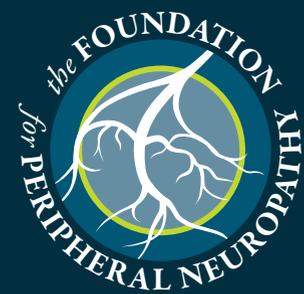


A BETTER FUTURE FOR THE  
**PERIPHERAL  
NEUROPATHY  
COMMUNITY**



**2023 ANNUAL REPORT**



It's been a rewarding year supporting the peripheral neuropathy community with our work at the Foundation.



READ ABOUT THE  
APPROPRIATIONS  
ACT



It's been a rewarding year supporting the peripheral neuropathy (PN) community with our work at *the* Foundation for Peripheral Neuropathy (FPN).

In 2023, we continued our advocacy work. Once again, we secured PN a spot on the list of topics eligible for research funds through a key Department of Defense (DoD) program. In addition to our continued work with the DoD, we expanded our efforts to focus on opportunities with the National Institutes of Health (NIH), the world's largest funding agency, for biomedical research. As a result, the Senate Committee on Appropriations recognized the importance of PN research and emphasized the need for the NIH to take a more coordinated approach to better understand the causes of PN and identifying potential new treatments.

Through *research funding*, *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.

We continue to fund, grow and promote our biobank as a research resource. The Peripheral Neuropathy Research Registry (PNRR) is the only PN biobank in the world. It's a key resource for patient information. What makes it truly unique is that it goes above and beyond the scope of what a single research

institution could manage to collect on their own. This valuable resource helps us better understand this far-reaching condition.



WATCH A VIDEO ABOUT THE PNRR



Research isn't our only focus. We also help patients cope with and manage the struggles brought on by PN. Our free online educational content was accessed over 50,000 times a month in 2023. This helps patients, families and care teams understand the causes and struggles of PN and navigate the diagnostic and care paths ahead.

Despite impacting approximately 30 million Americans, and over 190 million worldwide, PN remains an often unheard-of condition. To help combat this lack of understanding, in May 2023, we launched our largest awareness week campaign to date. We had over 103,000 interactions with the PN community. We're thrilled we were able to engage with long-time supporters and bring over 25,000 new people into the PN community in a single week!

As we look ahead to 2024, and all its potential, we are excited to continue capitalizing on our existing growth momentum. We'd never be able to grow awareness and support for the PN community without folks like you. Thank you for your dedication to our cause. Please continue to spread awareness about FPN, and the often-debilitating condition PN is. Together, we'll keep finding better treatments, and one day, cures.

Sincerely,

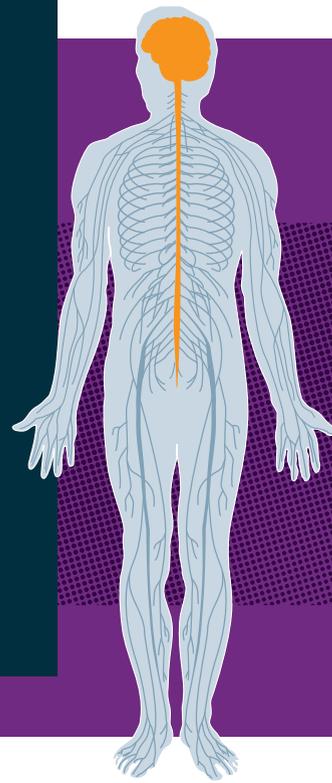
Lindsay Colbert  
Executive Director

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# What is peripheral neuropathy?

Peripheral neuropathy (PN) occurs when the peripheral nerves are damaged or destroyed, preventing them from sending messages between the brain and other parts of the body. Peripheral nerves are the nerves outside of the brain and spinal cord. A neurological disorder, rather than a disease, PN has hundreds of causes, and, possibly more devastatingly, endless unknown causes. Symptoms can vary significantly. While some individuals experience pain and numbness, others may encounter issues related to balance, mobility, loss of grip strength, and autonomic functions like blood pressure regulation and sweating.



- Central nervous system
- Peripheral nerves

## education



### We provide resources for the entire PN community.

Patients, family, friends, and healthcare providers can all find valuable information at [FoundationForPN.org](https://FoundationForPN.org). Our ever-expanding library of educational materials highlights causes and potential treatment options, medical advances, research, and ideas for living well with PN. We've expanded our webinar programming to nearly monthly, increasing access to PN content via live webinars and through recordings.

### Our support network continues to grow.

With hundreds of thousands of interactions across our media annually, we're helping patients improve the quality of their lives. We'll keep growing our educational reach by connecting with the PN community where they are. We're proud to provide high-quality educational experiences and materials at no cost. It's key to our mission of improving the lives of everyone impacted by PN.

50,000+  
VISITS TO OUR  
EDUCATIONAL  
CONTENT PER MONTH



WATCH  
OUR PAST  
WEBINARS

3700  
WEBINAR REGISTRANTS

# research



20 PNRR RESEARCH PROJECTS UNDERWAY

\$24,750 IMAGiNE STUDY FUNDING

\$506,000 INVESTED IN RESEARCH

## Our involvement in research continues to grow.

The Peripheral Neuropathy Research Registry (PNRR) is the only biobank of PN samples in the world. It is entirely managed and funded by FPN. With 20 projects currently underway, the biobank is crucial to developing a deeper understanding of what causes PN, and how it progresses. This will help develop better treatments and prevention tactics and lead us on the path to cures.

We're continuing our partnership with the American Brain Foundation and the American Academy of Neurology to fund early career researchers. The Clinical Research Training Scholarships (CRTS) are designed to encourage more scientists to pursue PN as their area of focus. Our third award goes to Francesco E. Michelassi, MD, Neuromuscular Research Fellow at Columbia University Irving Medical Center. Michelassi's research will specifically focus on chemotherapy-induced PN.

We continue to fund the IMAGiNE study, and specifically, help fund patient enrollments into this biobank. This international project focuses on a rare, auto-immune form of PN known as anti-MAG. In this condition, the person's own immune system attacks nerve cells, resulting in slowly progressive and debilitating PN. The project's goals are to identify and predict the disease progression and treatment response for anti-MAG PN patients.

## RESEARCH affiliates

- » 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)
- » Columbia University Irving Medical Center (USA)
- » Icahn School of Medicine at Mount Sinai (USA)
- » Institut Sant Pau Investigació Biomèdica (SPAIN)
- » Istituto Clinico Humanitas (ITALY)
- » Hôpital Bicêtre AP – HP (FRANCE)
- » Hospices Civils de Lyon (FRANCE)
- » Johns Hopkins Medicine (USA)
- » KU Medical Center – University of Kansas (USA)
- » Massachusetts General Brigham (USA)
- » Mayo Clinic, Rochester, MN (USA)
- » Michigan Medicine – University of Michigan (USA)
- » Northwestern University (USA)
- » The Ohio State University (USA)
- » Peripheral Nerve Society (USA)
- » University of Miami (USA)
- » University of Oxford (UK)
- » The University of Utah School of Medicine (USA)
- » Virginia Commonwealth University (USA)
- » Washington University in St. Louis – School of Medicine (USA)

# awareness + advocacy

We help the world realize the prevalence of PN through advocacy, awareness, and educational programs. An estimated 30 million people in the U.S. and over 190 million worldwide struggle with PN.

## We promote awareness of PN year-round.

Early May is when we focus our efforts and celebrate peripheral neuropathy awareness week. We spread awareness by educating people and expanding our PN community. In 2023, through organic community building, we had the most engagement during awareness week that we've ever had!

## We outfitted peripheral neuropathy supporters with hundreds of shirts.

Now they can better spread awareness in their everyday lives.



## We engaged with our existing community.

Sharing insights that illustrate the prevalence and severity of PN, and highlighting why donors support us, strengthens our connections to each other, and our call to fund research for better treatments and cures.



## We gave people materials to help them talk about peripheral neuropathy.

Armed with new ways to engage their personal community, we made it easier for them to tell their stories and talk with their healthcare providers.

With over 103,000 connections made during awareness week, we were able to bring over 25,000 new people into our community. This is only the beginning. Imagine what we can do if every week is treated like PN awareness week.

### HELP SPREAD AWARENESS

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

has ways you can help strengthen our community, spread awareness and support more research.

OUR NEXT BIG AWARENESS PUSH:

2024 AWARENESS WEEK:  
May 5-11



## Our advocacy work continues to pay off.

We have successfully lobbied for expanded federal funding for PN research, through programs such as the National Institutes of Health and the Department of Defense's (DoD) Peer Reviewed Medical Research Program (PRMRP). Peripheral neuropathy must be renewed as a condition eligible for funding annually in the PRMRP. We have succeeded in securing its inclusion every year since we began lobbying in 2019. In 2023, \$3.6 million was awarded to PN research projects, bringing the total DoD funds for PN research to \$19.2 million. Additionally, the Senate Committee on Appropriations recognized the importance of PN research and emphasized the need for the NIH to take a more coordinated approach.



# \$3.6M

DoD FUNDS TO NEW PN RESEARCH PROJECTS



# \$19.2M

TOTAL DoD FUNDS TO PN RESEARCH SINCE WE STARTED LOBBYING

reaching for BETTER TOMORROWS

MATCHED GIVING HELPS US REACH A NEW AUDIENCE

83 FIRST TIME DONORS

\$213,170 raised from Van Salmans' matched giving campaign FOR PN RESEARCH

A dark-themed graphic with a blue and orange color palette. It features a curved horizon line at the top. The text is arranged in a hierarchy, with the main headline in large white letters and supporting statistics in smaller white and orange text. A blue banner with white text is positioned across the middle. The bottom right corner has a pattern of orange dots.

## Faces of PN:

Walter



Walter van Woudenberg and his wife Els form a socially-minded couple. When they retired, they chose to go on a philanthropic journey. Walter was diagnosed with idiopathic peripheral neuropathy (PN) over 25 years ago. After his diagnosis, they shared experiences navigating the challenges of his condition, reinforcing their desire to make a difference in the lives of others facing similar struggles.

Their decision to focus on helping others was not taken lightly. They recognize the profound impact organizations like *the Foundation for Peripheral Neuropathy* (FPN) have on individuals and families affected by neuropathy. Walter and Els dedicate themselves to supporting causes close to their hearts. They have become advocates for raising awareness of PN and funding research to find better treatments and, one day, cures.

Now that he's 77 years old, Walter thinks back on his time with PN. He's determined and wears a big smile when he talks about his PN journey.

When diagnosed, Walter recalls the initial shock and dismay of learning about his condition: "I have what?" He started on a mission to keep his mobility and vitality. He was warned of the potential weakness and decline in his legs and hands, but Walter refused to give up.

He committed to staying healthy and fit. Now, Walter continues activities that bring him joy. He still mountain bikes, goes horseback riding, and skis challenging slopes. Walter has defied the limitations imposed by his condition. He credits his ability to keep active to the advice he received from Ahmet Höke, MD, PhD, FRCPC at Johns Hopkins, encouraging him to combat lethargy and reject the notion of giving up.

Walter finds immense satisfaction in knowing that his retirement years with Els are filled with personal fulfill-

EMBRACE  
THE  
ENJOYMENT  
OF A FULL  
LIFE

ment and purpose. They prioritized giving back to their community by supporting organizations like FPN. This shows their commitment to making a meaningful difference in the world.

To show his gratitude and support for the organization that has been a crucial part of his PN journey, Walter hopes others will join him in giving to *the Foundation for Peripheral Neuropathy*.

“I hope I can inspire some of you to work towards warding off the seemingly inevitable decline in mobility and embrace the enjoyment of a full life. There is so much data out there that can help you deal with this affliction. Even if you seem to have lost some mobility, start small. Get up and move. Try chair yoga or stationary bicycling, and keep walking! Research optimum diet and nutrition for PN. Check the impressive resources at the Foundation for the smartest use of supplements, natural remedies, PT, and pharma medicine if needed.

*And donate to the Foundation!”*

# financials

2023 OPERATING BUDGET: \$1,205,782

## income

100% philanthropically funded  
over \$887,000 raised

## expenses

63% of our budget is spent on impact work in awareness, education, advocacy, and research.

Our largest impact investment is *research*:  
37% of our 2023 spending supported PN research.





# 2023 DONOR ROLL

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*

## Visionary Circle

| \$50,000 & Above |

Lou Mazaway  
Jack Miller Family Foundation  
Van & Sue Salmans

## Ambassador Circle

| \$20,000 - \$49,999 |

Alnylam Pharmaceuticals  
Estate of Elvin C Downer Jr  
KAG Trust  
The Morningstar Foundation

## Achievement Circle

| \$10,000 - \$19,999 |

AstraZeneca  
Linda Burk  
CSL Behring  
Peggy & John Gall  
Johnson & Johnson Healthcare Systems Inc  
Jeffrey Katz & Beth Rogers  
Lynn & Robert Mobley  
The April Hughes Rath Living Trust

## Champion Circle

| \$5,000 - \$9,999 |

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Ezulwini Foundation Inc  
The Catherine L Heron & Albert C  
Schneider Charitable Fund  
Martha Huizenga  
Jacqueline Hurlbutt  
Johns Hopkins University  
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| \$2,500 - \$4,999 |

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Get the  
entire list



**Every effort has been made to ensure the accuracy of this report.** If you believe you've found an error, contact [info@tffpn.org](mailto:info@tffpn.org) about the issue.

## Friend Circle

| \$1,000 – \$2,499 |

John & Marilyn Alberti  
Anonymous (2)  
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Gregory & Carol Brabbee  
Andrew Brimmer  
Scott & Kay Brown  
Joseph & Theresa Butcher  
Dan & Kristin Draeger  
Richard & Ty Easley  
John & Ila Falvey  
Larry & Barbara Field  
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Joan Gillucce  
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The Elizabeth Wakeman Henderson  
Charitable Foundation  
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John Norris  
Daniel & Gail Rosen  
David Ryley  
Gary & Betty Saidel  
Will Schwalbe & David Cheng  
Charitable Fund  
Michael Schwerdtman  
Jane Schwocho  
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Elizabeth S Smallfelt Rev Trust 7-30-99  
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Ron Whitaker

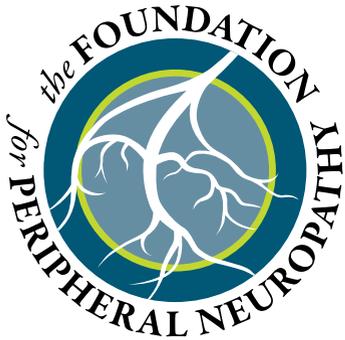
## Advocates Circle

| \$500 – \$999 |

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Philip Whitman  
David Wilson  
David & Sharry Wright



About the Foundation:  
*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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