

FPN News

the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

SPRING 2011

A MESSAGE FROM THE EXECUTIVE DIRECTOR



Sharing Stories

The vibrant colors of the budding flowers herald the arrival of spring and bring the promise of yet another new season. There's a special reassuring quality about seeing the first flowers of the year—the certain knowledge

that the dreary winter weather is behind us and the excitement of another new season looms.

This spring we are encouraging you to get personally involved in making Peripheral Neuropathy a thing of the past. There are countless ways to take part, whether you choose to participate in clinical research, fund our scientific and educational programs or simply help us raise awareness by sharing your personal stories with us.

Stories are the way we learn about each other. They interest us; they inspire us; they teach us. Some tell of the long, discouraging journey that eventually led to your diagnosis of PN. Others recount the treatments you've tried—what works and what doesn't. More talk about your pain—both physical and emotional—of living with PN every day. And through it all you're just relieved that someone is listening to your story... someone cares.

Your stories are important to share. The more you share them, the more others become aware of PN and the struggles it causes. Stories will help someone know that the pain, numbness and tingling that they've felt for years actually has a name. Sharing lets them know they are not alone.

Our Facebook community helps and encourages others. Each story is different, but the concern they show for each other is genuine... they've been there! You can also contact us to share your story at info@tffpn.org. Your story may get published in our newsletter, website or in press releases to tell the story nationally.

All of your stories will be used as encouragement for others. And your stories will join together to tell an even bigger story—the story of PN. What it is. How it affects you. The need for research and new treatments. The need for a cure.

If you haven't told us your story... we hope you will.

Pam Shlemon

Featured in this issue

FPN Profile | *Diane Jones*
Page 1, 6

Research | *News*
Page 2

Clinical Trials
Page 3

Living Well | *Diabetic Shoes, Preventing Falls*
Page 2, 3

Ask the Experts | *Q & A*
Page 5

No Limits – Riding Across America

**TAKE A
SEAT**
SHARING A RIDE ACROSS AMERICA

People with chronic conditions, like peripheral neuropathy and other physical impairments, often believe there are limits to what they can do. Pain can be ever present in their lives and their vitality for living can diminish. But think about this...even if you think you can't

do something, maybe you really can! British adventurer, Dominic Gill, set out to find some unique individuals who were willing to take on new challenges in spite of their limitations.

With an unusual tandem bike built with a recumbent front seat and secondary free-wheel mechanism, Gill organized a 4,000 mile cross-country bike trip. The bike allows weak or disabled individuals to tackle long distances. This unique journey was originally conceived

in 2006 when Gill met Ernie Greenwald of Lompoc, CA, while on his first tandem cycling expedition from Alaska to Argentina. Greenwald was a 70-year old with lymphocytic lymphoma who wanted to bike across America. He was filled with

passion to live an adventurous life despite his physical condition. Anxious to ride, Greenwald discovered that his cancer had spread and he was not going to be able to participate.

Gill was forced to set out on a different adventure. After mapping out his journey and breaking it down into 10 stages, Gill went out and found 10 new companions to accompany him—all perfect strangers and all with significant physical disability: Traumatic Brain Injury (TBI), visual impairments, myotonic muscular dystrophy (MMD), Parkinson's Disease, Cerebral Palsy, Peripheral Neuropathy (see Dianne Jones' story below), broken vertebrae, and Multiple Sclerosis. Leaving Santa Monica on July 5, 2010, the trip

(CONTINUED ON PAGE 3)

*...helping others overcome
adversities and break
boundaries is an honor*

DIANNE—CHICAGO TO CLEVELAND

Some might say Dianne Jones is one of the lucky ones. Diagnosed with idiopathic peripheral neuropathy 25 years ago, she experiences numbness and tingling but she has no pain. Her hands and feet are numb; moving around is difficult. She loses her balance, bumps into things, her gait is uneven. She is stiff and uncoordinated, and needs a railing to go up and down stairs. Her hands get really cold—or really hot.

Active in her real estate business and in her church, Dianne enjoyed many of her tasks: typing, sewing and mending, serving communion. She especially liked typing and was quite good. Now, she can't type or thread a needle. It started getting worse about 10 years ago.

She could walk fast but not slow—she lost her balance, she stumbled. Her doctor even noticed that she trailed her fingers along furniture to help her keep her balance—something Dianne was doing without thinking.

To keep from falling, Dianne purchased a cane. Onlookers often draw inaccurate conclusions when they see people fall; the cane helps Dianne's stability and sends the message to others that she has physical limitations. Dianne volunteers with the 'Culture Bus' that takes seniors with early memory loss to cultural events. Using her cane and struggling to walk, she is often seen as one of the patients. Still she enjoys the outings and is philosophical, "People need to do what they can."

Dianne and her husband Doug have always been active. They liked to bike, but when Dianne could no longer control her own bike, they bought a tandem. They try to ride 20 miles every week and even participated in a 300 mile race in Wisconsin.

INSIDE

- Giving "Outside the Box"
- New Research Partner

(CONTINUED ON PAGE 6)



NEW RESEARCH PARTNERSHIP—

The Foundation for Peripheral Neuropathy and Children's Hospital Boston are jointly supporting a proof of concept preclinical research project to find a new pain therapy for peripheral neuropathy. Having previously discovered a common variant in a gene



Children's Hospital Boston

called GCH1 that protects people (~3% of the population) from developing chronic pain

after nerve injury, Dr. Clifford Woolf and his team now wish to discover if drugs can mimic this so that we can pharmacologically convert people who, by virtue of the particular type of GCH1 gene they happen to have inherited, are at a high risk of pain, to resemble those that are at a low risk. This is a completely novel approach to drug development and to finding a new pain therapy.

The premise of the study is to test if two candidate inhibitors of GCH1 can produce analgesia. If the project is successful, the plan then is to immediately develop related compounds suitable for testing in patients with peripheral neuropathy. Because the target has been identified by human genetics we are confident that if we can find inhibitors that are as effective as the gene variant we will find a completely new class of drugs to treat persistent neuropathic pain. The fact that the gene variant confers protection against pain without any other apparent harmful effects indicates that such drugs may also have a low side effect profile. This is a study that is much too risky for pharmaceutical companies because it is a quite different model from how they develop analgesics, but the partnership between the Foundation and Children's Hospital Boston is willing to take the chance, because the science strongly supports it and the need is so great.

Dr. Clifford Woolf is the Director of the FM Kirby Center and Program in Neurobiology, Children's Hospital Boston and a Professor of Neurology and Neurobiology, Harvard Medical School

FAULTY AND FARAWAY MITOCHONDRIA CAN DAMAGE LONG NEURONS

Peripheral neuropathy may be triggered by the degeneration of mitochondria in neuronal axons far away from the brain. With over 100 debilitating disorders that affect millions in the US, Dr. Ahmet Hoke and his team at Johns Hopkins think they may have found part of the answer. Their work relies on the fact that neuropathy occurs more often and earlier in older, taller patients. In addition, patients suffering from various diseases such as HIV or diabetes are at higher risk for neuropathy.

Through examination of tissue samples from nerves taken at locations close to the spinal cord and farther away from it, such as in the feet, Hoke's team has been able to establish that mitochondria found at increasing distances from the spinal cord possess increasing numbers of mutations in the mitochondrial DNA. These mutations include defects that can affect how mitochondria work. Their findings explain why neuropathies start in the feet and then move up the legs and begin affecting the arms.

Though these present results are specific to HIV-neuropathy, Dr. Hoke believes that a similar mechanism may be at work in other diseases such as diabetes.

Source: Johns Hopkins University News-Letter

news Briefs

Can CIPN be Prevented?

Many treatments have been used to try and prevent Chemo-induced Peripheral Neuropathy (CIPN): Vitamin E, calcium and magnesium, anti-convulsants and other vitamins and supplements. So far, there is no sure way to prevent it but doctors continue to look for treatments that work. Clinical trials are needed so that volunteers can help researchers find out more about what helps. Cancer.org has more information about these potential treatments and what can be done with stop-and-go treatments to help lower the risk of CIPN.

Source: Cancer.org

New Treatments for Neuropathic Pain

Chronic neuropathic pain causes untoward amounts of suffering and costs millions of dollars a year in lost work and healthcare costs. Dr. John Peppin, Director of The Pain Treatment Center of the Bluegrass in

Lexington, KY, has published a new article outlining new treatments that are being researched with promising expectations. Two such targets, the transient receptor potential (TRP) channel agonists and cannabinoid agonists are areas of increased excitement. Dr. Peppin's article focuses on TRP channel agonists, Capsaicin, endocannabinoid receptor agonists, and pharmacologic versus recreational marijuana.

Source: Cancer.org

Genetic Test Could Predict When Myeloma Drugs Will Cause Peripheral Neuropathy

The Institute of Cancer Research (ICR) has published a new study stating that a genetic test has been found that predicts whether bone marrow cancer treatments, including thalidomide, are likely to cause peripheral neuropathy. All common treatment regimens for multiple myeloma, an aggressive cancer that affects a type of white blood cell in the bone marrow, contain at least one drug with the side-effect of peripheral neuropathy. Their findings indicate that each drug type causes neuropathy through a different biological pathway. The study raises the possibility that patients could have their blood screened for neuropathy risk genes.

Source: Hospital Pharmacy Europe

LIVINGwell

DIABETIC SHOES

"HOW DO THESE FEEL?"

—VS—

"HOW DO THESE LOOK?"

Some of you don't want to hear this, but your first thought when trying on shoes should be about feel—not look. Wearing ill-fitting shoes can cause a blister which, especially if you are diabetic, often turns into a deeper wound. And, if you can't feel it, it can lead to serious infection or an amputation.



Consider this when shopping for shoes:

FINDING THE RIGHT PAIR

- Get fit by experts**—make sure knowledgeable staff measures your foot
 - Check with your doctor**—some doctors carry special diabetic shoes
 - Go for comfort**—shoes should feel good and not need to be 'broken in'
 - Choose a rounded toe**—round toe boxes offer plenty of room
 - Think thick**—soles with good shock absorption
 - Consider special shoe**—ones with no seams and special insoles
- Often you can be reimbursed for diabetic shoes and/or inserts. Check with your insurance carrier.*

Source: Everyday Health



(CONTINUED FROM PAGE 1)

ended on October 16th in Central Park—104 days later.

So, when you think you can't do something, think of each of these companions and decide if you can! Each of us must be determined to live life to the fullest.

Universal Sports produced a new adventure series based on this journey: "Take A Seat: Sharing A Ride Across America." They show the powerful and inspiring stories of these courageous adventurers. David Michaels, Executive Producer said, "It is a powerful series that combines adventure and inspiration. Each of the companions has an incredible story to tell and watching the evolution of each story provides a compelling tale of making the impossible seem possible."

Dominic Gill summed it up this way, "As an adventurer, I was excited for the challenge of cycling across the United States, but to be able to do it while helping others overcome adversities and break boundaries is an honor."

The documentary series, which aired in April, can be seen on the Universal Sports website: www.universalsports.com/take-a-seat.

photo credit: Universal Sports

Neurological Disorders and Chronic Pain

The World Health Organization (WHO) participated in a collaborative project producing evidence that pinpoints neurological disorders as one of the greatest threats to public health. Unless immediate action is taken, the neurological burden is expected to become even more serious and unmanageable.

Neurological disorders is a broad term that includes neuropathic pain from diabetes, cancer, HIV/AIDS, and many other causes. Without prompt treatment for their pain, patients develop a chronic pain cycle including these signs and symptoms:

- *Immobility and consequent wasting of muscle, joints, etc.*
- *Disturbed sleep*
- *Poor appetite and nutrition*
- *Dependence on medication*
- *Over dependence on family and other caregivers*
- *Poor performance on the job, or disability*
- *Anxiety and fear*
- *Bitterness, frustration, depression and suicide*

Some recommendations and conclusions from the study are:

- Pain is a significant symptom in several neurological disorders adding significantly to physical and emotional suffering and often to disability.
- Neurologists and non-neurologists should ensure that pain is assessed carefully and recorded in terms of its origins, nature and severity prior to diagnosis and management.
- There is an urgent need for more research into chronic pain of neurological origin.
- There is an urgent need for specific pain education programs in undergraduate curricula for doctors, nurses, and other health professionals.
- There is a need to continue and expand postgraduate training in pain management.

Source: World Health Organization

LIVINGwell

PREVENTING FALLS

Peripheral Neuropathy can affect the way you walk which can increase your chance of falling. Here, some tips to help you prevent falls:



Outdoors

- ▶ Use a cane or walker
- ▶ Wear rubber-soled shoes
- ▶ Walk on grass if sidewalk is slippery
- ▶ In winter, put salt or kitty litter on sidewalks

Indoors

- ▶ Keep floors clear of clutter
- ▶ Use runners on slippery floors
- ▶ Carpets and rugs should be secure
- ▶ Do not walk in socks, stockings or slippers
- ▶ Wear low-heeled shoes
- ▶ Stairs should be well-lit and have handrails
- ▶ Put grab bars in the bathroom
- ▶ Use a rubber bath mat
- ▶ Keep a flashlight next to your bed

CLINICAL TRIALS

Glutathione in Preventing Peripheral Neuropathy Caused by Paclitaxel and Carboplatin in Patients with Ovarian Cancer, Fallopian Tube Cancer and/or Primary Peritoneal Cancer (NCT00979082)

National Cancer Institute

Sponsor: North Central Cancer Treatment Center

Drugs used in chemotherapy work in different ways to stop the growth of cancer cells either by killing the cells or stopping them from dividing. Chemoprotective drugs, such as glutathione, may help prevent peripheral neuropathy

caused by paclitaxel and carboplatin. The purpose of this interventional study is to see how well glutathione works in preventing peripheral neuropathy in patients with ovarian, fallopian tube and/or primary peritoneal cancer.

This study is currently recruiting female patients, ages 18 years and older. Please visit www.clinicaltrials.gov for all the details (type in the study number above). Based in Rochester MN, the study has 306 locations nationwide.

MC5-A Scrambler Therapy in Reducing Peripheral Neuropathy Caused by Chemotherapy (NCT01290224)

Mayo Clinic
Rochester, MN

Acupuncture for Chemo-Induced Peripheral Neuropathy (NCT00891618)

MD Anderson Cancer Center
Houston, TX

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

We are grateful for all those who have supported the Foundation during 2010

Platinum
\$10,000 & ABOVE

Anonymous
Elizabeth Easley
Harvey L. & Jan Miller
Jack & Goldie Wolfe Miller
Jack Miller Family Foundation

Gold
\$5,000–\$9,999

Silver
\$500–\$4,999

Desmond LaPlace
Donald Bishop
Donald Levinson
Eugene Richardson
F. M. Young
Frances O'Brien
Francis Abdou
Frank & Sherri Mariani
Gary Mori
Henry Louis
James & Karen Frank
John & Betty Steele
John H. Lillard
Jordon & Barbara Katz
Marshall Eisenberg
Michele Enright
Nancy Stubblefield
Richard & Carol Fleisher
Richard & Ty Easley
Robert & Malka Beren
Ron & Phyllis Shaw
Suzanne Goldstein
William Bryan
William Hagerty
YPO Windy City Chapter

Bronze
< \$500

Al Witten
Alfred Rakebrand
Amy Jordan
Anders Ingemarson
Ann LaVelle
Anna Brueggemann

Armand & Elaine Dann
Art Moorhead
Audrey Hittner
Barbara & Jack Ayres
Barbara Gaines
Bernard Hudacek
Bernard Johnson
Bernard Lucier
Betty McDermott
Beverly Kantor
Bill & Alice Mroz
Bob Bardoff
Bob Enkey
Carol Babbett
Carolyn Dorrell
Carolyn Quadarella
Cathy Aronson
Charles Cain
Charles Campbell
Charles Shedd
Chester Barszcz
Clarence & Maxine Lipnick
Clifford Creel
Connie Bork
Cynthia Chauhan
Cynthia Grant
Daniel Gallagher
Daniel Miller, Sr
Daniel Sedey
Darcy Magalsky
David & Dianne Lipkin
David & Kimberly Jung
David & Susan Johnson
David Crook
David Mikell
Deanna Benson
Dennis Dine
Dominick Spatafora
Don Kirkegaard
Donald Baumgartner
Donald Reich
Doris Dockstader
Dr. James & Elaine Smith
Dudley & Patricia Carnie
Earl Gunther
Edgar Bowers
Edmund & Eileen Shaheen
Edmund & Helene Shaheen
Elaine Ruschak

Elizabeth Bevington
Ellen Adey
Ellis Katz
Elmer Malzner
Esther Meyers
Francis & Marylyn Harvey
Frank & Grace Schmitz
Frank & Sandra Parrish
Frank Sauer
Frank Sinclair
Fred & Sherry Schuster
G Wieder
Gail Vono
Gene & Claudette Shamblin
Gene Rask
George & Clara Avlonitis
George DelMonte
George Koehler
Geraldine Ryan
Grace Cogan
Greg & Jacqueline Jackson
Guy & Miriam Large
Harold & Linda Rosenson
Harold Radday
Henry Harris
Herb Tannenbaum
Howard & Harriet Bernstein
I. Alan Cohen
Irene Raby
Jacob & Janice Brandzel
James & Barbara Hanig
James & Barbara Mulhinch
James & Carol Barcelon
James & Catherine Thoen
James & Kim Curtis
James & Mary Ann Sesma
James & Mary McShane
James Brandt
Jan Hergesheimer
Jane & Peter Johngren
Jason Ott
Jean Alberti
Jean Broom
Jean Brown
Jeanne Trespicio
Jeff & Debbie Brennan
Jerry & Dottie Chambers
Jerry & Judy Reinhold
Jerry Hecktman

Jessica Lichtenfeld
Jim & Linda McLaughlin
Joe & Sandy Wessels
Joe Diduro
Joe Salter
John & Gloria Mundwiller
John & Janet Phillips
John & Katherine Savage
John & Martha Dorsett
John McNeill
John Murphy
John Parker
John Tuleweit
John Werth
Jonathan Richman
Joseph Malkevitch
Joyce Boritz
Joyce Fowler
Joyce Kagan Charmatz
JT & Carolyn &erson
Julie Foster
Justin Pape
Karen Ryan
Kathleen Gates
Ken & Barbara Rix
Kenneth & Corinne Griffiths
Kenneth Deken
Kenneth L&on
Kenneth Schneider
Kevin & Brenda Parrish
Kyle Denning
Landon & Lisa Martens
Larry Cravalho
Larry Hyne
Larry Steiger
Larry Visk
Lawrence & Phyllis Savitt
Leslie Allen
Leslie Luce
Linda Torp
Lori Schwartz
Lucinda White
Lynn Chestler
M. Terry Thompson
Marcia Ruskin
Margaret Rataj
Margaret Sutherland
Margo Snoad
Marie Gilliam

Marilyn Muerder
Marjorie Barnard
Mark & Linda Engdall
Mark & Phyllis Stephens
Mark & Teresa Sulo
Martha Tinder
Marvin Davis
Mary Anne Stone
Mary Pennington
Matthew & Amanda Thompson
Matthew & Theresa Kushner
Melody Chatelle
Melvin & Judy Hecktman
Merrill & Carmen Porte
Mia Masten
Michael & Susan Spica
Michael & Valerie Lewis
Michael Moran
Michael P. Gau
Michael Sinclair
Mitchell Newland
Mona Kahney
Nancy Droste
Nancy Luce
Nancy Schaefer
Orlanda Olsen
Patricia Grant
Paul Mack
Paul Sadowitz
Peter Wenson
Philip Gloss
Phyllis Michels
Phyllis Walters
Ralph & Bonnie Mandell
Ralph & Brenda Greenawald
Randy & Kathy Kirkland
Richard & Karen Mrad
Richard Harrer
Robert & Christine Ruff
Robert & Margaret McWethy
Robert & Patricia Zogorski
Robert Curley
Robert Hirsch
Robert Lewis
Robert McKenzie
Robert Schauer
Robert Schwarz
Roger Rabyne
Ronald & Patricia Jo Ryan

Ronald & Ronda Matthey
Russell Agne
Russell Gillespie
Ruth Burness
Sam Brott
Sandra Lahey
Sandy Culver
Sara Johnson
Sarah Johansson
SBST Enterprises LLC
Servicemaster Original
Maintenance Services
Sharral Dicey
Shirley Moravec
Shirley Sandkam
Shiro & Catherine Shiraga
Steve & Phyllis Warshaw
Steven & Christine Shaner
Stuart & Ilene Strauss
Suzanne Knoll
Suzanne Mittenthal
Tali Galassi
Ted & Mary Frances Cull
Ted Gmeiner
Terry & Colleen Snow
Thomas & Cynthia Martin
Thomas Flannery
Thomas Piehl
Thomas Richmond
Thomas Weinardy
Tim Jorgensen
Tony Dacey
Verna Parker
Vincent Petruccillo
Virgil Siedhoff
Wayne Carter
Wayne Thomas
William & Jane Cole
William Amberg
William Luebbert
William Malicote
William Nies
William Taylor
Wolcott Ranck
WT & Ann Loveless

IN HONOR OF

Betty Soliven, MD
Charles Stephens
Chelsey Ring
F M Young

Florence Hergesheimer
Jack & Goldie Wolfe Miller
Jim Schultz
Marcia Gunther
Michael Kushner
Randy Fauque
Robert Kent Tinder

IN MEMORY OF

Bill Hittner	Larry Visk	Mary Brown	Shirley Bower
Alvin R Porte	Lorraine Rabyne	Mary McWethy	Sylvia Tannenbaum
Don Conner	Lt. Col. Ross Fabair,	Patricia M. Shay-	Thomas DiSalvo
Fred Ingerson Jr	USAF	Turner	Tom Enright
J Kevin Cogan	Marilyn Malzner	Richard E Moravec	W. King Engel
Kim Curtis' mom	Mark G. Sulo	Sherrie Moorhead	William J Bryan



TIPS FROM facebook

One of the benefits of our Facebook community is everyone sharing tips—especially what works. We've compiled a few of those tips here and hope that you learn something that may help you.

WHAT DRUGS HELP?

- Bill:** I take Neurontin morning and night, no ill effects other than a little constipation.
- Andy:** I take Cymbalta and it helps me a lot. Had some side effects at the beginning but they are gone. It took about 3-4 months.
- Allison:** My doctor just started me on Savella 2 weeks ago and it's helping me.

DOES ALPHA LIPOIC ACID HELP?

- Rusty:** It doesn't make it go away but it does help. My neuropathy has not progressed since I started taking it; in fact it is not as bad as it was.
- Julia Ost Hornsby:** Alpha Lipoic Acid and B vitamins are supposed to help. I also use 100% emu oil on my legs. Look for a company certified by the American Emu or the Australian Emu Associations.

TOPICAL CREAMS

- Jillian:** Got a prescription for 2.5% Lidocaine, 2.5% Prilocaine cream. It is the best thing I've found to help p.n. pain. Hope to help some people!
- Denise:** I use Bengay on my feet and then put loose socks on while I sleep
- Elenitsa:** I'm using Neuragen on my toes in the morning and night. Liquid works best for me.

WHAT ABOUT EXERCISE/PT?

- Annette:** Absolutely! Especially pool therapy and exercise; it is a must for at least 45 minutes a day, minimum 3 days a week.
- Denise:** YES. I have CIPN and if I don't exercise using a stationary bike and elliptical, I feel worse.
- Ken:** can't run but do aerobics on my Wii

PROFILE DONOR SPOTLIGHT

Creations by Jim— Giving Outside the Box



There are many creative ways to support causes that are near and dear to us. Jim Schultz, Wilmette, IL, suffering with peripheral neuropathy, found his interest in art and his experience as a graphic artist would enable him to contribute to the cause of PN research.

Diagnosed with idiopathic neuropathy in 1995, Jim entered a clinical trial for a drug that required 2 injections per day for 6 months. Two years later—no improvement. But, as Jim says, “you don’t know these things unless you try.” He has tried other multiple therapies to no avail but hot water therapy at the pool does help his legs. With electric shocks in his hands and feet that “knocked me off my feet”, and pain in his legs, feet, hands and face, he retired in 1998.

Through the encouragement of his wife, Pat, and with an attitude that keeps him as positive and active as possible, he began working with pottery. With good and bad days he tries not to let the neuropathy get the better of him. “Know your normal and your limitations each day”, he says. Making pottery was a good outlet for him and he learned how to use pottery wheels. Eventually his hands became so sensitive he had to find new ways to work the clay. He remembers, “Work that took a ‘normal’ person 15 minutes to do took me an hour.”

In 2007, he began glass melting using recycled glass to create unusual artistic pieces. He did glass blowing in the past but had to stop because he couldn’t feel the hot sensation of the glass.

His family said he should sell his pottery and glass pieces and donate the money to the cause of peripheral neuropathy. He decided that was a great idea—every dollar helps!

Jim shows his work at three street fairs a year, getting around in his mobile wheelchair. He says Pat has been his inspiration and driving force to keep him active and attending these fairs. She also keeps a positive focus on their efforts to raise money to educate people about PN and help fund research through their website.

All of the sales of his work are donated to The Foundation for Peripheral Neuropathy. You can view and purchase his work at: creationsbyjim.com.



Thank you, Jim; we appreciate your creativity and ongoing support!

ASK THE EXPERTS...

THE FOUNDATION HOSTS PATIENT SEMINARS ON CHEMO-INDUCED PERIPHERAL NEUROPATHY. HERE ARE SOME OF THE QUESTIONS THAT WERE ASKED DURING THE SEMINAR:

Q “I have CIPN. A neurologist said that I may have too much B6 in my system. Is that possible?”

A It is possible if you have been taking large doses of B6 supplements for a long period of time. The recommended daily amount of B6 for adults ranges from 1.3-1.7 mg. For more information on Vitamin B6: <http://ods.od.nih.gov/factsheets/VitaminB6-HealthProfessional/>. **Interesting fact:** Many energy drinks/shots contain high doses of Vitamin B6 (pyroxidine), as much as 40 mg per drink or 2000% above the daily recommended amount.

Q “We’ve been talking about ‘chemo-induced’ PN. What about radiation therapy; does it cause PN, too?”

A Although it is different, radiation therapy can cause a neuropathy at (or near) the site of the radiation, but generally not the systemic reaction that chemotherapy would cause. Neuropathy that develops as a result of radiation therapy can develop anywhere from 5-24 months after treatment. Neuropathy can be caused by radiation damaging the nerves directly or due to fibrosis or thickening of adjacent tissues as the body heals from the treatment.

Q “Why does my numbness in my feet & hands intensify, when I’m relaxed and prone (in bed) or why do I have more cramping in the middle of the night?”

A When the body relaxes at night, the nerves are not distracted as they are during the day. Many people with PN report that their symptoms are worse at night. This can render a person unable to achieve a restful night’s sleep and actually dread bedtime. Some options could include: medication adjustment, relaxation, and guided imagery (<http://tinyurl.com/4yy5glz>).

Please note: You should check with your personal physician before making any changes to your health care routine.

Responses provided by: Vicki M. Tysseling-Mattiace, PhD, PT; and Tony Cook, LPN, from Northwestern Medical Faculty Foundation; and Liz McTaggart, R.N., B.A., M.S.N

For more ideas on “Living with PN”, please visit our website: www.foundationforpn.org

General Giving

Donate online by visiting our website at www.foundationforpn.org, by phone: 1-847-883-9942, or by mail

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

Favors

In lieu of traditional wedding, shower, or party favors consider making a contribution in honor of your guests

Take Charge

Get creative with fundraising and host your own event! Visit our website to learn more about creative fundraising ideas

SPONSORSHIP OPPORTUNITIES

- PNRR ■ Young Investigator Awards ■
- FPN Research Symposiums ■ Educational Programs ■

MAJOR GIFTS

- Planned Giving ■ Matching Gifts ■
- Pledged Gifts ■ Stock Options ■

For more information about SPONSORSHIP OPPORTUNITIES and MAJOR GIFTS,

please call 847-883-9942 or email info@tffpn.org

DONOR/MATCHING GIFT INFORMATION

First Name _____ Last Name _____

Address _____

City, _____ State _____ Zip _____

Telephone _____

Email _____

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: _____

CUT OUT AND MAIL WITH YOUR DONATION TO:
 The Foundation for Peripheral Neuropathy
 485 Half Day Rd., Suite 200
 Buffalo Grove, IL 60089

Each week when Dianne goes to exercise class, Doug goes with her so she can hold on to him and maintain her balance through the moves.

Last year a friend of hers living in South Dakota saw an unusual tandem bike being ridden through town as she was driving down the street. She rolled down her window and asked what was going on. Dominic Gill explained what he was doing with 'Ride Across America' and she immediately told him about Dianne.

Dominic and Dianne eventually connected and she agreed to join the ride. Because she and Doug ride often, Dianne was confident in her ability to ride with Gill. But, she and Doug were used to riding on trails; Dom and the team were riding on roads. She was even more concerned about camping on the trip; it's much harder to get around in the dark with her balance issues. But when she heard the story of Ernie she was determined to go; she was saddened to hear that he did not live to see the ride completed.

Leaving from Buckingham Fountain in Chicago, Dianne had Doug at her side on his own bike. Traveling to the Rock and Roll Museum in Cleveland, they rode 400 miles

in 8 days. Along the way they became honorary members of a motorcycle club when Dianne noticed a couple of men wearing T-shirts with 'Black Pistons' on the front and wanted one. They all got shirts and the motorcycle club escorted them to a hotel, stopping traffic along the way to let them go through red lights. "Every day was different; every day was an exciting adventure"—that's how Dianne remembers those days.

So is she one of the lucky ones? Dianne is thoughtful, "...so many things you miss, as you think about it." She was graceful, she had balance, she could use her hands. She still wants to work but wonders, "How can you show up for a job interview with a cane?"

But, Dianne does think she is a lucky one. With her husband, she has a great support system which is very important to her. She adds, "People are very, very kind if you have a disability. They're curious and helpful and if you get out there and let people know what's going on, they will try to help you—they will do what they can."

Congratulations, Dianne, for taking the ride of your life!

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. 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.

Nonprofit Organization
U.S. Postage Paid
Buffalo Grove, IL 60089
Permit No. 255

Events

PN Resource Workshops

TOPIC
Varies

ONGOING

WHEN
The 3rd Friday of every month

TIME
11:30am—1:30pm

LOCATION
Prentice Women's Hospital
Conference Room Q – 3rd Floor
250 E. Superior St., Chicago IL 60611

TO REGISTER
jbreslow@nmff.org OR info@tffpn.org

NBC5 Healthy Living Challenge



A FREE two day event designed to capture the attention of health-conscious consumers offering free health tests & screenings, healthy cooking demonstrations, aerobics, and much more!

WHEN
October, 2011

LOCATION
Navy Pier, Chicago

MORE INFO TO COME

Living Well Patient Seminar —October

LOCATION
Cancer Wellness Center
Northbrook, IL

MORE INFO TO COME

CHECK OUR WEBSITE FOR UPDATES ON ALL EVENTS

BOARD OF DIRECTORS

- Jack Miller CHAIRMAN OF THE BOARD
- Richard Easley
- Shana Hayes
- Jack Kessler, MD
- Goldie Wolfe Miller
- Ron Shaw
- Dominick Spatafora

SCIENTIFIC ADVISORY BOARD

- Eva L. Feldman, MD, PhD
RUSSELL N. DEJONG PROFESSOR OF NEUROLOGY
DIRECTOR OF THE NEUROPATHY CENTER
UNIVERSITY OF MICHIGAN, ANN ARBOR, MI
- Roy Freeman, MD
PROFESSOR OF NEUROLOGY
DIRECTOR, CENTER FOR AUTONOMIC AND PERIPHERAL NERVE DISORDERS
BETH ISRAEL DEACONESS MEDICAL CENTER, BOSTON, MA
- Deborah Lee, MD, PhD
MEDICAL DIRECTOR, NEUROLOGY
BAXTER BIOSCIENCE, BAXTER HEALTHCARE, WESTLAKE VILLAGE, CA
- David M. Simpson, MD
PROFESSOR OF NEUROLOGY, NEUROMUSCULAR DISEASES
MOUNT SINAI MEDICAL CENTER, NEW YORK, NY



Find us on Facebook.com/
The FoundationForPeripheral
Neuropathy and become a fan.



Follow us! Twitter/
FoundationForPN

EXECUTIVE DIRECTOR
Pam Shlemon

SR. PROGRAM COORDINATOR
Brenda Navik

DESIGN
Richard Stadler Design, Inc.
www.richardstadlerdesign.com