



the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FPN | News

FALL 2020



FROM THE
EXECUTIVE
DIRECTOR

It is hard to stay positive during COVID-19; but like any challenge that comes into our lives un-

expectedly, it's how we react that defines us.

Here at *the* Foundation for Peripheral Neuropathy, we continue to fight for our patients and advocate for research, awareness, and finding answers to your many questions.

Despite the coronavirus, FPN continues its work:

- To lobby for PN on the Hill. In our second year of advocating for more dollars being earmarked for PN research, we are confident that our ask will soon be answered. (Read more about our advocacy efforts on page 3.)
- To raise awareness and increase knowledge about PN through our educational programs. Our webinars and social media campaigns are helping newly-diagnosed PN patients as well as longstanding patients and their families find answers along with guiding general practitioners on how to best treat their patients. (Read about our new programs on page 2.)
- To advance research. Through our unique biobank, the Peripheral Neuropathy Research Registry (PNRR), we have partnered with over a dozen institutions to conduct important studies and research projects. (Read more about the PNRR and our current research on page 2.) We also continue to enroll patients in the PNRR, though admittedly, at a slower pace due to COVID-19.

FPN remains strong during these unprecedented times—because we have to. I am confident that whatever negative impact the coronavirus has had on our organization and our patient population, we will persevere. YOU will persevere. We will fight together to overcome these adversities one day at a time, and we will be stronger because of it.

Thank you, and I wish you good health and happiness.

Lindsay

Lindsay Colbert

THE



OF NUTRITION

PATIENT PROFILE OF BARBARA MONTGOMERY



Barbara Montgomery is an active FPN volunteer, support group leader, and current peripheral neuropathy patient. She is also a Board Certified Holistic Health Coach from the Institute for Integrative Nutrition.

Barbara has taken her quest for information about her own health, with her mission to help others, to a new level through her studies and her coaching. FPN caught up with Barbara to find out more about what she is doing, and what inspires her.

What is your PN story?

In 2010, I noticed my right toes were numb. After several years, the numbness progressed to both feet, with the addition of burning, tingling and cold sensations, which were also starting in my hands. I visited several different doctors and was given a diagnosis of idiopathic neuropathy. I KNEW I had something wrong with my nerves, so I began to read and study on nerve damage. On my next visit to a fourth neurologist, I knew to ask him if the EMG test showed small fiber nerve damage, which I had just read about. He responded with “No, it only shows large fiber nerve damage.” Finally, I had put my own diagnosis together after five years of searching. Now what? My studies in health and nutrition have been a blessing as I have been able to connect with professionals, share my journey as well as various health suggestions to others with this painful and often debilitating disease. I have learned how nutrition, or lack of, affects our nerves. Not having anyone to learn from or share with was frustrating, and I thought there must be others in my area with this same disease, I searched for a support group and found there were none. Within a few weeks, I started the Las Vegas Neuropathy Support Group.

INSIDE

- Virtual Programming
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How did you discover wellness coaching and training?

In 2010 I had symptoms of heart issues which I ignored to the point that I nearly

(continued on page 3)

RESEARCH

CELEBRATING PN RESEARCH

the PERIPHERAL
NEUROPATHY

Research
Registry

Last quarter, FPN announced the exciting news of the Peripheral Neuropathy

Research Registry (PNRR) having reached its 2,000 patient enrollment milestone. This number is significant, as the cohort of patient samples now represents a critical mass for research, opening up more possibility for PN research using its patient data.

The PNRR is not just a collection of patient information gathered on a piece of paper, like many other patient registries that are out there—it is so much more! It is a **biobank of human DNA samples** from PN patients who have diabetic, chemo-induced, HIV/AIDS or idiopathic peripheral neuropathies. The PNRR collects basic patient information along with blood, plasma and serum samples, and preserves these de-identified (anonymous) samples in a warehouse for future research needs. These samples will undoubtedly advance knowledge about peripheral neuropathy, as researchers explore how to better diagnose, treat, prevent and even CURE peripheral neuropathy.

Interested in supporting a future research project?

Please contact FPN at info@tffpn.org or 847-883-9942

Already, a dozen research studies are underway using data from the PNRR, namely:

- 1. The Biomarker Study:** A research project that is identifying lipid levels in idiopathic PN patients in hopes of developing a new blood test to objectively measure pain levels in patients. This discovery could potentially alter how we assess patients with neuropathic pain and how we treat them.
- 2. Diabetic PN Pain Study:** A genetic analysis study on diabetic patients with painful versus non-painful neuropathy, which is aimed to diagnose patients with genetic susceptibility to pain, thus helping to identify treatment options that may be better targeted to alleviate pain.
- 3. Wallerian Degeneration:** A preventable degeneration mechanism, known as Wallerian degeneration, is suggested to be seen in chemo-induced PN patients. This study hopes to establish Wallerian-blocking drugs that are currently being developed, and could even indicate a role in diabetic neuropathy treatment options.

We are excited to have reached this significant milestone and look forward to new research opportunities being explored in our field!

Virtual Programming Opportunities



During these unprecedented times, FPN has shifted to virtual programming opportunities, to allow patients to safely and easily participate in our workshops and updates.

Already this year, we've held three webinars which focused on symptom management, getting the most out of your virtual visits with your doctor, and im-

proving your balance. A few more are already slotted for the last quarter of 2020, including a session on the impact that neuropathy has on the physical and emotional well-being of cancer patients and survivors, a session on diet and nutrition and a webinar on alternative treatments—just to name a few.

All of our virtual programs are offered live, recorded and available indefinitely on our online Media Center. Go to <https://www.foundationforpn.org/living-well/fpn-media-center/> to watch the recordings. Stay current about our upcoming events on our Event Webpage at <https://www.foundationforpn.org/events/>.

Virtual Parlor Meeting on Research

On October 20, FPN will host a virtual parlor meeting, featuring Dr. Ahmet Höke, Dr. Gordon Smith and Dr. Senda Ajroud-Driss. This panel discussion is exclusive to the Foundation's generous supporters and will provide timely updates on research

that is underway in the field of peripheral neuropathy. Furthermore, it will give donors first-hand access to top experts from elite research institutions across the United States—in the safety and comfort of their own homes.

Please contact FPN to register for this webinar (if your donation level qualifies) or check out our online Media Center at www.foundationforpn.org/living-well/fpn-media-center/ to watch the recording of this panel discussion, available only to our Premium Members, in the coming weeks. We hope to provide more exclusive programs like this in the near future to our closest friends and advocates—YOU!



ADVOCACY

AMID CHALLENGING TIMES, FPN CONTINUES ADVOCACY FOR PERIPHERAL NEUROPATHY RESEARCH FUNDING

Despite the challenges presented by the coronavirus pandemic and the recent budget stalemate, *the* Foundation for Peripheral Neuropathy continues to advocate for the designation of “peripheral neuropathy” as an eligible condition for research from the Department of Defense’s Peer-Reviewed Medical Research Program (PRMRP). Earlier this year, advocates across the country contacted their members of Congress, urging them to include this designation in the fiscal year 2021 Defense Appropriations Act. Prior to the pandemic, the Foundation met in person with staff from several Senate offices and, after the pandemic shut down public access to the Congressional buildings, resumed these meetings through the spring and summer via videoconference.

While we believe we are well-positioned to succeed, we may have to wait for some time before we find out if the peripheral neuropathy designation is included in the Defense Appropriations Act. In July, the House approved their version of the bill, but traditionally the House version does not include any designations and defers to the Senate. As of the writing of this article, the Senate has not even begun “marking up” any of its fiscal year 2021 appropriations bills, including the Defense Appropriations Act. Because of substantial differences of opinion between Democrats and Republicans over the appropriate level of funding for the next coronavirus relief and economic stimulus bill, all actions related to the fiscal year 2021 appropriations bills have ground to a halt. Final action on the appropriations bills may not occur until after the November elections, and may even be delayed into early next year. In the meantime, the Foundation will continue to communicate with members of Congress about the importance of including this designation in the final bill—whether it happens in the fall, winter, or sometime in 2021!

The Power of Nutrition (continued)



had a fatal heart attack. After an emergency stent was inserted, I decided I needed to know how to take care of myself as the Standard American Diet (SAD) was obviously the main cause of my illness. I researched and found how to become a health coach, and after a year received my certificate, which propelled me to commit the last 10 years to studying health. Most recently, I was selected as one of 50 worldwide applicants to be trained as an instructor with the Physicians Committee for Responsible Medicine’s Food for Life program. I am mostly whole food plant-based, and I have saved not only my life, but my son’s life, and I have been blessed to help many others I have counseled. Nutrition has made a difference in my neuropathy as well. Right now, I’m able to walk two–five miles a day, do aquacise two–three times a week and eat lots of fruits, veggies, nuts, and legumes. My neuropathy pain is still with me, but I know my food ‘pain triggers’ and quickly get back on track.

What would you like people to know about PN?

First, that “You Are Not Alone,” our Facebook group motto. I want people to know that many of us can be helped

“YOU ARE NOT ALONE”

through lifestyle changes, and that we have some control and say in this painful and often debilitating disease. Where doctors do not have answers, we can find help and if not a cure in our lifetime, at least support and some comfort in knowing we are having a say in our disease.

What inspires you?

I was taught to never give up and there is always a way. Our thoughts are powerful, and positive thinking can make a difference and change our lives. I love positive quotes and positive people with positive attitudes. Sometimes we cannot change our situations, but we can change our attitudes.

Barbara, you are an inspiration! What is your life motto?

“Be the master of your habits or they will be the master of you”

Ronald Lissak: Board Member, PN patient, and COVID-19 Survivor



Ronald Lissak joined FPN's Board of Directors on May 15, 2020, bringing valuable expertise as a businessman, board member of other nonprofits, and PN patient.

Most recently, Ron was interviewed by *Brain & Life* magazine for their June/July issue on his experience with COVID-19 and peripheral

neuropathy. Below is an interview excerpt as told by Ron, as we found his story to ring true with many other patients that we've spoken to who have fallen ill with the coronavirus.

About 11 years ago, I was diagnosed with peripheral neuropathy. As a result, I have numbness in my feet, calves, and hands, which gets worse at night.

Until I was infected with the coronavirus in March, my peripheral neuropathy was more annoying than painful. After I got sick, it went into overdrive. I had much more pain in my hands and feet, and my balance was affected.

Although repeatedly getting tested and having a negative result for the coronavirus, my COVID-19

symptoms were exhaustion, chest pain, diarrhea, terrible headaches, and loss of smell. Between the pounding headache, exhaustion, diarrhea, lack of appetite, and no sense of smell, I felt like I was going crazy.

Once my symptoms subsided, and I was released from the emergency department, I remained in quarantine for 20 days. The only people I saw were my doctors via telemedicine. My wife and sons would leave food outside the guest bedroom and knock. I was too exhausted to do anything.

I am better now but still easily fatigued. And my peripheral neuropathy is much worse. I had to increase my medications substantially—I take about five pills a day—but I'm working with my doctor to reduce the number again. I've slowly started exercising more, doing Pilates at home two or three days a week. By 8:30 p.m., I'm ready for bed, which is when the numbness and pins-and-needles sensations happen more frequently. My bout with COVID-19 is not finished by any means, but it's been wonderful to be home with my wife and sons.

We are so pleased to have Ron on our team and will stand beside him in his long road to recovery—not just with COVID-19, but battling his symptoms of peripheral neuropathy, too.

A SENSE OF BALANCE

A recent webinar, titled "A Sense of Balance," completed by Laura Jacobs, DPT from RxFunction and Lars Oddsson, PhD, Adjunct Professor, University of Minnesota, and CTO with RxFunction, covered an interesting topic related to our balance. The recorded webinar reviews the various senses our brain uses to control our balance. In case you missed it, here is a recap of what was shared.

The control of balance involves complex processing within the central nervous system (brain and spinal cord). To maintain upright balance, the brain integrates sensory information from our vision, our inner ear (the vestibular system), and our sense of touch from the feet and legs (the somatosensory system).

The visual input we gather through our eyes helps us maintain upright related to visual cues around us that are aligned with the direction of gravity. The vestibular system in our inner ear signals how our head is aligned with respect to gravity and whether its motion is changing. Lastly, the somatosensory system helps us sense joint position and touch. This includes pressure sensation on the bottom of our feet, which provides input to the brain during standing and walking to maintain our balance. Based on this incoming sensory information from these important systems, the body makes corrective movements with appropriate muscles to move the body in order to maintain balance. Consider that this sophisticated control is going on all the time, completely unconsciously (unless you are lying down), though, at any time you can decide to pay attention to your balance and "feel" your sway.

AN OVERVIEW OF CONTROL OF BALANCE

A review of research studies on how we know the balance system works presented by Lars Oddsson included the importance of light touch on our balance. This research shows that even using as little as one finger to touch an object can provide more stability to our balance than our vision! Additionally, research helps explain that the contributions to balance control from the three channels of sensory information may change with environmental circumstances. The central nervous system integrates these sources of information to ensure activation of relevant muscles to maintain upright balance and avoid falling.

For individuals who have peripheral neuropathy and sensory loss of the feet and legs, there is often a lost sense of when the feet are on the ground and a limited ability to detect sway when standing. As a result, patients are missing important information that the brain uses to control balance. Individuals with peripheral neuropathy are more unstable in standing and walking, placing them at an increased risk for falling.

If you missed this webinar opportunity and would like to learn more about this interesting topic, the recording can be viewed online in the FPN Media Center.

RxFunction™ is a medical device company with a mission to design and market medical technologies that restore balance, increase mobility, and enhance confidence for patients at risk of falling. Privately held and headquartered in Eden Prairie, Minnesota, RxFunction created the Walkasins® lower limb sensory prosthesis, building upon patented technology developed by co-founder and scientist Lars Oddsson, PhD. Laura Jacobs, PT, DPT, is a Clinical Services Specialist for RxFunction and is a Board-Certified Clinical Specialist in Neurologic Physical Therapy.

NERVE HEALTH THE POWER OF NUTRITION



Barbara Montgomery, featured in this issue as our patient profile, provides an overview of nutrition and healthy plant-based eating that she discovered through her studies and researching for her own health.

Over 20 million people in the US are affected by Peripheral Neuropathy, and you and I are part of that 6% population. However, there are things to help relieve symptoms. Researchers say chronic inflammation is the root cause of most diseases, including damage to our nerves.

We give nutrients to our plants, why not to our bodies?

A vitamin deficiency can be one contributing factor to PN, so good nutrition is often the first line of defense to improve our body and reduce nerve-related issues.

FOODS & SUPPLEMENTS:

1 WATER Dehydration can be a contributing cause of pain. Drink ½ your body weight in ounces per day.

2 NATURAL NUTRITION Vegetables, fruits, whole grains, legumes, beans, dark leafy greens.

3 OMEGA 3s Help reduce inflammation: Walnuts, chia seeds, flaxseeds, EPA & DHA supplements.

4 B VITAMINS Are useful in treating neuropathy as they support healthy nervous system function and can speed up nerve tissue regeneration. Too large a dose can cause nerve damage. Lack of B12 can cause numbness & tingling.

5 R-LIPOIC ACID Helps reduce pain. R-Lipoic is significantly more potent than Alpha Lipoic because the body “recognizes” it and “knows” how to use it.

6 CAPSAICIN CREAM Can be found over the counter. Helps reduce pain & can also be found mostly in hot peppers & small amounts in oregano, cinnamon & cilantro.

7 TURMERIC Main ingredient is curcumin, known for its anti-inflammatory, antioxidant, and analgesic properties. It may help to relieve numbness and tingling in hands and feet. Consume with black pepper as body doesn't absorb it well. It's so powerful that it matches the effectiveness of some anti-inflammatory drugs, without the side effects. It can be taken as a supplement

8 ACETYL-L-CARNITINE An amino acid and antioxidant. It may raise energy levels, create healthy nerve cells, and reduce pain. It can be taken as a supplement.

9 AVOID Sugar, processed meats, excessive salt, white flour & white rice, as these can be triggers for pain and inflammation.

The above and others not mentioned, with a diet full of anti-inflammatory foods & selected supplements can be a benefit to those of us that suffer from the sometimes-debilitating pain of neuropathy. Incorporating only one of the above will not likely produce the results you want, but by adding as many as you can on a daily basis is worth the effort.

Disclaimer: Please check with your doctor before beginning any diet or supplement regimens or changing your treatment plan in any way.

Barbara Montgomery is a Board Certified Holistic Health Coach, Instructor for Physicians Committee for Responsible Medicine's Food for Life Program, Certified Plant Based Cook, Whole Food Plant Based Certificate from e-Cornell & Member of American Association of Drugless Practitioners.

RESOURCES: <https://www.webmd.com/diet/anti-inflammatory-diet-road-to-good-health#1>
<https://www.foundationforpn.org/living-well/lifestyle/nutrition/>



Lindsay Colbert Completes the Challenge!

Over the last eight weeks, I led the FPN virtual team to complete the **HOKA ONE ONE “Run the L” Challenge**.

This unique challenge called on participants to run, walk or wheel the distance of Chicago's elevated train system (the “L”)—a total distance of 131 miles—from anywhere in the world! I was eager to sign up and encourage my family, friends and colleagues to support me and my efforts to

bring attention to *the Foundation for Peripheral Neuropathy* and its mission.

Peripheral neuropathy took a toll on my mother's life until the very end, and I know all too well about the challenge patients encounter in their daily fitness regimens due to the symptoms caused by PN. My mom couldn't even walk a block in her last years! So, during

these past eight weeks, I ran for my mom, to help find answers, and to bring much-needed awareness to this condition. I ran because I could, and I know that not everyone can.

This challenge was fun and meaningful, and I'm excited to continue the fight for peripheral neuropathy in my role as Executive Director of FPN. Thank you to those who supported me and the FPN virtual team!

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](https://www.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.



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For the most up to date news and information, visit our website:

WWW.FOUNDATIONFORPN.ORG

PLANNED GIVING

You have until December 31 to take advantage of the Charitable IRA Rollover for 2020!

For donors age 70½ or older, you can give directly from your IRA to the Foundation for Peripheral Neuropathy and not be taxed on the distribution. This donation counts toward your required minimum distribution as well.

For More information:
Check out this article on our website:
<https://www.foundationforpn.org/2018/04/24/donating-mini-mum-distribution-charity/>

As with any tax- motivated action, you should check with your tax, legal and/or financial advisor.

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