



the FOUNDATION for  
PERIPHERAL NEUROPATHY®

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# FPN News

FALL 2018



FROM THE  
EXECUTIVE  
DIRECTOR

This is a truly exciting time for the Foundation for Peripheral Neuropathy.

The Foundation continues to pursue an ambitious research agenda, harnessing the resources and expanding the expertise needed to enroll the over 1,600 total patients already registered into our Peripheral Neuropathy Research Registry. This biobank, the only one that is dedicated to PN, is an essential resource that will lead to a greater understanding of PN, improved diagnosis, and most importantly new treatments. I'm optimistic that we will reach our goal of enrolling 2,000 patients by 2020.

We also continue to lead the way in patient and caregiver education, having successfully hosted two Patient Conferences in 2018 – events which brings patients, caregivers and healthcare professionals together in one space to learn more about research and treatment options. We're looking forward to continuing these programs into 2019.

As a staff of only three people based in Chicago, however, we rely on you to help us spread awareness and be our feet on the ground in your territory. We recently launched a volunteer committee and are forever thankful of those of you who already raised your hands to donate your time and expertise to help forward our mission. Similarly, the value that our support groups have brought to local communities continue to be invaluable. If you'd like to learn more about getting involved and connected with other patients, please call us at 847-883-9942.

On behalf of the Foundation's Board of Directors and staff, thank you for your generous support in 2018. We are a public, charity foundation that is 100% donor funded; we couldn't do the great work without your generosity and energy. But we still need your support as we travel down this path together to uncover the underlying cause, develop effective treatments and one day a cure for PN. Support can come in many forms, whether it be financial or volunteer support, and makes a significant difference in our fight. Thank you for continuing to think of us as much as we think of you.

I am confident that we will continue to achieve the unimaginable together.

Lindsay Colbert

## WALKING WITH PERIPHERAL NEUROPATHY

by: Robert E. Manning from Prescott, Arizona

I was about 60 when I began to notice some numbness and discomfort in my left foot. I tried my best for a year or more to ignore it, but it wouldn't go away. In fact, the symptoms spread to my right foot. When I discussed all this with my primary care physician, he wisely suggested I see a neurologist. After the usual EMG and NCV tests (all of you reading this know the joys of these procedures), I was told I had peripheral neuropathy and that the cause was unknown. I panicked.

I'd enjoyed excellent health until that time, and I'd used it to maximum advantage—playing competitive sports and traveling widely. Did my PN mark the end of this happy phase of my life? My PN bothered me, both physically and psychologically. I experienced many of the common symptoms, numbness and a burning sensation in my feet, primarily. The medicines I was prescribed—gabapentin and amitriptyline—helped a lot, as did soaking my feet in cool water when the symptoms were at their worst. The psychological challenges were more difficult. Would I be able to continue to the active lifestyle that was so important to me?

With the support of my excellent doctors (Christopher Gibbons at Beth Israel Deaconess Medical Center in Boston and later Benn Smith at the Mayo Clinic, Phoenix), I modified the character of my lifestyle, but not the intensity. I gave up basketball (too easy to damage my feet and ankles) and poured my energy into walking and hiking. I was fortunate to live just a mile and a half from my office at the University of Vermont, and I walked back and forth every workday—religiously. My dear wife would often walk with me. And we turned our mutual interest in hiking into a passion—some might say obsession.

There's a trail in Vermont, aptly named the Long Trail. It's the first long-distance trail in America, running 275 miles along the ridgelines of the Green Mountains, from the Massachusetts border to Canada. We decided to walk the trail in sections on weekends, a day or two at a time. It was challenging, but we liked it, as every day was an adventure and it took us to parts of Vermont we weren't familiar with. My feet did great; in fact, they

felt better than when I wasn't out on the trail! (And I slept especially well, too.)

We were pleased with ourselves when we completed the Long Trail, but missed having a focus for our walks. So we sought out other long-distance trails, and were

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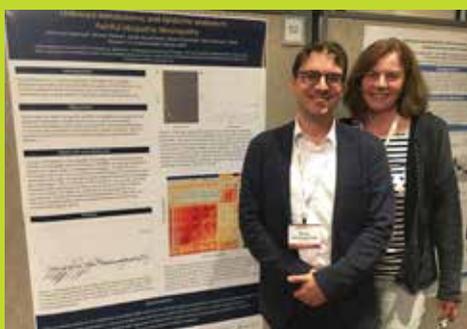
# UNBIASED BIOMARKER DISCOVERY IN PAINFUL IDIOPATHIC NEUROPATHY

*A research team from Johns Hopkins University, which included Simone Thomas and Perry van Doormaal, utilized samples from FPN's Peripheral Neuropathy Research Registry as the basis for their study to identify any biomarkers in patients who experience pain as a result of idiopathic peripheral neuropathy. The team presented their preliminary findings at the annual meeting of the Peripheral Nerve Society (PNS), which took place July 20-25 in Baltimore, Maryland.*

*Thomas gives her account of the study and its findings below.*

## The Search for Biomarkers Indicating Pain

The Peripheral Neuropathy Research Registry (PNRR) is a database and biorepository sponsored by the Foundation for Peripheral Neuropathy. One of the objectives formulated by the research scientists involved in the development of the PNRR is to use the collected information and blood samples



from the Registry to evaluate if there are any biomarkers associated with neuropathic pain.

For the initial pilot study, the database information was used to identify

blood samples from 30 patients with painful idiopathic neuropathy, and 30 patients with non-painful idiopathic neuropathy. The patients included in the pain group had to report intense pain as one of their symptoms (6-10 on the pain scale of 0-10) and had to take neuropathic pain medications. The patients in the non-painful group had to deny that they have pain associated with their PN and no prescription for neuropathic pain medications. The two groups were matched for gender, age and Body Mass Index (BMI).

After the blood samples were aliquoted at Johns Hopkins University School of Medicine, they were distributed to several laboratories where they

were (and still are) analyzed for lipids, proteins and metabolic biomarkers using mass spectrometry. When completed, the analysis will include approximately 2500 biomarkers: 618 lipidomics, over 1000 proteomics and about 700 metabolomics. The analysis of the blood samples for lipidomics was completed early this year together with an initial data set of 38 metabolomics. Preliminary results of the study indicate that there are some

### DEFINITIONS :

**Biomarker (or biological marker) :** A measurable substance in a cell or organism whose presence indicates a condition, disease, or medical state of a patient.

**Mass spectrometry:** An analytical technique that measures the mass of different molecules. Mass measurement is used to identify the type of molecule, or study molecular reactions.

**Lipidomics:** The studies of lipids and lipidome analysis. Lipids include fats, waxes, sterols, fat-soluble vitamins such as A, D, E, and K, and glycerides.

**Proteomics:** The study of proteins

**Metabolomics:** The study of metabolites. Metabolites are substances or small molecules formed in, or necessary for, metabolism—the chemical processes that occur within organisms in order to maintain life.

signature changes in the levels of certain lipids in idiopathic patients with pain versus no pain. The next step will be to validate these findings in a second cohort of (different) patients with idiopathic PN.

## *the* PERIPHERAL NEUROPATHY | Research Registry

The Peripheral Neuropathy Patient Registry (PNRR) is a unique national biobank focused on Diabetic, Chemotherapy-Induced, HIV/AIDS and Idiopathic neuropathies. The data in the PNRR aims to help researchers access detailed genotypic and phenotypic history and neurological examination information about people with painful and non-painful peripheral neuropathies. Ultimately, the major goal of the Registry is to improve the ability to diagnose, treat and prevent peripheral neuropathy.

To find out more about the PNRR, and how you can join this important program, please go to <https://www.foundationforpn.org/research/research-registry/> or call FPN at 847-883-9942.

This finding is significant in that it begins to highlight differences in patients who experience pain versus those that do not, and why. By learning where the differences lie, scientists may be able to determine how to better treat or prevent the pain that comes with neuropathy.

The initial metabolomics evaluation did not find any significant differences for the patients with pain versus no-pain, but a larger panel of metabolites is underway.

# FPN conducts survey to provide input to the FDA

It is estimated that 60% of peripheral neuropathy patients experience some sort of 'abnormal sensations,' most usually pain. With such a large population experiencing chronic pain, FPN went to its members for input on their condition, their experiences, and their views towards treatment in order to provide input to the FDA as the agency examines drug development and treatments for patients with chronic pain.

The survey group of patients responded definitively that current treatment options are not sufficient in fully treating their chronic pain. The survey group was concerned about accessibility to medications, current and future side effects, and overall cost and insurance coverage for their pain relief.

## THE RESULTS:

### *Symptoms and Daily Impacts of Chronic Pain:*

Our survey audience viewed themselves as managing their lives and their pain as best they can. When asked to rate their pain levels on a scale of 1-10, the average rating was a 5 representing moderate pain and impact. Still, our survey group found that mobility and their day to day activities were moderately to significantly impacted. They



were able to make modifications to their activities, but still felt the impact on their day to day lives and overall sense of well-being.

### *Patients Perspectives on Current Approaches to Treatment of Chronic Pain:*

Our survey group has tried a variety of medicinal and nonmedicinal treatments to manage their chronic pain. Gabapentin was by far the most popular medicinal treatment and considered fairly effective. For nonmedicinal treatments, 90% of patients ticked diet and exercise as treatment options, with a majority finding it effective. Still, no one treatment worked for every patient all the time. On a scale of 1–5, with 5 completely managing pain, the average was only 2.2 for effective pain management.

Most patients found themselves changing their treatments over time for a variety of reasons. Most popular answers were side effects, followed by a certain medication not working as well over time. Cost and lack of ability to refill prescriptions also were cited as reasons to change treatment regimes.

Most patients are looking for treatments that are effective, affordable and covered by insurance. The ideal treatments would have little to no side effects and reduce pain more effectively than current treatments do. In deciding on their treatments, they review recommendations from healthcare providers, potential side effects, safety, insurance coverage, availability and costs.

When asked about the downsides to current treatments, the overwhelming response was that current treatments do not reduce pain sufficiently. Side effects and resulting fatigue were also negative factors to current treatments.

Our survey group has encountered barriers to accessing or using treatments. Some of these barriers include cost, insurance not covering certain medications or treatments, and doctors who are not familiar with certain treatments—or even peripheral neuropathy as a condition. Some patients also cited their own physical limitations and a lack of availability or accessibility of certain treatments as a barrier to accessing medical treatments.

The respondents also continued to have concerns over their current treatments. Top concerns included long term impacts and side effects, needing higher doses for less or same results, and changing legislation or rules which might make treatments more difficult to access.

In general, our respondent group is looking for better treatment options with more pain management and less potential side effects or barriers to access.

## *Walking with... (continued)*

pleasantly surprised to find that there's a whole world full of them—literally. Since then we've walked dozens of the world's great long-distance trails—around Europe's Mont Blanc, across England, along the Inca Trail to Machu Picchu, the historic pilgrimage to Santiago de Compostello, California's John Muir Trail, along the great coastlines and mountain ranges of North America, Europe, New Zealand and Australia, through the Grand Canyon, atop the Great Wall of China, and much, much more. We've written about these adventures in two books and are working on a third ([www.extraordinaryhikes.com](http://www.extraordinaryhikes.com)).

It's been 12 years since my diagnosis and my PN still bothers me, but it hasn't bothered my ability to maintain and enjoy an active lifestyle. In fact, I'm convinced that staying active has helped me successfully cope with my PN. I take care of my feet, use hiking poles when I need them for balance (yoga is helping with that, too), take my medicines, and check in with my neurologist regularly. Maybe an active lifestyle—with a focus on walking/hiking—should be part of the prescription for dealing with PN.

# MANAGING AND COPING WITH PN

Until peripheral neuropathy is cured, patients will continue to ask how they can cope with this condition on a daily basis. Below are a few tips from our Washington, D.C. Support Group that we thought would be helpful to you as you and your family navigate how to live with peripheral neuropathy.

## DO

- Acknowledge the negative aspects of the illness
- Try to find positive aspects of the disorder (such as increasing empathy or the need for maintaining a balanced schedule)
- Get support from others (including family, friends, colleagues, and attending a PN Support Group near you)

## DON'T

- Dwell on what might have been if you were not diagnosed with PN
- Self-pity
- Ruminates about better times
- Think of yourself primarily as a "PN patient"

### Effective self-care skills to manage your PN:

**Take care of your feet,** especially if you have diabetes. Check your feet daily for signs of blisters, cuts or calluses. Tight shoes and socks can worsen pain and tingling and may lead to sores that won't heal. Wear soft, loose cotton socks and padded shoes. You can use a semicircular hoop, which is available in medical supply stores, to keep bed covers off hot or sensitive feet.

**Quit smoking.** Cigarette smoking can affect circulation, increasing the risk of foot problems and possibly amputation.

**Eat healthy meals.** If you're at high risk of neuropathy or have a chronic medical condition, healthy eating is especially important. Emphasize low-fat meats and dairy products and include lots of fruits, vegetables and whole grains in your diet. Drink alcohol in moderation.

**Massage.** Massage your hands and feet, or have someone massage them for you. Massage helps improve circulation, stimulates nerves and may temporarily relieve pain.

**Avoid prolonged pressure.** Don't keep your knees crossed or lean on your elbows for long periods of time. Doing so may cause new nerve damage.

### Suggestive skills for coping with PN:

*Living with chronic pain or disability presents daily challenges. Some of these suggestions may make it easier for you to cope.*

**Set priorities.** Decide which tasks you need to do on a given day, such as paying bills or shopping for groceries, and which can wait until another time. Stay active, but don't overdo.

**Acceptance & Acknowledgement.** Accept and acknowledge the negative aspects of the illness, but then move forward to become more positive to find what works best for you.

**Find the positive** aspects of the disorder. Of course you are thinking there is nothing positive about PN. Perhaps your outlook can help increase empathy, encourage you to maintain a balanced schedule or maintaining a healthier lifestyle.

**Get out of the house.** When you have severe pain, it's natural to want to be alone. But this only makes it easier to focus on your pain. Instead, visit a friend, go to a movie or take a walk.

**Get moving.** Develop an exercise program that works for you to maintain your optimum fitness. It gives you something you can control, and provides so many benefits to your physical and emotional well-being.

**Seek and accept support.** It isn't a sign of weakness to ask for or accept help when you need it. In addition to support from family and friends, consider joining a chronic pain support group. Although support groups aren't for everyone, they can be good places to hear about coping techniques or treatments that have worked for others. You'll also meet people who understand what you're going through. To find a support group in your community, check with your doctor, a nurse or the county health department, or go to FPN's website for a list of local PN support groups.

**Prepare for challenging situations.** If something especially stressful is coming up in your life, such as a move or a new job, knowing what you have to do ahead of time can help you cope.

**Talk to a counselor or therapist.** Insomnia, depression and impotence are possible complications of peripheral neuropathy. If you experience any of these, you may find it helpful to talk to a counselor or therapist in addition to your primary care doctor. There are treatments that can help.



**Peripheral Neuropathy Patient Conference** On October 13, the Foundation for Peripheral Neuropathy teamed up with Mount Sinai to host a Peripheral Neuropathy Patient Conference in New York City.

Participants who attended the conference, as well as those who watched via live broadcast, learned from world-class neurologists and researchers about pharmacological and non-pharmacologic approaches of neuropathic pain, the roles of opioids and medical marijuana, research updates, technology for pain treatment, and much more!

The Foundation is hopeful to launch additional conferences in a city near you in the future; but, in the meantime, you can watch a video recording of this event on our website at <https://www.foundationforpn.org/living-well/fpn-media-center>.

# DONOR SPOTLIGHT

## NAOMI KRONFIELD SHAPIRO'S LEGACY

FPN pays tribute to Naomi Kronfield Shapiro and her husband, Morris Shapiro, for their generous bequest.

Naomi struggled throughout her life with various medical ailments which caused her to lose her sight and hearing, but never her vision for a better world. Throughout her life, she gave to her community and to the people around her and did what she could to advance education, medical innovation, and a just and more equal society. Naomi had PN, which caused her great pain, but didn't deter her.

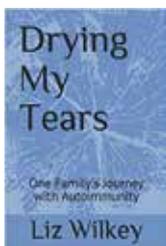
Upon her passing, as in life, Naomi and her husband chose to support those organizations that advanced that which they held most dear, including supporting *the Foundation for Peripheral Neuropathy*. Naomi's legacy shall be to hopefully, someday, see an end to the conditions from which she suffered. We are grateful to Naomi and honored to have been made a recipient of her generous gift.



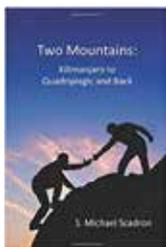
### From the Book Shelf

From time to time, we at FPN are introduced to books that we think may be of interest to our newsletter readers. Here are three reads that may be of interest:

The first two books give inspirational examples of what strength, family support, and courage can look like despite the battle of neuropathy-related diseases.

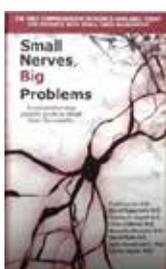


**Drying My Tears** by Liz Wilkey. The author tells her family's story of living and coping with autoimmune disorders, including peripheral neuropathy. She tells her tale with humor and honesty, and yet never loses her sense of hope.



**Two Mountains: Kilimanjaro to Quadriplegic and Back** by S. Michael Scadron. The author tells his tale of overcoming two mountains: Kilimanjaro and CIPD. Another first account story told with humor and ever hopeful.

The third book is an informative overview of small fiber neuropathy:



**Small Nerves, Big Problems** by Todd Levine, MD and a collaborating group of neurologists: A primer on small fiber neuropathy, from symptoms to treatments, explained in a straight forward manner. It can offer a good base from which a patient can determine what questions to even ask his own neurologist, when one doesn't even know where to begin.

### Are you a Caregiver?

If you are a caregiver for a patient who suffers from PN, please know that you are not alone—there are an estimated 65 million family caregivers across the United States. Nearly one-third of the U.S. adult population are caregivers, providing an average of 20 hours of care per week—with some providing care around the clock.

As a caregiver, you need information, education and tools that can help you manage the daunting tasks you face. Below are 10 tips for caregivers that we located through the *Caregiver Action Network* that may help you in this role:

1. Seek support from other caregivers. You are not alone!
2. Take care of your own health so that you can be strong enough to take care of your loved one.
3. Accept offers of help and suggest specific things people can do to help you.
4. Learn how to communicate effectively with doctors.
5. Caregiving is hard work so take respite breaks often.
6. Watch out for signs of depression and don't delay getting professional help when you need it.
7. Be open to new technologies that can help you care for your loved one.
8. Organize medical information so it's up to date and easy to find.
9. Make sure legal documents are in order.
10. Give yourself credit for doing the best you can in one of the toughest jobs there is!

When you become a family caregiver for the first time, you can feel overwhelmed and hardly know where to start. If you are interested in more resources, please look into the *Caregiver Action Network* (for free!) and take advantage of what they have to offer.

## You have until December 31 to take advantage of the Charitable IRA Rollover for 2018!

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-minimum-distribution-charity/>

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

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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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100%

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