



# eNcouragement

The Newsletter for The Minnesota Neuropathy Association  
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*“Providing hope and a better quality of life through educating and connecting members to medical resources and emerging technologies”*



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The MNA thanks all of you who have so faithfully sent in your membership contribution each year. Without, we would not be able to offer the programs, activities, monthly mailings, and newsletters that we have done in the past. Remember that our Board members are all volunteers; we have no paid staff.

The suggested yearly contribution is \$25.00. Mail your contribution, payable to MNA, to Myron Martin, 8100 Russell Avenue South, #127, Minneapolis, MN 55431.

Since we are a 501(c)(3) organization, your contribution is tax deductible. If you feel that your mailing label's date does not reflect your most recent membership contribution, please call Myron Martin, treasurer, 952-941-5372 to verify your information.

## Save the Date!

**Next Meeting** will be held Saturday, February 2 at 10 a.m. at St. Michael's in Bloomington

Topic: Circle of Conversation

**See enclosed flyer for additional information**

### The Foundation for Peripheral Neuropathy (FPN)

**Mission:**

**Dedicated to Reversing the Irreversible**

Visit their website: [www.foundationforpn.org](http://www.foundationforpn.org)

### Minnesota Neuropathy Association (MNA)

Visit our website: [www.neuropathy-mn.org](http://www.neuropathy-mn.org)

#### A Note from MNA

***Our newsletters contain a variety of information, and in each article we have identified the source, but the views and opinions of the articles do not necessarily represent the views of MNA, nor do they infer an endorsement of any product or service. They are not intended to replace medical or other professional advice and counsel.***

## **My athletic husband stumbled. He was tired. He had a disease we'd never heard of** By Lynn Peterson Mobley

We started our ascent of Italy's Stromboli volcano at dusk, as the Tyrrhenian Sea darkened behind us. It was a long, steady trek upward, but not an exhausting one. At the crater's rim, watching fountains and bombs of glowing lava exploding into the night sky, we soon forgot the effort it had taken to get there.

Going down, however, was unforgettably harder. The trail through the deep black sand blanketing the massive cone was impossible to follow by the paltry light of our helmet lamps. I had never witnessed my athletic husband struggle before. He stumbled down the mountain for two hours with borrowed walking sticks, falling more than once.

We had been hiking along the Volcano Route: Vesuvius, Amalfi's Path of the Gods, Vulcano, Etna. Robert was a fit 70-year-old then, never sick in his life. But after Stromboli, things weren't quite the same. Back in Rome for a few days before our flight home, he was aware of weakness in his feet and lower legs. His shoes slapped the sidewalks as if they were too big. It took forever to get back to our hotel after a day of sightseeing.

He was tired, yes, but this was different.

Later that year, in 2010, he was diagnosed with a disease that we had never heard of, and that he shared with millions of other Americans: peripheral neuropathy, or PN.

As we were to learn, the nervous system is composed of two parts. The brain and spinal cord make up the central nervous system, while the nerves running from them form the peripheral nervous system. PN encompasses damage to the nerves that deliver messages to or from the brain. Damage to the sensory nerves can mean tingling or numbness in the hands, feet and legs; damage to motor nerves that control the muscles causes loss of strength and balance; damage to the autonomic nervous system, which regulates automatic functions, affects things such as heart rate, blood pressure, bladder control and digestion, along with a host of other involuntary responses.

In Robert's case, numbness that had started in his feet was slowly working its way up his legs. He had begun using his muscles differently to compensate for information his nerves could no longer transmit. It had happened so quietly and slowly, he hadn't been aware of it until our Italian trip.

In a great many cases, PN is crippling, limiting mobility and increasing the likelihood of falls, which can be disastrous. The pain of PN in the extremities has been likened to a horrific case of shingles. For many, its debilitating pain prevents sleep and requires medication. My husband turned out to be in the minority of lucky ones who do not have any pain.

Most cruelly, with or without pain, the disease robs people of the things they loved doing — think tennis or dancing — and renders everyday activities such as walking the dog impossible. With the loss of balance, walking without support is risky, stepping over the cat can be deadly, and picking up the grandkids becomes just a memory.



Lynn Peterson Mobley and Robert Wilson Mobley at the beginning of their trek up Italy's Stromboli volcano in 2010. (Courtesy of Lynn Peterson Mobley)

Exercise can ameliorate some of the effects of nerve damage. The exercises that build up strength and promote balance can help preserve and improve the condition of the nerves, postponing their deterioration. But without adequate guidance, many patients can only feel their lives slipping away from them, with no relief in sight.

Estimates of the number of Americans with peripheral neuropathy vary, with the National Institutes of Health putting it at 20 million and the Foundation for Peripheral Neuropathy at 30 million. The foundation, which has established a research registry to compile data and biosamples on PN patients, sets the average age of those with the disease at 63, though onset often goes unnoticed.

For such a widespread malady, little research is being funded. In 2016, NIH granted \$122 million for the study of PN, while more than \$4 billion was awarded the same year for research on rare diseases. For whatever reason, perhaps because PN is just too ubiquitous, it fails to garner much attention. Although dangerous, it is not considered fatal. (While statistics are kept on deaths by falls, what causes the falls goes largely unreported.) And PN is a disease that generally attacks older people, who make terrible poster children.

Doctors cannot fix peripheral neuropathy, they don't know how to treat it, and in many cases they don't know what caused it. It is often up to the patient to find the way to live with the condition.

But patients might not understand that they have PN because their condition is often called by other names, such as nerve damage or nerve disease or diabetic nerve pain, making it harder for them to research ways to cope with worsening symptoms.

I was a month shy of 64 in 2017 when I decided I should start running again. Suddenly it seemed important to do something symbolic to defy aging, so I turned my morning walk in the woods into a morning run.

Within a few weeks, my lower back began bothering me, and I returned to walking. But I noticed that my feet felt funny. My toes felt as if my socks were bunched up beneath them, while the balls of my feet had become hypersensitive; a stray grain of cat litter underfoot was maddening. At first I chalked it up to jogging, but after a few months of discomfort I checked in with my doctor, who sent me to a neurologist.

Various possibilities were ruled out, one by one. No tumors, and while my spine was not in great shape, it could not be blamed for the numbing in my feet. A number of diagnostic tests were performed. I held off on the definitive test for last, because I did not

want to believe what was becoming increasingly probable.

Sure enough, that test, a biopsy of skin samples showing diminished numbers of nerves at various points along my legs, proved positive for small-fiber peripheral neuropathy: The sensory nerves were withering away.

When my neurologist learned that my husband also had PN, he immediately advised me to have our well water tested. Metals, chemicals, organic compounds, dozens of substances including mercury, arsenic, pesticides, herbicides and lead were tested for, and none turned up in unacceptable levels in our drinking water.

Robert and I have peripheral neuropathy that is "idiopathic," which simply means that there is no known cause. Nor is there a cure. And the prognosis is a sure if unpredictable deterioration in balance, strength and mobility.

Theories on the causes of PN abound. Some people claim that the statins we took for several years are responsible. Another theory links PN to cooking with aluminum. Probably unnecessarily, I jettisoned the heavy-duty aluminum pots and pans I had used almost exclusively for 30 years. In my initial panic I was willing to do anything to slow the pace of my illness.

I also joined a health club to work on strengthening the muscles that would help me remain steady in the years to come. This came with an unexpected bonus, because I am finding the mood elevation of an aerobic workout to be really enjoyable, if not outright addictive. My diet was fairly healthy to begin with, but it is better now and I shop more in the organic aisles. Too little, too late, but it can't hurt.

Robert has remained active, fighting to beat back the creeping numbness that robs him of his balance. He pesters his doctors, unwilling to accept that there is nothing more to be done.

In May of last year, we hiked in Sicily again. At that time, Robert could still do five or six miles a day, sometimes using hiking poles to steady himself. (It is odd but true that he finds uneven trails much easier to walk on than flat concrete.)

This year, though, after a minor injury led to a few months of near-inactivity, he lost so much strength in his legs that a hiking vacation was out of the question. Shocked by this, he joined my health club, where he pushes himself harder than he did at home. He feels a few pangs as he walks by the basketball court, now permanently off-limits, but he enjoys the bike and the pool well enough. I am proud of him, and grateful. He will be 80 in August, and he is not about to give up.



## The Benefits of Water Exercise

The Neuropathy Association of Texas (NATX) recently shared a presentation on aquatic exercise for neuropathy, presented by Julie O'Conner, Aquatic Specialist of Sun City Texas.

### Safety First!

- Tread carefully on slippery areas around the pool.
- Plan how to get in and out of the pool in a safe manner
- Wear aqua pool shoes in and around the water for both stability, and to protect your feet
- Remember to bring a water bottle to keep hydrated
- Do as much as you are comfortable doing, and build up to longer, more difficult workouts

### Types of Aquatic Exercise

- Shallow end: using different equipment or movements with correct posture
- Deep water movements (non-weight bearing)
- Swimming
- Ai-Chi (Tai Chi in water)
- Water strolling (walking about abdomen height. Hold your back straight and try not to walk on tiptoes
- Training or condition in water
- Hydrotherapy

Reprinted from "E-Tips" from Foundation for Peripheral Neuropathy

Powerlessness is its own special hell. Fortunately, the Peripheral Neuropathy Support Group of the DC Metro Area has been a boon, with members who share information and experiences that make us feel less alone and more hopeful. The Foundation for Peripheral Neuropathy has a wealth of information on its website, and it hosted a terrific patient conference in March at Sibley Hospital with a forum of researchers and doctors from Johns Hopkins, one place where PN research is being actively conducted. Trying to stay abreast of breakthroughs in treatment and ideas about the prevention of further deterioration is not as hard as we might have feared.

Our goal, which seems achievable, is to take at least one more of the trips we both loved, touring the countryside of Europe on foot or hiking the trails of the American West.

We shall see. Goals help. A cure would help a lot.

Washington Post, July 8, 2018

## October 25, 2018 Meeting

David Walk, M.D., Professor and Head, Neuromuscular Division - Department of Neurology - University of Minnesota addressed the group. Dr. Walk reviewed the classifications of neuropathy, major categories, methods of diagnosis, and an overview of current treatments.

## Finding Better Way to Quantify Neuropathy Symptoms and Treatment Efficacy

Most of the roughly 15.5 million cancer survivors in the U.S. receive chemotherapy, and roughly 65 percent develop some degree of the chemotherapy-induced nerve damage known as peripheral neuropathy.

Peripheral neuropathy simply means nerves outside of the brain and spinal cord are affected, and symptoms include numbness and tingling in extremities, and in about 30 percent of patients, pain. Neuropathy can drastically diminish quality of life--and in extreme cases, may necessitate chemotherapy dose reductions.

Unfortunately, neuropathy often goes underreported and untreated, said Ellen Lavoie Smith, associate professor at the University of Michigan School of Nursing. This happens because clinicians and researchers don't have a valid, standardized way to measure symptoms or the effectiveness of neuropathy treatments. Right now, the drug Cymbalta (duloxetine) is the only drug FDA-approved to treat painful neuropathy symptoms.

Some doctors and nurses ask patients about neuropathy, or whether they have symptoms of numbness and tingling, and others don't.

"If we don't have a reliable measurement tool, we can't know if the interventions are effective or not," Smith said. "Historically, it's possible that we've discounted treatments and said they are ineffective based on poor measurements."

Smith's lab wanted to find a better way to quantify neuropathy symptoms and treatment efficacy.

"The ultimate goal is to use a measurement tool in research and clinical settings that has been thoroughly tested and found to be reliable and valid. We believe we have that now," she said.

The neuropathy measurement tool Smith examined in her research is a questionnaire developed in Europe and owned by an international research network. It's a patient-reported outcome measure called the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Chemotherapy-Induced Peripheral Neuropathy Scale (QLQ-CIPN20).<sup>37</sup>

Findings suggest that with minor revisions, it could be universally adopted in both labs and doctors' offices to

help researchers and clinicians quantify and treat this painful condition.

Six previous publications provide evidence supporting the tool's effectiveness. However, two studies provide conflicting evidence about the instrument's validity, and another study suggests that minor revisions could improve that.

Some researchers use the questionnaire now, but for a variety of reasons it's not used in the clinic with cancer patients, Smith said.

"The next step is for researchers worldwide to consider using the same tool, because then the results from one researcher can be compared directly with results from the next," she said.

News Medical Life Sciences, April 17, 2018

## Health Tips

### Eat Less - Eat more. . .

Grabbing a 100-calorie snack pack of cookies or pretzels may seem virtuous, but it's more likely to make you hungrier than if you ate something more substantial, says Amy Goodson, RD, dietitian for Texas Health Ben Hogan Sports Medicine. "Eating small amounts of carbohydrates does nothing but spike your blood sugar and leave you wanting more carbs." Goodson recommends choosing a protein such as peanut butter or string cheese with an apple. "They are higher in calories per serving, but the protein and fat helps you get full faster and stay full longer—and you end up eating fewer calories overall," she says.

### Handwrite Notes to Boost Your Brainpower

Typing notes enables you to jot down more material, but you're more likely to remember those notes if you **handwrite them**, according to research from Indiana University. "To learn something means you have processed it," says Dr. Towfigh. "And when you take handwritten notes you 'process' or learn more information. You begin the learning process as you listen to the lecture." Plus, since you look at the page on which you are writing, you naturally review the material and reinforce the information you've already processed, Dr. Towfigh says.

From Health Magazine, August, 2017

## Could This Cell Save Your Life?

Stem cell therapy is an accepted treatment for just a short list of medical conditions. And yet some cell stem treatments are being offered for a wide range of illnesses. Those treatments are often ineffective and sometimes dangerous.

“There is an important difference between the stem cell treatments emerging from slow and careful study and the ones being sold for the thousands of dollars without any evidence of safety or efficacy,” states Orly Avitzur, M.D., Consumer Reports’ medical director. “But that difference is not being made clear to consumers.”

“Some institutions use patient testimonials to promote treatments that have not been scientifically proven. They create the impression that even though it’s experimental, it really works.” says Leigh Turner PhD, Bioethicist, University of Minnesota.

## How to protect yourself

The Food and Drug Administration (FDA), the international Society for Stem Cell research, and Consumer Reports medical experts advise you to be cautious when considering stem cell therapy.

Beware of the hype and hefty fees. Doctors testing stem cell treatment in carefully controlled clinical trials usually don’t promote their offerings with big, flashing advertisements that promised dramatic improvements or total cures. They also don’t charge a lot. There may be some minor fees for travel or other personal expenses, but the treatment itself should be free or low-cost to participants. “A large price tag – especially in the range of thousands of

dollars – should be a major red flag,” says Marvin M Littman M.D., Consumer Reports chief medical adviser. So should any doctor claiming to treat a wide range of medical conditions, such as autism, arthritis, and erectile dysfunction, with the same therapy. Different organs and body systems require different expertise – and different medicine – to treat, which is why most doctors specialize.



Ask questions. Any doctor who offers stem cell therapy should be able to explain where the cells will come from, what will be done to them before they’re injected into your body, and how, exactly, they will resolve your illness or injury. He or she should also be able to offer you proof of safety and efficacy, even for experimental treatments. Don’t settle for patient testimonials. Ask how many people the proposed therapy has been tested on – the more the better – and whether those tests were done in clinical trials or individual case studies. (Randomized controlled trials, where people given a treatment are compared with a control group that wasn’t, are best.) It’s also important to find out what the outcomes were. Ideally, side effects were minimal and significantly more people improved than did not.

Read the fine print. If the treatment is being offered as a clinical trial, make sure the trial has been vetted by the FDA, a process known as securing investigative new drug approval. The agency advises that you ask to see the actual approval letter to make sure it has been

issued specifically for the treatment you're considering. Treatments that have cleared this hurdle are much more likely to be safe than those that have not. You should also make sure that any informed consent document – an explanation of the experimental treatments that study participants are usually asked to sign – provides a clear description of the treatment being offered along with the risks, alternative options, and details about what to expect in the days and weeks after the procedure. It should not indemnify doctors or their institutions against liability for negligence.

Excerpts from Consumer Reports -- March 2018

## **Stay Positive When Pain is at Its Worst**

When you suffer with chronic pain, there are good days and there are bad days. On the good days, you can do what you need to do – go to work, pick up the kids, clean the house. But on the bad days it can be difficult to even get out of bed. Not only is the pain itself overwhelming, but the mental toll it takes can leave you wondering “How do I go on?” On these inevitable days when life seems bleak, there are some relatively simple things you can do to help pick yourself up and keep fighting. Here are five such methods.

### **Surround yourself with supportive people.**

If you are the type of person who finds comfort in being around others, seek them out. Although it may be tempting to hide yourself away from friends and family, try to resist that urge. But make sure you are surrounding yourself with the right kind of people. According to APM behavioral health specialist Mary Papandria, “If the people in your life are demanding and not very supportive, then it could actually make things worse.” Seek out people who are patient and understanding – whether that's friends or members of a support group.

**Breathe.** Deep breathing may sound simplistic, but it's an effective way to deal with

intense pain. Dr. Papandria suggests breathing in for a count of four, then breathing out for a count of four. So why is this an effective coping mechanism? “Deep breathing helps the person go from a stress response to a relaxation response,” she says. It's also a method of distraction; if a person is entirely focused on counting and breathing, they can't be focused on their pain.

### **Make a list of the good things in your life.**

One of the keys to pulling yourself out of depressive moods is overcoming your negative thought patterns. When you catch yourself thinking “It hurts so much. Nothing is working. I can't handle this anymore,” stop and take a step back. Get a pen and piece of paper and just start writing a list of all the positive things you have in your life, whether that's your loving family, your job, a pet or anything else. Use this to remind yourself that even though your pain may be bad right now, it won't always be like that.

**Refocus your attention.** Sometimes you just need to distract yourself from the pain. Although it might seem difficult to refocus your attention away from the pain, says Dr. Papandria, you should still try. Engage in a hobby, read, stretch or just listen to music. You can try anything that helps you refocus your attention away from the pain and onto something more enjoyable.

### **Seek help from a behavioral health specialist.**

Engaging a behavioral health specialist as a component of a multidisciplinary treatment plan can help you start to address and work through your negative thought patterns. Behavioral health treatment will include such techniques as cognitive reframing, by which a specialist can help you identify and challenge the irrational thoughts you may have in relation to your situation. “These techniques help the patient be less negative in their thought patterns, but also realistic,” says Dr. Papandria.

From Pain Management Network  
Newsletter, November 22, 2017

## Benefits of a Good Vocabulary!

I recently called an old Engineering buddy of mine and asked what he was working on these days.

He replied that he was working on "Aqua-thermal treatment of ceramics, aluminum, and steel under a constrained environment."

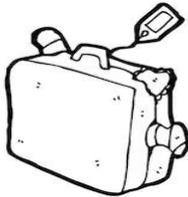
I was impressed until - upon further inquiry, I learned that he was washing dishes with hot water under his wife's supervision!



**Question:** What do you call a snowman with a six pack?

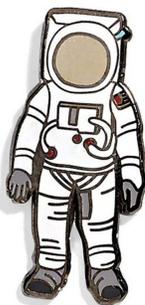
**Answer:** An abdominal snowman!

A man sued an airline company after it lost his luggage. Sadly, he lost his case.



**Question:** What did Neil Armstrong do after he stepped on Buzz Aldrin's toe?

**Answer:** He Apollo-gized.



## Board Members

Questions? Comments? Let your MNA Board know your thoughts and ideas! Contact information:

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**Have ideas for the newsletter?**  
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