Supporting the peripheral neuropathy journey of patients around the globe.
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.

**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.

**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.

**EDUCATION** | We’re continually providing quality resources to patients and their caregivers. We’re discovering new therapies, identifying new healthcare 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.
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 $150,000 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.
**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

<table>
<thead>
<tr>
<th>6,000</th>
<th>37,500</th>
<th>370,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Webinar guests</td>
<td>Email subscribers</td>
<td>Web sessions</td>
</tr>
</tbody>
</table>

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

<table>
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<tr>
<th>280</th>
<th>WITH A REACH OF 180,958,469</th>
<th>$180,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media placements</td>
<td>RAISED</td>
<td></td>
</tr>
</tbody>
</table>

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.

What causes PN?

60% DIABETES
23% IDIOPATHIC (UNKNOWN)
10% CHEMOTHERAPY
2% HIV/AIDS
5% OTHER

30 SUPPORT GROUPS AROUND THE GLOBE

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

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

<table>
<thead>
<tr>
<th>Expenses</th>
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<tbody>
<tr>
<td>Program Services</td>
<td>561,396</td>
<td>-</td>
<td>561,396</td>
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<tr>
<td>Administrative and general</td>
<td>138,004</td>
<td>-</td>
<td>138,004</td>
</tr>
<tr>
<td>Fundraising</td>
<td>188,016</td>
<td>-</td>
<td>188,016</td>
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<tr>
<td><strong>Total expenses</strong></td>
<td><strong>887,416</strong></td>
<td>-</td>
<td><strong>887,416</strong></td>
</tr>
</tbody>
</table>

| 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 |

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.”
## Visionary Circle
$50,000 & Above
- Lou Mazawey
- 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
- Alnylam Pharmaceuticals
- Estate of Elvin C Downer Jr
- John & Peggy Gall
- Joseph Hoobyar
- LivOn Laboratories Inc
- The Morningstar Foundation
- Rett Oren
- The Catherine L. Heron & Albert C Schneider Charitable Fund
- Estate of Elizabeth M Taylor

## Champion Circle
$5,000 - $9,999
- Anonymous
- Jeffrey Bergeron
- Estate of Barbara Brown Tucker
- Ezulwini Foundation Inc
- Martha Huizenga
- Jacqueline Hurlbutt
- The David Johnston Fund
- Jeffrey Katz
- Joan & George Kessel Foundation

## Innovator Circle
$2,500 - $4,999
- Anonymous (2)
- Dick & Karen Baker
- Chris Bigelow, in honor of Tom Giallanza
- Randy Bramel
- Richard Cline
- Michael Clune
- Southwest Ford, in memory of Charles Garner Durant
- Kirk Graves
- Hamilton Partners Inc
- Kathryn & Luke Kissam
- Murdy Foundation
- Brian Musso
- Craig Noble
- Marjory A Reid
- Tom & Wendy Rosenthal
- Bill Steen
- Susan & Walt Waldrop

## Friend Circle
$1,000 - $2,499
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- Richard Allen, in memory of Charles Garner Durant
- AmazonSmile Foundation
- Anonymous (2)
- Richard & Johanna Baker
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- James Butler, in memory of Beatrice Butler
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- Robert & Amy Chin
- Jim & Diana Conroy
- Betty & Al (William) Davis
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- Tom & Susan Durant, in memory of Charles Garner Durant
- Kevin O’Hara
- Paul O’Reilly
- Josh & Toni Osborne
- Michael & Anna Owen
- Paula Polma, in memory of Charles Garner Durant
- Jeff Quicksilver
- Reese Family Charitable Foundation

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Wagler & Sons Construction Inc
Mike & Lisa Ward, in memory of Charles Garner Durant
Malcolm & Donna Wattman
James Wood Motors, in memory of Charles Garner Durant
David Yeager

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$500 - $999
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- Merritt & Debra Aden
- Anonymous
- Apple
- Steven Armbrust
- John Aymond
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- Neil Bogue
- Joan Bomstead
- Linda & Jefferson Braswell
- Dale & Michael Bukaty
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- Thomas Collins
- Matt Darnall
- James David PhD
- Kyle Denning
- Ralph Desmarais
- Louise & Christopher Doyle
- Ron Dreher
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- Lane & Joanna Gerber
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- Edmund Hardy
- Richard Harris
- Richard Harris Jr
- Jacqueline Jackson
- Dorian Jimenez, in memory of Charles Garner Durant
- Robert Wood Johnson Foundation
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- Perry Richardson MD
- Lilah & Brian Rippett
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- Joseph Talty
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- Scott Trunk, in memory of Elizabeth Trunk
- Kenneth A Wentink
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- Zeus Battery Products

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Kathy Beltinck, in memory of Charles Beltinck
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Robin Benoy
Deanna Benson
Louise Benson
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Harvey & Lois Berman
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Hillena Beyene
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Randall Blair
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John Campanello & Family, in memory of Charles Garner Durant
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Jimmy & Cathy Campbell, in memory of Charles Garner Durant
Mitchell Campbell, in memory of Linton Campbell
Shai Campbell
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Sue Canfield
Thomas Canfield
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Marchelle Carleton
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Walter Carlson
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Karen Franzone
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Darrell & Dorothy Gosnell, in memory of Dennis Sendrey
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J C & Donna Graham, in memory of Cyrice Theberge
Ronald Graham
Douglas & Delia Graner
Rick Gravely, in memory of RoAnne Hopkins
Deborah Gray
Thomas Gray, in memory of James W Gray
Eileen Green
Michael Green
The Green Family
1996 Living Trust
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Elaine Greenstone, in honor of Gregory Maassen
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John Gregor
Kenneth Gregor
David Gregory
Kevin Greig
Lou & James Greil
Debra Gressel
Blake Griffths, in memory of Gordon Lessard
Louis Grimaldi
Thomas & Mary Grodkiewicz
Thomas Gross MD
Jay Grossman
Michael Grunberg
Steven Guberman, in memory of Susan L Greenblatt, PhD
Lori Guerin
James Gummert
Laura Guthrie
John Guyton
Frederick Haas
Jeffrey Haas
James Haderlein
Adam Hadi, in memory of Vincent Aquino
Daril & Janet Hahn
Neal & Nancy Hahn
Barbara & Jan Halper
Marion Halverson
Mary Hama
Elliott Hamilton
Robert Hamilton
Markie Hancock
Caitlyn McGraner, in honor of Shereda Buckingham
Wilda McGraw
Dennis Mcguire
Susan McHugh
Terry Mckay
Kim Mckeon
Linda McKown
Charlene McLaughlin
Kay McLaughlin
Rose McLaughlin
Barbara McMahon, in memory of Elizabeth Gaynor
Susan McMasters
Robert & Meredith McNab
Dorinda McNamara
Debby McNeil
Margaret (Peg) McNulty
Chad McNutt
John & Leslie McQuaide
Kaye Mears
Ronald Medford
Nancy Mee
Melissa Meehan
Laurie S Mehalic
Philip Melchiorre
Carmen Melendez
Fae Melmon
Philip Meloon
Rosanne Nelson
Jerry Mendenhall
Lucille H Mense
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Sharon Metcalf
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Vance & Patricia Meyer
Cheryl Meyers
Jonathan Michaeli
Kent Mickelson
Margo Mickelson, in memory of Raymond Mickelson
David Miedema
Ernest Migoya
Marietta Miick
Debra Milek
Catherine Millard
Barbara Miller
Gary & Beth Miller
Jeff Miller
Larry & Brenda Miller
Leslie Miller
Steve Miller
Thomas Miller
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Tamara Moeller
James Moffat III
Abdul Mohidin
Dhanpat Mohnot MD
Patricia & Robert Molinari
Patricia Moller
Gail Moloney
David & E Barbara Monaghan
Edna Montemayor
Dan & Pat Moore
Harold Moore
John Moore
Larry Moore
Vicki Moore
Maria Morales
Michael Moran
Harold Mordkofsky
Anthony Moreschi
Vivian Morgan
Nancy Morrill
Elaine Morris, in memory of Charles Garner Durant
James Morris
Lloyd Morrison
Naomi Jane Morrison
Richard Morrison
Carol & Kenneth Morrissey
Jane & Paul Morton
Kit Mosden
Barbara Moss
Diane Mowitz
Pat Moyle, in memory of Jeremy Moyle
Bruce Muller
Hugh Mullin
Diane Murray
Jim Murray
Donald Mutterperl
Bentley Myer
Karen & Philip Nagel
David Nagle, in memory of Shirley Nagle
Gwen Nail, in memory of Bonnie Stahl
Robert Nankin
Mark Nash
Pam Nashman
Ahmad Nasir
Thomas & Marian Nau
David Neal
Varda Negnewitzky
Glenda Nelson, in memory of Jim Dillon
Brad Neumann
Stanley Nevins
Roberta Neway
The Nancy R Newman Rev Living Trust
Stuart Neye
Ethel & Alexander Nichoson Foundation, in honor of Shanna Patterson
Chris Nickas, in memory of Harry Cardosi
Michael Niebling
Glennon Nieman
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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.