



FPN NEWS

FALL 2022



From the Executive Director



Dear FPN Friend:

Thank you so much for being a part of *the* Foundation for Peripheral Neuropathy’s success over the last 15 years. Today, I ask you to join me in celebrating our organization’s monumental 15-year anniversary, and everything we’ve accomplished together so far in the field of peripheral neuropathy.

In this edition, like any other, our articles highlight what we’ve done and continue to do every day to help improve the lives of millions of patients living with this debilitating condition – from updates on

(LETTER continued on page 2)

Faces of PN: *Linda Petiot*

At *the* Foundation for Peripheral Neuropathy, we like to share with our readers stories of hope from peripheral neuropathy patients who are living their best lives, despite the odds being stacked against them. Linda Petiot, president of the Calgary Neuropathy Association (CNA) and FPN supporter, is another example.

We sat down with Linda to learn about her journey in more detail.

FPN: Please tell us a little about yourself.

Linda: I’m a life-long learner who landed a volunteering job with the Calgary Neuropathy Association (**CNA**), educating, and supporting those with neuropathy. This is where I am meant to be. In my professional career, my work was to analyze needs and problems and then

(LINDA continued on page 2)

“As Foundation president, I am very proud of the strides our small organization has made in achieving our goals on behalf of the PN population, recognizing we have a long way to go.”

LOU MAZAWAY
FPN Board President



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research advancements to our continuous work in patient advocacy. We're also fortunate to be able to highlight the amazing folks that do inspiring things to advance our mission daily – including a final update from Gregory Maassen's cross-country e-bike tour of the USA to raise awareness and funds for FPN.

Please know that your continued support allows us to fight for more answers and support PN patients. Thank you so much for your help and generosity. We are lucky to have you as a part of our family.

With thanks,

Lindsay
Lindsay



(LINDA continued from page 1)

write about what I had learned in a clear and concise way, so solutions could be discussed and built. The skills I developed over 30 years set me up for my work with the CNA. I've been volunteering now for six years with them, and for me, it is all about helping people find ways to ease their symptoms, their challenges and their minds.



FPN: *What is your connection to peripheral neuropathy?*

Linda: I have Charcot-Marie-Tooth (CMT) disease which affects much more than my hands and feet. I spend a lot of time digging up things to relieve neuropathy symptoms, and the impacts that come with them, like isolation, and mobility, functional and mental health challenges. CMT is a hereditary form of neuropathy under the muscular dystrophy umbrella. It was genetically passed down to me from my dad, and in turn, I passed it to one of my sons. Getting diagnosed with CMT was puzzling and a relief at the same time. I'd never heard of it and couldn't even spell it; but it explained a lot of things: Why I was clumsy all my life. Why I had shooting pains everywhere—feet to lips. Why I couldn't even, no matter how I much wanted to, wear pretty shoes.

FPN: *When and how were you diagnosed with peripheral neuropathy? Who diagnosed your PN?*

Linda: About a decade ago, and after years of complaining to any doctor who would listen about his weakening legs and shooting pains, my dad was diagnosed by a neurologist. It baffles me to this day why it took so long for someone to identify it. The symptoms are so obvious once you know them. I was in the office at the time my dad was told about his diagnosis, and so the neurologist turned to me and asked if I had similar symptoms. After a brief chat, he nodded and said, "you should book an appointment with me." Once I was diagnosed, and it was confirmed through genetic testing, my son, who also has symptoms, was tested.

FPN: *How have you been managing your PN?*

Linda: I tell people, "I must do 50 things a day to manage my neuropathy." It turns out it is closer to 40 things every day and another 20 as needed. My top management strategies are meditation, a variety of exercises, and avoiding sugars.

FPN: *What do you wish people knew about PN?*

Linda: Peripheral neuropathy is not just about nerve pain. It's also about the many other ways it impacts each person. I wish people understood it leads to isolation. It leads to repeated, progressive losses of function, and grief for each loss. For some, it leads to an inability to work, resulting in a loss of financial stability. For people with neuropathy, I wish they all knew how to find the resources and supports they each need. For those

people's friends and family, I wish they knew their support can make a big difference. Their compassionate ear, time spent visiting, rides to appointments, or helpful chores are the difference between someone feeling ignored and being heard; feeling discarded (or isolated) and feeling worthy of support; feeling helpless and feeling like someone has your back.

FPN: *What inspires you to face peripheral neuropathy head-on, and how do you do it?*

Linda: I look at my dad, who didn't know what was wrong for so long and now is in a wheelchair, in part, because he didn't have the knowledge and skills I have. I believe with all I have learned, I have at least some ability to slow down my neuropathy's progression through my own good habits. I don't want neuropathy to take my joys or my golden years from me, and that means doing whatever I can now. If I'm going down, I'm going down fighting!

FPN: *What advice would you give others going through the same journey?*

Linda: Try things, find what works for you and keep doing it. Never stop trying. And learn how to talk to your medical and support teams.

FPN: *What is your motto to live by?*

Linda: Educate yourself, try the stuff that makes sense, keep what works, and help someone else do the same.

Thank you so much for taking the time to share your inspirational journey, Linda. I think everyone learned that even for hereditary neuropathies, such as CMT, lifestyle is still an important intervention mode, as it is for all forms of neuropathy.

Gregory Maassen's E-Bike Tour:

Completed!

On August 2, 2022, Gregory Maassen completed his 4,500-mile cross-country e-bike tour in San Francisco. He began his journey on April 2, leaving his hometown of Washington, D.C., by electric bicycle to raise awareness for peripheral neuropathy, while simultaneously establishing a new bike route across the U.S. Gregory is the first person to ride an e-bike coast to coast in the United States.

The Foundation's executive director, Lindsay Colbert, was joined by Gregory's wife, local firefighters, Dr. Jeffrey Ralph from UCSF, local PN patients and supporters as he crossed the finish line in San Francisco.

In a statement released on August 2, Gregory said, "This fundraiser, using an e-bike to traverse the Lincoln Highway for the very first time, is a tribute to the special friendship between the Dutch and the Americans." He added, "it celebrates the longest uninterrupted peaceful relationship that the United States has with any foreign country. This journey also supports millions of people everywhere suffering with peripheral neuropathy." Gregory not only became an American citizen during this tour, but he also successfully raised over \$175,000 for the Foundation for Peripheral Neuropathy.

Additionally, to commemorate this achievement, San Francisco Mayor London Breed declared August 2, 2022, "Dr. Gregory Maassen and Peripheral Neuropathy Awareness Day" in San Francisco.

Learn more about Gregory's journey at ebiketour.org or by reading some of the media coverage from across the country housed at FoundationForPN.org/ebike-media.



FPN is an organization that takes a comprehensive view to eliminate peripheral neuropathy as a disease, from patient education, to research, to advocacy. This 360-degree emphasis is critical to their success.

KRISTY TOWNSEND, PHD
FPN Board Member



FPN's Peripheral Neuropathy Biobank

In 2008, FPN announced the development of the Peripheral Neuropathy Research Registry (PNRR) – a unique biobank of human samples and DNA – to facilitate groundbreaking research for PN and to find cures for this debilitating condition.

So far, over 2,300 patients have enrolled in the PNRR making this cohort a significant data set for researchers to use. Discoveries have already been shared, most recently concluding that vitamin B6 levels do not correlate with the severity of neuropathy. Many more findings are anticipated to be revealed soon, and new studies are continuously underway.

the PERIPHERAL NEUROPATHY Research Registry

In this issue, we're happy to share a handful of the recent studies underway that have commenced:

1. Metabolomics, an emerging and rapidly evolving field, has been highlighted as one of the broadest and more reliable tools for physiological status investigation, discovery of new biomarkers, and metabolic pathway analysis. Metabolomics involves quantitative detection of a large number of small molecule metabolites in biological systems, and their steady-state levels can be regarded as the ultimate response of biological systems to genotype, phenotype, and environment. This study will utilize metabolomics to identify novel plasma metabolomic signatures associated with diabetic neuropathy.
2. Myopathy (muscle weakness) is more common in patients with diabetic PN (DPN) compared to those with idiopathic PN. Analyses will be performed on data records of 120 diabetic PN patients enrolled in the PNRR, checking for frequency and severity of myopathy in patients with DPN compared to those with idiopathic PN (IPN), as well as other variables (such as glycemic control, age, pain severity, medications or duration of diabetes diagnosis) contributing to the presence of myopathy.
3. Data from 120 patients with DPN will be compared to the data of 120 patients with IPN to evaluate for the frequency, pattern (motor versus sensory) and degree of demyelinating properties measured by nerve conduction studies (NCS) in patients with DPN compared to those with IPN.
4. Distal sensory loss and reduced or absent ankle jerk tendon reflex are the most common onset symptoms for polyneuropathy. Some studies indicate that age as well as height influence the presence of the ankle reflex, and both height and age are some of the well-established factors that influence abnormal outcomes of NCS. This study will utilize the PNRR data of all patients enrolled with diagnosis of idiopathic polyneuropathy, to evaluate for the effects of patient height and age and its influence on sural nerve sensory action potential parameters and ankle tendon reflex responses.
5. Machine learning algorithms on PNRR data variables will be explored to run data analyses and assess and describe clusters for PN with regard to patient, symptom, nerve conduction, and bloodwork characteristics. Machine learning algorithms used in this manner can potentially identify clusters of different causes of PN and how these causes are correlated with PN disease manifestation. Ultimately, with these findings, the hope is to aid in predicting and identifying better diagnostic causes of IPN.
6. A retrospective case-control study is underway with a goal of identifying the clinical characteristics of neuropathies associated with metabolic syndrome (MetSyn). Hypothesis is that patients with MetSyn neuropathy have a different phenotype in comparison to patients who do not fulfill MetSyn criteria, and that each MetSyn component has different degrees of contribution to neuropathy. Data collected from 487 PN patients (144 DPN; 343 IPN) will be analyzed.



Nine Benefits of Exercise for Older Adults

Source: Garage Gym Reviews

It's never too late to start an exercise routine and enjoy becoming the fittest and healthiest you've ever been.

Everyone, regardless of age, can and will benefit from exercise. Whether you've never exercised before, or you're rekindling an old habit, here are nine big benefits of exercise for seniors to keep you motivated for the long haul.

1. Bone Health: Preventing osteoporosis
2. Muscle Health: Preventing sarcopenia
3. Cardiovascular Health: Blood pressure, cholesterol and more
4. Maintain Independence: Strength, balance, and coordination
5. Decreases risk of depression
6. Helps you find a community
7. Improves memory
8. Increases cognitive function
9. Improves quality of life

All exercise improves quality of life through a marriage of all these benefits. Between stronger bones and muscles, a healthier cardiovascular system, better coordination and balance, better memory, and a healthy social life all put the "golden" in your golden years.

Read about all the benefits at www.garagegymreviews.com/benefits-of-exercise-for-older-adults

This article is intended for educational purposes only, and is not intended as a substitute for medical advice. For such advice, consult your physician or other qualified healthcare professional.



“Adults with high physical activity levels have... a biological aging advantage of nine years over those who are sedentary.”

(Source: <https://news.byu.edu/news/high-levels-exercise-linked-nine-years-less-aging-cellular-level>)



PN Advocacy Update

FPN works tirelessly to support public policies that benefit people with peripheral neuropathy. Advocacy and public policy work are important for advancing research into finding new treatments and, ultimately, cures for peripheral neuropathy. FPN advocates for federal and state legislation as well as regulatory actions that will eventually benefit you, our patients. We are continuously working to ensure you have access to high-quality, affordable, evidence-based care and treatments.

Peripheral Neuropathy Research at the Department of Defense (DoD)

In 2020, Congress for the first time included peripheral neuropathy as an eligible condition for study through a \$370 million fund administered by the DoD known as the Peer Reviewed Medical Research Program (PRMRP). This important breakthrough was a direct result of the nationwide advocacy of the peripheral neuropathy community. This accomplishment will allow our research community to apply for funding from a federal program to which they previously did not have access.

On July 28, 2022, the Senate Committee on Appropriations released a “draft” version of the fiscal year 2023 Defense Appropriations Act. We are pleased to report that this draft legislation, if enacted, would renew peripheral neuropathy as an eligible condition for research from the PRMRP at the DoD. The draft bill would also appropriate \$370 million for the PRMRP in fiscal year 2023.

We still have a long way to go in this process, but this is an important first step. Congressional leaders must first agree to overall spending levels for fiscal year 2023, and this will likely not happen until after the November elections. However, if an agreement is reached and a final appropriations bill is crafted for consideration, it will more than likely include the renewal of peripheral neuropathy as an eligible condition for the PRMRP. If enacted, this would be the third consecutive year that the condition has been included in the PRMRP.

To view the 2021 PRMRP awarded projects that amounted to over \$8 million, please go to: FoundationForPN.org/awards.





New FPN Staff

Since our last edition, we're pleased to welcome two new staff members, Jane Bartmann and Jennifer Riskind, to our team. Please join us in welcoming them to the FPN community! Read their bios and how they will serve the Foundation at FoundationForPN.org/leadership.

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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.



MAKING AN
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AND IN THE
FUTURE

You can help us continue to improve the lives of people with peripheral neuropathy and inspire future scientific research and discoveries with a legacy gift.

We have teamed up with experts from Merrill Lynch to bring you information on charitable planned giving and planned giving tools.

To learn more, please contact Jennifer Riskind, our new Director of Development & External Affairs, at 847-808-4374 or visit FoundationForPN.org.