

FPN *Print* NEWS

SPRING 2025



From the Executive Director

Dear FPN friends:

Earlier this year, I worked on a program with a courageous man who overcame a serious injury. Hearing about his long recovery made me admire his strength and positive attitude. Now in his every day, he shares his story to inspire others, reminding everyone to make the most of life. He doesn't let his injury make choices for him—he stays in control.

His journey reminds me of the many neuropathy patients I meet. Your strength amazes me, and it pushes me to keep fighting for better treatments and, one day, cures. You are not alone – *the* Foundation for Peripheral Neuropathy is here for you.

With that, I'm excited to welcome our new Board President, Ron Lissak, and Board Vice President, Kristy Townsend, PhD. In 2025, we also added two new staff members. This growing and dedicated team of patients, doctors, researchers, and caregivers that I am proud to be a part of will help take our work to the next level.

I hope you enjoy this issue, filled with updates on research, advocacy, and ways to get involved!

Thank you,

Lindsay
Lindsay

Tiffany Li, PhD, awarded scholarship for neuropathy research

Tiffany Li, PhD, has been awarded the 2025 Clinical Research Training Scholarship (CRTS) to support her important research on chemotherapy-induced peripheral neuropathy (CIPN). The CRTS is a multi-year scholarship program providing funding for emerging experts in neuropathy, supporting their efforts to advance treatments, prevention, and cures for peripheral neuropathy (PN).

Li's research aims to find special markers in the body that can show when nerve damage is starting, before it becomes a bigger problem. By finding these markers, Li hopes to help doctors detect nerve damage

RESEARCH continued on page 2 >

RESEARCH continued from page 1 >

during chemotherapy and adjust treatment if needed. Catching damage early could reduce the long-term effects of CIPN. This is especially important for younger and older cancer patients, who are affected more by nerve damage.

"One key reason for my interest in chemotherapy-induced peripheral neuropathy, is that unlike many other neuropathies, it provides a unique predictability—we know exactly what the toxic insult is, neurotoxic chemotherapies, and we can pinpoint its onset with precision,

tied directly to the administration treatment," states Li.

Tiffany Li, PhD, is a researcher at the University of Sydney's Faculty of Medicine and Health. She earned her PhD in 2024 and holds a master's degree in biostatistics from Macquarie University. Li's two-year \$150,000 scholarship is funded solely by FPN, in partnership with the American Brain Foundation and the American Academy of Neurology.



What's a DAF?



Fundraising 101: Maximize your impact with a Donor-Advised Fund

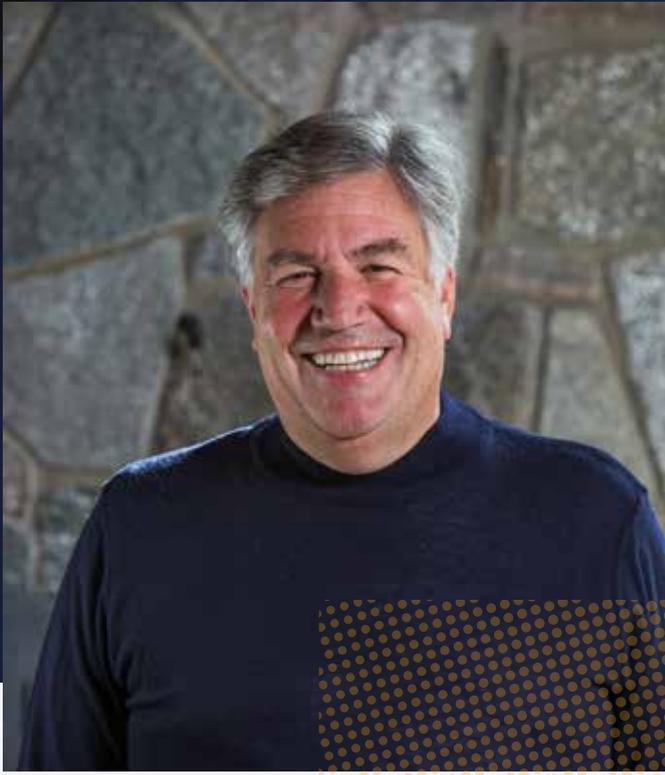
Support groundbreaking research and vital resources for those living with peripheral neuropathy through a Donor-Advised Fund (DAF). A DAF allows you to simplify your giving while maximizing tax benefits, making it easy to support FPN in a meaningful way.

By contributing to a DAF, you receive an immediate tax deduction in the year you donate, even if grants are made later. DAFs also allow you to streamline your giving by consolidating multiple charitable donations into one account. You can donate appreciated assets like stocks or real estate directly to your DAF, maximizing your contribution and allowing your funds to grow tax-free before distributing them to FPN.

Many financial institutions, such as Fidelity Charitable and Schwab Charitable, offer DAFs. When you're ready to give, you can easily recommend a grant to FPN through your DAF provider.

Read more about the benefits of setting up a DAF by scanning this QR code. Contact our Director of Development, Katie Britton at 847-808-4374 or katie@tffpn.org for more information.





Meet Ronald Lissak

NEW PRESIDENT OF FPN
BOARD OF DIRECTORS

We are proud to announce Ronald Lissak as our new President of the Board of Directors, effective January 1, 2025. With a distinguished career in the medical device industry and a personal connection to neuropathy, Ron brings a wealth of experience, dedication, and a clear vision to his new role.

Ron currently serves as Executive Vice President and General Manager of Positrigo Inc., a cutting-edge company that manufactures specialized systems for Alzheimer's and other neurological diseases.

Diagnosed with idiopathic peripheral neuropathy over 20 years ago, Ron has firsthand experience with the challenges of living with PN. "I have been very fortunate to have excellent care from physicians across the country, from Montefiore Medical Center to Dartmouth Hitchcock and the Mayo Clinic," he shared. "It's crucial to find a physician who truly understands your disease."

Ron has served on the FPN Board for the past five years. Reflecting on his tenure, he shared, "I've been inspired by the commitment of the FPN

I've been inspired by the commitment of the FPN staff and the broader community.



staff and the broader community. It's a privilege to be part of an organization that is making a real difference in the lives of those living with PN."

Looking ahead, Ron's priorities include expanding FPN's reach and impact. "With the funds we've received this past year, we will be able to expand our initiatives in funded research, lobbying, and patient education through our webinar series. There are 30 million people living with PN, and I hope we can touch more of their lives," he said.





iMAGiNe Research Study

We are proud to support the ongoing research efforts of anti-MAG neuropathy, a rare autoimmune form of peripheral neuropathy via the iMAGiNe research study.

The iMAGiNe Study continues to make impressive strides in advancing the understanding and treatment of IgM-associated polyneuropathy. One of the most exciting updates is the release of a new research article called, "Rasch-built Overall Disability Scale for IgM-associated polyneuropathy with and without anti-MAG antibodies (IgM-RODS)." After seven years of teamwork, researchers have created the IgM-RODS. This is a new tool that helps doctors better understand how the disease affects patients, including their ability to do everyday tasks and participate in social activities. This tool will make future clinical trials more accurate by providing better measurements, which will improve both the quality of the data and how patients are followed over time.

In 2024, FPN paid approximately \$5,000 to support patient enrollment across seven different countries and centers into this study. We also funded the first year of a three-year grant to support the research staff who oversee the biobank of patient data and biological samples.

Thank you to our ongoing partners for this project:

Johns Hopkins (USA)

University of Michigan (USA)

Royal London & Newham Hospital (UK)

Aarhus University (Denmark)

Hospices Civils de Lyon (France)

Istituto Clinico Humanitas (Italy)

Hospital de la Santa Creu i Sant Pau (Spain)

Hôpital Bicêtre (France)

University Medical Center Utrecht (Netherlands)

We are committed to advancing research and understanding of this rare form of neuropathy in the years to come.





FPN research grant updates

THE IMPACT OF OUR DONORS

Our clinical research scholarships (CRTS) are in their third year of awards. These awards are only possible due to the generosity of our donors. We caught up with our first recipients, Paula Barreras, MD and Erika Williams, MD, PhD, who are now more than halfway through their grant period.

Exploring Small Fiber Neuropathy in Sarcoidosis



Mapping the Hidden Wiring of Our Body



Advocacy update

We are excited to continue our advocacy work. It's one of our most impactful programs, yielding over \$19 million in neuropathy research funding since 2021.

With the recent shift in political power this past January, there's increased focus on cutting federal spending. These proposed cuts could impact critical programs like the National Institutes of Health (NIH) and Congressionally Directed Medical Research Program (CDMRP) – both programs that we target in our advocacy work.

For neuropathy, this means we must work harder than ever to protect the \$370 million allocated to the Department of Defense's (DoD) Peer Reviewed Medical Research Program (PRMRP). Our goal is not just to maintain this funding but to grow it, ensuring continued support for research that improves the lives of those affected by peripheral neuropathy (PN). Thanks to our advocacy work, PN has been included as an eligible condition since 2021, and this critical funding was secured again in fiscal year 2024.

As we send this newsletter to print, we are planning for Advocacy Day on Capitol Hill, organizing a day of meetings with lawmakers to renew PN's designation within the PRMRP and raise awareness of the condition. We look forward to our efforts securing PN as an eligible research topic for another fiscal year.

Want to know more? Watch our latest advocacy webinar on the FPN website to learn what's happening on Capitol Hill, get insider updates, and discover actionable steps you can take to help push for more funding for PN research. Together, we can create real change and improve the lives of everyone affected by PN.



In this issue:



FROM THE EXECUTIVE DIRECTOR..... 1

TIFFANY LI, PHD, AWARDED RESEARCH SCHOLARSHIP 1

DONOR-ADVISED FUNDS..... 2

RONALD LISSAK, NEW BOARD PRESIDENT..... 3

IMAGINE RESEARCH STUDY 4

RESEARCH GRANT UPDATES..... 4

ADVOCACY UPDATE..... 5

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The information contained in this newsletter is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.

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