

# Advocacy continues to fund neuropathy research

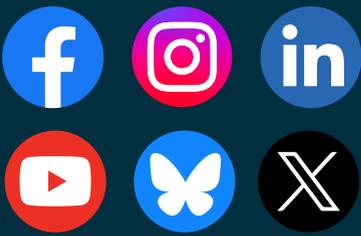
## NEUROPATHY NEWS



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FALL 2025



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LINKS AT [LINKTR.EE/TFFPN](https://linktr.ee/tffpn)



# Raising \$18K for FPN Day

October 15, 2007 is the day FPN was founded, a day when a bold mission began. Thanks to supporters like you, we now help tens of thousands of patients around the world, fund important research, and give medical professionals the tools they need to best serve patients.

This upcoming FPN Day, mark your calendar to celebrate our 18th anniversary by joining our community of changemakers and making a gift to help us reach our \$18,000 goal.

Don't want to wait? Donate today and write "FPN Day" on your check or when you donate online.

[FoundationForPN.org/donate](https://FoundationForPN.org/donate)



## FoundationForPN.org

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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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# Advocacy updates



In 2025, funding for the Peer Reviewed Medical Research Program (PRMRP) was cut from \$370 million to \$150 million. At the end of July, the Senate agreed on a new plan for the 2026 Defense Budget. It brings PRMRP funding back to \$370 million and once again lists peripheral neuropathy as a condition that can be researched. This is good news, but it is not the final bill yet. We expect more updates later this year, with the final decision likely to be made in December.

We've also made progress with the National Institute of Neurological Disorders and Stroke (NINDS), which is part of the National Institutes of Health (NIH). There have been

a lot of changes in research this year, and we want to make sure our research community understands them. We're excited to keep working with other groups at the NIH, like the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Cancer Institute (NCI).

Lastly, our partnership with the Department of Veterans Affairs grew so we can better support a community that is frequently impacted by neuropathy, raising more awareness about neuropathy.

We're proud to keep speaking up and pushing for more research and support for our PN patient community!





## From the Executive Director

### **Dear FPN supporter,**

I'm excited to share some great things we've done this year — and it's all thanks to you! Because of your support, *the* Foundation for Peripheral Neuropathy (FPN) has made big progress in helping patients and pushing research forward.

#### **Here are a few highlights from 2025 so far:**

- » About 20,000 people watched our webinars, and 750,000 people visited our website to learn more about peripheral neuropathy.
- » We raised over \$150,000 to fully fund another research scholarship, with help from a matching gift from one of our donors.
- » Our advocacy work helped make sure peripheral neuropathy stayed on the Senate's Defense Appropriations bill for the 6th year in a row — making neuropathy eligible for \$370 million in research funds.

Behind all these numbers are real people who inspire us every day. People like Dieter R., a neuropathy patient who runs marathons to raise money and awareness for FPN, show us why this work matters so much.

In the next few months, we'll keep working hard to reach our yearly fundraising goal, build even stronger research partnerships, and get ready for our 18th anniversary celebration!

Thank you for being a part of this journey. We couldn't do any of this without you.

Sincerely,

Lindsay Colbert



Lou Mazawey



## Leaving a Legacy

This August, for National Make-A-Will Month, we were excited to share the news about the new Mazawey Legacy Circle.

This special group honors people who plan to support FPN in the future by including us in their wills or estate plans. These generous gifts will help us work toward a future without neuropathy.

The group is named after Lou Mazawey, a former president of the FPN board and a current board member. Lou is also a PN patient, a donor, and a leader in retirement and employee benefits law. His kindness and support have helped our organization grow, and his legacy will continue to guide us in the years to come.

I'm creating a legacy gift for the future of FPN by naming the Foundation as a major beneficiary of my 401(k) retirement plan. I know whatever strides we make to benefit the PN community need to continue after my lifetime and am hopeful my legacy gift will achieve its objectives.

Lou Mazawey

When you include FPN in your will or estate plans—just like Lou and many others—you help move research forward and help more people learn about peripheral neuropathy. Together, we can make life better for future generations.

If you've already planned to give a gift in the future, or you're thinking about it, we want to thank you. You can join the Mazawey Legacy Circle by filling out the reply card included with this message.

Your kindness, now or later, helps us get closer to better treatments and cures for PN.



# RUNNING FOR



## A DECADE OF DETERMINATION

BY DIETER R. | PN PATIENT, AVID MARATHON RUNNER

This year marks a significant milestone for me: My 10th time running Chicago! What started as a personal challenge after the tragic Boston Marathon bombing in 2013 has blossomed into a decade-long journey of resilience, determination, and now, a platform to raise awareness for a cause very close to my heart.

In 2013, at 55, I was hardly what you'd call a "runner." I embarked on a journey of endless training miles. From the scenic coastal roads of New Hampshire to the beautiful city paths along the Charles River, I proudly completed my first marathon in 4 hours and 12 minutes, feeling happy and strong.

### My PN journey: *Finding strength in motion*

Besides the concerns about the condition of my heart, 2023 brought a new, unexpected challenge: a suspicion of peripheral neuropathy (PN) in November, followed by a diagnosis of idiopathic polyneuropathy in January 2024. The burning and hypersensitivity in my feet caused by the nerve damage introduced a new layer of complexity to my marathon training. Initially, I was worried the 2024 Marathon might be my last.

However, I found ways to adapt and manage my symptoms. Physical therapy played a crucial role in strengthening my core and

# RA REASON



2013 | 2014 | 2015 | 2016 | 2018 | 2019 | 2021 | 2022 | 2024 | 2025

improving my overall fitness. Special insoles in my running shoes, fine-tuning my Gabapentin medication and applying Lidocaine patches before the race all contributed to a successful 2024 marathon. While it wasn't my fastest, it was undoubtedly my most consistent, a testament to overcoming the hurdles peripheral neuropathy presented. Running, and exercise in general, has become an integral part of my daily life and a vital tool in managing my symptoms. I'm excited and ready for the upcoming 2025 Chicago event!

## Running to raise awareness: *Join me in supporting FPN!*

My personal experience with peripheral neuropathy opened my eyes to the incredible value *the* Foundation for Peripheral Neuropathy (FPN) offers to patients. I realized running Chicago would be an ideal event to shine a light on this often-misunderstood nerve condition. My goal is to not only challenge myself physically but also to raise vital funds and awareness for neuropathy research, education, and patient support.

You can view Dieter's 2025 marathon page and contribute to his fundraiser at

<https://fundraisers.hakuapp.com/Dieter-CHI2025>





# 2025 webinar highlights

We work with amazing experts who share important information about peripheral neuropathy (PN). You can find recordings of our webinars online. We encourage you to watch, or rewatch, them anytime. Here are a few of our favorites this year:



## Why participate in clinical trials?

We welcome Jennifer Gewandter, PhD, MPH, from the University of Rochester in this webinar. Dr. Gewandter talks about the importance of clinical trials for research and how they work.



## Emerging options for neuropathic pain management

Featuring Brian Callaghan, MD from the University of Michigan, patients learn about different ways to treat nerve pain, their cost, and what results patients can expect from them.



Got a topic in mind?  
Email us: [info@tffpn.org](mailto:info@tffpn.org)



FoundationForPN.org/past-webinars



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FIND ALL THESE  
WEBINARS AND  
MORE ONLINE



## Myths vs facts: Deepening understanding and raising awareness

In this webinar, FPN board member Shanna Patterson, MD, MS, of Mount Sinai New York clears up common misunderstandings about neuropathy. Whether related to its causes, symptoms, treatments, or overall impact on health, Dr. Patterson helps explain things that many people may know or may have heard wrong.

## UPCOMING WEBINARS

- » Oct. 22 | Exercise & physical therapy with PN
- » Nov. 13 | National Family Caregivers Month
- » Dec. 10 | Inside our biobank, the Peripheral Neuropathy Research Registry

**Details at**  
**FoundationForPN.org/events**



# Updates in research



## New research partner

We're happy to welcome the University of North Carolina at Chapel Hill to our Peripheral Neuropathy Research Registry (PNRR) biobank team as a new enrollment and research center. They are now one of eight research centers working with us to help fight neuropathy.

## New research discoveries

Two new studies using data from the PNRR were recently published. Below is a quick summary, with more details at:

[FoundationForPN.org/pnrr-publications](https://FoundationForPN.org/pnrr-publications)

One study found that people with diabetes-related nerve damage had more pain and worse nerve problems. It also showed that people with other health issues, like those from metabolic syndrome, had even more pain and nerve damage.

The second research finding looked at a protein called neurofilament light. People with higher levels of this protein often had more serious nerve pain.

## Updates from the iMAGiNe study

Two new studies from the iMAGiNe research group were also published. This group studies a rare type of neuropathy called anti-MAG. You can find more details about the FPN-funded research at [FoundationForPN.org/imagine-study](https://FoundationForPN.org/imagine-study)

## Clinical Research Training Scholarship (CRTS) updates

### 2023 WINNERS

**Erika Williams, MD, PhD**

Studying the automatic nervous system and how its nerve cells change with disease

**Paula Barreras, MD**

Studying the link between a disease called sarcoidosis and small fiber neuropathy

### 2024 WINNER

**Francesco Michelassi, MD, PhD**

Studying how a cancer treatment may cause nerve damage, known as Chemotherapy-Induced Peripheral Neuropathy (CIPN)

### 2025 WINNER

**Tiffany Li, PhD**

Studying new ways to find early signs of CIPN





## The impact of early-career research grants

Earlier this year, FPN promised to raise \$150,000 to pay for next year's Clinical Research Training Scholarship (CRTS) for peripheral neuropathy. We reached our goal and are excited to read the applications in November to choose the best research project to support.

The CRTS is a special scholarship that gives money to new researchers who are just starting their careers. It helps them study ways to treat, prevent, or even cure peripheral neuropathy. Giving young scientists this kind of support early on helps them stay focused on this important work for many years in the future.

FPN has supported emerging experts since 2023's award cycle. We are proud to call these awardees members of our research community.

**Interested in funding an emerging scholar's research project?**

Reach out to us at [info@tffpn.org](mailto:info@tffpn.org) to learn more.



“This grant has been absolutely critical seed funding. It's given me the protected time to pursue the science, and that's a tremendous gift.

Erika Williams, MD, PhD | 2023 recipient

“There are very few people who want to study PN [due to the lack of funding], but I'm a physician scientist looking for ways to treat this disease in [a patient's] lifetime. Because of this grant, I have been able to continue my research.

Francesco Michelassi, MD, PhD | 2024 recipient

“One key reason for my interest in chemotherapy-induced peripheral neuropathy, is that unlike many other neuropathies, it provides a unique predictability—we know exactly what the toxic insult is, neurotoxic chemotherapies, and we can pinpoint its onset with precision, tied directly to the administration treatment.

Tiffany Li, PhD | 2025 recipient



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**FPN DAY IS**  
**Oct. 15**

**DETAILS  
INSIDE**

