

## NOF News

### Healthy Bones, Build Them for Life® PATIENT REGISTRY

*Translating Your  
Journey to Progress*



If you or someone you love has osteoporosis or osteopenia, you have the power to improve the quality of care for these diseases. By joining the [Healthy Bones, Build Them for Life® Patient Registry](#), you will have the unique opportunity to share your experiences, life lessons and insights. The first of its kind tool in the bone health field, the Registry surveys both patients and caregivers about how osteoporosis and osteopenia impact their lives. This patient-focused survey yields critical information regarding what patients need and want most. Help us make a difference. **Please [Join Now](#) and share with others who may be interested!**

Here's how it works: patient-reported information is collected anonymously, combined and analyzed by the National Osteoporosis Foundation (NOF) to map out the patient journey. These results will shine a spotlight on the greatest needs to NOF and the broader bone health community. While keeping the data secure and anonymous, NOF will carefully review and tally the responses. This patient journey will provide NOF and other

## Osteoporosis "In the News"

### The Daily Meal, March 2020

#### [Ways You Didn't Know Your Body Changes After 50](#)

*Smoking, inactivity and high alcohol consumption can also adversely affect bone health, but one of the most impactful lifestyle choices that can reduce the risk of osteoporosis is committing to a well-balanced diet.*

### Dallas Morning News Online, March 2020

#### [5 Tips to Strengthen Your Bones](#)

*Claire Gill states that "for older adults who fall or break a hip, it may mean not being able to participate in family vacations anymore or not doing certain activities."*

### MSN Health CA, Feb. 2020

#### [40 Ways to Slash Your Risk of Osteoporosis](#)

*According to the National Osteoporosis Foundation (NOF), 54 million Americans either have osteoporosis or are at risk for it due to low bone mass.*

### Advent Health, Feb. 2020

#### [Detect Osteoporosis with a DXA Scan](#)

*When Do I Need a DXA Scan? The*

members of the healthcare community a course to follow -- pointing out knowledge gaps or unmet needs -- based on the invaluable feedback from patients.

Here's a top-line sample of interesting findings already generated:

- Only 44 percent of participants have a family history of osteoporosis.
- The top comorbid condition is depression (9%); scoliosis (8%) is second.
- Of those participants not taking osteoporosis medication, a quarter (25%) have had medication prescribed, but are choosing not to take it and to try to manage the disease on their own. Nearly a quarter (22%) are not taking medication due to the fear of side effects.
- 83 percent of participants have had a drug holiday initiated by their provider.
- The most commonly taken medication is alendronate (54% have taken it at some point) followed by hormone therapy (30% have taken it at some point).
- Only 35 percent of patients have received specific recommendations from their healthcare provider on exercise for osteoporosis or general health.

Thanks to everyone who has participated in Registry to date. [Click here](#) for a summary of learnings. Please remember that your continued participation will help us learn more so that we can move ahead with programs to improve quality of life and quality of care.



## May is National Osteoporosis Month

*National Osteoporosis Foundation shares a user-friendly list.*

### **MSN Health & Fitness, Jan. 2020** **[The Most Common Health Problems In Your 40s](#)**

*According to the National Osteoporosis Foundation, 54 million Americans have low bone density or osteoporosis and the disease causes about two million broken bones each year.*

### **NOF Welcomes New Colleagues**

*Michael Potin*

Michael Potin joined the NOF team in October 2019 as Database Manager. Prior to his current role, Michael worked at ZERO – The End of Prostate Cancer as a Database Coordinator where he processed gifts, managed the database and direct mail outreach and played a lead role to ensure smooth day-to-day operations. From 2011 to 2016, he was a Development Associate at Virginia Theological Seminary, assisting in fundraising efforts and managing the annual phonathone. In both positions, he learned valuable skills in fundraising, database management, and teamwork.

Having family members that suffer from osteoporosis, Michael is committed to his work at NOF. Additionally, with his diverse skill set and knowledge base, he hopes to substantially advance NOF's mission with new, top-of-the-line databases that fuel the team's ability to fight osteoporosis. Michael works closely with NOF's Chief Administrative Officer Debbie

With May just weeks away, it's prime time to remind everyone that osteoporosis is responsible for more than two million broken bones annually in the U.S. at the cost of a staggering \$52 billion. Chronic bone disease is a silent killer that is both preventable and treatable. Americans of all ages need to take charge and understand the importance of good bone health. Learning the facts about osteoporosis, staying active and eating a well-balanced diet consisting of plenty of dairy, fish and other lean proteins, fruits and vegetables are easy, actionable first steps. Stay tuned for more information, updated resources and getting involved via social media for National Osteoporosis Month 2020.



## **NOF is an Official Charity Partner of the 2020 TCS New York City Marathon**

NOF was selected as an official charity partner of the 2020 TCS New York City Marathon. This world-renowned marathon – the largest in the world -- will celebrate its 50th anniversary on Sunday, Nov. 1. To commemorate this milestone year, NOF has recruited five inspired, dedicated women over the age of 50 to join its Be Bone Strong team. The team is committed to showcasing the critical importance of bone health in active aging. The 2020 TCS New York City Marathon provides a unique platform for our devoted runners to raise awareness and encourage others to prevent osteoporosis and broken bones by taking steps to promote strong bones for life. Our Be Bone Strong team will raise much-needed funds to help NOF improve patient care, support those who have broken bones due to osteoporosis and educate the public about this

Erikson and truly believes that there is no challenge they cannot overcome together.

### *Lisa Tumminello*

In January 2020, Lisa Tumminello began her position of Senior Director, Patient Education, Engagement and Advocacy at NOF. Her background is steeped in a variety of awareness and education initiatives designed to impact behavior. She has a diverse history of designing integrated campaigns in the fields of sleep and healthy eating/lifestyle – all from a proactive posture with the goal of helping others to live their best life. From a personal perspective, Lisa has always made it her mission to learn about the preventive steps to help ensure good health. Making it her mission to practice what she preaches, she has already made many of NOF's key messages her own.

At NOF, her role is primarily focused on patient/caregiver education. She is working closely with the team on the [Healthy Bones, Build Them for Life® Patient Registry](#), growing both the Support Groups and the Ambassador Leadership Council members, a variety of advocacy-based programs and seasonal projects like National Osteoporosis Month and the 2020 TSC New York City Marathon.

## **NOF Partners**

### **Medical Fitness Network**

chronic disease. NOF's own Trustee and Bone Health Ambassador, Barbara Hannah Grufferman, is the Be Bone Strong Team Captain. Ms. Grufferman is a nationally recognized advocate for positive living and an avid marathoner. We will keep you informed on exciting marathon details in upcoming issues.

## Advocacy Update

### Coalition to Strengthen Bone Health Meeting

On Feb. 4, NOF held the first meeting of 2020 for Coalition members. Attendees were encouraged to use the Milliman Report findings in reports to leadership, membership and constituents via NOF's slide presentation. In addition, they were asked to have one representative from their organization join NOF at a meeting with Dr. Dorothy Fink, Deputy Assistant Secretary for Women's Health and Director of the Office on Women's Health in the Office of the Assistant Secretary for Health at HHS.

Two action alerts on the NOF website related to Medicare Reimbursement for DXA:

<https://www.nof.org/news-events/advocacy/> requested that members share information through their advocacy channels for H.R. 2693 <https://bit.ly/2H97Gw5> and for S.283 <https://bit.ly/2UnkUgg>.

### Meeting with Dr. Dorothy Fink at Health and Human Services

On Feb. 19, the NOF team, Dr. Andrea Singer and NOF policy consultant Peter Reinecke were joined by Phyllis Greenberger from Healthywomen.org (representing the Coalition to Strengthen Bone Health) for a meeting with Dr. Fink. The meeting's purpose was to introduce Dr. Fink and her colleagues to the NOF and the Coalition to Strengthen Bone Health, highlight findings from the Milliman Economic Burden Report and seek support for educational activities and/or a campaign to promote bone health in the U.S.

Dr. Fink, an endocrinologist by training, is very



NOF and the Medical Fitness Network have partnered to provide a health resource that helps connect osteoporosis patients with qualified fitness and healthcare providers.

Visit the Medical Fitness Network: [www.medicalfitnessnetwork.org](http://www.medicalfitnessnetwork.org).

### Next Avenue



Please visit NOF's partner, NextAvenue, a public media site providing news, information and advice for America's 50+ population.

Visit NextAvenue.org: [www.nextavenue.org](http://www.nextavenue.org).

### Patient Access Network



NOF is pleased to announce it has become an Alliance Partner of the Patient Access Network (PAN) to provide educational resources to osteoporosis patients who request

familiar with osteoporosis and overall bone health. Dr. Fink was supportive of the need for greater awareness about osteoporosis and issues related to the disease and shared several insightful suggestions. NOF will be following up on all of her recommendations and will share progress in future issues of this newsletter.

NOF is grateful to Amgen and UCB for ongoing support for NOF's National Bone Health Policy Institute and advocacy efforts on behalf of DXA reimbursement.

### Join NOF's Ambassadors Leadership Council



Our Ambassador Leadership Council is now 155 members strong! If you're interested in making an impact and initiating a positive change for osteoporosis, please consider joining.

An Ambassador's primary role is to advise and support NOF leadership and help make inroads in the medical, business and philanthropic sectors within their communities. Involvement is tailored to areas of interest, time constraints and expertise. Visit the web page below to learn more and for a list of current Ambassadors:

<https://www.nof.org/news-events/advocacy/ambassadors-leadership-council/>.

If you are interested in becoming an Ambassador or would like to nominate someone, please contact us at [info@nof.org](mailto:info@nof.org) with the subject line Ambassador Nominee.

support from PAN for medical expenses.

Visit the Patient Access Network:  
[www.panfoundation.org](http://www.panfoundation.org).

### Huffington Post

THE  
HUFFINGTON  
POST

NOF is grateful to the Huffington Post and our Bone Health Ambassador, Barbara Hannah Grufferman, for continuing to feature information about osteoporosis and bone health in its blogs.

Click here to subscribe to Barbara's Huffington Post blog:  
[www.huffingtonpost.com/barbara-hannah-grufferman](http://www.huffingtonpost.com/barbara-hannah-grufferman).

# Connect with NOF

## Inspired Talk

NOF's online support community, hosted by Inspire, is a safe and secure place to connect with others, ask questions and share experiences and information about osteoporosis and bone health. Membership now connects more than 52,000 individuals. Read the [press release here](#) to learn more. This online community is free to join and open to patients, caregivers and anyone interested in osteoporosis and bone health.

Links to two current topics on the community are included below. Become a part of our growing community, join these discussions and connect with people with similar experiences as yours.

- Diet and Nutrition

<https://www.inspire.com/groups/national-osteoporosis-foundation/topic/diet-and-nutrition/?origin=tfr>

- Exercise and Physical Therapy

<https://www.inspire.com/groups/national-osteoporosis-foundation/topic/exercise-and-physical-therapy/?origin=tfr>



## Ask the Expert

Kathleen Cody  
Executive Director, American Bone Health

**Q: With 2020 marking the 30th anniversary of American Bone Health, will you please share**

**how the organization is commemorating this milestone?**

A: Throughout the year, American Bone Health is honoring all of the individuals who have helped build the organization and supported our work in their communities. With their help, we are engaging, educating and empowering people across the country to make bone health a priority.

**Q. American Bone Health is 1 of 14 members of the Coalition to Strengthen Bone Health under the Bone Health Policy Institute. Will you please share why it was important for American Bone Health to join the Coalition?**

A. When we survey people at our community programs, we learn that most of them do not have a bone health plan. Over half of them (62%) tell us that they didn't think bone health was important. We need to change that perception! There are many steps that people can take to stay strong, independent and fracture-free for life. Making this happen will take a consistent collaborative effort by many organizations, and we are pleased to be at the table.

**Q. We understand that peer educators form the backbone of American Bone Health and are such a vital resource. Will you please provide additional insight about this invaluable group of volunteers?**

A. Our trained Peer Educators all come to us because osteoporosis has affected them in some way. Whether it is their personal experience with bone loss or they have cared for a loved one with osteoporosis or they are working with clients who are at risk of fractures, they are passionate about increasing awareness. Peer Educators teach others about bone health and how to prevent bone loss and fractures, and they tell us how grateful people are for the information. That feedback on the importance of bone health and the work they are doing inspires them to do more.

**Q. Are there any other resources you would like to showcase?**

A. In recent years, we are seeing bone loss and fractures affecting not only adults over age 65, but also those who are younger. There are many

reasons this could be happening, including other medical conditions or medications. We need to step up our efforts to help people understand their risk and put a bone health plan in place. We have two resources that are incredibly helpful in giving people a road map to bone health.

- The American Bone Health Fracture Risk Calculator™ helps adults over age 45 know their risk in an easy- to-understand format that they can take to their doctor.
- We also have a new interactive guide for people who have recently been diagnosed with osteoporosis. We guide people along the bone health journey, empowering them with the best information available.

Both of these resources are on our website:

[www.AmericanBoneHealth.org](http://www.AmericanBoneHealth.org).