



# Neuropathy Hope

## Hope Through Caring and Education

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

May 2009  
Volume 5  
Issue 5

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## ■ There May Yet Be Time to Register for the Annual Meeting

This newsletter may get to you earlier than usual. The deadline to register for the Annual Meeting is April 20. If you plan to come, please get your registration in by this date. There is no charge for this event. A continental breakfast and box lunch are included. Register on line at [www.pnhelp.org/happenings/meetingregistration.php](http://www.pnhelp.org/happenings/meetingregistration.php) or call toll-free 877-622-6298.

### NCCNA's Annual Meeting

**Monday, April 27, 2009**  
Woodland Community  
and Senior Center  
2001 East St., Woodland.

**Deadline to register  
is April 20**

Event: NCCNA's Annual Meeting, Monday, April 27, 2009, 9 a.m. – 3 p.m., Woodland Community and Senior Center, 2001 East Street, Woodland. Speakers: Dominick Spatafora, President, Neuropathy Action Foundation; Scott Fishman, M.D., Chief of the Division of Pain Management and Professor of Anesthesiology and Pain Medicine at the University of California, Davis; Mae Denman, Gentle Yoga therapist.

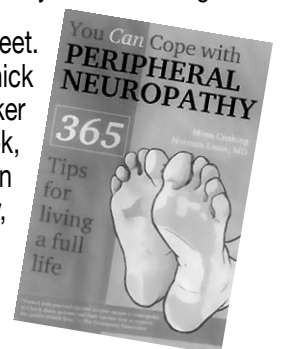
We applaud the Woodland, Davis, and West Sacramento PN Support Groups for hosting this year's Annual Meeting. A special thanks to Delia Genera, Leader of the Woodland PN Support Group, for organizing and inspiring those in all the groups to take part. We will have the largest attendance of any

Annual Meeting we have had. The participation of leaders and members of these groups contributed greatly to this wonderful turnout. Many thanks to all. The Woodland Community and Senior Center is a co-host of this event. They provided the space to us without charge and have been helpful in a number of other ways. Thanks also to the staff of the Woodland Community and Senior Center. All members actually participated in funding this event as NCCNA paid for the food for the breakfast and lunch.

## ■ Neuropathy Action Awareness Day in Sacramento – June 25

The Neuropathy Action Foundation (NAF) is again sponsoring Neuropathy Action Awareness Day, a conference for people with neuropathy and those who care about them. Previously held in San Francisco, this year it is coming Sacramento. Details are still being developed. The day seminars are usually without charge, but there is a cost for the dinner. This has usually been at a reduced cost for those with neuropathy and one caregiver.

Registration and exhibits open at noon at the Sheraton Grand Hotel, 1230 J Street. NAF will pay for the valet parking. The conference itself starts at 12:30 PM. Dominick Spatafora, NAF President, will welcome and give an overview of the day. The first speaker is Mims Cushing, acclaimed writer and author. She will have copies of her new book, *You Can Cope With Peripheral Neuropathy: 365 Tips for Living a Full Life*. Norman Latov, MD, PhD, is co-author. Bev Anderson, NCCNA President, and Martha Chandley, long-time supporter of neuropathy education and action, contributed material for this book and were in contact with Mims during its writing. They are excited to welcome this dynamic, east coast lady they know only through phone and e-mail contact.



“Good Immune Systems Go Bad in Neuropathy” is the topic Jen Seda, MD, Director of US Product Management, Talecris Biotherapeutics, is presenting. Michelle Vogel, Executive Director, Alliance for Plasma Therapies, and Margaret Reilly, Program Manager, Health Insurance Counseling and Advocacy Program (HiCAP) will speak on “Understanding Your Health Insurance and Championing Healthcare Rights for Yourself and Others.”

Eric I. Hassid, MD and Marco Vespignani, ND, Institute for Restorative Health, Davis, CA, popular speakers at last year's conference, will present “Alternative Options in Treating Neuropathy.” Todd Levine,

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

## 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

**Suzanne Lieban**  
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**Dick Ward**  
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**Penni L. Smith**  
Technology Director

**Michael Green**  
Director

**Sandra Vinson**  
Director Emeritus

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

### Alturas

Judy Briener  
For current information  
(530) 233-4733

### Arcata

3<sup>rd</sup> Thursday, 12:30 PM  
Senior Resource Center  
Of Humboldt  
321 Community Park Way  
Martha Bolt (707)825-9454  
**Speaker: Bev Anderson**  
**NCCNA President**

### Auburn

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

### Berkeley

3<sup>rd</sup> 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

### Concord

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

### Crescent City

Friday, May 22, 10 AM  
Call for location  
Bev Anderson (877) 622-6298 (toll free)

### Davis

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

### Elk Grove

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

### Eureka

3<sup>rd</sup> Wednesday, 10 AM  
Humboldt Senior Resource Ctr.  
1910 California Street  
(707) 268-8937  
**Speaker: Bev Anderson**  
**NCCNA President**

### Folsom

1<sup>st</sup> Thursday, 1 p.m.  
Journey Church  
450 Blue Ravine Rd., K-2  
Lorraine (916) 983-4023  
Beverly (916) 984-4302  
**Welcome new Leader:**  
**Amy Considine**

### Fort Bragg

10 AM, Tuesday, May 19  
Call for location  
Bev Anderson (877) 622-6298

### Fresno

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

### Grass Valley

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

### Jackson

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

### Lincoln

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

### Livermore

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

### Merced

2<sup>nd</sup> Thursday, 1 PM  
Central Presbyterian Church  
1920 Canal Street  
(The Hoffmeiser Center across  
the street from the church)  
Susan Baldasano (209) 617-6283  
**Speaker, Bev Anderson**  
**NCCNA President**

### Modesto

3<sup>rd</sup> Monday, 10:30 AM  
Denny's Restaurant  
1525 McHenry Ave.  
Noreen Jones (209) 846-0954

### Monterey

3<sup>rd</sup> Wednesday, 10:30 AM  
odd numbered months  
First Presbyterian Church  
501 El Dorado St.  
Don & Ann Trout (831) 372-6959  
**Come to the meeting in May.**

### Napa

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

### Oakland

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

### Placerville

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

### Redding

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

### Reno, NV

2<sup>nd</sup> Tuesday, 6:30 PM  
Fire Station #11  
7105 Mae Anne Ave.  
Marsha Campbell (775) 851-0499  
LadyJane2b@sbcglobal.net

### Roseville

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

### Sacramento

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

### San Francisco

Call to be sure of meeting day & time.  
UC-San Francisco Med Ctr.  
400 Parnassus Ave.  
Amb. Care Ctr. 8th Flr. , Rm A888  
Rowena Mah, RN (415) 502-5064  
Rowena.mah@ucsf.edu.  
**May 28, Speaker, Bev Anderson**  
**NCCNA President**

### San Jose

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

### San Mateo

3<sup>rd</sup> Thursday, 1 PM  
St. Andrews Lutheran Church  
1501 S. El Camino Real  
Bev Anderson (877) 622-6298 (toll free)  
**Bev Anderson,**  
**NCCNA President**

### San Rafael

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

### Santa Cruz

3<sup>rd</sup> Wednesday  
Trinity Presbyterian Church  
420 Melrose Ave.  
Mary Ann Leer (831) 477-1239  
maleer@comcast.net

### Santa Rosa

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

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### **Sonoma**

1<sup>st</sup> Friday, 10:30 a.m.  
Vintage House  
264 1<sup>st</sup> Street  
Joann Bertolucci (707) 996-8336

### **Sonora**

4<sup>th</sup> Monday, 2 PM  
Sonora Regional Medical Center  
Conference Room  
L.D. Wright (209) 533-2887

### **Stockton**

3<sup>rd</sup> Tuesday, 4 p.m.  
Service First of Northern California  
102 W. Bianchi Rd.  
Bev Mallette (209) 944-7815

### **Susanville**

1<sup>st</sup> Saturday, 10:30 A.M.  
Jackie Woodson (530) 257-4693

### **Truckee**

April thru October, 3<sup>rd</sup> Monday, 1 PM  
Truckee Pines Apartments  
10100 Estates Dr.  
Bev Anderson (877) 622-6298

### **Turlock**

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

**Speaker: Bev Anderson**  
**NCCNA President**

### **Ukiah**

Monday, May 18, 1:00 PM  
Call for location  
Bev (877) 622-6298

**Speaker: Bev Anderson**  
**NCCNA President**

### **Walnut Creek**

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

### **West Sacramento**

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

### **Woodland**

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

### **Yuba City**

Fremont-Rideout Medical Center  
970 Plumas St, Yuba City  
1<sup>st</sup> Flr. Conference Room  
Bev Anderson (530) 389-2416

### **Yreka**

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

**Come to the meeting in May.**

## President's Message

By Bev Anderson



### **Membership is important to NCCNA,**

but also to your support group, if you choose to participate in a group. If you are receiving this newsletter, you are probably already a member. You,

however, probably know others with neuropathy who are not yet members. I ask you to strongly encourage them to take this step. Given that we prorate the dues so they are \$2.50 less each month as the year progresses, in May the dues for 2009 are \$20. This is a great time to talk to people in your group and people you know with neuropathy about joining. If the person chooses not to be in a support group or lives at such a distance that this is not available, they can become an At-Large Member.

If the person chooses to join, it is good that they fill out the form in the brochure or the regular membership form (downloadable from [www.pnhelp.org](http://www.pnhelp.org)) to send with their check. If, however, this is not available, they can send their check marked "membership" to NCCNA, P.O. Box 6985, Auburn, CA 95604, indicating either the group they choose to affiliate with or an indication of "At-Large." We also need complete contact information, including a phone number and e-mail address, if any, as well as whether they want to receive the newsletter by e-mail or standard mail.

Anyone who chooses to receive the newsletter by e-mail gets the newsletter earlier and a friendly note from Penni L. Smith, our technology director. You also get a specially programmed document with tabs to click to bring you to the article you choose from the table of contents on the front cover.

May 10-16 is Neuropathy Awareness Month. To help people to be more aware of neuropathy, let's make May **Membership Recruitment Month** and see how many new members we can bring in. We are almost back over the 700 mark (we always lose a few at the beginning of the year). Do you suppose we could break 800 or more by the end of the year?

*Bev*

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### **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.

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#### **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).

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#### **HMO Help Center**

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

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#### **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".

## DISCOUNTS FOR NCCNA MEMBERS

Give 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  
Fx (530) 885-3074  
Mon.- Fri. 9-5:30,  
Sat. 9-5, Sun. 11-4

[www.footpathshoes.com](http://www.footpathshoes.com)

They carry SAS, Dansko, Merrell, Finn, MBT, Keen, Naot, Reiker, Ecco, Teva, Clark, Wolky, Mephisto, and Earth shoes.

10% off the regular price. Bev Anderson is a regular customer for shoes and slippers.

### Fortuna

Strehl's Family  
Shoes & Repair  
Corner of 12th & Main  
1155 Main Street  
Fortuna, CA 95540  
(707) 725-2610  
Fx (707) 725-0192

Strehl's carries the brands of shoes most kind to neuropathic feet. Marilyn Strehl, C. PED is a Certified Pedorthic. Discount of 10% given. A sizable number of the Eureka PN Group buy shoes here. Marilyn is a member of NCCNA.

### Elk Grove

Shoes That Fit  
8649 Elk Grove Blvd.  
Elk Grove, CA  
(916) 686-1050

20% Discount

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## Peripheral Neuropathy Literature Review #2

By William B. Donovan MD

As described in the last neuropathy newsletter, we can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over a hundred medical articles a month written on PN.

I review these references and select good articles that might be most interesting to us neuropathy sufferers. As mentioned in the last newsletter, we will be looking at articles on prevention, evidenced-based treatment, alternative treatment, and novel research.

This is the link to PubMed, the website that will take us to the NLM:  
[www.ncbi.nlm.nih.gov/pubmed/](http://www.ncbi.nlm.nih.gov/pubmed/)

If you are reading this article on the computer, just click on the 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 do it.

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 press the ENTER key. You will then see a one paragraph abstract of the article as well as links to related articles.

Here are a few PMIDs:

- 18021866 Prevention of PN due to shingles.
- 17920770 Evidence-based first line treatment of neuropathic pain with gabapentin and pregabalin; tricyclic antidepressants and dual uptake inhibitors of norepinephrine and serotonin; and lidocaine patch.
- 17065669 Alternative treatment of distal symmetric polyneuropathy with alpha-lipoic acid.
- 17909094 Novel genetic research with nerve growth factor.

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## Be an Asset to Your Support Group

help people get information about their condition. They can find out about tests and treatments that have helped other people. They can be heard and understood. Most importantly, they can find hope.

Be an asset to your support group. You can really help others if you:

- Share your experiences, but realize that every person is different and others must work with their doctors to make the right decisions for them.
- Don't try to "fix" others or solve their problems. Sometimes, all a person needs is someone who cares enough to listen.
- Always be courteous and respectful.
- Help out. There is something everyone can do to make the group successful. Ask your leader what is needed. Or consider being a leader yourself.

## Neuropathy Action Awareness Day – continued from page 1

MD, Banner Good Samaritan Medical Center and Clinical Assistant Professor, University of Arizona, and Gil I. Wolfe, MD, FAAN, Dr. Bob and Jean Smith Foundation Distinguished Chair Professor of Neurology, UT Southwestern Medical School, will present "Neuropathy 101 for Patients."

At 4:30 p.m. the final session ends and the reception and silent auction begins, followed by dinner from 6-8 PM. The dinner program features Jeffrey Ralph, MD, Assistant Clinical Professor, University of California, San Francisco Medical Center and Director of The Neuropathy Center

sponsored by The Neuropathy Association. He will present "Neuropathy 101 for the General Public." The "You Are Our Hero Award" will be presented. Assemblywoman Mary Hayashi (D-Hayward) will speak briefly. State Senator Leland Yee (D-San Francisco) will stop by to say a few words. A celebrity guest and Dominick Spatafora will close the program.

Please remember that a limited number of hotel rooms for those living a distance away and staying for the dinner are available. Several have already been reserved. Send an e-mail to [info@pnhelp.org](mailto:info@pnhelp.org) or call 877-622-6298 if this is something you need.

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# ■ Report From The Legislative Task Force On Peripheral Neuropathy

*Pursuant to ACR 87 (Hayashi, Statutes of 2008) the Legislative Task Force on Peripheral Neuropathy convened in Sacramento, California on Wednesday, March 25, 2009. The goal of the group was to submit recommendations to the state Legislature on public and physician awareness of the diseases, as well as promoting early diagnosis, treatment and management of peripheral neuropathy. The task force was comprised of providers specializing in neuropathy, researchers of the disease, patient advocates and pharmaceutical companies. The task force meeting was sponsored by the Neuropathy Action Foundation, a non-profit advocacy organization dedicated to ensuring neuropathy patients receive proper treatment and information.*

## INTRODUCTION

Peripheral neuropathy is one of the most common diseases affecting more than 20 million Americans, yet remains an enigma to many. Neuropathy means disease of one or more nerves. Neuropathies can be sensory, motor or autonomic. Sensory nerves tell us how things feel. Motor nerves stimulate muscle contraction and initiate movement. Autonomic nerves control functions that our bodies don't consciously regulate, such as breathing and heart rate. Symptoms present depend on the type of nerve and the location. The symptoms are usually numbness, tingling, pain and/or weakness. Someone with a neuropathy may notice one of these symptoms or he or she may notice that it is harder than normal to do something, such as raising an arm over the head, getting up from a seated position or walking up stairs. There are more than 100 types of PN, but the exact type in any given case depends on exactly how nerves are injured.

There are several causes of peripheral neuropathy including medical problems such as diabetes, genetic, nutritional deficiencies, toxins, compression/trauma and infiltration by tumor. In about 30 percent of patients, a specific cause of neuropathy cannot be found—even after an exhaustive search. These neuropathies are called idiopathic.

Neuropathic pain is costly. Individuals affected by neuropathic pain are oftentimes high users of the health care system as they search for relief from persistent suffering. Much of the available cost data defines costs relative to chronic pain in general so that costs attributable to neuropathic pain are contained with those numbers. Direct and indirect costs of persistent pain, including neuropathic pain, are derived from economic, human, and societal components. The economic burden relates to direct medical costs and productivity loss in the workplace. Chronic pain sufferers may become unemployable or remain underemployed. The National Institute for Occupational Safety and Health estimates that chronic pain costs \$100 billion annually in lost workdays, medical expenses, and other benefit costs.

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**The National Institute for Occupational Safety and Health estimates that chronic pain costs \$100 billion annually in lost workdays, medical expenses, and other benefit costs.**

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In terms of human costs, living with chronic pain affects patients' day-to-day ability to function. Physical and mental problems include difficulties in sleeping, impaired concentration, and a decline in cognitive abilities. Pain contributes to disruption of sleep patterns, which can foster irritability, leading to enhanced sensitivity to pain, and the patient becomes caught up in a vicious cycle. While there is no

cure for peripheral neuropathy, medications and treatments can, in certain instances, provide a treatment option that will allow the individual to live a reasonably normal life. An estimated 20 million Americans (2 million Californians) have neuropathy, although the number of individuals diagnosed is far lower. It is quite common for neuropathies to be misdiagnosed or undiagnosed for years. It is because of this lack of knowledge about the condition that this task force is so vitally important. Public awareness for neuropathies is important, not just for the general populace but for the medical community.

## TASK FORCE DISCUSSION

After hearing presentations about Neuropathy and new research that could help better understand the roots of neuropathy, the task force focused its discussions on three goals:

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## DISCOUNTS FOR NCCNA MEMBERS

*Continued from page 4*

### Sacramento

Dr. Tracy Basso, one of our medical advisors and a member of NCCNA, is happy to offer NCCNA members a 15% discount on purchases at Shoes-n-Feet.

Shoes-n-Feet specializes in comfort shoes, many that are stylish, and carries such brands as Actrix, Aravn, Brooks, Dansk, Naut, Finn, Comfort, and New Balance among others. Most, if not all their shoes, accommodate orthotics. Store employees provide great customer service ensuring the shoes you purchase fit properly, provide good support and feel comfortable.

4740 Natomas Blvd.  
Suite 130  
Sacramento, CA 95835  
(916) 419-0040

### West Sacramento

Beverly's Never Just Haircuts & Lilly's Nails  
2007 West Capitol Ave.  
W. Sacramento, CA  
Tues.-Fri. 9-5,  
Sat. 9-1, Closed  
Sunday & Monday.  
Walk-Ins Welcome  
Hair (916) 372-5606  
Nails (916) 346-8342

The hairdressers and manicurist do great work and are real nice and accommodating. They have a number of older male & female clients and are familiar with neuropathy. Their prices are among the most reasonable around. 10% off the regular price. Sandra Vinson is one of their regular hair, manicure, and pedicure clients.

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## DISCOUNTS FOR NCCNA MEMBERS

*Continued from page 5*

### Additional Discounts

More discounts will be added when someone obtains the agreement of a business that they will offer a discount to members showing their cards. If you talk to someone, you can tell them that they will be listed each month in our newsletter 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).

An agreement form will be mailed to the business and upon its being signed and returned, their business will be added to the next newsletter.

## Legislative Task Force Report – *continued from page 5*

- Public and physician awareness
- Access to proper treatment
- Early diagnosis and treatment

### **PUBLIC AND PHYSICIAN AWARENESS**

Because patients can acquire peripheral neuropathy in myriad ways, it has often been difficult for patients and physicians – especially those who do not have experience in neurology or neuropathy – to diagnose. This leads to years of pain and discomfort for patients, who feel unheard. The Task Force identified several easy ways to increase awareness, some of which would require buy-in at the legislative level, others would require coordination of stakeholders and private funders. Those ideas are included in the attached recommendations, but range from finding lawmakers and staff who have neuropathy and can advocate on the issue, to having a Capitol Lobby Day to educate lawmakers and staff about the disease. The Task Force also discussed non-legislative ways to promote awareness among the public and physicians, which included seminars specifically for physicians who provided more general care.

### **ACCESS TO PROPER TREATMENT**

The Task Force also placed significant focus on access to proper treatment. The problem, unfortunately, is that once an individual is diagnosed, it has become increasingly difficult for that individual to obtain access to therapies, such as IVIG and other medications that can treat the condition. For example, the main barrier to obtaining access to IVIG is that payers, most notably government payers such as Medicare and Medicaid are not providing adequate reimbursement for the therapy. As a result, physicians and hospitals that would normally purchase IVIG to treat peripheral neuropathies frequently avoid doing so because the reimbursement for the therapy is not sufficient to cover the costs associated with purchasing and administering the therapy. Following the example set by government payers, more and more private payers and managed care plans are also restricting access to neuropathy therapies.

Similarly, neuropathy patients are finding it difficult to access appropriate oral medications due to cost-saving measures by health plans. Step therapy, or “fail first” policies, are used by health plans to help control costs. Some plans require neuropathy patients to try up to five

different medicines before they have access to the one their provider determined was best for them. By the time the patient cycles through the two to four medications to get to the one that works, the patient is angry and the provider has spent hours of his/her time, resulting in the actual costs of care being higher than just approving the right drug initially. Requiring patients to “fail first” may cause unnecessary delays in access, and compromises patient care.

Additionally, health plans often force neuropathy patients to take medications that are off-label for neuropathy; essentially requiring patients to use treatments and medications that have not been FDA-approved for the disease. Plans are forcing neuropathy patients to try less expensive off-label drugs first before they approve a physician’s request to use newer on-label drugs. This is dangerous because it is an example of an insurance company second-guessing a physician/provider’s expertise and their ability to practice medicine.

### **EARLY DIAGNOSIS AND TREATMENT**

Discussion of Early Diagnosis and Treatment significantly overlapped with the discussion about Physician and Patient Awareness on Neuropathy. This topic was closely related to the discussion about physician awareness. The Task Force discussed how it could borrow ideas from other successful campaigns to treat chronic disease, such as Diabetes. The American Diabetes Association distributed a simple questionnaire that could be adapted for use in identifying sufferers of peripheral neuropathy. Frequent mandated screenings as well as a Center of Excellence model to help get patients to physicians with experience on peripheral neuropathy could also help identify and treat patients earlier.

### **CONCLUSION**

Health care costs increase at a pace that is three times inflation. Given that patients who suffer from peripheral neuropathy experience significant pain and are high users of the healthcare system, it is increasingly important that patients who suffer from peripheral neuropathy are diagnosed and treated sooner in order to control costs. Proper treatment of pain should be basic health care. Based on this first Task Force meeting, it is clear that there is much to do in order to advance the profile of peripheral neuropathy. This Legislative Task Force should continue to meet periodically, as part of a Neuropathy Coalition, in order to push its agenda forward.

## ■ Appendix I: Task Force Recommendations

The Task Force is pleased to present the following recommendations to the Legislature, some of which require legislative or executive branch action while others require continued coordination among interested private parties.

### PROMOTE PUBLIC AND PHYSICIAN AWARENESS

- Create a Statewide Public Affairs Campaign and Use Public Service Announcements (PSAs) and Billboards
- Create a Statewide Neuropathy Week or Month
- Host a Neuropathy Day at the Capitol in Sacramento
- Identify a Celebrity Spokesperson
- Identify Legislators and Legislative Staff who Have Neuropathy
- Educate Legislators and Their Staff About Neuropathy
- Encourage Legislators to Write About Neuropathy in Their Constituent Newsletters
- Hold Community Forums for Providers
- Request State Agencies Have Links to Neuropathy Organizations on Their Websites
- Regional Presentations on Neuropathy to Educate Primary Care Providers and Others About the Disease
- Explore Voluntary CME Sponsored Events to Satisfy Requirements for Pain Management Requirements
- Encourage Statewide Medical Specialty Organizations To Hold Seminars at Statewide Meetings
- Reach out to Medical Schools and Residency Programs to Encourage Neuropathy Education as Part of Curriculum, or as Part of Residency or Intern Program

### ACCESS TO APPROPRIATE TREATMENT

- Introduce and Support Legislation that Would Prohibit Step Therapy, Fail-First and Forced Off-Label Policies

The Legislature should pass legislation that would prohibit health plans or insurers from requiring patients to use a different medication than the one prescribed by the physician/provider. The legislation should prevent the practice of “step therapy” or “fail first.” Legislation should also restrict health care plans or insurers from switching patients to off-label prescriptions, which requires patients to use medications or treatments that have not been FDA approved for their particular condition. This policy takes healthcare decisions away from the physician/provider and has the potential to harm patients.

- Introduce and Support IVIG Standards of Care Legislation

The Legislature should pass legislation to enact state standards of care for IVIG. The standards would specify what would be required in order to provide IVIG and also would require that medical institutions throughout the state either stock IVIG or have direct access product in order to obtain IVIG in a short period of time. Standards would also require insurance coverage for the screening and testing procedures necessary to detect peripheral neuropathies. Lastly, such standards would also require that insurers cover all brands of IVIG, and other treatments that may be required for the treatment of peripheral neuropathies. Because IVIG is a biologic manufactured from human blood plasma, each brand of IVIG is formulated differently and has variations in its compositions. As a result, the varying brands of IVIG have different labeled indications and many physicians use their judgment, as well as trial and error, in determining which brand may work most ideally. It is not uncommon for a neuropathy patient to react quite well with one brand, while with another brand face adverse conditions and unsuccessful treatment. Therefore, it is imperative that California payers, both public and private, cover all brands of IVIG, allowing the physician to work with their patient to administer the brand that will lead to the best medical results.

- Promote the Premise That Patients Should Have Access to Their Needed Therapies and Medications Based on Clinical Need Without Influence By Payers
- Educate Patients on the Differences Between Insurance Policies/Types of Insurance
- Educate Legislators on IVIG and Other Neuropathy Treatments
- Create A Neuropathy Coalition That Develops A “Best Practices” Model Through the Department of Public Health, Using The Diabetes Coalition’s Efforts as a Template
- Pass Legislation that Would Require Similar Formulary-Challenge Ability at the Department of Insurance Side, Which Already Exists on Department of Managed Health Care-Level

### PROMOTE UNDERSTANDING OF EARLY DIAGNOSIS, TREATMENT AND MANAGEMENT

- Conduct Frequent Statewide Mandatory Awareness Screenings
- Create a Questionnaire Screening
- In Elementary, Middle, and High School, Mandate a Curriculum that Includes Physical Activity
- Identify Experts in Neuropathy – Create Regional Centers of Excellence Focused on Neuropathy

## 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.

•••

### Board Members

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

•••



## The Northern California Chapter of The Neuropathy Association

A California public benefit, nonprofit,  
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## ■ Give a Gift of Education

Neuropathy is a very common disease, yet many people don't know about it. The Northern California Chapter of the Neuropathy Association considers education a primary part of our mission.

If your family and friends—or even your healthcare providers—don't understand how neuropathy affects your life, consider giving them a gift of membership in the NCCNA. They'll get this newsletter each month with the valuable information it contains, plus periodic correspondence that will help them understand all the ramifications of neuropathy.

You can also help spread the word by distributing NCCNA brochures. We will be happy to send you some to pass out or provide for distribution in healthcare offices, pharmacies, libraries—anywhere there is a rack of similar literature. Call our toll free number (877) 622-6298 or send an e-mail to info@pnhelp.org to request material.

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## SAVE THE DATE!

Be sure to mark your calendar!

**3rd Annual Neuropathy Action Awareness Day**  
**Thursday, June 25, 2009**

More info: [www.neuropathyaction.org](http://www.neuropathyaction.org)



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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)  
(Prorated for new members at \$2.50  
per each month left in the year)

All contributions are tax-deductible.

We are supported by dues-paying members,  
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