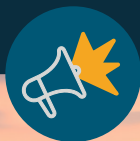


SPRING 2026

NEUROPATHY NEWS



Advocating for Peripheral Neuropathy

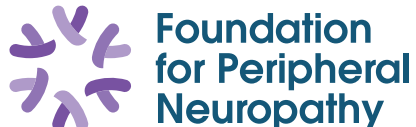


Foundation
for Peripheral
Neuropathy

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PG. 9: MORE ON OUR NEW LOGO



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The information contained in this newsletter is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.

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From the Executive Director



Hello friend!

I joined FPN nine years ago while I was actively caring for my mom, who had diabetic neuropathy. She passed away at 69 during my first year here. I continue this work in her honor and for everyone living with neuropathy. I truly believe in our mission, and I know we are making a real difference.

In this issue, you'll see the difference we're making—whether you're a patient, caregiver, or researcher. You'll meet two new research scholarship recipients whose work we will start funding in June. We're also giving a \$525,000 research grant over three years to study a rare type of neuropathy.

You'll read about our recent advocacy wins, too! And be sure to save the date for Peripheral Neuropathy Awareness Week, May 3-9, 2026. No matter where you live, there are many ways you can get involved.

Lastly, I'm excited for you to meet Jane A., a longtime friend of FPN. Her story is inspiring and reflects the many stories we hear every day that keep us going.

I hope you enjoy this issue and thank you for supporting our important work.

Lindsay Colbert

I'm Still Here! by Jane A.

WHY AM I STILL HERE?

I've often wondered why I'm still here. Why I say this begins with my being "run over" by a car in 1993. As my husband and I were crossing a street on a crosswalk, a car stopped for us. Unfortunately, another car didn't see the stopped car and ran into it. The stopped car then ran into me and pushed me 30 feet into the air. Believe it or not, I stood up and my husband carried me onto the sidewalk. The paramedics who came, people in restaurants, and others couldn't believe that I survived. At the emergency hospital, my elbow was stitched, but I had no broken bones. Some people said that I had a guardian angel. My sister gave me a guardian angel pin which I wear to this day.

A NEW DIAGNOSIS AFTER THE ACCIDENT

But did this accident cause other health problems? No one can say. One week after the accident, while being checked by an endocrinologist, a goiter was discovered on my neck, which wasn't there at the time of the accident. So on to a wonderful endocrinologist at Keck



Photos courtesy of Jane A.

Medical Center in Los Angeles who truly saved my life. When my husband and I moved to Washington DC, I was referred to another endocrinologist who three years later said that I needed to have the goiter removed due to Hashimoto's Thyroiditis. It has been treated through medication for 28 years with no other problems.

RETURNING HOME, THE POWER OF POSITIVITY

Moving back to California (I'm a Los Angeles native) helped me, first to San Diego and then back to LA. I have always been happiest here where people smile

more (maybe it's the sunny weather) and seem to tie in with my practice of the power of positive and hopeful thinking. I would need this power for what was to come – peripheral neuropathy.

HMM...SOMETHING ELSE IS GOING ON

I started to go to a neurologist for vertigo, which I had since I was a child. The neurologist helped me greatly by practicing the Epley Movement when I was really dizzy. It always helped me immediately, except when my husband and I tried it at home!

I realized that my kind neurologist suspected something else in the years that he had been my doctor. At this point I had burning in my ankles and shins. During the typical tests he performed each time I came for an appointment, he said that I probably had peripheral neuropathy but needed to do further tests.

CUE DR. FRANKENSTEIN

So, with my consent he performed nerve conduction studies (NCS) and electromyography (EMG), blood tests, and more. The only thing that helped with this was my sense of humor, where I from then on called him Dr. Frankenstein! The diagnosis was idiopathic small fiber neuropathy.

THE B6 BOMBSHELL

One of the important factors was the extremely high level of Vitamin B6. I had a 107 level, where normal is between 2 and 22! Vitamin B6 can be very dangerous for some people. To this day, I don't eat anything with Vitamin B6. Also, based on reading about gluten-free diets, knowing



others on this diet, and advice from my advanced thinking gynecologist (she was gluten-free), I went on this diet along with my lactose-free diet. It is not fun eating at home! I have never gone back to a regular diet for 13-1/2 years. [KB4.1] I am always on the search for knowledge, especially in terms of drugs. I couldn't agree more than with another patient who said in his patient story that there must be something better than Gabapentin in all these years!

A 'THANK YOU' PARTY

On a positive note, after five years of PN, I gave a "Thank You" party to all who had been kind, helpful, cheerful, positive, smiling, hopeful, and humorous. I included my friends, doctors, acupuncturist, and a psychologist who specialized in hypnosis and meditation. My husband, who also has hope and is very positive, helped me. I believe in surrounding oneself with people who meet the above characteristics.

FINDING MY PEOPLE

It has also been helpful to join others with PN (not the "handwringers" one sometimes meets) such as the Foundation for Peripheral



Neuropathy and the Western Neuropathy Association.

HOPE, SMILES, AND CARRYING ON

As for my neurologists, two of them left me to move elsewhere. I am very loyal and they were very good. Today, my neurologist is Dr. Ha, at Cedars-Sinai in Los Angeles, which is a wonderful medical institution. He shares a positive attitude with me.

I share hope with other patients who have written stories here. I try to pass positive thinking to others, smile most of the time (most people smile back, except for a few grouches), surround myself with friends, and never give up! Maybe I see a little better as to why "I'm Still Here!"

PATIENT VOICES

DRIVING ADVOCACY, RESEARCH, EDUCATION



Do you have a story to tell?

Your story has power. It can inspire others, inform research, and help lawmakers understand the urgent need for progress.

If you are a PN patient, caregiver, or medical professional, we want to hear from you.

Submit your story:
foundationforpn.org/share-your-story/



FPN community survey: help shape our work

Whether you are living with PN, caring for someone who is, or working in the medical field, your feedback helps us understand the challenges you face and the support you need.

Take the survey:
<http://bit.ly/4dvlEBl>



In their own words

By patients, for patients! Read and watch real stories from people living with PN on our website. These stories remind people they're not alone, and that their experiences are real and worthy of compassion.

foundationforpn.org/blog/?category=stories



MAY 3-9 2026

Save the date

PN

| PERIPHERAL NEUROPATHY |

AWARENESS WEEK



Want to support the Foundation and spread awareness of PN? Check out our Bonfire store!

bonfire.com/store/fpn

Get the gear you need to advocate for more PN research, so we can have better treatments, and one day, cures.





Advocating for Peripheral Neuropathy

For over seven years, FPN has been actively working on The Hill in Washington, DC to help bring attention and U.S. federal funding to peripheral neuropathy (PN) research.



One of the Foundation's biggest wins came in 2020, when peripheral neuropathy was approved as a research topic in the Department of Defense's Peer Reviewed Medical Research Program (PRMRP). Before this effort, many U.S. lawmakers had never heard of PN, even though it affects about 30 million Americans. Since then, Congress has renewed this designation every year, leading to nearly \$24 million in research funding for peripheral neuropathy between 2021 and 2025.

FPN also works closely with the National Institutes of Health (NIH). In February, representatives from FPN met with leaders at the NIH. We jointly asked the PN research community to take action by applying for NIH grants, supporting funding across different institutes, helping train and mentor early-career researchers, and spreading the word in their local communities. Taking these steps will grow the number of quality neuropathy research projects. This can lead to better treatments and, one day, even cures.

Lastly, the impact of FPN's Advocacy Day, first held in 2025 and most recently took place on March 11, has been significant. During these events, patients, researchers, staff and board members meet with members of Congress to share personal stories and explain why PN research matters. These face-to-face meetings help build strong relationships that support future funding.

Want to help us advocate for PN? There are plenty of opportunities to get involved.



foundationforpn.org/advocacy/



**MORE ON 2026
ADVOCACY DAY**

Photos courtesy of Amanda Homscheid, Katie Britton, Jane Bartmann, iStock



2026 Neuropathy Advocacy Day Requests

- » Renew the PRMRP designation of “peripheral neuropathy” in the fiscal year 2027 Defense Appropriations Act
- » Appropriate not less than \$51.3 billion for NIH in fiscal year 2027
- » Include report language in the fiscal year 2027, Labor-Health and Human Services-Education Act directing NIH to increase and better coordinate PN research across its institutes.

Read the full Advocacy Day recap on our blog:



foundationforpn.org/neuropathy-advocacy-day-2026-fpn/

2026 NEUROPATHY ADVOCACY DAY

March 11, 2026: Our impact on the Hill

11 states represented

19 advocates for PN

34 meetings on Capitol Hill

WHY I WENT TO ADVOCACY DAY

I’m here to represent the veteran community and every other person suffering from peripheral neuropathy. Hopefully we can get the funds we need to fight this awful disease.

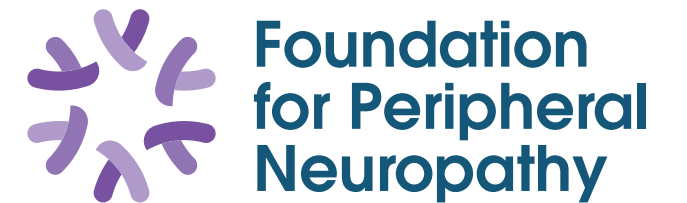
Michael H.
PN patient

A clearer look for the same mission

For people living with peripheral neuropathy, the goal is clear: better care, better treatments, and one day, cures. That goal guides everything we do.

As the Foundation for Peripheral Neuropathy has grown, it has become more important that people can easily find us, recognize us, and trust the information and research we share. Our previous logo was often hard to read, especially online, which made that harder to do.

That’s why we’ve updated our logo.



Board growth



George Montague



Jennie Starr

In 2025, FPN added two new board members to help guide its work. George Montague joined as the new Treasurer. He has many years of experience in healthcare and finance and wants to help FPN use its money wisely and grow its impact for people living with peripheral neuropathy.

Jennie Starr also joined the board. She has worked in law, tech, and biotech, and even started and ran a nonprofit while raising her children. Her mother’s experience with

peripheral neuropathy led her to support FPN’s mission. Jennie plans to help with outreach, marketing, and partnerships so the Foundation can reach more people and support more research.

PLEASE JOIN US IN WELCOMING GEORGE AND JENNIE TO OUR LEADERSHIP TEAM!

This change is not about looks alone, and it does not change our mission or priorities. The designer who created the new logo lives with peripheral neuropathy himself, bringing personal experience to the work.

Our mission remains the same. We’re simply improving how we show up to better support it.



Connecting patients, experts and resources

Our monthly webinars offer educational content for all members of the PN community: patients, physicians, researchers and caregivers. You can register to attend live, or watch the recordings whenever you have time.



Here's a couple of our recent favorites:

Regain your balance: Therapy and exercise for neuropathy patients



youtube.com/watch?v=Njw7zbXa4Ww

Mark Fasick and Dr. LeeAnn Manoni from the NeuroBalance Center share how the body's balance system works and why it matters, along with simple exercises that help improve balance.

New tax law changes make giving easier

New federal tax rules make it even better to support our mission to fund research and help people affected by PN.

Most taxpayers take the standard deduction. Now, they can also deduct up to \$1,000 (single filers) or \$2,000 (married couples) for donations to qualified charities like FPN. This does not include gifts made through donor-advised funds.

If you are age 70½ or older, you can give up to \$111,000 from your IRA directly to FPN through a Qualified Charitable Distribution (QCD). This gift counts toward your required minimum distribution and is not taxed.

You can also include FPN in your will or estate plans through a bequest, beneficiary designation, or other planned gift to create a lasting impact.

Members of the Mazawey Legacy Circle are honored for their promise to support research, education, and patient care for many years to come.

Please talk with your tax advisor to find the best option for you. To learn more, visit our website or email info@tffpn.org.



youtube.com/watch?v=2KMk63VvXbc

Inside our biobank: FPN's Peripheral Neuropathy Research Registry

Dr. Ahmet Höke, a neurologist at Johns Hopkins and lead investigator of the study, shares discoveries made through the biobank, current research projects, and how this work continued to bring hope for better treatments for peripheral neuropathy. Additionally, board member, Adam Halper, talks about the impact of the biobank from his perspective as a patient.

GOT A TOPIC IN MIND?



Email us: info@tffpn.org

UPCOMING WEBINARS

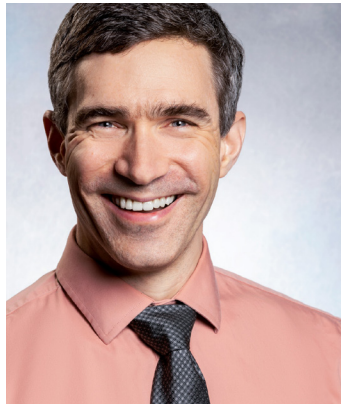
Details at FoundationForPN.org/events



Updates in research

FPN welcomes new training grant recipients

We are proud to announce the two newest recipients of the 2026 Clinical Research Training Scholarship in Peripheral Neuropathy. This is a two-year grant of \$150,000 that supports early-career researchers in their important work.



Christopher Cashman, MD, PhD, is a neurologist at Mass General Brigham and a teacher at Harvard Medical School who studies why the longest nerves in the body are often damaged first. Cashman's research looks at how aging and damage to mitochondria, the parts of cells that make energy, can cause nerve damage, especially in the far ends of long nerves.



Ariel Zhang, MD, PhD, is a postdoctoral fellow at Lewis Katz School of Medicine at Temple University. In her current postdoctoral work, she studies mechanisms of neuropathy associated with chemotherapy. Currently, Zhang is studying how certain chemotherapy drugs harm nerve cells. Zhang hopes to find new treatments to protect nerves during cancer therapy.



New anti-MAG neuropathy research underway

Thanks to our grant, a three-year biomarker study just started in the Netherlands through the iMAGiNE Study. This research will look at how a rare autoimmune form of neuropathy (anti-MAG neuropathy) starts, changes, and affects people differently. Biomarkers may reveal early signs of worsening disease. FPN is funding this important research project, with a grant of approximately \$525,000.

This research study will look at better ways to track and predict how IgM-related peripheral neuropathy changes over time. Researchers will follow patients for several years and collect blood samples and health information at different visits. First, they will study many proteins in the blood to find early warning signs that may show when a patient's condition is getting worse. These findings are then checked in patients from other countries to be sure the results are reliable. Next, the researchers will group patients into smaller subgroups based on symptoms, test results, and biomarkers, since the disease affects people in different ways. Finally, the team will look to use this information to improve a tool that can help predict how the disease may progress in the future. The goal is to better understand the disease, improve research studies, and support more personalized care for patients.



DID YOU KNOW?

Everyone who supports this research study will get special access to a private online talk with the lead researcher. You'll hear directly about the research and the steps taken to complete the study. Donate to this research project today to make sure you receive an invitation.



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PERIPHERAL NEUROPATHY AWARENESS WEEK

MAY 3-9, 2026

MORE
ON PG. 5

