention. We hope to accomplish this by reducing redundant activities, harnessing social media and the internet to share our messages and to utilize the resources we have been given creatively and collaboratively.

As always, our work would not be possible without your generosity and support. We are exceedingly grateful to the NOF Board of Trustees, staff, members, partners, donors, and volunteers, whose support makes our work possible, and whose strong commitment will help us advance better bone health for all.

Sincerely,



*Claire Gill*

Claire Gill  
Chief Executive Officer



*Robert F. Gagel*

Robert F. Gagel, M.D.  
Chairman



# PATIENT EDUCATION & SUPPORT HIGHLIGHTS



## SUPPORT GROUPS UPDATE

With our Building Strength Together® support group program as one of NOF's most important assets, in 2020 we launched an intensive effort to identify how we can better support their needs. With all support groups meeting virtually due to COVID-19, we launched a bi-monthly educational curriculum kit offering support group leaders seasonal information about nutrition, exercise, falls prevention, and other lifestyle practices that they can pass along to their members. This dynamic groups include 24 organizations across the country. We look forward to reinstituting live events post-pandemic and hope to grow this important resource to more local communities in the years to come.

## HELPING OTHERS AGE WITH GRACE

This year, we were thrilled to add Sarah Purcell to our team of dedicated volunteer moderators for our online support community and as a member of our Ambassadors Leadership Council. Sarah's personal goal is to age with grace, and she works to help others do the same by helping them find all the ranges of motion they have in every joint and allowing their bodies to adapt to the increased demand over time. She aims to spread the word that you can grow stronger and healthier with age.

Sarah's own diagnosis of osteoporosis in 2016 guided her to support women across the globe with healthy and empowered aging as a movement teacher focusing on Pilates and yoga, as well as functional movement and strength training.



In addition to serving as a volunteer moderator for NOF's online community and as a member of NOF's Ambassadors Leadership Council, Sarah leads an online Bone Boot Camp, an at-home strength training program for women with low bone density. Sarah aims to help her clients not only get stronger, but to also relieve, reduce and remove signals of the recurring aches and pains that come with age. Through all of her work, Sarah's passion is to help women like herself who are dealing with a low bone density diagnosis and are seeking natural pathways to continue to lead a full and active life.

## NOF'S ONLINE COMMUNITY HOSTED BY INSPIRE

NOF's online community continues to be a safe place where patients and caregivers affected by osteoporosis come together to share helpful advice and support one another. We were pleased to see community membership grow to nearly 60,000 in 2020 and remain thankful to our dedicated team of volunteer moderators for the countless hours they invest making sure all community members receive timely responses to their questions and concerns.

This year, longtime volunteer moderators Sandi Elkin and Susie Hathaway stepped away from the community to focus on their family needs. Sandi served as a volunteer moderator for the online community almost since its inception, passionately supporting fellow patients on their journey with osteoporosis. Susie also served the online community for many years, lending her exercise expertise to help community members with tips to exercise safely, build stronger bones, and prevent falls. Sandi and Susie have both been an integral part of our community and moderating team and will be greatly missed.

With Sandi and Susie's departure, we welcomed Burta Guray Samli and Sarah Purcell to our team of online community moderators. Originally from Izmir, Turkey, Burta has lived in the United States since 2011 and has always been passionate about health and alternative medicine. Since being diagnosed with osteoporosis in 2018, Burta has been managing her condition with the help of trusted medical providers as well as physical therapy. She also walks regularly and follows a healthy diet. Burta's goal is to help others better their health through awareness and education.

Burta and Sarah join our team of dedicated volunteer moderators, which includes Pam Flores, Larry Jankowski, CBDT, and Ray Morgan who have served the community for several years.





# PROGRAM AND OUTREACH UPDATES



## HEALTHY BONES, BUILD THEM FOR LIFE® PATIENT REGISTRY

A first of its kind tool in the osteoporosis field, the Healthy Bones, Build Them for Life® Patient Registry surveys patients and caregivers about how osteoporosis and osteopenia impact their lives. This patient-reported information is collected anonymously, combined, and analyzed by NOF to map the patient journey and identify what patients need and want the most.

People living with and affected by all stages of osteoporosis are invited to participate in the Healthy Bones, Build Them for Life® Patient Registry by completing regular, ongoing surveys. With more than a thousand responses to date, we gleaned many helpful insights to help us understand the patient journey. Seeking funding for additional surveys in 2021 will be a key priority as we work to continue collecting patient information and feedback.

## HEALTHY BONES: HEALTHY COMMUNITIES

Launched in 2019, the Healthy Bones: Healthy Communities training program engages a national medical cohort focused on osteoporosis and healthy bones, targeting the educational and support needs of family physicians, internists, and advanced practice providers. The content focuses on everything from basic bone biology to osteoporosis epidemiology, diagnosis, and management.

Through the program, we're training family practice, internal medicine, and/or obstetrics/gynecology providers in each community to become "bone health experts", and to serve as resource and referral for other local clinicians. This year, we shifted to a virtual program format and hosted successful programs in Spokane, WA and Columbus, OH. The program will resume in 2021 with four more training sites.

## CLINICAL EDUCATION AND MEDICAL AFFAIRS

In 2020, NOF's professional membership grew to nearly 500 members. Via the Professional Learning Center, from January to October 2020, NOF provided more than 1,600 continuing education credits to 220 learners. We currently offer 77 activities that can be claimed for 68.75 credits.





**RAISING  
AWARENESS**

## SOCIAL MEDIA OUTREACH

Throughout 2020, we aimed to share valuable information on bone health to expand and deepen conversations on osteoporosis and provide a safe forum for discussion across our social media platforms. As a result, from January to December of 2020, our Facebook and Twitter audiences both grew by more than 12 percent. We also launched an Instagram presence, attracting nearly 250 followers.



More than **9,800**



More than **6,300**



**246**

## BONETALK PODCAST

NOF's monthly BoneTalk podcast and blog share inspiring conversations on bone health. Featuring different experts each month, in 2020 we examined issues around osteoporosis from diverse perspectives including those of patients, healthcare providers, caregivers, policy makers, researchers, advocates, and innovators. Averaging more than 1,000 listeners and visitors each month, the BoneTalk podcast and blog have educated participants on bone health, healthy active aging, and strategies to live their best life.

## NATIONAL OSTEOPOROSIS MONTH

To celebrate National Osteoporosis Month in May, we launched a digital calendar sharing 31 Ways to Stay Bone Strong and encouraging people to learn and practice one tip each day of the month to better protect their bones. We also launched the 10,000 Steps a Day in May Challenge, encouraging people of all ages to commit to taking 10,000 steps each day in May. Those sharing images of their step trackers on social media and tagging NOF in the posts, were entered into a drawing to receive small prizes from NOF.

We also hosted a webinar highlighting findings from the report NOF commissioned from the actuarial firm, Milliman, on the Economic Burden of Osteoporosis and Fractures. Several hundred people joined the webinar live and on demand. The new report provides the latest and most detailed state level review of the incidence of osteoporotic fractures, their healthcare impact, and associated Medicare costs.





**ADVOCACY**

## FRACTURE PREVENTION COALITION UPDATE

Throughout 2020, NOF continued working as a member of the Fracture Prevention Coalition (FPC). NOF and hundreds of physician groups, companies, and advocacy groups all unite as the Fracture Prevention Coalition and work to pass legislation to improve access to bone density (DXA) testing. We extend special thanks to Hologic and Amgen for their continued sponsorship of our FPC activities, which included weekly Coalition calls and maintenance of the database of active, grassroots constituents who are committed to improving access to bone density testing for all Americans.

## NATIONAL BONE HEALTH POLICY INSTITUTE

NOF's Bone Health Policy Institute was launched in 2019 to raise awareness and drive policy that supports patients with osteoporosis and their caregivers. This year, our Coalition to Strengthen Bone Health membership grew to include 15 leading national organizations and we convened three virtual meetings of the coalition. Together, we are advocating to create policies for healthy, strong bones and healthier aging.

On behalf of the National Bone Health Policy Institute, we sent letters to the Chairman/Ranking Member of the Appropriations Committee and the Chairman/Ranking Member of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies outlining the osteoporosis crisis in the U.S. and providing suggested language to use in the FY21 Appropriations Report. Our efforts were successful, and osteoporosis and fractures were included in the Senate's FY21 Appropriations Report to the Department of Health and Human Services.

We also drafted and submitted four comment letters to the Centers for Medicare and Medicaid (CMS) with our feedback and thoughts on issues including expanding and maintaining access to telehealth services for Medicare beneficiaries during the COVID-19 pandemic, Part B payment policies and the Quality Payment Program to protect Medicare beneficiaries access to timely osteoporosis diagnosis, prevention and treatment options, and the policy and regulatory revisions in response to the COVID-19 public health emergency.

We also continued working with the independent actuarial firm Milliman to analyze the state-by-state economic and clinical impact of osteoporotic fractures suffered by Americans insured by Medicare. The reports will be available in early 2021 and will provide the latest and most detailed state-level review of the incidence of osteoporotic fractures, their health care impact and associated Medicare costs.



## SPECIAL THANKS TO THE MEMBERS OF NOF'S AMBASSADORS LEADERSHIP COUNCIL

An NOF Ambassador is a well-informed, passionate, and often persuasive individual who cares deeply about those who suffer from osteoporosis. Our Ambassadors are adept at making an impact and sparking positive change in their field, sector, or community. We added 14 ambassadors in 2020, bringing our current total number of Ambassadors to 164. Also, this year we updated our ALC Member Welcome Materials, developed and distributed bi-monthly email updates focused on advocacy, fundraising and education, and recruited ALC members to respond to specific policy requests, including patient access to Part B drugs during the COVID-19 pandemic and telemedicine.

### AMBASSADOR SPOTLIGHT—TIRELESS DEDICATION TO BONE HEALTH

***E. Michael Lewiecki, MD, FACP, FACE, FASBMR, CCD, is Director of the New Mexico Clinical Research & Osteoporosis Center and Director of the Bone Health TeleECHO (Extension for Community Healthcare Outcomes) at the University of New Mexico Health Sciences Center in Albuquerque, NM. He is a long-time member of NOF's Board of Trustees, serves on NOF's Ambassadors Leadership Council, and works tirelessly to make the latest bone health research and guidance available to osteoporosis patients, caregivers, and healthcare professionals regardless of location.***

*Dr. Lewiecki founded the Bone Health TeleECHO to bring the latest research and information directly to healthcare professionals focused on osteoporosis and metabolic bone diseases and he regularly collaborates with NOF on TeleECHO initiatives. As author of more than 300 scientific publications on osteoporosis and the assessment of skeletal health, Dr. Lewiecki also regularly serves as a media spokesperson for NOF, helping translate scientific information and data to be easily understood by osteoporosis patients and the general public. As a telehealth advisor for NOF, he drafted a "how-to" guide on getting the most out of telemedicine visits, which is posted to the NOF website and has been shared numerous times via NOF's newsletters and social media channels and provided to support group leaders.*





**PHILANTHROPY**



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

In 2020, NOF's sources of support included the following:

- **Individuals:** NOF's many generous donors gave \$1,174,000, approximately 32% of total annual revenue.
- **Pharmaceutical Companies:** Pharmaceutical company funds accounted for 31% of annual revenue.
- **Other Corporate Support:** Corporations support NOF's mission through sponsorships, corporate gifts, educational grants, employee matching programs, in-kind contributions, and more. Corporate support accounted for \$171,000, or approximately 5% of annual revenue.
- **Other Organizations:** Support from other organizations, including family foundations and other nonprofits, accounted for \$127,300, approximately 4% of annual revenue.

## NOF SUPPORT STATEMENT

*To accomplish our 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.*

## PAUL G. ROGERS CIRCLE OF CHAMPIONS

Named for NOF's Founding Chairman, the Honorable Paul G. Rogers, this giving circle recognizes individuals and families who are strong advocates for a healthy America. 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 overall mission and the Honorable Paul G. Rogers' vision of preventing osteoporosis and broken bones and promoting strong bones for life.

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Susan L. Greenspan, MD<sup>T</sup>

Kenneth W. Lyles, MD<sup>T</sup>

## ENDURING FRIENDS

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

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

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## ANNUAL GIVING

NOF thanks 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 and spare millions of Americans from the pain, disability, and loss of independence that fractures cause. **Thank you!**

### REMEMBERING OUR DEAR FRIEND AND COLLEAGUE DEANN SHAFFER

*On July 15 of 2020, our dear friend and colleague DeAnn Shaffer succumbed to her long battle with leukemia. DeAnn served NOF for 10 years and worked tirelessly as the Chief Financial Officer helping to balance the budget and get the organization on a positive course after many years of financial difficulties. We will all remember DeAnn's sense of humor and the grit she showed through such a long and tiring battle with cancer. We'll remember her fondly and are extremely grateful for the generous estate gift she left for NOF.*



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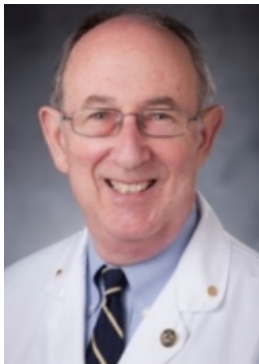




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# 2020 FINANCIALS

## NATIONAL OSTEOPOROSIS FOUNDATION

### STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2020 AND 2019

	2020	2019
<b>ASSETS</b>		
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 2,794,552	\$ 2,953,679
Contributions and bequests receivable	129,276	89,668
Prepaid expenses	68,004	59,092
Inventory	82,039	85,446
Total current assets	3,073,871	3,187,885
 PROPERTY AND EQUIPMENT, AT COST, NET	 6,977	 5,907
 INVESTMENTS	 3,670,241	 3,362,924
 Total assets	 <u>\$ 6,751,089</u>	 <u>\$ 6,556,716</u>
 <b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable and accrued expenses	\$ 211,455	\$ 192,367
Deferred revenue	1,152,832	1,341,436
Total current liabilities	1,364,287	1,533,803
 <b>OTHER LIABILITIES</b>		
Obligations under charitable gift annuities	90,740	96,480
Deferred rent	136,554	145,186
Total liabilities	1,591,581	1,775,469
 <b>NET ASSETS</b>		
Without donor restrictions	3,863,141	3,053,513
With donor restrictions	1,296,367	1,727,734
Total net assets	5,159,508	4,781,247
 Total liabilities and net assets	 <u>\$ 6,751,089</u>	 <u>\$ 6,556,716</u>



# 2020 FINANCIALS

## STATEMENT OF ACTIVITIES

YEAR ENDED DECEMBER 31, 2020  
(WITH COMPARATIVE TOTALS FOR THE YEAR ENDED DECEMBER 31, 2019)

	2020			2019
	Without Donor Restrictions	With Donor Restrictions	Total	Total
<b>SUPPORT AND REVENUE</b>				
Grant and contributions	\$ 628,628	\$ 1,267,298	\$ 1,895,926	\$ 2,807,249
Membership dues	59,697	-	59,697	72,434
Royalties and consulting income	395,686	-	395,686	402,496
Interdisciplinary Symposium on Osteoporosis	-	-	-	125
Legacies and bequests	787,226	-	787,226	181,001
Publication sales	54,930	-	54,930	111,398
Donated services and materials	2,816	-	2,816	2,251
Miscellaneous income	4,729	-	4,729	7,152
Net investment income	421,005	3,160	424,165	603,506
Net assets released from restrictions				
Satisfaction of program restrictions	1,701,825	(1,701,825)	-	-
<b>Total support and revenue</b>	<b>4,056,542</b>	<b>(431,367)</b>	<b>3,625,175</b>	<b>4,187,612</b>
<b>EXPENSES</b>				
Program services				
National Bone Health Alliance (NBHA)	283,837	-	283,837	184,718
Patient Education	344,297	-	344,297	358,131
Professional Education	905,668	-	905,668	1,339,468
Advocacy	908,653	-	908,653	1,141,663
Communications	154,439	-	154,439	90,327
Membership	19,990	-	19,990	35,855
Research	-	-	-	60,966
<b>Total program services</b>	<b>2,616,884</b>	<b>-</b>	<b>2,616,884</b>	<b>3,211,128</b>
Supporting services				
Fundraising	392,652	-	392,652	896,206
Management and general	237,378	-	237,378	350,313
<b>Total supporting expenses</b>	<b>630,030</b>	<b>-</b>	<b>630,030</b>	<b>1,246,519</b>
<b>Total expenses</b>	<b>3,246,914</b>	<b>-</b>	<b>3,246,914</b>	<b>4,457,647</b>
<b>CHANGE IN NET ASSETS</b>	<b>809,628</b>	<b>(431,367)</b>	<b>378,261</b>	<b>(270,035)</b>
<b>NET ASSETS</b>				
Beginning of year	3,053,513	1,727,734	4,781,247	5,051,282
End of year	\$ 3,863,141	\$ 1,296,367	\$ 5,159,508	\$ 4,781,247



NATIONAL  
OSTEOPOROSIS  
FOUNDATION



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