

# FPN News

the FOUNDATION for  
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FALL 2017

## OPIATES FOR NEUROPATHIC PAIN: PROBLEM OR PANACEA?

Pain is a primary symptom of many peripheral neuropathies (PN), but what treatments are available for dealing with this problem? Several classes of drugs have been shown to be effective in treating pain and some of these can be effective in PN. However, there is certainly room for improvement as many PN patients do not obtain satisfactory relief.

Opiates are the most powerful class of pain killing drugs we know of, but their use is problematic when treating chronic diseases such as PN. Indeed, the widespread chronic use of opiates has resulted in an epidemic of drug addiction throughout the country. Although long term opiate preparations were advertised in the 1990s as being safe, it is now clear, with the benefit of hindsight, that this was not the case. Many individuals became addicted to these preparations and have subsequently turned to illegal sources of “street” opiates now that supplies of prescription opiates are less available. Unfortunately, many new and incredibly powerful opiates synthesized by illegal laboratories have now appeared on the streets. A major feature of opiate use is that at higher concentrations they inhibit respiration and this can rapidly be fatal. Consequently, overdoses of illegal opiates are now the leading cause of death for young people in this country and over 60,000 deaths resulted from opiate overdoses in the last year.

One important question therefore is whether it is possible to improve on the properties of opiates and produce drugs that are as effective for pain but free of their addictive potential? Opiate pharmacology began with the use of crude opium isolated from the opium poppy plant. This substance was used by man as an anodyne

(CONTINUED ON PAGE 3)

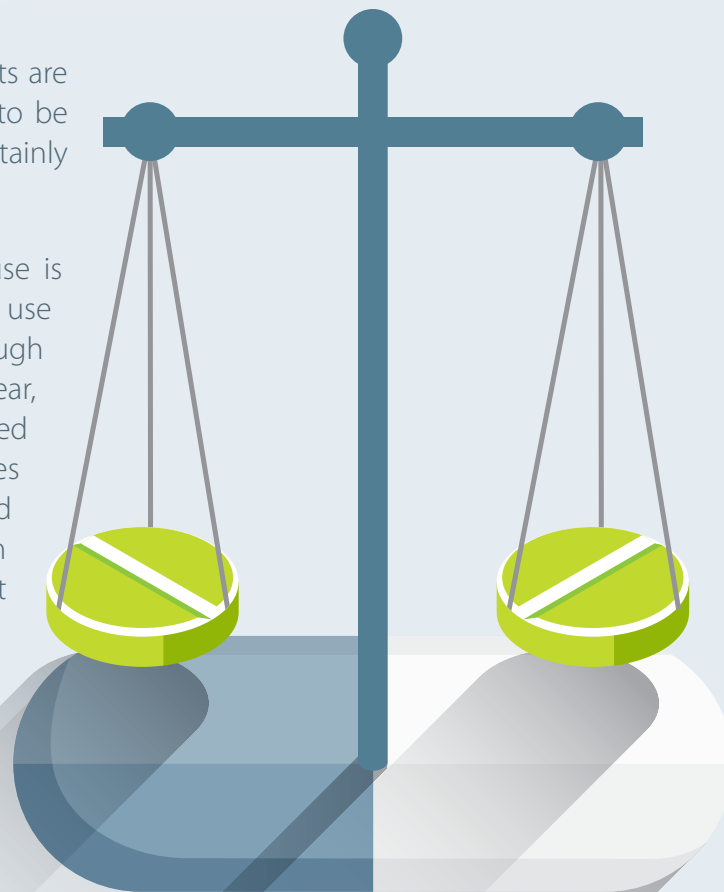


Illustration: Richard Stadler Design, Inc.

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## PATIENT PROFILE | Bobby Rigney



When asked about his journey with neuropathy, Bobby Rigney began: “Well, I was born in a log cabin that I built with my own two hands,” explaining that no matter the details of his symptoms and diagnosis, his sense of humor has been crucial for him while accepting his new life with neuropathy. Bobby had been an avid runner for 30 years, and he remembers the day well— Texas Independence Day— March 2, 2011— that he developed back pain unlike any he had experienced before. The next day, his toes were tingling.

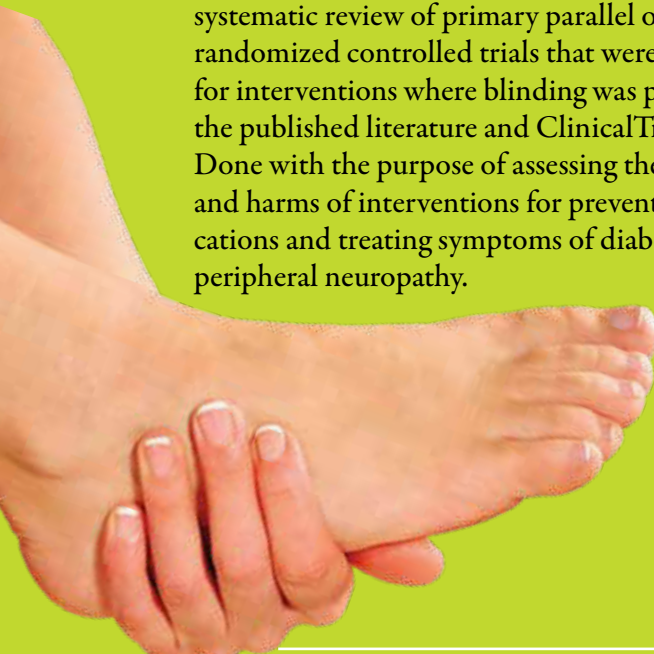
Guessing this numbness might be due to an electrolyte imbalance, Bobby consulted his urologist. Being advised that was unlikely, he sought his PCP who immediately diagnosed him with spinal stenosis. After being referred to a physiatrist, a chiropractor, and a neurologist who diagnosed his neuropathy with an EMG, Bobby opted for lumbar decompression surgery to treat the spinal stenosis. Before the surgery, however, his doctor found a benign sheath tumor around a nerve in his vertebrae from an MRI scan. In removing the tumor, Bobby suffered some damage to his L5 nerve root which lost the signal from his vertebrae to his left foot. His neuropathy symptoms worsened, and although his foot was numb, he was still able to feel burning pain. Throughout all the back-and-forth with all his various healthcare providers, Bobby made sure to always keep his PCP, the “quarterback” of his healthcare team, informed.

While it was a struggle to adjust to his new, slower pace of life, Bobby was particularly grateful to his physical therapists for helping him confront his new limitations and

(CONTINUED ON PAGE 4)

## PREVENTING COMPLICATIONS AND TREATING SYMPTOMS OF DIABETIC PERIPHERAL NEUROPATHY

In March 2017, the Agency for Healthcare Research and Quality published a systematic review of primary randomized controlled trials and nonrandomized studies with a concurrent comparison group for the prevention of diabetic peripheral neuropathy (DPN) complications. For the treatment of DPN symptoms, they included a systematic review of primary parallel or crossover randomized controlled trials that were blinded for interventions where blinding was possible from the published literature and ClinicalTrials.gov. Done with the purpose of assessing the benefits and harms of interventions for preventing complications and treating symptoms of diabetic peripheral neuropathy.



### KEY FINDINGS INCLUDE:

- **Intensive glycemic control is not more effective than standard control for preventing foot ulcers but prevents amputations.**
- **Intensive glycemic control has higher rates of hypoglycemia than standard treatment.**
- **Home monitoring of foot skin temperature, therapeutic footwear, and integrated foot care are effective for preventing foot ulcers.**
- **Pregabalin, oxcarbazepine, duloxetine, venlafaxine, tricyclic antidepressants, tramadol, tapentadol, botulinum toxin, alpha-lipoic acid, and spinal cord stimulation are effective for reducing pain. However, oral drugs and spinal cord stimulation have substantial adverse effects.**
- **Longer term pharmacologic studies and studies of nonpharmacologic approaches for pain management, perceived risk of falling, and falls are needed.**

To read the complete report visit:  
<https://effectivehealthcare.ahrq.gov>

## SIGMA 2 RECEPTOR/TMEM97 AGONISTS PRODUCE LONG-LASTING ANTINEUROPATHIC PAIN EFFECTS IN MICE

Researchers at The University of Texas have discovered a potent non-opioid pain reliever that acts on a previously unknown pain pathway. They say the synthetic compound, known as UKH-1114, is as effective at relieving neuropathic pain in laboratory mice as gabapentin, but lasts much longer.

Now scientists need to find out if drug is safe, effective and nonaddictive in humans — a process that could take years. But the potential of having a new treatment for neuropathic pain that is not an opioid has huge implications.

Source: [pubs.acs.org](https://pubs.acs.org)



## APTINYX CONDUCTS PHASE 2 TRIALS OF INVESTIGATIONAL THERAPY FOR NEUROPATHIC PAIN AND FIBROMYALGIA

The biopharmaceutical company Aptinyx recently announced updates regarding its two Phase 2 clinical trials evaluating the company's lead therapy candidate, NYX-2925. This therapy aims to treat pain associated with fibromyalgia and neuropathic pain associated with diabetic peripheral neuropathy (DPN).

NYX-2925 is a modulator of the N-methyl-D-aspartate (NMDA) receptor, which is involved in the process that causes chronic pain. The investigational therapy binds to a distinct, recently discovered site on the NMDA receptor to modulate NMDA-receptor-channel opening and enhance synaptic plasticity. This unique method was shown to be effective in animal models of several pain conditions and had a favorable safety profile.

The second Phase 2 trial (NCT03219320) is enrolling patients to evaluate NYX-2925 as a treatment for neuropathic pain associated with DPN. This trial will enroll approximately 300 patients with type 2 diabetes who will receive oral doses of either NYX-2925 or a placebo once daily for four weeks.

Source: [fibromyalgianewstoday.com](https://fibromyalgianewstoday.com)



## news Briefs

### PERIPHERAL NEUROPATHY PATIENT CONFERENCE

On October 21, the Foundation for Peripheral Neuropathy teamed up with Northwestern University's Feinberg School of Medicine to host a Peripheral Neuropathy Patient Conference in Chicago, Illinois.

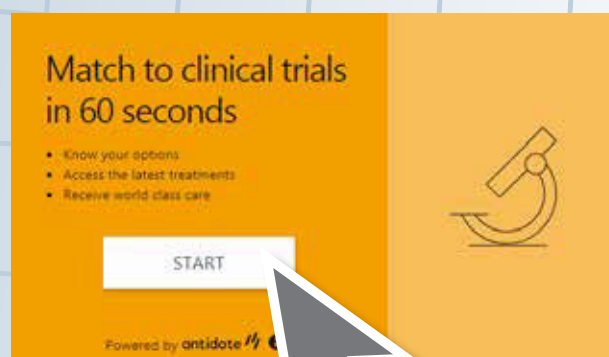


Over 100 people in attendance, plus even more via live-streaming, learned from world-class neurologists and researchers about the opioid epidemic, clinical research trials in peripheral neuropathy, new treatment options, and complementary and alternative therapies in pain management.

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

### Easy New Way to Find a Peripheral Neuropathy CLINICAL TRIAL Near You

Participating in a clinical trial is an invaluable way to get involved in the pursuit of a cure for Peripheral Neuropathy. The Foundation for Peripheral Neuropathy has partnered with "Antidote" to help you find and take part in a clinical trial that is right for you! All you have to do is answer a few questions and the "smart search engine" will match you to a trial quickly and easily. Visit our website now and give it a try:  
<https://www.foundationforpn.org/research/clinical-trials/>





from before the advent of writing in the 3rd millennium BC. Recreational use of opium in Europe and America really began in the 19th century, particularly inspired by the great Romantic writers such as Coleridge and De Quincey whose “Confessions of an English Opium Eater” was a considerable popular success and fueled interest about the effects of opium throughout Europe.

It wasn't until the early 19th century that the active natural components of crude opium were isolated. These were the drugs morphine and codeine. Drug companies in the 19th century attempted to improve on the activity of these substances and produce non-addictive drugs that could replace morphine. One of the first of these to be invented was the semisynthetic morphine derivative heroin which was produced

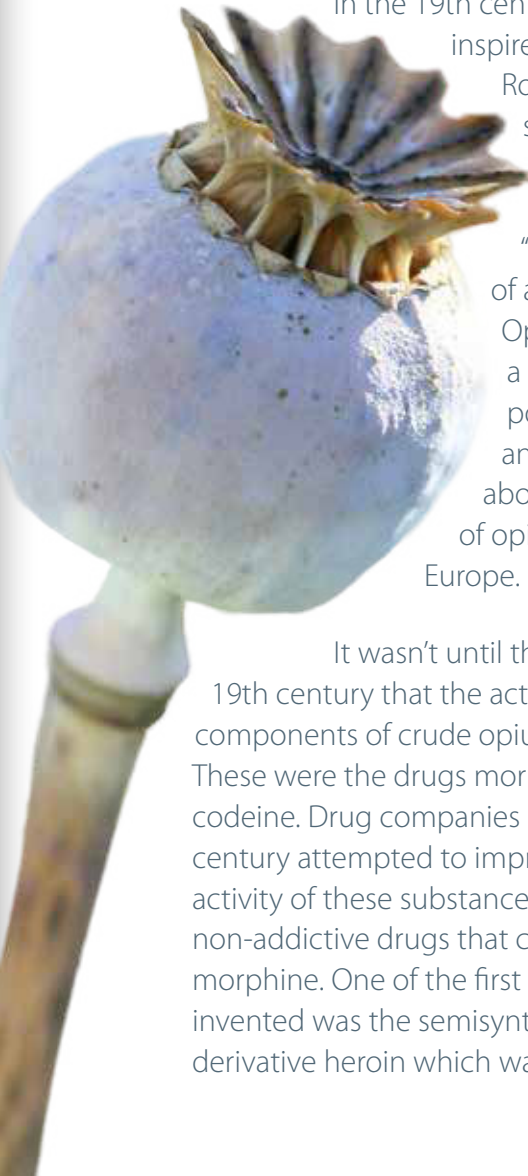
by the Bayer company in Germany and marketed in 1898. Subsequently, there have been literally thousands of attempts to produce synthetic opiates leading to a wide variety of clinically effective substances that are used today. However, the goal of dissociating the addictive effects of opiates from their analgesic actions have not been successful.

Research aimed at producing non-addictive opiates continues to this day. All of the active opiates that have been made to date work by activating a special protein that exists in pain nerves called the opiate receptor. The activation of this receptor produces the pain killing effects of opiates but also produces their addictive effects and other undesirable side effects. Now scientists are trying to make opiates that activate receptors in different ways so that they only produce their pain killing effects and are free of side effects. Indeed, new substances called “biased agonists” have now been designed that only produce the pain killing effects. Experiments in animals suggest that these new substances may act as non-addictive opiates for the treatment of neuropathic pain.

In addition to the production of non-addictive opiates, other types of drugs may also be helpful for painful neuropathies. For example, there is great interest in the use of cannabis in the treatment of pain of this type, particularly since medical cannabis has become available in the majority of states. In January 2017, the National Academy of Sciences published a report on the medical uses of cannabis. The report suggested that there was now good evidence that herbal cannabis was an effective treatment for a number of disorders, including neuropathic pain. Hence, cannabis may be a useful alternative for the treatment of painful neuropathies.

Overall a great deal of recent progress has been made on elucidating the neural networks that underlie neuropathic pain. This information should allow scientists to develop novel therapies targeted at relieving this debilitating disease.

Richard J Miller, PhD  
Alfred Newton Richards Professor  
Feinberg School of Medicine  
Check out [richardjmilller.org](http://richardjmilller.org)



## FPN REPRESENTED AT NINDS FORUM FOR NON-PROFITS

Earlier this month, the National Institute for Neurological Disorders and Stroke (“NINDS”), a division of the National Institutes of Health (“NIH”), held the 2017 Non-profit Forum at its headquarters in Bethesda, Maryland. Lou Mazawey, FPN’s Board President, attended the meetings—the first time FPN was represented—on September 5 and 6. While major players in the area of neuromuscular disorders—such as Parkinson’s, Alzheimer’s, Multiple Sclerosis, Muscular Dystrophy and Epilepsy—were represented, so were many small organizations representing subsets or variants of the larger populations.

Business sessions at the two-day meeting focused on the following themes, which appealed to a wide swath of those attending:

- strategies non-profits can use to maximize the value from their limited budget dollars,
- challenges in managing the cost of new drugs and ensuring their access to large numbers of patients,
- better assessing the results of clinical trials, including patient functionality (mobility, energy levels, etc.) in evaluating new products. Attendees noted that wearable technology (similar to “Fitbits”) could be quite valuable in measuring these areas.

While at the conference, Lou met informally with senior staff members at NINDS, and had a lengthy conversation with Glen Nucholls, Ph.D., whose area of responsibility as Program Director includes PN in the category of an “inherited neuro-muscular disease.” Lou expressed concern about the lack of active research projects involving PN and discussed efforts the Foundation is making to enhance the visibility of PN in the medical communities, including through its distinguished Scientific Advisory Board.

Listening to the presentations, and speaking informally with attendees, Lou was struck by the fact that peripheral neuropathy is not alone in the many variations of possible causes, as well as in patients’ symptoms. Perhaps the majority of the neurological disorders display similar variability—although PN probably affects the largest number of Americans of all the conditions represented at the Forum.



*Pictured: FPN president, Lou Mazawey. The FPN was selected to display a poster that contained key information about the FPN, its goals and recent accomplishments.*



develop a strategy to cope. In one of his sessions, Bobby experienced the undoubtable connection between his mind and his physical symptoms and has since committed to practicing gratefulness and a positive spirit. He notes that it's important to "know who your cheerleaders are and to let them know that you are thankful for them. To stay positive is to be grateful—they reinforce each other. All this ties into being self-aware, and as humans, we all want to understand, and to be understood."

Bobby commits to staying active and being very involved in his community, explaining, "We have to come to grips with our neuropathy in a practical way, and the most practical way is to get engaged with a group that understands." He has a near perfect attendance at the Austin-West support group meetings and

regularly participates in Tai Chi classes, which have significantly helped his proprioception (position sense) and overall health. Quoting Woody Allen, Bobby stresses that "Eighty percent of success is showing up."

He shares, "You really have got to have a community for support, and for me, associating with my local organization, the Neuropathy Alliance of Texas in Austin, as well as my national organization, the Foundation for Peripheral Neuropathy, is just something that I need to do for myself—I get more out of it than I can give back. It's a social support, it's a technical support, and it's just plain community and fellowship. I support the Foundation for Peripheral Neuropathy because it supports me and my health. It helps me learn to live the way I want to become."

## DONOR SPOTLIGHT

### WALTER VAN WOUDEBERG AND SASKIA KEYES



When idiopathic neuropathy struck Walter van Woudeberg at age 55 in the late 1990s, he was surprised by the lack of information and understanding of the disease. Walter scanned the available literature, visited with neurologists, and tried many of the "cures" offered by various supplement websites, chiropractors, and electrical stimulation techniques such as "TENS" options and machines. He found little or no relief in any of them.

Then in 2008, when his daughter Saskia Keyes also displayed symptoms of PN, they started their quest for relief together. Disappointed in most of the offered "cures" and reluctant to be subjected to the negative side effects of the many common drug options, Walter and Saskia focused on whole

body wellness, with specific attention to fitness, daily workout routines, best possible diet, and holistic treatments such as massage, acupuncture and vitamin supplements from reputable sources.

Says Saskia (age 43): "We found extensive information on diet and drug treatments, but most of it was pretty old, and did not provide much by way of latest research or findings to provide non drug relief for idiopathic PN. As daughter and father, we share information and try out new techniques to get relief."

Walter (age 71): "I find that a pretty rigorous daily workout routine and muscle stimulation is essential in delaying the inevitable progression of the disease. If I skip a few days of exercise,

the PN symptoms are heightened, and sleep as well as daytime functioning is adversely affected. I cycle, walk, ski, practice yoga, and stay in the best shape possible"

In August 2017, Walter and Saskia each pledged \$5,000 to fund the Foundation for Peripheral Neuropathy's quest for research findings specific to idiopathic peripheral neuropathy. Their gifts aim to assemble the latest science on all of the options available to help sufferers of idiopathic neuropathy select the best relief for their affliction.

**Hoping to support the Foundation's mission to dramatically improve the lives of people with peripheral neuropathy, Walter and Saskia challenge YOU to add to their donation and help advance research for idiopathic peripheral neuropathy.**

*Enclosed is a donation form for your convenience.*

Please join the conversation on the Foundation's Facebook page at: [www.facebook.com/FoundationForPeripheralNeuropathy](http://www.facebook.com/FoundationForPeripheralNeuropathy).

# LEAVE A LEGACY

## Charitable Bequest

A charitable bequest can be a meaningful way to make a gift to the Foundation for Peripheral Neuropathy. A bequest made through a will or living trust has many benefits:

- **Estate Tax Reduction:** A charitable gift may reduce estate taxes assessed at your death.
- **Revocability:** A charitable bequest is revocable, so you may make changes to the beneficiaries of your estate throughout your lifetime.
- **Flexibility:** This type of gift can be directed to any program of the Foundation.
- **Control:** When you include a charitable bequest in your estate plans, you have access to the assets during your lifetime, ensuring that the funds are there if you need them to provide for unexpected occurrences.

## IRA Charitable Rollover

Congress has renewed legislation that allows you to make a tax-free gift from your individual retirement account (IRA). Known as the IRA Charitable Rollover, this law no longer has an expiration date, so you are free to make annual gifts to the Foundation for Peripheral Neuropathy from your IRA now and well into the future. If you are 70½ and older, these benefits apply to you:

- **Your gift will be put to use today**, allowing you to see the difference your gift is making.
- You pay **no income taxes** on the gift. The transfer generates neither taxable income nor a tax deduction, so you benefit even if you do not itemize your tax deductions.
- If you have not yet taken your required minimum distribution for the year, your IRA gift can satisfy all or part of that requirement if the gift is transferred directly from your IRA to FPN.

*To inquire about making a charitable bequest or an IRA charitable rollover, please contact the Foundation for Peripheral Neuropathy at 847-883-9942 or [info@tffpn.org](mailto:info@tffpn.org).*



# Relieving numbness and pain with acupuncture.

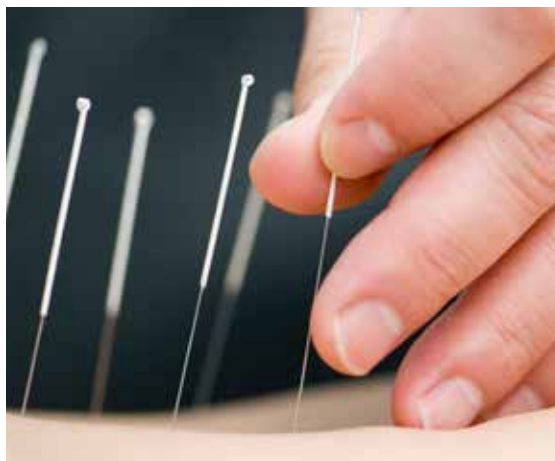
## *How does it work?*

By Lindy Camardella, L.Ac, Dipl. OM, MSTOM

Some of us may take for granted being able to pick up a plate without dropping it, or going for a walk without tripping because you can't feel your feet. But for people suffering from peripheral neuropathy, these everyday moments can be a challenge.

In Chinese Medicine, peripheral neuropathy is classified under *wei zheng*, which is considered a "wilting condition." With a wilting condition, factors either internal or external cause the body to lose its nourishment, resulting in a 'wilting' of the body. The classic Chinese explanation is that channels of energy run in regular patterns through the body and over its surface. These energy channels, called meridians, are like rivers flowing through the body to irrigate and nourish the tissues. The improved energy and biochemical balance produced by acupuncture results in stimulating the body's natural healing abilities, and in promoting physical and emotional well-being.

More than half the people with diabetes develop some type of neuropathy. Peripheral neuropathy can also be brought on by autoimmune diseases and other disorders, infections, alcohol abuse and vitamin deficiencies, as well as certain medications like chemotherapy.



How each person experiences peripheral neuropathy varies, and so does how the condition is treated. Some individuals are incorporating acupuncture, along with their other treatments, as a way to manage peripheral neuropathy.

Acupuncture has been used for centuries to treat many conditions and relieve pain. Now, some experts are saying acupuncture can be helpful in relieving nerve pain.

In a recent meta analysis (Acupuncture for Treatment of Peripheral Neuropathy: A Systematic Review and Meta-Analysis, *Journal of Alternative and Complementary Medicine*, March 2017) that compared the results of different studies on peripheral neuropathy, the conclusion was that acupuncture is beneficial in some peripheral neuropathies (particularly non-idiopathic), but more rigorously designed studies using sham-acupuncture control are needed to characterize its effect and optimal use.

### What does acupuncture for peripheral neuropathy entail?

When you first meet with an acupuncture practitioner, he/she will ask you questions as part of your intake. It is important to know that questions about your sleep, digestion, energy level, mood, etc. may not seem immediately relevant, but are key to figuring out your individual treatment plan.

You'll want to make a note of where and when your peripheral neuropathy bothers you the most, and let your practitioner know. For some, it may be the inside or outside of the feet, for others it is between the toes or up the legs—the possible combinations are endless.

Once your acupuncture practitioner creates a customized plan for your treatment:

- You will probably lie on a table or relax in a recliner, depending on the office.
- Your practitioner will insert single use needles into the skin, depending on where the pain or numbness is located.
- The needles usually stay in from 10-40 minutes. Some people raise the concern about being afraid of needles, but once the needles are in with a slight pinch, they are usually quite comfortable.
- This is an excellent opportunity to close your eyes and relax. Even if you don't completely fall asleep, use this time for reflection, mindfulness and taking some deep, relaxing breaths.

Treatment success often takes more than one session, and the rate at which each person responds varies. Those that find relief may experience less pain, less numbness and tingling, increased ease of moving, or sleeping through the night without waking from pain. For many, the pain starts to subside more quickly, and the increase in feeling returns a little more slowly.

When considering treatment options for peripheral neuropathy, remember to consult with your doctor first.

Ms. Camardella is a Licensed Acupuncturist and expert in Oriental Medicine with the Momentum Health Center in Arlington Heights, IL.

## FINDING THE RIGHT CANE

A cane might be just what you need to improve your stability and balance. To avoid falls and instability, it's important to select the right cane and use it properly. Here's what you need to know:

### TYPES AND FIT

**Standard:** These canes have a T- or C-shaped handle. They are good if you need help with balance.

**Offset:** These can bear more weight with the shaft bending outward. The handle is usually flat making it a good choice for people whose hands are weak.

**Multi-leg:** With three or four short legs, these offer the most support. This type of cane can stand on its own when not in use.

**Handle:** Try different handles to determine what's best for you. Avoid metal handles which can be slippery when you perspire or too cold on cold days.

**Length:** Stand up straight, wearing your regular shoes. Let your arms hang at your sides. Have someone measure the distance from the floor to the inside of your wrist of the hand you'll be using. When you use your cane your elbow should be flexed to a 15- to 30-degree angle.

### HOW TO USE THE CANE

- 1 Hold the cane in the hand opposite the side that needs support.
- 2 Position the cane about 4 inches to the side of your leg.
- 3 Distribute your weight evenly on both legs, using the cane for support.
- 4 Shift your weight to the stronger leg.
- 5 Place the cane a few inches ahead of you, bringing your weaker leg forward with the cane.
- 6 Once in position, move your stronger leg up even with the cane, and start again.

As you gain experience, move the cane and your weaker leg forward at the same time. Move your stronger leg forward, beyond the cane. Be sure to place the cane on the ground firmly and not too far ahead of yourself.

Source: Chicago Tribune/Harvard Health



## LETTERS FROM FANS

"I am grateful to have found this site. It helped me make choices about medications I might try. I'm not trying a new medication that has freed me from opioids and equally freed me from extreme pain. I believe in educating myself and have learned a lot from FPN. Thank you." *Virginia*

"I can't say enough for all the good your organization does. Neuropathies are painful, maddening and takes over your life. I would give anything if we could find a cure." *Sharon*

"I am very happy to hear that you have such a friendly staff. Looking forward to learning more and even hearing of a cure one day." *Ernesto*

"I am excited to have found your organization. After looking at your site and reading lots of your articles, I'm having more hope for my future." *Lynda*

11/28/2017  
#GIVING  
TUESDAY  
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CALENDARS!

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For the most up to date news and information visit our website

[WWW.FOUNDATIONFORPN.ORG](http://WWW.FOUNDATIONFORPN.ORG)



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

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

Accelerating a cure for peripheral neuropathies

Funding collaborative efforts of leading scientists

Raising awareness of peripheral neuropathy

### SUPPORT US IN ADVANCING A CURE!

FPN IS A NON-PROFIT ORGANIZATION,  
FUNDED SOLELY BY PEOPLE JUST LIKE YOU.

100%

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

### MAKE A DIFFERENCE TODAY

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

For more information about giving, including bequests and sponsorship opportunities

Contact  
Lindsay at  
847-883-9951  
or at  
Lindsay@  
tffpn.org

Your gift to the Foundation means you are sharing in our commitment to dramatically improve the lives of those living with peripheral neuropathy.

QUESTIONS?  
FEEDBACK?  
CONTACT US AT:  
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847-883-9942



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