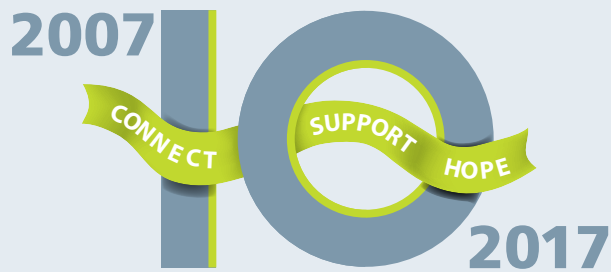


# FPN News

the FOUNDATION for  
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FALL/WINTER 2016



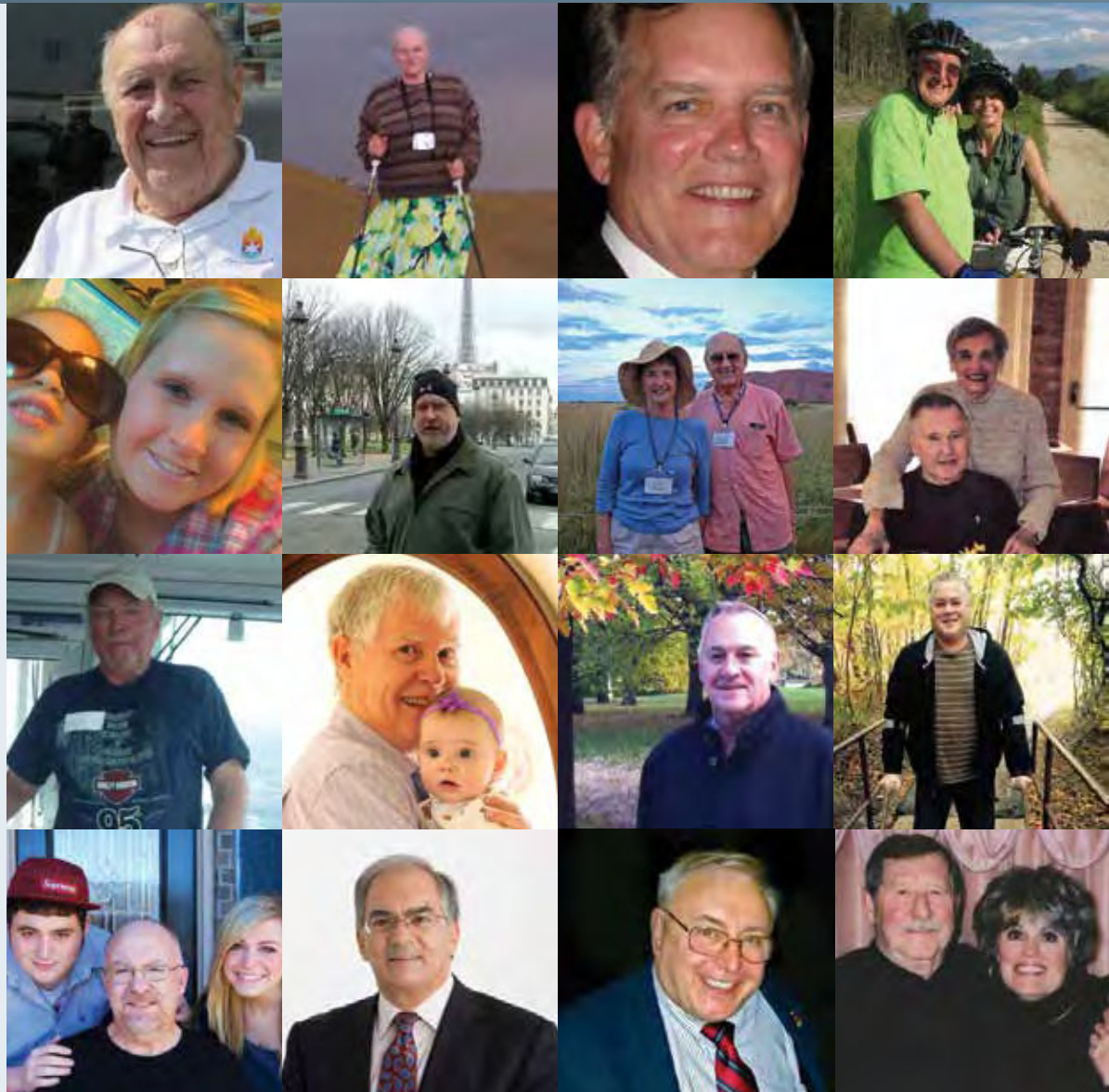
This issue marks an exciting milestone for us at the Foundation for Peripheral Neuropathy (FPN), October 2016 begins our 10 year anniversary. To celebrate, we have created a special anniversary issue that both draws from the past and offers a glimpse into the future.

FPN is about people living with neuropathy. This has never changed. And it has made the Foundation a leader in this area.

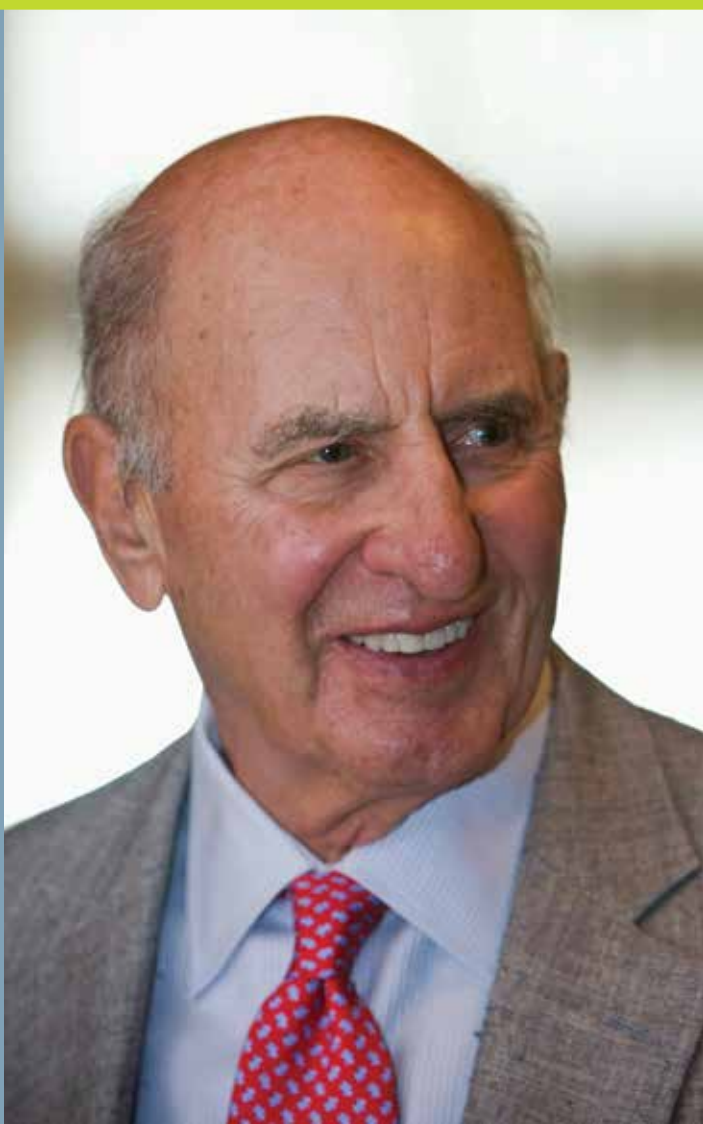
Our mission is to dramatically improve the lives of people living with peripheral neuropathy (PN)—to mobilize scientific leaders and aid in the development of scientific innovation in order to advance new medicines and ultimately a cure for a disease that attracts little attention even though it impacts over 30 million Americans and many more world-wide.

A look back at our achievements offers a glimpse into the future—

(CONTINUED ON PAGE 3)



OVER THE PAST TEN YEARS WE HAVE SHARED WITH YOU MANY STORIES—SOME POIGNANT, SOME HUMOROUS, BUT ALL INSPIRING. TO ALL OF THOSE WHO HAVE BEEN SO GENEROUS IN ALLOWING US A GLIMPSE INTO YOUR EXPERIENCES LIVING WITH PERIPHERAL NEUROPATHY, YOUR STORIES SERVE AS A BEACON OF COURAGE AND HOPE THROUGH CHALLENGING TIMES AND REVEAL NOT JUST YOUR STRENGTH AND RESILIENCE BUT ALSO THE WAY FORWARD FOR THOSE WHO FOLLOW, THANK YOU!



## RECOGNITION OF A LEADER

by Pam Shlemon

*The Foundation has always taken the approach to focus primarily in three key areas: raising awareness, education and research. We are proud of our accomplishments in the short amount of time we have been in existence. These include the first of its kind Peripheral Neuropathy Research Registry (PNRR) to our successful bi-annual symposia, patient support groups, patient outreach and advocacy efforts and I can't leave out our world-class website that provides the most comprehensive information and resources on neuropathies.*

*None of this would have been possible without the support of one important individual, Jack Miller. Jack and I started this organization together and it is with great pleasure and reward to see how far we have come.*

*The Foundation may have started 10 years ago, however, Jack's story started in 1995 when he began suffering from neuropathy symptoms. Over the past two decades Jack has faced the challenges of living with neuropathy and has made a commitment to improve the lives of all individuals who suffer with this "hidden disease." In 1999, Jack began his journey to support peripheral neuropathy*

### INSIDE

- 2016 Symposium highlights
- Finding a patient advocate

(CONTINUED ON PAGE 7)

## VITAMIN NICOTINAMIDE RIBOSIDE PROTECTS MICE FROM DIABETES COMPLICATIONS

A naturally occurring vitamin, nicotinamide riboside (NR), can lower blood sugar levels, reduce fatty liver, and prevent peripheral nerve damage in mouse models of prediabetes and type 2 diabetes (T2D), according to a new study by researchers at the University of Iowa and the Iowa City VA Health Care System.

The findings provide a scientific rationale for conducting human trials to test the effects of NR on metabolic disorders including prediabetes and T2D, as well as obesity, fatty liver disease, and neuropathies.

NR is a vitamin precursor (A precursor is an inactive substance converted to an active one. Some vitamins can be made in the body from precursor molecules.) of NAD<sup>+</sup>, an important cellular metabolite that is required for cells to convert fuel into energy, but which declines with age. NR is currently attracting a great deal of attention for its potential role in improving metabolic health and promoting healthy aging.

As had been shown in previous studies, NR greatly protected the prediabetic and T2D mice from weight gain due to the high-fat diet. But the new study also showed that NR had other beneficial effects on whole body metabolism in the prediabetic and T2D mice. NR also protected against peripheral nerve damage, or neuropathy, a common, serious complication of prediabetes and T2D.

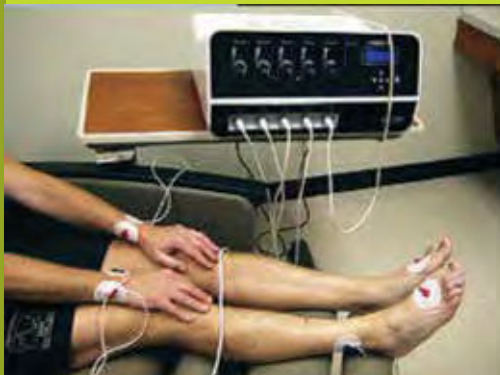
The study also showed that a non-invasive test measuring nerve density in the mouse corneas was a sensitive and accurate biomarker of neuropathy. This test, known as corneal confocal microscopy, is already used on people in the clinic and could, therefore, be a useful tool for researchers to track the neuro-protective effects of NR in human trials.

Source: University of Iowa Health Care, May 2016

## WHAT IS SCRAMBLER THERAPY, AND HOW DOES IT WORK?

By Dr. Thomas Smith, Johns Hopkins Medical Center and Dr. Charles Loprinzi, Mayo Clinic

Scrambler Therapy (marketed as Calmare™ therapy in the United States) is a new type of pain relief that uses a rapidly changing electrical impulse to send a “non-pain” signal along the same pain fibers that are sending the “pain” stimulus. Dr. Tom Smith of Johns Hopkins and Dr. Charles Loprinzi of Mayo Clinic began studying Scrambler Therapy (ST) to treat chemotherapy-induced peripheral neuropathy (CIPN) patients. While cleared for safety by the FDA in 2009 there are still questions about Scrambler Therapy’s efficacy.



EKG electrodes are used to transmit the electrical impulses in a treatment lasting for 30–45 minutes for up to 10 days in a row (excluding weekends). Patients reported a feeling like being bitten by electrical ants, or bee-stings. If the treatment is working, the sensation changes to a “hum” in the nerve and goes to the ends of the nerve. Treatments start above the painful area, trying to replace the pain with a “non-pain” stimulus, and sometimes can work progressively down the legs and arms as pain relief occurs.

Drs. Smith and Loprinzi did a trial of Scrambler Therapy, treating 16 patients with refractory CIPN (present for at least 6 months, and refractory to medications); the group had a 60% reduction in their CIPN pain—in 10 days of treatment. Of the 16 patients they treated, essentially all reported some benefit, including 4 whose pain resolved to “0.” Function improved in most patients including less interference with walking and sleeping, for at least 3 months.

Colleagues at Mayo Clinic repeated the study in a larger group of CIPN patients with similar results. However, well-designed, large, high statistical power, randomized controlled trials comparing Scrambler Therapy to “sham” (electrodes in the wrong place” and to TENS (trans-cutaneous electrical stimulation.) and sponsored by the NIH or someone who is not trying to sell the machines are needed.

That said, at least 20 scientific reports have noted no harm in any trial, with most reporting a substantial relief of pain. Dr. Smith and his colleagues have been using ST routinely at his center (Johns Hopkins Sidney Kimmel Comprehensive Cancer Center) and believes there is benefit to some patients. At the same time, he is humbled by the many therapies that have shown promise in phase II trials only to be no better than placebo or sham in Phase III trials.

For a more detailed version of this article, visit our website: [www.foundationforpn.org/research/](http://www.foundationforpn.org/research/)

## news Briefs

### Third Biannual International Research Symposium

The Foundation for Peripheral Neuropathy hosted its third International Research Symposium: Advances in Neuropathy—Emerging Therapies, September 7-9, 2016. The symposium brought together 90 basic scientists and clinical



researchers from academia, the pharmaceutical industry, Federal Drug Administration and the National Institute of Health to review the current state of knowledge in chemotherapy-induced peripheral neuropathy (CIPN), drug development for neuropathic pain and the use of cannabis in peripheral neuropathies. The speakers and panelists were selected from a wide range

of disciplines with the goal of fostering interaction among scientists that normally would not meet together. Each session of the meeting was followed by a panel discussion with questions from the audience.

The first session focused on CIPN, including new approaches for small molecule (substances that are able to enter cells easily because of their low molecular weight) drug discovery, the challenges of measuring CIPN and the role of the oncologist in identifying and treating CIPN. Session two addressed what is in the drug development pipeline for neuropathic pain and strove to identify roadblocks in development of more effective therapies for a condition that has huge public health implications. The third session was dedicated to the growing interest in cannabis. Presentations started with a review of the basic science of cannabis as an analgesia and updates on clinical trials. The final presentation was a two part “pro and con” on the use of cannabis for treating neuropathic pain by two leaders in the research field.

Videos from this 2016 symposium will be published on the website in November.

### A NOTE FROM OUR SCIENTIFIC BOARD MEMBER

*I've been a partner to Foundation for Peripheral Neuropathy (FPN) since the earliest days of its founding and I'm proud of that association. FPN is the only nationwide patient advocacy group championing for all patients with various forms of peripheral neuropathy.*

*Unlike some of the neurodegenerative diseases such as Alzheimer's or ALS, peripheral neuropathy does not attract as much attention for research and funding levels are dismal compared to its huge public health impact. The Peripheral Neuropathy Research Registry (PNRR) is the first of its kind in the field and has already generated valuable insights into idiopathic neuropathy through collaboration with industry and academicians. This research would not have been possible without continued support from the FPN. Biomedical research is slow and it can be frustrating to our patients and to those who treat them, but I believe with the involvement of FPN, the scientific community will eventually accomplish the goals set by FPN's founder, Mr. Jack Miller. We will find and identify all causes of peripheral neuropathies and develop innovative therapies to treat them.*

Ahmet Höke MD, PhD  
Professor of Neurology and Neuroscience  
Johns Hopkins University School of Medicine  
FPN Scientific Board Member

**OUR RESEARCH**

It is FPN's vision to bring experts together to work in a collaborative environment in order to advance research. In 2009, we assembled a few leading experts in the field of peripheral neuropathy research to determine how FPN could best invest our funds. Our goal was to make a long-term impact that required collaboration among clinicians, academia, pharma, and NIH. That is how the idea of creating the first Peripheral Neuropathy Research Registry came to be. FPN recognized the need and the long-term impact a research registry and biorepository would have on the scientific community by changing the paradigm in which scientists share their work.

*the* PERIPHERAL NEUROPATHY | Research Registry

This initiative is a multi-year project and required a significant capital investment of five million dollars and an investment of \$600,000 annually to grow and maintain the PNRR.



In 2009, we established our scientific advisory board and contracted with Indiana University (IU) Department of Medical and Molecular Genetics (Division of Hereditary Genomics) to help us design and host the PNRR with the biological samples (DNA, plasma and serum) that are collected from each patient. In 2011, we recruited four scientists from prestigious academic centers across the country chosen for their particular research interest peripheral neuropathy.

In 2015, with the support of Bristol-Myers Squibb, we were able to expand to five PNRR study sites. In 2016 we added our sixth PNRR study site. These PNRR scientists are engaged in a research collaboration that builds on their collective strengths.

**What do we collect from patients?**

*Patient history, a standardized neurological examination, and most importantly, a blood sample*

**Why a blood sample?**

*From the blood sample DNA, serum and plasma is extracted. The DNA will be used for genetic studies and the serum & plasma will be used to identify biomarkers.*

**Why are biomarkers important?**

*Biomarkers are biological measurements that can be used to predict risk of disease, to enable early detection of disease, to improve treatment selection and to monitor the outcome of therapeutic interventions.*

The end goal of the PNRR is to improve diagnosis, aid in the development of drug discovery, establish a framework for clinical trials and find a cure for peripheral neuropathy.

***This natural history study of peripheral neuropathy is filling a huge gap in the field, stimulating both basic and clinical research***

We are excited about the future of the PNRR and the study results that will come from the data and biospecimens. In the coming months, will be sharing the first published scientific study results generated by the data in the PNRR.

**SYMPOSIA**

The Foundation hosted its first bi-annual international symposium in 2012. The goal of these small, unique style conferences is to bring together a multi-disciplinary group of scientists and clinicians representing academia, pharma, National Institutes of Health (NIH), and the Food and Drug Administration (FDA), all who have a role in developing effective treatments and eventually a CURE. Typically individuals from such diverse backgrounds do not convene to discuss the challenges brought forth in developing drugs. FPN's goal is to provide a forum for open discussion to bring the challenges of drug discovery for peripheral neuropathies to the forefront. It allows participants to collaborate with the intention of uncovering the roadblocks in translational research in order to move the field forward.

**What exactly is "translational research"?**  
*The term refers to the "bench-to-bedside" harnessing knowledge from basic sciences to produce new drugs, devices, and treatment options for patients that can be used clinically or commercially.*

A second goal of the symposia is to foster development of new investigators in the peripheral neuropathy research field. These symposia are designed to give junior investigators an opportunity for one-on-one interaction with leaders in the field and help shape the final recommendations that will come out of the symposium. The Foundation is proud to have provided over \$100,000 in travel awards to 45 junior investigators to attend the last 3 symposia. These junior investigators were nominated by the speakers as rising stars in the field of neuropathic pain.



The third goal is to share the findings from each of these meetings. Findings from our 2012 *Challenges in Developing Novel Therapies for Peripheral Neuropathies* and our 2014 *Designing Innovative Therapies for Neuropathic Pain* were published as supplements in the Journal of the Peripheral Nervous System (JPNS). Findings for the 2016 symposium will be published in the JPNS March 2017 issue.

We recently concluded our 2016 symposium on September 9th, *Advances in Neuropathy-Emerging Therapies*, with over 90 participants. It was one of the best to date with feedback including "it is the best scientific meeting I have ever attended; it provided collaboration among a multidisciplinary group of experts involved in patient care and drug development."

**HERE ARE JUST A FEW OUTCOMES FROM OUR SYMPOSIA**

- 67% of attendees learned of a new technique or resource that will be useful in their work.
- 75% of attendees said the sessions gave them ideas for new research possibilities that they would like to pursue in their labs.

***We asked the question – "What did you like most?"***

- "High level of expertise"
- "Combination of basic and clinical researchers. The mixture of academic and industry participants provides perspectives that are integral to developing treatments for patients. That is the ultimate goal for all of our work."
- "The excellent scientific content and small size, allowing productive interaction between the participants to brainstorm new research projects and new research collaborations."
- "The broad range of attendees to give flavor from all areas of research and development."

So we ask ourselves, with all of this information gathered from our 3 symposia what do we do next to continue on this trajectory and bridge the gap between basic science and translational research to bring effective treatments to patients? The Foundation's next step will be to identify the one burning issue from each symposium and then initiate small working groups that will address the questions over the course of the next 2 years. Working groups will present their progress at FPN's 2018 symposium.

*continued on the following page*



## AWARENESS AND EDUCATION

Awareness and education is at the forefront of our mission.

The overall goal of patient education is to build awareness of the effects of peripheral neuropathy, to provide an ongoing resource to patients, families and healthcare providers and to share news of treatment developments and pain management opportunities.

Our commitment has remained constant throughout our 10 years. In 2015 we were proud to welcome the former Neuropathy Association members and happily began serving them. With our small but efficient staff we have answered and helped over 30,000 patients via phone calls and emails.

We also transformed the Foundation's website making it more user-friendly and taking cues from you to enhance the content and accessibility. We started with 1,500 hundred hits to our website per month and 10 years later we have over 60,000 hits per month.

Our E-News and E-Tips reach over 50,000 con-

stituents monthly and to date we have published 16 printed newsletters.

This past year the Foundation was invited to participate in several pharmaceutical companies' stakeholder engagement meetings. We see a paradigm shift where more and more pharmaceutical companies are engaging patients and leading patient advocacy organizations in their ongoing efforts to forge better paths to achieve outcomes-based, high-quality patient care. These meetings spark provocative, actionable dialogue on some of the critical issues impacting patient care, including how to best insert the patient voice into evolving health care decision making.

In 2017, the Foundation will be developing a physician portal to provide materials and resources for physicians to distribute to patients, and plans to convene a national patient conference.

This celebration gives us the opportunity to honor the progress we've made as we cast a hopeful eye toward the future.

**Thank you all, each of you, our generous donors, members, readers, our research partners, scientific advisory board and board of directors—past, present—for giving. These relationships, for some now a decade long, have been the lifeline of our endeavors.**

For 10 years, the Foundation for Peripheral Neuropathy has been a trusted guide for many traveling a number of different paths to discover how to cope gracefully with peripheral neuropathy.

Today, we are at an important crossroads—a defining moment that will shape the Foundation and allow us to take a leadership role in development toward a cure. The key to our success will be the willingness of each of you to participate and to invest in the work the Foundation is doing on your behalf.

## —forever grateful—

The Foundation for Peripheral Neuropathy helped my husband and we are forever grateful. My husband had seen many specialists over 3 years time and was given the diagnosis of idiopathic peripheral neuropathy. We tried everything, all the products and nothing relieved the pain.

I finally started looking online for any help possible as we did not seem to be getting the right help from the doctors. I came across the website for the Foundation for Peripheral Neuropathy. I was amazed at the information, the resources and the distinguished doctors and members of the scientific community all working together to be a part of the solution to find a cure for this disease. I reached out to the foundation and was contacted by Pam Shlemon, the President. She took the time to speak with me about the disease and in hearing my husband's symptoms referred us to Cedar Sinai in Los Angeles. After the most thorough examination my husband ever received, he was told he does not have PN, but Morton's neuroma.

While that is not good news to receive, he at least understood why nothing he was trying helped his pain. We were able to go to a podiatrist and an acupuncturist and now he is working on the specific area that has the nerve damage. Because of Pam's knowledge we were able to seek out an expert in the field and understand what

my husband had. While many friends of mine have peripheral neuropathy from a variety of reasons, I have referred them to the website.

This organization is by far the best source for current information and at the forefront working with the top specialists in the medical community to ultimately find a cure for PN. FPN organizes a yearly conference which allows doctors and scientists from all over the country learn about current treatments, cutting edge research and the best part of the huge conference is the Foundation provides a forum for all the doctors and researchers to collaborate, provide an opportunity to build relationships and work TOGETHER towards finding a cure.

Within this outstanding organization you have an extremely COMMITTED team, who is very KNOWLEDGEABLE about this disease, who CONNECT patients, doctors and researchers together across the country to work TOGETHER to find a cure. They PROVIDE resources to help people looking for answers, and keep people INFORMED with constant communication. That is a lot for any organization and this organization does it with a small team!

My wish is for everyone in the country (better—around the world) to learn about this organization, to spread the word to their friends, family and co-workers and for everyone to contribute to their resources which will enable them to reach more people.

**Patti Davis**  
FPN Board Member

## CLINICAL TRIALS

### Topical Cryotherapy in Reducing Pain in Patients With Chemotherapy Induced Peripheral Neuropathy or Paclitaxel Induced Acute Pain Syndrome

NCT02640053

This randomized pilot clinical trial studies topical cryotherapy (a procedure in which an extremely cold liquid is used to freeze and destroy abnormal tissue) in reducing pain in patients with chemotherapy induced peripheral neuropathy or paclitaxel induced acute pain syndrome. Peripheral neuropathy is a nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. Paclitaxel produces a disabling syndrome of acute aches and pains. Topical cryotherapy may help relieve pain from peripheral neuropathy or acute pain syndrome caused by chemotherapy.

**Sponsor** Academic and Community Cancer Research United, National Cancer Institute

**Location** IL, MI, MN, SC, SD, WI

### MCS-A Scrambler Therapy or TENS Therapy in Treating Patients With Chemotherapy-Induced Peripheral Neuropathy

NCT02722434

This randomized clinical trial studies how well MCS-A scrambler therapy or transcutaneous electrical nerve stimulation (TENS) therapy work in treating patients with chemotherapy-induced peripheral neuropathy (a nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body). MCS-A scrambler therapy is a type of treatment for nerve pain that uses electrodes placed on the skin, where electricity is carried from the electrodes through the skin and blocks the pain. TENS is a procedure in which mild electric currents are applied to some areas of the skin. It is not yet known whether TENS therapy is more effective than MCS-A scrambler therapy in treating chemotherapy-induced peripheral neuropathy.

**Sponsor** Mayo Clinic, National Cancer Institute

### Comparison of treatment in real life situations (pain controls)

A common cause of neuropathy is diabetes, but in about 25 to 50% of the population no cause is found. This group is often referred to as cryptogenic sensory polyneuropathy (CSPN). This study looks at four different drugs in patients with CSPN and plans to determine which drug is most effective: nortriptyline, duloxetine, pregabalin, or mexiletine.

**Sponsor** PCORI: Patient-Centered Outcomes Research Institute

**Location** Nationwide (contact FPN)

VISIT [WWW.CLINICALTRIALS.GOV](http://WWW.CLINICALTRIALS.GOV)  
FOR CONTACT INFORMATION FOR EACH SITE

## COMPLEMENTARY THERAPIES

# Yoga Training Your Body, Mind and Spirit to Deal with PN

If you or someone you love is living with the chronic symptoms of peripheral neuropathy, you know how debilitating the pain and discomfort can be on your reserves of strength, energy and sense of well-being. With no cure or guarantee of relief from medications or devices, complementary therapies can prove vital for improving quality of life. Doctors often suggest exercise to improve strength and balance and a general sense of well-being. Yoga has the potential to do all of that as well as promote relaxation, body awareness and simple peace of mind. Yoga techniques have also been shown to help in pain management allowing the patient to minimize medication usage.

A 2014 study showed yoga is a promising therapeutic modality for neurodegenerative diseases. The ten month course of therapeutic yoga included poses and breathing exercises. It resulted in improved lower back pain; improved flexion of the patient's hips, knees, and ankles; improved propulsion phase of walking; improvement in the patient's ability to stand and balance without an assistive device; and measurable improvements in quality of life. (PubMed ID 26770098)

In May 2015, the Scientific Director of the National Center for Complementary and Integrative Health (NCCIH) at the U.S. National Institutes of Health (NIH), Catherine Bushnell, gave a lecture at the American Pain Society's annual meeting. She presented findings from cutting edge research on the ability of yoga to counteract chronic pain. Bushnell summed up the findings of her research by saying, "Practicing yoga has the opposite effect on the brain as does chronic pain."

Bushnell and her colleagues are conducting research aimed at discovering non-pharmacological treatments for pain. They've found that chronic pain can be prevented or reversed through mind-body practices like yoga or meditation. Many people do not realize that yoga exercises and concentrative techniques were originally designed and practiced primarily to make the body healthy and strong so that one could sit immobile for meditation without discomfort. Yoga techniques can help minimize the brain's acknowledgment of painful stimuli.

When you think of yoga, your first image might be of someone standing on their head or balancing on one leg! But there are many types of yoga from which to choose. With different styles of yoga, you can improve your strength, flexibility, and balance.

All yoga styles release tension in your body, quiet your mind, and help you relax. To get the most benefit, you should choose a yoga style that matches your current comfort and fitness level, as well as your personality and goals for practicing yoga.

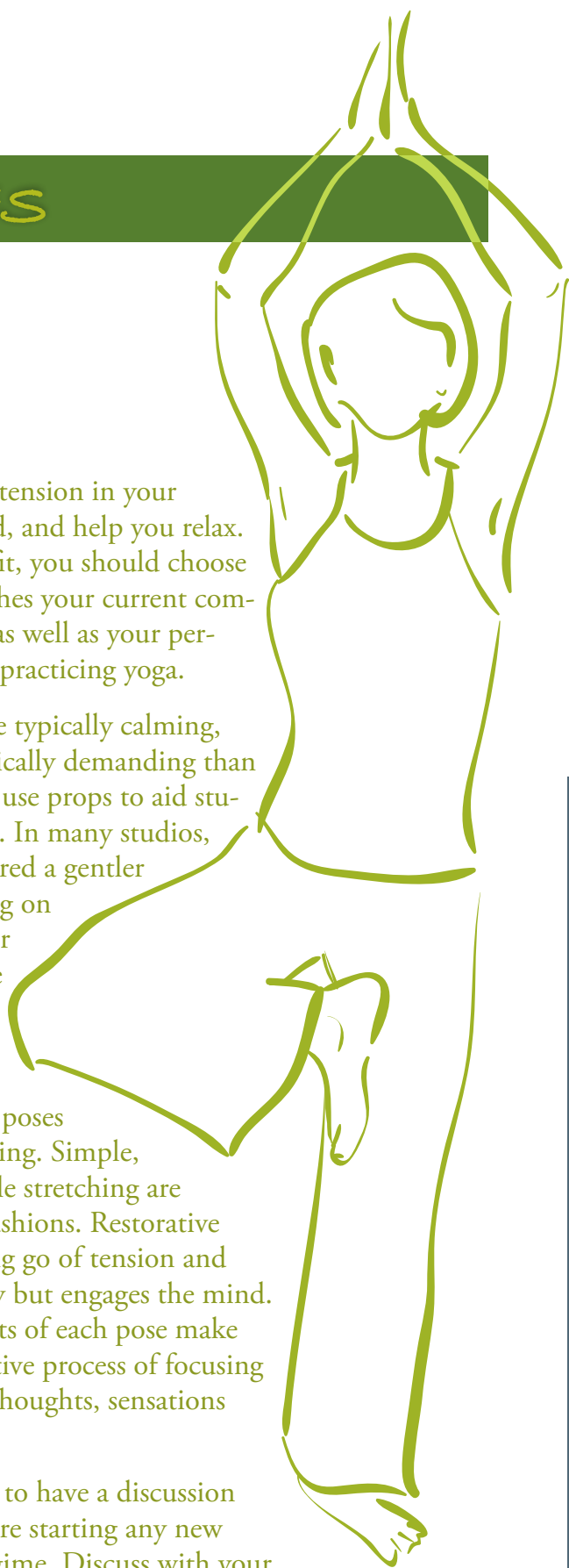
Gentle yoga classes are typically calming, relaxing and less physically demanding than other classes and may use props to aid students in their practice. In many studios, Hatha yoga is considered a gentler form of yoga. Focusing on the basics, these slower moving classes require you to hold each pose for a few breaths. "Restorative yoga" also focuses on gentle poses with conscious breathing. Simple, relaxed poses with little stretching are often supported by cushions. Restorative yoga is all about letting go of tension and stress; it rests the body but engages the mind. The breathing elements of each pose make restorative yoga an active process of focusing the mind on healing thoughts, sensations and emotions.

It is always important to have a discussion with your doctor before starting any new therapy or exercise regime. Discuss with your doctor reasonable limits and goals for yourself and be sure to understand how yoga may be a good addition in your overall health management plan.

At the end of a yoga class it is traditional to say "namaste" to your instructor and classmates, which loosely means "I bow to godly/good qualities within you"

Namaste.

*Source: [americanyogaassociation.org](http://americanyogaassociation.org)*



Black Friday. Cyber Monday.  
**#GIVINGTUESDAY**  
November 29, 2016

The Foundation for Peripheral Neuropathy (FPN) is excited to participate this year in the international movement dedicated to giving and sharing called #GivingTuesday. Watch your email for announcements on how you can support FPN on #GivingTuesday by sharing YOUR story and helping us build awareness of PN.

## BOARD MEMBER SPOTLIGHT



The Foundation for Peripheral Neuropathy is excited to welcome our newest member to our Board of Directors, Adam Halper. Adam is a strategy consultant at McKinsey & Company where he has advised clients in the healthcare, high-tech and basic materials industries. Prior to joining McKinsey, Adam earned a JD from the University of Michigan Law School and an MBA from Oxford where he served as a portfolio manager for the business school's venture fund.

Having developed peripheral neuropathy at the age of 28, Adam is intimately familiar with the challenges presented by the condition. He is deeply committed to improving the lives of PN patients around the world through better treatment options and greater awareness of current best practices in managing PN.

# Symposium Excerpts

## Basic Science of Cannabis and Analgesia II

**Andrea Hohmann, PhD**, Linda & Jack Gill Chair of Neuroscience, Professor, Indiana University, Bloomington, IN

In summary our studies suggest that therapeutic strategies targeting the endocannabinoid system show promise for suppressing chemotherapy-induced neuropathic pain and other forms of neuropathic pain. Inhibition of endocannabinoid deactivation outside the CNS [central nervous system], activation of cannabinoid CB2 receptors, and allosteric modulators of CB1 receptors signaling is sufficient to suppress neuropathic pain with limited side effects and no abuse liability that we've been able to measure. Further clinical trials to assess the impact of cannabinoids on chemotherapy-induced neuropathic pain and other forms of neuropathic pain are clearly warranted.

## Mitotoxicity as the cause of CIPN

**Garry Bennett, Ph.D.**, Adjunct Professor, Department of Anesthesiology, School of Medicine, University of California San Diego, California

After a brief course of chemo, two, three weeks later we started to see the symptoms. The animals become hypersensitive to touch. They had mechanical allodynia. They become hypersensitive to pin prick. That's mechanical hyperalgesia. They also become hypersensitive to cold. Remarkably, they do not become hypersensitive to heat. Peripheral neuropathy is produced by nerve trauma. Heat hypersensitivity is a prominent syndrome, but we never see it in any of the chemo therapeutics. This delay to onset is in the clinic, and it's called coasting. We see it reliably in our animal models as well. We have repeated this kind of work now with paclitaxel, vincristine, oxaliplatin and bortezomib.

The clinical description suggests that these neuropathies are very similar. In the animals they're identical. There's no question that all of these drugs are producing the same neuropathy, which is good news. It means we have to figure out one thing, instead of four or five different things.

## Cannabis in Neuropathic Pain-Focus on HIV PN

**Mark Wallace, MD**, Chair, Division of Pain Medicine, Professor of Clinical Anesthesiology, University of California, San Diego

In summary, I have been using this therapy for 20 years now. I've treated hundreds and hundreds of patients. It's a very important part of my practice, and I view it as a pharmaceutical. When I prescribe it, I refer them to a naturopathic doctor who provides a consultation for dosing guidelines. I then follow up with the patients. I try to determine what they are using and what is working or not working. It goes into their medical records and it's been a very useful therapy.

## Pain Strategies & the Tetrahydrobiopterin (BH4) Pathway

**Stephen Zicha, PhD**, Executive Director, Head of Translational Sciences, Quartet Medicine, Cambridge, Massachusetts

These data show that the reduction of elevated BH4 levels after nerve injury reverses pain-like behaviors in rodent models of neuropathic pain and validate the role of BH4 as a critical mediator of peripheral nerve dysfunction. We believe that the development of these biomarkers as tools to objectively assess BH4 inhibition and guide dose selection in clinical trials will be beneficial in the development of new therapeutics. Overall, these data suggest that modulation of BH4 may offer an alternative to existing pain therapies that largely target the central nervous system.

## Mechanisms and Genetics of Chemotherapy-induced Peripheral Neuropathy (CIPN)

**Nathan P. Staff, MD, Ph.D.**, Assistant Professor of Neurology—Mayo Clinic, Rochester, Minnesota

I hope I've convinced you CIPN is a complex disorder, associated with significant morbidity, and that genetic susceptibility in CIPN involves multiple pathways that end with the peripheral nerve. Stem cells, I think hold promise for research in neurologic disease, both with the disease in a dish model, hopefully in the future with individualized assays, and then maybe down the line the therapeutics in the future.

## RECOGNITION OF A LEADER (CONTINUED FROM PAGE 1)

research by providing 6 million dollars in seed money to endow a professorship and create a peripheral neuropathy center at the University of Chicago. That program continued until mid-2007 and shortly thereafter we established The Foundation for Peripheral Neuropathy.

During the last nine years, Jack's stewardship of the Foundation has been characterized by innovative ideas, strategic thinking and most valuable of all, his tireless efforts to increase the visibility of peripheral neuropathy on a national level. The resulting goodwill has become a

huge asset to us, and the Foundation will continue to prosper as we drive our efforts forward with our meaningful and valuable programs that Jack helped to create. These programs will undoubtedly have a positive and lasting impact on the PN community worldwide and they already have made a difference by giving hope to those who deal with this chronic disease on a daily basis

Earlier this year Jack stepped down as our Chairman but remains committed to our mission. His energy and devotion to the role will be impossible to match, but he leaves the Foundation a better organization and

on a strong footing for those who follow.

The Foundation will remain true to Jack's vision: finding better treatments and ultimately a cure. We will continue to be the leading voice for the PN community determined to help patients live a better quality of life while providing hope for future without neuropathy.

Jack's generous philanthropic investments of nearly \$13 million dollars has been without fanfare and he does so willingly with the hope that someone next door or down the street, whose face he may never know or see will be strengthened from his actions.

Living Well

## PROFESSIONAL PATIENT ADVOCATES: Making Sure You Have Someone on Your Side

When you're ill it can be difficult to take in all the information from the myriad of sources with whom you need to interact for healthcare: doctors, nurses, pharmacists, hospitals, rehab centers, insurance providers, etc. Plus, the confluence of aging baby boomers with an ever more complex, cost-conscious health care system creates a complicated environment that even Lewis and Clark would have had a hard time navigating. Some hospitals and HMOs hire nurses and social workers to help patients, but there remains a huge unmet need, which may be filled by self-employed "patient advocates" – a growing service of professionals and even volunteers committed to helping you get the care you need and deserve.

Private patient advocates are not affiliated with hospitals or doctors. Instead they work as private consultants. The advocate might help patients pick doctors, schedule appointments, accompany patients to doctor appointments to take notes and ask questions. They may research medical treatments, discuss treatment options, assist in finding a specialist or hospital and/or keep track of prescriptions. Many patient advocates will help with medical equipment purchases, handling insurance claims, disputing hospital bills, and negotiating with insurers who've rejected policyholders for coverage. They may also educate family members on how to support the patient during a hospital stay, for example, ensuring that the pills really are meant for the patient.

Advocates say they fill a gap in the health care system by making sure their clients are educated. They say their involvement relieves stress, especially for those dealing with serious or chronic illness, and that their vigilance and expertise can avert medical errors.

### Finding a Patient Advocate

It is important to distinguish hospital patient advocates from the private patient advocate. Hospitals may offer customer service by a staff person called "patient advocate." This person can be called upon by a patient or their family member when they run into problems that relate to care, or payment for that care. A hospital's patient advocate can be invaluable; however, empowered patients recognize that this patient advocate draws a paycheck from the hospital. As such, their allegiance will be to the hospital, and is often not the best person to help in a difficult situation.

Volunteers can be wonderful and the price may be right, but they often don't have the experience you need to be sure you're getting the best care possible. There is no nationally recognized accreditation (so beware someone who claims to be "certified") but there are some specialized programs available and patient advocacy is now taught in some universities.

While private patient advocacy is a growing career, patient advocates are still not easy to find. Here are some websites you can check:

- **AdvoConnection provides a free searchable directory of advocates who offer a variety of services <http://advconnection.com/>**
- **The National Association of Health Advocacy Consultants (NAHC) site also offers a list of advocates who belong to this organization <http://nahac.memberlodge.com/>**

Before making a selection, you should interview potential patient advocates to get a sense of whether they can help you, what the process will entail, and how much their services will cost. It is important to have an idea of what kind of advocacy help you are seeking. There are no standard fees or standard procedures because, of course, every patient is unique and every case is different. That said, they should be able to give you satisfactory answers to the following questions:

- 1 Have you handled cases similar to mine?**
- 2 Have you had any training as a patient advocate?**
- 3 Do you have background or training in the services I need?**
- 4 What do you charge for your services?**
- 5 How long will it take to perform the services I need?**
- 6 Do you have time to handle the work I need to have done?**
- 7 Are you on call 24/7? Or do you have specific hours?**
- 8 Where are you located?**
- 9 Do you have references?**
- 10 Do you provide written reports about the services you have provided?**

Once you've made your choice for an advocate, ask them to put the answers to these questions in writing, along with a signed contract to be sure you agree on what is expected.

## LETTERS FROM FANS

Pam Shlemon and FPN have been tremendous sources of important information I needed to understand my diagnosis of peripheral neuropathy and figure out how to best live life with PN. FPN has been the best source of established and developing information on PN.

**Randy Bramel, FPN member and board advisor**

I just wanted to say that I am so glad I found this foundation having been diagnosed with PN just before my 20th birthday. I truly appreciate all the advice you have to share and am encouraged by other peoples stories. Many thanks & regards to the team

K. M.

I think that's a brilliant idea & will definitely get started on creating a support group of my own. Your website has helped me a great deal, once again thanks so much for all the help & advice shared!

**Kay M. (South Africa)**

YOU CAN SEND US QUESTIONS OR FEEDBACK AT  
**INFO@TFFPN.ORG**  
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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

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Please use the enclosed donation envelope (or donate online at [www.foundationforpn.org](http://www.foundationforpn.org)) to support the on-going work of the Foundation.

Contact  
**Pam Shlemon**  
at 847-883-9951  
or at  
[pam@tffpn.org](mailto:pam@tffpn.org)

For more information about giving, including bequests and sponsorship opportunities

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