FPN member NEWS

SPRING 2023



From the Executive Director

Dear FPN Friend:

The beginning of the new calendar year seems like an obvious time to look at our accomplishments from the recent year and to also talk about new beginnings.

First, I want to thank you for continually supporting our mission. Thanks to the generosity of our donors in 2022, we were able to support two valuable research projects – a $150,000 research grant to support the IMAGiNe Study and a $256,000 research grant to fund new patient enrollment in our very own biobank, the PN Research Registry (PNRR).

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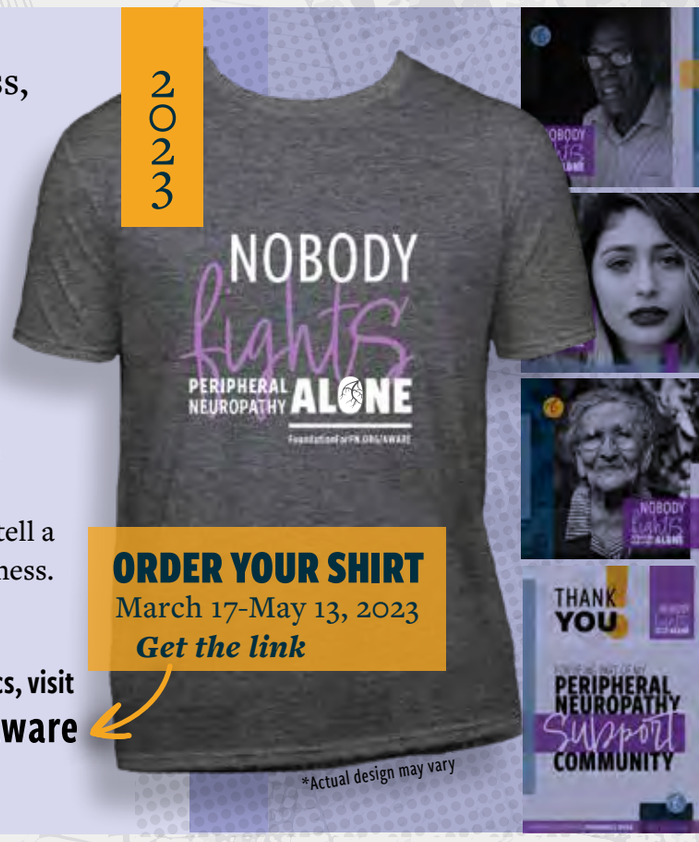
Save THE DATE

PERIPHERAL NEUROPATHY AWARENESS WEEK MAY 7-13

Help us raise awareness, to accelerate understanding of this condition and amplify the need for ***more*** peripheral neuropathy ***research***.

Order a shirt*, thank someone who's provided support, share your story, post our graphics, tell a friend; it all helps build awareness.

For more details, links and graphics, visit FoundationForPN.org/aware



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DEDICATED *to* REVERSING *the* IRREVERSIBLE

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From the Executive Director

New in 2023, we're funding two Clinical Research Training Scholarships, for a total of $300,000, and expanding our advocacy work to include the National Institutes of Health (NIH) funding opportunities, leveraging our advocacy work to further PN research and the advancement of new discoveries.

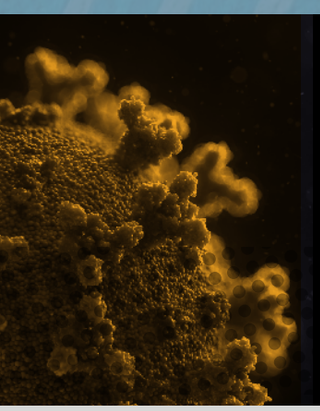
FPN will continue to support its patients by providing updated resources throughout our website, so please stay tuned for new information slotted for release later in 2023. We are also excited to launch an awareness campaign over National PN Awareness Week from May 7-13. We hope you'll support our efforts, a few of which are being highlighted in this issue – the new PN shirts being my personal favorite.

These are exciting times for the organization, and I encourage you to take advantage of the many benefits FPN offers. Thank you for reading our spring issue, filled with some important updates and interesting reads. Please let me know how we can best continue to serve you and thank you again for being a part of our community!

Be well,

Lindsay

Lindsay Colbert



Neuropathy Can Result from SARS-CoV-2 Infection

Evidence exists that neuropathy can result from SARS-CoV-2 infection, presenting as new tingling, burning or numbness within two months of COVID-19 illness. Most patients who received treatment improved. Read the full update at **FoundationForPN.org/covid**.

Dr. Gregory Maassen Joins Board



We are pleased to welcome Dr. Gregory Maassen to our Board of Directors, effective Jan. 1, 2023.

Gregory brings a wealth of international experience to our organization, specializing in managing and restructuring large, complex, and high-profile donor-assisted programs, as well as skills in videography, multimedia production, and strategic digital marketing.

In 2019, Maassen was diagnosed with post-infectious small fiber neuropathy and was introduced to *the* Foundation *for* Peripheral Neuropathy for its wealth of patient resources and support. Gregory's e-bike tour across the U.S.A. in 2022, to raise awareness for PN and establish a new cross-country bike route, allowed us to get to know each other. We're elated Gregory has agreed to serve on our board.

Please join us in welcoming Gregory to the team!

> **Don't give up. Plan, stop searching Dr. Google for answers and seek support.**
>
> **GREGORY MAASSEN**
> **Newest FPN Board Director**

Faces of PN: Randy Lavinghouse

AN FPN SUPPORTER AND PN PATIENT SHARES HER STORY

FPN: *Tell us a bit about yourself.*

Randy: I grew up in Philadelphia and ended up going to college at Boston University to become a physical therapist. I moved around a bit in my 20s – I love to travel – and had always wanted to see what it would be like to live in San Francisco. I moved there, eventually met my husband and ended up raising our family there while still pursuing my physical therapy career.

FPN: *Tell us about your diagnosis.*

Randy: I was officially diagnosed with PN 10 years ago. Initially the diagnosis was idiopathic, and then I learned that my father and an aunt also had neuropathy, so we thought it might be hereditary. I had some of the symptoms for years, but ignored them. I had longstanding knee issues, and had surgery to remove a nerve tumor, so assumed the symptoms were from that. But in July of 2012, I started having abnormal muscle contractions and weakness in my foot. I saw a neurologist. When he gave me my diagnosis, he told me he had good news and bad news. The good news was that I didn't have ALS or MS. The bad news was that I had PN.



FPN: *How do you manage your condition?*

Randy: First and foremost, I am lucky to have a very proactive neurologist. He had blood work done, and I was found to have MGUS, an abnormal protein in the blood, which could in time turn into multiple myeloma. My neurologist and hematologist monitor me very closely, drawing blood every four months. This relieves a lot of my worries, as I know if something develops, we will catch it early.

As far as handling my PN, I was able to reduce my need for gabapentin by devoting myself to a healthy diet and exercise that truly makes a difference for me. I exercise daily. I do core exercises, lying down, standing and on a balance ball to strengthen my core. This helps with balance and stability. I also walk 3-5 miles a day and garden to work on hand strength and dexterity. Practicing tai chi helps with balance and spatial awareness, because my PN causes a loss of sensing where my body is in space. The repetitive movements also help with motor control. Lastly, I take supplements, alpha lipoic acid and turmeric, which help with the pain and numbness/tingling.

FPN: *How has your career as a physical therapist helped you manage your PN?*

Randy: I specialized in neuro in acute rehab settings, working with stroke patients, so I understand neurological impairment. My physical therapy expertise taught me that visual cues can help motor control. For example, I often have problems when eating because of numbness in my hands. I will drop my fork. But if I look at my hand while cutting food, the visual feedback to my brain helps me control the movement. I use skills gained from my physical therapy career to help me compensate for my symptoms, such as strengthening exercises, including core work, which in turn helps me control my movement. I do tai chi, which helps with strength, balance, and body spatial awareness.

FPN: *How do you stay so upbeat, despite your condition?*

Randy: I feel lucky that it's not worse, like ALS or MS. That puts my condition in perspective. I have a husband, children and a grandchild who I love and who love me. I have good friends. I have always felt that I needed to stay strong and healthy for them. Everybody has difficulties, and when I listen to other people's troubles, I think my situation isn't so bad. I have a lot of things to live for! I try to do things that keep me positive and help keep me from being anxious or depressed. Meditation helps. So does social interaction and having a positive outlook.

FPN: *What advice would you give other PN patients?*

Randy: I know PN impacts everyone differently, but I would say there are some commonalities. Do the research, look at diet and supplements, and then choose what works for you. But I would tell everyone to try and keep yourself as active as possible. I know it is hard when you are in pain or have balance issues, but in the long run, being active will make you feel better, physically and mentally. It will improve your mood to keep you going.

Thank you for sharing your story with us, Randy.

Our Continued Advocacy Work



In 2020, the peripheral neuropathy research community achieved a huge breakthrough when Congress included ***peripheral neuropathy*** as an eligible condition for study in the Department of Defense's (DoD) Peer Reviewed Medical Research Program (PRMRP) for the first time. Thanks to our continued advocacy efforts, the condition has been renewed for fiscal years 2022 and 2023, as part of the annual Defense Appropriations Act approved by Congress. In the most recent round of applications, peripheral neuropathy (PN) projects were awarded $4.6 million dollars, bringing the total awarded to PN projects in the first two years of inclusion to $13 million.

In 2023, the Foundation will continue our work to preserve this designation. We'll also build on these efforts by engaging in a new strategy to elevate the profile of (and increase research funding for) PN with the National Institutes of Health (NIH), the world's largest medical research agency. The NIH spends approximately $210 million on peripheral neuropathy, which is a small portion of their overall annual budget of $45 billion. Our plan is to increase our advocacy efforts to increase funding opportunities for PN research, hopefully utilizing even more PRMRP and NIH dollars.

Most NIH research on peripheral neuropathy is funded by the NIH's National Institute of Neurological Disorders and Stroke (NINDS). The Foundation will be working with NINDS to secure the involvement of other related institutes and centers at NIH. For example, because of the correlation between cancer chemotherapy and diabetes and PN, we will be seeking new relationships with the National Cancer Institute and the National Institute of Diabetes and Digestive and Kidney Disorders. We will also work to develop an NIH-led interagency group, involving these institutes, as well as officials from the DoD and the Veterans Administration, for the purposes of developing a comprehensive federal plan for better understanding the causes of peripheral neuropathy and developing new treatments. Lastly, we'll work with Congress and the NIH to develop a new Idiopathic Neuropathy Center of Excellence program to develop research centers devoted to better understanding the causes of, and finding potential new treatments for, idiopathic neuropathy.

All these efforts will involve advocacy with both the NIH and Congress. We'll keep you up to date as our work progresses. Get updates between member newsletters by signing up for our monthly emails, or on our blog, at FoundationForPN.org.

Clinical Research Award Recipients Announced

Paula Barreras, MD, Neuroimmunology Fellow at Johns Hopkins Hospital and Erika Williams, MD, PhD, Neuromuscular fellow at Massachusetts General Brigham are receiving the inaugural Clinical Research Training Scholarships (CRTS).

Through these awards, FPN is providing $300,000 in PN research funding. Barreras will study if small fiber neuropathy in sarcoidosis patients is driven by inflammation, and if so, if anti-inflammatory or immunosupressive treatments will help, while Williams will work to develop a gene expression map for the autonomic nervous system. The awards are overseen by the American Brain Foundation and the American Academy of Neurology, and awarded in partnership with FPN. We're delighted to support young investigators and fund additional peripheral neuropathy research. Learn more about the studies and the CRTS program at FoundationForPN.org/CRTS.

> **I am very happy and grateful for this opportunity, and I hope I can have an impact on the understanding of this disease.**
>
> **PAULA BARRERAS, MD**

> **I know so many patients now with neuropathy through clinical life, and those are the stories that... have brought me into the field.**
>
> **ERIKA WILLIAMS, MD, PHD**



Membership Has Benefits

New in 2023, FPN is planning to transform our premium membership program into the *FPN Members Society*, with a minimum donation of $50 (a $20 increase). The new structure will allow greater flexibility in gift amount and benefits, deeper access to FPN leadership, and more meaningful long-term partnerships. The increased membership rate will support FPN's expanded advocacy efforts, increased investment in research and educational resources for the peripheral neuropathy community.

The FPN Members Society launches June 1, 2023. Those who renew at the old rate before June 1 will keep their membership status for 12 months, and then be offered renewal at the new rate in 2024.

More detailed information will be forthcoming in April. We hope you will be pleased with the new opportunities afforded and that you will remain a valued FPN member.

Connect With Us

We're happy to annouce we'll be attending the following scientific meetings in 2023:

American Academy of Neurology Annual Meeting
Boston, Mass., USA |April 22-27

Peripheral Nerve Society Annual Meeting
Copenhagen, Denmark | June 17-20

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485 E Half Day Rd, Suite 350, Buffalo Grove, IL 60089

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REVERSING *the* IRREVERSIBLE

info@tffpn.org | 847-883-9942 | **FoundationForPN.org**

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.



IMAGINE study

the FOUNDATION *for* PERIPHERAL NEUROPATHY

FPN Contributes $90,000 to IMAGINE Study for anti-MAG Peripheral Neuropathy Research

Exciting PERIPHERAL NEUROPATHY RESEARCH

An international research collaborative, the IMAGINE Study works to monitor and predict the progression of this rare form of peripheral neuropathy.

Through the generosity of donors like you, we're able to support the IMAGINE study with a $150,000 research grant to fund new patient enrollment. $90,000 of these funds, spent in 2022, resulted in over 150 new patients enrolling in the study.

Read more about the work your dollars support at **FoundationForPN.org/imagine-study**.