



# NEUROPATHY NEWS

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. 4

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

April, 2007

American Medical Association Home Medical Encyclopedia

## NEUROPATHY ACTION AWARENESS DAY

**Tuesday, June 26, 2007**

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

This event is sponsored by the Neuropathy Action Foundation whose commitments are to Public Awareness, Physician Education, and Patient Empowerment. The Northern California Chapter of The Neuropathy Association has decided that working together we can better accomplish our mutual goals so we urge you to use the Registration Page included in this newsletter to pay the \$25 for the dinner and come for the whole event, if at all possible. We hope to have a sizable number present to mix with the doctors and others that are coming to be sure they know how PN really feels. Please note that those with PN pay \$25. It says that those that do not have PN pay \$75. However, if a person is a spouse, significant other, or caregiver of a person with PN, they also pay \$25. This was clarified quite recently.

The event opens at 12:30 p.m. with a Health Fair. The fair includes exhibits and concurrent seminars. A partial listing of the exhibitors includes: American Red Cross, Nu Factor, Centers for Medicare and Medicaid Services (CMS), Pfizer, Inc., California Department of Insurance, Eli Lilly and Company, American Diabetes Association, Rebuilder Medical, Anodyne Therapy, LLC, UCSF Massage Booth (Free Massages for Attendees!!!), The Northern California Chapter of The Neuropathy

Association, Diabetes Teaching Center at UCSF, GBS/CIDP Foundation International, Department of Managed Healthcare (DMHC), Health Insurance Counseling & Advocacy Program (HICAP), and American College of Traditional Chinese Medicine.

Seminars include: “Patient Empowerment: Know Your Healthcare Rights” with a 3 person panel, “IVIG at Home, A Treatment Option for Neuropathies.” David Philips, Ph.D. speaking on “Neuropathy Mystery Solved: dormant nerve cells, electronic pacemaker for the legs, and depleted oxygen. Neuropathy is reversible.” “Acupuncture: A Remedy for Pain,” “Feldenkrais Method-An Awareness Through Movement Lesson,” and “Neuropathy 101 and Ask the Experts” led by Michael Gibbs, M.D., Kaiser Walnut Creek Neurologist, Jonathan Katz, M.D., California Pacific Medical Center neurologist, and Jeffrey Ralph, M.D., University of California San Francisco Medical Center neurologist and Director of The Neuropathy Center there.

At 5 p.m. the Reception with entertainment and silent auction begins. **Dinner is at 6 p.m.** The Evening Keynoter is California Insurance Commissioner, Steve Polzner. California Assemblywoman Mary Hayashi will also attend. Entertainment and Presentation is by Grammy and Golden Globe Nominated Artist Frank Stallone.

Neither NAF nor NCCNA endorses any product, treatment or speaker. We ask you to consult with your personal physician regarding any of these you may see or hear about at this event.

**Plan now to be there.**

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

Group/Date/ Time	Place	Program	Contact
Auburn-Day 1 <sup>st</sup> Monday, 1:30 PM	Woodside Village MH Park 12155 Luther Rd., Auburn	Neuropathy awareness	Terri Stennes, 916-663-3108 bridget@infostations.net
Auburn-Eve 1 <sup>st</sup> Monday, 7 PM	Sutter Auburn Faith Hospital 11815 Education Street, Auburn	Speaker expected	Bev 530-389-2416 <a href="mailto:bj@foothill.net">bj@foothill.net</a> , Grant 530-887-9881
Berkeley 3 <sup>rd</sup> Monday, 6-8 PM 1 <sup>st</sup> Month of each quarter	Lutheran Church of the Cross 1744 University Ave., Berkeley	No meeting this month.	Alan Dampsey, 510-527-3568 adampsey@comcast.net
Concord, 3 <sup>rd</sup> Tuesday, 1:30 PM	First Christian Church 3039 Willow Pass Rd., Concord	Neuropathy awareness	Ernette Rivera, 925-889-2484 ernette5712@sbcglobal.net
Davis 2 <sup>nd</sup> Wednesday 2 PM	Institute for Restorative Health, 1460 Drew Ave. across from Kaiser	Come and be helped!	Martha Chandley, 916-371-1125 kairoschandley@sbcglobal.net
Elk Grove 2 <sup>nd</sup> Tuesday, 2 PM	Elk Grove Senior Center 8830 Sharkey Ave, Elk Grove	Come and be helped!	Michael Colozzi, 916-421-8103 Susi Watson 916-354-0483
Folsom 2 <sup>nd</sup> Tuesday, 3:15 PM	Creekside Oaks Retirement Residence 1715 Creekside Drive.	Come and be helped!	Lorraine 916-983-4023, Beverly 916- 984-4302
Grass Valley 2 <sup>nd</sup> Monday, 1:30 PM	GV United Methodist Church 236 S. Church St., Grass Valley	Come and be helped!	Bev 530-389-2416 Betty Gears 530-432-7774
Jackson 3 <sup>rd</sup> Tuesday, 10 AM	Amador County Senior Center 229 New York Ranch Rd. Jackson	Call Darlene for meeting information.	Laurie 209-223-0442 Darlene 209-296-1760
Lincoln 3 <sup>rd</sup> Tuesday, 1 PM	Raley's Event Center 765 S. Hwy 65, Lincoln	Come and be helped!	Joe Facha 916-408-2007 Lavern 916-408-2007
Livermore 4 <sup>th</sup> Tuesday, 10 AM	Heritage Estates 900 E. Stanley Blvd.	Come and be helped!	E. Lorene Stack 925-447-6158
Monterey 3 <sup>rd</sup> Wednesday, 10:30 AM	First Presbyterian Church 501 El Dorado St.	Come and be helped!	Don & Ann Trout 831-372-6959
Napa 1 <sup>st</sup> Thursday, 2 PM	Napa Senior Center 1500 Jefferson St., Napa	Come and be helped!	Ron Patrick 707-257-2343 bonjournal@aol.com
Placerville 4 <sup>th</sup> Weds., 1:30 PM	Placerville Senior Center 937 Spring St., Placerville	Come and be helped!	Arlene Middlebrook, 530-626-1098 Dan Hudgins, 530-622-5188
Rancho Cordova, 2 <sup>nd</sup> Tuesday, 7 PM	Mather Field Veterans Hospital Bldg. #728, Hospital Way, MF	This group is in the planning stage.	Bev Anderson 530-389-2416 Charlie Green 916-363-1052
Redding, Restarting soon		Call Sandi Deome (530)365-7081 for info	Bev Anderson (530)389-2416
Redwood City, 1 <sup>st</sup> Tuesday, 2 p.m.	Bakers Square Restaurant 949 Veteran's Blvd., Rdwd Cty	Come and be helped!	Annette Devost 650-595-2478
Reno, NV 2 <sup>nd</sup> Tuesday, 6:30 PM	Fire Station #11 7105 Mae Anne Ave., Reno	John & Barbara Gunther Nikken consultants "Magnetic Therapy for Neuropathy"	Marsha Campbell 775-851-0499 <a href="mailto:LadyJane2b@sbcglobal.net">LadyJane2b@sbcglobal.net</a>
Roseville 2 <sup>nd</sup> Tuesday, 7 PM	Point West Sr. Res., 5161 Foothills Blvd., Roseville	Come and be helped!	Marilyn Larson 916-771-8435 Helen Astill 916-782-6208
Sacramento 3 <sup>rd</sup> Tuesday, 1:30 PM	Northminster Presby. Church 3235 Pope Street, Sacramento	Come and be helped!	Anne Fletcher 916-391-3317 Myke Taylor 916-487-2903
San Francisco – Wed. Jan. 10, 10-11:15 a.m.	UC-San Francisco Med Ctr. Amb. Care Ctr. 8th Flr. , Rm A888, San Francisco	Come and be helped!	Amy Mahoney, 415-353-2312 <a href="mailto:amy.Mahoney@ucsfmedctr.org">amy.Mahoney@ucsfmedctr.org</a>

Group/Date/ Time	Place	Program	Contact
San Jose 3 <sup>rd</sup> Saturday, 10:30 AM	O'Conner Hospital, 2105 Forest Ave, SJ DePaul Conf. Rm., San Jose	Come and enjoy!	Ann Louie, 408-282-0780 Glenda Whiteside, 408-378-6691
Santa Cruz – Call Mary Ann for date and time.	Life Oak Senior Center, 1777 Capitola Rd., Santa Cruz	Come and be helped!	Mary Ann Leer. 831-477-1239 <a href="mailto:MALEER@SURFNETUSA.COM">MALEER@SURFNETUSA.COM</a>
Santa Rosa, 1 <sup>st</sup> Thursday, 10:30 AM	Santa Rosa Senior Center 704 Bennett Valley Rd, SR.	Come and be helped!	Ginger Minnich, 707-829-2934
Sonora. Meeting, Oct. 30 Last Monday, 2-4 PM	Sonora Regional Medical Center Conference Room	Come and be helped!	Ed Minium (209)586-3702
Stockton 3 <sup>rd</sup> Tuesday, 4 PM	Central United Methodist Church 3600 Pacific Avenue.	Come and be helped!	Mary & Case Klooster (209)463-5985
Walnut Creek	Rossmoor, Hillside Clubhouse Vista Room, Walnut Creek	<b>If you are interested in helping this group restart, call Ginny or Bev Anderson (530)389-2416.</b>	Ginny Olson, 925-947-3158 <a href="mailto:riovwo@comcast.net">riovwo@comcast.net</a>
West Sacramento 3 <sup>rd</sup> Wednesday, 2:00 PM	AF Turner Branch, Yolo County Library, 1212 Merkley Ave. WS	<b>Note new day and time.</b> Come and be helped!	Sandra Vinson, 916-372-6093 <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	Come and be helped!	Delia Genera 530-661-3238
Yuba City 2 <sup>nd</sup> Monday, 7 PM	Sutter Estates 1230 Plumas Street, Yuba City	Come and be helped!	Nancy Escudero, 530-673-3608 <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**

April 10 is our Annual Meeting and Group Leaders Gathering. This means anyone who is, has been, or is willing to be part of the Leadership Team of a support group. If your Leader can't come, maybe you can come to get the information. We need to know who is coming so we can have a count by April 2.

We will present the Annual Report with highlights of 2006 and the annual financial report, have time to get acquainted with leaders from other groups, and culminate with a speaker who will inform and entertain you – Marco Vespignani, N.D. He is a naturopathic doctor and Medical Director Women's Health and Restorative Health Services, Institute for Restorative Health in Davis. Sandra Vinson, member of the NCCNA Board of

Directors and one of Dr. Vespignani's patients, is coordinating arrangements and food for this meeting. She gives good reports of the care she is receiving and is enthusiastic about what he will bring to this gathering.

### **Notes on the Registration form for June 26**

The cost is \$25 for patients with neuropathy. It is also \$25 for spouses or other caregiver coming with the patient. It is \$75 for those who are not patients with neuropathy nor caregivers for someone who does.

At the bottom of the Registration Form is a note titled Accommodations for Disabilities. This is a statement required by the facility to cover anything that someone may require. This does not apply to those with neuropathy unless you have another disability. The building is ADA accessible with ramps and elevators. **Leaders, please make copies of this form for those in your group who do not receive the newsletter.**

## **LOCAL SUPPORT GROUP NEWS**

### **Monterey PN Support Group**

Monterey has chosen the 3<sup>rd</sup> Wednesday of each month at 10:30 AM as their meeting time. Don Trout, Leader, reports their group is growing. Their local newspaper not only put the announcement of their upcoming meeting in it, they looked up the NCCNA website and included this.

### **Website**

Have you checked out [www.neuropathy-nca.org](http://www.neuropathy-nca.org)? Susi Watson has done a great job as webmaster. Our new Member of the Board of Directors, Penni Smith, will be taking this responsibility. We look toward the time soon when the website will link to The Neuropathy Association website and they will have a link to ours. We have had assurance that this is definitely possible.

### **Congratulations to**

#### **Livermore PN Support Group**

Bart Costerus, Treasurer, sent a note with a membership check recently that shows their positive attitude in developing their support group:

*Hi Bev, I enclose a \$24 check for... 2007 NCCNA membership and a \$50 check from the Livermore-PN Support Group. This last check is to repay NCCNA – with sincere thanks – for the seed money sent us to help us to get off the ground. We hope that it can help start another support group. From all indications, I think it is safe to say: “We made it!”*

#### **Reno PN Support Group**

Marsha Campbell, Reno PN Support Group Leader, sends in information about their meetings several months ahead. On April 10, while she is in Sacramento for the Group Leaders Gathering, Davene Kaplan, an Assistant Leader, will facilitate the meeting featuring John & Barbara Gunther, area independent Nikken, Inc. consultants.

May 10, they will hear from Marsha’s primary care physician, Dennis Brown, MD. He is an Internist and Specialist in Osteoporosis. He diagnosed her neuropathy and will talk about Osteo and Neuropathy. On June 12, Marsha will report on the April 10 Group Leaders Gathering and Annual Meeting.

She says that other meetings in the planning stages include “Aromatherapy,” guest doctors, neurologist, podiatrist, and so forth.

### **Folsom PN Support Group**

Folsom had its first meeting at Creekside Oaks Senior Residence in March. It went quite well with 5 people from the Residence in attendance. Obtaining Anodyne Therapy when your insurance won’t cover it was a topic of discussion.

### **Auburn-Evening PN Support Group**

The room was full of people to hear William Gilbrech, DPM talk about foot care and neuropathy. Many in the audience were or had been his patients. He actively diagnoses peripheral neuropathy in patients coming in because “their feet hurt” and reporting other symptoms. Anodyne Treatments are available in his office. Some patients are helped a great deal. He reminded us to care for our feet, examine them every day, and don’t go barefoot.

### **SUGGESTIONS TO BEAT CHRONIC PAIN**

Woman’s World in January 2006 suggested these ways to help chronic pain:

1. Eat the better protein – fish. Omega-3 oils are quite helpful. If not fish, you can take Omega-3 as a supplement.
2. Rub on the right cream. They suggest Celadrin that can be found in major retail drug stores. It may be called ReVivex. For burning pain, the article recommended Zostric or other capsaicin cream as it short circuits the pain signals before they reach the brain.
3. Take in more Vitamin D – Taking 800 IUs of Vitamin D can dampen aches in four months.
4. Spice up your menu – with ginger. It has 477 different active ingredients.

### **ACETYL-L-CARNITINE**

Reuters Health reported “People with diabetes related nerve damage may find pain is relieved by taking a compound related to the popular supplement L-carnitine - provided the treatment is started early. Acetyl-L-carnitine (ALC) is not currently approved in the US for treating nerve pain, “but it is used widely for painful neuropathy in patients with diabetes and AIDS in Europe,” Dr. Anders A. F. Sima from Wayne State University School of Medicine in Detroit, said in a telephone interview.

**RESEARCH REPORT FROM STANFORD**  
**Yuen So, M.D., Ph.D., Professor of Neurology and Neurosciences, Stanford University (A NCCNA Medical Advisor and speaker at our 2005 Conference) and Charles Cho, M.D., Assistant Professor of Neurology and Neurosciences collaborated on this report.**

**We will have research reports from persons at institutions doing the research in this newsletter as we are able to obtain them.**

**Peripheral neuropathy affects over 20 million people in the United States alone.** Although it is seldom life-threatening, it is a major cause of discomfort, pain, or even permanent disability. Numerous diseases such as inflammation, immunologic change, virus infection, toxic exposure, and metabolic disorders can trigger neuropathy. As many as 60% of all diabetic patients have some form of neuropathy. If not appropriately diagnosed and treated, the initial symptoms often lead to numbness, weakness and pain. For the past several years, we at the Stanford University Medical Center have been active in research to advance our understanding of different types of neuropathy. Our research falls broadly into three categories: understanding of the problem, diagnosis of neuropathy, and treatment of the symptoms.

**There are many areas in the field of peripheral neuropathy that have not received proper attention.** One particular area is the issue of quality of life in people suffering from the condition. We have carried out an extensive survey of dozens of patients seen in our Stanford clinic. Our survey covers various issues in daily activities. One particularly sensitive area we came across is the question of driving safety. We hope to finish data analysis and reach some conclusions in coming months.

**On the issue of testing and diagnosis, we started a blood collection program in people with neuropathy over a year ago.** The goal is to apply modern molecular biology techniques to uncover markers that are useful in the diagnosis of different types of neuropathies. This is a laborious process that involved collecting specimens and clinical data from a large number of patients. We

then use statistical analysis to make sense of the data. If successful, it will enable physicians to make some neuropathy diagnosis just with a simple blood test. It has the promise of eliminating or at least reducing the need of cumbersome or uncomfortable procedures such as EMG (electromyography and nerve conduction study) and nerve biopsy. We are also involved on a national front in drafting a position paper on the use of various physiological tests in diagnosing radiculopathy, a nerve problem at the spinal root level. As part of both patient care and research, we continue to innovate to find better diagnostic techniques, especially in employing techniques such as diaphragm electromyography, motor unit number estimation, root stimulation and many others that are not widely available in the community.

**The treatment of neuropathy and improving the quality of life should be the ultimate goal.** Our work includes both evaluation of existing treatments and finding new novel treatments. For the first, one of us recently published a position paper on behalf of the American Academy of Neurology on the subject of surgery in diabetic neuropathy. For the second, we are involved in multiple clinical trials testing promising new compounds as well as using old drugs in new ways. Recent examples include the use of prosaptide (a novel compound that unfortunately did not seem to work), NGX (a unique capsaicin-based topical treatment that seems to reduce neuropathic pain), a new IVIG formulation for chronic inflammatory demyelinating polyneuropathy (widely known as CIDP), and the use of topiramate (Topamax<sup>®</sup>) for refractory diabetic neuropathic pain. We are presently testing NGX again and also pregabalin (Lyrica<sup>®</sup>) in the treatment of pain in HIV neuropathy. Other potential treatments are currently in planning stage.

**Peripheral neuropathy is a multi-faceted disease.** There are many worthwhile issues to explore, and investigators are limited by time and funding. A cure, or at least improvement in quality of life, is possible only through increased attention to the disease and funding of research. We are grateful to grass root support groups and patient organizations in their continuing effort to raise

awareness of the disease. Also, their contribution to patient education is priceless and absolutely makes our work at the Stanford Neuropathy Clinic easier.



## MARTHA'S CORNER

News from Martha Chandley, PN resource extraordinaire

### INFORMATION ON WEB SITES

[www.neuropathy.org](http://www.neuropathy.org). The Neuropathy Association web site with a Discussion Board where you can ask other patients for information!

[http://www.neuro.wustl.edu/neuromuscular/nal\\_tbrain.html](http://www.neuro.wustl.edu/neuromuscular/nal_tbrain.html)

This is the diagnostics entry point for the neuropathy section of the huge neuromuscular conditions database at Washington University of St. Louis' medical website. It is written primarily in outline form, and mostly for medical professionals, but it is extraordinarily comprehensive; going through the links and sub links reveals a wealth of info on neuropathy (and other neuromuscular conditions).

[www.lizajane.org](http://www.lizajane.org) (*We'll have a few copies of her lists at the Davis meeting.*)

Our good friend Liza Jane provides a spread sheet of neuropathic conditions listing just about any test one can think of to investigate neural conditions. Its format enables one to track test results over time to look for patterns, and to suggest tests to doctors they may not otherwise think of.

<http://www.thecni.org/reviews/13-2-p07-treihafthtm>

#### **Painful Feet: The Small Fiber Neuropathies**

One of the best articles I know written about small-fiber neuropathies, which can be difficult to diagnose, as the "standard" test for neuropathy often comes up "normal" and fails to reveal them (and meanwhile patients suffer). The reference list is excellent--it includes many of the seminal papers on skin biopsy, autonomic testing, and small-fiber vasculitis and other causes of small-

fiber dysfunction (these can themselves be investigated if one wants).

<http://www.dcmsonline.org/jax-medicine/2000journals/august2000/neuropathies.htm>

#### **Current Concepts In The Diagnosis And Treatment Of Peripheral Neuropathies**

Another good paper--this one from Dr. Alan Berger and his colleagues at Jacksonville Shands. It provides a good overview of diagnosis and treatment options for various kinds of neuropathies, and suggests a particular categorizing method to understand them.

<http://care.diabetesjournals.org/cgi/content/full/26/5/1553>

#### **Diabetic Care, Diabetic Autonomic Neuropathy**

If you ever wanted to understand diabetic autonomic neuropathy, this article's for you. In fact, Dr. Aaron Vinik is probably the world's leading expert on diabetic neuropathy of all kinds, and googling his name can keep you busy for months. (This article has a reference list one could choke on, but it contains almost every important paper on diabetic neuropathy written in the last 30 years.)

<http://www.neuropathymd.org/topical/18/Neuropathy%20and%20Monoclonal%20Gammopathy.pdf#search='Latov%20Monoclonal'>

#### **Peripheral Neuropathy and Monoclonal Gammopathy.**

Another Latov article on an often overlooked generator of neuropathy--para or M-proteins in the blood, sometimes related to blood dyscrasias; and for those who like to look up many conditions in one place, I highly recommend the Emedicine series of articles; just go to emedicine.com. You have to sign up as a user, but then you can peruse the database. The material is dense--written for medical personnel, again--but highly comprehensive.

**Our current membership is over 400.  
How soon can we top 500?**