

FPN *print* NEWS

FALL 2024



From the Executive Director

Dear friends:

Earlier this year, I had an opportunity to connect with neuromuscular specialists at the largest peripheral nerve meeting in the world – the Peripheral Nerve Society Annual Meeting in Montreal.

Sitting in a 500-seat lecture hall for four days of presentations, I learned about the latest and greatest in PN research. But most importantly, I saw firsthand how instrumental we are in this work.

FPN's biobank of blood, plasma and serum samples from nearly 3,000 PN patients has already shown five

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The power of advocacy

By Sumedha S.

While many people become acquainted with peripheral neuropathy (PN) due to their own diagnosis or that of someone close to them, my introduction to PN was rather unconventional. I am a rising freshman at UCLA, pursuing Biology on the Pre-Medicine track. I am deeply passionate about advancing therapeutic options in pain medicine, and I became particularly interested in PN. Since 2023, I have been actively involved with the Foundation for Peripheral Neuropathy (FPN).

After beginning my research on PN in my sophomore year, I felt compelled to explore it beyond just research. I began advocating to my local Congressional leaders about including PN as an eligible condition in the Peer-Reviewed Medical Research Program (PRMRP) Bill

to receive Department of Defense research funds. This effort was a success! I am proud to have played a role in renewing PN as a priority in this research arena.

During these efforts, I have learned a lot about getting your agenda heard, as it is a major mission of the Foundation. I learned that you should have a strong “why” when asking others to support your cause. With a strong reason, it becomes intuitive for others to understand why our goal is meaningful. I learned that persistence is key to making change for a cause you believe in. Getting PN into the PRMRP Bill was no easy feat, but with determination from hundreds of people, we achieved our goal. I now believe that no goal is impossible to reach.

I admire the community FPN has built. They have supported those

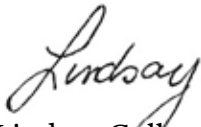
PN RESEARCH continued on page 2 >

(LETTER continued from page 1)

published discoveries with six more coming in 2024/25 on the topics of Metabolic Syndrome, Vitamin D, Neurofilament light, Prediabetes, Diabetes, Idiopathic and Chemo-induced neuropathies. While in Montreal, I shook the hands of dozens of existing (and countless more incoming) researchers who are using these samples for their research.

I also met with a group of anti-MAG neuropathy researchers, who are a part of a 10-country consortium that FPN funds to continue the understanding and analysis of this rare form of neuropathy. During our meeting, the 300th patient was entered into the database. This is significant because clinical research studies can start with these samples – including research on biomarker studies, disease status and progression studies. It was an honor to have been instrumental in the cohort's success to date, and to be in the room to celebrate this milestone.

I'm excited to see what's next. I'm humbled by the crucial role we play in PN research, advocacy and education. Thank you for being a part of our organization and entrusting us to serve as your premier resource of information.


Lindsay Colbert



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suffering from peripheral neuropathy, not only from an educational standpoint, but also an emotional one. I want to spread the word about the condition and continue educating the world about PN because with more awareness comes a greater desire to make a change.



Research Update: Metabolic Syndrome

Written by Shanna Patterson, MD, MS, Mount Sinai Medicine

Recent years have brought significant increases in our understanding of the variety of possible causes for peripheral neuropathy. While these advances are fantastic, it still is true that for many patients the cause of their neuropathy remains unfortunately unknown. Simultaneously, in recent decades we have seen a global rise in obesity, and related metabolic syndrome. Metabolic syndrome is a medical constellation of symptoms that includes obesity, dyslipidemia (high cholesterol or high triglycerides, for example) and prediabetes. A link has been observed between metabolic syndrome and peripheral neuropathy – especially sensory neuropathy, which is characterized primarily by numbness, tingling or pain. Studies have shown that even in the absence of diabetes, metabolic syndrome alone is associated with an increased risk of neuropathy.

The paper “Metabolic syndrome and peripheral neuropathy” published in *Muscle & Nerve* by Wiley, provides new details about the suspected mechanisms of how metabolic syndrome causes neuropathy. Not only does this potentially offer an answer for some patients with neuropathy who otherwise have not known what the cause of their neuropathy might be, but it also offers some exciting new insights into potential treatments. This is because various aspects of metabolic syndrome can be improved through lifestyle modifications, such as regular exercise, as well as dietary changes. As described at the end of the paper, several studies have shown that a regular exercise program was linked with improvement in neuropathy, including an improvement in pain. Other neuropathy treatments targeting weight loss are also being evaluated, but hopefully, what we have learned here so far can help many people who are currently struggling. Though it is certainly easier said than done, this data seems to emphasize that it is important to keep moving!



By Shari P.

I first started feeling symptoms of peripheral neuropathy in my late forties, but I had no idea what they were. The tingling, numbness, and occasional pain in my feet mystified me. It didn't have a huge impact on my life, but it was very uncomfortable.

The testing process was long, but finally, I received a diagnosis: peripheral neuropathy caused by congenital lumbar degeneration. I had been diagnosed with lumbar degeneration in my 20s and was receiving consistent chiropractic treatment, but now, I needed to address peripheral neuropathy. Since the doctor who diagnosed me was based in Massachusetts, and I had just moved to Bermuda, I was left to figure it out on my own. So I began researching treatments.

I discovered the “Numb Toes and Other Woes” book series, which provided valuable information. I also learned about The ReBuilder®, a TENS machine developed by the son of a peripheral neuropathy patient. I've used it twice daily since discovering it and, now at 77, my symptoms—tingling, numbness, and pain—have remained confined to my feet and haven't worsened noticeably.

The extent to which remedies can help manage symptoms varies hugely from one person to

Faces of PN: Shari

MY JOURNEY WITH
PERIPHERAL NEUROPATHY

We need to accept the things that happen to us as life goes on, and learn to deal with them as well as we can.



another, but over time, I've found several remedies helpful for my neuropathy including Vick's Vaporub®, Alpha Lipoic Acid, pain patches, Lion's Mane mushroom supplements, Vibram® Five Fingers shoes, among others

My mindset now is to “recognize the difference between what you can reasonably do and what you can't, and eliminate the latter from your life.”

We need to accept the things that happen to us as life goes on, and learn to deal with them as well as we can. Thanks to *the Foundation for Peripheral Neuropathy*, progress is being made in treating this condition, despite its many varying causes and symptoms. We need to be patient and to help when and where we can.



Vetting information on PERIPHERAL NEUROPATHY

Assessing neuropathy-related claims for scientific and medical accuracy

Peripheral neuropathy is challenging to diagnose and treat. This leaves patients vulnerable to false claims about miracle cures or other pseudoscientific (falsely or mistakenly claimed, or not regarded as being based on scientific method) information that may be seen on social media, in advertising or via poorly vetted news outlets.

Determine if a claim is reliable and accurate by looking for common red flags, using critical thinking skills and understanding frequent characteristics of pseudoscience.

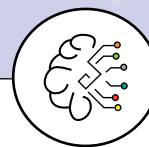
Information gathered by Kristy Townsend, PhD, neuropathy researcher, The Ohio State University, and Jane Bartmann, FPN staff

* used with permission of Melanie Trecek-King from ThinkingIsPower.com



CHARACTERISTICS OF PSEUDOSCIENCE*

1. Is unfalsifiable (can't be proven wrong)
2. Relies heavily on anecdotes, personal experience and testimonials
3. Cherry picks confirming evidence while ignoring/minimizing disconfirming evidence
4. Uses technobabble, words that sound scientific but don't make sense
5. Lacks plausible mechanism, no way to explain it based on existing knowledge
6. Is unchanging, doesn't self correct or make progress
7. Makes extraordinary or exaggerated claims with little evidence
8. Professes certainty, talking of 'proof' with great certainty
9. Commits logical fallacies, arguments contain errors in reasoning
10. Lacks peer review, goes directly to the public, avoiding scientific scrutiny
11. Claims there is a conspiracy to suppress their ideas



CRITICAL THINKERS*

- » Are aware their thinking is flawed
- » Think about how they think
- » Are curious and inquisitive
- » Separate their identity from their beliefs
- » Welcome criticism from others
- » Use evidence to arrive at conclusions and maintain a healthy level of skepticism
- » Avoid black and white thinking and are comfortable with ambiguity and uncertainty
- » Are humble



COMMON RED FLAGS

1. **Stories instead of proof:** claims are often based on personal stories from a few people or on studies that weren't done well or were too small to be trustworthy.
2. **Emotional tricks:** claims try to make you feel emotional or desperate, saying that big companies or doctors ignore treatments that are natural or cheap. In reality, doctors and scientists want to find good treatments no matter where they come from or how much they cost.
3. **Confusing language:** ads use complicated medical words or explanations that can't be checked with reliable sources.
4. **Hidden truths:** claims say there is a "secret" truth about your illness that doctors are hiding from you. In reality, medical science is excited to share new findings.
5. **Asking for money:** site/post/ad often asks for money as a big part of its message.

VET SOURCES FOR ACCURACY

Sites ending in .com (vs .org, .edu or .gov) need more scrutiny. Are they trying to sell a product? How do they validate their claims? Peer-reviewed research in respected journals is best – but even then, science and medicine constantly evolve as new and better information are available.

Employ the critical thinking skill of skepticism: learn more about the website or organization. Do some research. Who are the people behind the claims? What is their motivation? Are there any reports of fraud or conflicting evidence?

RESOURCES FOR VETTING ACCURACY

- » FTC scam reporting: [FTC.gov](https://www.ftc.gov)
- » Quack Watch: [QuackWatch.org](https://www.QuackWatch.org)
- » US Clinical Trials Registry: [ClinicalTrials.gov](https://www.ClinicalTrials.gov)
- » US FDA approved treatments: [FDA.gov](https://www.fda.gov)

mark your calendar

DAY OF GIVING

On Oct. 15, we're celebrating our 17th anniversary with a day of giving. Our goal is to raise \$17,000 to support patients who want a world without peripheral neuropathy.

PN summer education series

Our summer education series was a success! Are you one of the 3,100 people (and counting!) who watched? We covered a variety of topics, from the basics of neuropathy, to healthy living, managing symptoms and advocating for PN research. We heard personal stories of resilience, and gleaned hope from those living fulfilling lives despite a PN diagnosis, and those working to ensure PN research gets more funding in the future.

Scan the QR code to watch this series.

Visit [FoundationForPN.org/webinars](https://www.FoundationForPN.org/webinars) for upcoming programs. Topics like genetic testing and sleeping with PN are already in the works. More webinars are added regularly.

watch how



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DEDICATED to REVERSING *the* IRREVERSIBLE

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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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Make a difference with your IRA



If you're 70½ or older, you can support *the* Foundation for Peripheral Neuropathy through a qualified charitable distribution (QCD) from your IRA. This allows you to transfer funds directly from your IRA to the Foundation, fulfilling your required minimum distribution (RMD) without paying income tax on the donated amount. It's a win-win: you meet your RMD and support a cause close to your heart.

Donating from your IRA is simple and tax efficient. A QCD excludes the donated amount from your taxable income, which can lower your overall tax bill, especially if you don't itemize deductions. By transferring your IRA distribution directly to the Foundation, you help advance our mission to improve the lives of those affected by peripheral neuropathy. Consult your financial advisor or IRA custodian to see how you can make a lasting impact today.