



the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FPN | News

SPRING 2019



FROM THE
EXECUTIVE
DIRECTOR

Dear Friends,

At the Foundation for Peripheral Neuroapthy, we are looking forward to another promising year of working alongside you, and so many others in our community, to live out our mission to serve as the premier resource of information for patients, fund collaborative efforts of leading scientists, raise awareness and accelerate a cure for PN.

Perhaps one of the most energizing projects we continue to engage in is our effort to build a unique biobank of blood, plasma and serum samples of patients who suffer from peripheral neuropathy—called the Peripheral Neuropathy Research Registry. Since 2012, we have been collecting data from patients who have diabetic, chemo-induced, idiopathic and HIV/AIDS peripheral neuropathies to help advance research. With over 1,650 subjects in our biobank, we are entering an exciting time of new research discoveries being validated with human samples. Additionally, in January, we added a new partner clinic at the Washington University School of Medicine in St. Louis, joining our other five research sites across the country who are accepting new enrollments and leading the charge in PN research.

While we advance research for treatments and a cure, we also understand the responsibility and opportunity we hold in improving lives today. In this issue of our Spring Newsletter, you'll learn more about emerging drug developments to hopefully prevent chemo-induced PN, new pain management and treatment options, and helpful coping tips for diabetics – among other things. I hope that you find this information helpful.

Finally, we don't take for granted all of the help you've provided to us in the past, whether it be from a financial donation, attendance at one of our events or support group meetings, or advocating on our behalf. Thank you. We need you just as much as you need us so please continue to show up and we promise that we will do the same.

Thank you for all of the ways you support the Foundation for Peripheral Neuropathy!

Sincerely,

Lindsay Colbert

ACCENTUATING THE POSITIVES

By: Bill Nolan

Fortunate, what does it mean? Favored by or involving good luck. Lucky. It may seem odd to hear someone who is writing about a medical condition lead off the story with the word fortunate, but that's exactly how I feel. My view of this condition is a little unconventional, but hopefully after reading this article people will understand and maybe even feel empowered.

After I was diagnosed, I knew I needed to find a doctor who would look at the big picture, one who would work with me. For me, I knew that going with a strict Western Medicine approach might not be the answer.

I ended up choosing an Integrative Neurologist. Integrative medicine, as defined by the American Board of Integrative Medicine® (ABOIM) and the Consortium of Academic Health Centers for Integrative Medicine, is "the practice of medicine that reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic approaches, healthcare professionals, and disciplines to achieve optimal health and healing".

This was the approach I was looking for. And I was not disappointed. I started seeing my new doctor in February 2018 and continue to see her to this day. My doctor and Integrative Medicine opened doors for me that were previously closed. In my case we have used a combination of dietary changes, conventional medication, tai chi, yoga, acupuncture, and medical cannabis. And it's working.

I am a chef by trade and have been cooking for over 20 years, but what I am learning from my doctor now is nothing short of amazing. I'm learning about inflammation, how diet can affect it, how our environment influences our health, and how working on the mind-body connection can do more good than you can imagine. This is when the word luck started to enter my consciousness.

I was driven to share what I learned. I did my research and found the Foundation for Peripheral Neuropathy. I have about 12 years of non-profit experience in my past, so I thought, what better way to share

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- A Christmas Legacy
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KEY DATA FROM FPN PATIENT REGISTRY HIGHLIGHTED IN TOP MEDICAL JOURNAL

In January 2019, a study was published by the *Journal of the Peripheral Nervous System* on the design and characteristics of patient data collected from the Peripheral Neuropathy Research Registry (PNRR). This is the first ever overall study on the PNRR and one that truly highlights the importance of this dataset for current and future research in the field of peripheral neuropathy.

In this study, the design, types of data collected, characteristics and ongoing analysis on the dataset are discussed. A brief summary of the findings is as follows:

The Search for Biomarkers Indicating Pain

- Of the 1,150 patients included in this data review, idiopathic PN patients formed the largest group, accounting for 52% of the participants. Diabetes was the cause for 31% of the patients, 10% had HIV/AIDS, and 7% of the participants had Chemotherapy-Induced PN. (*Idiopathic PN refers to patients for whom the cause of PN is not known or identified.*)
- Eighty percent of participants were between 50 and 80 years old, and 5% were under the age of 40.
- About 60% of the participants in the study were male; 40% were female.
- The majority of the patients were Caucasian/white (83%), while only 10% were African American/black.

Results

- Numbness was the most common symptom, reported by 85% of all enrolled patients, followed by autonomic

symptoms (80%), pain (70%), balance issues (66%), and muscular weakness (56%).

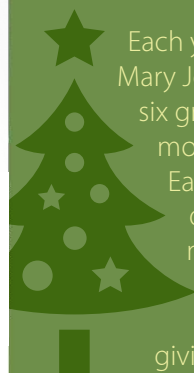
- For the entire cohort, 62% reported sleeping difficulties. Sleep disturbance was more common among those with Diabetic PN and Chemo-induced PN compared to idiopathic PN and HIV-PN.
- Painful symptoms were reported by 70% of the idiopathic PN and CIPN patients, 66% in the HIV-PN, and by 77% in the DPN group. The most common areas of pain were reported in the feet (93%), then legs (53%), hands (35%), and arms (15%). In reference to the Numeric Rating Scale, the median pain rankings were reported at 6 or 7, with a peak at pain levels 7 or 8.
- The most common abnormal testing result was glucose. The median HgbA1c in the DPN group was 6.3 compared to 5.6 in the three other categories. Other abnormal testing results included various protein levels.

This initial study utilizing the patient samples from the PNRR highlights the utility of this biobank as a clinical research tool for future studies. As more patients continue to enroll in the PNRR, *the Foundation for Peripheral Neuropathy* is optimistic that more researchers will express interest in utilizing this unique data set for their scientific discoveries in the field, yielding more answers for clinicians and patients alike.

To learn more about our Research Registry, including enrollment interests, financial support and data requests, please contact us at 847-883-9942 or info@tffpn.org.

DONOR SPOTLIGHT

A LEGACY OF LOVE AND KINDNESS



Each year at Christmas, Mrs. Mary Jo Tucci gave each of her six grandchildren an amount of money to be given to charity.

Each year, the grandchildren were able to give the money as a donation to a charity or a cause of their choice. This gift of giving became a tradition in the Tucci family, year after year, with so many charities benefiting from Mary Jo's lesson in kindness.

When Mary Jo passed away in October 2018, her husband, Mike, continued the tradition by giving

each of their grandchildren, (now all young adults in their 20s) an amount to be given to a charity and a cause of their choosing. The grandchildren discussed their intent, and decided to pool their resources together to give a gift to *the Foundation for Peripheral Neuropathy* in tribute to their grandmother, who suffered from the pain of peripheral neuropathy.

We at FPN are touched and honored to be the recipient of this gift. We thank Michael Sessler, Kate Sessler, Maddie Sessler, Tim Tucci, Michael Tucci, and Sarah

Babcock for allowing us to play a part in paying tribute to their loving grandmother, and to Mr. Michael Tucci and his wife Mary Jo for bestowing the gift of kindness and giving in their family. We will be sure to use this gift in the best way possible to help patients with peripheral neuropathy who, like Mary Jo, know too well the effects of this condition. More importantly, we will remember Mary Jo's legacy of love and kindness that allowed us to be a part of the Tucci family tradition.

New Drug Development Underway to Prevent Chemotherapy-Induced PN

Neuropathy is a common side effect of certain medications, especially those used to treat cancer with chemotherapy. According to the latest statistics from 2018, approximately 50% of chemotherapy patients develop persistent peripheral neuropathy—mainly due to neurotoxic drugs that are used in chemotherapy to fight cancer.

Two of the most commonly used cancer-fighting drugs that cause PN are paclitaxel and cisplatin. These drugs are used to kill tumor cells, introducing

new toxins into the body which can cause peripheral neuropathy immediately following treatment and may last lifelong.

In October 2018, Dr. Ahmet Hoke, MD, PhD, of Johns Hopkins University in Baltimore reported having developed a potential treatment to prevent a major side effect of chemotherapy drugs. Dr. Hoke and his colleagues identified an FDA-approved preservative used in pet food, called ethoxyquin, as a candidate to prevent neuropathy caused by paclitaxel and cisplatin.

Back in 2013, Hoke and his colleagues demonstrated in mice that ethoxyquin modulated the chaperone activity of heat shock protein 90 (Hsp90) and blocked the binding of the proteins ataxin-2 and SF3B2. Reducing the levels of these proteins prevented the axonal degeneration that the drug paclitaxel causes. In 2016, they further showed ethoxyquin also prevented cisplatin-induced neuropathy in mouse models. In both of these studies, ethoxyquin was shown to prevent peripheral neuropathy without blocking the chemotherapy drug's ability to kill tumor cells.

To improve ethoxyquin's drug-like properties, Hoke's group synthesized a novel analogue named EQ-6.

EQ-6 has shown to prevent the loss of epidermal nerve fibers in mice and other animal models.

If all goes as hoped, phase 1 human trials of EQ-6 will start in about 24 months.

Currently, there is no way to prevent chemotherapy induced PN and symptomatic treatments are marginally effective. Antidepressant duloxetine (Cymbalta) has been shown to reduce neuropathic pain associated with chemotherapy and is often prescribed by neurologists. Finding additional ways to reduce chemotherapy-induced neurotoxicity may allow more patients to be treated with chemotherapy, and at higher doses.



Dr. Ahmet Hoke, MD, PhD, of Johns Hopkins University

Dr. Ahmet Hoke currently serves as FPN's Scientific Advisory Board Chairman

Accentuating the Positives (continued)

and help others than with FPN! This is where my food blog began. This was perfect. I had a chance to give back and to share. In my blog I relate what healthy eating for PN means to me, what foods we should concentrate on and what foods to avoid. It's simple when you break it down. I now avoid dairy and sugar, eat a variety of vegetables and less meat, try to eat organics when possible, and include an exercise regimen. Overall, I am healthier and far happier.

Today my journey continues, because you know it's all about the journey. I didn't invent any of the things that help me deal with my condition, I give all of the credit to my doctor. Without her I would not be where I am today. I've learned how to treat my condition, both physically and mentally. I know it's an evolutionary thing. My PN may never go completely away, and I'm just fine with that. Am I fortunate? Incredibly fortunate. In fact, I'm currently



working with my doctor on an exciting new project with a strong focus on food as medicine. More on that in future blog posts.

My message to those reading this with PN is to accentuate the positives, for there are positives in everything. You only need to uncover them or find a person who can help you uncover them. PN can be dealt with to a degree, find out how to do it. Make lemonade out of those lemons.

Bill Nolan is a professionally trained chef and current owner of Nolan Hospitality, a food-focused company based in Darien Illinois. Catch Bill's posts on food and health on our website, www.foundationforpn.org.



TREATMENT OPTIONS *and* PAIN MANAGEMENT

The three broad categories of pain management include medications, interventional therapies, and physical or psychosocial therapies. Generally speaking, a single medication will usually be inadequate to treat symptoms of peripheral neuropathy, and typical analgesics such as acetaminophen, non-steroidal anti-inflammatory drugs, or weak opioids are nearly always ineffective. However, the combination of medications and interventional treatments can be very effective with neuropathic pain.

The only drug classes with solid evidence of effectiveness are tricyclic anti-

depressants, such as amitriptyline and serotonin-norepinephrine reuptake inhibitors like duloxetine, which are considered first-line treatments. The antiepileptics pregabalin and gabapentin are also first-line, but best for peripheral neuropathic pain. Combining either of these antiepi-

leptics with a tricyclic antidepressant can be more tolerable and effective than monotherapy, particularly for diabetic neuropathic pain

Second-line treatments include lidocaine 5% patches, capsaicin 8% patches, and tramadol (primarily for peripheral neuropathic pain), which work in some patients, but often modestly, and with low success rates.

BotulinumtoxinA as a third-line treatment has proven particularly beneficial for peripheral neuropathic pain and neuropathic pain resulting from diabetes, herpes, and trigeminal neuralgia. Opioids such as oxycodone and mor-

phine are also considered third-line treatment for neuropathic pain, but are less effective and more prone to misuse, overdose, morbidity, death, and diversion.

Patients who do not show adequate response to medications may try interventional treatments such as nerve blocks, modulation of specific neural structures, or surgical procedures for targeted drug delivery, but risks for infection or other adverse effects are possible.

Cognitive behavioral therapy would need to be part of an interdisciplinary approach, just as would biofeedback, acupuncture, mindfulness meditation, or other nonpharmacological approaches if any of those offer a patient some additional relief.

Although emerging, the practice of identifying specific phenotypes to better determine course of treatment is promising for a future of personalized medicine.

Source: "Neuropathic Pain: Navigating the Challenges of an Elusive Disease," by Tara Haelle, MS, www.NeurologyAdvisor.com

Disclaimer: This article and the opinions within originated from Neurology Advisor. As with all medical information, FPN encourages you to check any and all treatment options with your primary care physician or neurologist before undergoing a new treatment plan.

FPN Welcomes New Board Member, Van Salmans



On February 1, 2019, Van Salmans joined FPN's Board of Directors.

Van Salmans serves as a consultant to Salmans & Associates, a cheese marketing and sales company, which he founded and sold after 40 plus years in the dairy industry. Van received his B. A. in economics from Stanford University and his M.B.A from the University of Chicago Booth School of Business.

Van resides in the Greater Chicago area.

Van first noticed a nerve condition in 1998 and has coped with the progression of peripheral neuropathy ever since. He is committed to increasing the awareness of, raising funds for and helping find cures for PN. He hopes FPN is able to assist in reaching a new level of national commitment to a disease affecting approximately 30 million Americans.

As a lifelong competitive golfer, Van believes that staying as active as one can along with continued exercise is one of the best ways to cope with and manage PN.

Please join us in welcoming Van to our team!

LETTERS FROM FANS

Thank you for all the information we support the Foundation for Peripheral Neuropathy and its efforts to 'Reverse the Irreversible'. We applaud your work and the good it does for all who suffer this disease.

Anonymous Donor

It is so nice to have a place to realize it is not just me. I don't feel so alone.

Katrina

Thanks for being here. My husband was surfing the web trying to find a legitimate site for us to find some helpful information. He stumbled upon the Foundation. It's helping to guide us and is starting to become invaluable to us.

Kim



Managing Your (Diabetic) Peripheral Neuropathy

Neuropathy is a common complication of both type 1 and type 2 diabetes. If you're diabetic and also overweight, have high blood pressures, high triglyceride levels, or plaque buildup in your heart's arteries, your odds of development diabetic peripheral neuropathy (DPN) go up.

Here are 10 coping tips, shared with FPN by Barbara Montgomery, Las Vegas Support Group Leader:

1. Manage your numbers: High blood sugar over time damages nerves and the small blood vessels that support them. When your blood sugar level is consistently in the normal range, you lower the chance of complications like DPN and help stop it from getting worse.



2. Exercise: Moderate physical activity can delay problems and even reverse symptoms. Aside from that, it helps your balance and strength, so you're less likely to fall. Adults shouldn't skip exercise for more than 2 days in a row and get a total of at

least 150 minutes a week. Brisk walks are a great way to start if you aren't working out regularly yet.

3. Stop smoking: It's linked to low oxygen in your blood, which means tissues like your blood vessels and nerves may not get enough oxygen either. It also creates "free radicals" that can damage cells, harms the lining of blood vessels, makes it harder to control your blood sugar, and causes inflammation.



4. Eat healthy: Fruits, vegetables, whole grains, low-fat dairy, lean proteins, fish, and high-fiber and low-salt foods are good for you whether you have diabetes or not. Good nutrition helps keep your body strong and working well. That includes your nerve endings and blood vessels. Eating well is also important to manage your weight and blood sugar.

5. Vitamins D and B12: People who don't get enough of these tend to develop DPN. Sunlight is a good source of vitamin D, as are cheese, egg yolks, mushrooms, and fatty fish like tuna,

salmon, and mackerel. Fish and red meat have vitamin B12. Some foods have these vitamins added, too, like orange juice, soy milk, and cereals. Taking vitamin D supplements when you have DPN may ease symptoms, but it doesn't look like B12 supplements help.



6. Medication: Over-the-counter pain relievers like ibuprofen don't usually work for DPN. But some prescription medicines that treat depression and seizures—including duloxetine, gabapentin, pregabalin, and tricyclic antidepressants—might make it hurt less. You often take them at night so you sleep better. They can have unpleasant side effects though, so talk to your doctor about what the right choice is for you.

7. Capsaicin: Put it on your skin in a cream, ointment, or patch, and it breaks down substances in nerve endings so they can't send pain signals. One study found that people who used a capsaicin patch one time for 60 minutes had pain relief for up to 12 weeks.



8. Acupuncture: One study found it to be better than traditional medication for DPN symptoms, and typically with few side effects. It may work by triggering your body to use the energy and chemistry of your immune system to help heal and reduce pain. Look for a certified practitioner if you want to try it.



9. Biofeedback: Chronic pain is one of several conditions this therapy is used for. While you learn relaxation techniques, your vital signs, like heart rate and blood pressure, are tracked with sensors. You see your results on a screen so you can tell how well you're doing. You work toward getting the same results without the monitoring equipment.

10. TENS: For severe pain, your doctor might suggest transcutaneous electrical nerve stimulation (TENS). You use a device that sends small electrical pulses through your skin either near where it hurts or at your spine. The idea is to block or confuse the pain-triggering messages your body is sending to your brain. It's generally safe, but there's little evidence this treatment is effective for DPN.

MAKING AN IMPACT TODAY AND INTO THE FUTURE

You can help us continue to improve the lives of people with peripheral neuropathy and inspire future scientific research and discoveries with a legacy gift.

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

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



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



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

The information contained in this newsletter is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.



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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.

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.

Contact Nancy at **847-808-4374** or at **nancy@tffpn.org**

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