

# FPN News

the FOUNDATION for  
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FALL 2009

## A MESSAGE FROM THE EXECUTIVE DIRECTOR



## Dedicated to Reversing the Irreversible.

Welcome to our inaugural issue of FPN News. Our message will focus on the founding principles of our mission; improving the lives of people living with peripheral neuropathy and funding research dedicated to reversing the irreversible. During the last year we have been shaping our foundation to be the catalyst for:

- advancing the pace of collaborative and innovative scientific discovery
- accelerating a cure for painful neuropathies
- raising awareness of peripheral neuropathy

We are excited about what lies ahead. Throughout 2009-2010, we look forward to launching a host of new programs, including the FPN-Data Repository and expanding our FPN-Research Grants. There will also be new programs to promote awareness and stimulate living well with PN; FPN-E-news alerts, seminars and workshops. All of us at FPN are committed to bring about change to this "hidden" disease that affects 1 out of every 15 Americans or 20 million people nationwide. With staggering numbers such as these, it is just not about simply raising and spending more money. It is being strategic in our efforts to make a greater impact.

Our mission can only be sustained through the generosity of people who share our vision to advance research and provide an improved quality of life for those living with PN. With your contribution, you become an important part of our success and a special part of our family. We hope that you will share in our commitment to dramatically improve the lives of those living with peripheral neuropathy. If every person afflicted by PN donated **only** \$1 we could raise an estimated \$20 million towards research and be one step closer to a cure!

Together, we **will** conquer this disease.

Warm Regards,

Pam Shlemon

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## Coping with the Pain of Neuropathy.

One of the most difficult side effects of neuropathy is chronic pain. Often described as intense, burning, tingling, shooting, or feeling like electric shocks, it can be constant or it can come and go. People have numbness, prickling sensations, sensitivity to touch, or muscle weakness. Something as simple as a light touch, cold, or even taking a shower can result in severe pain.

Neuropathic pain can significantly impact a person's daily functioning and quality of life. Many people experience loss of physical activity, difficulty sleeping, lack of energy, drowsiness or difficulty concentrating, a sense of uncertainty about the future, and feelings of helplessness. Learning to manage the pain is important to your health and well being.

**Treatment** Most treatments today are centered on pain reduction and improvement in function. Effective treatment for injured nerves (neuropathic pain) often requires a combination of medicines,

### Learning pain management is important to your well-being

exercise, and other therapies. It can take some time to find the combination that is right for you.

A mild neuropathy may respond to a simple over-the-counter drug, like aspirin. Or, your doctor may prescribe one or more medicines for you. "More commonly used medicines include neuropathic pain agents, most often, anti-seizure medicines or certain anti-depressants," says A. Gordon Smith, M.D., associate professor of neurology and pathology at the University Of Utah School Of Medicine. Some people find success with a lidocaine patch, or creams containing capsaicin, a natural substance that releases heat. Most medicines used for neuropathic pain help "calm down" the nervous system and reduce the pain.

Supportive treatments include occupational or physical therapy to increase muscle strength, mobility and function. External support, an orthopedic insert or specially designed shoe, can even out an improper gait; a hand or foot brace can relieve nerve compression.

**Trying Something Different** More patients, and some doctors, are exploring less traditional pain fighters such as holistic therapies. Others incorporate holistic therapies with traditional medicine.

"Some supplements are being studied," Smith says, but Elizabeth McTaggart, RN, MSN, nurse clinician at the PN clinic at Northwestern University's Feinberg School of Medicine, cautions, "Even if it seems to come from a reliable source, talk to your physician about supplement usage."

(CONTINUED ON PAGE 2)



## Olympic Gold Medalist & Foundation Supporter.

The year was 1936 and the Olympics were taking place in Berlin. A 17-year-old swimmer, Adolph Kiefer, wasn't interested in the gathering war clouds; he was in Berlin to swim. And swim he did.

**Setting Records at 17** Young Adolph set an amazing record: the 100-yard backstroke in under one minute! That record—and the Kiefer name—probably would have gained greater recognition if Jesse Owens, a master in another field, hadn't held the media's attention.

Kiefer dominated international races in the backstroke as well as the individual medley. In a career that spanned more than 2000 races, he lost only twice. Kiefer's backstroke records lasted an astonishing 15 years.

**Beyond Swimming** A little known fact is that Kiefer was asked to audition for the original movie role of Tarzan, but answered the call of arms instead. During World War II he

(CONTINUED ON PAGE 4)



The year was 1936 and 17 year old Adolph Kiefer made Olympic history. Today he continues in the same spirit, fighting to find a cure for PN.

## INSIDE

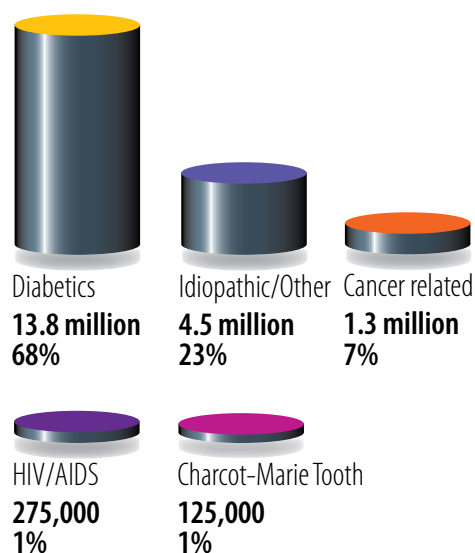
- One Son's Story
- Ask the Expert

**Tips for Managing Chronic Pain** Pain can alter your life and relationships. But, it doesn't have to. Learn how to manage the day-to-day stress that can make the pain feel worse by adopting a healthy lifestyle.

- **Proper Nutrition**—Eat a balanced diet to feel and function better. Drink plenty of water. Reduce sugar, salt, and fat.
- **Stop smoking**—By constricting blood vessels, your symptoms may worsen.
- **Reduce/avoid alcohol**—Alcohol can induce, and aggravate, neuropathic pain.
- **Sleep**—Plan to get at least 6 hours each night. The body restores many of the hormones it needs to function.
- **Exercise**—It can reduce cramps and improve muscle strength. Make sure to find an option that works with your abilities. "Consider an indoor pool; water exercises are often less painful," McTaggart suggests.
- **Relaxation techniques**—Consider meditation, yoga, tai chi, biofeedback, and deep breathing techniques. "It's hard to think of anything that stress helps, so stress management can be helpful," Smith says.
- **Journal your pain**—Keep a daily journal to see what triggers or alleviates your pain.

Acknowledge how your pain affects you. You may feel overcome by sadness and anger or anxious about how pain has upset your life. Share your feelings and frustrations with family, friends and your health care team. Accept their support and find new ways to cope. *Regain control of your life!*

## PN FACTS



**20 million Americans suffer from all forms of PN; 1 out of every 15 people you know!**

- There are 100 identified types of PN. There are no cures and it is difficult to treat and often unresponsive to available therapies
- The cause of Idiopathic PN is unknown
- 33% of all HIV/AIDS patients have PN
- 10%-20% of all cancer patients have PN
- 60% of all diabetics have PN
- Diabetes, cancer and HIV alone are expected to increase the prevalence of PN by more than 10% by 2012

## COSTS

- Diabetes is the #1 cause of PN, costing the US economy—\$13 billion annually
- Federal funding for PN research is less than \$3.00 for every American with this disorder

## PAGE 2 WORLD-WIDE

- Leprosy is the #1 cause of PN
- PN as a complication of Guillen-Barre syndrome accounts for 1.7 cases/100,000 people annually

Source: World Health Organization, National Institutes of Health

# RESEARCH FOUNDATION RESEARCH

**JOHNS HOPKINS UNIVERSITY** In peripheral neuropathy the axon (nerve tail) degenerates. What if you could stop that degeneration, even reverse it? And what if you could do so by redirecting the use of drugs already being used for something else? Those are just two of the questions a team at the Johns Hopkins University Peripheral Nerve Program is seeking to answer using the \$1 million multi-year grant from FPN.



"Our overall objectives are to enhance translational research and bring new treatments to patients with PN," says Ahmet Hoke, M.D., Ph.D, director of the Neuromuscular Division, who's heading this team. "In Year 1 we screened a large library of compounds and found 2,000 drugs that might be revitalized for fighting PN. From these we've isolated four that seem to hold promise," he adds. The next step will examine the axon regenerative potential of these compounds in animal modes of PN regeneration.

Hoke and his team are also hoping to find ways to use robotics to screen hundreds, even millions of compounds, increasing the speed of the process. "It takes about 10 years to bring a totally new drug to market," Hoke says, "but if we can succeed in 'repurposing' an old drug, we might substantially cut the time PN patients wait for relief."

### NORTHWESTERN MEDICAL FACULTY FOUNDATION (NMFF)

"For many PN patients, the endless round robin from one doctor or service to another can be both expensive and frustrating. Many drop out of the system because they can't keep coming and going from one doctor to another," says Dr. Jack Kessler, Chairman of the Neurology Department at NMFF.

That's why last year the department of Neurology at NMFF received a \$1 million multi-year grant from FPN for a model clinic providing multi-disciplinary care for PN patients. "It's sort of a one-stop shopping approach to their care. Among the staffers we have three neurologists, a pain specialist, a nurse, and a physical therapist. The latter is critically important; too often therapy designed to reduce pain and/or keep people active is often delayed or even overlooked," Kessler says. Having experts and testing options under one roof speeds diagnosis and treatment and means people are more likely to maintain therapy.

"As the patient base evolves our physicians will increasingly focus on developing in-house clinical trials or acquiring industry ones. The long-term goal will be to develop a translational research program that spans the spectrum from federally funded research grants to patient care protocols."

### FPN-SHARED PERIPHERAL NEUROPATHY DATA REPOSITORY (FPNDR)

To further promote a collaborative research environment, we have initiated the development of the FPNDR. This project is a centerpiece of the Foundations effort to facilitate basic and clinical research studies that will yield an understanding of the etiology and pathogenesis of painful peripheral neuropathies. This initiative will lead to the development of new evidence-based diagnostic and treatment methodologies, cures and/or prevention.

FPN envisions the data repository as a mechanism to facilitate and encourage active collaborations that will lead to sharing and education. A national and international adoption of the FPNDR will allow for investigators to virtually pool their data, share common resources and conduct multi-institutional research studies through the FPNDR collaborative environment.

## news Briefs

**Less sweat, more neuropathy** A novel technique to measure the density of autonomic nerve fibers that innervate sweat glands could help determine the extent and progression of peripheral neuropathy. "We could already quantify small sensory fibers using intra-epidermal nerve fiber density (IENFD) analysis of skin biopsies but, until now, had no means to quantify autonomic nerve fibers...." explains Roy Freeman, MD (Center for Autonomic and Peripheral Nerve Disorders, Beth Israel Deaconess Medical Center, Boston, MA). Source: Nature News/Neurology

**Neuropathic Pain: The Sea Provides a New Hope of Relief** A compound initially isolated from a soft coral (*Capnella imbricata*) collected at Green Island off Taiwan, could lead scientists to develop a new set of treatments for neuropathic

pain—chronic pain that sometimes follows damage to the nervous system. New, effective and safe painkillers are urgently needed for patients with neuropathic pain," says Dr Zhi-Hong Wen, who played a key role in a research study searching for novel compounds that have potential for use in pain relief. Capnellene, was originally isolated in 1974, but it is only recently that scientists have started to appreciate its potential. Capnellene is interesting because its structure is very different from pain-relieving drugs currently in use. Initial experiments suggested that it may have pain-relieving properties. They found that the compounds significantly reduced pain-related activities in isolated microglia, and that these compounds also significantly reversed hyperalgesic behavior in the experimental rats. Source: Science Daily

To learn more about these articles visit our website at [www.foundationforpn.org](http://www.foundationforpn.org)

## CLINICAL TRAILS

A clinical trial is a medical research study of human volunteers to answer specific questions about new drugs or new treatments and is used to determine whether they are both safe and effective. All clinical trials have guidelines about who can participate. The inclusion and exclusion criteria are an important principle of medical research that helps to produce reliable results.

Why participate in a clinical trial?

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available and help others by contributing to medical research.

Overall, the clinical trial phase for new drugs or treatments can take many years, and might still result in rejection by the FDA if the data isn't conclusive enough

or drug safety can't be satisfactorily demonstrated.

Listed below are a few clinical trials currently recruiting participants. To learn more visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov), search for clinical trials and enter the name of the trial. You can also search for all clinical trials related to peripheral neuropathy by entering "peripheral neuropathy."

Randomized Placebo-Controlled Trial of Glutamine for Breast Cancer patients with Peripheral Neuropathy

Hematopoietic Stem Cell Support in Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Effect of Weight-Bearing Exercise on People with Diabetes and Neuropathic Feet

Acupuncture for Chemo-Induced Peripheral Neuropathy

## PROFILE DONOR SPOTLIGHT

### One Son's Story

Eric Enright and his dad shared a special bond. Theron 'Tom' Enright had spent his life in service to his community as a fire fighter but when Eric was born his dad embraced fatherhood—they were inseparable.

Tom also enjoyed golfing with his buddies. Then, he began losing his grip on his golf clubs. At first, it seemed humorous—sometimes a club would land in the water. Eventually it became evident that there was something wrong.

In February, 1997, medical tests revealed that Tom Enright had Peripheral Neuropathy (PN). With no underlying cause, his diagnosis was idiopathic peripheral neuropathy. Tom's condition worsened and eventually he began using a walker, but he still made sure he was actively involved in Eric's life.

Tom had bypass surgeries in 1998 and 2001; he began dialysis in February 2009. But, what Eric remembers is his father's struggle with his PN. "My father wasn't concerned with his shortness of breath, or with the inconvenience of the day to day struggles surrounding kidney dialysis. Instead, he kept talking about the way his legs continually twitched and his toes frequently ached. It wasn't chest pains that bothered him as much as we once thought, yet it was the effects of PN that kept him awake and uncomfortable." Eric thought about how unfair it was that his father had to suffer most with the disease that probably played the least role in taking his life.

Sadly, on April 9, 2009, at age 86, Tom Enright passed away—apparently from a stroke. While making funeral arrangements, Eric and his mom, Michele, decided to honor Tom by finding a way to do something about the most debilitating, painful issue that affected Tom's life everyday. Eric and a friend searched the internet looking for organizations that could help others with PN and a memorial campaign was launched to support our research—Supporting the Cause.

We recognize and appreciate Eric's dedication to his dad and his efforts in letting others know of the work we are doing to help PN sufferers. We extend our thanks to many of Tom's friends and relatives who have contributed to the memorial. Eric plans to continue helping our Foundation raise funds—Tom Enright's legacy lives on!



MAKING A **difference** TOMORROW

### Why Do People Give to Charity?

There are probably a million reasons why people give to charity. According to *The Network for Good* here are some of the top reasons:

- ✓ Someone I know asked me to give and I wanted to help them
- ✓ Tax deduction
- ✓ Want to feel as if one is changing someone's life
- ✓ Feel a sense of closeness to a community group
- ✓ Memorialize someone
- ✓ Raised to give to charity – tradition
- ✓ Good image for myself/company
- ✓ Building a legacy that perpetuates me, my ideals or my cause
- ✓ Feeling fortunate and want to give back to others
- ✓ Religious reasons
- ✓ Want to be seen as a leader
- ✓ Emotionally moved by someone's story

*Giving is as personal an issue as it can get. There are no set rules as to why people give. The secret is for each non-profit to touch the right charitable chord.*

*It is our hope that the Foundation for Peripheral Neuropathy will touch you. We are working for a cure that touches the lives of millions of people. We hope that one of these reasons will inspire you to make your tax deductible gift today.*

### DONOR INFORMATION

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

Address \_\_\_\_\_

City, \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

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Donation Amount  
 \$50  \$100  \$200  \$500  \$1,000  \$5,000  \$10,000  Other \$ \_\_\_\_\_

Check Please make checks payable to: "The Foundation for Peripheral Neuropathy"

Credit Card Information  
 Amex  Visa  Discover  MasterCard

Name on Credit Card: \_\_\_\_\_

Credit Card Number: \_\_\_\_\_

Credit Card Expiration Date: \_\_\_\_\_

## ASK THE EXPERTS...

■ Dr. Waden Emery III, MD ■ Karen Sheppard, PT

**Q** "What's the most important rule about exercise and physical therapy in regards to peripheral neuropathy?"

**A** Forget the old gym rule of "no pain, no gain." It is critical to both your physical and mental well-being that you stay active, but people with neuropathy should not work through their pain. Instead, the exercise or physical therapy for each individual must take into account the extent of inflammation of their nerves, amount of damage to their nerves, the degree of blockage to them, and how much they have been injured. With exercise for the neuropathies a little is a lot, and quality, focus, and regularity are all-important. This is ultimately more critical than how much exercise you do.

**Q** "What symptoms will tell me if I'm working too hard, or using the wrong exercise program?"

**A** Overuse of inflamed or injured nerves will cause them to stop working temporarily. You may feel a cement-like numbness in your feet and legs, or other strange and painful symptoms in your body. Pay attention to these symptoms; do not work through the pain or you may increase these side effects.

**Q** "Why should someone with neuropathy do daily exercises?"

**A** You want to be able to maintain muscle strength. Staying fit will also help you to enjoy a more active lifestyle, which in turn helps fight problems like depression.

**Q** "So what exercises are recommended?"

**A** The best exercises are low impact, like a stationary bicycle. Swimming is highly recommended, so find someplace with an indoor pool to maintain a year-round program, like a health club or a university. The latter often offer pool availability at very low-cost rates. Learning your limits, knowing how to pace yourself, adjusting daily activities, and exercising correctly are important insights for anyone with neuropathy.

**Please note: Don't start any of these options without consulting with a PN expert first.**

**For more exercise ideas, please visit "Living with PN" on our website at: [www.foundationforpn.org](http://www.foundationforpn.org)**

# LIVING *well*

## Are you an informed patient?

Be your own medical advocate so you are informed about your healthcare options and receive the best treatments available.

- Request and retain a copy of your medical records, tests & x-rays
- Understand your treatment plan and incorporate it into your daily routine.
- Be aware of your symptoms and report any changes to your doctor.
- Know your health care benefits; make sure you read the fine print.

## Ask your Health Care Team

Being your own advocate also means becoming educated about your neuropathy.

- What are the possible symptoms?
- What treatment options are available?
- How do I deal with the pain? What is my pain management strategy?
- Would I benefit from physical or occupational therapy?
- What are the possible side effects from my medication?
- Are there benefits to taking medications at certain times of the day?
- Is my neuropathy hereditary?
- Am I a candidate for clinical trials?
- Are there diet or lifestyle changes that can improve my symptoms?

*Don't stop living!*

Living with neuropathy can mean having to face new limitations on your activities or abilities. It is vital to take time each day to reconnect with something that brings you happiness.

YOU CAN SEND US QUESTIONS OR FEEDBACK AT [INFO@TFPN.ORG](mailto: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](http://WWW.FOUNDATIONFORPN.ORG)



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## the FOUNDATION for PERIPHERAL NEUROPATHY®

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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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## Olympics CONTINUED

joined the US Navy to serve as a chief petty officer. He quickly moved through the ranks, becoming a first lieutenant by the war's end.

Because of his incredible knowledge of aquatics, Kiefer was asked by the Navy to put together new guidelines and a training manual for water safety. Kiefer himself trained 13,000 wartime instructors, who then returned to training camps and taught the program to more than two million enlistees. No one knows how many lives Kiefer's training manual/methods saved.

Kiefer opened Kiefer & Associates, an aquatics supply company, in 1947. He's been aided every step of the way by his wife of 68 years, Joyce. The company has been in the forefront of innovation ever since it opened.

## Fighting Peripheral Neuropathy (PN)

Diagnosed with idiopathic PN two decades ago, Adolph continues to struggle with the toll it has taken on him. He has lost the ability to use his hands and the mobility needed to walk without assistance. Today at the age of 91, Adolph continues to remain active by swimming with his wife Joyce everyday using water weights that he developed. He continues to play a vital role in his company, going to work five days a week.

Adolph Kiefer and the Foundation for Peripheral Neuropathy are now working together to fight for a cure. We hope that you will join the Kiefers and be part of a very important team... a team dedicated to reversing the irreversible.



Mr. Kiefer still active at the company he founded 62 years ago.

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