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The Newsletter of The Northern California Chapter of The Neuropathy Association  
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*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.*

Vol. 2, No. 5

“Neuropathy, a term for all disorders of peripheral nerves”

May, 2007

American Medical Association Home Medical Encyclopedia

## **LET'S ALL MEET IN SAN FRANCISCO FOR THE**

### **NEUROPATHY ACTION AWARENESS DAY**

**Tuesday, June 26, 2007**

**University of California, San Francisco  
Mission Bay Conference Center  
1675 Owens Street  
San Francisco, CA 94143**

***YOU ARE NOT ONLY INVITED.  
YOU ARE NEEDED.***

The Neuropathy Action Foundation invites us to this event. They are formed to promote knowledge of neuropathy among the general public and with the health care community. This is so very needed and they are making good progress. They are getting people from the public, health care professionals, and outstanding exhibits to come to this event. They very much need people like us to be their evidence of the need for help for people with neuropathy. **This is our opportunity to be part of the answer to the lack of funding for research and the lack of knowledge of PN. We talk about it. Are we willing to do anything to help?**

This is your opportunity to get acquainted with people with PN from other parts of Northern California and hear their familiar but unique stories as you share yours with them while you tour the exhibits, relax in seating areas, share ideas and treatment info, and have dinner together. .

The Health Fair from 1 – 5 p.m. is free. If you want or are able to be there for just this portion, send the registration form included in this newsletter in so they know how many are coming. You don't need to send any money.

The Dinner is \$25 per person with neuropathy and one other person such as a spouse or caregiver. Those without neuropathy, other than the one mentioned above, are \$75. Send your check for this amount with the registration form if you can stay for dinner.

If you are riding the bus traveling the I-80 corridor from Auburn, you must pay for dinner since the bus will be there through that time. **There is no charge for the bus.** Those riding the bus will send their registration form in with their check and will be contacted by Grant Whitney, NCCNA Vice President if you live near I-80. If you want to contact him to be sure you are on that list call (530)887-9881.

#### **Driving Directions**

**From 280 North:** Exit at Mariposa St. and turn right, Turn left on 3<sup>rd</sup> St. and go two blocks, turn left onto 16<sup>th</sup> St., Turn right onto Owens St., Turn right into the parking garage.

**From the East Bay/Bay Bridge:** After crossing the Bay Bridge, exit at 5<sup>th</sup> Street (first San Francisco Exit) and turn right onto Harrison, Turn right on 4<sup>th</sup> St., Turn left on King St., Turn right onto 3<sup>rd</sup> St. just before AT&T Baseball Park, Cross the 3<sup>rd</sup> St. Lefty O'Doul Bridge and continue south on 3<sup>rd</sup> St., Turn right on 16<sup>th</sup> St., Turn right onto Owens St., Turn right into parking garage. (Directions - Continued on pp. 3&4)

**AFFILIATE NEWS** Listed below is information about upcoming meetings and where to learn more about them.

| Group/Date/<br>Time   | Place  | Program                                    | Contact   |
|---|--|--|---|
| Auburn-Day<br>1 <sup>st</sup> Monday, 1:30 PM                                       | Woodside Village MH Park<br>12155 Luther Rd., Auburn                             | Neuropathy awareness                       | Terri Stennes, 916-663-3108<br>bridget@infostations.net   |
| Auburn-Eve<br>1 <sup>st</sup> Monday, 7 PM  | Sutter Auburn Faith Hospital<br>11815 Education Street, Auburn                   | Speaker expected                           | Bev 530-389-2416 <a href="mailto:bj@foothill.net">bj@foothill.net</a> ,<br>Grant 530-887-9881           |
| Berkeley<br>3 <sup>rd</sup> Monday, 6-8 PM<br>1 <sup>st</sup> Month of each quarter | Lutheran Church of the Cross<br>1744 University Ave., Berkeley                   | No meeting this month.                     | Alan Dampsey, 510-527-3568<br>adampsey@comcast.net  |
| Concord,<br>3 <sup>rd</sup> Tuesday, 1:30 PM  | First Christian Church<br>3039 Willow Pass Rd., Concord                          | Neuropathy awareness                       | Ernette Rivera, 925-889-2484<br>ernette5712@sbcglobal.net   |
| Davis<br>2 <sup>nd</sup> Wednesday 2 PM   | Institute for Restorative Health, 1460<br>Drew Ave. across from Kaiser           | Neuropathy awareness!                      | Martha Chandley, 916-371-1125<br>kairoschandley@sbcglobal.net   |
| Elk Grove<br>2 <sup>nd</sup> Tuesday, 2 PM  | Elk Grove Senior Center<br>8830 Sharkey Ave, Elk Grove                           | Neuropathy awareness                       | Michael Colozzi, 916-421-8103<br>Susi Watson 916-354-0483   |
| Folsom<br>2 <sup>nd</sup> Tuesday, 3:15 PM  | Creekside Oaks Retirement Residence<br>1715 Creekside Drive.                     | Neuropathy awareness!                      | Lorraine 916-983-4023, Beverly 916-<br>984-4302   |
| Grass Valley<br>2 <sup>nd</sup> Monday, 1:30 PM                                     | GV United Methodist Church<br>236 S. Church St., Grass Valley                    | Neuropathy awareness!                      | Bev 530-389-2416<br>Betty Gears 530-432-7774  |
| Jackson<br>3 <sup>rd</sup> Tuesday, 10 AM   | Amador County Senior Center<br>229 New York Ranch Rd.<br>Jackson                 | Call Darlene for meeting<br>information.   | Laurie 209-223-0442<br>Darlene 209-296-1760   |
| Lincoln<br>3 <sup>rd</sup> Tuesday, 1 PM  | Raley's Event Center<br>765 S. Hwy 65, Lincoln                                   | Neuropathy awareness                       | Joe Facha 916-408-2007<br>Lavern 916-408-2007   |
| Livermore<br>4 <sup>th</sup> Tuesday, 10 AM   | Heritage Estates<br>900 E. Stanley Blvd.   | Neuropathy awareness                       | E. Lorene Stack 925-447-6158  |
| Monterey<br>3 <sup>rd</sup> Wednesday, 10:30 AM<br>of odd numbered months           | First Presbyterian Church<br>501 El Dorado St.                                   | Neuropathy awareness                       | Don & Ann Trout 831-372-6959  |
| Napa<br>1 <sup>st</sup> Thursday, 2 PM  | Napa Senior Center<br>1500 Jefferson St., Napa                                   | Neuropathy awareness                       | Ron Patrick 707-257-2343<br>bonjournapa@aol.com   |
| Placerville<br>4 <sup>th</sup> Wednesdays., 1:30 PM                                 | Placerville Senior Center<br>937 Spring St., Placerville                         | Neuropathy awareness                       | Arlene Middlebrook, 530-626-1098<br>Elaine Repass 530-622-2224  |
| Redding,<br>Restarting soon   |  | Call Sandi Deome<br>(530)365-7081 for info | Bev Anderson (530)389-2416  |
| Redwood City,<br>1 <sup>st</sup> Tuesday, 2 p.m.                                    | Bakers Square Restaurant<br>949 Veteran's Blvd., RdwD Cty                        | Neuropathy awareness                       | Annette Devost 650-595-2478   |
| Reno, NV<br>2 <sup>nd</sup> Tuesday, 6:30 PM  | Fire Station #11<br>7105 Mae Anne Ave., Reno                                     | „  | Marsha Campbell 775-851-0499<br><a href="mailto:LadyJane2b@sbcglobal.net">LadyJane2b@sbcglobal.net</a>  |
| Roseville<br>2 <sup>nd</sup> Tuesday, 7 PM  | Point West Sr. Res.,<br>5161 Foothills Blvd., Roseville                          | Neuropathy awareness                       | Marilyn Larson 916-771-8435<br>Helen Astill 916-782-6208  |
| Sacramento<br>3 <sup>rd</sup> Tuesday, 1:30 PM                                      | Northminster Presby. Church<br>3235 Pope Street, Sacramento                      | Neuropathy awareness                       | Anne Fletcher 916-391-3317<br>Myke Taylor 916-487-2903  |
| San Francisco – Call Amy<br>Mahoney to be sure of the<br>meeting day and time.      | UC-San Francisco Med Ctr.<br>Amb. Care Ctr. 8th Flr. , Rm A888, San<br>Francisco | Neuropathy awareness!                      | Amy Mahoney, 415-353-2312<br><a href="mailto:amy.Mahoney@ucsfmedctr.org">amy.Mahoney@ucsfmedctr.org</a> |
| San Jose<br>3 <sup>rd</sup> Saturday, 10:30 AM                                      | O'Conner Hospital, 2105 Forest Ave, SJ<br>DePaul Conf. Rm., San Jose             | Neuropathy awareness                       | Stan Pashote (510)490-4456  |

| Group/Date/<br>Time                                | Place   | Program  | Contact  |
|--|---|--|--|
| Santa Cruz – Call Mary Ann for date and time.      | Life Oak Senior Center, 1777 Capitola Rd., Santa Cruz       | Neuropathy awareness   | Mary Ann Leer. 831-477-1239<br><a href="mailto:MALEER@SURENETUSA.COM">MALEER@SURENETUSA.COM</a>          |
| Santa Rosa, 1 <sup>st</sup> Thursday, 10:30 AM     | Santa Rosa Senior Center 704 Bennett Valley Rd, SR.         | Neuropathy awareness!  | Ginger Minnich, 707-829-2934   |
| Sonora. Meeting Last Monday, 2-4 PM                | Sonora Regional Medical Center Conference Room              | Neuropathy awareness   | Ed Minium (209)586-3702  |
| Stockton 3 <sup>rd</sup> Tuesday, 4 PM             | Central United Methodist Church 3600 Pacific Avenue.        | Neuropathy awareness   | Mary & Case Klooster (209)463-5985   |
| Walnut Creek                                       | Rossmoor, Hillside Clubhouse Las Trampas Room, Walnut Creek | <b>If you are interested in helping this group restart, call Bev Anderson (530)389-2416.</b> | Sigrid Lott (925)935-2031  |
| West Sacramento 3 <sup>rd</sup> Wednesday, 2:00 PM | AF Turner Branch, Yolo County Library, 1212 Merkley Ave. WS | Neuropathy awareness   | Sandra Vinson, 916-372-6093<br><a href="mailto:slvins11@charter.net">slvins11@charter.net</a>            |
| Woodland 1 <sup>st</sup> Monday, 4:30 p.m.         | Woodland Senior Center 610 Lincoln Ave, Woodland            | Neuropathy awareness   | Delia Genera 530-661-3238  |
| Yuba City 2 <sup>nd</sup> Monday, 7 PM             | Sutter Estates 1230 Plumas Street, Yuba City                | Neuropathy awareness!  | Nancy Escudero, 530-673-3608<br><a href="mailto:nancychristina1@yahoo.net">nancychristina1@yahoo.net</a> |

**Please realize that even though a speaker is not listed, it doesn't mean there won't be one. It is hard to know far enough ahead to meet the deadline for this publication. Some of the best meetings, however, are sharing and discussion meetings. Local e-mail, news flyers, newspaper, and phone calls may be used to inform you more about the meeting but any time the group meets, it is worth being there.**



### **PRESIDENT'S REPORT by Bev Anderson**

Regularly we complain that the health care community, especially doctors and even neurologists are not informed about neuropathy and don't seem to be very interested or concerned. Maybe it is because we are not that interested or concerned ourselves unless we are suffering greatly.

What are you willing to do to make the fact of peripheral neuropathy known? Have you taken one of the "Peripheral Neuropathy" booklets from NINDS/NIH and our NCCNA Brochure to each of your doctors?

Are you willing to find a few hours a week to telephone, put notices in the newspaper, book speakers, or serve as leader to facilitate the meetings? Is finding helps and cures for neuropathy important enough to you?

To have a support group, we need a leader and help for that leader we call a Leadership Team. We have several groups that may need to be abandoned because of lack of leadership. This is because no one who is able is willing to set aside at least part of something else they are doing and lead or help lead a support group.

*A special hurrah, this month, goes to Stan Pashote, the new Leader of the San Jose PN Group. Ann Louie chose to resign because of long hours at work. Stan has been Assistant Leader and agreed to step up to Leader.*

### **Directions if you are taking BART to the Neuropathy Action Awareness Day**

From the 16<sup>th</sup> Street Bart Station exit the Bart Station using not the main entrance but the exit to the left of the turnstiles. Walk to the right toward the sidewalk of 16<sup>th</sup> St., The UCSF Shuttle stop is in front of the Burger King Restaurant. Take the Red Shuttle to the Mission Bay Conference Center.



## MARTHA'S CORNER

News from Martha Chandley, PN resource  
extraordinaire

### **A Report on Dr. Vespignani's HEALTHIER Workshop**

**Sandra Vinson, NCCNA Board Member &  
West Sacramento Contact - 916/372-6093**

Not everyone can involve people in a delightful, fun and funny interactive process of sharing information that can lead to healthier lives. Sandra Vinson did just that on March 21 with great enthusiasm and charm as she shared about her improving health, thanks to a great pain relieving compound developed by pharmacist Jerra Banwarth, treatments by Dr. Hassid and Dr. Vespignani, all of whom are at IRH. She's learned to eat healthier and is losing significant weight without dieting, and has been more empowered for her life with neuropathy. This brief report can not recapture the spirit of her presentation or the richness of Dr. Vespignani's model, but here's hoping it will whet your appetite for your own personal experiences with him at his workshops or in his clinical practice.

**H.E.A.L.T.H.I.E.R** is a four week interactive lifestyle modification workshop designed to jump start us toward healthier living. This is a great foundation for truly committing to a process that can make your life more like thriving rather than suffering with your chronic condition.

**H stands for hydration**, 8-10 glasses of liquids a day to ensure proper fluid and PH balance for several organic systems in the body.

**E stands for eating balance. That means** emphasizing lots of nutrient rich, functional foods, like colorful fruits and vegetables; ten grams of protein by 10 am from lean meats, fish and legumes; whole grains, like the delicious whole protein quinoa salad we sampled; etc.

**A stands for activity.** All kinds of activity, from doing yard and house work, simple exercises like ankle circles and flexes that are particularly great for PN, and a good mix of cardio, strength training, resistance and stretching regimen. Sandra demonstrated several fun, simple moves we can do at will.

**L stands for laughter.** We do too little of this and Sandra demonstrated some delightful

tips for stimulating the kinds of full body laughter that release the endorphins that increase our sense of well-being.

**T stands for thoughts.** This recognizes that our negative or positive thoughts can make a really significant difference on how we feel and how we approach our health problems like PN. Positive is infinitely better for all of us!

**H stands for helping.** This means getting outside ourselves and caring for others in simple ways that build them up. "Optimum health is realizing that all people are in need of help." (That's one reason why the Yolo PN groups mission statement includes **Mutual Support.**)

**I stands for the I of you.** Who else do you want to be/do for, recognizing that caring for ourselves, doing things that will help optimize our health, are essential for thriving with chronic conditions.

**E stands for envisioning.** Recognizing that optimum health takes effort and planning. So, what actions will we take today, this week and month, to ensure that we may thrive?

**R stands for repeating and restoration.** Are you practicing your health vision plan, are you getting appropriate, restful sleep? Both are essential for optimum health, thriving with neuropathy.

### **Driving Directions Continued**

**From the North Bay/Golden Gate Bridge:** After crossing the Golden Gate Bridge, drive east on 101 (Doyle Drive) towards downtown, Exit at Marina Blvd. and follow Marina Blvd. past Fort Mason. Turn left onto Bay St., Turn right onto the Embarcadero. After passing under the Bay Bridge, the Embarcadero will become King St., Turn left onto 3<sup>rd</sup> St. just past the baseball stadium, AT&T Park, Cross the 3<sup>rd</sup> St. Lefty O'Doul Bridge and continue south on 3<sup>rd</sup> St., turn right on 16<sup>th</sup> St., turn right onto Owens St., Turn right into the parking garage.

**From the Caltrain station:** Muni Bus #15 – Take #15 bus to 16<sup>th</sup> St. Go right down 16<sup>th</sup> St. then turn right onto 4<sup>th</sup> St. The Mission Bay Conference Center is to the left. **The UCSF China Basin Shuttle pick-up is in front of the Caltrain Station on 4<sup>th</sup>** This shuttle will take you directly to the Mission Bay Campus. The Mission Bay Conference Center is also conveniently located near the soon to come 3<sup>rd</sup> Street Muni Light Rail.

## California NEUROALLIANCE

### Conference Report

Bev Anderson (President) and Sue Ingle (Auburn-Evening PN Group) attended the CalNeuroAlliance Legislative Conference, March 26 & 27 at the Sheraton Grand Hotel in Sacramento. Monday began with a 6-member panel presenting the various approaches to the Health Reform Act under consideration. Presentations were made on the Governor's plan, the Republican Caucus plan, the Assembly Speaker's Plan, and Senator Sheila Kuehl's bill. A variety of speakers culminating with Assemblyman Mervyn Dymally, Chair, Assembly Health Committee keynoting at the Dinner.

On Tuesday they were on different legislative visiting teams visiting 4-5 legislative offices. They talked with legislators or staff members about two Family Leave Bills, paid and unpaid, and what we want to see included in the Health Reform Act when it is put together.

Currently the **Family Leave Bills** that set up the facilitation of people taking time off to care for themselves or an ill relative do not both include an independent adult child, grandparents, siblings, domestic partner, grandchildren, or parents-in-law. It was recommended that these be added.

These safeguards were requested for the **Health Care Reform:**

- Comprehensive Health care services (benefit) package – all the services needed by one with a neurological disease
- Home and community-based long-term care
- Choice of doctors and specialists
- Affordable care
- Guaranteed insurance renewals
- End of life care
- Prescription drug coverage

Sue, who regularly uses a scooter and electric wheelchair, was delighted to see so many active, intelligent people also using scooters and chairs due to other neurological diseases like multiple sclerosis. Sue recently had foot surgery and needed to keep her foot up. She drove in with her foot propped up on top of the handlebars.

## NEWS NOTES

### Stanford Research

Last month, this newsletter featured an article by Drs. Yuen So and Charles Cho, Stanford Neurologists, reporting on PN research there. One major study mentioned was the blood marker study to find a way to diagnose PN through a simple blood test.

We have a connection to this study. Several years ago we conducted a raffle. The proceeds went to help support this study.

### Stanford Study Seeking Participants

**Self-Management@Stanford Healthier Living with Diabetes** is a workshop and study given on the Internet. Researchers at Stanford University are currently recruiting participants with type 2 diabetes to an online self-management study. Study participants will have an opportunity to receive free diabetes self-management materials, receive free lab tests, and can participate entirely over the Internet. To learn more access <http://diabetes.stanford.edu>. If you are a Native American, access <http://indiandiabetes.stanford.edu> Click on LEARN MORE and complete the short form

### Always Count Your Pills/Capsules

Before you leave the pharmacy, in your car, or first thing upon arriving home, count your medications to see if the number you receive matches the number you are supposed to get listed on the container. These are loaded by machinery that is not always accurate. Recently one person found that instead of 30 as listed, she had received 28. This was true of other medications as well.

## PERIPHERAL NEUROPATHY

### By Norman Latov, M.D., Ph.D.

This book can be ordered from your local bookstores or purchased on line from Amazon.com and, probably others. It is \$19.95 from the publisher, Demos Medical Publishing 1-800-532-8663, \$13.57 from Amazon.com and others. If you if your total is more than \$25 from Amazon, you get free shipping. You could buy two and give one to your doctor or make it an opportunity to pick up one or more of the John Senneff books for little more than the one.

