



Neuropathy Hope

Hope Through Caring and Education

A newsletter for members of the
Northern California Chapter of The Neuropathy Association (NCCNA)

July 2009
Volume 7
Issue 7

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GROUND ZERO CAUSES NEUROPATHY

Rev. Dr. Toby Nelson was the speaker at the Grass Valley PN Group meeting on June 8. Toby is a member of the National Response Team that responds to disasters as a part of Homeland Security. He has done this work for some years along with being a local pastor.

On 9/11, he was a pastor in New York City, not too far from the Twin Towers and was on the scene of the disaster shortly after it happened. Some from his church died there. He showed photos and told about his experience at the site over a period of months. It brought the scene back to the remembrance of those present.

Here are several statements that may not have been clearly said at the time of the event that Toby used to give focus:

People who jumped were reported at the time to be committing suicide or seeing if they could jump and survive; but rather, it is thought now, the fire forced them out. When the towers came down, they brought down 13 other buildings in their vicinity. Trinity Church served as the chief center for working with people looking for friends and relatives, as well as offering counseling and acting as a medical clinic. It was in the vicinity and spared. Toby worked there a great deal, as part of his education resulted in a degree in psychology. The white powder that filled the air, piled up on shoes, and covered the ground was pulverized cement dust which included what amounted to the cremation of people who died in the building. It was highly toxic.

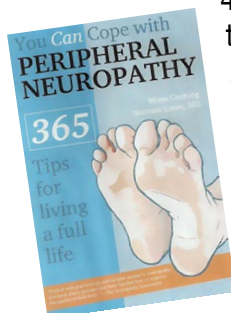
The people working at the site had respirators, but they were not powerful enough to allow them enough oxygen to work and talk, so most did not use them. The masks also impeded breathing, so most set them aside. Approximately eighty percent of the people who worked there

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MIMS CUSHING'S BOOK TO HAVE AUDIO VERSION

You Can Cope With Peripheral Neuropathy, the new book out by Mims Cushing and Norman Latov, MD, will be turned into an audio book through a company called Read How You Want. People can go online to find out more, or call the company directly at 917-434-6144 and ask for Tricia Roth for more information. Or email her at tricia@readhowyouwant.com. The book, endorsed by The Neuropathy Association, is in its second printing. It was written up in *Neurology Now* and a review will appear in the August IV Living magazine.



Also, The Neuropathy Association is putting one tip a day online from the book and will do so for 365 days. If you aren't getting these practical tips yet, call the Association at 1-800-247-6968. This book, published by Demos Press, is available through bookstores both on the street and on the Web.



N
NCCNA
PO Box 6985
Auburn, CA 95604
Tel: 530-389-2416
info@pnhelp.org
www.pnhelp.org

CONGRATULATIONS to MARTHA CHANDLEY "You Are Our Hero" – see page 4

Affiliate News

Listed below is information about upcoming meetings and where to learn more.

2009 NCCNA Board of Directors

Bev Anderson
President

Laura Niznik
Vice President

Penni L. Smith
Treasurer-Secretary
Technology Director

Amy Considine
Administrative Director

Michael Green
Director

Sandra Vinson
Director Emeritus

Dick Ward
Director Emeritus

Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.

Newsletter Design by

 Diane Blakley
Designs

Alturas

Judy Briener
For current information
(530) 233-4733

Auburn

1st Monday, 1:30 PM
Woodside Village MH Park
12155 Luther Rd.
Charlene Amos (530) 823-1504
Sharlene McCord (530) 878-8392

No meeting in July or August

Berkeley

3rd Monday, 6-8 PM
1st Month of each quarter
Lutheran Church of the Cross
1744 University Ave.
Alan Dampsey (510) 527-3568
adampsey@comcast.net

Be sure to come to the July meeting.

Clearlake (Forming)

Barbara Dryden (707) 994-2202

Colusa (Forming)

1st Presbyterian Church
326 Jay Street
Betty Yarwood (530) 458-2908

Concord

3rd Tuesday, 1:30 PM
First Christian Church
3039 Willow Pass Rd.
Ernette Rivera (925) 689-2464

Crescent City

Sutter Coast Hospital
800 E. Washington Blvd.
Judy Wolfe (707) 464-3008

Davis

2nd Wednesday 2 PM
Institute for Restorative Health
1460 Drew Ave.
Mary Sprifke (530) 756-5102

No meeting in July or August

Elk Grove

2nd Tuesday, 2 PM
Elk Grove Senior Center
8830 Sharkey Ave.
Michael Colozzi (916) 421-8103

Eureka

3rd Wednesday, 10 AM
Humboldt Senior Resource Ctr.
1910 California Street
(707) 268-8937

Folsom

1st Thursday, 1 p.m.
Journey Church
450 Blue Ravine Rd., K-2
Lorraine (916) 983-4023
Beverly (916) 984-4302

Fort Bragg

Call for time & location
Mildred (707) 964-3030

Fresno

3rd Tuesday, 11:15 AM
Carrows Restaurant
1484 E. Shaw Ave.
Maria Chavez (559) 437-9787

Grass Valley

2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church St.
Sally (530) 268-1017

No meeting in July or August

Jackson

3rd Tues., 10 AM-odd numbered months
Amador County Senior Center
229 New York Ranch Rd.
Laurie, (209) 223-0442
Darlene, (209) 296-1760

Lakeport (Forming)

Roberta Millard (209) 263-6891

Lincoln

3rd Wednesday, 1 PM
Raley's Event Center
765 S. Hwy 65
Diana Borg (916) 408-7017

No meeting in July or August

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
E. Lorene Stack (925) 447-6158

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeister Center across
the street from the church)
Susan Baldasano (209) 617-6283

Modesto

3rd Monday, 10:30 AM
Memorial Medical Ctr. Bldg
McHenry Village
1700 McHenry Ave., Ste 60B
Noreen Jones (209) 846-0954

Speaker: Jeffrey S. Levin, M.D.

FAAN on neuropathy

Monterey

3rd Wednesday, 10:30 AM
odd numbered months
First Presbyterian Church
501 El Dorado St.
Don & Ann Trout (831) 372-6959

Napa

1st Thursday, 2 PM
Napa Senior Center
1500 Jefferson St.
Ron Patrick (707) 257-2343
bonjournal@hotmai.com

Oakland

1st Thursday, 1 PM
Grand Ave. 7th Adventist Church
278 Grand Ave.
Kathleen Nagel (510) 653-8625

Placerville

4th Wednesday, 1 PM
Placerville Senior Center
937 Spring St.
Frank Ruscoe (530) 647-0777

Redding

2nd Wednesday, 1:30 PM
Neighborhood Church of Redding
777 Loma Vista
Bill Morehouse (530) 221-3082
Carol Reeves (530) 549-4351

Reno, NV

2nd Tuesday, 6:30 PM
Fire Station #11
7105 Mae Anne Ave.
Gail Gutendorf (775) 626-1434

Roseville

2nd Tuesday, 7 PM
Sierra Point Sr. Res.
5161 Foothills Blvd.
Mary Lou Ward, (916) 772-5598

No meeting in July or August

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Anne Fletcher, (916) 391-3317
Myke Taylor (916) 487-2903

No meeting in July

San Francisco

Call to be sure of meeting day & time.
UC-San Francisco Med Ctr.
400 Parnassus Ave.
Amb. Care Ctr. 8th Fl., Rm A888
Rowena Mah, RN (415) 502-5064
Rowena.mah@ucsf.edu

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital,
2105 Forest Ave.
SJ DePaul Conf. Rm.
Stan Pashote (510) 490-4456

Speaker: Ms. Shasta Tierra
Accupuncture & Yoga Instructor

San Mateo

3rd Thursday, 1 PM
St. Andrews Lutheran Church
1501 S. El Camino Real
Bev Anderson (877) 622-6298 (toll free)

No meeting in July or August

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Ave.
Barbara Webb (415) 453-9678

Santa Cruz

3rd Wednesday, 1PM
Trinity Presbyterian Church
420 Melrose Ave.
Mary Ann Leer (831) 477-1239
maleer@comcast.net

Santa Rosa

1st Thursday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Rd.
Willie Quarante (707) 544-3236

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Sonoma

1st Friday, 10:30 a.m.
Vintage House
264 1st Street
Joann Bertolucci (707) 996-8336
No meeting in July

Sonora

4th Monday, 2 PM
Sonora Regional Medical Center
Conference Room
L.D. Wright (209) 533-2887
No meeting in July or August

Stockton

3rd Tuesday, 4 p.m.
Service First of Northern California
102 W. Bianchi Rd.
Bev Mallette (209) 944-7815
No meeting in July or August

Susanville (To be announced)

Susan Ellen (530) 257-3864

Truckee

April thru October, 2nd Tuesday, 1 PM
Truckee Pines Apartments
10100 Estates Dr.
Bev Anderson (877) 622-6298

Turlock

2nd Wednesday, 10 AM
Covenant Village Adm. Bldg.
2125 N. Olive St.
Dee Muhlenbruch (209) 667-0042

Ukiah

Call for schedule
Bev (877) 622-6298

No meeting in July or August

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse,
Las Trampas Room, Walnut Creek
Nancy Ostrander (925) 930-9524

West Sacramento

3rd Tuesday, 2 PM
West Sac Fire Station #45
Community Room
2040 Lake Washington Blvd.
Sandra Vinson (916) 372-6093
slvins11@charter.net

No meeting in July or August

Woodland

1st Monday, 3:30 PM
Woodland Comm. & Senior Center
2001 East St.
Delia Genera (530) 661-3238

No meeting in July or August

Yuba City-Marysville

St. Andrew Presbyterian Church
1390 Franklin Rd.
Ken Lux (530) 673-3479

Yreka

2nd Thursday, 2 PM – Odd numbered months
Meadowlark Assisted Living Center
Terry Rees (530) 842-1577
Gene Arnold (530) 842-7744

President's Message

By Bev Anderson

After several years of active service on our Board of Directors, our Treasurer, Dick Ward, has retired from the Board. His military and business background have been valuable in helping the Board through a difficult time of restructuring to meet IRS requirements. He will be missed.

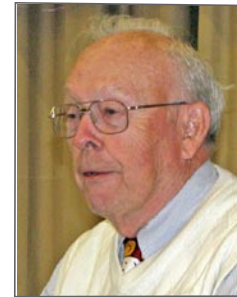
Penni L. Smith is our new Treasurer. Penni is a software developer and has written software for several companies including major financial companies. She developed NCCNA's Membership Accounting Management Application (MAMA), and will be completing what is needed for groups to access their own membership and financial records soon. In addition to being Treasurer, Penni is serving as Secretary temporarily and continues as Technology Director.

Amy Considine is now our Administrative Director, a new title better reflecting the duties that were done by the Membership Chair position. She will be responsible for keeping our membership records up-to-date and handling our accounts receivable.

Your Board of Directors is a working board. This means that what is accomplished is done by the people on the Board, for the most part. We do hire a few things out. We now have a professional layout editor who has sharpened the look of NEUROPATHY HOPE. I know you have noticed as many have remarked that it has a fresher appearance. Some of our financial accounting is done by a firm in Grass Valley. We have a mailing service that addresses and mails our newsletter and large volume letters to our membership and others. Almost everything else, however, falls to the Board of Directors. The Board gets much done, but there is much more that could be done with more people available.

I'm requesting that you think about someone you know who has skills that would be of help to the Board. Maybe it is even you who would like to serve on the Board. Amy Considine found us on the web and volunteered. She is a tremendous asset, a fast learner. The person does not have to have neuropathy to be on the Board. The only requirements are to be a member of NCCNA, be actively using e-mail, get along well with others, and to have a skill the Board needs which is pretty much a variety.

If you or someone you know is interested, please call me at 877-622-6298 (toll free) or send a note to info@pnhelp.org.



Dick Ward

Help With Health Care Challenges

If number not in your area, call the one listed and ask for the right number.

HICAP Health Insurance Counseling

for seniors and people with disabilities. Call Seniors First /SeniorLink at 1-800-878-9222 to make an appointment.

•••

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage. Tollfree (888) 354-4474 or TDD (916) 551-2180. In Sacramento, (916) 551-2100. www.hrh.org.

•••

HMO Help Center

Assistance 24 hours a day, seven days a week. (888) HMO-2219 or (877) 688-9891 (TDD).

•••

DRA's Health Access Project

Free publications about the health care and insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

Bev

HELP WANTED

Here are current needs for help. If you or someone you know could assist with any of these, please call us toll free at (877) 622-6298.

Data Entry Assistance

We need help entering some data into our new software, an easy-to-use web application. This can be done from your home.

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Board Members

Special needs are in public relations, computer skills, and knowledge of nonprofit organization development, and accounting

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CONGRATULATIONS MARTHA!

Martha Chandley received the “You Are Our Hero Award” at the June 25, Neuropathy Action Awareness Day. Martha has been actively involved in leading groups, writing a newsletter, responding to phone calls for information, and generally getting the word out about neuropathy for a number of years. She had the inspiration for the bus posters. We had a number more than we could place on buses. Many groups now have one or more of them to put up to mark their meeting site. Also out of this project came our logo of the hand and foot and indications of symptoms of neuropathy. Martha started the three Yolo County groups – West Sacramento, Davis, and Woodland. Currently, Martha is getting some well-earned rest and time to pay more attention to her health and other activities that she finds of need or interest.

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COMPOUNDING PHARMACIST SPEAKS IN SACRAMENTO

Compounding pharmacist John Richards, who is the owner of the Professional Village Pharmacy at Arden Way and Professional Village Drive in the North Area, spoke to the Sacramento PN Support Group recently. Professional Village Pharmacy is the only compounding pharmacy in Sacramento and has staff that can provide medications tailored to individual special needs. For example, they can develop a liquid form of a medication for a patient who has trouble swallowing pills. John Richards is also on staff at the UCSF and UOP medical centers to provide specialized pharmacy support. He also works with pain specialists to formulate transdermal products to bypass the liver and avoid side effects.

He stressed the need to keep all drug use “under one roof” to avoid harmful interactions. He distributed a handout titled “Update on Managing Neuropathic Pain.” He said that PN sufferers have commonalities, but also many differences; each is a work in progress. He strongly feels that medication needs to treat the actual problem, not develop side effects which may require additional medication.

John spoke of a multiple approach of managing PN using topical lotions with pain killers, diabetic socks, proper shoes, and exercise, as well as medications. Although the organic causes of PN vary, pain is a symptom of the underlying causes.

He talked about some alternatives to prescription drugs such as alpha lipoic acid, magnesium, calcium, and vitamins. He cautioned against excessive B6, however. Also, he encouraged exercise such as Yoga, Tai Chi, walking and suggested that relaxation techniques such as meditation could be beneficial.

John Richards contact information is Professional Village Pharmacy, 1701 Profession Village Drive, Sacramento 95825. Phone (916) 483-3455, e-mail crpharmd@msn.com. John’s pharmacy offers a beneficial free service: if you bring in all of your prescriptions and supplements, one of the staff will examine to assure against drug interactions.

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OPPORTUNITY TO COMMUNICATE

By the end of 2009, a new Strategic Plan for 2010, 2011, and 2012 needs to be in place.

We would like to invite anyone interested in giving input for this plan to a meeting in August. The meeting will be in the general Sacramento area, but has not been determined yet. A questionnaire will also be sent out to all members so that no member will be left out of the process. Please respond by e-mail to info@pnhelp.org or by note to NCCNA, P.O. Box 6985, Auburn, CA 95604 if you want to be included in this meeting. A copy of the current Strategic Plan is available on our website at www.pnhelp.org or can be obtained by requesting it be mailed to you.

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PETER GRAF OF GRASS VALLEY GETS HAND CONTROLS

Peter Graf, a member of the Grass Valley support group, was interested in getting hand controls. He found good information in Penni Smith's detailed article that is available on our website at www.pnhelp.org/resources/handcontrols.html. He then did extensive research to find out where in the area hand control installation is done and what the requirements are. This is his report. Peter's information will help you evaluate what is available in your area if you are not near Sacramento.

It took a bit of fumbling through the yellow pages and the internet, but I finally came up with four places for installation of automobile hand controls in the Sacramento area. I couldn't find anything closer for us in the Auburn/Grass Valley area. Here's the list with costs and conditions:

- (1) **Nor-Cal Mobility, Inc.**
3127 Fite Circle Suite B
Sacramento, CA 95827
Manager: Alex Grzebcki
1-800-225-7361 (this will connect you to the Chico office, they can transfer you to Alex)
Cell phone for a direct call to Alex in Sacramento is (916) 662-4665
www.norcalmobility.com.
Cost is \$960.

They require a doctor's approval for the installation of a hand-control for the customer.

- (2) **Sacramento Van Conversions**
5821 Florin Perkins Rd.,
Sacramento, CA 95828
916-381-8267
www.sacvans.com
Cost is \$1150

No conditions other than signing off on a liability release.

The other two facilities require the customer to obtain a certificate of completion after a two hour course with a "certified" driving school instructor in a hand-control equipped vehicle. The quote from one such school was \$240. In addition, the instructor is required to inspect the customer's vehicle after installation for a further charge of \$150. They claim this is necessary to protect them from liability. The quoted installation cost for each of these is \$950. Adding the \$390 for the required instruction and "certification" brings the total cost to \$1340.

- (3) **Driving Specialties**
2216 Cemo Circle, Suite A,
Rancho Cordova, CA 95670
916-635-2765
www.drivingspecialties.net
Cost for installation \$950 plus \$390 for "certification".



MPS Monarch Mark 1-A Hand Controls at Sacramento Van Conversions

- (4) **Ability Center**
6550 Freeport Blvd. #A,
Sacramento, CA 95822
Manager is Kevin Horn
916-392-1196
www.abilitycenter.com
Cost for installation \$950 plus \$390 for "certification"

I will be happy to answer anyone's questions and share my own installation experience with anyone who is interested. My number is (530) 265-0941

Note from Penni: I have had hand controls installed twice now, and did not have to provide any certification or doctor's notes. The DMV does not require any special instruction or endorsement. Also, you can rent a car with hand controls without even having to prove you know how to use them. Therefore, I really wonder if it is legal for the companies to require these extra items. It seems to me this would constitute discrimination against the disabled. We are investigating this matter. In the meantime, you might want to argue these points.

Also, many car companies will provide reimbursement for customers that need adaptive equipment installed in a new car.

DISCOUNTS FOR NCCNA MEMBERS

The following companies or individuals have agreed to give NCCNA a discount to NCCNA members. Give them a call or visit. If you chose to purchase the service or wares of any on this list, pull out your NCCNA Membership Card and claim the discount.

Auburn
The Footpath
825 Lincoln Way
Auburn, CA 95603
(530) 885-2091
www.footpathshoes.com
NCCNA Discount:
10% off the regular price shoes.

Elk Grove
Shoes That Fit
8649 Elk Grove Blvd.
Elk Grove, CA
(916) 686-1050
NCCNA Discount:
20% off the regular price shoes.

Fortuna
Strehl's Family Shoes & Repair
Corner of 12th & Main
1155 Main Street
Fortuna, CA 95540
(707) 725-2610
Marilyn Strehl, C.PED is a Certified Pedorthic.
NCCNA Discount:
10% off the regular price shoes.

Sacramento
Shoes-n-Feet
4740 Natomas Blvd.
Suite 130,
Sacramento, CA 95835
(916) 419-0040
NCCNA discount:
15% off the regular price

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DISCOUNTS FOR NCCNA MEMBERS

Continued from page 5.

West Sacramento Beverly's Never Just Haircuts and Lilly' Nails

2007 West
Capitol Ave., West
Sacramento, CA
Hair – (916) 372-
5606 Nails – (916)
346-8342
NCCNA discount:
10% off the regular
price

Additional Discounts

Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail info@pnhelp.org. We'll mail an agreement form to the business, and once we have it, we'll get them on this list.

■ **Peripheral Neuropathy and Peripheral Arterial Disease: What's the Difference?**

By Dr. Tracy Ferragamo, DPM

(NOTE: Tracy Ferragamo, DPM, is one of NCCNA's Medical Advisors. She sent this article which describes Peripheral Neuropathy and Peripheral Arterial Disease. You may have someone in your area with the same training on decompression surgery as she describes. This surgery is not for everyone and is not something to rush into. It has been helpful for some. Having an evaluation from a recognized expert in the field is an option. Dr. Ferragamo's office is at The Davis Podiatry Center, (530) 753-9080 www.DavisPodiatryCenter.com. If you are not near Davis, you can call to find out if there is someone Dr. Ferragamo knows in your area. She will be glad to let you know.)

Many diabetics and non-diabetics can suffer from painful peripheral neuropathy of the feet or poor blood supply to the feet and legs (known as peripheral arterial disease). Some persons may have both conditions present. The signs and symptoms of peripheral neuropathy and peripheral arterial disease can overlap and mimic each other. Symptoms can include tingling, pain, burning, numbness, shooting sensations, cramping, or a sensation of "thick skin" or that the part is "asleep". The symptoms may vary with positioning and activity level.

Although the conditions may imitate each other, the causes are often unrelated. It is imperative to distinguish between peripheral neuropathy and peripheral arterial disease because the treatments are quite different.

PERIPHERAL NEUROPATHY ("PN") has many causes, but sometimes occurs when nerves traveling through anatomical tunnels become "pinched" in these tunnels due to scarring or nerve swelling. Initially the toes and feet may tingle and burn, but, if left untreated, can eventually become numb. Skin ulcers and bone infections may result when patients don't realize their skin is breaking down. Many people have been told there is no treatment besides antidepressants or anti-seizure medication which may help mask symptoms, but not stop the progression of the disorder.

There is now available a new form of surgery to relieve neuropathy pain and restore sensation to the feet. The procedure is called peripheral nerve decompression surgery and is performed by about 300 trained and certified surgeons

across the United States. The procedure is similar to carpal tunnel surgery in that it opens the tunnel that houses the pinched and compressed nerve.

PERIPHERAL ARTERIAL DISEASE

("PAD") occurs when the arteries supplying oxygenated blood to the legs and feet become stenosed, or partially plugged up with plaque or calcium deposits. This in turn starves the feet and legs of oxygen causing pain, burning and/or cramping as well as the possibility of ulcerations and gangrene. This is usually a progressive disease and the longer it is left untreated, the more invasive the cure. Fortunately, there is a relatively new minimally invasive procedure to literally "clean out" the arteries to restore blood flow.

After a thorough examination and non-invasive in-office nerve testing, vascular testing, and other testing as necessary, the doctor will be able to identify which condition the patient is suffering with.

The surgical procedure to relieve neuropathy takes about one hour and is performed on an out-patient basis. The patient is usually back in shoes 3 weeks following the procedure. Pain relief is often immediate although it can take several months for symptoms to stop. Patients diagnosed with peripheral arterial disease are directly referred to a vascular medical group for further consultation and evaluation. The vascular specialists are experienced with non-invasive and other vascular procedures needed to restore blood flow. Each patient is treated on an individual basis.

NATIONAL INSTITUTES OF HEALTH

The National Institute of Neurological Disorders and Stroke (NINDS) conducts and supports research on brain and nervous system disorders. Created by the U.S. Congress in 1950, NINDS is one of the more than two dozen research institutes and centers that comprise the National Institutes of Health (NIH). NIH, located in Bethesda, Maryland, is an agency of the Public Health Service within the U.S. Department of Health and Human Services. NINDS has accepted a central position in the world of neuroscience for 50 years.

More than 600 disorders afflict the nervous system. Common disorders such as stroke, epilepsy, Parkinson's disease, and autism are well-known. Many other neurological disorders are rare—known only to the patients and families affected, their doctors, and scientists who look to rare disorders for clues to a general understanding of the brain, as well as for treatments for specific

diseases. Neurological disorders affect an estimated 50 million Americans, exacting an incalculable personal toll and an annual economic cost of hundreds of billions of dollars in medical expenses and lost productivity.

The mission of the NINDS is to reduce the burden of neurological disease – a burden born by every age

group, every segment of society, and people all over the world. To accomplish the goal the NINDS supports and conducts research, both basic and clinical, on the normal and diseased nervous system, fosters the training of investigators in the basic and clinical neurosciences, and seeks better understanding, diagnosis treatment, and prevention of neurological disorders. ◀ INDEX



Partner with Your Provider By Penni L. Smith

Even if your doctor is highly specialized, devoted to continuing education, and dedicated to excellence, it is simply impossible for him or her to know everything about any particular disease. This is even more the case for a condition as varied and challenging as neuropathy. You can't leave your health care solely in your doctor's hands. Become a partner in your care and treatment.

- **Learn about your condition.**

Make liberal use of the internet and read up on symptoms, treatments, and research. Use trusted sources. Not sure how? Your public librarian can assist you. Also, this is a great benefit of NCCNA support groups. Members share about tests and



treatments they have experienced, which may give you ideas to pursue.

- **Ask questions.**

Bring a list with you to every doctor's visit. No question is inappropriate if you have a concern.

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Ground Zero Causes Neuropathy – continued from page 1

are now dead or disabled, he said. Most of the dogs died after a few months.

After describing the scene and making the above comments and more, Toby told about his neuropathy. Prior to 9/11, he had none. He was at the site almost daily for nine months. Some weeks after that time, he started feeling tingling and numbness in his toes, which has now progressed up his legs to near the knees. He was diagnosed with neuropathy that most surely was caused by the toxic cloud he worked in. Others have also developed neuropathy. There is a study being conducted of the people who worked there and what happened to their health. He will ask for their data on neuropathy and let us know.

Toby finished his talk and mentioned that he had also been assisting people at the Super Dome after

Katrina, until the workers were told to leave for their own safety. He said that 60 people died there due to conditions that ensue when thousands of people are kept with no food, water, or sanitary facilities for several days. Someone asked if he had any video of that stored in his laptop. He showed a 3 minute video of some of what he experienced. Again, the toxins could well have added to his neuropathy. It helped us have a great respect and concern for those who respond to disasters and help the best they can. The good deeds can be repaid with health concerns including neuropathy.

The photo on page 1 was found at www.kobey.com. At the time of production, we were unable to find the real source of this photo. If you know the photographer, please contact us and we would be happy to give the proper credit.

CORRECTION:

In last month's newsletter, the article "Annual Meeting a Success" incorrectly identified gentle yoga instructor Mae Denman as Mae Denham in the print version. In the electronic version, we fixed the article, but the caption still ended up with a typo that had her as Mae Denham. Her correct last name is Denman.

We regret the errors, and apologize to Mae.

Note:
Mae's handout, mentioned in that article, is now available on our website at <http://www.pnhelp.org/happenings/spring09.html>.



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Partner with Your Provider *continued from page 7*

- **Insist on explanations and discuss options.**

Have your doctor fully explain why he has ordered a specific test and what it will show. Ask why he wants to pursue a specific treatment. Inquire about possible outcomes and side effects. If you don't understand, ask him to rephrase it until you do.

- **Realize that not every test or treatment is appropriate.**

Tests and treatments have costs, both financial and physical, and benefits. The doctor may recommend against a particular test or treatment if the benefits are limited compared to the costs. Get a full explanation, but realize that not every option is right for you.

- **Bring someone with you.**

Another person may hear things differently than you do, may have other questions, and may help you remember both things you need to tell the doctor and things the doctor has to say.

- **Don't accept a brush off.**

You know your body better than anyone. Don't let the doctor dismiss you by saying it's all in your head. Don't accept that there's nothing more that can be done. Even if that was true last year, it may not be true today—new things are being learned all the time, and new treatments and tests are developed.

- **Switch doctors if necessary.**

If your doctor is disrespectful, won't answer your questions, won't explain your options or his recommendations, or ever discourages you from seeking a second opinion or educating yourself, find another one.

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Hope through caring and education

Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year (due each January)

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