

# FPN News

the FOUNDATION for  
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

SUMMER 2013

## A MESSAGE FROM THE EXECUTIVE DIRECTOR



Each year FPN is making progress toward reaching our goals and those of the peripheral neuropathy (PN) community—improving quality of life, advancing new treatments and a finding cure for PN. As a new organization established in late 2007, we didn't have name recognition or a large constituent base, and peripheral

neuropathy was not widely recognized or talked about. However, being a new organization in this field also brought certain advantages. It gave us the opportunity to study what other nonprofits were doing—what was working and not working. With guidance from our Scientific Advisory Board and research partners, we designed a research strategy focused on advancing new therapeutic drugs for neuropathic pain and accelerating a cure for PN.

One of our initial investments—the creation of the Peripheral Neuropathy Research Registry (PNRR) will allow for various types of research, education and outcome improvement initiatives. I am happy to announce we have reached the first milestone toward our preliminary goal of enrolling 1000 patients. FPN's bi-annual International Research Symposia brings together basic and clinical scientists from academia, Pharma, NIH and FDA to address and unlock the roadblocks in developing effective therapies for peripheral neuropathies and neuropathic pain.

The 2012 symposium focused on challenges in developing novel therapies for peripheral neuropathies, see page 3. The 2014 Research Symposium will focus on preclinical drug development and optimizing phase II clinical trials.

Our education and awareness initiatives have given us the opportunity to hear from our PN community about the lack of useful resources available to patients. Understanding this need, the Foundation is taking measures to become the leading source of information for the PN community. Today, we are excited to launch the new **Living Well with Peripheral Neuropathy** section on our website—you will find educational materials, tips, tools and benefits to help patients, caregivers and practitioners alike. These resources plus Premium Membership content will help you take advantage of best practices to live well, and learn how to advocate for your own best medical care. To learn more, please see the article on page 5.

If you are interested in becoming a member, please complete the enclosed registration form on page 5 or visit our website, [www.foundationforpn.org](http://www.foundationforpn.org), for quick and secure online registration.

The Foundation for Peripheral Neuropathy is sustained in large part by philanthropic contributions from those who believe in our mission. Even with a loyal membership base, without donations foundations like ours could not exist, groundbreaking research would not take place, and innovative new treatments might never make it to market. Ongoing progress is a collaborative investment. More than ever, we need the PN community to become part of the solution—every effort and each gift has the ability to make a transformational impact.

Warmest Regards,

Pam Shlemon

## What's the Difference?

Pharmacological interventions, sometimes effective, do not always meet the needs of peripheral neuropathy patients to resolve their symptoms and may produce difficult side effects which affect their quality of life. With the current limitations of today's conventional treatments and drugs, patients often look to other modalities to achieve any measure of symptom management or to minimize side effects. Statistics show that less than 50% of patients experience substantial benefit from existing drugs. And, of that 50%, only 30–40% achieve significant reduction in their pain.

In the past, we identified medicine and medical care with our family practitioners or the specialists they referred us to who would help us manage a more complex medical diagnosis. However, today there are unconventional treatments being practiced in the United States. It can be confusing to decide which ones to pursue that may provide relief and enable patients to achieve independence and enhance their quality of life.

So what are the different types of medicine, and what does each one do?

(CONTINUED ON PAGE 4)

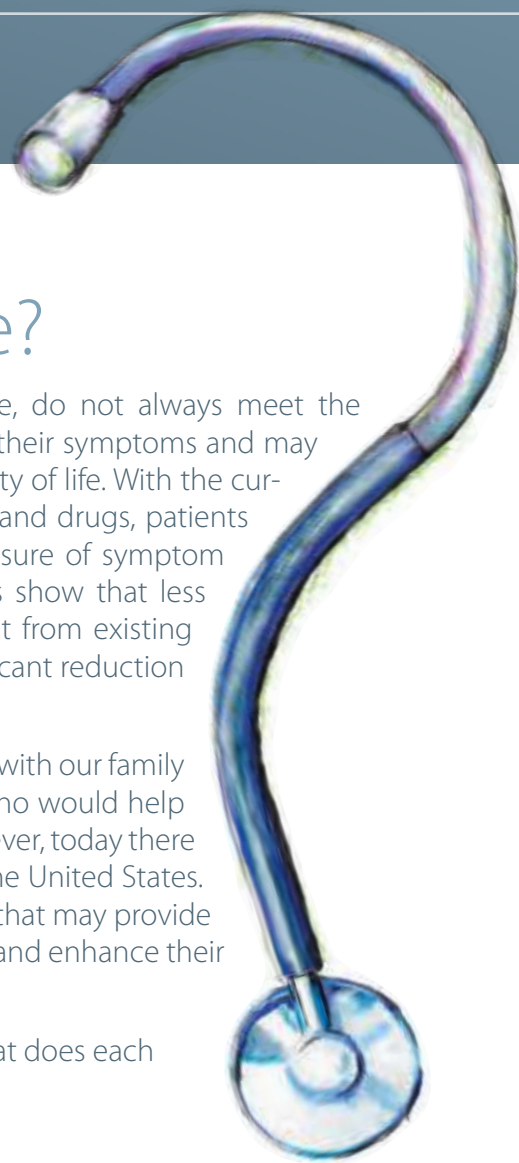
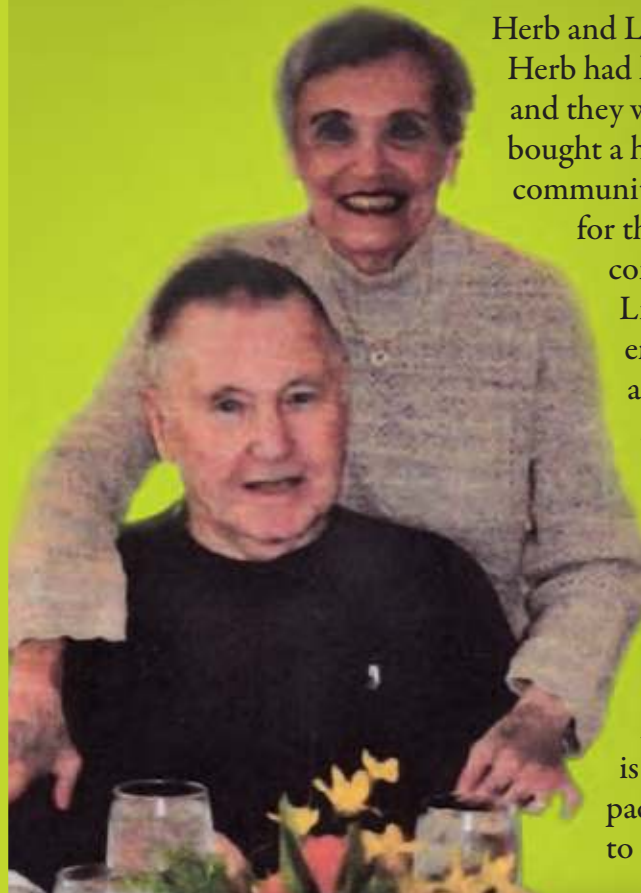


Illustration: Richard Stadler

## STILL GOING STRONG!

Herb Fine is 92 years young. A veteran and retired lawyer, Herb has always had a passion to learn and to live life to the very fullest. He practiced law and worked in the courts of New York City for many years. Even at 81, he attended classes at the Florida Atlantic University Division for Lifelong Learning three times a week. He and his wife of 67 years, Lucy, have raised three children and traveled extensively—all over the world.



Herb and Lucy moved to Maryland in 2005 as Herb had had several operations to his right hip and they wanted to be nearer their family. They bought a home in Leisure World, a Silver Spring community that bills itself as 'The Destination for the Ageless Generation'! Today, Herb continues to take classes at the Center for Lifetime Learning at Leisure World. He enjoys writing and publishes articles and anecdotes in the Leisure World News.

Through the years Herb suffered many health crises—multiple hip surgeries, he has only one functional lung and he has had a stroke. Feeling the symptoms of peripheral neuropathy (PN)—pain in his legs and feet—he was diagnosed with PN in 2004. He learned from his neurologist that there is no cure. He can only walk about 20 paces with his cane before he has to stop to catch his breath and he has constant, severe pain from his PN. The Veterans Administration provided him with an electric wheelchair and you can be sure it never stops! It is

## INSIDE

- New FPN Membership Opportunity
- TaiChi for PN

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# RESEARCH

## PHASE 1/2 OPEN-LABEL DOSE-ESCALATION STUDY OF PLASMID DNA EXPRESSING TWO ISOFORMS OF HEPATOCYTE GROWTH FACTOR IN PATIENTS WITH PAINFUL DIABETIC PERIPHERAL NEUROPATHY

Senda Ajroud-Driss, Mark Christiansen, Jeffrey A Allen, John A. Kessler; Northwestern University

Diabetic peripheral neuropathy (DPN) occurs in approximately 50% of all patients with diabetes and is one of the most common and debilitating complications associated with the disease. Most patients with painful DPN (PDPN) suffer from sleep deprivation, depression, and impaired quality of life due to chronic pain.

In an effort to develop an effective treatment for PDPN, we investigated the therapeutic potential of a novel drug candidate, VM202, a plasmid DNA containing a therapeutic gene, HGF-X7, which produces two forms of hepatocyte growth factor (HGF). Hepatocyte growth factor helps the growth of blood vessel and nerve fibers and may promote nerve regeneration.

Twelve patients met the screening criteria, were enrolled, and treated with VM202. The twelve patients in 3 cohorts (4, 8 and 16 mg) received two sets of HGF injections separated by two weeks. Safety and tolerability were evaluated and the visual analog scale (VAS), the short form McGill questionnaire (SF-MPQ), and the brief pain

inventory for patients with diabetic peripheral neuropathy (BPI –DPN) measured pain level throughout 12 months after treatment.

Hepatocyte growth factor

This Phase I/II clinical trial evaluated the safety, tolerability and preliminary effectiveness of injections with VM202. Intramuscular administration was safe and well-tolerated at doses as high as 16mg. Two injections of VM202 with an interval of 2 weeks reduced the VAS scores for at least 12 months.

As medications for relief of neuropathic pain were added, there may be concerns about the effects of these drugs masking the effectiveness of VM202. There were minor changes in pain medications in 4 of the 12 patients; two subjects reduced their doses by 75% or completely stopped their medication as their pain improved significantly after VM202 treatment. Although their pain levels noticeable reduced at the times of the medication changes, they continued to steadily decrease until the end of the study.

Conclusions about the possible effectiveness of VM202 treatment are limited due to the small sample size. A major rationale behind HGF treatment for PDPN is HGF's potential for modification of the disease process with the possibility of regenerative responses. The present study showed that the two intramuscular injections were safe and effective. This apparent clinical response couple with the known properties of HGF suggests that VM202 may be able to modify the course of the disease.

## NEUROPATHIC PAIN THERAPY: FROM BENCH TO BEDSIDE

Mirsoslav "Misha" Backonja, MD

Neuropathic pain is a result of complex interactions between peripheral and central mechanisms with multiple potential therapeutic targets. However, the complexity of these mechanisms and relative youth of translational pain research, which is in its infancy, have prevented translation of successful basic bench research to human therapy. Translational pain research holds the promise of advancing pain therapy. Most treatment efforts have been focused on acute symptomatic relief. Substantial therapeutic impact will only be achieved when safe and effective neuropathic pain treatments are developed that correct the underlying mechanisms. A major limitation is that the 'translation' has been unidirectional, from the bench to the bedside. Chronic neuropathic pain and its impact of function and quality of life is an inherently human experience. Thus, to develop effective therapies, translation must occur in the opposite direction, from the bedside back to the bench.

Source: *Seminars in Neurology*

## NUTRACEUTICALS AND CHEMOTHERAPY INDUCED PERIPHERAL NEUROPATHY (CIPN): A SYSTEMATIC REVIEW

Schloss JM, Colosimo M, Airey C, Masci PP, Linnane AW, Vitetta L.

The University of Queensland, School of Medicine, Centre for Integrative Clinical and Molecular Medicine, Level 5, TRI, Princess Alexandra Hospital, Woolloongabba, Brisbane, Australia

Chemotherapy induced peripheral neuropathy [CIPN] is a common significant and debilitating side effect resulting from the administration of neurotoxic chemotherapeutic agents. These pharmacotherapeutics can include taxanes, vinca alkaloids and others. Moderate to severe CIPN significantly decreases the quality of life and physical abilities of cancer patients and current pharmacotherapy for CIPN e.g. Amifostine and

antidepressants have had limited efficacy and may themselves induce adverse side effects. To determine the potential use of nutraceuticals i.e. vitamin E, acetyl-L-carnitine, glutamine, glutathione, vitamin B6, omega-3 fatty acids, magnesium, calcium, alpha lipoic acid and n-acetyl cysteine as adjuvants in cancer treatments a systematic literature review was conducted. Revised clinical studies comprised of randomized clinical trials that investigated the anti-CIPN effect of nutraceuticals as the adjuvant intervention in patients administered chemotherapy. Twenty-four studies were assessed on methodological quality and limitations identified. Studies were mixed in their recommendations for nutraceuticals. Currently no agent has shown solid beneficial evidence to be recommended for the treatment or prophylaxis of CIPN. The standard of care for CIPN includes dose reduction and/or discontinuation of chemotherapy treatment. The management of CIPN remains an important challenge and future studies are warranted before recommendations for the use of supplements can be made.

Source: 2013 Elsevier Ltd and European Society for Clinical Nutrition and Metabolism

## WEIGHT-BEARING VS. NON-WEIGHT-BEARING EXERCISE FOR PERSONS WITH DIABETES AND PERIPHERAL NEUROPATHY: A RANDOMIZED CONTROLLED TRIAL

Mueller MJ, Tuttle LJ, LeMaster JW, Strube MJ, McGill JB, Hastings MK, Sinacore DR

Persons with diabetes mellitus (DM) and lower extremity pathology such as peripheral neuropathy (PN) have an almost 3-fold increase in risk of limited mobility compared to those having neither. The most frequently reported mobility limitations are related to an inability to walk a quarter mile and to climb 10 steps without resting. Substantial functional limitations, especially in weight-bearing activities have been found, especially in women with DM and PN.

Considerable research has documented the benefits of moderately intense physical activity, but little research has been conducted investigating the effects of exercise among people with DM and PN. Even though the study was limited to 29 participants and only 12 weeks, data showed that the weight-bearing group (walkers) showed greater gains than the non-weight-bearing group (stationary upright or recumbent cycle) over time. Using a Six Minute Walk Test, people in the weight-bearing group showed greater gains in daily step count and their walking distance compared to the non-weight-bearing group. Additional research is needed to determine whether higher intensity /duration and a combination of weight-bearing and non-weight-bearing exercise would further improve outcomes without jeopardizing safety.

Source: *Archives of Physical Medicine and Rehabilitation*

# news Briefs

## Challenges in developing novel therapies for peripheral neuropathies: a summary of *The Foundation for Peripheral Neuropathy Research Symposium 2012*

The first scientific meeting of The Foundation for Peripheral Neuropathy was successful in bringing together basic and clinical scientists from academia, NIH, FDA, and industry to outline the roadblocks in developing effective therapies for peripheral neuropathies and neuropathic pain. Developing regenerative therapies will require better understanding of the mechanisms of axonal degeneration in multiple disease models. In terms of evaluating the role of animal models in pre-clinical effectiveness studies, it was clear that some of the animal models had shortcomings because of the outcome measures that are used (not relevant for

human condition) and the lack of rigor with which they are conducted (unblinding is a major issue). Clinical trials face a major problem with false negative studies and the field needs more innovative trial designs to combat this issue. Surrogate markers can probably aid in this regard but they need to be validated in multiple studies.

Source: Journal of the Peripheral Nervous System.  
Full article can be found on our website

## Advisory Board Invitation

Dr. David Cornblath, FPN Board member, has been invited by Dr. Giuseppe Lauria, of IRCCS Fondazione Istituto Neurologico "Carlo Besta", Division of Neurology IV Neuro-Immunology and Neuromuscular Diseases, Milan, Italy, to represent the Foundation on their External Advisory Board. He will be consulting on their new project, "Probing the role of sodium channels in painful neuropathies" (PROPANE).

## PARTNER SPOTLIGHT

### THE GREATER GOOD

Commitment and dedication...in today's fast-paced world it can be difficult to find someone who really understands what those words mean. We are constantly bombarded by new messages and images, causes and interests, and our focus can easily get redirected to something new.

Dr. Ahmet Höke, Professor of Neurology and Neuroscience at Johns Hopkins University, knows what it means to be committed to a cause and a goal. From receiving his medical degree from Hacettepe University School of Medicine, in Ankara, Turkey, to completing his Ph.D. in Neuroscience at Case Western Reserve, he has been focused on neuroscience and neuromuscular diseases. His neurology residency was at Johns Hopkins and he completed a neuromuscular fellowship at the University of Calgary.

In addition to his dedication as a neurologist that focuses on diagnosing and treating patients with PN, Dr. Höke is currently the Director of the DB Drachman Division of Neuromuscular Disorders at Johns Hopkins. He leads the research laboratory at Johns Hopkins School of Medicine where they study the basic biology of peripheral axons and Schwann cells, and disorders affecting the peripheral nervous system. He is Editor-in-Chief of *Experimental Neurology*, a journal of Neuroscience Research; editor of the textbook, **Erythropoietin and the Nervous System**; and has published over a hundred scientific articles.

Dr. Höke is committed to his patients, his research, and the Foundation for Peripheral Neuropathy (FPN). His partnership with FPN began in early 2008, and he has been committed to promoting the Foundation and our work ever since. He is actively involved in many aspects of our programs and gives generously of his time and professional expertise.

As a member of the Peripheral Neuropathy Research Registry (PNRR), Dr. Höke's team actively enrolls patients that will ultimately help researchers better understand the cause and origin of PN and further their research for better treatments. He was chair of our 2012 FPN International Research Symposium and is co-chair of the 2014 Symposium. He has presented at several FPN patient seminars and fundraising events.

Often, even though we may feel strongly about a certain cause, we find ourselves sitting back and waiting until we have more 'time'. Dr. Höke is an example of someone who is committed to getting it done and we are grateful for his support!



## 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:** 617-632-0899

**Icahn School of Medicine at Mount Sinai:** 212-241-0784

**Johns Hopkins:** 443-287-0627

**Northwestern University:** 312-695-7950

### The Purpose of this Study is to Determine if Tetrodotoxin (TTX) is Effective in the Treatment of Pain Resulting from Chemotherapy Treatment (TTX-CINP-201)

(NCT01655823)

**Wex Pharmaceuticals, Inc.** Various locations

The proposed study will investigate the efficacy and safety of multiple dose levels of TTX versus placebo in moderate to severe neuropathic pain caused by chemotherapy.

### Alpha-lipoic Acid in Patients at Risk for Paclitaxel Induced Neuropathy (NCT01313117)

**Northwestern University Chicago, IL**

There is some evidence that alpha-lipoic acid (ALA), an antioxidant compound, protects neurons after exposure to paclitaxel. The purpose of this study is to assess the safety and tolerability of ALA and to find the best dose of ALA in patients that receive chemotherapy.

### Effect of Pregabalin Treatment in Patients with Diabetic Nerve Pain Who Currently Use a Non-Steroid Anti-Inflammatory Drug (NSAID) for Another Pain (NCT01455415)

**Pfizer Various locations**

This study is to test the effectiveness of pregabalin in treating nerve pain caused by diabetes. The suitable subjects will be patients who also use a non-steroid anti-inflammatory drug (NSAID) for another pain which is not related to the diabetic nerve pain.

You can read more about these clinical trials at [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

**CONVENTIONAL** The standard form of care in the U.S., often referred to as Western medicine, practitioners hold M.D. (Medical Doctor) or D.O. (Doctor of Osteopathy) degrees. They work together with other licensed health professionals that provide the support services that are critical to patients. These professionals include registered nurses, anesthesiologists, physical and occupational therapists, and many others to provide the best possible care for patients. They determine diagnosis and treatment based on the medical knowledge and experience they have gained through conventional education or practice, using drugs, surgeries, or physical therapies.

**COMPLEMENTARY** While complementary and alternative forms of medicine are often thought of interchangeably, there are differences. Complementary therapies are used together with conventional medicine. This might include a regimen of vitamins, supplements, herbs, and 'natural' substances to be used in conjunction with other medications.

**ALTERNATIVE** Alternative therapies, on the other hand, are used in place of conventional medicine. One example would be if you choose to do yoga instead of a physical therapy regimen. Both complementary and alternative therapies (CAM) are referred to as Eastern medicine as many of the therapies originated in China.

**INTEGRATIVE** A total approach to health care, integrative medicine combines conventional and CAM therapies into a treatment plan where there is some high-quality evidence of safety and effectiveness.

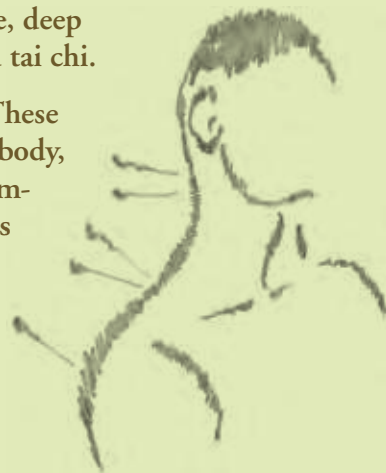
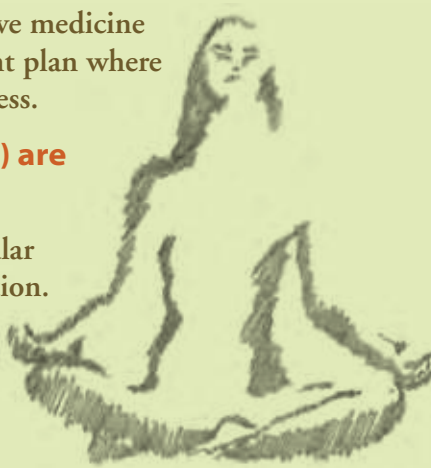
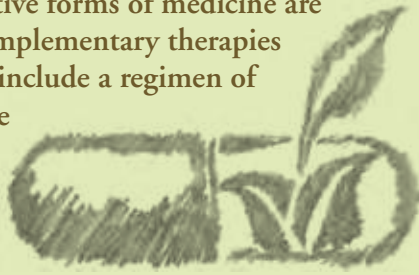
**Complementary and alternative medicines (CAM) are divided into several broad categories:**

**NATURAL PRODUCTS** This category is the most popular form of CAM, used by more than 15% of the U.S. population. These include herbal medicines, vitamins, minerals, and products sold over the counter as dietary supplements.

**MIND AND BODY MEDICINE** Using mind and body practices that focus on the interactions among the brain, mind, body, and behavior, to affect physical functioning and promote health. Examples are: Meditation, yoga, acupuncture, deep breathing exercises, hypnotherapy, progressive relaxation, and tai chi.

**MANIPULATIVE AND BODY-BASED PRACTICES** These practices focus primarily of the structures and systems of the body, including bones and joints, soft tissue, and circulatory and lymphatic systems. Spinal manipulation and massage fall into this category.

**ENERGY MEDICINE** is among the most controversial of the CAM therapies. These therapies involve the manipulation of various energy fields to affect health. The most common practices include those involving electromagnetic fields (magnet and light therapy).



Many of the CAM therapies have not been evaluated in rigorous controlled clinical trials, as has been the standard for pharmacotherapies utilized in Western medicine. In an attempt to address this limitation, the National Center for Complementary and Alternative Medicine, part of the National Institutes of Health, has developed an international presence in the field of complementary and alternative medicine. With a mission to explore and evaluate complementary and alternative therapies, it oversees many research projects in the United States—whether they are safe and whether they work.

As with any medical treatments, there can be risks with CAM therapies. And, while it is important to be aware of the risks, it is also encouraging to hear about the CAM therapies used by many PN sufferers. Just like conventional therapies, there is not one treatment that worked for everyone. Sometimes they had to try several different therapies, but some of them did find relief. It can be a matter of a little, short-lived relief, but when you live with the daily pain and symptoms of PN, it can be a welcome respite. The real goal is to find a treatment that is safe and will not do you any harm.

Complementary and alternative therapies should not replace your conventional care. The best approach is to integrate these therapies with your current treatments. If you are interested in adding CAM therapies to your medical program, please go to our website and find out more about how complementary therapies might be of benefit for you.

# LIVINGwell

## HOW TO TALK WITH YOUR DOCTOR ABOUT PAIN

Each person experiences pain differently, so chronic pain can be a hard medical condition to address. But, it is important for you to communicate effectively with your healthcare professional to develop a treatment plan that's right for YOU.

► **Pain Journal** 67% of healthcare professionals want to see a pain journal. You are the only one who can tell what you are experiencing. Most pain is rated on a scale of 1 – 10 with 1 being No Pain and 10 being Worst Pain. Knowing how to categorize your distress is also important: None, Annoying, Uncomfortable, Dreadful, Horrible, and Agonizing. Be sure to take your pain journal to your appointments.

► **Expectations** 71% want their patients to tell them what they expect from treatment. Do you expect to totally resolve the pain? Reduce it by 50%? What medications do you currently take for the pain? What relief, if any, do you experience? How long does it take to feel relief? What other symptoms do you need to discuss? Do you need to be referred to a pain specialist?

► **Daily Living** 68% want to know how pain affects day-to-day activities. What tasks are you no longer able to perform? Which of your daily activities are you most interested in resuming? Are you feeling isolated?

Healthcare professionals wish patients would share more information with them. Make sure you are fully prepared for your medical appointments.

SOURCE: PARTNERSAGAINSTPAIN.COM



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**TAKE CHARGE OF YOUR HEALTH!**

The concept of **living well!** reflects the best achievable state of health—physical, mental and social—for those with peripheral neuropathy and also for family, friends and caregivers.

The resources found on our new web pages will make you better informed, more hopeful and empowered to take on the daily challenges of living with PN.

Show your support for FPN by becoming a member today. It's easy! Sign-up for FREE online or complete the registration below. Get even **more** content as a **Premium Member** for only \$30 a year—**that's only \$2.50/month!**—and receive continued delivery of our newsletter **FPN | News**.

To access all the great "Living Well" resources, register FOR FREE! or purchase a Premium Membership



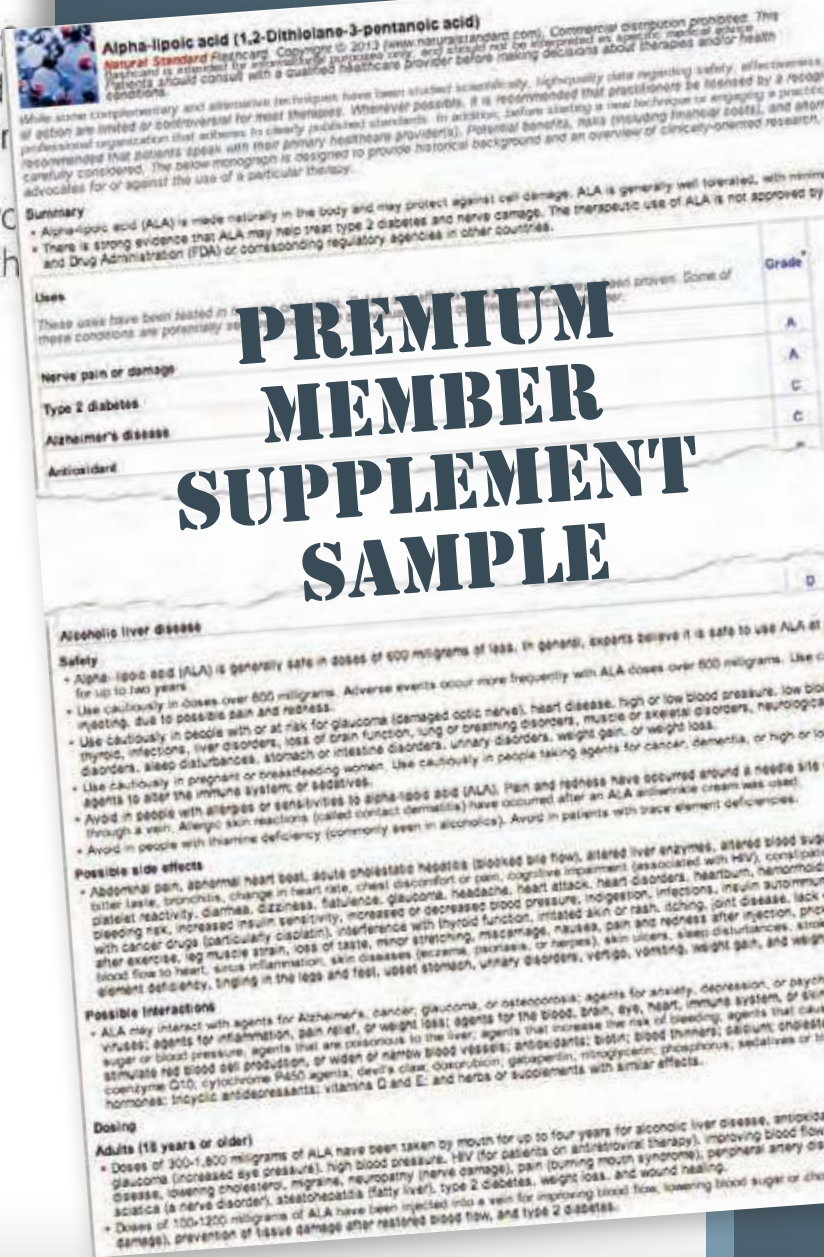
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## TIPS FROM facebook

**I WISH...** Sometimes we come away from a doctor's appointment wishing we had known which questions we should have asked. We have to make another appointment, try and get help over the phone, or resort to the internet to see what we can find out. We asked our facebook community for questions about PN that they wished they had known to ask their doctor on their first appointment. Here's what they had to say...

-  **Tim:** Are you familiar with my condition? If he said 'no', I could have saved us both a lot of time.
-  **Kathy:** If you can't figure this out, can you please send me to a neuropathy expert? I wasted a lot of time with doctors who didn't know what to do.
-  **Ruth:** What determines if you have Neuropathy and how do you know which one I have?
-  **Ellen:** Think long and hard about how to describe your pain. I came away from office visits feeling that my doctors just didn't understand my pain.
-  **Debbie:** I began developing symptoms in my late teens, what could I have done at that young age to start nerve damage?
-  **Maria:** Is it normal to have neuropathy 15 years after having chemotherapy?
-  **Shelley:** Will a gluten free diet help? She much later discovered that a gluten free diet helps her symptoms.

## FPN Book Club

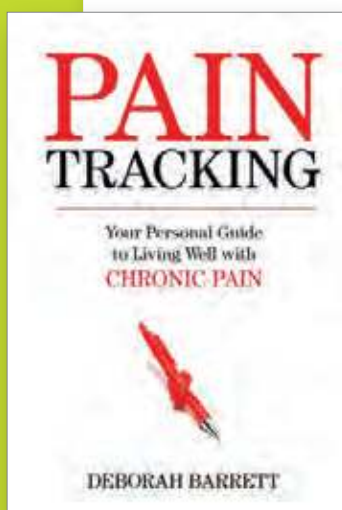
### *Pain Tracking: Your Personal Guide to Living Well with Chronic Pain*

People with chronic pain face a confounding set of decisions, which are made even more difficult when pain fuels desperation and answers are not forthcoming. Our new book club selection will help you assess data specific to your experience. Then, as you understand what does and does not actually work, you can improve how you manage your pain.

**Pain Tracking**, by Deborah Barrett, PhD, MSW, will be an invaluable tool for:

- People living with pain
- People who care about someone living with pain
- Healthcare providers

It is a learning process that will lead to discoveries that are relevant to anyone struggling with chronic pain. It may be difficult to believe that studying your pain experience can transform your life, but this is the best method to learn what works.



We hope you embrace the process of pain tracking that helps you monitor your experiences and make a plan that will help you live well!

# TAI CHI

## FOR PERIPHERAL NEUROPATHY

David-Dorian Ross, American TaiChi champion

Researchers have determined that an ancient Chinese health practice called Tai Chi (Taiji) may provide benefits to people who suffer from PN.

### How Tai Chi Can Help

A 2010 study published in the American Journal of Chinese Medicine from the Department of Kinesiology, Louisiana State University, showed that Taiji practice actually increases the nerves' ability and speed of sending signals back to the brain and spinal cord. After only a few weeks of Taiji practice, patients with PN can improve physical function and it is a safe and effective intervention.

Taiji can significantly improve balance, reducing both the likelihood and the fear of falling. Since the mid-1990's the Surgeon General has recommended that people over the age of 65 practice Taiji to improve balance and stability. One reason Tai Chi is so effective is that it teaches you to re-integrate the muscle control of legs, hips and low back. As we get older, or succumb to the side effects of diseases like diabetes, we start to lose muscle strength and function in certain areas of our bodies. Often this is a function of lifestyle—you know the old saying, "Use it or lose it."

People with Peripheral Neuropathy tend to be less active because of the pain and uncertainty that comes with movement. And the less active they are, the more that whole body synergy is lost. It's a vicious cycle. But Taiji can re-awaken the connections between muscles in the body, and between the muscles and the mind. Studies on Taiji and PN show that the more someone with Peripheral Neuropathy learns to use their whole body for both exercise and simple daily tasks—even walking!—the less pain they experience, and the more comfort they have in their bodies overall.

### Recommendations

As with any new exercise program, I recommend starting small and easy, but the good news is that Taiji is as easy as walking and may be less demanding! I am looking forward to providing some simple steps to making Taiji a part of your daily life and reducing the pain levels for those suffering from this disease.

*Learn more about Tai Chi and David-Dorian Ross in the Living Well with Peripheral Neuropathy section of our website.*

## 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 your questions.

### Q Can nerve damage cause itchiness?

A Yes, but this is an uncommon complication of nerve damage. Within a nerve there are nerve cells that normally carry the itch sensation and when the nerve is injured those nerve cells can send impulses to the brain when they are not supposed to; patients then can experience what appears to be an itching sensation in the area where the nerve used to innervate the skin.

### Q Can you have a normal nerve study & still experience loss of feeling attributed to neuropathy?

A Yes, especially if the neuropathy affects selectively only the small sensory nerve fibers that go to the skin. These small nerve fibers lack insulation (i.e. myelin) around them and they are difficult to study with regular nerve conduction studies. In general nerve conduction studies evaluate the integrity of large myelinated (i.e. insulated) nerve fibers such as motor nerves that go to muscles or proprioceptive sensory nerves that go to joints and muscles and are responsible for perception of balance. Small nerve fibers cannot be evaluated with routine nerve conduction studies so a patient with neuropathy that affects only the small nerve fibers may have a completely normal nerve conduction study. In order to evaluate the small unmyelinated nerve fibers, one has to do a skin biopsy and stain the skin samples for nerve fibers and evaluate them pathologically.

### Q Is there a connection between stress and nerve pain?

A Many patients with neuropathy complain that their nerve pain increases during times of stress. This can be both emotional and physical stress; and the emotional stress does not have to be due to negative events but can even be brought upon by positive changes in someone's life. The molecular mechanism of this is unknown but stress has many effects on different organs of the body and it likely increases irritability in nerve fibers that are partially damaged due to neuropathy.

For more information please visit our website: [www.foundationforpn.org/research](http://www.foundationforpn.org/research)

(CONTINUED FROM PAGE 1)

what he calls, "An essential element of my ability to function."

With Herb's positive attitude, he has not allowed the obstacles of PN to take over his life. He continued being active and, after finding other people at Leisure World also suffering with PN, in 2008 he decided to form a support group. Leisure World provided a meeting site...the rest is history.

They started with 8 people in the group; there are now 177 registered members of the support group. They meet once a month inviting healthcare professional speakers, including physicians and nurses, to come and provide educational information and resources to the group in a positive environment. Our Executive Director, Pam Shlemon, was the speaker at a recent support group meeting on 'Nutrition and Exercise.'

Herb uses several drugs rotated through the day and night—trying to alleviate the pain—all to no avail. He uses foot creams and ointments when the redness,

swelling, and pain in his feet become really severe. The creams help, but he still awakens every 2-3 hours each night.

In spite of his health issues, Herb is committed to one hour of exercise each day. He has installed side bars on the toilet to help him maneuver, and uses them to do pushups. His active exercise routine is 80 pushups, 80 leg kicks (to the side and the rear), and 200 heel or calf raises (raises on his toes)—three times a day. For each set he adds some sitting and floor exercises—leg raises, then lying on his side and pointing his foot up and down. He said he recently sprained his shoulder but he is working through it! He and Lucy still drive but they have to stay local and he is feeling the need to discontinue some of the activities they have always enjoyed.

Herb recently celebrated his 92nd birthday with champagne and cake. As Herb says, "We've had great fun; it has been a wonderful life." What an inspiration!

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

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the FOUNDATION for PERIPHERAL NEUROPATHY®

485 Half Day Rd., Suite 200  
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*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

**PATIENT SEMINARS**  
**OCTOBER 17, 2013**  
**THE EMOTIONAL TOLL OF PN**  
Cancer Wellness Center  
Northbrook IL  
*Speaker: Julian Breslow, LSW*

**OCTOBER 29, 2013**  
**MANAGING PAIN AND NEUROPATHY**  
Wellness Place  
Palatine IL  
*Speaker: Judith Paice, PhD, RN, Director, Cancer Pain Program, Feinberg School of Medicine*

*Patient seminars are generously supported by an educational grant from Baxter Healthcare Corporation*

**PLEASE VISIT THE MEETINGS & CONFERENCES PAGE OF OUR WEBSITE FOR CURRENT DETAILED INFORMATION. WATCH OUR WEBSITE FOR NOTICES ABOUT FUTURE WEBINARS!**

To learn more about peripheral neuropathy and the Foundation visit our website

[www.foundationforpn.org](http://www.foundationforpn.org)

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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