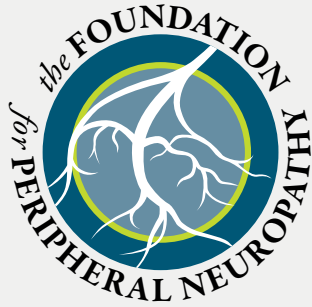




Supporting the
peripheral neuropathy
journey
of patients
around the globe.

2022
ANNUAL
REPORT



2022 ANNUAL REPORT

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An estimated
30 million Americans,
and millions more worldwide,
are **affected by PN**.

2022 was a **record year** for *the Foundation for Peripheral Neuropathy.*

ADVOCACY | For the third consecutive year, peripheral neuropathy (PN) was an eligible condition for funding from the United States government, already awarding over \$13 million research dollars to PN-designated projects. That's a testament to the commitment and compassion of our volunteer advocates, FPN peer-reviewers, and dedicated research community. We've asked more from our donors and research partners than ever; but the result of our increased efforts is undeniable.

AWARENESS | Our commitment to awareness demands attention from all areas – and thankfully we saw just that. In 2022, Gregory Maassen, (who became a board member in 2023) completed a 4,500 mile cross-country, e-bike tour to raise awareness for PN. Dr. Maassen began his journey in Washington, D.C., traveling by electric bicycle for four months to San Francisco. He was the first person to ride an e-bike coast to coast in the United States, establishing a new cross-country bike route while simultaneously raising over \$180,000 to support our work.

RESEARCH | I am proud to report that we funded two new research projects in 2022, in addition to our own biobank (the Peripheral Neuropathy Research Registry) at \$225,000. We funded \$90,000 towards the iMAGiNe Study, a research project dedicated to anti-MAG PN, and we also pledged to support two Clinical Research Training Scholarships, totaling \$300,000, to help promote new researchers coming into the field.

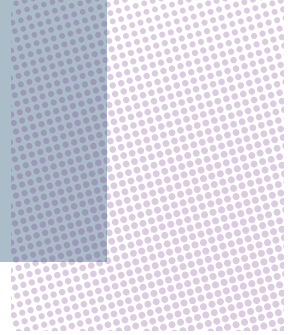
EDUCATION | We're continually providing quality resources to patients and their caregivers. We're discovering new therapies, identifying new health-care specialists, and supporting patient education by offering monthly programs and constant updates to our website.

Our accomplishments from 2022 are embodied in our vision for the future – the hope for a better tomorrow for patients with peripheral neuropathy. We know cures are attainable, and more answers are out there – if we continue to work together. Thank you so much for joining us.

Sincerely,


Lindsay Colbert, Executive Director

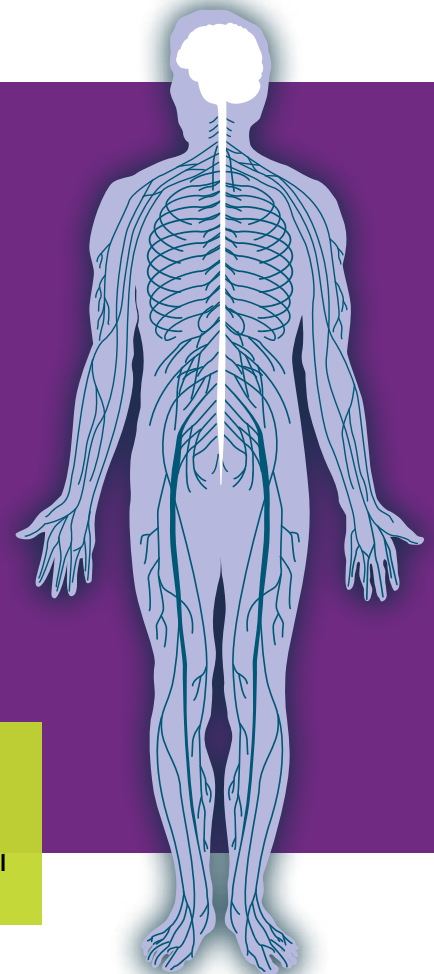




Through research funding, awareness and patient education, our work advances our mission to improve the lives of patients living with peripheral neuropathy and accelerates the development of treatments, and one day, cures. Established in 2007 as a 501(c)3 nonprofit, 82% of our funding comes from individual donors.

What is peripheral neuropathy?

Peripheral neuropathy (PN) occurs when the peripheral nerves are damaged or destroyed and can't send messages from the brain to other parts of the body. A neurological disorder, rather than a disease, PN has hundreds of causes, and possibly more devastatingly, endless unknown causes. Patients often display symptoms of pain, numbness or balance and mobility issues.



○ Central nervous system

● Peripheral nerves

RESEARCH

The Foundation directly funds research awards and grants through collaboration with top neuroscientists, physicians, and healthcare providers. Under a new partnership with the American Brain Foundation and the American Academy of Neurology, we accepted our first applications for the **Clinical Research Training Scholarships (CRTS)** in 2022. Two \$150,00 awards will be distributed to the inaugural recipients, Paula Barreras, MD, Neuroimmunology Fellow at Johns Hopkins Hospital and Erika Williams, MD, PhD, Neuromuscular fellow at Massachusetts General Brigham, who are young, emerging researchers in the field.

Additional research support is provided through our biobank, the **Peripheral Neuropathy Research Registry (PNRR)**. The only biobank of its kind, the PNRR houses DNA and data on peripheral neuropathy patients from around the globe. Through the Foundation's funding, we were able to collect an additional 165 samples in 2022, bringing our total database to 2430 patients as of December 31.

2430
ENROLLMENTS
IN **PNRR**

150
ENROLLMENTS IN
iMAGINE STUDY
RESEARCH PROGRAM
FUNDED

ACCEPTED FIRST
APPLICATIONS
FOR **CLINICAL**
RESEARCH TRAINING
SCHOLARSHIPS

18 ACTIVE **PNRR**
RESEARCH PROJECTS

80% INCREASE IN **PNRR**
RESEARCH PROJECTS IN 2022

61% OF FPN *annual* budget
funded **RESEARCH**

AWARENESS

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

Through our advocacy work, 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, and in 2022, \$3.4 million was awarded to PN research, bringing the total DoD funds received since we started lobbying to \$13 million.

\$13 million AWARDED IN
DoD funding

6,000
WEBINAR GUESTS

37,500
EMAIL SUBSCRIBERS

370,000
WEB SESSIONS

Cross-country e-bike tour
to raise awareness for PN

280
MEDIA
PLACEMENTS

WITH A REACH OF
180,958,469

\$180,000
RAISED

4,685
MILES TRAVELED

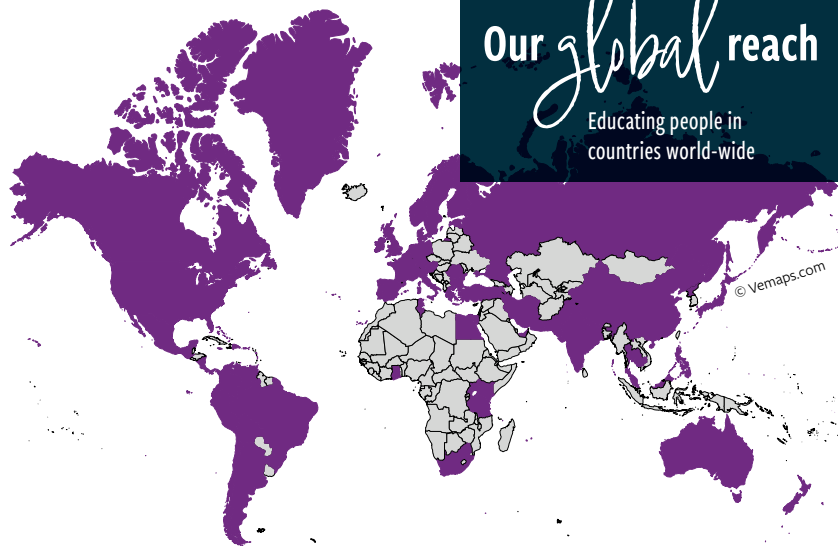


Thanks
to Gregory
Maassen, PhD,
for making
this possible!

EDUCATION

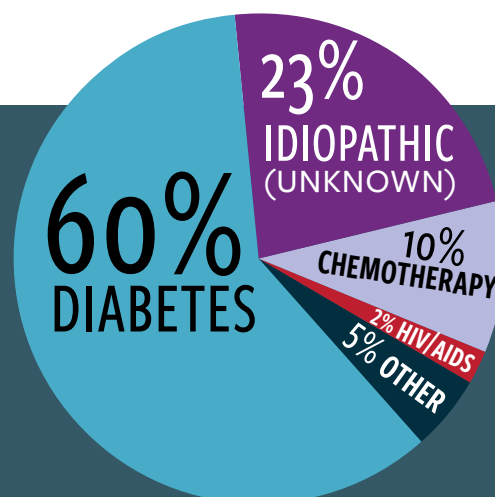
Our ever-expanding library of educational resources highlights causes, medical advances, research, and tips for living well with PN, providing information for the entire PN community of patients, family, friends and healthcare providers. We've increased our webinar offerings to nearly monthly, expanding access to content for the PN community.

Our network continues to grow. With over 13,000 Facebook followers, 37,500 email subscribers and over 450,000 interactions across our media annually, we're helping patients improve the quality of their lives. We're proud to be an integral part of the peripheral neuropathy community, partnering with researchers and other organizations around the world.



30 SUPPORT GROUPS AROUND THE GLOBE

What
causes
PN?



RESEARCH partners

- » The American Academy of Neurology
- » The American Brain Foundation
- » Aarhus University Hospital
- » Beth Israel Deaconess Medical Center
- » Clinical Center of Serbia Neurology Clinic
- » Icahn School of Medicine at Mount Sinai
- » Institut Sant Pau Investigació Biomèdica
- » Istituto Clinico Humanitas
- » Hôpital Bicêtre AP – HP
- » Hospices Civils de Lyon
- » Johns Hopkins Medicine
- » KU Medical Center – University of Kansas
- » Michigan Medicine – University of Michigan
- » Northwestern University
- » Peripheral Nerve Society
- » The University of Utah School of Medicine
- » Washington University in St. Louis – School of Medicine

2022 FINANCIALS

Revenues and Other Support	Without donor restrictions	With donor restrictions	Total
Donations	\$ 999,787	\$ 73,249	\$ 1,073,036
Interest and dividends	14,141	-	14,141
Realized loss on investments	(24,489)	-	(24,489)
Unrealized gain on investments	610	-	610
Net assets released from restrictions	110,391	(110,391)	-
Total revenues and other support	1,100,440	(37,142)	1,063,298

Expenses

Program Services	561,396	-	561,396
Administrative and general	138,004	-	138,004
Fundraising	188,016	-	188,016
Total expenses	887,416	-	887,416

Increase (decrease) in net assets	213,024	(37,142)	175,882
Net assets, beginning of year	1,603,501	171,885	1,775,386
Net assets, end of year	\$ 1,816,525	\$ 134,743	\$ 1,951,268

Staying hopeful about the future of neuropathy

Meet FPN supporter
Paul O'Reilly

When a crisis happens – like losing a loved one or getting diagnosed with a chronic illness – you have two choices: You can be paralyzed by fear or sorrow, or you can find the strength within you and find a way forward.



Meet Paul O'Reilly. Paul identifies as a lifelong learner. He'd be the first to tell you he's curious and likes to try new things. It's led him down four career paths. Paul started out as a banker, which segued into a

career in marketing. Then a stint in economic development led to working as a consultant for city workforce development departments. "It was my job to figure out how to help the city's workforce providers to strengthen their relationships with businesses to find training and jobs for their workforce," says Paul. "I would look at what they wanted to accomplish

and then figure out how to get there.” Paul’s inveterate problem-solving nature was his saving grace when he was diagnosed with peripheral neuropathy (PN) in 2014.

Paul started having pain in his feet nine years ago. It was so intense; he could barely walk. His doctor couldn’t figure out what was wrong. He spent a year in pursuit of a diagnosis before he started doing his own research, which led him to a neurologist who diagnosed his idiopathic PN and offered a plan to treat it. His neurologist started gabapentin for the pain. As Paul describes it, “it helps, but it is not perfect. Getting the dosage right was a lot of trial and error.”

Paul embraced trying new things to figure out what works best for him. He even invented his own orthotic inserts, cobbled together from multiple over the counter commercial products. “I saw five different podiatrists, they couldn’t find anything to help me. So, I experimented and came up with my own.” Always looking for new things to try continues as a theme in Paul’s life. He believes there is no one-size-fits-all solution for PN.

Many PN patients say it’s important to stay positive, but Paul thinks of it differently. For him, there are two elements to pain: the physical nerves sending signals to his brain and the emotional reaction to his pain. He feels his emotional reaction, the feelings you have about wanting to stop the pain, and then pretty much constantly paying attention to that feeling magnifies the physical sensation of his pain. “So I made a conscious choice to stop thinking about it – mind over matter. In time, I trained myself to view the level of pain I was feeling was normal. That allowed me to adapt and keep going despite the pain. My neurologist told me that he thinks I actually retrained my brain, that I changed my neural reaction to the pain in my feet.” This enabled Paul to cut his dosage of gabapentin in half.

Paul’s research led him to *the* Foundation for Peripheral Neuropathy. He found the lack of general knowledge about PN within the medical community frustrating. The Foundation provided both information and a community. About six years ago, he met Foundation staff at a conference in Los Angeles. This led to Paul consulting for the Foundation and provided the opportunity for him to join the review panel for the Department of Defense’s Peer Reviewed Medical Research Program. “It makes me feel hopeful about neuropathy, and medicine in general,” Paul says. “Being able to review these grant proposals has spurred questions I can ask my own doctor and makes me feel more in control of my PN.”

Paul advises other PN patients to find out what works for you, keep asking questions and trying new solutions. Not everything you try will work, but eventually you will find things that do. “Even with this condition, I feel strongly that life is a gift I don’t want to waste,” Paul explains. Paul lost his husband a few years ago, but still, he says, “I choose to try new things. I choose to be involved with the Foundation because being part of a community helps me stay positive.”

Paul admits he doesn’t benefit from support group meetings, but reaching out to the Foundation is his way of asking for help, a way of finding resources so he can experiment and find solutions that work for him. Support matters, and it goes both ways. Paul puts it this way, “Support from the Foundation and its community helps push down the fear so you can keep trying and learning about what can help you. And supporting the Foundation is a no brainer. More donations mean more investment in research and more information for patients. Support means you are not paralyzed; it means you are choosing to keep going.”

“IT MAKES ME
FEEL HOPEFUL
ABOUT
NEUROPATHY,
AND MEDICINE
IN GENERAL.”

Supporting the Foundation for Peripheral Neuropathy

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\$50,000 & Above

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Jack Miller Family
Foundation
Van & Carolyn Salmans
Ernest & Janet Winkler
Revocable Trust

Ambassador Circle

\$20,000 - \$49,999

Averitas Pharma Inc
Robert & Lynn Mobley

Achievement Circle

\$10,000 - \$19,999

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of Charles Garner Durant
Alnylam Pharmaceuticals
Estate of Elvin C Downer Jr
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The Morningstar Foundation
Rett Oren
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Albert C Schneider Charitable
Fund
Estate of Elizabeth M Taylor

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Angela Pampalone, in memory of Vincent Aquino	Jean Peroutka	Peter Principato, in memory of Vincent Aquino	Rosemary Richards
Vincenza Pampalone, in memory of Vincent Aquino	Rebecca Perry, in memory of Vincent Aquino	Kerri Prong, in memory of Gordon Lessard	Gord & Debra Richardson, in memory of Gordon Lessard
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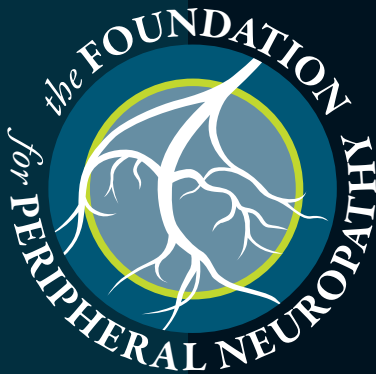
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