



the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FPN | News

SPRING 2018

A MESSAGE FROM THE EXECUTIVE DIRECTOR



Last fall, the Foundation celebrated its tenth anniversary. In its first decade, we have much to celebrate. FPN reached 70% of its enrollment goal for the Peripheral

Neuropathy Research Registry, partnered with over 200 health centers around the world, and hosted its first Patient Conference. As the Foundation begins its second decade, it recommits itself to serving as the premier resource for patients and their families, providing the latest breakthroughs in both medical and alternative treatments, and being a place to connect with others affected by peripheral neuropathy.

In this issue of our newsletter, there are two research articles that I want to point out, which I believe highlight the Foundation's successes from our first decade, as well as bring tremendous hope to our research efforts in the foreseeable future.

First, data from the Peripheral Neuropathy Research Registry (PNRR) helped scientists examine the relevance of mutations in sodium channels, yielding a new discovery in peripheral neuropathy research (read more on page 2).

And second, Dr. Gordon Smith and Dr. Noah Kolb summarize a study on how patients can proactively deal with CIPN symptoms (read more on page 1 and 3), which further parallels other studies in which nurses and medical coaches make a huge difference in diabetic outcomes in those with diabetes.

I am excited to serve as FPN's new Executive Director alongside the Foundation's dedicated Board of Directors. Being a small organization that supports a national community of approximately 20 million patients, every patient that relies on us, every donor who supports us, and every researcher who dedicates their work to neuropathy really means a lot to us!

I'd be remiss to not thank our dedicated members like you for choosing to support FPN. We, the staff, and the Board of Directors of the Foundation are grateful for your support. Please continue to share ANY ideas you have for how we may better serve the community and create a better future for people with PN.

Lindsay Colbert

A NEW APPROACH TO CIPN SYMPTOM MANAGEMENT

Noah Kolb M.D., University of Vermont, Assistant Professor of Neurological Science
Gordon Smith M.D., Professor and Chair of Neurology, Virginia Commonwealth University

Major progress has been made in the fight against cancer. Data from the National Cancer Institute (NCI) at the National Institutes of Health (NIH) show that cancer mortality declined 13% between 2004 and 2013, and innovative new treatments promise continued progress. The number of people in the United States living beyond a cancer diagnosis was 14.5 million in 2014, and this number is expected to climb to 19 million by 2024. This treatment success has prompted a new focus on managing the side effects of cancer treatments among those many who survive.

One of the most common problems faced by cancer survivors is chemotherapy induced peripheral neuropathy (CIPN). Many of the most frequently used chemotherapy drugs for the most common forms of cancer can cause peripheral neuropathy, resulting in pain and numbness in the feet and legs and gait instability, which in turn lead to falls and fall related injuries, reduced independence and decreased quality of life. Furthermore, CIPN sometimes necessitates lowering the dose of a chemotherapy drug, or even stopping it, which may impact the effectiveness of cancer treatment. Unfortunately, there are not yet any medications or other treatments that have been found to reduce CIPN risk, so the current focus is on managing symptoms after they develop and preventing negative health outcomes. The approach to managing these symptoms is multifaceted and often includes patient education, medications, physical therapy and acupuncture.

Communication between a patient and their care team is critical to optimize CIPN treatment. Most often, conversations about symptoms only take place at doctors' appointments when there are many topics to cover and questions to address, most importantly management of the cancer. Sometimes, patients are reluctant to bring up their CIPN symptoms for fear that there is nothing that can be done. This means that in the time between visits when patients are experiencing their symptoms there often isn't an open dialogue.

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A CIPN research team based at the University of Vermont and University of Utah recently published the results of a large study designed to tackle this problem. During chemotherapy, all

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Illustration: Richard Tisdale Design, Inc.

PERIPHERAL NEUROPATHY RESEARCH REGISTRY YIELDS NEW DISCOVERY

In 2012, *the* Foundation for Peripheral Neuropathy (FPN) initiated and funded the Peripheral Neuropathy Research Registry (PNRR) to advance research in acquired axonal peripheral neuropathies, which affects millions of Americans. Stemming from PNRR data, a new discovery in peripheral neuropathy research emerged.

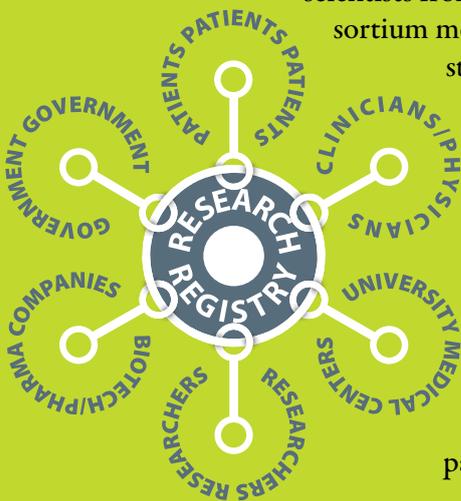
On December 15, 2017, the first scientific study utilizing the patient data from the PNRR was published. In the study, scientists from Bristol-Myers-Squib and consortium members of the PNRR demonstrate that there is no difference in mutations in sodium channels among patients with and without painful neuropathy.

Prior to this study, smaller studies had indicated that certain mutations in sodium channels that govern neuronal excitability were more common among patients with painful neuropathy. Based on

these observations, several companies had started making drugs that block these sodium channels, although none of them had reached the clinical trial stage yet.

This important study, however, points out that these so-called “disease causing” mutations are not enriched in patients with painful neuropathy and that blocking them may not have any specific therapeutic efficacy in treating pain in patients with peripheral neuropathy. This observation will likely save pharmaceutical companies from wasting a lot of resources and money on a therapeutic target that may not have worked. It will likely force them to look to other molecular targets to treat neuropathic pain.

The Peripheral Neuropathy Research Registry (PNRR) was organized by *the* Foundation for Peripheral Neuropathy in 2012 to facilitate both basic and clinical research studies that are expected to improve understandings of the etiology and pathogenesis of peripheral neuropathy (PN). Ultimately, the major goal of the Research Registry is to improve the ability to diagnose, treat and prevent peripheral neuropathy. As of March 2018, there are over 1,450 patient samples in the Registry.



news Briefs

PERIPHERAL NEUROPATHY PATIENT CONFERENCE

On March 10, *the* Foundation for Peripheral Neuropathy teamed up with Johns Hopkins University to host a *Peripheral Neuropathy Patient Conference* in Washington, DC.



Participants who attended the conference, as well as those who watched via live broadcast, learned from world-class neurologists, medical specialists and researchers about

the latest in PN research, coping skills for patients with painful neuropathies, the role of physical therapy and exercise, and the Peripheral Neuropathy Research Registry (PNRR).

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>.

FPN LAUNCHES FPN AMBASSADOR COMMITTEE

The Foundation for Peripheral Neuropathy recently launched a volunteer committee that will help the staff and Board of Directors advance the mission to find better treatments and a cure for peripheral neuropathy. This committee will be focused on advocating for PN and/or raising money to support the Foundation’s world-class scientists, top-notch programs, and groundbreaking research.

The Foundation is a 100% donor-funded organization that supports a patient population of over 20 million Americans. As a Foundation with both a small staff and a commitment to funding the expensive scientific research needed to arrive at a cure, FPN benefits *enormously* from every additional dollar or volunteer hour that is received. Simply put, given the sheer number of patients affected by PN today, your opportunity to have a positive impact on millions of lives (by working hand-in-hand with the Foundation) is considerable.

To learn more about volunteering with the Foundation on the FPN Ambassador Committee, please contact Nancy Frohman, Director of Development and Marketing, at nancy@tffpn.org and let her know what you’re interested in helping with.



patients in the study reported their neuropathy symptoms daily using an automated phone system. Half of the patients simply reported their symptoms and were instructed to contact their doctor for any questions, concerns or to discuss treatment options. The other half of the patients received a phone call from a nurse practitioner to discuss treatment options any day they reported moderate to severe neuropathy symptoms. The nurse practitioners used expert consensus and evidence based national guidelines to select appropriate treatments. All participants could receive any type of neuropathy treatment so there was no difference between the treatments available to both groups. The study found that the group that received the phone

call had an over 75% reduction in both moderate to severe neuropathy symptoms and distress associated with those symptoms compared to those who did not receive a phone call.

The findings of this study suggest there is significant opportunity to improve the standard model of CIPN care. Simply increasing communication between patients and providers (who were well informed regarding treatment guidelines), particularly when symptoms were moderate or severe, resulted in significant improvement in symptoms.

The lessons from this trial are broadly applicable to the most common forms of neuropathy in the US including diabetic and cryptogenic/idiopathic neuropathy because the treatment options are very similar. In all of these neuropathies effective treatment often centers on finding the right drug and right dose for each individual patient. Many patients try more than one drug before achieving symptom improvement. The more frequently the care team and patient communicate the more quickly dosages can be changed or new medications can be prescribed. This

study also emphasizes the need for the care team to be abreast of current treatment guidelines for symptom management and highlights the important role advanced practice providers (such as nurse practitioners and physician assistants) can play.

The potential benefits of increased communication are not limited to medications. In both geriatric and cancer patients, the development of neuropathy is associated with the risk of falling. Physical therapy can reduce this risk but the key is to identify fall risk before an injury occurs. Early communication about balance difficulty can help reduce the risk of falling rather than dealing with the consequences afterwards.

Mobile technology such as smart phones and tablets and telemedicine promise to significantly enhance the ability of the care team to communicate with patients in between in person visits. Some of these resources are already available to some patients. For others, the results of this study suggest simply calling their care team when new symptoms develop or change to discuss treatment options can be very helpful in managing symptoms and improving quality of life.

Ask the Foundation: Balance Tips



Anyone living with the effects of peripheral neuropathy is well aware of how important balance is to one's sense of movement and sense of independence. Here are four manageable tips to improve your balance and stability.

- 1** Walk with your feet apart, as if you're straddling an imaginary line, for optimum support. When you are turning, turn your feet first, then your body.
- 2** When sitting down, rest your hands on the arms of the chair (making sure the chair is sturdy and can support you!) and lower yourself into the chair. When getting up, lean forward, as if leaning your nose over your toes, and use your hands on the arms of the chair to stabilize yourself as you get up. Make sure you are stable and balanced once you are out of the chair before you start walking.
- 3** Research has shown that strengthening the muscles in your legs, thighs, and core increases stability. Strength training (see our website for exercises), marching in place, and small foot and leg lifts help. Make sure you have a chair, counter or wall to hold onto for your safety and confidence. Yoga and Tai Chi help build critical balance as well.
- 4** Walking with a friend or family member, assistive walking devices, and anything else that gives you confidence in your own balance and ability to move is important to your being able to maintain your mobility safely.

National Health Observances (NHO) are special days, weeks, or months dedicated to raising awareness about important health topics. This year, **Peripheral Neuropathy Awareness Week** will take place **May 6-12**.

SPOTLIGHT

and healthcare providers. The more people who know about peripheral neuropathy, the number of people affected by the condition, and how this number is expected to grow, the greater the likelihood that valuable resources will be directed to PN research and new treatment options. How can you help?

PERIPHERAL NEUROPATHY AWARENESS WEEK IS MAY 6-12, 2018

The Foundation asks you to join the movement and help raise awareness and support for PN patients, caregivers and healthcare providers. Among many ideas, you can help us spread the word in your neighborhood through **local fundraisers**, by **contacting local media**, and/or by **sharing your story** about coping with PN with your friends, neighbors and colleagues.

The more than 20 million Americans diagnosed with PN deserve better than being told there is no answer. These patients are not statistics—they are our mothers, fathers, sisters, brothers, colleagues and friends. They need our help. Let's come together the week of May 6 to show our support!

**More ways on how you can get involved will be shared in the coming month.
STAY TUNED!**

FPN Welcomes Two New Board Members in March



Dr. Senda Ajroud-Driss and Dr. Gordon Smith recently joined FPN's Board of Directors, each bringing valuable, scientific expertise in the field of peripheral neuropathy and research.

Dr. Ajroud-Driss has been involved with the Foundation for over a decade, serving as the Northwestern University contact for the Peripheral Neuropathy Research Registry (PNRR). Dr. Driss is Board Certified in Neurology and in Neuromuscular Medicine. She is currently an Associate Professor in the department of Neurology at Northwestern University and also serves as the program director for the neuromuscular fellowship program.



Dr. Gordon Smith is Professor and Chair of the Department of Neurology at Virginia Commonwealth University. Prior to this role, he served as Vice Chair for Research, Chief of the Division of Neuromuscular Medicine and Director of the Jack H. Petajan EMG Laboratory at the University of Utah, where he served as Utah's contact for the PNRR. Smith's National Institutes of Health (NIH)-funded research team focuses on peripheral neuropathy in diabetes and obesity. He has a particular interest in biomarker development and novel clinical trial design in peripheral neuropathy.

Please join us in welcoming Dr. Ajroud-Driss and Dr. Smith to our team!

QUESTIONS?
FEEDBACK ?
CONTACT US AT:
INFO@TFFPN.ORG
847-883-9942



LETTERS FROM FANS

Thank you for all the information you have provided over the past few years. There is no one in my area that has the knowledge that your foundation has provided.

Deadra

Enjoyed the last newsletter – very well done and informative!

Lee

I'm so glad that I discovered this foundation. Gives me hope! **Clara**

Thanks for being here. Living with PN can be very difficult. It's nice to know there are people out there that actually care.

David

The Foundation for Peripheral Neuropathy newsletter, FPN News, is published two times a year—Spring and Fall.



Tips

Careful! Those supplements may do more harm than good!

The Journal of the National Cancer Institute recently published the findings of a study done by researchers at the Mayo Clinic on the effects of acetyl-L-carnitine (ALC) on chemotherapy-induced peripheral neuropathy in women being treated for breast cancer with taxane-based chemotherapy. The study, which studied a sample of women over a two year period, concluded that the women who took ALC had worse CIPN than their counterparts taking a placebo over the same period.

The conclusions from this study were twofold. First, surprising to some as ALC had initially been thought to have protective benefits, this study indicates that there may likely be negative repercussions from taking the supplement during chemotherapy in terms of the longevity, severity, and the very occurrence of CIPN. Secondly it highlights that any treatment, including supplements or other alternative therapies that seem to be natural and safe, need to be vetted with consistent and stringent rigor in order to truly understand the implications, and reviewed as part of a patient's overall medical treatment by the primary physician to ensure no complications or side effects. What seems 'natural' or harmless may in fact cause more harm than good!

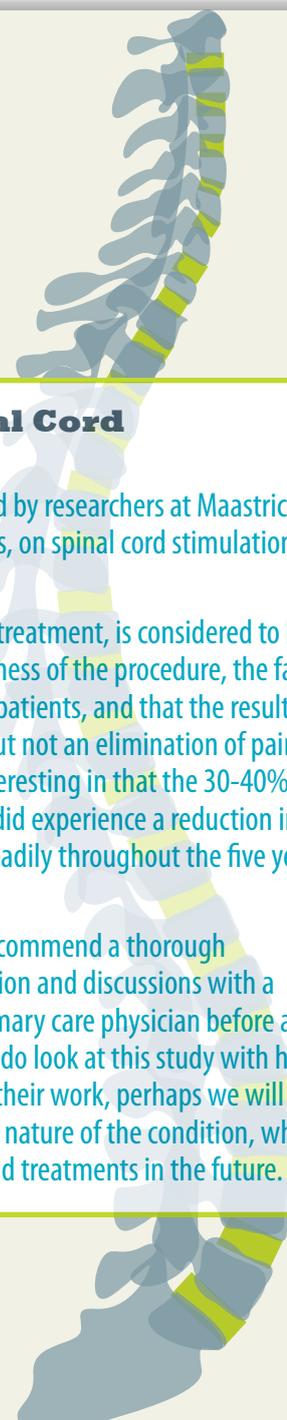


Efficacy of Spinal Cord Stimulation

A recent study was conducted by researchers at Maastricht University, in the Netherlands, on spinal cord stimulation for patients with neuropathy.

Spinal cord stimulation, as a treatment, is considered to be a last resort given the invasiveness of the procedure, the fact that it is not successful in all patients, and that the results may be a reduction in pain but not an elimination of pain. Nonetheless, this study is interesting in that the 30-40% of patients in the study that did experience a reduction in pain, the reduction lasted steadily throughout the five years of the study.

As with all procedures, we recommend a thorough neuropathy and pain evaluation and discussions with a patient's neurologist and primary care physician before any procedure is undertaken. We do look at this study with hope that as researchers continue their work, perhaps we will see greater understanding of the nature of the condition, which can lead to breakthroughs and treatments in the future.



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.

MAKE A DIFFERENCE TODAY

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

OUR MISSION IS TO DRAMATICALLY IMPROVE THE LIVES OF PEOPLE LIVING WITH PERIPHERAL NEUROPATHY BY:

Serving as the premier resource of information for patients, their families and healthcare provider

Accelerating a cure for peripheral neuropathies

Funding collaborative efforts of leading scientists

Raising awareness of peripheral neuropathy

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%

100% of our \$1.2 million budget comes from our readers, making mostly small, affordable donations. We rely on your gifts to advance our unique programs and support scientific research, which will lead to better treatments for patients who suffer from peripheral neuropathy.

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For more information about giving, including bequests and sponsorship opportunities

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