

2024 ANNUAL REPORT



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Focusing on *research, patient education* and *advocacy*, our work advances our mission to improve the lives of patients living with peripheral neuropathy and accelerate the development of treatments, and one day, cures. As a 501(c)3 nonprofit, we are 100% philanthropically funded.

Dear supporters,

Another year is in the books. We're excited to share our 2024 impact with you, which included an increased focus on even more peripheral neuropathy (PN) research funding.

We continue to offer grants to early-career researchers. This is key to engaging future generations of investigators in PN research. These projects also advance our understanding of PN, leading to promising research paths for future studies to build on.

Our biobank, the Peripheral Neuropathy Research Registry, continues to fuel PN research progress. The samples and data make many PN research projects possible, and in 2024 led to three research publications.

While we have increased our focus on research, we have not reduced our work in other areas. Our advocacy work continues to pay off and gives PN researchers access to funding through key Department of Defense grants.

We keep producing educational webinars and resources for the entire PN community. These resources help patients learn to be their own best advocate while seeking diagnosis and treatment options. These materials offer valuable information on understanding PN and managing care for patients.

We continue to promote awareness of PN, and the needs of the 190 million people it touches worldwide. This happens through focused efforts during awareness week in May. It also happens through our social, educational offerings, web content and conversations with our multi-faceted community throughout the entire year.

Flip through the rest of this report to see details on our work in research, advocacy and education, working in tandem to increase awareness and produce better outcomes for PN patients now and in the future.

Thank you for your continued support,

  
Lindsay







# RESEARCH

## **CRTS** || Clinical Research Training Scholarships

We accepted the third year of applications for early career research scholarships in peripheral neuropathy (PN). Our 2024 recipient, Francesco E. Michelassi, MD, PhD is working on research focused on chemotherapy-induced PN. These awards offer insight into PN now, and help ensure the pool of researchers working on PN continues to grow and flourish in the future. These awards are funded by FPN, and made possible through a partnership with the American Brain Foundation and the American Academy of Neurology.



## **iMAGiNE STUDY** || Anti-MAG peripheral neuropathy research

We continue to fund anti-MAG peripheral neuropathy research through the iMAGiNE study. The objectives of the study are to identify clinical and biological criteria to help the neurological community monitor and predict the progression of this rare form of peripheral neuropathy, and to identify effective treatments.

## **Website** || Funding and research updates

Our website offers the scientific community funding updates, grant opportunities and valuable resources for their research.



## Research affiliates || Working with researchers around the globe

- » The American Academy of Neurology (USA)
- » The American Brain Foundation (USA)
- » Aarhus University Hospital (DENMARK)
- » Beth Israel Deaconess Medical Center (USA)
- » Clinical Center of Serbia Neurology Clinic (SERBIA)
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- » University of North Carolina (USA)
- » University of Oxford (UK)
- » The University of Utah School of Medicine (USA)
- » Virginia Commonwealth University (USA)
- » Washington University, St. Louis – School of Medicine (USA)

### PNRR || Peripheral Neuropathy Research Registry research updates

- » Vitamin D: Research indicates no link between low vitamin D levels and worsened peripheral neuropathy symptoms in idiopathic cases
- » New Biomarker Discovery: Researchers identified unique protein and lipid signatures in idiopathic peripheral neuropathy patients with neuropathic pain, potentially leading to a new blood test for objective pain measurement
- » Novel Pain Mechanisms: New findings suggest new mechanisms of pain in idiopathic peripheral neuropathy, prompting further research at Johns Hopkins Medicine using mouse models to explore mechanisms further
- » Three new studies began in 2024, using data from the PNRR

3

PNRR research  
publications  
in 2024

22

active  
PNRR research  
projects total



# ADVOCACY + AWARENESS

## **NIH** || National Institutes of Health

We expanded efforts to focus on opportunities with the NIH. The NIH is the world's largest funding agency for biomedical research. Their involvement is key to expanding PN research and accelerating treatments and cures.



## **DoD PRMRP** || Department of Defense Peer Reviewed Medical Research Program

Due to our efforts, peripheral neuropathy (PN) was once again included as an eligible condition to receive research funds from the Department of Defense. Through this program, researchers from around the country can apply for grant funding for their PN research. A \$370 million budget was approved to support research on PN and 41 other conditions for the 2024 fiscal year. Three PN projects received over \$3.5 million in funds.

## **Awareness** || Making PN seen

Through our work, in print, digital and in person, we continue to spread awareness of PN. We highlight the struggles of patients, and the need for better treatments. We share that our focus on research is driven by our desire to develop cures. Through these efforts, we expand our community and broaden our network of supporters.

**3,600**

EMAIL SIGNUPS

**3.5M**

IN DoD FUNDS

**1400**

DONORS



# EDUCATION

## **Webinars** || Live programming offers access to experts

We hosted 14 webinars in 2024. We even had our first ever summer web series, hosting six webinars in four weeks. We engaged 4400 participants through the series. Sessions covered a range of topics, like the basics of peripheral neuropathy (PN) managing symptoms and hearing stories from patients about their personal PN journeys. Want to watch? Use the QR code below.

2024 PN Summer education Series

**4000**  
**VIEWS**

**2700**  
**REGISTRANTS**



**WATCH NOW**

## **Website** || Free education for the masses

Our website continues to be a premiere educational resource on PN. Utilized by patients and caregivers from the PN community, it provides information for every step of the PN journey.

**9,170**

**WEBINAR  
REGISTRATIONS**

**26.3K**

**VIDEO VIEWS**

**2M**

**WEB VISITS**



# Building a Legacy of Hope:

## My journey with peripheral neuropathy and the Foundation



### By Lou Mazawey

PN PATIENT, FPN BOARD  
PRESIDENT 2016-2024,  
MOVE TO BOARD MEMBER  
FOR 2025

In 2003 I was diagnosed with peripheral neuropathy (PN). In my case, it's Anti-MAG PN, a rare autoimmune variant affecting as few as 7/100,000 PN patients. Fortunately, I was soon under the care of one of the world's experts on the subject, Dr. David Cornblath, on the faculty at Johns Hopkins in Baltimore, Maryland.

Dr. Cornblath was also on the Board of *the Foundation for Peripheral Neuropathy* (FPN), which he encouraged me to join to help make a difference for PN patients nationwide. Early in 2016, he introduced me to Jack Miller and his wife, Goldie Wolfe Miller, who started FPN initially as a private foundation in 2007 to lead research efforts and gather experts in the field. We had a very good visit at their home and I joined the board. Soon after, Jack decided to take a less active role, and I was privileged to be elected his successor as board president. Around that time in 2016, Lindsay Colbert joined FPN as its Executive Director, and FPN – now a nonprofit – was off to a critical new phase of growth and development.

Over the last eight years, working with Lindsay, the board and staff, I have overseen and supported the growth of FPN in key areas, including:

- » Establishing a federal advocacy program, where FPN successfully lobbied for expanded federal funding for PN research, through programs such as the National Institutes of Health (NIH) and the Department of Defense's (DoD) Peer Reviewed Medical Research Program (PRMRP).
- » Building a partnership with the American Brain Foundation and the American Academy of Neurology to fund early career researchers through FPN's Clinical Research Training Scholarships (CRTS).
- » Providing continued funding for the IMAGiNE study (which I 'seed funded' in 2015), an anti-MAG PN biobank used to identify and predict disease progression and treatment responses.

- » Continuing to fund, grow and promote the Foundation's Peripheral Neuropathy Research Registry (PNRR), a major PN biobank of diabetic and idiopathic PN patients and a key resource for PN research.
- » Expanding education and awareness by sponsoring patient education events in major US cities.
- » Pivoting in the pandemic to create online webinars, and continuing that online programming to this day to provide resources to a broader, worldwide audience.

As the years have passed, my PN has progressed slowly and I have limited my activities in some ways. Nevertheless, I am grateful for the experience of meeting PN patients from across the country, and tried to help many of them through their PN journeys. And I have been pleased to provide meaningful financial support each year to help enable the ongoing work of FPN – a very small non-profit with a huge patient population – to do the same.

Recently, I decided to take one more important step. 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 am well aware that whatever strides we are able to make to benefit the PN community need to continue after my lifetime and after my service on the board ends in the next four years. I am hopeful my legacy gift will achieve its objectives.

The challenges we face are substantial! I ask fellow PN patients to join me in supporting FPN to provide a better future for us all.

## PAY IT FORWARD

Like Mazawey, you can ensure those affected by PN have hope, support and more research funding. Consider including the Foundation in your estate plans. Contact us at [info@tffpn.org](mailto:info@tffpn.org) to learn how your legacy can make a difference.



## 2024 Financials\*

Operating budget: \$1,258,632

Revenue: \$1,797,563

*100% philanthropically funded*

### Investment in impact work:

(research, advocacy, education, awareness)

63%

(\$793,378)



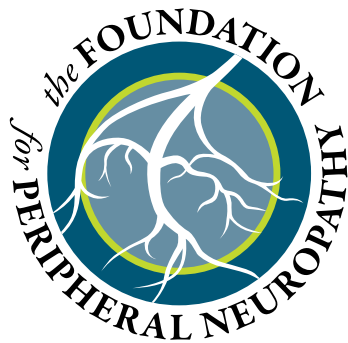
### Largest impact investment:



**RESEARCH**

41% (\$525,640)

\*Unaudited numbers



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YOUR SUPPORT FUNDS RESOURCES THAT HELP THE PN COMMUNITY LIVE BETTER LIVES, AND RESEARCH IN THE PURSUIT OF IMPROVED TREATMENTS, AND ONE DAY, CURES

*thank you*

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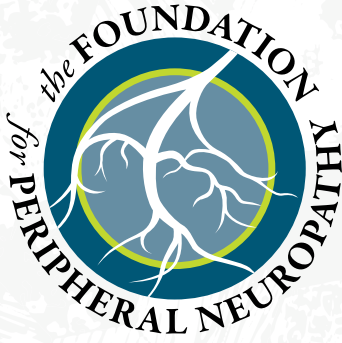
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*the Foundation for Peripheral Neuropathy* is a 501(c)3 nonprofit committed to improving the lives of those affected by peripheral neuropathy through awareness, education, advocacy, and research to advance the discovery of new therapies and cures.

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