



the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FPN | News

SPRING 2020



FROM THE
EXECUTIVE
DIRECTOR

Dear Friends:

The year 2020 has started off with a BANG!

The Foundation continuously amazes me with the research that we're embarking on and the programs that we oversee—and it is in large thanks to the support we receive from donors like you. Thank you for helping us to provide answers and hope to those in need.

Already this year, FPN funded a new research study using bio samples from our very own PN Research Registry (read more on page 2). This study holds much promise in finding commonalities in genetic markers of PN, and we're beyond proud to be the reason why this research is possible. And last month, we hosted a successful patient education webinar, the first of its series (read more on page 2). Our volunteers have also stepped up in 2020, drafting original content for our communications and serving as leaders of our many PN support groups. Our cohort is strong and mighty—and always growing and learning!

Every day, my staff and I talk with patients whose primary goal is to help others cope, by sharing tips and feedback. We also meet with family members and friends of PN patients who want to help their loved ones and choose our organization as a vehicle for doing just that. We continue to bear witness to countless, selfless acts by you and patients like you and it fills us with love, pride and energy to keep up with this great work.

One such individual that recently got our attention was Allison Stone, a young woman who is organizing a walk/run in honor of her dad who has CMT. We are thankful that Allison wants to help us both raise awareness for PN as well as solicit donations to our organization.

In closing, I hope that you feel a sense of pride to be a part of our network. I know that I do, and I am so thankful. Please keep reading and supporting us, so that we can keep supporting you when you need it most.

Warmest regards,

Lindsay
Lindsay Colbert



Meet Allison

Allison Stone is one of our newer and younger FPN Ambassadors. Allison is organizing "Got Nerve?," a 1-kilometer walk/run through historic downtown Fredericksburg, Virginia on June 13, 2020, to raise money for PN research and awareness for FPN. Allison shared some of her story with us.

Tell us about yourself.

I am a third year undergraduate student at BYU studying neuroscience. I am the second of 13 children, and have grown up in a military family moving around all of my life. Because of that, I love to learn about other cultures and can speak four languages. I love to try new things, especially those that nobody thinks can be done. I have a dream to teach science or medicine, and run my own farm.

What is your connection with peripheral neuropathy?

I learned about peripheral neuropathy a few years ago when my dad was diagnosed with Charcot-Marie-Tooth (CMT) Syndrome. My grandfather also has CMT.

Tell us about "Got Nerve?" What is it, how did you get the idea, what inspired you to do it?

"Got Nerve?" is a charity run/walk to raise funds and awareness for neuropathy research. The idea was started off as just that, an idea. I have participated in a variety of different races throughout my life (it was something that my dad and I did together when I was in middle school) and many of them were for a cause. So I thought it would be awesome if we could put together something like that. I wanted this to be something that brought us together, and allowed us

to help fight this with him. I wanted to get the community involved too.

It took several months, but I am

(continued on page 3)

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RESEARCH

PREDISPOSITION OF PN BY GENETIC MARKERS?



One of the original objectives of our very own Peripheral Neuropathy Research Registry (PNRR) was the search for genetic markers predisposing patients to develop peripheral neuropathy. Thanks to several generous donations, *the Foundation for Peripheral Neuropathy* is currently funding such a study through the genomic testing laboratory at Washington University in St. Louis (WUSTL) using the data and samples collected in the PNRR biobank.

In this study, researchers at WUSTL will analyze the genomes of 300 patients with idiopathic sensorimotor neuropathy through whole genome sequencing—which has

become a standard analysis method to search for genetic markers in many diseases. Unbiased data analyses will then evaluate if any genetic variants are more commonly present in the PNRR cohort. These samples were acquired from the PNRR and hand-selected as ones that are most likely to provide a yield.

It has long been suggested that genetic factors may predispose patients to develop polyneuropathy under certain conditions. For example, some patients receiving chemotherapy develop severe polyneuropathy, while others receiving the same regimen demonstrate no evidence of impaired nerve function. For other patients, no underlying medical condition or life-style habit causing polyneuropathy can be identified. It is hypothesized that these patients have a genetic marker which predisposes them to develop polyneuropathy in the presence of otherwise benign medical conditions, or because of age.

As additional funding becomes available to FPN, whole genome sequencing will be planned for additional PNRR patient samples.

AAN & PNS MEETINGS

The Foundation for Peripheral Neuropathy will be attending two, high-level meetings in the upcoming quarter to gain the latest insights on PN research and developments. These conferences offer an opportunity for the Foundation to have one-on-one discussions with experts in the field and learn about the latest research across specialties in peripheral neuropathy.

The American Academy of Neurology's Annual Meeting will be held in Toronto, Ontario, Canada in April 2020. This meeting is one of the most comprehensive neurology meetings in the world.

The Peripheral Nerve Society's Annual Meeting will be held in Miami, Florida in June 2020. Presentations by scientists will teach about the most current and groundbreaking developments in the field, including Charcot-Marie-Tooth and Related Neuropathies, Inflammatory Neuropathy, Toxic Neuropathy and Diabetic Neuropathy. *Stay tuned for updates.*

Announcing FPN's NEW Patient Education Webinars

On March 4, 2020, *the Foundation for Peripheral Neuropathy* hosted its first PN Patient Education webinar on Living Well with Peripheral Neuropathy. The webinar featured Dr. Shanna Patterson, FPN's Patient Education Advisor and Assistant Professor of Neurology at Mt. Sinai West in New York. Dr. Patterson presented suggestions for managing the symptoms of peripheral neuropathy, as well as answered patients' questions related to PN.

You can still catch "Living Well with Peripheral Neuropathy: Managing the Symptoms of Peripheral Neuropathy." The webinar has been recorded, and is available for viewing on the FPN Media Center webpage.

Future webinars will be announced on our website as well as through our e-Newsletters, so please stay tuned.



FOUNDATION LAUNCHES ADVOCACY CAMPAIGN TO INCLUDE PERIPHERAL NEUROPATHY IN DEPARTMENT OF DEFENSE MEDICAL RESEARCH BUDGET

On February 10, the President sent his fiscal year 2021 budget request to Congress (including both the House of Representatives and the Senate), and this coincidentally kicked off the Foundation's advocacy efforts to increase federal funding for peripheral neuropathy research. Specifically, the Foundation is requesting that Congress include "peripheral neuropathy" as a condition eligible for study by the Department of Defense's (DoD) medical research programs.

Every year, Congress approves DoD's budget through enactment of the Defense Appropriations Act. Within this massive spending bill, Congress allocates roughly \$1 billion for a variety of medical research programs designed to address specific health challenges faced by our men and women in the Armed Services. Later this year, when the Senate Appropriations Committee "marks up" its version of the fiscal year 2021 Defense Appropriations Act, it will list within the bill the conditions that are eligible for study under a \$360 million research program known as the Peer-Reviewed Medical Research Program (PRMRP). Every year, the Senate lists several dozen conditions. In order for a condition to be

included in this list, at least one senator must submit a request for that condition to the Appropriations Committee.

In February, the Foundation called upon its grassroots advocates across the country to urge them to contact their House Representatives and their Senators in support of having this request submitted by several senators. In response, the Foundation has met directly with a number of Senate offices to reinforce our grassroots campaign. Because of the strong application of this research to thousands of U.S. veterans, the request to include peripheral neuropathy was also endorsed in a letter by the Veterans for Common Sense and the Vietnam Veterans of America.

The Senate Appropriations Committee may soon begin its process of marking up the fiscal year 2021 appropriations bills, though it is uncertain when the committee will consider the Defense bill. As soon as the committee approves its bill, we will know if our efforts to include peripheral neuropathy have been successful. However, because this is an election year, it may be possible that this action doesn't occur until the fall or even after Election Day in November.

Stay tuned and visit our website for updates and opportunities for you to get involved.



Got Nerve? (continued)

now working with the city of Fredericksburg, VA for "Got Nerve?". The race will take runners and walkers along the heritage path of that historic city. We hope that it becomes an annual thing, and keeps getting bigger and can spread to other states. I told my dad about it just before we did this article, and it was such a fun surprise! He was very emotional.

What inspires you about your mom and dad, your dad living with neuropathy and your mom as his partner and support?

My dad inspires me in every way because he has found a way to live the best life possible, despite having to adjust what he does due to his diagnosis. He had to retire from the military last summer because the neuropathy has progressed to the point where he can't safely run anymore to pass the physical test. So, he has found other ways to stay in shape and loves teaching spin classes now. He is optimistic about finding a good job and is basing it off of how he can best provide for our family. My mother has been an excellent support in that this change of career will also require some lifestyle changes for us as a family. She has been optimistic and supportive, learning about

his neuropathy and what we need to prepare for as it progresses. She encourages him to keep living the best life possible. They are both just incredible examples of taking what life gives you and making the very best of it.

You are studying neuroscience at school. What do you want to do with your studies and hope to achieve?

In short, I want to change the world! I believe that there is so much for us to learn about the brain and its connection to everything we do. I have a dream that we can use science to inspire people to ask questions and overcome limitations. I just believe that knowledge empowers people, and want to use that to teach people to ask questions and find answers.

What would you love for people to know about PN?

I would love for people to know that there is so much room for improvement in our understanding of the disease. I would love for more people to be seeking for a cure and doing research. I want people to know that there is hope for the future.

What is your hope for the future?

My hope for the future is to inspire others to go out and try their hand at changing the world! I want people to see that anything is possible if you really want it and are willing to work for it.

Thank you Allison. We know our future is bright in your good hands!

WANT TO SUPPORT ALLISON AND "GOT NERVE?"

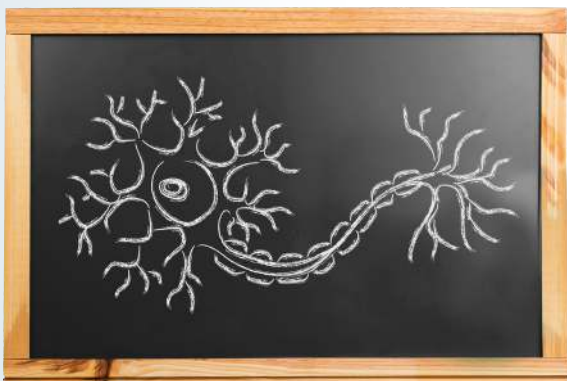
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NERVE BASICS

Janice Wiesman, MD FAAN

Author of *Peripheral Neuropathy: What It is and What You Can Do To Feel Better*



The popular use of the word “nerves” refers to feeling anxious or courageous. People say: “I have a case of the nerves” or “I lost my nerve.” This article is not about that. It is about the anatomical structures that are nerves. Nerves are the electrical wiring of our bodies that allow our brain to receive information from the outside world and the means by which our bodies act on the outside world.

Neurons are the cells that make nerves. Neurons sit in the spinal cord or in a chain that runs along the

spinal cord. Each neuron has a long, arm-like extension, called an axon. A nerve is a bundle of hundreds of thousands of axons that run in a connective tissue sheath. Even though a single axon can only be seen with a microscope, a nerve can be seen with the naked eye. It can be touched and surgery can be performed on it.

Nerves are a true miracle of nature. An electrical impulse travels down the axons like electricity down a wire where it causes the release of a specialized protein called a neurotransmitter. The neurotransmitter attaches to receptors on the surface of another neuron, or muscle or gland. This causes the neuron to send electricity down its axon or causes a muscle to contract or causes a gland to release its product. This sounds like a complicated sequence, but it all happens in a few thousandths of a second.

Neurons and their axons are divided into three functional categories: motor, sensory and autonomic. Motor nerves run from the spinal cord out to muscles and control voluntary movement. Sensory nerves bring information from specialized receptors in the skin, joints and sense organs, like the eyes and tongue, to the spinal cord and this information is transmitted to the brain. So, we do not “feel” with our skin or nerves; we feel with our brain. Autonomic nerves govern “automatic” functions like heart rate, temperature, sexual function and movement of the intestines, among others.

Axons are also categorized by size. Autonomic axons are the thinnest, motor are the thickest, and sensory

axons have a range of sizes in between. This is important for understanding the types of symptoms experienced by people with neuropathy.

Each axon is surrounded by fatty coating, called myelin, which is like the insulation of wires in a home in that it protects the axon and lets the electrical impulse travel down the axon faster. Thin axons have a thin myelin sheath and conduct their electrical impulses slowly, about 20 miles per hour. Axons with a large diameter and thick myelin coat conduct electricity at about 130 miles per hour.

Autonomic axons are thinnest. The next largest group are the sensory axons. Since their insulative coating is thin, they are most susceptible to damage by toxins and mechanical forces, such as compression. Within this group, the thinnest, most slowly conducting axons transmit information about pain and temperature. The thickest sensory axons, which conduct electricity most quickly, transmit information about deep pressure, vibration, and the position of joints. Motor axons are the thickest, and conduct electricity the fastest.

The difference in conduction speed between the thinnest sensory axons and the thickest is noticeable in everyday life when you stub your toe. The axons that mediate the pressure sensation of the “stub” conduct at 130 miles an hour, while the axons that mediate the pain conduct at 20 miles an hour. The “stub” information gets to your brain faster than the pain information, and so you feel the stub first and then the pain.

I hope this short primer serves as a useful basis for understanding the articles to come. I look forward to writing to you again.

5 MYTHS ABOUT TRAVELING WITH A DISABILITY

Fifty percent of seniors have some type of disability. With an aging Baby Boomer population, the number of travelers with accessibility needs is only going to increase. There are numerous accessible travel myths out there... here are five of the biggest ones:

1. I'll use the internet to plan my accessible vacation There's an enormous amount of accessible travel information on the internet. Unfortunately, there's also an enormous amount of accessible travel *misinformation* too! On discussion boards, able-bodied travelers with the best of intentions will eagerly give you advice without understanding your individual accessibility needs. Once that advice is on a discussion board, who is going to remove it when it becomes out of date? The reliability of accessible tour providers advertising on the internet varies greatly. So when you find an accessible van transfer in Nassau on the internet, will it show up on time? (hint: not likely)

2. I'll figure it out when I get there Did you miss out on the Capitoline Museums in Rome because you didn't know there was a hidden accessible side entrance? Did you realize that Fort San Cristobal is a short walking/rolling distance from the San Juan cruise port, but it's all uphill? Planning ahead is one of the keys to a successful accessible vacation. Even if you can figure it out when you get there, do you really want to be spending your precious vacation time “figuring things out?”

3. Physical barriers are the only accessibility barriers Unfortunately, physical barriers aren't the only barriers that make accessible travel difficult. “Permission” is another significant obstacle. In the Vatican, you have to have a wheelchair or mobility scooter to avoid the stairs into the Sistine Chapel. If you show up for a Ryan Air flight without booking boarding assistance in advance, you're likely to be disappointed. In Santorini, accessible tours are available, but the accessible vans don't have permission to go to the accessible port of Athinios, so disabled guests have to climb the stairs at the Old Port to take the cable car up to meet their accessible tour.

4. All cruise lines have similar accessibility While onboard accessibility on many cruise ships is similar, there are huge differences in terms of what they offer for accessible shore excursions. While Royal Caribbean and Celebrity have historically been the leaders in accessible shore excursions, several other cruise lines including Disney Cruise Line, Silversea Cruises, MSC Cruises, Regent Seven Seas Cruises, and Oceania Cruises are undergoing major revamps of their accessible shore excursion programs. This time next year, you will be absolutely amazed at the accessible onshore experiences you can book through many of the cruise lines.

5. You're disabled...you can't go there Although successfully planning an accessible vacation is difficult, it can be done! With the help of reliable and knowledgeable accessible tour operators like Sage Traveling, or Accessible Caribbean Vacations, people with disabilities can experience the ice bar in Stockholm, view glaciers in Switzerland, ride a gondola in Venice, discover the ruins of Pompeii, scuba dive in Cozumel, or visit Mayan ruins in Costa Maya.

This article was shared with FPN by Sage Travel, www.sagetraveling.com.



Integrative Treatments for Neuropathy: Vitamins and Supplements

There are well-tolerated vitamins and supplements with evidence showing benefit in neuropathy and neuropathic pain. Vitamins and herbs are not subject to rigorous federal regulatory oversight and can have potential interactions with pharmaceutical agents. Therefore, even though these supplements are available over-the-counter, treatment should be under the guidance of an experienced healthcare professional.

Alpha-lipoic acid (ALA) is a naturally-occurring fatty acid that can be found in foods in small amounts such as yeast, spinach, broccoli, potatoes, and organ meats. As an anti-oxidant, it is thought to be protective against free radical damage. ALA in supplement form has been extensively studied and used in Europe for the treatment of neuropathy associated with diabetes. It has been shown to improve symptoms of neuropathy and may help to protect against nerve damage. The oral form is generally well tolerated, but side effects can include stomach upset.

Acetyl-l-carnitine (ALC) is an amino acid that is naturally produced by the body and helps produce energy. As a supplement, it has been extensively studied in neuropathy associated with diabetes. Studies have shown ALC to improve the pain of diabetic neuropathy as well as aid in nerve regeneration. Although generally well tolerated, there is a potential for gastrointestinal side effects.

Omega-3 fatty acids found in foods such as fatty fish, walnuts, and flaxseed are crucial to nerve health. These essential fatty acids (EFAs) cannot be made by the body and must be supplied by the diet. Since the covering of the nerves, the myelin, are comprised of 70% fats, EFAs are required for myelin function. Omega-3 fatty acids in supplement form have been found to be protective against peripheral nerve damage from chemotherapy, and may also improve the nerves' ability to regenerate.

Gamma-linolenic acid (GLA), is an omega-6 fatty acid found in evening primrose oil and borage oil. GLA is an essential component

of myelin, and studies support the use of GLA to improve nerve function in neuropathy associated with diabetes. Talk to your doctor before taking omega-3 or omega-6 fatty acid supplements if you are prescribed a blood thinning agent such as warfarin, clopidogrel or aspirin.

Curcumin is a natural component of turmeric root. It is one of the most widely-used and researched natural medicines for pain. Curcumin has been shown to lower oxidative stress, pain, and inflammation as well as to have neuroprotective effects.

Vitamin D Research has noted an association between low vitamin D levels and the presence and severity of neuropathy in diabetes and after chemotherapy. Vitamin D levels can be monitored by a simple blood test. Supplementation and brief daily sun exposure as well as foods rich in vitamin D may be recommended to keep vitamin D levels within the normal range.

B Vitamins There is scientific evidence to support the use of B vitamins for neuropathy, especially when there is a deficiency of B vitamins in the body. Vitamin B12 deficiency is common in the U.S., due to diet, medication use, and the reduced vitamin absorption which occurs with aging. Some forms of B vitamins may be better able to be used by the body. These forms are the methyl-folate form of folate, methylcobalamin form of vitamin B12, pyridoxal-5-phosphate form of vitamin B6 and benfotiamine form of vitamin B1. There is clinical trial evidence supporting the use of these B vitamins to reduce the symptoms of neuropathy associated with diabetes. A cautionary note is that very high and sustained dosages of vitamin B6 at greater than 200 mg daily may cause toxicity leading to neuropathy.

Dr. Julie Rowin is a neurologist and neuromuscular specialist who practices integrative medicine in the Chicago area.

Website: www.julierowinmd.com

Link to full article:

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The FPN e-Catalog on Peripheral Neuropathy

Do you ever read an article in one of FPN's newsletters or emails, and then want to read it again but forget which issue it was in? Well, now we have a solution. In response to many of our readers' requests, we have developed the FPN e-Catalog on Peripheral Neuropathy. Categorized by topic and complete with direct links to articles, videos, and newsletters, our e-Catalog is now available on our website. You can find the catalog at: www.foundationforpn.org/living-well/fpn-media-center.

Examples of topics include Balance, Diabetic Peripheral Neuropathy, Exercise, Medication and Treatments, and much more.

For more information about our e-Catalog, or for a complete list of topics, contact us at info@tffpn.org.



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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®

485 Half Day Rd., Suite 350
Buffalo Grove, IL 60089
info@tffpn.org
847-883-9942

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WWW.FOUNDATIONFORPN.ORG

The Foundation for Peripheral Neuropathy hopes our mission is important to you and that, by supporting us, we help you fulfill your personal objectives for charitable giving.

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Please use the enclosed donation envelope (or donate online at www.foundationforpn.org) to support the ongoing work of the Foundation.

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