



# Neuropathy Hope

*Hope through caring, support, research, education, and empowerment*

A newsletter for members of the  
Pacific Chapter of The Neuropathy Association (PCNA) / Western Neuropathy Association (WNA)

January 2015  
Issue 1  
Volume 13

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Coping With Chronic Neuropathy

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www.pnhelp.org

## **TNA (THE NEUROPATHY ASSOCIATION) DISSOLVES. PCNA IS AN INDEPENDENT CORPORATION – IT WILL CONTINUE WITH A CHANGED NAME. IT WILL SOON BE THE WESTERN NEUROPATHY ASSOCIATION (WNA).**

On Tuesday morning, December 2, 2014, I received a call from Jim Gardner, Chairman of the Board of The Neuropathy Association, that the papers had been signed the night before to dissolve The Neuropathy Association (TNA) and all collected information would be passed to The Foundation for Peripheral Neuropathy in Illinois. It was described that they were 'passing the torch'. The Foundation for Peripheral Neuropathy has a research focus, but it is planning to make its information resources more widely known and available along with the material they receive from The Neuropathy Association. We are pleased to learn that this information will be available to us as well as our support group leaders. We and those of you that receive The Neuropathy Newsletter have known for some while that The Neuropathy Association was facing financial challenges. This resolution to their challenges helps to maintain a strong research presence.

The Pacific Chapter of The Neuropathy Association is a California Public Benefit Corporation completely separate from The Neuropathy Association so the only change is that the affiliation agreement is dissolved and the name will be changed to reflect that it is no longer a chapter. On Monday, December 15, 2014, the PCNA Board of Directors voted to change the name to the Western Neuropathy Association to represent outreach in the western United States. All relationships, benefits, and responsibilities with individuals, support groups, other organizations, or businesses will continue.

In early January, a teleconference with all group leaders across the country who are able to call in at the time is planned by The Foundation for Peripheral Neuropathy to introduce themselves and describe what help they can make available to group leaders. There are two types of support groups involved in this process--incorporated groups similar to PCNA, which is the largest of the incorporated groups, that provide networking and insurance benefits, and the other type is the ones that look to The Neuropathy Association for help but are independent. Texas is among the incorporated category, which has three

groups and may soon have a few more. The other incorporated chapters are just one group, as far as we know now. Gene Richardson of The Neuropathy Support Network has counseled with some and provided encouragement. It is a period of transition and everyone is dedicated to ensuring the viability of all groups who want to remain active. Updates will be included in this newsletter as they unfold.

Previously, The Neuropathy Association had a printed newsletter that was published periodically, but it was transitioned to an electronic-only format. A number of you paid annual dues to support TNA as I have. The Foundation for Peripheral Neuropathy also has a membership and has a monthly e-mail newsletter. In addition, there is a twice a year newsletter that is mailed to members. Their annual dues are \$30. We ask that you join PCNA when your dues are due or join if you haven't yet done so. The name change does not require any added amount. There will just be a name change on the membership card you receive once our new name has been approved through the various legal channels. We recommend that you also join The Foundation for Peripheral Neuropathy (FPN) so you receive the information they will be distributing.

Here is the letter that was sent out from The Neuropathy Association:

### **THE NEUROPATHY ASSOCIATION**

December 2014

Dear Friends,

1+1=3 may earn little Johnny a failing grade in school, but it can be a winning formula for The Neuropathy Association and the Foundation for Peripheral Neuropathy (FPN), two organizations with the same goal—finding cures for Peripheral Neuropathy (PN) and, before cures are found, helping patients live better lives.

Since 1995, The Neuropathy Association (the Association) has focused its efforts on helping and healing people with peripheral neuropathy through awareness, education, support, advocacy, and

# Roster of Our PCNA/WNA Information and Support Groups

## 2015 PCNA/WNA Board of Directors

**Bev Anderson**  
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**Karen Polastri**  
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Secretary

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Treasurer

**Sandra Grafrath**  
Director

**Brad Livingood**  
Director

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Emeritus


**Sandra Vinson**  
Emeritus

**Dick Ward**  
Emeritus

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

**Bev Anderson**  
Editor

Newsletter Design by

 Diane Blakley  
Designs

## CALIFORNIA

### Alturas

For information call:  
Bev Anderson (877) 622-6298

### Antioch-Brentwood

3<sup>rd</sup> Wednesday, 2 PM  
Antioch-Kaiser, Sand Point  
Watch for sign or check at desk.  
Bev Anderson 877-622-6298

### Auburn

1<sup>st</sup> Monday, 11 AM  
Woodside Village MH Park  
12155 Luther Road  
Sharlene McCord (530) 878-8392

### Bakersfield

3<sup>rd</sup> Wednesday, 1:30 PM  
Stockdale Moose Lodge  
905 S. Stine Rd..  
David Wollard (661) 663-9406

### Berkeley-Oakland

3<sup>rd</sup> Wed., 3-4 PM  
North Berkeley Senior Center  
1901 Hearst Ave.  
Kathleen Nagel (510) 653-8625

### Carmichael

2<sup>nd</sup> Tuesday, 1:30 PM  
Eskaton  
3939 Walnut Ave.  
Karen Robison (916) 972-1632  
*Call Karen before coming as it is a gated  
community and sometimes the day/time  
changes. She welcomes newcomers!*

### Carmichael

3<sup>rd</sup> Thursday, 6 PM  
Atria El Camino Gardens  
2426 Garfield, Ave.  
Tanysha Kaye (916) 488-5722

### Castro Valley

2<sup>nd</sup> Wednesday, 1:30 PM  
First Presbyterian Church  
2490 Grove Way (next to Trader Joe)  
Judson Leong (510) 581-6697

### Clearlake

For information, call  
Bev Anderson (877) 622-6298

### Concord

3<sup>rd</sup> Thursday, 1:30 PM  
First Christian Church  
3039 Willow Pass Road  
Wayne Korsinen (925)685-0953

### Crescent City

For information call:  
Bev Anderson (877) 622-6298

### Davis

2<sup>nd</sup> Tuesday, 3:30-5:00 PM  
Davis Senior Center  
646 A Street  
Mary Sprifke (530) 756-5102

### Elk Grove

2<sup>nd</sup> Tuesday, 1 PM  
Elk Grove Senior Center  
8830 Sharkey Avenue  
Roger White (916) 686-4719

### Eureka

For information call:  
Earlene (707) 496-3625

## Folsom

3<sup>rd</sup> Monday, 1:00 PM- odd numbered months  
Journey Church  
450 Blue Ravine Rd.  
Bev Anderson (877) 622-6298

## Fort Bragg

For information call:  
Betty Adams (707) 964-3327

## Fresno

3<sup>rd</sup> Tuesday, 11:00 AM  
Denny's Restaurant  
1110 East Shaw  
Marvin Arnold (559) 226-9466

## Garberville

For information call:  
Bev Anderson (877) 622-6298

## Grass Valley

2<sup>nd</sup> Monday, 1:30 PM  
GV United Methodist Church  
236 S. Church Street  
Salli Hearn (530) 268-1017

## Jackson

For information, call  
Bev Anderson (877) 622-6298

## Lakeport

For information call  
Mito Shiraki (707) 245-7605

## Lincoln Hills

Thurs., Oct. 23, 1:00 PM  
Bev Anderson (877) 622-6298

## Livermore

4<sup>th</sup> Tuesday, 10 AM  
Heritage Estates  
900 E. Stanley Blvd.  
Sandra Grafrath (925) 443-6655

## Madera

For information, call  
Bev Anderson (877) 622-6298

## Merced

2<sup>nd</sup> Thursday, 1 PM  
Central Presbyterian Church  
1920 Canal Street  
(The Hoffmeiser Center across the  
street from the church)  
Larry Frice (209) 358-2045

## Modesto

3<sup>rd</sup> Monday, 10:30 AM  
Trinity United Presbyterian Church  
1600 Carver Rd., Rm. 503  
Monte Schrader (209) 531-3838

## Monterey

3<sup>rd</sup> Wed., 10:30 AM-odd numbered months  
First Presbyterian Church  
501 El Dorado Street  
Don & Ann Trout (831) 372-6959

## Napa

1<sup>st</sup> Thursday, 2 PM  
Napa Senior Center  
1500 Jefferson Street  
Ron Patrick (707) 257-2343  
bonjournapa@hotmail.com

## Oxnard

For information call:  
Bev Anderson (877) 622-6298

## Placerville

For information, call  
Bev Anderson (877) 622-6298

## Quincy

1<sup>st</sup> Thursday, 1 PM  
Our Savior Lutheran Church  
298 High St.  
Stacey Harrison (530) 283-3702

## Redding

For information call:  
Tiger Michiels (530) 246-4933

## Redwood City

4<sup>th</sup> Tuesday, 1 PM  
Sequoia Hospital Health and  
Wellness Center  
749 Brewster Avenue  
Stan Pashote (510) 490-4456

## Roseville

2<sup>nd</sup> Wednesday, 1PM-odd numbered months  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Carol Brosk (916) 531-2752

## Sacramento

3<sup>rd</sup> Tuesday, 1:30 PM  
Northminster Presby. Church  
3235 Pope Street  
Charles Moore (916) 485-7723

## Salinas

Contact Bill Donovan  
(831) 625-3407

## San Francisco

4<sup>th</sup> Thursday, 10 AM  
UC-San Francisco Med Ctr.  
400 Parnassus Avenue  
Amb. Care Ctr. 8th Flr., Rm A888  
Y-Nhy (e nee) Duong  
Nhy-y.duong@ucsf.edu

## San Jose

Next meeting Jan. 17, 10:30 AM  
3<sup>rd</sup> Saturday, 10:30 AM  
O'Conner Hospital  
2105 Forest Avenue  
SJ DePaul Conf. Rm.  
Stan Pashote (510) 490-4456

## San Rafael

3<sup>rd</sup> Wednesday, 1 PM  
Lutheran Church of the Resurrection  
1100 Las Galinas Avenue  
Scott Stokes (415) 246-9156

## Santa Barbara

4<sup>th</sup> Saturday, 10AM-odd numbered months  
The First Methodist Church  
Garden & Anapamu  
Shirley Hopper (805) 689-5939

## Santa Cruz

3<sup>rd</sup> Wednesday, 1PM-odd numbered months  
Trinity Presbyterian Church  
420 Melrose Avenue  
Mary Ann Leer (831) 477-1239  
maleer@comcast.net

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## President's Message

By Bev Anderson

Happy 2015. I hope it is a great year for all of us. My dream is that neuropathy will be brought into focus for the nation and that it will receive the attention it deserves for research, better treatments, and even a cure for at least some types of neuropathy. I know you join me in that.

I have an apology and a story that goes with it. Many times I've said that if you are having difficulty driving with your feet, you might try hand controls. I may have sounded off handed, like it was easy to do. I apologize. It isn't. My neuropathy has become a bit worse with my right foot not having the strength to continue managing the trip from the gas to the brake and back again totally accurately. Stress started to build up so I decided to take my own advice.

The installer I chose based on a recommendation was Driving Specialties in Rancho Cordova. They started with an orientation appointment whereby you meet with a person from the driving school they contract with to see if you are a good candidate. I passed that, but rather than the push-pull of the left handed equipment, I opted for the right hand up and down lever. I learned to drive on a stick shift as many of you have possibly done so letting my left hand be the basic driving hand and my right for the controls seemed best for me.

It cost more than I'd planned as they team with Bond Driving School for lessons until they are comfortable in letting the person take the equipment home with them due to insurance concerns. I thought it would come easy, but it didn't. Several people told me that they had it installed, were told in about a sentence or two how to drive it and drove off. I needed the instructions on how the equipment



– Continued on page 6

### Help With Health Care Challenges

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

#### Medicare

[www.Medicare.gov](http://www.Medicare.gov)

•••

#### The Affordable Health Care Act

For current information go to [www.HealthCare.gov](http://www.HealthCare.gov)

•••

#### HICAP

#### Health Insurance Counseling

for seniors and people with disabilities.  
[www.cahealthadvocates.org](http://www.cahealthadvocates.org)  
/HICAP/  
Call (800) 434-0222 to ask a question or 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](http://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, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

## PCNA/WNA Information and Support Groups – continued from page 2

### Santa Maria

2<sup>nd</sup> Tuesday, 12:00 Noon  
Elwin Mussel Senior Center  
510 Park Street  
Wanda (805) 938-1086  
Mary (805) 344-6845

### Santa Rosa

1<sup>st</sup> Thursday, 10:30 AM  
Santa Rosa Senior Center  
704 Bennett Valley Road  
Larry Metzger (707) 541-6776

### Sonoma

For information, call  
Bev Anderson (877) 622-62988

### Sonora

For information, call  
Bev Anderson (877) 622-6298

### Stockton

For information, call  
Bev Anderson (877) 622-6298

### Susanville

For information call:  
Bev Anderson (877) 622-6298

### Thousand Oaks Region

Emmanuel Church  
588 Camino Manzanitas Room 9  
Mel Staton (805) 482-8607

### Truckee

For information call:  
Bev Anderson (877) 622-6298

### Tulare-Visalia

For information call  
Bev Anderson (877) 622-6298

### Turlock

3<sup>rd</sup> Monday, 1 PM  
Covenant Village Adm. Bldg. Classroom  
2125 N. Olive St.  
Joanne Waters (209) 634-0683

### Ukiah

Last Tuesday, 5:30 PM  
North Coast Opportunities (NCO)  
413 N. State St.  
Shirley Blattner (707) 621-0208  
Carole Hester (707) 972-2795

### Walnut Creek

4<sup>th</sup> Friday, 10 AM  
Rossmoor, Hillside Clubhouse  
Las Trampas Room  
David Woods (925) 287-8100

### West Sacramento

No meeting until new leader is found  
Sandra Vinson (916) 372-6093  
slvins11@gmail.com

### Woodland

No meeting until new Leadership Team forms.  
Elizabeth Chaudhry (530) 661-3859

### Yreka

For information call  
Bev Anderson (877) 622-6298

### Yuba City-Marysville

Next meeting, Jan. 13  
2<sup>nd</sup> Tuesday, 10:30 AM  
St. Andrew Presbyterian Church  
1390 Franklin Rd.  
(next to Winco Shopping Center)  
Ken Lux (530) 673-3479

### NEVADA

#### Reno-Sparks

For information call  
Bev Anderson (877) 622-6298

### OREGON

#### Brookings

For information, call  
Robert Levine (541) 469-4075

#### Grant's Pass

3<sup>rd</sup> Wednesday, 10:30 AM  
First Christian Church  
305 SW H Street  
Carol Smith (541) 955-4995

#### Medford

For information call  
Mike (714) 866-2954

#### Portland

For information call  
Joe Mozena (503) 505-0692 or  
Bev Anderson (877) 622-6298

#### Salem

3<sup>rd</sup> Monday, 6:30 PM  
Community Health Education Center  
Salem Hospital Campus, Bldg. D  
890 Oak Street SE  
Michael (503) 857-3508  
[newsforsalem@gmail.com](mailto:newsforsalem@gmail.com)

Start a support group in your area: Contact Bev Anderson at (877) 622-6298 or [info@pnhelp.org](mailto:info@pnhelp.org)

## CANNABIS (MARIJUANA) FOR PERIPHERAL NEUROPATHY

At a recent meeting of the Monterey Peripheral Neuropathy Support Group, we heard a presentation by Deborah Malka, MD, PhD, on Pain Management, Natural Alternatives for Health. Dr. Malka practices in Monterey and Santa Cruz, and is recognized for her expertise in prescribing cannabis for chronic pain. Recently she spoke to the Pain Support Group at the Community Hospital of the Monterey Peninsula, and last year, with the county assistant district attorney, gave a grand rounds presentation to the hospital medical staff.

Dr. Malka opened by saying that she prefers to use the term cannabis rather than marijuana to emphasize its therapeutic rather than its recreational connotation. She informed us that, although the prescription of cannabis is not permitted by federal law, its sale through licensed dispensaries is sanctioned by California among a growing number of states.

Although she acknowledges that smoking cannabis is not good for the lungs, and can produce some cognitive impairment and reduction in psychomotor skills while driving, it is not toxic to other bodily systems as are many synthesized medications.

Dr. Malka showed us a cannabis salve that can be applied topically in order to achieve local analgesia, typically on the feet in the evening. She also showed us the tincture (alcoholic

extraction) available in a one-ounce dropper bottle for oral use.

Cannabis is also available in an oral capsule and a smoked cigarette, which are shorter acting than the butter and food forms of the drug. Typically the cost of the medication is about \$100 a month.

Dr. Malka has found that most of her patients on cannabis have been able to greatly reduce, if not discontinue, potent opiate narcotics including hydrocodone, oxycodone and morphine. She explained that cannabis has the ability to block pain transmission peripherally. It is also an anti-inflammatory as well as a muscle relaxant and antidepressant.

The principle forms of cannabis include cannabidiol (CBD), which has more peripheral effect, and tetrahydrocannabinol (THC), which has more effect centrally (brain).

It is possible to adjust the prescription of these two chemicals in the tincture to minimize intoxication while maximizing analgesia.

William B. Donovan, M.D.

NOTE: Dr. Malka charges \$110 for an initial evaluation and \$80 for a follow-up appointment. Contact information: [www.cannabisplus.net](http://www.cannabisplus.net) [dmalka@comcast.net](mailto:dmalka@comcast.net) or 831-426-7744

## PERIPHERAL NEUROPATHY LITERATURE REVIEW

By William B. Donovan, M.D.

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over 100 medical articles a month written on PN.

I review these references and select articles that would appear to be most interesting to us neuropathy sufferers. This is the link to **PubMed** that will take us to the **NLM**: [www.ncbi.nlm.nih.gov/sites/entrez](http://www.ncbi.nlm.nih.gov/sites/entrez)

If you are reading this article on the computer, just click on the above link to go there. If you are reading the print edition of the newsletter, type this link into the address bar of the browser on a computer. If you don't know how, get a librarian or friend to help you.

After you get to **PubMed**, you will see a line that says "**Search PubMed**" followed by "**for**" and a space. Every article in the **NLM** is given a **PMID**, an eight digit identification number. I will give you **PMID** numbers of the selected articles. Type the **PMID** into the space after the "**for**" and click on "**Go**" at the end of the space, or press the ENTER key on your keyboard. You will then see a one paragraph abstract of the article appear, as well as links to related articles.

This month's PMIDs:

- 22717465 Pre- and post-testing of patients with diabetic peripheral neuropathy subjected to a 10-week aerobic and strengthening exercise program revealed significant reduction of pain; increased intraepidermal nerve fiber branching (on skin biopsy); and decreased neuropathic symptoms.
- 22809652 A Cleveland Clinic review of the opioid buprenorphine (Subutex®) supports its use as a "first line

analgesic" for the treatment of cancer and neuropathic pain. Its advantages include: less tolerance and constipation, less respiratory depression and cognitive impairment, fewer side effects, and greater safety and effectiveness with the elderly.

- 22810071 A detailed review of the differential diagnosis and treatment of immune-mediated neuropathies, both involving the myelin sheath and neural vasculature. The article compares the findings in Guillain-Barre, the various demyelinating neuropathies, myasthenia gravis, botulism poliomyelitis, tick paralysis, toxic states and carcinomatosis, as well as hematologic conditions that can underlie these neuropathies.
- 22893563 Diabetic peripheral neuropathic pain which is responsive to duloxetine (Cymbalta®) showed a drop in pain score in proportion to the level of baseline score.
- 22909343 A Turkish study of dialysis patients with neuropathic pain and pruritis (itching), both of which responded to both gabapentin (Neurontin®) and pregabalin (Lyrica®).
- 22972149 An Oxford Cochrane Database study of "... randomized double-blind placebo-controlled studies of at least 6 weeks duration, using low-concentration (<1%) topical capsaicin to treat neuropathic pain," suggesting that capsaicin at this concentration is "...without meaningful effect beyond that found in placebo creams."
- 22898039 This meta-analysis of four prospective randomized and three retrospective clinical trials demonstrated decreased incidence of chemotherapy (oxaliplatin)-induced acute and cumulative neurotoxicity with Ca/ Mg infusions compared to placebo.

## A DAY IN THE LIFE OF A NEUROLOGIST

A neurologist's first focus is the Central Nervous System, which means they pay the most attention to the brain and the spinal cord and anything that is causing concern there. Some of these are multiple sclerosis (MS), Amyotrophic lateral sclerosis (ALS), Parkinson's disease, Familial Tremor, strokes, Cerebral palsy, dementia, seizure disorders, spinal stenosis, and injuries caused by accidents or assaults.

Neurologists have to be good at diagnosis of a multitude of problems. They do a range of nerve and muscular testing, EMG/NCV, and blood tests for a neuro-muscular evaluation for all types of neurological problems including neuropathy. EGG is used with seizure disorders. Some neurologists are better at diagnosis than others. Much depends on training and experience. Doctors tend to not want to deal with hard to treat patients, but the limited number of neurologists in any area, if they have a neurologist, doesn't allow them to choose. It is wisest to be as easy to treat and as cooperative a patient as possible.

A typical day goes like this: 7-9 a.m. at the hospital to see in-hospital patients and any that have come in during the night that are suffering a condition requiring a neurologist if they haven't already been called by the Emergency Room staff to come in immediately as they were on call. Days can have heavier or lighter caseloads. 9 a.m. more or less, the neurologist is in the office to deal with the caseload of the day for which appointments have been made. Typically, they can see 20-30 patients a day. These can be:

- Follow up of previous visit
- Patient recently discharged from the hospital
- Meeting and testing of new patients including those with neuropathy

- Workmen's Comp evaluations
- Phone calls to doctors or receiving some from doctors and other needed contacts, possibly a family member with a concern

The office staff works very hard and is glad for the times when the neurologist takes time off during the week so they can catch up on paperwork, billing, transcribing, processing the testing so there is a quick turnaround with results and myriad of other details. The office manager has to know all that is going on and thus is your best resource to work well with the doctor. They are responsible for expediting and organizing for your care so showing them respect is a good strategy.

It is good to remember that the neurologist has to be a very bright person to do what he or she does. However, they are also human beings with spouses and families that can need help. So neurologists have stresses the same as other people in addition to their professional life. They have their own personality as do we all. It is advised to respect your neurologist's time by being punctual for appointments, having done what the doctor asked you to do at the last appointment, and being able to tell the doctor what you did and the results. If you don't do what the doctor says to do, it is lost time and you may be worse than the last time they saw you. They are at a loss to know how to treat you if you don't follow through on the treatment so they can tell if it made a difference. Most doctors are not good with small talk as they don't have time, so be organized, come with anything you want to ask or tell on paper so you won't forget it or beat around the bush trying to remember how you wanted to say it.

(Author: Bev Anderson after interviewing a friend who was, for many years, the office manager for a very busy neurologist.)

### DISCOUNTS FOR PCNA MEMBERS

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

**Anodyne Therapy**  
Infrared Light Therapy equipment - **\$50 off Model Freedom 300 (single leg at a time) and \$50 discount on Model 120 that does both legs at the same time.** Contact: 800-521-6664 or [www.anodynetherapy.com](http://www.anodynetherapy.com)

**HealthLight** Infrared Light Therapy equipment - **10% off Single Boot System and Dual boot system.** Contact: 888-395-3040 or [www.healthlight.us](http://www.healthlight.us)

**Auburn**  
**The Footpath**  
825 Lincoln Way  
(530) 885-2091  
[www.footpathshoes.com](http://www.footpathshoes.com)  
**PCNA Discount: 10% off the regular price shoes.**

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

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

**Sacramento**  
**Midtown Comfort Shoes**  
3400 Folsom Blvd.  
(916) 731-4400  
**PCNA discount: 15% on the regular price.**

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## SAVE THE DATE & PRE-REGISTER

# The 2015 Annual Conference

## April 22, 2015

### Jelly Belly Factory, Fairfield, CA.

Save a place for yourself and encourage others to also pre-register by sending the \$20 per person Conference Fee to PCNA/WNA, P.O. Box 276567, Sacramento, CA 95827-6567.

## DISCOUNTS FOR PCNA MEMBERS

Continued from page 5

### West Sacramento

#### Beverly's Never Just

#### Haircuts and Lilly' Nails

2007 W. Capitol Ave, West Hair-(916) 372-5606

Nails-(916) 346-8342

**PCNA discount: 10% off the regular price.**

### Neuropathy Support Formula

(1-888-840-7142) is a supplement that a sizable number of people are taking and reporting it has helped them. The company gives members of PCNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back.

### Free DVD on

#### "Coping with Chronic Neuropathy"

introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at [www.neuropathysupportnetwork.org/order-neuropathy-dvd.html](http://www.neuropathysupportnetwork.org/order-neuropathy-dvd.html)

### 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](mailto:info@pnhelp.org).

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

## A SUDDEN SURPRISE WE SHOULD BE AWARE OF

(This story could help all to be aware of this possibility. This month, I needed this information and found it too late to get a lady to the ER before the event happened and she couldn't walk. This is from a publication of the GBS/CIDP Foundation International.)

For Matt, the storm came suddenly. A week of excruciating pain in his extremities made it clear that he needed help. It was not a moment too soon. He collapsed walking to the car to go to the ER. "I landed hard halfway between our house and the car," he reported. Matt could not walk again for nearly three months.

Matt found a port in the storm. During his second visit to the ER, his doctors were familiar with GBS (Guillain-Barre Syndrome) and identified it. He was admitted immediately into the ICU. Within hours he was treated with intravenous immunoglobulin (IVIG).

A worse problem arose: Matt's body did not react to the medication. "I was in terrible pain – shooting from my right shoulder to my left thigh," Matt remembers. "That's when things started to get fuzzy." He needed an advanced level of treatment. Matt's doctors transferred him to another hospital's Neuro ICU. Now he was in the care of some of the finest neurologists in the country. His lungs were shutting down so they put him on a respirator and started him on propofol.

"For 28 days, I was in a perpetual dream state," he vaguely remembers. However, Matt's condition was no dream. His condition continued to worsen despite the change in treatment to plasmapheresis. It was not until the third set of treatments that his body began to respond.

It was scary for his entire family, not just for Matt. As a father of a six-month-old, the thought of him dying, even if the possibility was remote, put everyone on edge. In the time he was there, the drugs and the feedings took their toll. Matt came to the hospital at 160 lbs., a runner of up to 16 miles at a time. He left a wispy 120 lbs. in a wheelchair, barely able to lift his arms.

After months of continued therapy, he is back to work. He is not able to run yet, but can walk longer distances. He is catching up with his family, especially his daughter now three years old. He expresses his thanks to all that came to his aid from his family, the hospital, the community and the GBS/CIDP Foundation International that came alongside him to encourage, explain, and have people who had experienced what he was going through spend time with him.

That is what happens with many that go to support groups and find people who know what they are going through because they have been there or are having the same problems currently.

### President's Message – Continued from page 3

worked and the driving supervision. After nearly six hours of training at two hours each time, I finally was able to keep them in the car and drive home. I don't have to drive to Rancho Cordova again until the yearly inspection and adjustment of the equipment.

On the way home with the equipment, I had a very efficient brake to depend on. Being in stop and go rush hour traffic and with two sections where work was being done and several lanes merging into one was not a panic situation. I drove with more confidence. It still will take practice and getting fully used to but the corner is turned and giving up driving which I could see coming soon is not likely to happen. I'm finding

driving at night out of my familiar area is not as comfortable so I try to avoid that as much as possible.

Thank you for all the encouragement and support you gave in 2014. It is much appreciated. I trust you will renew your dues and many more will join in 2015. The impact that can be made is magnified by the number of people involved. Even just paying your dues is seen as a vote for progress in bringing attention to neuropathy so progress can be made toward better treatments and even a cure.

*Beverly*

## TNA (The Neuropathy Association) Dissolves – Continued from page 1

research. We have made tremendous progress during those nearly 20 years, growing into an organization with a global online reach. We have

championed the development and approval of IVIG; created National Neuropathy Awareness Week; testified before Congress for more neuropathy funding; provided numerous research grants; and have played a direct role in creating the soon-to-be released National Pain Strategy, a major advance in treatment and care. And, every day, we have strived through our network of support groups, chapters, Neuropathy Medical Centers of Excellence, and affiliated researchers and physicians to provide the highest level of service to the neuropathy community.

Given that commitment to high-level service, and taking into account New York law and a number of other factors, we have now concluded that the best course of action for the Association is to dissolve and ‘pass the torch’ to the Foundation for Peripheral Neuropathy. In doing so, we have chosen a strategic partner that we fully support and trust will achieve our mutual goals in the future. The decision to close our doors is difficult, but the decision to select FPN to continue to work on behalf of The Neuropathy Association’s donors is the right choice. We believe the result will be a single and powerful charitable 501(c)(3) organization that will capitalize on the strengths of both organizations to better serve the PN community.

As The Neuropathy Association begins to wind down, the Association and FPN are working together to ensure you will continue to receive seamless and uninterrupted support. Here is what you should know:

- Both organizations have a website which will be directed into one more comprehensive and informative website ([www.foundationforpn.org](http://www.foundationforpn.org)). Similar to the Association, FPN provides their members with a bi-monthly electronic newsletter and a bi-annual printed newsletter. By joining FPN’s membership (which can be done online or by mail at the address listed below), you will be able to continue to receive these very informative and educational publications.
- Both organizations have been doing work in Washington to get more support for research, building upon The Neuropathy Association’s relationships and FPN’s symposium involvement with the National Institutes of Health. FPN will continue this work and we hope these efforts will allow for additional funding in this field.
- If you have been involved with the Association’s Facebook chats in the past, we encourage you to join FPN’s Facebook page for similar opportunities in the future.
- During the past two years, the Association has offered a series of webinars that have afforded patients educational information on neuropathy. FPN will begin offering webinars and plans to expand these programs and offerings by utilizing its extensive contacts in the peripheral neuropathy scientific and clinical fields, thus making them more robust and beneficial for all.
- Over the years, the Association has helped develop support groups across the country. FPN can become a valuable resource for these support groups—through its website, connection to experts in the field of neuropathy, patient videos, and providing meeting literature. We encourage you to visit FPN’s website at

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

In addition, FPN is focused on two major initiatives that will make a significant impact in research to find new treatments and cures. The first is the creation of The Peripheral Neuropathy Research Registry (PNRR).

This registry collects blood samples and extensive personal histories of carefully screened patients from four of the nation’s leading medical facilities focusing on peripheral neuropathy. Included are Johns Hopkins in Baltimore, Northwestern University Medical Center in Chicago, Beth Israel in Boston, and Mount Sinai in New York. With a generous grant from Bristol-Myers Squibb, they will soon be adding a fifth partner on the west coast, the University of Utah. The goal of the registry is to provide data and samples to researchers worldwide to further their efforts to diagnose, treat, and eventually cure peripheral neuropathy.

As part of FPN’s research portfolio, FPN holds International Research Symposia bi-annually. Scientists, clinical researchers, industry, and NIH, FDA and nominated junior investigators from around the world come together to discuss the challenges of drug discovery for peripheral neuropathies with a goal of uncovering roadblocks in order to move the field forward. The last two such seminars focused on finding ways to speed clinical trials to get new medical cures to the sufferers faster.

So, yes, 1+1 can equal 3... or even 4, or 5 or more.

The Association is grateful to have served the neuropathy community for the past two decades. As we say goodbye and close our doors, we are confident the Foundation for Peripheral Neuropathy’s efforts will result in better treatments sooner and, eventually, a faster path to cures. We want you to know that all of the initiatives above are critical and very deserving of your financial support. We encourage you to direct all future donations to the Foundation for Peripheral Neuropathy as it continues this important work. We can assure you with great confidence that “Donor Intent” will carefully be observed and that, under this new arrangement, your donations will go toward supporting your goals.

Finally, we extend our heartfelt thanks to all of you who have supported The Neuropathy Association over the last 20 years. As you begin to enjoy this holiday season with family and friends, we encourage you and our family to make your year-end gifts to the Foundation for Peripheral Neuropathy to support our mutual goal: fighting and curing neuropathy.

Wishing you good health and holiday cheer,  
James R. Gardner  
Chairman of the Board

\*We greatly appreciate the Foundation for Peripheral Neuropathy’s funding that enabled the Association to provide this broad mailing so that we could inform our supporters of these changes. Because the Association believes it to be of the utmost importance that our constituents know where to turn for support in our absence, we have shared our contact list with FPN so they can keep you apprised of pertinent information, developments, and opportunities. If you would like to reach out to FPN directly, please contact them at [info@tffpn.org](mailto:info@tffpn.org); (877) 883-9942; or 485 Half Day Road, Suite 350, Buffalo Grove, IL 60089.



## The Pacific Chapter of The Neuropathy Association

A California public benefit, nonprofit,  
tax exempt corporation

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Call PCNA/WNA using our toll free phone numbers:

**(877) 622-6298** • Email: [info@pnhelp.org](mailto:info@pnhelp.org)

• PN Information/Advice • Support Group Inquiries

**(888) 556-3356** • Email: [donnad@pnhelp.org](mailto:donnad@pnhelp.org)

• Membership Information/Inquiries • Sponsorships

• General Organizational Inquiries • [www.pnhelp.org](http://www.pnhelp.org)

**SAVE THE DATE!**  
**Annual Conference**  
**April 22, 2015**  
Jelly Belly Factory, Fairfield, CA

## "Coping with Chronic Neuropathy"

Free DVD on "Coping with Chronic Neuropathy" is available by contacting the Neuropathy Support Network at [www.neuropathysupportnetwork.org/order-neuropathy-dvd.html](http://www.neuropathysupportnetwork.org/order-neuropathy-dvd.html)

COPING WITH CHRONIC NEUROPATHY is a real life story full of information, hope, humor and challenge. The 2014 revision of this production is introduced by Dominick Spatafora (Neuropathy Patient) Founder and President of the Neuropathy Action Foundation in Los Angeles, California. The seminar is endorsed and recommend by Alan Berger MD FAAN, Professor and Chairman, Dept. of Neurology, UF Health@Jacksonville; by Thomas Brannagan MD FAAN, Professor and Chairman, Department of Neurology, Columbia University, NYC; and by practicing Neuromuscular Neurologist Waden Emery MD FAAN of Lighthouse Point, FL. You will not only learn what Peripheral Neuropathy is, but you will also learn what it is not. This is important if you are to avoid lots of snake oil exaggerated promises and claims of magic cures.

Surviving beyond the challenges of the disease is the theme throughout, with insights shared on how to use anger as power, while facing the question of "why me", yet holding onto the fun from your inner child. Discussed is the power of faith, increasing your neuropathy knowledge, getting and giving patient support, and learning to adapt to the changes neuropathy brings to lives - while remaining focused on getting help for your neuropathy.

Critical issues such as getting support from the doctor, family and from the work place are topped off with a chapter on the reality of a patient's world and the importance of finding a secret place of peace. The seminar leaders poem "When is it Enough?" inspires us, read to the music from "You Lift Me Up" while his two supporting doggies bring the DVD to a close.



## The Pacific Chapter of The Neuropathy Association (PCNA)

A California public benefit, nonprofit,  
tax-exempt corporation.

Bev Anderson, Editor

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PCNA Headquarters: [donnad@pnhelp.org](mailto:donnad@pnhelp.org)

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

All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

*This newsletter is designed for educational and informational purposes only. The information contained herein 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. The Pacific Chapter of the Neuropathy Association (PCNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. 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.*