

FPN News

the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

SPRING 2014

A MESSAGE FROM THE EXECUTIVE DIRECTOR



Our Invitation TO HOPE

The Foundation for Peripheral Neuropathy positions itself at the nexus of research, awareness and advocacy for the conditions of peripheral neuropathy. We place those that suffer from PN in the forefront of our efforts by reaching out with educational seminars, newsletters, therapeutic interventions, health and diet information, clinical trial opportunities and much more. We also serve as a conduit between patients and caregivers so that patients can find the care they need and clinicians can better serve and understand their conditions and symptoms. In addition, our Peripheral Neuropathy Research Registry gathers vital data from patients to make it available for research efforts throughout the country. And critical to our progress is the collaboration we foster in PN research. From gifted and dedicated clinicians, scientists, industry and government we craft a comprehensive understanding of the field and determine the research and treatment areas that hold the most promise in developing new and effective therapies that can reverse, reduce and one day eliminate peripheral neuropathy.

Our second scientific symposium held earlier this year, brought together basic and clinical scientists, representatives from the pharmaceutical industry, and National Institutes of Health, to discuss strategies for optimizing preclinical development, research initiatives that could advance the current therapeutics, and new directions in the field. The meeting was successful in identifying new challenges in preclinical and early clinical drug development approaches, specifically the need for both phenotypic and mechanism-based screening approaches. We recognized the urgent need to develop resources for biomarker discovery and the infrastructure required for clinical trials. We also developed a better understanding of the industry perspective and the new role academic drug discovery centers play in speeding candidate drug identification. Our challenges moving forward include closing the gap between basic research and clinical application, optimizing Phase II clinical trials and critical in those efforts will be the expansion of the PNRR.

We simply would not be here without the support of our friends, supporters and donors—thank you for allowing us to pursue our mission. One day, scientists will find a cure for Peripheral Neuropathy but that discovery is made by many years of experiments and requires years of support through organizations like the Foundation for Peripheral Neuropathy. As we continue to support each other and our cause, we will continue to make a huge impact on the landscape of neuroscience. When hope leads to desire, and desire leads to action, we can't help but be encouraged. Just as the signs of spring are undeniable, so too are the signs of progress for us living with PN. We ask that you continue to play an active part in spreading our invitation of hope by joining with the foundation in a pivotal way.

A donation of \$100, \$500, \$1000 or even \$5000, may mean that someday you can hear the phrase, "Our 'winter' is over and a cure is finally on the way."

Pam Shlemon

Chemotherapy and Peripheral Neuropathy

"Neuropathic pain associated with the administration of chemotherapy agents has been widely reported in both controlled and uncontrolled studies. On the one hand, more patients are experiencing excellent outcomes of chemotherapy with prolonged survival. On the other hand, increasing numbers of patients are unable to complete full treatment because of the development of chemotherapy-induced neuropathy. Long-term management of pain is therefore becoming one of the most challenging aspects of treatment for neurologists and oncologists." Sophie M. Colleau, PhD, Editor, *WHO Cancer Pain Release*

Chemotherapy-induced peripheral neuropathy (CIPN) is a serious side effect of treatment with certain chemotherapeutic agents. The severity of peripheral neuropathy varies with the type of agent used, the cumulative dose, the duration of treatment, and patient risk factors (such as diabetes).

(CONTINUED ON PAGE 3)



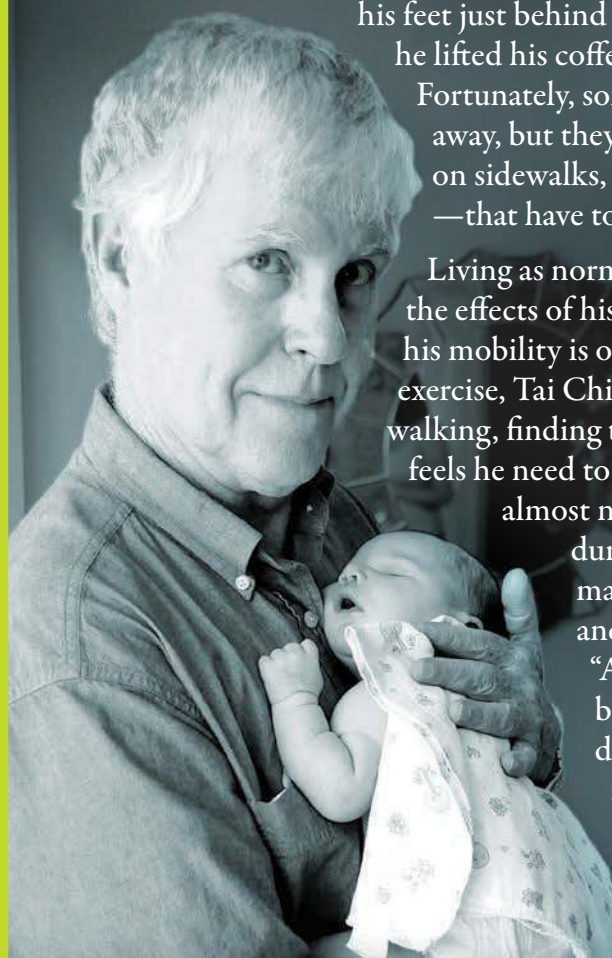
Seated Man (Meditation) by Jacques Lipchitz
Image courtesy of the Metropolitan Museum of Art

IF HE PERSEVERED, SO CAN I

About 15 years ago, Lance Quesenberry began developing peripheral neuropathy—he was 50 years old. His symptoms started with slight numbness in his feet just behind his toes; then a quiver in his left hand as he lifted his coffee cup. His handwriting became impaired. Fortunately, some of those early symptoms have gone away, but they have been replaced by others—tripping on sidewalks, dizziness, feet rolling over to the outsides—that have to be managed from day to day.

Living as normally as possible has helped him minimize the effects of his neuropathy. His focus is to assure that his mobility is optimal. He enjoys yoga, weight bearing exercise, Tai Chi, balance practice, water exercise and walking, finding time each day to do the exercises that he feels he need to do. Water exercise makes his feet feel almost normal for a while. A rest or meditation during the afternoon revives him. He maintains his weight by eating a healthy diet and uses supplements and vitamins. He says, "A good foot cream can calm down the burning in my feet and at the end of the day nothing feels better than soaking my feet in epsom salts." Then he massages his feet with a few drops of oil. He feels an ice pack can also be very comforting on the feet.

Balance can be a daunting challenge with neuropathy so Lance walks—a lot. Retro walking (walking backwards), walking in



INSIDE

- 15 Tips to Boost your Well-being!
- Great Apps for a Healthy Lifestyle

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NEUROMODULATORY TREATMENTS FOR CHRONIC PAIN: EFFICACY AND MECHANISMS

Mark P. Jensen, Melissa A. Day and Jordi Miró

Chronic pain is common, and the available treatments do not provide adequate relief for most patients. Neuromodulatory interventions that modify brain processes underlying the experience of pain have the potential to provide substantial relief for some of these patients. The purpose of a review published recently in *Nature Reviews*

is to summarize the state of knowledge regarding the efficacy and mechanisms of noninvasive neuromodulatory treatments for chronic pain. The findings provide support for the efficacy and positive side-effect profile of hypnosis, and limited evidence for the potential efficacy of meditation training, noninvasive electrical stimulation procedures, and neurofeedback procedures. Mechanisms research indicates that hypnosis influences multiple neurophysiological processes involved in the experience of pain. Evidence also indicates that mindfulness meditation has both immediate and long-term effects

on cortical structures and activity involved in attention, emotional responding and pain. Less is known about the mechanisms of other neuromodulatory treatments. On the basis of the data discussed in this Review, training in the use of self-hypnosis might be considered a viable 'first-line' approach to treat chronic pain. More-definitive research regarding the benefits and costs of meditation training, noninvasive brain stimulation and neurofeedback is needed before these treatments can be recommended for the treatment of chronic pain.

Source: *Nature Reviews/Neurology*

DESIGNING INNOVATIVE THERAPIES FOR NEUROPATHIC PAIN

2014 FPN International Research Symposium

The first scientific meeting of The Foundation for Peripheral Neuropathy was held in 2012 and outlined the roadblocks in developing effective therapies for peripheral neuropathies and neuropathic pain. Among the challenges identified were the lack of alignment between pre-clinical and clinical results, specificity of outcome measures used in both clinical and pre-clinical trials and lack of rigor with which both clinical and pre-clinical trials have previously been conducted. The 2012 meeting attendees also acknowledged the necessity of more innovative trial designs for developing effective therapies for peripheral neuropathies and neuropathic pain.

To address these issues, the Foundation for Peripheral Neuropathy held a 2nd scientific symposium on March 12-14, 2014. This meeting

“Thank you so much for organizing this outstanding and stimulating symposium. It is a rare opportunity for all of us working in the field of neuropathy to have a venue, where we can brainstorm ideas and discuss collaborations to bring the field forward. I look forward to further interactions based on this meeting in Chicago.”

URSULA WESSELMANN, MD, PHD

brought together basic and clinical scientists studying peripheral neuropathies and neuropathic pain and representatives from the pharmaceutical industry, and National Institutes of Health, to discuss strategies for optimizing preclinical development, research initiatives that could advance the current therapeutics, and new directions in the field. The symposium was divided into four topics; each included a series of lectures followed by a panel discussion with extensive audience participation.

The meeting identified new scientific and technical opportunities for collaboration based on advances in basic neuroscience, opportunities in preclinical trial design, new approaches in small molecule drug discovery, and industry interest in advancing therapeutics.

We will be publishing these findings and the strategies that might be important during the design of clinical trials in order to translate basic scientific discoveries

into successful therapies for patients with peripheral neuropathies in a supplement of the *Journal of the Peripheral Nerve Society*.

“...thank you very much for including me in last weeks' conference. I greatly enjoyed the speakers and learned a tremendous amount about not only advancing therapies for peripheral neuropathy but the process (and pitfalls) of performing clinical pain trials.”

CARTER JONES, MD, PHD—JUNIOR INVESTIGATOR

news Briefs

Prevention and Management of Chemotherapy-Induced Peripheral Neuropathy in Survivors of Adult Cancers: *American Society of Clinical Oncology Clinical Practice Guideline*



A group of researchers recently conducted a clinical study to provide evidence-based guidance on the optimum prevention and treatment approaches in the management of chemotherapy-induced peripheral neuropathies (CIPN) in adult cancer survivors.

On the basis of the paucity of high-quality, consistent evidence, there are no agents recommended for the prevention of CIPN. With regard to the treatment of existing CIPN, the best available data support a moderate recommendation for treatment with duloxetine. Although the CIPN trials are inconclusive regarding tricyclic antidepressants (such as nortriptyline), gabapentin, and a compounded topical gel containing baclofen, amitriptyline HCL, and ketamine, these agents may be offered on the basis of data supporting their utility in other neuropathic pain conditions given the limited other CIPN treatment options. Further research on these agents is warranted.

Source: *Journal of Clinical Oncology*

CLINICAL TRIALS

Heavy Metal Exposure in Predicting Peripheral Neuropathy in Patients with Stage I-III Breast Cancer Undergoing Chemotherapy

(NCT01982591)

This research trial studies heavy metal exposure in predicting peripheral neuropathy in patients with stage I-III breast cancer undergoing chemotherapy. Studying samples of blood and urine in the laboratory for heavy metal exposure from patients receiving chemotherapy may help doctors find out whether side effects from chemotherapy are related to heavy metal exposure.

Sponsor Fox Chase Cancer Center/National Cancer Institute (NCI)

Locations PA/various

The Efficacy of Acupuncture in Treating Chemotherapy Side Effects in Breast Cancer Patients

(NCT01996410)

The goal of this study is to determine if acupuncture improves multiple symptoms associated with chemotherapy on the MD Anderson Symptom Inventory (MDASI), including peripheral neuropathy.

Sponsor OhioHealth

Locations OH

Patients experience sensory symptoms ranging from tingling to painful burning in the toes and feet, and also involvement of the fingers and hands, often described as a stocking-and-glove pattern. The onset of CIPN is progressive, although some patients have rapid onset following administration of chemotherapy. Some patients are unable to complete the optimal treatment regimen because of the distress caused by neuropathic pain.

The pain associated with these neurotoxic effects can be prolonged, severe and relatively resistant to intervention. The predominance of CIPN is documented frequently by these treatment agents:

Vincristine
taxanes (Paclitaxel)
BORTEZOMIB (VELCADE)
platinum-based agents
(Cisplatin, Oxaliplatin)

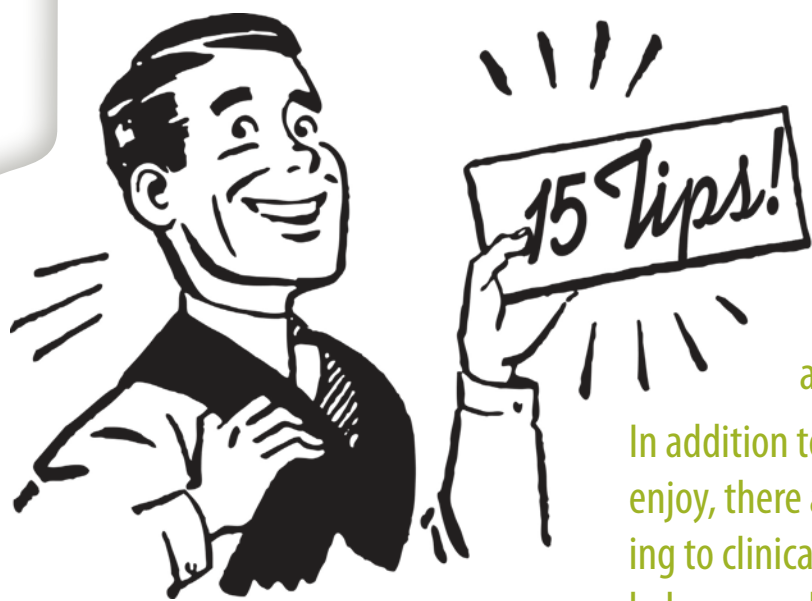
DIAGNOSIS DILEMMA Scales are available to measure toxicity, pain, neuropathy, functional changes and quality of life. Current approaches to assessment in the clinic are often inadequate and contribute to the lack of knowledge regarding the true prevalence of CIPN and its long-term consequences.

Tools are needed that are sensitive enough to monitor clinically significant changes as patients go through the chemotherapy regimen so drug dosages can be tailored to individual patients. It is important that oncologists communicate to patients the importance of providing accurate descriptions of their symptoms in spite of the potential effects such informa-

tion may have on the physician's decision to modify the treatment program. The most important clinical objective is to determine the level of functional impairment involving activities of daily living since this finding is critical to determine the need to modify, interrupt or discontinue the chemotherapy.

TREATMENT STRATEGIES The best treatment would prevent CIPN, yet the optimal agent has not yet been found. Since prevention is not yet available, controlled trials are needed to test the efficacy of analgesics to relieve pain associated with CIPN. The current consensus is that pain management for CIPN should be guided by the same principles as other types of neuropathic pain, and should include opioid analgesics, antidepressants and anti-convulsants. As with disease-dependent painful neuropathies, treatment needs to be individualized with the practitioner searching for the best analgesic for each patient. Opioids can be effective, but usually at higher doses, which may lead to more adverse effects. An important recommendation in initiating pharmacologic therapy for neuropathic pain is to introduce one drug at a time, with gradual upward regulation, based on the patient's response.

A recent report that examined patients with chronic chemo-neuropathy one year or more after initial treatment using pain diagrams, pain descriptors, and pain medication histories shows that chemotherapy-related neuropathy is both very persistent and also resistant to therapy once the transition to chronicity is crossed. Therapies would best be directed at protection as opposed to alleviating the symptoms. Identifying better neuroprotective agents so patients can enjoy longer life expectancies without a reduction in quality of life must be a priority. A better understanding of the peripheral mechanisms of neuropathic pain is needed to improve therapeutic options.



15 TIPS TO BOOST YOUR WELL-BEING AND HAPPINESS

Taking better care of your body boosts your well-being fairly fast. "Exercising and eating well provide nearly instant benefits, helping the body and the mind to manage most any difficulties, including anxiety and depression," according to clinical psychologist and certified life coach John Duffy, PsyD.

In addition to nourishing your body and participating in physical activities you enjoy, there are many other ways you can improve your mental health. According to clinical psychologist Ryan Howes, PhD, "well-being is associated with balance, understanding, acceptance and constant growth."

- 1 ACCEPT YOUR EMOTIONS** Some people spend more energy on avoiding their emotions than others do on actually feeling them. The key is to give yourself unconditional permission to feel your feelings. Writing about negative emotions also helps. Research has shown that people who write about their deepest emotions are less depressed and more positive about life.
- 2 TAKE DAILY RISKS** Structure and routine are important but if you get stuck in a rut that means you're not growing. Challenge yourself each day—talk to someone new, assert yourself, trust someone—anything that pushes you out of your comfort zone.
- 3 IDENTIFY AND USE YOUR INDIVIDUAL STRENGTHS** They will help you feel energized and empowered. Take an assessment if you are not sure of your strengths.
- 4 BE INTROSPECTIVE** Avoid coasting through life without assessing yourself. Step back and consider where your thoughts, feelings and behaviors are coming from. Consider: Is that thought helpful? Is that behavior necessary? Is there a better option?
- 5 LIVE IN THE PRESENT** Take responsibility for what you are doing or creating today, right now. Try not to relive the past or dwell on the future.
- 6 LAUGH** Sometimes, we take life far too seriously. Kids laugh about 200 times per day; adults laugh an average of 15 times per day. See a funny movie or play games like Charades or Apples to Apples.
- 7 DETERMINE AND LIVE YOUR PERSONAL VALUES** These will guide you through life, helping you make the right decisions and keeping you on track. Knowing and living your values will lead to a sense of balance, confidence and fulfillment.
- 8 KEEP TABS ON YOUR THOUGHTS** Without even knowing it, you might be caught in a vicious cycle of negative thoughts. Not only do these thoughts sink our mood but we also start to see them as truths. Challenge and replace negative ones.
- 9 GET RID OF ROTTEN EGGS** There's usually at least one rotten egg in your life that's dragging down your mental outlook. Identify your rotten eggs and figure out how to remove them. Even small annoyances can add up and chip away at your mood and well-being.
- 10 PRACTICE GRATITUDE** You'll find you shift your overall outlook on life when you come from a perspective of gratitude. Make a list of three things you're thankful for every morning.
- 11 DISCOVER OR REDISCOVER A PASSION** It can do great things for your overall sense of well-being.
- 12 DO WHAT MAKES YOU HAPPY FIRST THING** Start your day off on a positive note by engaging in an enjoyable activity every morning.
- 13 SURROUND YOURSELF WITH POSITIVE SCENTS AND SOUNDS** Our surroundings can affect our well-being. Create a positive feeling at home with lemon, peppermint or other essential oils; listen to different kinds of music.
- 14 GET INSPIRED** Find inspiration in everything from subscribing to a daily quote to listening to uplifting audio books to reading magazines with exciting ideas.
- 15 CARVE OUT TIME TO MEDITATE** Protect a few minutes each day to sit, relax and breathe. You don't need much time or effort to meditate, and it's quite soothing.

ASK THE EXPERTS...

This month, we are answering questions that have come to us through our **FPN Inbox**.

Please contact us at info@tffpn.org, if you have any questions you would like to have answered!



QA Can you please make sure everyone knows of the dangers of fluoroquinolones?

The U.S. Food and Drug Administration (FDA) has required the drug labels and Medication Guides for all fluoroquinolone antibacterial drugs be updated to better describe the serious side effect of peripheral neuropathy. This serious nerve damage potentially caused by fluoroquinolones may occur soon after these drugs are taken and may be permanent. The risk of peripheral neuropathy occurs only with fluoroquinolones that are taken by mouth or by injection. Approved drugs include Levaquin, Cipro, and others. www.fda.gov

QA Are nerve blocks helpful in treating peripheral neuropathy?

It rarely works for people with diffuse polyneuropathy because you can't block all of the nerves. Often it is used for focal nerve injuries or very focal neuropathies. It can be effective in patients who develop complex regional pain syndrome. *Ahmet Höke, MD, PhD, Johns Hopkins Hospital*

QA Is it possible that chronic hypothyroidism is the cause of PN?

Hormonal imbalances can disturb normal metabolic processes and cause neuropathies. For example, an underproduction of thyroid hormones slows metabolism, leading to fluid retention and swollen tissues that can exert pressure on peripheral nerves. Overproduction of growth hormone can lead to acromegaly, a condition characterized by the abnormal enlargement of many parts of the skeleton, including the joints. Nerves running through these affected joints often become entrapped. www.ninds.nih.gov/disorders/peripheralneuropathy

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David Comblath
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In Memory of

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GREAT APPS FOR A HEALTHIER LIFESTYLE

Healthy living and technology don't often walk hand in hand, but you can enhance your life with these digital helpers. If a mobile app can help you turn on your home alarm, start your car, and pay your bills, one can certainly help you live a healthier life. Here are some of the most popular apps that can help you live a healthier life starting today



MyFitnessPal

When it comes to health and fitness tracking, MyFitnessPal is a crowd favorite with a database of over three million foods to help you keep track of how much food you're really eating. Best part of the app is a bar code scanner for store-bought food items.

Cost: Free
Platform: iOS and Android



Fooducate

This grocery store navigator aims to help people better analyze food labels and get key information by scanning items right in the store and highlighting the products' positive and negative attributes. It will even offer up a healthier alternative if one is available.

Cost: Free
Platform: iOS and Android



Calm

This app is designed to reduce stress and bring a little more calm into your life by offering a seven-step program to give users the tools they need to become calmer. There are also seven guided relaxation sessions (ranging from two to 30 minutes) and 10 beautiful nature scenes from which users can choose a calming background for their phone.

Cost: Free
Platform: iOS and Android



ZocDoc

If you're looking for a physician in a major metropolitan area, ZocDoc might be the app with the answers. Using the same strategies as popular restaurant apps, it uses your location and patient reviews to connect you with a doctor when you need one. The app also facilitates making (and canceling) appointments straight from your phone.

Cost: Free
Platform: iOS and Android



Expereal

Track your mood and see how it changes over time. This app sends reminders for users to rate how they're feeling on a scale of 1 to 10 and creates a graph showing the progression of their mood over the course of time. Since humans are notoriously poor judges of how they felt just yesterday, this app is designed to give an accurate representation of our emotional state over time.

Cost: Free
Platform: iOS and Android



CareZone

This app is created with the caregiver in mind. Whether childcare or eldercare, relaying information to all parties involved can be an issue. This app allows you to sync calendars and schedules, keep track of medication and important numbers, create to-do lists, and leave notes for other caregivers to ensure that everyone's on the same page.

Cost: Free
Platform: iOS and Android



Drugs.com Medication Guide

This app can help you keep track of your medicine all in one place digitally. Enter each medicine you take, the conditions you're treating, any allergies you may have, and then use the app to manage your meds. You can also use the app to check for potential negative interactions between meds and possible side effects.

Cost: Free
Platform: iOS and Android



Lumosity

Developed by a team of neuroscientists, this app features games that enhance memory, attention, and creativity. It uses games and quizzes to sharpen your brain and cognitive skills through daily exercises. Just by inputting stats like age and gender, you can get personalized brain-training plans that target different areas of cognitive function. The app even lets users see how their sleep and mood affect their brainpower.

Cost: Free, but memberships are available for full range of features
Platform: iOS only

LETTERS FROM FANS

"I appreciate your perspective and suggestions. That is what I was hoping for." *Richard, TN*

"I just joined the site. Thanks for what you are doing." *Craig, NC, Disabled Veteran, Executive Director, Vets-Help.org/Team Patriot*

"As a just brand new Premium member, I will be happily announcing our new affiliation to your group. I'm looking forward to a mutually supportive relationship. Thanks for all your encouragement and help and I am looking forward to working with FPN." *Robin, CO*

"Thank you very much for your time to answer my questions. I also would like to mention how extremely helpful I found your website—the pages that describe recommended exercises with clear pictures, as well as inspiring personal stories. With much appreciation for all your Foundation is doing in an area in which research and informed advice are lacking, I appreciate it all very much!" *Pholini, UK*

"I have found your organization to be by far the best source of information and advice. I have learned from your in-person workshops as well as your online information. The website is excellent. Many thanks for your fine work and dedication." *Steve, IL*

MAKE A **difference** TODAY

Every contribution is significant. You can support The Foundation for Peripheral Neuropathy through:

- **Donations to the Annual Fund**
Annual Fund gifts are used to underwrite immediate needs and to fulfill the mission and vision of the foundation.
- **Memorial/Tribute/Honor Gifts**
Provide a special way to celebrate the memory of a loved one, a birthday, anniversary, wedding, holiday or an occasion of significance for someone you love.
- **Major Gift Contributions**
Generous and transformational gifts to sustain and grow the Foundation for Peripheral Neuropathy
- **Grants**
Provide support through a commitment from your personal, family or corporate foundation.

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Use the enclosed donation envelope or donate online by visiting our website at www.foundationforpn.org, by phone: 1-847-883-9942, or by mail

For more information about giving and sponsorship opportunities please contact Pam Shlemon at 847-883-9951 or at pam@tffpn.org

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circles (good for physical and mental benefits), and walking straight lines. If there isn't a straight line, he imagines one. It works! He tries to find soft surfaces to walk on, like grass, as concrete can cause foot pain and burning. Other simple things are standing on one foot to brush his teeth, shave (no cuts so far), and wash dishes (nothing broken). He tries to be imaginative when practicing his balance—making it fun.

Wearing quality shoes is a must to minimize pain and assure safe walking. He likes Allen Edmonds dress shoes with rubber soles. The rubber sole assists with traction and decreases general foot pain; it even prevents foot heat on hot days. He now has more shoes than his wife in his quest to be pain free.

Routine medical care is very important to Lance's well-being. He sees Dr. Ahmet Höke, a neurologist at John Hopkins Hospital, for his neuropathy;

his general practitioner is a holistic doctor who has helped him with nutrition and supplements. Several physical therapists have helped improve his neuropathic feet and dizziness. He uses mainstream PT as well as Integrative Manual Therapy, which can assist with the pain.

Lance had a good role model for living with PN. His father was diagnosed with motor neuropathy resulting from alcohol use or borderline diabetes when he was 62 years old. He had foot drop that worsened with time but he walked until his condition deteriorated. He went to water aerobics and when he could no longer do that, he did weights and the stationary bike. His doctors were amazed that he continued to walk (with two canes in his later years) until his death at 87 years old. He is an inspiration and as Lance says, "If he persevered, so can I!"

YOU CAN SEND US QUESTIONS
OR FEEDBACK AT
INFO@TFPN.ORG
OR CALL US AT
847-883-9942



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Our mission is to dramatically improve the lives of
people living with Peripheral Neuropathy.

The Foundation for Peripheral Neuropathy will be the catalyst for advancing innovative therapeutic developments and accelerating a cure for painful neuropathies by funding collaborative efforts of leading scientists and physicians. We will strive to raise awareness of peripheral neuropathy through outreach programs to patients, their families and healthcare professionals.



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the PERIPHERAL NEUROPATHY | Research Registry

There are many who believe that the PNR is a critical step to finding new, effective treatments for PN. One patient, having heard about the Registry through the FPN newsletter and website, made arrangements to visit Mount Sinai while traveling in New York from Miami recently. From numerous phone calls they knew to bring past medical information about their PN and scheduled a complete workup so they could be added to the registry. Their goal was to have their information included in the registry with the hope that others could benefit in the future from more information learned to provide better treatments and a possible cure.

We hope that more dedicated patients, like this one, will want to be part of this important project. If you would like to be included in the PNR, please contact one of the registry sites for an appointment:

Beth Israel Deaconess Medical Center, Boston
617-632-0899

Johns Hopkins Medical Center, Baltimore
443-287-0627

Icahn School of Medicine at Mount Sinai, New York
212-241-0784

Northwestern Memorial Medical Center, Chicago
312-695-7950

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