



FPN *print* NEWS SPRING 2024



From the Executive Director

Dear friends:

I hope this issue finds you well.

I am eager to share that FPN is currently undergoing strategic planning. It is our goal to continually improve our organization and its worth in the PN community. As with any strategic planning, we are identifying how we can best fit into this cog of scientific experts and patients who are desperate for cures. Our staff and dedicated boards are involved in key discussions that will soon lead to some exciting

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State of PN research

By Nathan Staff, MD, PhD, Mayo Clinic, Rochester, Minn.
FPN SCIENTIFIC ADVISORY BOARD CHAIR

Peripheral neuropathy is an incredibly common condition, impacting approximately 2% of the population and up to 10% of those over age 60. With an aging population, neuropathy will continue to become even more prevalent. Common neuropathy symptoms include pain, numbness, imbalance, and weakness; however, symptoms are quite heterogeneous and can range from numb toes to disability requiring wheelchair.

There are many causes of neuropathy, but in the West the most common are diabetes mellitus, hereditary, and idiopathic; with autoimmune, toxins,

vitamin deficiency, infections, and cancer-related causes being rarer.

While treatment for most neuropathies focuses on symptom management (e.g., pain) and physical therapy, some types of neuropathies have specific effective therapies, such as immunotherapy for chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) or targeted genetic treatments for familial amyloid polyneuropathy due to TTR mutations.

Peripheral neuropathy research continues to move forward, albeit at a slower pace than any of us would desire. Animal models of neuropathy continue to be an important means of dissecting pathomechanisms of neuropathy and have been the bedrock of much of our understanding in this disease. However, with advanced,

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big data (i.e., -omics) approaches, neuropathy research is poised to better utilize human data to understand the complex environmental and genetic components that underlie, or at least contribute to, many types of neuropathies. This increasing recognition of the important use of human clinical data and biosamples to investigate complex aspects of neuropathy positions the FPN PN Research Registry (PNRR) to continue to be a unique and valuable resource going forward.

Other important areas of neuropathy research include:

- » Modeling of neuropathy using human neuronal systems, such as induced pluripotent stem cell (iPSC) derived neuronal cultures, which allow for detailed studies of neuropathy in the human biological milieu.
- » The discovery, and the potential pharmacological targeting of common pathways of axonal degeneration (SARM1) raise hope of medications that may be able to help treat or prevent most types of neuropathies.
- » Increasing understanding of nerve regeneration pathomechanisms, which may lead to new therapies for established neuropathies.

There is continued reason for hope that new therapies for peripheral neuropathy will be developed in the near term, and the efforts of FPN are instrumental for that future.



Welcome our newest Scientific Advisory Board member: David Bennett, MB, PhD

David Bennett, MB, PhD, is a professor of neurology and neurobiology at the University of Oxford and consultant neurologist at Oxford University Hospitals in the UK. He is head of the Division of Clinical Neurology at the University of Oxford and a senior research fellow of Green Templeton College. His research focus is to understand the pathogenesis of neural injury and neuropathic pain and ultimately improve the clinical management of this debilitating condition.



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shifts – all with a focus on advancing new discoveries and answers for those impacted by this devastating condition.

In this issue, we are highlighting some of the exciting research underway in the field. With more scientific knowledge about this condition

From the Executive Director

will come greater understandings. I am optimistic about the future and am excited to share more information about our new chapter as it unfolds.

Thank you!

Lindsay
Lindsay Colbert



Faces of PN: *Susan*

OVERCOMING CHALLENGES WITH PERSEVERANCE AND SUPPORT

Greetings, FPN Community! My name is Susan W., and I am thrilled to share my journey with you as a longstanding supporter of FPN. Living in Bethesda, Md., my husband and I cherish our time spent at our cabin in New Hampshire, surrounded by the beauty of Mount Monadnock. Our favorite activities include walking, biking, and, most importantly, creating memories with our eight grandchildren.

In May 2009, my life took an unexpected turn when I was diagnosed with colon cancer. Following surgery in June, I embarked on a challenging chemotherapy journey in July. Although neuropathy was anticipated as a side effect of one of my chemo drugs, I was fortunate to have it well controlled throughout my six-month treatment. Welcoming the New Year in 2010 marked the end of my chemotherapy, filled with the hope that each day would bring renewed strength and a fading memory of the side effects.

However, just six weeks later, while in Florida, the full force of peripheral neuropathy hit me like a wave. Experiencing shooting pain down my arms and legs, I found myself unable to walk without assistance, and even the beach sand felt like shards of glass. Suddenly, my battle with cancer transformed into a battle with PN.

Upon returning home, I sought information on managing neuropathy and discovered *the Foundation for Peripheral Neuropathy*. My initial inquiries were met with a helpful response, introducing me to a PN Biobank – the Peripheral

Neuropathy Research Registry – that supports groundbreaking research. Drawing from my career at the National Cancer Institute, where I understood the significance of preserving biological samples, I was impressed that a small organization like FPN spearheaded this vital project.

It's heartening to see a small organization make significant strides in advancing peripheral neuropathy research.

SUSAN



FPN has been an invaluable resource for me, offering publications, webinars, and a supportive community for those dealing with PN. While I initially joined as a contributing member, what excites me the most is FPN's commitment to basic biomedical research, especially supporting young investigators and inspiring a new generation in PN research. I believe that future research will lead to innovative approaches, potential therapy, a cure, or even prevention for PN. Recognizing the high cost of research, I've increased my support for FPN and plan to continue contributing generously. Thank you, FPN, for being a beacon of hope and support for individuals like me navigating the challenges of peripheral neuropathy with resilience and determination.



NEW

Biobank research

New research from the Peripheral Neuropathy Research Registry (PNRR):

- VITAMIN D INSUFFICIENCIES IN PATIENTS WITH PERIPHERAL NEUROPATHIES**
Vitamin D deficiency is a worldwide pandemic and affects 60% of the population. Our partners will analyze if vitamin D deficiency or insufficiency will contribute to PN symptoms and progression.
- NEUROFILAMENT LIGHT CHAIN PLASMA LEVELS IN A LARGE COHORT OF PATIENTS WITH CRYPTOGENIC SENSORY POLYNEUROPATHY**
Neurofilament light chains (NfL) are associated with axonal degeneration, and elevated NfL levels have been observed in many neuromuscular diseases, including PN. This suggests NfL plasma levels as a potential biomarker to monitor disease activity in polyneuropathies, which would be of particular interest for future intervention trials.
- CHARACTERIZATION OF PATIENTS WITH IDIOPATHIC SMALL-FIBER NEUROPATHY**
An epidemiologic study based on the PNRR, preliminary evidence suggests dysimmune/inflammatory causes to play a major role in the pathomechanism of some patients with idiopathic SFN.
- HYPOTHYROIDISM IN PATIENTS WITH IDIOPATHIC AND DIABETIC POLYNEUROPATHY**
This data analysis project seeks to confirm previous findings that hypothyroidism is correlated with more rapid advancement of PN, and to check if hypothyroidism also leads to advanced symptoms in patients with idiopathic PN.
- NERVE ENTRAPMENTS IN PN PATIENTS**
The link between diabetic PN and issues like carpal tunnel syndrome and ulnar nerve entrapment is well documented. This is the first study of the link in a large cohort of patients with idiopathic PN.



ABOUT THE PNRR

Use the QR code to watch a short video, or visit FoundationForPN.org/PNRRpatient



IMAGINE A
WORLD WHERE
FUTURE GENERATIONS
WON'T SUFFER
FROM PN

Unlocking the power of PLANNED GIVING

Planned giving is a thoughtful and strategic way to leave a lasting impact. It ensures your philanthropic goals will continue for years, even decades, beyond your lifetime. You can help us fulfill our mission, whatever the future holds.

WILL PLANNING: SIMPLE AND FLEXIBLE

An easy and popular way to leave a legacy is by making a gift through your will or living trust. The bequest can be a percentage of your assets or a fixed amount. Have your attorney use this language: "I give, devise, and bequeath to *the Foundation for Peripheral Neuropathy*, whose office address is 485 E. Half Day Rd., Ste. 350, Buffalo Grove, IL 60089, [*written amount or percentage of the estate*] for its unrestricted use and purpose."

BENEFICIARY DESIGNATIONS: NAMING FPN

There are two primary ways to make a beneficiary designation:

1. Name FPN as a primary or secondary life insurance beneficiary and
2. Make a gift by naming FPN as a remainder beneficiary in your 401(k) or IRA.

Read about IRA charitable rollovers, charitable remainder trusts, charitable gift annuities, and charitable lead trusts at FoundationForPN.org/PlannedGiving.



A role for neurologists in *diabetic peripheral neuropathy* (DPN)

SOURCE
Pauline Anderson
MedScape Today, Nov 21, 2023



Eva L. Feldman, MD, PhD, a professor of neurology at the University of Michigan, Ann Arbor, and a FPN Scientific Advisory Board member, recently discussed the global burden of diabetic peripheral neuropathy, and the potential role for neurologists in treating it.

"We as neurologists have to be cognizant of risk factors that contribute to both injury to the peripheral nervous system and to the central nervous system," she told Medscape Medical News.

"The rise in diabetic neuropathy over the last few decades has paralleled the obesity pandemic and the related diabetes pandemic," said Feldman. Some 60%–65% of Americans are now either overweight, defined as body mass index (BMI) between 25 and 30, or obese, BMI greater than 30. Of the more than 32 million people in the U.S. with diabetes, Feldman estimates 27% to 42% are living with DPN.

"We need to go from sick care to well care, from treating disease to preventing disease," she said. "When a patient comes to me, regardless of their neurologic complaint, if they're overweight, I will address weight, and I will address their blood pressure and encourage them to continue to address that with their family doctor."

Feldman also emphasized the importance of physical activity and diet. She pointed to recent research showing aerobic exercise can improve DPN, as can a diet with monounsaturated and polyunsaturated fats instead of saturated fats, and a diet that's rich in fiber, vegetables, and fish. She also advocates for collaboration with other specialties to offer patients a more "holistic" approach to care.



Scientific Advisory Board

The Foundation's volunteer Scientific Advisory Board is comprised of world-renowned peripheral neuropathy experts. (List overleaf.) They guide the Foundation's research activities, seeking out the most innovative and promising neuropathy research projects for support.

This board's focus remains on improving and advancing discoveries from data collected from the Peripheral Neuropathy Research Registry (PNRR), the Foundation's prestigious biobank of DNA samples from over 2,500 PN patients.



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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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Celebrating

PERIPHERAL NEUROPATHY AWARENESS WEEK

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