



the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FPN | News

SPRING 2022



FROM THE
EXECUTIVE
DIRECTOR

Dear FPN Members:

It is during times of expansion that I am most proud to be a part of *the* Foundation for Peripheral Neuropathy (FPN), working to advance research, raise awareness and support patients across the world. For 12 years, we have collectively gained more knowledge about this disease and funded hundreds of research grants to drive transformational change—and 2022 will be no different!

I say “times of expansion,” because this organization is moving to the next level, and I’m thrilled you are here joining us for the ride.

- Our work in advocacy has brought its fruits, being recently awarded \$8 million in research funding for peripheral neuropathy by the Department of Defense. This significant funding will allow seven PN research projects to move forward—all thanks to FPN’s commitment to advocacy and our priceless volunteers.
- With President Biden’s diagnosis of mild sensory peripheral neuropathy last fall, we are eager to continue to shed light on PN and now hope to work closely with Capitol Hill to make lasting changes for our patients and their advocates at a higher level. PN Awareness Week is May 1-7, 2022, and FPN will spearhead the efforts.
- Our PN Research Registry continues to enroll new patients and conduct new research, a couple of which are highlighted within this newsletter.

(continued on page 3)

eBike Across the USA



Gregory Maassen, Ph.D., is no stranger to challenges and adventures. In his years working and traveling the world as a senior executive with USAID programs, he has tackled many complex problems head-on. When he was diagnosed with peripheral neuropathy in 2019, he attacked this new obstacle the same way: determined to embrace this new challenge and live his life to the fullest. With encouragement from his doctor, Ahmet Höke, M.D., Ph.D., FRCPC, from Johns Hopkins, Gregory took on exercise as a way to combat the symptoms of PN.

Gregory became an avid cyclist, using an electric bicycle for his exercise routine. According to Gregory, “I started to e-bike as normal cycling was too difficult. It has saved my life. I would like to encourage PN patients to exercise and possibly use e-bikes. Many cannot walk, but they can e-bike. He founded E-bike Lovers (ebikelovers.com) to provide members with free, high-quality e-bike travel experiences. Now, three years later, he can say that he has managed to reduce his symptoms and is committed to helping raise money for research, as well as raising awareness for peripheral neuropathy.

To this end, Gregory is taking on a new challenge.

Gregory will ride an e-bike over 3,400 miles following the historic Lincoln Highway to create awareness for peripheral neuropathy. This is the first-ever use of an e-bike on this specific route. A fundraiser for *the* Foundation for Peripheral Neuropathy, Gregory follows President Eisenhower in his footsteps when he traveled along the historic Lincoln Highway in 1919. Gregory chose the route to honor President Eisenhower who oversaw the liberation of the Netherlands, Gregory’s native country, during WWII.



INSIDE

- Upcoming Meetings
- New Research Funding
- PN Book Reviews
- Neuropathic Itch

(continued on page 3)

RESEARCH

THE PNRR: WHAT'S NEW?

the PERIPHERAL NEUROPATHY | Research Registry

The Peripheral Neuropathy Research Registry (PNRR) remains a cornerstone in FPN's quest to discover more treatment options and hopefully, one day, cures for peripheral neuropathies.

Here is one exciting new discovery that came from our bio-bank since our Fall 2021 Newsletter:

- ▶ **Vitamin B6:** There is debate regarding the threshold at which intake levels can cause neurological symptoms through vitamin B6. In a recent study funded by FPN, researchers learned that vitamin B6 levels do not correlate with the severity of neuropathy. The study included 261 patients enrolled in the PNRR. Analysis included toe strength, vibration sense, and deep tendon reflexes, or patient-reported numbness or pain intensity. This study suggests that moderately-elevated plasma B6 levels, even in the 100 to 200 µg/L range, are not associated with significantly

worse neuropathy signs or symptoms. Although standard supplementation of B6 does not appear to have a major negative effect, this study does not directly answer whether stopping supplementation will have a beneficial effect.

Here is one new project that is underway from Zurich University of Applied Sciences:

- ▶ A new study will utilize machine learning algorithms on PNRR data variables to run exploratory 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 idiopathic neuropathy.

Visit <https://www.foundationforpn.org/current-research/> to stay current with new research being performed from the PNRR.

FPN Funds New Research Grants

In partnership with the American Academy of Neurology (AAN) and the American Brain Foundation (ABF), FPN is pleased to



announce its future funding of two clinical research training scholarship grants in peripheral neuropathy. The awards will be given to early career clinical and biomedical researchers focused on peripheral neuropathy.



These awards will be reviewed by top experts in the field in an effort to promote research in peripheral neuropathy among a new generation of scientists. If you would like to learn more about these scholarships and how you can play a role in our efforts, please contact us at info@tffpn.org.

SOMEONE YOU KNOW HAS PERIPHERAL NEUROPATHY
30 MILLION AMERICANS DO!

SAVE THE DATE
Peripheral Neuropathy Awareness Week
May 1-7, 2022

Check your emails before and during the week to learn how you can get involved.

UPCOMING MEETINGS:
FPN is pleased to rejoin the international meetings this spring:

- **American Academy of Neurology**
April 2-7, 2022, Seattle, Washington
- **Peripheral Nerve Society**
May 14-17, 2022, Miami, Florida

Gregory will commence this four-month expedition on April 2, 2022, from his home of Washington, D.C. He plans to finish in San Francisco around August 1, 2022. He will bring along Dutch wooden shoes, reminiscent of his Dutch heritage.

According to Gregory: "This fundraiser is a tribute to the Dutch-American friendship, the longest uninterrupted peaceful relationship with any foreign country, and to those who suffer from peripheral neuropathy. Peripheral neuropathy affects millions of Americans, but research is underfunded. We need to find a cure for all those who silently suffer from this debilitating condition."



Gregory's journey will include more than 60 stops following the Eisenhower-Lincoln Highway-Transcontinental Cycling Route. You can cheer Gregory on, join him for part of his



journey, or just support him in his quest to raise money for peripheral neuropathy awareness. To find out how you

can join in this amazing adventure, go to <https://www.foundationforpn.org/upcoming-events/> or to Gregory's website: www.ebiketour.org.

From the Executive Director (continued)

- Furthermore, FPN is expanding its presence in the field of PN research even more so by partnering with the American Academy of Neurology (AAN) and the American Brain Foundation (ABF) to fund clinical research training scholarships in neuropathy—furthering our expansion of research grants and partnerships with leading neurological organizations.
- Expanding our educational resources and upgrading our website is another example of such growth! Last quarter, we launched a new and better website. Have you seen it yet? I know you will enjoy it!

These are unprecedented times, and there are many, many ways to engage in philanthropy and activism. We hope FPN has given you the tools and the confidence to give it your all, and give it your all today. Stay safe and stay active! Thank you for being a part of our team, and I hope you enjoy this edition.

Cheers,



Lindsay

DOD'S PRMRP NEUROPATHY RESEARCH AWARDS

The Department of Defense's (DoD) Peer-Reviewed Medical Research Program (PRMRP) has determined the grant applications that it wishes to award for fiscal year 2021. In this first year that applications were accepted for research in peripheral neuropathy, 41 applications out of over 1000 applications received focused on peripheral neuropathy. The DoD is recommending awarding a grant for seven of these applications, for a total amount of \$8 million in funding!

This \$8 million in research funding would not have been possible without the advocacy efforts of the PN community. In 2020, *the* Foundation for Peripheral Neuropathy put out a call to action to our constituents and our partners, asking our community

to submit requests to their senators to include PN as an eligible condition in the PRMRP. And the community responded. Individuals, families, patient advocates, support groups, and researchers contacted their senators by letter, email and phone.

Through the actions of many who brought the importance of funding PN research to light, we saw a great return on our efforts and financial investment. FPN, supported by its dedicated donors, expended \$85,000 in advocacy and other costs (and many people's good efforts) to bring about \$8 million in funding. For those of us who like to look at ROI, we are pleased with these results. We look forward to continuation of the program in coming years.

What's next? Stay tuned for more details on the funded projects on our website. We will also share how you can help FPN in its mission to advocate for more funding for peripheral neuropathy research.



What is Small Fiber Neuropathy?

Many of our readers are constantly asking about small fiber neuropathy (SFN), so let's take a minute to review and learn about this important and all-too-common type of PN!

In this type of neuropathy, the small sensory nerves and autonomic fibers are affected. Symptoms include numbness, burning, and pain, often starting in the feet. Although it can be caused by diabetes, small fiber neuropathy also has been linked to

thyroid disease, chemotherapy (due to the toxins introduced into the body), dysfunction of connective tissues, and other causes. It can also affect the digestive system, cause fatigue, and trigger chronic pain. Consequently, it is sometimes misdiagnosed as fibromyalgia. For this reason, researchers are exploring effective screening options, such as sensory testing and a skin biopsy using a sample taken from the lower leg in which the nerve fibers in the skin are counted.

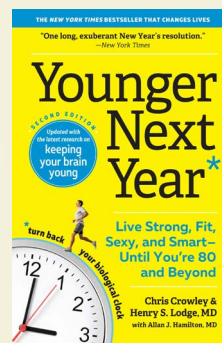
TO LEARN MORE, PLEASE VISIT www.foundationforpn.org.

FPN'S BOOK NOOK

FPN thanks Jeffrey Cooper for his contribution to our Spring Newsletter—reviewing three books that we thought would be of interest to our patients.

Jeff was diagnosed with peripheral neuropathy in August 2021. Since then, he has focused on reading, exercising, learning all he can about peripheral neuropathy, and living every day to the fullest. Jeff lives with his wife (and exercise partner) in Connecticut.

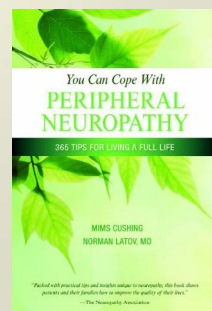
If you are looking for inspiration to get your exercise program going, read **Younger Next Year**. I read it, and I was literally inspired by it. It has totally changed my attitude about exercise



from something that was a chore to what I now consider to be a privilege. Now I am doing cardio and strength training five to six days a week, first thing in the morning. If you

follow the book's recommendations, you can delay mental and physical aging dramatically and also greatly reduce your chance of significant illness and injury due to aging. Although this is not a book on neuropathy, the experts on PN tell us that exercise is one thing we can do to help improve our PN symptoms without medication. This book is a page turner and highly recommended.

You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life, by Mims Cushing and Norman Latov, MD, Ph.D., is all about how to cope with peripheral neuropathy. I didn't count the suggestions, but it

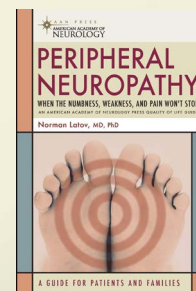


may very well include 365 tips.

Mims Cushing writes 10 of the 13 chapters. Dr. Latov writes three chapters. Mims Cushing lives with peripheral neuropathy and has published extensively in magazines and newspapers and has a few other books. Norman Latov is

Professor of Neurology and Neuroscience and Director of the Peripheral Neuropathy Clinical and Research Center at Weill Cornell Medical College.

Because the book was published in 2009, some references are a little dated; but can be easily overlooked because there are so many good ideas about coping with PN. If you have PN and are looking for ways to cope, this book will give you many good ideas and is well worth it. This book is an easy read of 232 pages and is available on Amazon for Kindle for \$10 or on paperback for \$15.



Peripheral Neuropathy by Norman Latov, M.D., Ph.D., describes the biology of nerves, nerve functions and how they can be distorted, as

well as the symptoms, diagnosis, and treatment of PN.

The following are the chapters in the book:

- What Is Peripheral Neuropathy?
- Function and Organization of the Peripheral Nerves
- Understanding the Symptoms of Peripheral Neuropathy
- Evaluation and Diagnosis
- Causes of Peripheral Neuropathy
- Management of Neuropathy
- Sharing Stories and Experiences
- Appendix: Resources

If you are new to peripheral neuropathy, this is a good overview. This book is an easy read of 151 pages available on Amazon for Kindle or paperback for about \$10.

Understanding Neuropathic ITCH

Itch is a unique sensory experience that is encoded by genetically distinguishable neurons both in the peripheral nervous system and central nervous system to elicit a characteristic behavioral response (scratching). Itch interacts with the other sensory modalities at multiple locations, from its initiation in a particular dermatome* to its transmission to the brain, where it is finally perceived.

**A dermatome is an area of skin in which sensory nerves derive from a single spinal nerve root.*

In a recent study out of Johns Hopkins University School of Medicine, Dr. Xintong Dong and his researchers summarize the current understanding of the molecular and neural mechanisms of itch by starting in the periphery, where itch is initiated, and discussing the circuits involved in itch processing in the central nervous system.

Itch perception and processing rely on dedicated sensory neural circuits. In the periphery, itch-specific neurons convey sensory information to the spinal cord, where the information is relayed by interneurons and integrated with other sensory modalities, pain and

touch. Other neurons then synapse onto projection neurons whose axons connect with itch-sensing neurons and other brain areas.

Despite exciting progress, several key questions still remain to be answered.

First, the genetic and environmental causes of multiple chronic itch conditions in humans remain elusive. Mouse genetics has been enormously useful in dissecting both the molecular and circuit mechanisms of itch. Yet mice and humans bear many functional distinctions in immunological, dermatological, and neurological perspectives.

Besides changes in immunological factors and concentrations of itch mediators, morphological and gene-expression alterations in the itch neurons themselves may be of central importance. Mouse models of dry skin and allergic contact dermatitis revealed higher itch fiber density in the epidermis and enhanced expression of itch receptors in the spinal cord, likely contributing to the diseased animals' significantly increased response to itchy stimuli.

Second, it is unclear how itch information is conveyed by the spinal projection neurons and how itch is decoded from other nociceptive senses

in the brain. The identity of projection neurons connecting itch-sensing neurons is likely key to the question. The cellular and molecular natures of peripheral and spinal neurons that mediate mechanical itch are also unknown. And it is curious whether mechanical and chemical itches are represented differently in the brain since in everyday experience both senses are perceived and conceptualized as "itch," and both elicit scratching responses.

How itch and all other somatosensory features are represented in the somatosensory cortex and other higher brain centers are also open questions. In theory, itch sensation should be topographically represented in the thalamus and primary sensory cortex, reflecting specific dermatomes where the stimuli are initiated.

Last but not least, the knowledge accumulated from skin immunology and neurophysiology can likely be extended to the mucosal system, which is the other barrier surface heavily involved in host defense and chemical sensation.

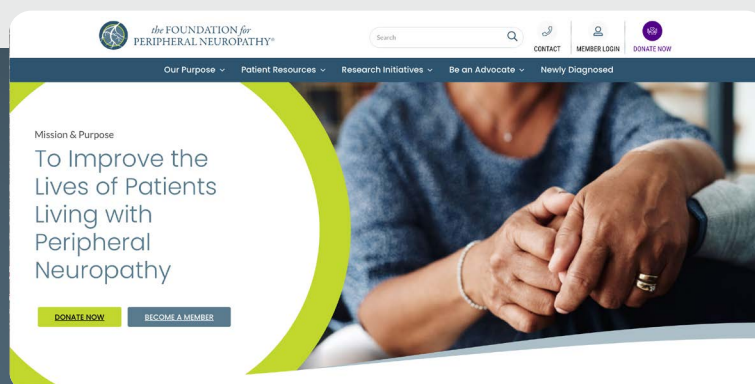
For those of our patients who suffer from neuropathic itch, please know that further studies are being performed to answer some of these outstanding questions.

FPN'S WEBSITE HAS A NEW LOOK!

Since our last edition, FPN underwent a redesign of its website. Already a proven resource for patients, caregivers and healthcare providers alike, the new look of the website aligns with our focus and allows

for an easier search of the numerous resources that the Foundation offers, including: a directory of neurologists and other healthcare providers, current news updates, scientifically-backed treatments, research updates and much, much more!

Thank you to our donors for supporting our mission and allowing us to transform this educational resource into a worldwide tool that we can be proud of. Visit us at www.foundationforpn.org today!



MAKING AN IMPACT TODAY AND INTO 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.

The Foundation for Peripheral Neuropathy has teamed up with experts from Merrill Lynch to bring you information on charitable planned giving and planned giving structures.

To learn more, contact Nancy at **847-808-4374** or go to our website at **www.foundationforpn.org**.



Like us on **Facebook.com/FoundationForPeripheralNeuropathy** and join the conversation.



The Foundation for Peripheral Neuropathy newsletter is published two times a year—spring and fall.

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.



the FOUNDATION for PERIPHERAL NEUROPATHY

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