



# Neuropathy Hope

## Hope Through Caring and Education

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

September 2009  
Issue 9  
Volume 7

President's Report:  
Strategic Planning  
Day, Sept. 26

Welcome to New  
Board Members

The Neuropathy  
Association (TNA)  
Membership

Roseville PN March  
Meeting Report

Q's & A's on  
Physical Therapy

Autonomic  
Neuropathy

My Chronic Illness



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## **PRESIDENT'S REPORT: COME TO STRATEGIC PLANNING DAY, SEPT. 26**

Every member has a special invitation to participate in strategic planning for our 2010, 2011, 2012 years. People in leadership positions are especially encouraged to come. A survey will be mailed early in September. The Strategic Planning Day is Saturday, September 26, 10 a.m. to 3 p.m. (We may finish earlier but we have this time frame available.) You'll have the opportunity to visit the renowned Sacramento Shriners Children's Hospital, 2425 Stockton Blvd, Sacramento, as we will meet in the hospital's auditorium. There will be all-day coffee, tea, and ice water and a catered lunch. The Board authorized groups to use funds in their sub-accounts to pay 20 cents a mile for a car with one or more members to come to this event if they choose to do so. Some groups have chosen to do this for some activities previously.

Responses from the survey will be available to those who come in person. The plan is to have a general overview to prepare for the activities; to break up into subgroups described below, come back together and each group presents their recommendations. The whole group will give input as to what they think most important to achieve in each category. All lists will be given to a Drafting Committee that will come together in October to prepare the final plan to present to the Board for their discussion and approval. It will then be sent out for comment before the Board reviews the comments and makes the final adoption of the document.

In late 2006 and early 2007, the Board did basically the same thing and invited Nicki

Shearer of the Sacramento PN Group to work with us. A survey was also sent out. This was put together into the plan we are just finishing. Some of this is fully completed, some will need to be carried forward in possibly a different approach, and some are not now timely. The size and capability of the Board and the help of groups make a great difference in what can be accomplished

Here are the Brainstorming Groups planned for Strategic Planning Day, Sept. 26. You will want to come with at least some idea of which area(s) fits you best.

- Support Groups – building local groups, developing regional connections
- Publicity – promotion, getting the word out about neuropathy and what we are doing
- Fundraising – techniques and ideas to use
- Membership – increasing and retaining membership
- Health Care Community – how best to communicate with these people, what do we want to happen because of it
- Board Development – size of Board, organization, communication

To give you a feeling for what was planned and accomplished in these areas, here are the goals and objectives from the 2007-2009 Strategic Plan. Goals and objectives must be humanly possible, a fit for our organization in that they support the Mission Statement, and financially feasible given the growth and fundraising success spelled out in support of NCCNA. The objectives are stated as the expected situation at the end of 2009.

**(Membership and Group Development) 1.** NCCNA is a network of 50 support groups extending to every population center in Northern California so that, except in largely rural areas,

– Continued on page 6

## 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

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

### Brentwood (Forming)

Thursday, Sept. 24  
Call for time & location.  
Bev Anderson (877) 622-6298

### Castro Valley (Forming)

Call for time & location.  
Bev Anderson (877) 622-6298

### Clearlake (Forming)

Barbara Dryden (707) 994-2202

### Colusa (Forming)

1<sup>st</sup> Presbyterian Church  
326 Jay Street  
Betty Yarwood (530) 458-2908

### Concord

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

### Crescent City (Forming)

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

### 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

### 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

### Fort Bragg (Forming)

Oct. 8, 10:30 AM  
Mendocino Coast District Hospital  
700 River Drive, Mendocino  
Mildred (707) 964-3030

### Fresno

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

### Gilroy (Forming)

Thursday, Sept 17, 1:30 PM  
Call for location  
Bev Anderson (877) 622-6298

### Grass Valley

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

### Hayward (Forming)

Call for time & location.  
Bev Anderson (877) 622-6298

### 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

### **Come to September meeting.**

### Lakeport (Forming)

Roberta Millard (209) 263-6891

### 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

### Madera (Forming)

Monday, Sept. 14, 2:30PM  
Madera United Methodist Church  
500 Sunset Ave.  
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)  
Susan Baldasano (209) 617-6283

### Modesto

3<sup>rd</sup> Monday, 10:30 AM  
Memorial Medical Ctr. Bldg  
McHenry Village  
1700 McHenry Ave., Ste 60B  
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  
Speaker: Bev Anderson, NCCNA President

### 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.  
Gail Gutendorf (775) 626-1434

### 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

### Salinas (Forming)

Thursday, Sept. 17, 10:30 AM  
Denny's Restaurant  
1255 De La Torre  
Bev Anderson, (877) 622-6298

### 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

### 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  
Speaker: Bev Anderson, NCCNA President

### San Leandro (Forming)

Call for schedule  
First Presbyterian Church  
180 Estudillo Ave.  
Bev Anderson (877) 622-6298

### **San Mateo**

Sept. 23, 1 PM  
St. Andrews Lutheran Church  
1501 S. El Camino Real  
Bev Anderson (877) 622-6298 (toll free)  
**Speaker: Nancy Schuet, Foot Rescue**

### **San Rafael**

3<sup>rd</sup> Wednesday, 1 PM  
Lutheran Church of the Resurrection  
1100 Las Galinas Ave.  
Ben or Frances Borok (415) 892-7772

### **Santa Cruz**

3<sup>rd</sup> Wednesday, 1PM  
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

### **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 PM  
Service First of Northern California  
102 W. Bianchi Rd.  
Bev Mallette (209) 944-7815

**Susanville** (To be announced)  
Susan Ellen Houston (530) 257-3864

### **Truckee**

April thru October, 1<sup>st</sup> Thursday, 1 PM  
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

### **Ukiah**

Call for schedule  
Bev Anderson (877) 622-6298

### **Walnut Creek**

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

### **Watsonville** (Forming)

Friday, Sept. 18  
Call for schedule  
Bev Anderson (877) 622-6298

### **West Sacramento**

3<sup>rd</sup> Tuesday, 2 PM  
Call for location  
Sandra Vinson (916) 372-6093  
slvins11@charter.net

## **WELCOME TO NEW BOARD MEMBERS**

We were delighted to welcome three new people to the Board of Directors. They found us through our membership in The Non Profit Resource Center and BoardLink. Each is becoming actively involved in an area of interest. They plan to participate in the Strategic Planning Day so if you come you can meet them in person.

**Karen Polastri** serves as the Executive Director for the Occupational Therapy Association of California. She has served on a number of boards with various associations, and has a background in marketing, management, and public relations. Her broad range of experience could really help us as we grow through the next stage in our development. She does not have neuropathy herself, but is interested in healthcare issues.

**Casimir Sammanasu** was born in India and received degrees in chemistry and education there. Since moving to the US, he has lived in Chicago, Texas, and California's bay area before moving to Lincoln. He does not have neuropathy, but he is diabetic and concerned about the possibility. He has much project management experience and has done a lot of corporate training. He may be able to develop training modules for our groups.

**Wayne Hewlett** has worked almost all his professional life as an engineer with Hewlett-Packard (no relation). He has masters degrees in finance and computer engineering, and has done most of his work on procurement issues. He has optical neuropathy, an area we don't know much about. Wayne was involved in a fundraising effort for Harvard Optical Neuropathy Organization to Restore Sight (HONORs), and personally raised more than \$5,300 in pledges by running the Boston Marathon in April 2009.

### **Affiliate Listing – *continued***

#### **Woodland**

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

#### **Yuba City-Marysville**

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

#### **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 September Meeting**

◀ INDEX

▲ TOP

### **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](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 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".

## PROFESSIONAL MEMBERS

Dr. Raymond M. Stephens  
Neurology Medical Group of Diablo Valley  
Walnut Creek, CA  
925-939-9400

...

## THE NEUROPATHY ASSOCIATION (TNA) MEMBERSHIP

Many of you are members of The Neuropathy Association and many are not. There are several levels of membership. The first two are: General Member – send any amount under \$35 and you will receive one issue of the Neuropathy News newsletter. Contributing Member – send \$35 and you will receive an annual subscription to Neuropathy News (3 issues) and a copy of the booklet ***Explaining Peripheral Neuropathy***. A major transformation of the newsletter occurred with the current issue. It has color, is a much larger size, like a newspaper, and more content.

TNA finds cutting research on neuropathy to help fund, provides the Neuropathy Centers at several hospitals across the country including the one for Northern California at UC – San Francisco Medical Center. They track federal legislation and provide expert testimony in hearings for bills affecting us. If you feel you can afford it and want to join, send \$35 to The Neuropathy Association, P.O. Box 26226, New York, NY 10117-3422. Check out their website at [www.neuropathy.org](http://www.neuropathy.org).

## REPORT OF ROSEVILLE PN MARCH MEETING

Our member Jack stood up and had the honor to introduce our wonderful speaker for the month of March, Mr. Dave Scurti, CP, CPed, BEO, of Pacific Medical, Inc. He is located at 4232 H Street, Suite 2, Sacramento, CA 95819. He can be reached at (916) 706-1520. Dave has served in the Orthotic and Prosthetic field in multiple positions starting from the ground up and has become well known throughout that industry. Dave Scurti has spoken internationally and domestically sharing his experiences and knowledge of prosthetics, orthotics and diabetic care. He is certified by the American Board of Certification and has been in the Sacramento area for over 14 years. Prior to opening his office at Pacific Medical, he was employed as the Clinical Director for Sunrise. In addition to his duties as a director, he also acted as their education coordinator for both their domestic and Chinese offices.

Dave showed such heartfelt passion and was very educated in his work that he had all whopping 25 of us glued straight ahead. We were able to ask questions and he answered them in detail. He provided education on proper footwear and biomechanics of the foot during the gait cycle and how it relates to neuropathy.

Dave could not express any more the importance of checking both feet everyday for ulcerations of any kind. The worst case scenario would be amputation if not cared for properly.

He provided great information on what the difference is of a pronated foot versus a supinated foot: The pronated foot is one in which the heel bone is angled inward and the arch tends to collapse. A person that has overly pronated feet is sometimes said to be “knock-kneed.” Custom-fit Arch Supports can help to correct this problem.

Although less common, a supinated foot is one in which the heel bone angles outward and the arch maintains a relatively high appearance. A person that has supinated feet is sometimes said to be “bow-legged” or have a “high arch,” with their weight supported primarily on the anterior of their feet.

At the end of meeting, we all gave a nice big hand for Dave. – Barbara Watkins, Notetaker

◀ INDEX

## AUTONOMIC NEUROPATHY

By Christopher Broadbridge, Clinical Development Consultant

Autonomic neuropathy is a term describing damage to the nerves of the autonomic nervous system. The autonomic nervous system (ANS) branches throughout the entire body and connects to and controls all of the body's organs. When autonomic nerves are damaged, a very wide range of symptoms may result. Some diseases, such as diabetes, cause a gradual degrading of the ANS, and thus, autonomic neuropathy may be found in its early stages or in more advanced stages. In early stages, obvious symptoms may be absent, but in later stages, telltale symptoms may include one or more of the following: dizziness or lightheadedness after standing, blood pressure falls after standing, loss of bladder or bowel control, problems regulating body temperature or sweating, a racing pulse while resting, chronic dry mouth, or sexual dysfunction (including erectile dysfunction in males).

◀ INDEX ▲ TOP - Continued on page 7

## ■ Q'S & A'S ON PHYSICAL THERAPY

By Lt. Col. Eugene B. Richardson, USA Retired, MDiv, EdM, MS and CIDP Patient for 41 years.

*Lt. Col. Eugene B. Richardson, well-received speaker at support groups in Florida and the East Coast and a good friend of Mims Cushing, recently joined NCCNA.*

**Q: “Should someone with neuropathy do daily exercises so they don’t lose muscle strength?”**

**A:** It is important to work closely with your treating physician insuring that it is okay to enter into an exercise or physical therapy program. That being said, the proper exercise and supervised physical therapy can be very important components in any complete treatment approach to many peripheral neuropathies. The best exercises are low impact, which are the right kind for anyone with neuropathy. The wrong kind or too much exercise will increase symptoms because damaged nerves will attempt to work in overload. Many neuropathy patients will tell you that swimming is one of the best exercises for the neuropathy patient. Mims Cushing in her 2009 book, *You Can Cope With Peripheral Neuropathy: 365 Tips for Better Living* (www.amazon.com) has great suggestions on this subject from patients who have been there.

**Q: “Will physical therapy cure neuropathy?”**

**A:** Some neuropathy patients go to physical therapy (PT) with unrealistic goals, thinking that PT is a cure for neuropathy. PT does NOT cure neuropathy. One exception is entrapment neuropathies. A skilled physical therapist can be very helpful in relieving the pressure on the nerve(s).

Important goals for physical therapy or exercise are to maintain muscle strength, improve gait, balance, and flexibility, improve balance issues and the ability to walk (using both the eyes and feet) and increase one’s being able to hold things, and more.

Muscle weakness, muscle atrophy, loss of coordination, dizziness, loss of feeling in the feet and hands, all demand the attention of an expert physical therapist that is knowledgeable about the effects of various types of neuropathy on muscle and nerves.

**Q: “What have you learned about exercise, physical therapy and the symptoms of neuropathy?”**

**A:** DO NOT work through the pain if you have neuropathy. Gym coaches may have taught you “no pain, no gain” --- DO NOT even go there! With neuropathy the quantity and focus of exercise or physical therapy is determined by your diagnosed condition, symptoms, and pain. Exercise and physical therapy must take into account the extent of inflammation of the nerves, amount of damage to the nerves, the degree of blockage to them, and how much they have been injured.

**Q: “Can you do harm with the wrong type or quantity of exercise?”**

**A:** Yes. With exercise for the neuropathies, a little is a lot and quality, focus, and regularity are all important. Those things are more important than how much exercise you do. With neuropathy you must dismiss much of what you have been taught about exercise. As mentioned above, you must NOT work through the pain or you may increase your symptoms. Over use of inflamed or injured nerves will cause them to stop working temporarily and you may feel a cement-like numbness in your feet and legs, or other strange and painful symptoms in your body.

A good physical therapist with knowledge of the neuropathies should understand you. If you cannot get to a physical therapist, then request the booklet “*Exercising for the Neuropathies*,” published by The Neuropathy Association --- a very helpful guide.

Learning your limits, knowing how to pace yourself, adjusting daily activities and exercising correctly, are important insights for physical therapy or any exercise program for a person with neuropathy.

*Acknowledgements: Dr. Waden Emery III, MD, Board Certified Neurologist, Lighthouse Point FL Karen Sheppard, Physical Therapist, Fort Lauderdale, FL References: “Balance Problems in PN”, Gentiva Home Health’s Safe Strides Program, Harold Kuphaldt, PT, Safe Strides Program Director, Sacramento, CA*

### 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

– Continued on page 6

## 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.

## **President Report: Come to Strategic Planning Day, Sept 26** *-continued from page 1*

a support group is within 50 miles of each person in Northern California. (There is a good possibility this goal will be completed by the end 2009.) 2. NCCNA is an organization with over 600 members. (Currently we are approaching 800 members.) 3. NCCNA encourages support groups to fill at least two leadership team positions – leader and treasurer. (This is a work in progress.) 4. NCCNA conducts Spring and Fall Leadership Gatherings for communication, encouragement, training, and planning. (This was started but became one meeting combined with other members at the Annual Meeting.) 5. NCCNA designs events to raise funds as well as to publicize and empower NCCNA and its members for furtherance of its mission. (We have raised funds through mailings but not through events so this remains on the table.)

### **(Connecting With the Health Care Community)**

1. NCCNA is well known to and interactive with the health care community. (There has been great improvement but this is an area where work must be done. All the objectives under this goal would be good to revisit.)

### **(Supporting Research)**

1. NCCNA discovers appropriate clinical trials and other research opportunities and encourages membership involvement. (Those made known to us have been publicized in NEUROPATHY HOPE. A few members have participated.)

### **(Publicity, Promotion, and Relationship Development)**

1. NCCNA distributes upgraded brochures, newsletters, and other publications. (This has been done but is also a work in progress.) 2. Update NCCNA's website regularly and have links to other organizations such as The Neuropathy Association and the Neuropathy Awareness Foundation. (This was done immediately.) 3. NCCNA is regularly supported in print, auditory, visual, and Internet media coverage. (Progress has been made here but much yet remains to be done.)

**(NCCNA Development)** 1. NCCNA is led by a Board of Directors consisting of 9 members. (If all people who were on the Board and those added in the years had remained, we would have surpassed this.

Currently, there are 8 board members.) 2. Develop subcommittees on which some members other than Board members serve. (This needs more development.) 3. NCCNA raises additional funds to support expansion of the organization. (Grants and the fundraising letter that is now sent out twice a year have made progress here.) 4. NCCNA contracts with a part-time secretary to deal with membership and the newsletter and adds additional staff to work with the NCCNA Board as funds are available. (We hired a newsletter editor and continued with our financial accounting service but have not yet reached this point.) 5. NCCNA offers information and assistance to people in other areas wishing to start neuropathy support groups. (We have encouraged a few leaders in Southern California and sent information to several in other states. We also sent information to our member in Geneva, Switzerland and she has started a support group there.) 6. NCCNA provides Directors and Officers insurance (This was done immediately and now includes the leadership teams of support groups. The policy is to safeguard NCCNA if we are sued because of the behavior of any of these people.)

**Directions to Shriners Children's Hospital** (Stockton Blvd. between X and Y Sts.)

**From the north (Sacramento International Airport, Redding):** Take I-5 S to US 50 E and merge onto US-50 E. Take 34<sup>th</sup> Street exit (left lane) and turn left on 34<sup>th</sup> Street, turn right on T Street, turn right on Stockton Blvd.

**From the northeast (Reno):** Take I-80/Capital City Fwy, toward Sacramento/State Hwy 99 S. Slight right at Capital City Fwy, W, take US 50 E exit to I-5/S Lake Tahoe, keep left at the fork to continue toward 34<sup>th</sup> St., turn right on T St., Turn right on Stockton Blvd.

**From the south (Stockton, Modesto, Fresno):** Follow I-5 N to I-80/US-50 exit toward S. Lake Tahoe. Merge onto US-50 E, exit at 34<sup>th</sup> St. Turn left at 34<sup>th</sup> Street. Turn right on T St., Turn right on Stockton Blvd.

**From the east (Placerville, Lake Tahoe):** Take US-50 to Stockton Blvd. exit. Turn left on Stockton Blvd.

**From the west (Davis, San Francisco):** Take I-80E to Sacramento, continue on Capital City Fwy E/US-50 E, continue to follow US-50 E. Stay to the left lane. Take 34<sup>th</sup> St. exit, turn left on 34<sup>th</sup> St., Turn right on T Street, Turn right on Stockton Blvd.

## ■ MY CHRONIC ILLNESS

By Lorraine L. Brooks, NCCNA Member in West Sacramento PN Group

My chronic illness started in 1999. The symptoms were extreme muscular and joint pain, gastrointestinal distress, and extreme fatigue. The fatigue was so bad that I couldn't get out of bed for days at a time (almost as if I'd been drugged).

I started recording my visits with Dr W. at the Med Clinic on Folsom Blvd. in early 2000. I was diagnosed as hypothyroid. All other lab tests were in the normal range. Dr W. prescribed anti-depressants and said she didn't know what else to do for me. I changed doctors. (By the way, Dr W. is no longer practicing).

The new doctor, Dr B., is with UC Davis Medical Center. Dr B. ordered a battery of tests and referrals to specialists. I saw a neurologist, a rheumatologist, etc. I had numerous scans and lab tests. No diagnosis. During the period of 2000 thru 2005, my pain would relocate to different areas of my body. For almost a year, the pain settled in my lower back and it was almost impossible to turn or rise from a prone position. I tried acupuncture. It didn't help. Dr B. thought I "probably" had fibromyalgia. She prescribed anti-depressants for "whatever was going on with me".

I had a wonderful, well paying job for 8 years. They were aware of my health problems and allowed me to work a flexible schedule. But that was over at the end of 2005. In 2006 my daughter was diagnosed with Tropical Sprue, aka Celiac Disease. This is an immune system disorder and tends to run in families. Dr B, a gastroenterologist, and a nutritionist were unable to give me additional information at that time. I got the information I needed on the internet and through a support group. I started on a gluten free diet. It was a year-long learning curve but I finally had the Celiac Disease under control. As a side note, the U. S. medical providers have become more informed about this disease the past few years.

One of the symptoms of Celiac Disease is malabsorption of nutrients, especially the B vitamins. Even though my GI symptoms were controlled, I still had muscle pain and extreme fatigue. Vitamin deficiency is common with Celiac Disease. Dr B. would not order the lab tests. I consulted with a highly recommended doctor that specializes in nutrition, Dr Kwiker of Health Assoc, and was tested and started on a few vitamin infusions, nutraceuticals, and a healthy eating lifestyle. He said to eat only unprocessed food and food that was good for my body which is food that my body could utilize. Guess what, this means no junk food. Within a few months, the muscular

*- continued on page 8*

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### Autonomic Neuropathy – Continued from page 4

Having painful neuropathy does not mean that autonomic neuropathy is also present. One may occur without the other. It is therefore important for high risk patients (e.g., those with diabetes) to be evaluated specifically for autonomic neuropathy. It's difficult enough to have to manage diabetes, but when autonomic neuropathy is present, the challenges for both patient and doctor increase. Both have to be more vigilant to symptoms and take special precautions where daily activities, exercise, and medications are concerned.

An example of this vigilance should include, for example, sexual function in diabetic men. In some cases, impotence is due to DAN and is more than likely a sign of some blood vessel and heart issues as well. Simply treating these men with oral drugs, such as vardenafil (Levitra) or sildenafil (Viagra) may, in effect, mask the signs and symptoms of heightened cardiovascular risk.

Autonomic neuropathy is usually found among people with those disorders and diseases that precipitate it. The most commonly recognized "secondary cause" is diabetes, with about 25% of diabetics having diabetic autonomic neuropathy (DAN), whereas Parkinson's disease, multiple system atrophy, and pure autonomic failure are primary causes that are less common. DAN increases the risk of sudden cardiac death by 3-4 times when it is present in a person with diabetes—all the more reason to get tested for autonomic neuropathy.

Current medical guidelines now recommend tests that employ special measurements of "heart rate variability" (HRV) or of sweating. Don't let autonomic neuropathy go undiagnosed!

**CORRECTION:**  
In the July 2009 issue, we did not list Georgia Richardson of the Sacramento PN Group as the reporter for *Compounding Pharmacist Speaks in Sacramento*.

Our apologies to Georgia.



## The Northern California Chapter of The Neuropathy Association

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### My Chronic Illness – Continued from page 7

and joint pain was almost completely gone. Why did it disappear? I think it was because I started taking Omega 3's. Some of you may remember a PN meeting at the Trinity Church in 2008 where Dr T. said that there was better than 80% pain reduction with Omega 3's than with N-saids, plus no side effects.

I don't know where I would be today if I hadn't been proactive about my health.

- (1) I changed doctors.
- (2) I tried new things, such as acupuncture and a gluten free diet.
- (3) I used the internet, health foundations, and talked to people to obtain information and help. Alternative doctors treat the whole person.
- (4) I learned to be specific with complaints to the Dr.
- (5) If surgery is an option, always get a second opinion. ◀ INDEX

Mark your calendars. Planning for 2010-2012

## Strategic Planning Day

September 26, 10 AM-3 PM • Sacramento, CA

All members are invited.



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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,  
contributions by members and friends, and,  
occasionally, small grants.

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