

FPN News

the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

WINTER 2014

A MESSAGE FROM THE EXECUTIVE DIRECTOR



As 2013 ends and we reflect on the advances made over the past seven years and address the vast challenges that remain, I am proud to tell you we are gaining more knowledge and finding answers. We are encouraged about new research developments taking place globally and those that will emanate from our own Peripheral Neuropathy Research Registry (PNRR). Thanks to the work we have done—awareness, education, research—and the work of thoughtful committed citizens, we will press on to find new therapies and a cure. Together we're able to impact our own lives and lives of so many more.

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.” —Margaret Mead

Over the next year, the Foundation intends to deepen its research platform through the PNRR and the 2014 FPN International Research Symposium. Expanding and increasing patient enrollment to make the data available to researchers, enabling investigators to develop new therapeutic avenues directly tied to our patients greatest needs. Our bi-annual research symposium will bring together basic scientists, clinical researchers and industry experts from five countries to review the current state of drug development for neuropathic pain in peripheral neuropathies and identify roadblocks in development of more effective therapies for a condition that has huge public health impact.

Collaboration and partnership with a broad range of stakeholders allows us to sustain our commitment to be the 'gold-standard' of resources by sharing knowledge and bolstering our website to become the most reliable resource center for peripheral neuropathy. While we focus on delivering meaningful solutions and resources to the challenges of living with PN, we also recognize our unique opportunity to mitigate the potential impact PN has on society.

During this holiday season, as you reflect on your own generous spirit, please consider making a year-end gift to FPN. Everyone has something to give and in today's world, that is a beacon of hope for the future.

With thanks and warm wishes for your health and prosperity,

Pam Shlemon

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Where to Start...

In an age of information overload, it can be a challenge to find the best information—for whatever we need. For someone dealing with a health issue, there are thousands of internet sites devoted to every imaginable health topic. You can spend hours looking from site to site. The challenge? How to sift through all of the resources to determine what the 'good information' is and which should be ignored. And if you don't have access to the internet, the challenge can be even greater.

For a condition shared by so many, peripheral neuropathy (PN) is often misunderstood and under-diagnosed. There doesn't seem to be a lot of good information or the good information is too hard to find. Sometimes we don't know where to look, who to ask, or what to ask. The Foundation has always considered it our mission, and responsibility, to provide the best educational resources for patients struggling with peripheral neuropathy.

The first step is to think about the kinds of help you might need. Maybe you live alone, so there is no one living in your home available to help you. Or, maybe you don't need help right now but might in the future. Everyone has a different situation, but one way to begin is to look at any illnesses that you have. Talk to your

(CONTINUED ON PAGE 3)



LUCK OF THE IRISH!

For years, Richard Dolan knew what it felt like to live with nerve pain. He spent many years suffering with trigeminal neuralgia, a neuropathic disorder characterized by episodes of intense pain in the face, originating from the trigeminal nerve. Having had “every treatment known to man”, he decided several years ago to have surgery to try and treat the neuralgia. Doctors performed a microvascular decompression and he woke with no pain. He couldn't believe it!

Then he realized he had another problem that had been slowly progressing, though mostly unnoticed, for years...peripheral neuropathy in his feet and legs. His neuropathy became “full blown” about five or six years ago and he describes his symptoms as “the usual, conflicting effects— your legs feel cold, but they aren't cold; tingling, but not in a pleasant way”. His symptoms are most apparent at night when he tries to sleep.

He has been taking medication to help relieve the unpleasant sensations and has tried some other types of treatments, like massage, but they have not been effective for him. He exercises every day because it makes him feel better to keep moving. He is not incapacitated from the activities he enjoys, but life holds it challenges.

Richard talks about trying to keep a positive attitude about his life — full of family, and an old house “that always needs maintenance.” With three children and five grandchildren nearby, he stays busy. He belonged



INSIDE

- Resources you can use!
- Stand Together

(CONTINUED ON PAGE 6)

NEUROPATHIC PAIN: A PATHWAY FOR CARE

The British Pain Society (BPS), affiliated with the International Association for the Study of Pain (IASP), commissioned working groups to develop five care pathways for pain to assist the management of certain pain conditions. The pathways were chosen due to the high frequency of their presentation, geographical variability in access to treatment, variation in clinical case management, or a combination of these issues. One of the pathways chosen was neuropathic pain.

Neuropathic pain is defined by the IASP as 'pain arising as a direct consequence of a lesion or disease affecting the somatosensory system', a diverse network of receptors and processing centers that produce sensory modalities such as touch, temperature, body position, and pain. Neuropathic pain is additionally

described as a particularly unpleasant type of pain whose characteristics contribute to poor general health and quality of life.

While chronic pain affects up to 47% of the British population, it was believed that only 1% suffered from neuropathic pain. In reality, they now believe that this number is closer to 8%. This increase in prevalence could be due to the recognition that neuropathic mechanisms contribute to many types of chronic pain and that patients and professionals are more aware of neuropathic pain because of greater availability of treatments and educational initiatives.



The development of the Map of Medicine care pathway for the management of neuropathic pain, published in *British Journal of Anaesthesia*, is based on new evidence,

consensus, and the interests of service users. Their research presents the care pathway and accompanying evidence base, highlighting its salient features and discussing important treatment points.

The key points of their study are:

- Neuropathic pain is a challenging pain syndrome to treat effectively
- Diagnosis of neuropathic pain can be 'possible', 'probably' or 'definite', all potentially requiring treatment
- The review outlines a new practical guideline to the comprehensive management of neuropathic pain
- The current evidence base has clear research gaps that need to be addressed

Their conclusion is that by combining professional healthcare skills with the pathway outlined the burden of neuropathic pain on patients can be reduced.

PAINFUL AND PAINLESS DIABETIC NEUROPATHY: ONE DISEASE OR TWO?

Painful diabetic polyneuropathy (PDPN) is generally considered a variant of diabetic polyneuropathy. The primary purpose of comparison has been to better understand the mechanisms of neuropathic pain for determining risk factors and to help recognize who might benefit from treatment. A recent study in *Current Diabetes Reports* was done to determine whether painless DPN is the same as painful DPN, and why some people develop painless neuropathy while others develop painful neuropathy. To compare the two types, the study included the clinical correlates of PDPN, its distinctive framework

of symptoms, signs, and functional and structural nerve abnormalities, the question of large and small fiber involvement, the peripheral pain mechanisms, the central processing of pain, and new insights into the pathogenesis of pain in peripheral neuropathies and PDPN.

The conclusion of the study was that there was no clear profile of who would develop PDPN. Painful and painless DPN share most risk factors though obesity was more prevalent in the painful form. Neuropathic pain can develop or persist at advanced stages of DPN, and an increasing severity of sensory deficits is associated with an increased risk of developing neuropathic pain. Neurologic biomarkers for the development

of neuropathic pain are still missing.

So the answer to the question is still unanswered. Peripheral nerve damage can take different directions, in a dynamic way that might change throughout the stages of nerve disease. New findings indicate a role in neuropathic pain from genetics, inflammation, and the central processing of pain. Future studies and research will be needed to help identify genetic markers for pain, pain phenotypes, the role of pain transmission, the natural history of PDPN in diabetes to help detect risk markers that can become potential targets for intervention, and make a more accurate diagnosis of neuropathic pain and PDPN.

news Briefs

Parkinson disease (PD) is a multifocal, degenerative neurological disorder. Increasing evidence indicates involvement of the peripheral autonomic nervous system. Research to discover biomarkers for PD could also lead to advances in some types of peripheral neuropathy.

α-Synuclein in Cutaneous Autonomic Nerves

The goal of this study was to develop cutaneous biomarkers for PD. Twenty patients with distal sensory and autonomic neuropathy underwent examinations, autonomic testing, and skin biopsies to measure α-Synuclein density within the epidermis, and nerve fibers that stimulate the sweat glands (sudomotor) and 'move the hair'—gooseflesh (pilomotor). They concluded that α-Synuclein was present at higher levels in the autonomic nerves than in the sensory nerves and that it could prove to be a useful biomarker.

Is α-Synuclein Rising to the Surface as a Diagnostic Biomarker for Parkinson Disease? (Editorial)

The long held hope that a remedy will be discovered to halt the progress of Parkinson disease (PD) will require the identification of early, accurate, and accessible biomarkers. Also in Neurology, editors write that if neuronal pathology leading to PD was shown to involve peripheral nerves and be present in a more safely accessible tissue, the ability to detect diagnostically valid α-Synuclein pathology at the body's surface would be a welcome advance.

Research showed the ratio of α-Synuclein to nerve density, not skin volume, was increased in PD, correlating to decreased autonomic nerve fiber density, impaired autonomic function, and staging of PD. Together these are convincingly pathologic. Larger studies are needed to confirm the findings, and in comparison to other α-synucleinopathies, including pure autonomic failure, and multiple system atrophy.

Source: Neurology

CLINICAL TRIALS

Peripheral Neuropathy Research Registry

The PNRR is actively enrolling PN patients and collecting data that will be used by researchers to:

- Understand the disease
- Improve diagnosis of PN
- Develop new effective treatments
- Disseminate knowledge to researchers and clinicians
- Find a cure for the disorder

The PNRR is focused on chemotherapy-induced, diabetic, idiopathic, and HIV/AIDS neuropathies. To enroll, please contact one of these sites:

Beth Israel, Boston, MA 617-632-0899

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

Johns Hopkins, Baltimore, MD 443-287-0627

Northwestern University, Chicago, IL 312-695-7950

Placebo-controlled Safety and Efficacy Study of Pregabalin in Subjects With Post-traumatic Peripheral Neuropathic Pain

(NCT01701362)

This study is designed to investigate if pregabalin is effective in treating neuropathic (nerve) pain resulting from peripheral nerve trauma due to a traumatic or surgical event.

Sponsor Pfizer

Locations Various

doctor about how these health problems could make it hard to get around or take care of yourself. Help getting dressed in the morning, fixing a meal, or remembering to take medicine may be all you need to stay in your own home.

Is it getting harder to turn a door knob or put on your socks? Devices are available to make daily activities easier. There are organizations that have information on assistive-technology products designed to make it easier for people to do things for themselves. Are you having trouble walking? Perhaps a walker would help. If you need more, think about getting an electric chair or scooter. These are sometimes covered by Medicare. Do you need someone to go with you to the doctor or shopping? Volunteer escort services may be available. If you no longer drive a car, check if there are free or low-cost public transportation and taxis in your area. Maybe a relative, friend, or neighbor would take you along when they go on errands or do yours for you.

In order for you to get the best care possible, and find all of the resources you need to manage your neuropathy and general healthcare, we have put together a list of organizations that can help you. You will find them in our article, **RESOURCES YOU CAN USE!**, below.

Often though, the services that people are looking for are right in their own neighborhood or city. These suggestions may be a place to start:

- The hospital, clinic, or medical center where you see your doctor.
- Most hospitals also have a social work, home care, or discharge planning department. Be sure to ask the hospital about transportation or practical assistance. Talk to a hospital financial counselor in the business office about developing a monthly payment plan if you need help with hospital expenses.
- The public library is an excellent source of information, as are patient libraries at many medical facilities.

- State, local or county government agencies may offer low-cost transportation (sometimes called para-transit) to individuals unable to use public transportation. Most states also have an Area Agency on Aging that offers low-cost services to people over 60.
- The Foundation for Peripheral Neuropathy (www.foundationforpn.org, 877-883-9942, info@tffpn.org)

Our expanded website has information on diagnosis and treatment, neurologists, complementary and integrative medicine, research news, educational opportunities, and living well. Vetted through some of the most renowned experts in PN, our information is reliable and trustworthy. We encourage you to take full advantage of these resources.

No matter what type of help you are looking for, the only way to find resources to fit your needs is to ask the right questions. When you are calling an organization for information, it is important to think about what questions you are going to ask before you call:

- How do I apply for this service?
- Are there eligibility requirements? What are they?
- Do you have any other suggestions or ideas about where I can find help?
- Is there an application process? How long will it take? What information will I need to complete the application process? Will I need anything else to get the service?

The most important thing to remember is that you will rarely receive help unless you ask for it. In fact, asking can be the hardest part of getting help. Don't be afraid or ashamed to ask for assistance. There are people and services that can ease your burdens and help you focus on living well.

You can always count on **The Foundation for Peripheral Neuropathy** to assist you in finding valuable resources. Below is a list of national agencies you may want to contact for additional services.

MEDICATIONS

- **Medicare** (www.Medicare.gov, 800-633-4227; or www.SSA.gov, 800-772-1213): Find doctors, providers, hospitals, plans & medical suppliers.
- **Medicaid** (www.Medicaid.gov, or see CMS): A joint federal and state program that helps with medical costs like nursing home care and personal care services, for some people with limited income and resources.
- **Centers for Medicare & Medicaid Services** (www.CMS.gov, 877-267-2323): Full-service government agency that coordinates Medicare/Medicaid, and provides regulations and guidance, research, statistics and education.
- **Partnership for Prescription Assistance** (www.PPARx.org, 888-477-2669): Helps qualifying patients without prescription drug coverage get the medicines they need.
- **NeedyMeds** (www.NeedyMeds.org, 800-503-6897): Offers up-to-date applications and information so that you can apply directly to drug manufacturers and other organizations that provide assistance.
- **Drug Companies**: Many drug companies offer prescription drug assistance programs for those who have difficulty paying for their medications. These often require a physician's application on behalf of the patient, a prescription, proof of financial need, and a patient consent form. (www.PhRMA.org, 800-762-4636)

DISABILITY/ASSISTIVE DEVICES

- **Social Security Administration** (www.SSA.gov, 800-772-1213): Apply for disability, Medicare or retirement benefits.

- **AbleData** (www.abledata.com, 800-227-0216): Provides objective information about assistive technology products and rehabilitation equipment.

AGING

- **National Institute on Aging** (www.nia.nih.gov/health, 800-222-2225): Disseminates information about aging and advances in research to the public.
- **Administration for Community Living** (www.acl.gov, Eldercare Locator (to find local resources): (800) 677-1116): Provides resources to connect people with disabilities, older adults, caregivers, families, and professionals to important federal, national, and local programs and information.

COMPLEMENTARY & ALTERNATIVE MEDICINE

- **National Institutes of Health—National Center for Complementary and Alternative Medicines** (www.nccam.nih.org, 888-644-6226): Defines, through rigorous scientific investigation, the usefulness and safety of complementary and alternative medicine interventions and their roles in improving health and health care.

CHRONIC PAIN

- **American Chronic Pain Association** (www.theACPA.org, 800-533-3231): Offers peer support and education in pain management skills to people with pain, family and friends, and health care professionals.

VETERANS BENEFITS

- **US Department of Veterans Affairs** (www.VA.gov, 800-827-1000): Provides a wide range of benefits including Disability, Education and Training, and Medical Treatment.

CAREGIVING

- **Caring for your Parent/Elders** (www.pbs.org; type Caregivers in the search bar): Provides a wealth of resources for people caring for aging parents, other relations, or friends; also valuable for those who expect to become caregivers.
- **Family Caregiver Alliance** (www.caregiver.org, 800-445-8106): Addresses the needs of families and friends providing long-term care at home.
- **Meals on Wheels** (www.mowaa.org/, 888-998-6325): Serves meals to homebound seniors, allows them to live independently, in their own homes.

TRANSPORTATION SERVICES

- **Centers for Medicare and Medicaid Services** (www.CMS.gov, 877-267-2323): Full-service government agency that coordinates Medicare/Medicaid, and provides regulations and guidance, research, statistics and education.
- **Program of All-inclusive Care for the Elderly (PACE)** (www.medicare.com; type PACE in the search bar, 800-633-4227): A Medicare and Medicaid program that helps people meet their health care needs in the community instead of going to a nursing home or other care facility.
- **Your local Area Agency on Aging (AAA), Council on Aging (COA), or senior center** will probably be the best source of information about transportation services in the area.

TIPS FROM FACEBOOK JOIN OUR 'VIRTUAL SUPPORT GROUP'

We get a lot of questions from the PN community about Complementary and Alternative Therapies (CAM). We added a new section to our website to answer some of those questions and bring some attention to this sometimes controversial topic. Recently we asked our facebook community what CAM therapies they had tried, and what kind of results they had.

Georgie: Honey—95% of my pain has gone. A spoonful of each: Winter Park Honey's "Local Wildflower" and "Buckwheat Honey with Cinnamon and Turmeric."

Molly: Cannabis tincture applied directly to the skin—it is a miracle worker!!!

Jina: Turmeric (600mgs) and Alpha Lipoic Acid (300mgs) daily. I walk with no pain most days. I have also used tiger balm on my feet.

Mimi: Yin Yoga helps me deal with the pain.

Valerie: Medical massage using cold rocks and cold packs for burning hands and feet, and special cooling creams on feet.

Kim: Acupuncture has worked wonders; totally relieved the pain.

Shelley: Gluten free and nightshade-free diet helps. Walking—I use a rolling walker now; it REALLY helps. Massage and a prescription compounded pain cream and/or lidocaine cream.

Fran: Acupuncture for me was a great, albeit temporary, relief.

Dolores: My best solution is gluten free. Lowering the inflammation naturally has lowered my pain level to a more tolerable level; I am sleeping better at night.

Garrick: I have a TENS unit which only works when I'm using it, once I stop the relief only lasts an hour or so.

Reminder: These results are individual; not everyone will get the same results from each therapy. Please check with your doctor before beginning any new treatment regimen.

STAND TOGETHER

It's always surprising to us that so few people know about peripheral neuropathy or its debilitating symptoms—except the patients, and their loved ones, who often suffer silently and alone, not knowing what to do. What can be done to gain better recognition of this disease, and increase research funds to find more effective treatments, and a cure?

Jack Miller, our founder has given more than \$15 million to fund research and make a difference. A fellow sufferer, he knows what it means to live with PN on a daily basis. But, neuropathy just isn't getting the attention it needs. While other national organizations have become household names, we haven't engaged the community and made the progress that we were hoping for.

Nancy Goodman Brinker founded the Susan G. Komen Breast Cancer Foundation in honor of her sister. As of 2010, Komen has spent over \$1.5 billion for cancer research, with 91% of its donations coming from the public. The Centers for Disease Control and Prevention, reports less than 3.5 million people have ever been diagnosed with breast cancer.

Michael J. Fox founded The Michael J. Fox Foundation for Parkinson's Research. The Foundation has invested more than \$350 million in research to date. An estimated five million people are living with Parkinson's disease today.

John O'Hurley lost his beloved sister, Carol, to epilepsy. He wanted to raise awareness of epilepsy and educate the public so he works with the American Association of

Neurology, the American Brain Foundation, and the American Epilepsy Society. In 2008, \$145 million was spent on epilepsy research. Epilepsy affects approximately less than three million people in the US.

There are many organizations that have similar stories—and similar successes. Someone stood up to help to raise awareness, and impact funding, for little known diseases that became personal to them. During the process, everyone learned more about these diseases and more research dollars—public and federal—have been allocated to finding new treatments, and looking for cures.

Breast cancer, Parkinson's, and epilepsy combined affect fewer people in the US than those that have peripheral neuropathy. Yet they got attention because someone stood

ASK THE EXPERTS...

This month we're focusing on some of the questions that continue to get asked.

Q Does massage therapy help neuropathy in my feet?

A Massage therapy will not cure neuropathy, but may relieve some symptoms such as cramping or certain types of pain. It may also improve circulation during the massage which may well feel good. Overall, massage therapy can be beneficial by alleviating stress and promoting relaxation, both of which may be helpful as part of a comprehensive wellness strategy. (Vicki M. Tysseling-Mattiace, PhD, PT; and Liz McTaggart, R.N., B.A., M.S.N)

Q Is there a definitive test to diagnose peripheral neuropathy?

A Evaluation by a neurologist of any form of peripheral neuropathy is a crucial first step toward ensuring that the most cost-effective and beneficial test is matched to the individual patient's presenting neuropathy. Experts in neuromuscular disorders noted that diagnosis of peripheral neuropathy is complex because it is a diverse disorder with many causes; there is no simple approach to evaluate and diagnose neuropathic pain. More research is needed to define effective and efficient strategies for the diagnostic evaluation of peripheral neuropathy. (Neurology Today, 2012)

Q Are painful peripheral neuropathies common among patients undergoing chemotherapy?

A Peripheral neuropathy is a widespread side effect of treatment with certain chemotherapeutic agents. The pain associated with these neurotoxic effects can be prolonged, severe and relatively resistant to intervention. The overall incidence of chemotherapy-induced peripheral neuropathy [CIPN] and associated neuropathic pain is not clearly delineated, although it is documented frequently with vincristine, taxanes and platinum-based agents. (Judith Paice, Director of the Cancer Pain Program at Robert H. Lurie Comprehensive Cancer Center of Northwestern University, and a Research Professor of Medicine, Northwestern University, Feinberg School of Medicine)

For more information please visit our website: www.foundationforpn.org/research

up and spoke up. They came forward and did something!

Mr. Miller is standing up for PN but he can't do it alone. Just like the other organizations, he needs people who care about making a difference and who will stand with him. We appreciate our loyal supporters and all of our new members, but we need to do more to reach the PN community. Are you willing to lend your talents, your connections and your resources to help support his efforts? You, your family members, and all those with a connection to PN—we can all stand up and be counted!

If you want to be involved, please contact Pam Shlemon, Executive Director: info@tffpn.org or 877-883-9942.

complementary THERAPIES

BIOFEEDBACK AND CHRONIC PAIN When pain kicks in, so does stress and tension. As the pain builds, we unconsciously clench our muscles, respiration and heart rate accelerates, and skin temperature drops. As the pain builds, our bodily tension response only serves to worsen our experience of that pain.

Fortunately, although pain causes unconscious bodily reactions, we can learn to regulate our body and perform relaxation exercises that can counter this tension response and reduce feelings of pain.

Biofeedback may help reduce your stress and cope with pain you may experience from peripheral neuropathy. During a biofeedback session, the therapist applies electrical sensors to different parts of your body to monitor your body's physiological response to your peripheral neuropathy symptoms. This technique helps people recognize how pain causes changes in their body. It teaches people exactly how, when and where to relax. Once people can recognize what pain does, they can learn to control this reaction and reduce the experience of pain.



What Is a Biofeedback Session Like?

A biofeedback session can take place in a variety of health clinics. A session typically lasts for an hour or less, and it is not an uncomfortable experience.

Patients are connected to the measuring instrumentation and see or hear visual or auditory cues that indicate change in whatever is being measured (tension or breathing, for example). Patients then try through learned techniques to control their bodily reaction, and can see how well they control it through the instrument's display response.

Ultimately, after repeated biofeedback sessions, patients learn to recognize these physical changes without the need for instrumentation.

Biofeedback Works Best as an Adjunct Therapy

Studies have shown that biofeedback is most effective when applied as a complementary or adjunct therapy to other forms of pain management.

Does Biofeedback Work? Biofeedback is an accepted complementary pain management therapy that has been clinically studied and proven to work better than placebo.

Some people find biofeedback difficult to master. People who do gain mastery over the technique may not find any appreciable pain relief from it. Others find it quite helpful.

Biofeedback is a low-risk, worthwhile complementary pain management therapy that does not conflict with other forms of pain control. Most practitioners recommend biofeedback therapy as part of a comprehensive biopsychosocial approach to the management of pain.

SUBMITTED BY: HOWARD FELDMAN, PHD, NORTHWESTERN INTEGRATIVE MEDICINE, CHICAGO IL

BOOK CLUB

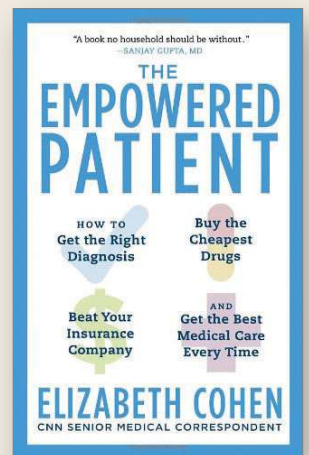
The Empowered Patient

by Elizabeth Cohen

CNN Senior Medical Correspondent, uses real-life stories—including her own—and shrewd advice to provide guidance on how you can become your own advocate and navigate the minefield of today's healthcare system. You will discover how to:

- Find a doctor who "gets" you and listens to you
- Ask the right questions for the best treatment
- Make the most out of a short office visit
- Cut out-of-pocket costs for prescription drugs
- Harness the internet for medical issues
- Fight back when claims are denied

This book provides advice on how to get the right diagnosis, buy the best-priced medications, better understand how to work with your insurance company, and get the best medical care that you can.



Do you have a book recommendation? We want to hear from you! Contact us at info@tffpn.org with your comments and ideas.

NOTE: All books featured in FPN Book Club are read and approved by FPN staff.

LETTERS FROM FANS

ABOUT FPN "Thank God for your organization. I wish you prosperity and that your research is ultimately successful." *AK*

ABOUT THE 2012 FPN SYMPOSIUM "I attended and gave a quick talk last year. It was a very good forum to learn the latest in neuropathic pain." *Tony Ho, AstraZeneca*

ABOUT OUR VIDEOS "I learned more from these two videos than from anything provided by my primary neurologist or anywhere on the Internet. I cannot thank you enough for having such valuable information available." *William C.*

ABOUT THE EXPANDED WEBSITE "Thank you from the bottom of my affected feet! I want to let everyone know there is help on your website." *Jean S.*

MAKE A difference TODAY

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

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

GET INVOLVED

- Follow us on Facebook!
- Share this newsletter!
- Contact us to lend your time and talent!

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

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

As a registered 501 (c) (3) not-for-profit organization, all donations made to the Foundation are tax exempt to the fullest extent permitted by law.

to a support group for neuralgia patients after his surgery. He hoped he could find another one to help him deal with his peripheral neuropathy. His lone granddaughter had been asking him to buy a computer so they could exchange emails, so he bought a computer. But, since she lives only a few blocks away and they see each other often, he used it to look up information about peripheral neuropathy.

He found The Foundation for Peripheral Neuropathy website and learned about our connection to Johns Hopkins. He calls it, “serendipity”. He contacted Pam Shlemon, the Executive Director, who talked extensively with him and put him in touch with our partners at Johns Hopkins. Richard made an appointment and went to see Dr. Ahmet Höke, Director of Neuromuscular Division and a professor at Johns Hopkins School of Medicine.

Saying he was “blown away”, by his experience at Johns Hopkins would be putting it mildly. In a recent email with Ms. Shlemon he wrote, “I can now shower you, Johns Hopkins, and Dr. Höke with my undiluted praise and gratitude. I met with Dr. Höke and was unprepared for the scope of the examination and his encyclopedic knowledge of all the latest studies. It was surely the ‘luck of the Irish’ that I stumbled upon you. I am most grateful for your help and guidance.”

One of the goals of FPN is to provide the resources needed for patients to ‘Live Well with Peripheral Neuropathy’. For Richard, Dr. Höke has started him on a new path—new medications, more knowledge. He says his symptoms are better and he now feels like there is some hope for the future. We are happy to hear that we are making a difference!

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



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WWW.FOUNDATIONFORPN.ORG



the FOUNDATION for PERIPHERAL NEUROPATHY®

485 Half Day Rd., Suite 200
Buffalo Grove, IL 60089

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

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

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Events

NEW FOR 2014...WEBINARS!
FPN will participate in a Webinar January 8, 2014 with Ovarian Cancer National Alliance and National Lymphedema Network to talk about Chemo-induced Peripheral Neuropathy. Watch for details on our website and E-newsletters.

PATIENT SEMINARS:
We will continue partnering with other organizations to offer educational patient seminars—details soon!

2014-FPN INTERNATIONAL RESEARCH SYMPOSIUM
Designing Innovative Therapies for Neuropathic Pain
March 12-14, 2014

—Invitation only for basic and clinical researchers, industry leaders and physicians—

WATCH THE MEETINGS AND CONFERENCES PAGE OF OUR WEBSITE TO GET ALL THE DETAILS. ALSO, WEBINARS AND SEMINARS ARE POSTED ON OUR FACEBOOK PAGE AND IN THE FPN E-NEWS!



SurveyMonkey

In an effort to continue expanding and enhancing our valuable resources, we have created an online survey that we would like for you to complete. It will only take a few minutes of your time but will provide us with important information so we can develop the materials you want for our website and publications.

To access the survey, go online and type this online link into the search bar...you will automatically be directed to the survey:

www.surveymonkey.com/s/YCHFR5D

We are looking forward to hearing from you!

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

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