

FPN News

the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FALL 2012

A MESSAGE FROM THE EXECUTIVE DIRECTOR



“Unless commitment is made, there are only promises and hopes... but no plans.”

~ Peter F. Drucker

The Foundation for Peripheral Neuropathy's humble beginnings stemmed from a personal pledge to fight a devastating diagnosis. In 1995, Jack Miller learned he has Peripheral Neuropathy. Five years ago this fall, Jack took the promise he made to himself and his family a giant step further by publicly committing to fight the debilitating disease. Armed with a generous amount of time, good intention and financial resources, Jack Miller founded The Foundation for Peripheral Neuropathy (FPN), a nonprofit organization committed to dramatically improving the lives of people living with PN.

Since October 2007, The Foundation has had the opportunity to expand and welcome a distinguished group of partner institutions, practitioners, patients and philanthropists. We have hosted an International Research Symposium, launched a groundbreaking patient registry, invited thousands of people to complimentary education seminars, and provided free resources, insight and hope to a PN community that affects millions of Americans.

The Foundation for Peripheral Neuropathy is proud of our considerable progress and a true measure of our success is the continued support of those who have contributed to our growth and development.

If you are part of the contingency that has supported FPN by donating your time and gifts, we sincerely thank you for your contribution. If you have yet to make a donation, please consider doing so this holiday season.

FPN strives to turn a touch that hurts into a hand that heals and we cannot provide this relief alone. Together, we can turn the hope of a better quality of life into a reality for the 1 in 15 Americans suffering with Peripheral Neuropathy.

Wishing you and your family a happy and healthy holiday season.

Pam Shlemon

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Clinical Trials—Necessary for Success

Since the beginning, the Foundation for Peripheral Neuropathy has been, and continues to be, committed to research—*advancing innovative therapeutic developments and accelerating a cure for painful neuropathies*—all with the hope of finding new and more effective treatments for peripheral neuropathy.

Clinical trials are an integral part of the research cycle. Developing new drugs and treatments requires much effort and testing, and depends on patients like you to determine whether the treatment will be safe and effective. Sometimes the treatments are new drugs; sometimes the treatments are a new combination of drugs or new ways to use existing treatments. These trials are focused on looking at ways to improve the lives of people living with chronic illnesses.

People participate in clinical trials for various reasons. Healthy volunteers want to help others and contribute to advancing medical science. Patients also want to help others but might be drawn to the newest treatment or additional care and attention from clinical staff. Clinical trials offer hope for many people and an opportunity to help researchers find better treatments for the future.

So, what is clinical research? Medical research that involves people who agree to participate in carefully conducted studies that might ultimately uncover better ways to prevent, diagnose, treat, and understand human disease. These trials include new treatments and therapies, long-term natural history studies provide valuable information about how disease and health progress. The

(CONTINUED ON PAGE 3)



Clinical trials are an integral part of the research cycle

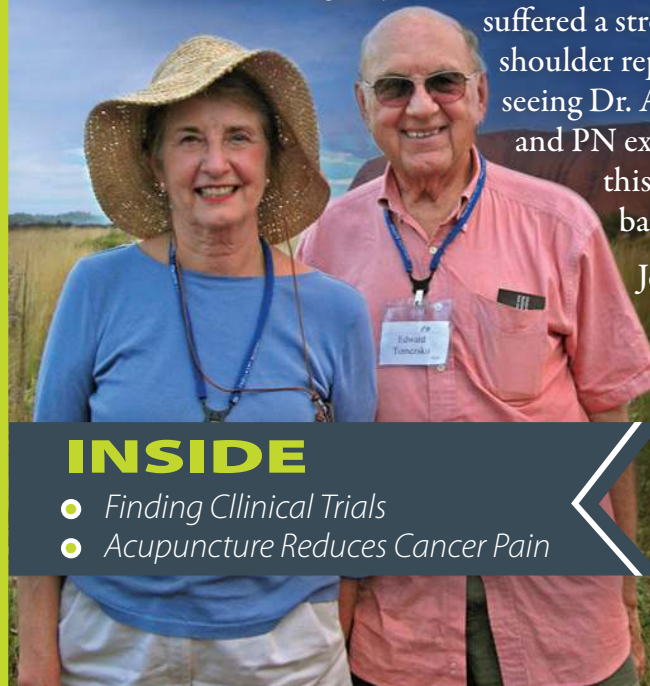
LOOKING FOR A MIRACLE

Ed and Jean Tomezsko share more than most married couples...they both have PN. Ed can trace his back to about 1985 while on a business trip to Colorado. Hiking in the mountains and hopping from rock to rock, Ed noticed an unusual balance issue—wobbling as he crossed a stream on the rocks. Feeling uncomfortable, he continued over the stream. Over the next several years, Ed described the foot sensation to his internist as having to “walk on wet sponges”. The doctor indicated it was probably a slow developing neuropathy and to “keep on exercising” which he does regularly.

Between 1985 and 2002, Ed had multiple joint replacements due to arthritis from an old college injury: both knees, both hips. He recovered fully, but suffered a stroke in 2003. In 2009, he underwent shoulder replacement surgery. In 2010, he began seeing Dr. Ahmet Höke, Professor of Neurology and PN expert at Johns Hopkins University. By this time, Ed's ability to walk and keep balanced was a challenge.

Jean first noticed tingling in her big toe around 1996, after she had been line dancing. Jean has idiopathic PN that has spread through both feet, extending half way up her legs, and in her hands and half way up her arms. Her symptoms are tingling with a feeling of her feet being bound by

(CONTINUED ON PAGE 6)



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RESEARCH

HIV DISEASE AND PERIPHERAL NEUROPATHY

According to the World Health Organization and Centers for Disease Control, human immunodeficiency virus (HIV) has infected approximately 35 million people worldwide, with close to 2.7 million new infections each year. The number one neurological complication that



HIV+ individuals experience is distal symmetrical polyneuropathy —more commonly called peripheral neuropathy (PN). The symptoms of HIV-PN are similar to symptoms often found in people with PN from other causes.

Two of the leading risk factors for developing HIV-PN are aging and taking neurotoxic drugs. Neurotoxic drugs include many that have been used commonly in the past to treat HIV or HIV-related conditions. The most familiar ones are the HIV drugs commonly called the “d-drugs:” ddI

didanosine, Videx®), d4T (stavudine, Zerit®), and ddC (zalcitabine, Hivid®). Additional risk factors for patients of developing HIV-PN can be poor immune function, taking combination antiretroviral treatments, alcoholism, and co-existing illnesses (i.e. diabetes, hepatitis C). Usually, HIV-PN is diagnosed based on signs and symptoms reported to a primary-care provider or neurologist. Tests can be done to determine if there is a problem with the peripheral nerves.

Over forty clinical studies have been conducted to provide a treatment for pain relief in HIV-PN. Unfortunately, no agents have been approved by the Food and Drug Administration (FDA) for treatment. Recently, Qutenza® patch was up for review by the FDA for approval. The possibility that Qutenza® could be approved for HIV-PN showed promise, but due to the lack of inconsistent efficacy in the clinical trials, the FDA review panel did not provide approval. Controlling a patients’ chronic pain can require a combination of drugs and other therapies. Because there are no approved drugs for HIV-PN, all drugs used are considered “off label” treatments. Off label treatments are medicines that have been approved by the FDA for another type of chronic pain condition. One must remember to discuss any medications, supplements, or therapies that are currently being used with your health care provider.

This overview was provided by The Mount Sinai NeuroAIDS program that was developed in response to the expanding needs of patients with HIV-associated neurologic disorders. Its director, Dr. David Simpson, has been involved in the field of NeuroAIDS since its inception, and has been a leading clinical investigator since that time. The research activities of this program have spanned a wide variety of single- and multi-center projects. The NeuroAIDS program has joined the Foundation for Peripheral Neuropathy (FPN) consortium to develop a PN patient registry that includes patients diagnosed with HIV-associated PN.

EXCITING NEW RESEARCH ON THE HORIZON

New therapeutic drugs for neuropathic pain are urgently needed due to the poor effectiveness and burdensome side effects of currently available treatments. In 2006, Dr. Clifford Woolf, MB, BCh, PhD, and his team at Children’s Hospital Boston, discovered a new protein pathway that plays a key and totally unsuspected role in producing neuropathic pain. This finding has provided them a unique opportunity to develop a novel class of drugs acting on a new target that is highly suitable for treating peripheral neuropathy.



Last year FPN funded a pilot project for Dr. Woolf and his team to test their discovery. When he and his team completed the first phase of their new project they had identified, synthesized and validated a new chemical compound that they believe will be very suitable for beginning development of a novel analgesic for the management of neuropathic pain. “The compound is very potent – significantly better than any currently available inhibitors of the pathway and produces no signs of acute toxicity, but does show analgesia in preclinical models” reported Dr. Woolf.

With these positive results, Dr. Woolf has applied to the National Institutes of Health, which sponsors a drug development program - the Blueprint Drug Discovery Program, for funding to assist in turning their discovery into a new medication. The NIH program is designed to take a promising compound lead and optimize it through multiple rounds of chemical changes into a drug with all the properties suitable for use in patients. While review of the grant application is pending, additional funding now would greatly accelerate the project and substantially increase the likelihood of success.

news Briefs

Acupuncture Reduces Cancer Pain— *University of Maryland Study*

Peripheral neuropathy is a common side effect for patients taking bortezomib to treat their multiple myeloma. According to new research conducted at the University of Maryland School of Medicine in Baltimore, acupuncture relieves the pain for these patients. This finding is significant since bortezomib induced pain can be a dose-limiting factor for treatments. In the study, no adverse effects were reported from the acupuncture treatments and patients experienced long-lasting pain relief.

Blocking Neuropathic Pain Before It Starts

Researchers at Boston Children’s Hospital and Massachusetts Institute of Technology have developed a new way to delay neuropathic pain in animal models. Using tiny spheres filled with a powerful anesthetic, a single injection delayed pain by two days; three injections over the course of 12 days delayed the pain by about a month. After injection, the animals showed no pain-related activity for up to 60 days. “We need to see whether it’s safe to block nerve activity for this long. We don’t want to trade one problem for another”, says Daniel Kohane, MD, PhD. The results of this study were published online in Proceedings of the National Academy of Sciences.

CLINICAL TRIALS

A Placebo Controlled, Randomized, Double Blind Trial of Milnacipran for the Treatment of Idiopathic Neuropathy Pain

(NCT01288937)

Columbia University/Forest Laboratories
New York NY

Many clinical trials for neuropathy pain are done in patients with diabetic neuropathy. However, idiopathic neuropathy accounts for 25% of all neuropathies, and over 50% of small fiber neuropathies. The information in this study will provide information on whether milnacipran will provide benefit for neuropathic pain.

Neurofeedback and Pain

(NCT01278225)

MD Anderson Cancer Center Houston TX

The goal of this study is to learn if using a non-invasive therapy, called ‘neurofeedback training’ can help teach patients ways to modify their brain waves to decrease the perception of pain and improve quality of life.

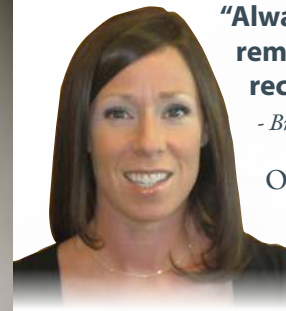
A Study to Evaluate the Efficacy and Safety of a Single Application of QUTENZA Compared to that of Placebo in Reducing Pain Intensity in Subjects with Painful Diabetic Peripheral Neuropathy (PDPN)

(STEP) (NCT01533428)

Astellas Pharma Inc. Multiple states/locations

You can read more about these clinical trials at www.clinicaltrials.gov

DEVELOPMENT CORNER



"Always give without remembering and always receive without forgetting."

- Brian Tracy

Often the holidays are the time of year that we are invited to contribute to the charities that feed, teach, help, and heal our communities.

The Foundation for Peripheral Neuropathy (FPN) recognizes that there are many worthy causes soliciting support and we are humbled by the generosity of those in our PN network.

By now you've likely received a mailing from us, respectfully requesting a year-end gift to benefit our organization. If you have yet to donate to the Foundation, hopefully the progress highlighted bi-annually in the pages of this newsletter will encourage you to do so. If you regularly contribute to FPN, we hope our positive momentum motivates your continued support again this holiday season.

For those of you who have attended one of our free education seminars, perused our publications, been referred to an outstanding healthcare provider, or connected with a fellow patient via a service provided by The Foundation for Peripheral Neuropathy, please consider giving that same gift of hope and opportunity to another. All gifts are tax-deductible and each contribution helps enhance our education, programming and resources.

Thank you.

Best wishes for a happy and healthy holiday season.

Kristen Daniels
Director of Development

PROFILE DONOR SPOTLIGHT

LET'S PULL TOGETHER

When you've been married for 58 years, life hasn't always been easy—even if you marry your best friend. Janet and Jack Phillips married when she was 15 years old and they built their life around family with summer vacations in Wisconsin teaching the kids and grandkids to fish and organizing hayrides at home. They shared a love of music and for years played in a band; Jack played drums, Jan was a vocalist. Life was full.

When Jack developed pain and tingling in his feet, life changed. He was diagnosed with idiopathic PN in 2002. As his disease progressed, his hands started burning and tingling. When he couldn't play the drums anymore, he was devastated. The doctor tried every available medication to help ease Jack's pain. He said Jack had the worst case of PN he had ever seen.

Looking for information on the web, they found the Foundation for Peripheral Neuropathy. It was what they were looking for with information, research, and resources. It helped Jack know that he was not alone—that he wasn't the only one affected. They began donating to FPN with every appeal they received. Jan just knew that, "somewhere out there will be a cure for this horrible disease."

As she remembers, "His whole life was affected. He couldn't walk, his hands were like claws, and the pain was horrendous!" She used to wrap his feet and hands in ice to try and ease the pain. PN took its toll. They weren't able to get out much but every week Jan drove them on weekly picnics using a TV tray in the van as a picnic table. And, one of Jack's favorite things to do was hang out with Jesse, their beloved dog, his own version of animal therapy.

"Jack had a great sense of humor, and together we laughed our way through everything" says Jan. What is her hope? "I would urge everyone to donate. Please send

...together we laughed our way through everything! in whatever you can; let's pull together to find a cure. My husband passed this fall, but I will continue to do what I can. Even if one person can be helped that is one less person who will have to go through what my Jack did."

Our deepest sympathies go out to Jan, along with a special thank you for her long-standing support to FPN. Will you join her?



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 or Twitter!
- 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 Kristen Daniels at 847-883-9961 or at kristen@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.

LETTERS FROM FANS

"Just a note to tell you how thankful (that) someone is finally making a national stab at trying to unravel this disease. Thank you for your vision and efforts." *Anna*

I am extremely impressed with your new educational online videos! For anyone who cannot make your symposia these are a true godsend. *Dave*

I appreciate your PN newsletter and hope that you will continue to send it to me on a regular basis. *Don*

I received all of the information you sent me; it was very informative. *Sydney*

That chart for the effective dosing of the medication was very helpful. *Jack*

primary goal is to get new treatments approved by the U.S. Food and Drug Administration (FDA). Clinical trials are closely monitored by regulatory authorities and the process can take many years. It all begins in the laboratory where researchers test new therapies and treatments. The most promising experimental treatments are moved into clinical trials, which are conducted in four (4) phases, each one having a different purpose:

PHASE I Using a small group of people (20–80), researchers test for safety and identify side effects

PHASE II Using a larger group of people (100–300), the experimental drug or treatment is further evaluated for safety and effectiveness

PHASE III Using an even larger group of people (1,000–3,000), studies continue to determine effectiveness, monitor

side effects, compare it with standard or equivalent treatments, and collect information that will allow the experimental drug or treatment to be used safely

PHASE IV Once a drug is approved by the FDA and made available to the public, researchers continue to track for safety, seeking more information about risks, benefits, and optimal use.

Before entering a clinical trial, you will be required to sign an informed consent which provides you with key facts about the trial. It outlines the details of the study (purpose, duration, required procedures), the risks, and potential benefits. You should weigh the risks carefully before agreeing to participate.

However, the potential benefits of a well-designed and well-executed clinical trial are many. You will play an active role in your healthcare and gain access to new research treatments before they are widely available.

You will receive regular and careful medical attention from a research team that includes doctors and other medical professionals. You will help others by contributing to medical research.

The stakes are high. Clinical trials are necessary but the cost is staggering. In 2007, according to The Center for Information & Study on Clinical Research Participation, the average cost of moving a new drug from the test tube to the market ranged from \$500–\$800 million. While FPN and other organizations provide some funding, major funding is provided by pharmaceutical companies and the National Institutes of Health.

It is critical that patients become involved in their healthcare. Your commitment to the process is needed—from participation in clinical trials to helping FPN provide funding. We need to move the progress forward for everyone who is counting on us!

PNRR—PROMISE FOR THE FUTURE

the PERIPHERAL NEUROPATHY

Research Registry

Johns Hopkins has had a successful year enrolling patients in the PNRR. Andrea Kelley, Research Coordinator, provided FPN with this update:

“Since our site began presenting the PNRR study to our clinic patients, we have received nothing but positive responses. Our patients are excited and eager to participate in a study that researches peripheral neuropathy and hopes to shed light on this condition; over 90% of our patients who were approached about this study are participating. Patients are willing to participate because there is not much being done to further understand this disease which affects so many. We have received many calls from all over the country from patients and families of those with peripheral neuropathy who are looking for more information to get involved with this study. They believe this study is promising and has the ability to help so many. While the participants are aware that this study may not directly help them, they are willing to contribute to this study to help those in the future. They love knowing that they are involved in making a difference that will help researchers develop additional treatments, or possibly even a cure, for this disease.”

To make an appointment to enroll in the registry, please contact your preferred consortium site:

Beth Israel (Boston)—Peggy Rose: 617-632-0899
Johns Hopkins (Baltimore)—Andrea Kelley: 443-287-0627

Mount Sinai (NY)—Mary-Catherine George: 212-241-0784
Northwestern (Chicago)—Sabeeha Mukit: 312-695-7950

Contact FPN for further information
877-883-9942
or
info@tffpn.org

LIVINGwell

INTEGRATIVE MEDICINE FOR PAIN MANAGEMENT

Complementary therapies have moved into the mainstream to help patients deal with pain and treatment side effects, especially for cancer. Dr. Nancy Snyderman, Chief Medical Editor for NBC, was featured recently on *Nightly News with Brian Williams*, to discuss the benefits of these therapies. One therapy Dr. Snyderman particularly recommended is biofeedback. “Being able to image a part of your body, harness thought, and control things like heart rate and blood pressure and minimize pain is astonishing”, she said.

Partners Against Pain recommends complementary therapies be used in conjunction with traditional western medicine—together referred to as integrative medicine—and in coordination with your primary physician and disease specialists. Other complementary therapies that can be useful in managing chronic pain are:

- ▶ **Acupuncture:** family of procedures that involves stimulating anatomical points on the body
- ▶ **Hypnosis:** heightened state of concentration and focused attention; hypnosis helps a person deal with a specific health problem, such as chronic pain, while remaining relaxed and calm

- ▶ **Meditation:** mind-body technique that teaches a person to focus attention to the flow of emotions and thoughts, increasing calmness and physical relaxation to improve physiological balance
- ▶ **Physical Therapy:** treatment of an injury or disease, using therapeutic massage, mobilization and physical movement, education, water therapy, and heat or ice to help improve function

- ▶ **Tai Chi:** derived from martial arts and rooted in self-control, thought to be calming and relaxing, providing both physical and psychological benefits
- ▶ **Medications:** critical component of managing diseases and alleviating painful conditions
- ▶ **Patient responsibility:** be accountable for your own mental and physical health

Finding Clinical Trials

The U.S. National Institutes of Health provides a site where registered clinical trials are listed: ClinicalTrials.gov. You can find information about trials that are *Open* and *Closed*. *Open* trials refer to trials that are either *Recruiting* or *Not yet Recruiting*. *Closed* trials include *Active/Not Recruiting*, *Completed*, *Suspended*, *Terminated* and *Withdrawn* trials. All of the trials are available for viewing.

This site might seem a bit daunting to navigate, but with a little practice, you will learn your way around.

- ▶ From the home page, click on the **Find Studies** tab on the upper navigation bar or on the **Search for Studies** box in the middle of the screen.
- ▶ Type in your search criteria; e.g. disease area AND the city/state or the research site OR just the disease area.

Example: "chemo-induced neuropathy AND Illinois"

- ▶ A list of search results will be displayed. The total number of studies found is shown in the shaded box above the results, along with your search terms. Check the box "include only open studies" to access studies that are recruiting:
 - ☑ **Include only open studies**
- ▶ The first column of the search results list, **Rank**, indicates the order in which the studies are listed. Studies that most closely match your search terms are listed first (1, 2, 3, etc).
- ▶ The **Status** column shows which studies are open, or recruiting new volunteers, and which studies are closed, or not recruiting new volunteers. If you checked the box to include only open studies, the Status column will read **Recruiting/Not yet Recruiting**.
- ▶ The **Status** column will list all of the studies available. Find one you are interested in and, to find out the details of the trial, click on the name:

Example: [Chemotherapy and Pelvic Radiation Therapy With or Without Additional Chemotherapy in Treating Patients with High-Risk Early Stage Cervical Cancer after Radical Hysterectomy](#)

- ▶ Scroll through the page to find out more about the study such as:
 - **ClinicalTrials.gov** identifier (number)
 - **Sponsor**
 - **Date** the trial was registered/begun
 - **History of updates**
 - **Purpose**
 - **Eligibility**
 - **Inclusion and Exclusion Criteria**
 - **Locations and Contacts**

If there are no clinical trials being conducted based on your search criteria, there will be a message indicating **no studies found for:** (the search criteria you entered) in the shaded box.

- ▶ Continue searching using broader/different search terms until you find an appropriate trial.

ASK THE EXPERTS...

Our facebook fans are always anxious to learn more about peripheral neuropathy and what they can do about it. Here, Dr. Ahmet Höke, Professor of Neurology, Johns Hopkins University, answers some of their questions:

Q My feet get very red (sometimes it's embarrassing); is there a connection between my PN and my red feet??

A Yes, the redness in the feet can be related to peripheral neuropathy. We do not know for sure why or how it happens but a certain proportion of patients with PN have symptoms in their feet where they turn red or purplish. We think it may be related to involvement of the small nerve fibers that control blood flow in the feet.

Q How is "foot drop" connected to PN? What can I do about it?

A "Foot drop" occurs due to involvement of the motor nerve fibers that go to a muscle below the knee that allows one to bend their ankle up. At earlier stages when the foot drop is not very severe, wearing lace-up high-top boots or using an assistive device such as Ossur ankle-up brace can help. When it is more severe, an ankle foot orthosis (AFO) is needed; this would require custom fitting by an orthotist.

Q People don't understand when I have bad days. How can I help them understand how painful they are?

A Patients with PN can experience fluctuations in their symptoms throughout the day, sometimes within a week or month. They may have good or bad days, weeks or months. Some factors that bring on these "bad" days are stress (both emotional and physical), disturbed sleep (make sure you get evaluated for sleep apnea), diet, and even weather. Some patients experience an increase in their symptoms during cold winter months; others in hot summer weather.

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

TIPS FROM facebook

When you are struggling with a chronic disease, sometimes it's hard to keep your spirits up. Our facebook community shares some of their favorite ways to make them 'feel better' on those bad days. Many mentioned that they like warm or hot (depending on tolerance), relaxing baths—some with Epsom salts or bubbles.

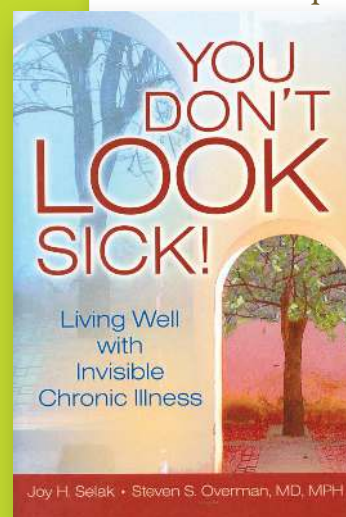
- 👍 **Christine:** Distracting myself by writing poetry to share with others and help pull us all up.
- 👍 **Leslie:** My daughter and I watch 'Seinfeld' and laugh ourselves silly.
- 👍 **Greg:** Nappy time!
- 👍 **Robert:** Sit by the koi pond and try to relax to the sound of the waterfall.
- 👍 **Karen:** Do yoga and read a good book.
- 👍 **LeeAnn:** Baking helps me focus. And, I'm working on quilts again.
- 👍 **Wendy:** One crazy tip....I set a limit on how long to allow myself to feel bad.
- 👍 **Emily:** Soak my hands and feet in cold water... just enjoy not being in pain for that moment.

FPN Book Club

Many PN patients, and others trying to cope with chronic illness, struggle with trying to help their families, friends, and even their healthcare providers, understand what they are going through. Joy Selak, who suffers with several chronic illnesses, had the same struggle and decided to write her story. Her book, *You Don't LOOK Sick: Living Well with Invisible Chronic Illness*, is a very personal account of her experiences. Her doctor and co-author, Dr.

Steven S. Overman, adds his commentary as they explore Joy's journey to accept the reality of chronic illness while passing through the phases she labels Crisis, Stabilization, Resolution and Integration.

Joy writes, "Because I don't look sick, I don't get much acknowledgment for being sick." We hope this month's book club selection will provide some help and hope for those of you who are on this journey with her.



straps. When she was diagnosed, the doctor said she had a slow progression of PN and eventually she would need braces to walk. A year later her symptoms remain stable. Her doctor believes her PN may be the result of a viral infection.

Both Tomezsko's maintain a three-times-a-week exercise regimen. Ed works out to maintain muscle strength and balance. Jean adds an exercise bike so she can avoid pressure and discomfort from a sole treadmill regimen, as recommend by Dr. Höke. Ed relies on his "not giving up" attitude and his hope that a drug trial shows up soon. "I am an optimist by nature. The challenges are walking easily and comfortably—not easy to do, I now use a cane. As Dr. Höke says, I feel with my eyes."

Today, Jean and Ed continue to travel extensively even with the challenges of living with Peripheral Neuropathy. As Jean reflects, "To be honest, I am hardly aware that I have PN because it is so mild.

However, Ed's progressive PN affects his ability to walk and move so profoundly that I am very aware of his struggles and the fear of him falling. So far, that has not taken place because of Ed's awareness of his own limitations and commitment to exercise. Seeing the courage of others with disabilities, seeing the courage of my husband and receiving the help of others helps us cope. I tell our four daughters he is the most courageous person I have ever met."

Ed concludes, "FPN keeps me aware of progress and hopeful for a drug trial. They referred us to Dr. Höke who is encouraging but a cure is not probable. He has clearly explained the situation and now I understand—I will not die because of this disease, but I will die with it. Because of this, we see FPN as worthy of our financial support. Some say that I am looking for a miracle cure, maybe I am. I'll take anything I can get."

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

The Foundation for Peripheral Neuropathy newsletter, **FPN News** is published two times a year, Spring and Fall. For all who subscribe to our FPN newsletter, you will also receive our, **FPN E-news bulletin**. To receive the **FPN E-news bulletin**, please sign up on our website.



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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SEE WHAT'S NEW!
We are redesigning the FPN home page soon. It will be fresher and include more links to important information—we hope you will visit www.foundationforpn.org

Events

PATIENT SEMINARS

November 29, 2012
NEUROPATHIC PAIN AND /GBS-CIDP

Location: TBD, Houston TX

Speakers: David Cornblath, MD, Professor of Neurology, Johns Hopkins and Kazim Sheikh, MD, Professor of Neurology, University of TX Medical School at Houston

March 21, 2013
THE EMOTIONAL TOLL OF PN

Location: Cancer Wellness Center, Northbrook IL

Speaker: TBD

May 11, 2013
CHEMO-INDUCED PN

Location: Robert H. Lurie Comprehensive Cancer Center, Chicago IL

Speaker: TBD

May 18, 2013
TOPIC: TBD

Speaker: Dr. David Simpson, Professor of Neurology, Mount Sinai School of Medicine, New York NY

May 21, 2013
PN—MANAGING THE PAIN

Speaker: Judith Paice, PhD, RN, Director, Cancer Pain Program, Feinberg School of Medicine Wellness House, Hinsdale IL

VISIT THE MEETINGS & CONFERENCES PAGE OF OUR WEBSITE FOR DETAILED INFORMATION.



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FPN | E-News

Are you receiving FPN E-News...our free monthly newsletter? Each month we send information about PN...general information, news articles, tips from Facebook, meetings, and our new book club. There's something different every month. If you are not receiving our FPN E-News please visit our website to register. If you have registered and are not receiving the E-News call us at 847-883-9942. We hope to hear from you soon!

To learn more about peripheral neuropathy and the Foundation visit our website at www.foundationforpn.org.

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DIRECTOR OF DEVELOPMENT
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