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 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.

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.

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
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.
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.
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 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.
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-
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

Visionary Circle
| $50,000 & Above |
Lou Mazawey
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 |
Anonymous
Averitas Pharma Inc
Ezulwini Foundation Inc
The Catherine L Heron & Albert C Schneider Charitable Fund
Martha Huizenga
Jacqueline Hurlbutt
Johns Hopkins University
The David Johnston Fund
Joan & George Kessel Foundation
Marguerite Marsh
Kathleen McKee
Craig Noble
Rett Oren
Yvonne & Leslie Pollack Foundation Inc
William Prinzmetal

Innovator Circle
| $2,500 – $4,999 |
Anodyne Therapy LLC
Anonymous
Randy Bramel
James David PhD
Gary Ford & Nancy Ebb
Kali & Tom Giallanza
Teresa Graham
James & Patricia Hemak
Inspire
Kathryn & Luther Kissam
Lavinghouse Family Charitable Fund

LivOn Laboratories Inc
The Moloney Family Foundation
Murdy Foundation
Joe Nichols
Sharon L Poe
Tom & Wendy Rosenthal
H Martin Smith III
Bill Steen
Susan & Walt Waldrop
Malcolm & Donna Wattman

Every effort has been made to ensure the accuracy of this report. If you believe you've found an error, contact info@tffpn.org about the issue.
Friend Circle
$1,000 – $2,499
John & Marilyn Alberti
Anonymous (2)
The Robert M Beren Foundation Inc
Chris Bigelow
Gregory & Carol Brabbee
Andrew Brimmer
Scott & Kay Brown
Joseph & Theresa Butcher
Dan & Kristin Draeger
Richard & Ty Easley
John & Ila Falvey
Larry & Barbara Field
Sidney & Madeline Forbes
Rochelle Friedman MD
Joan Gillucce
Thomas Gross MD
Gulf Coast Community Foundation
Adam Halper
Jerry Hasting & Sara Pederson-Hasting
The Elizabeth Wakeman Henderson Charitable Foundation
Pamela Jacobs
Kristine Jones
Kimberly Juda
Jeff Kinney & Rebecca Bourret
Thomas Lamberti
John Leen
Gregory Maassen & Janet Katz
Marsha Mai
Joseph Martin
John & Mary McGuiness
James Moshenko
Paul O’Reilly
Josh & Toni Osborne
Reese Family Charitable Foundation
Alexandra Richardson
John Rorris
Daniel & Gail Rosen
David Ryley
Gary & Betty Saidel
Will Schwalbe & David Cheng Charitable Fund
Michael Schwerdtman
Jane Schwocho
Ruth Scott
Stuart Simon
Elizabeth S Smallfelt Rev Trust 7-30-99
Colleen Smitherman RN PhD
William & Sylvia Stack
Nancy Timmer
Ron Whitaker

Advocates Circle
$500 – $999
Janelle Aamot
Merritt & Debra Aden
AlgoTx
AmazonSmile Foundation
Bob & Jane Anderson
Anonymous (2)
Dottie Bennett
Laura Bishop
The Boeing Company
Melinda Brown
John & Kathleen Buban
Dale & Michael Bukaty
Joe Campbell
Brenda Carter
Thomas Collins
Juliet Cronin
Mary Jane Crozier
John & Carol Curci
Kyle Denning
Louise & Christopher Doyle
Ron Dreher
Jerry & Steve Drucker
Tom & Rebecca Eisiminger
Donald & Marguerite Erickson
Frank Ewasyslyn
Janet Felton
Robert & Diane Filler
Christopher Fleming
Fortune Family Foundation Inc
Paul Franz & Shari Loo
Avram & Rhoda Freedberg
Ronald & Sue Fritz
John A Gary
Frances Gerngross
Ricky & Sook Hall
Richard L Harris
Heiss Family
Doris & Martin Hoffman Family Foundation
Harold & Kathy Hull
Mark & Kris Jablonski
Robert Wood Johnson Foundation
Jon Kaplan & Joyce Wilkerson
Geoff Kary
Maheswari Karunamoorthy
Mary A Kelly
Bill Kiser
Jennifer Kornacki
David R Lambert
Frances Landfear
Mark Lofgren
Robert J Lueders
Doug Macdonald
Larry Mayhue
Linda Mazawey
Zachary Mazurek
James McCarl
Don McCormack
Michael Meszaros
Meta
Philip Moccio
Karen & Philip Nagel
Phyllis Odell
June Maguire Ozmon
Joseph & Jone Parr
Ted & Harriette Perlman
John & Kay Pfenninger
John Piper
Frederick Pisanelli
Perry Richardson MD
Andre Rose
Hal Rosenbluth
Sangamo Therapeutics
Lester Schwartz
Stephanie Sumpter
John Trotter
Kenneth A Wentink
Steve Wheeler
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.

2023 Board of Directors
Lou Mazawey PRESIDENT
Senda Ajroud-Driss, MD
Adam Halper
Scott Hirsch TREASURER
Ronald Lissak
Gregory Maassen, PhD
Jack Miller CHAIR EMERITUS
Van Salmans
Gordon Smith, MD, FAAN
Kristy Townsend, PhD

2023 Scientific Advisory Board
Nathan P. Staff, MD, PhD CHAIR
Consultant and Research Chair, Department of Neurology, Professor of Neurology
Mayo Clinic, Rochester, MN

David Bennett, MB, PhD
Professor of Neurology and Neurobiology
University of Oxford, United Kingdom

Eva Feldman, MD, PhD
Professor, Neurology
University of Michigan

Ahmet Höke, MD, PhD, FRCPC
Professor of Neurology and Neuroscience Director, Neuromuscular Division
Johns Hopkins School of Medicine

Sandra Rieger, PhD
Associate Professor
University of Miami Health System

Steven S. Scherer, MD, PhD
Professor, Neurology
University of Pennsylvania

2023 Patient Education Advisor
Shanna Patterson, MD
Site Medical Director, Neurology
Mount Sinai West/Mount Sinai Morningside

FoundationForPN.ORG