

PN News

Yolo County

VOL. 6, NO. 1

JANUARY 2008

The mission of the Yolo Neuropathy Groups is to insure, through Information, Empowerment and Mutual Support that all may have hope and no one faces their peripheral neuropathy alone.

"Coming together is a beginning; keeping together is progress; working together is success." Henry Ford

Martha Chandley, Editor (916) 371-1125 kairoschandley@sbcglobal.net

Yolo Neuropathy Groups did not meet in December.

Hope everyone had a blessed and glorious holiday season!

January meetings in Woodland and Davis will meet at the regular time and place.

Note change for earlier West Sacramento gathering because of the library book sale.

Let's celebrate getting through 2007 and setting neuropathy goals for 2008.

Woodland: Monday, January 7 at 4:30 PM for a potluck gathering
at the Woodland Community & Senior Center, 2001 East Street
Contact: Delia at 530-661-3705 or Donna at 530-661-3705

Davis: Wednesday, January 9 at 2 pm at the Institute for Restorative Health & Physical Edge,
1460 Drew Avenue. Contact: Martha at 916/371-1125 or Donna at 530-661-3705

West Sacramento: Tuesday, January 15 at 2 pm at the Turner Library, 1212 Merkley Ave.
Contact: Sandra at 916-372-6093 or Martha at 916-371-1125

THANKSGIVINGS FOR SO MUCH!

New Foot Wear Benefit Available for NCCNA's 2008 Members!

Thanks to the generosity of Tracy Basso, DPM and owner of Shoes 'n' Feet (4740 Natomas Blvd. Ste 130, Sacramento, CA 95835 – north of Arco Arena, 916-419-0040), NCCNA members will receive a 15% discount on specialty shoes purchased at the store with presentations of their 2008 NCCNA membership card at the time of purchase! The staff is exceptionally trained for delivering a perfect fit from among their great quality and attractive shoe choices. Thanks to NCCNA board member and West Sacramento co-leader, Sandra Vinson, for her fruitful proposal to Dr. Basso!

Medicare patients who have **diabetic neuropathy** are potentially eligible for additional savings through Medicare's **therapeutic footwear program**. Thanks to our friend **Bill End** for this recent Diabetic Tip of the Day information: If your physician can certify that you are in a plan of diabetes care, have evidence of foot disease and need therapeutic footwear, you should be able to secure special accommodations, such as custom-molded shoes, extra depth shoes, inserts and some shoe modifications. Your podiatrist then writes the prescription to be filled by a qualified supplier (such as **Shoes 'n' Feet**) and file the forms with Medicare. Be clear about the actual prices and how much Medicare will eventually pay. You will pay up front, but the cost can be reimbursed up to 80% of reasonable costs. Ask your podiatrist for proper forms and referrals.

(If you haven't already sent in your 2008 dues payment, do please enclose a check for \$24 made out to NCCNA and send it to the NCCNA address, along with the completed membership form on the next to the last page of this issue of *PN News*. And thanks to all who have done so already!)

Neuragen Product Now at California Longs Drugs!

We were delighted to learn in December that our Halifax, Nova Scotia friends at **OriginBioMed**, had made arrangements with **Longs Drugs** to carry our old neuropathic pain relief friend – **Neuragen** – in California! Some of you have had difficulties in finding the product in recent weeks, but we and OBM are in conversation with Long's management to promote greater local store visibility. We know this topical homeopathic and essential botanical oils product can do so much to help manage our various neuropathic symptoms from such conditions as diabetic neuropathy, post-herpetic neuralgia (shingles pain), fibromyalgia, spinal compression and sciatica, post-surgery, accident, chemotherapy damage and other damaged nerve discomfort.

OBM has two product sizes costing \$30 and \$56; while this is pricey, it really is worth the cost because the product works so well on our particular kinds of pain. Just a few drops, two to four times a day, massaged into a pain area, will provide significant relief to keep us going. One of our members recently used it on her feet during a European tour and was able to do a great deal of walking for the first time in ages. Some of us have mixed the liquid with a little grape seed oil to apply on large areas, such as our backs.

Do yourself a favor, drop by your area Longs Drugs and give the product a try. Attached to this newsletter is a product card with a picture of a Neuragen bottle, if you don't see the product readily available, please show the card to the pharmacy manager, explaining that corporate management has assured us the stores should be well stocked. There are numerous Longs Drugs in the region, including Davis and Woodland, several across Sacramento, Carmichael, Elk Grove and beyond in adjacent counties.

*(Thanks to our compound pharmacist friend, **Jerra Banwarth**, for having carried the product for us at **Prescription Specialists** in Woodland in recent years and for continuing to be available to us at the Institute for Restorative Health for other topical neuropathy compound products!)*

Yolo Community Foundation Philanthropy Day Awards

One of the very special institutions in Yolo County working to improve the lives of its citizens is the **Yolo Community Foundation**. Since 2001, YCF has worked hard to fulfill its long term, most worthy and honorable mission of matching the philanthropic interests of area donors with the needs and opportunities of Yolo County. YCF's program funds are allocated for agricultural heritage, arts and culture, environment, basic human needs, education, health, and community development projects.

One of YCF's new program services in 2007 has been a kind of "support group" for non-profit organization leaders who have gathered for monthly roundtable discussions to share helpful information and provide mutual support. Representatives from your Yolo Neuropathy Groups have been warmly welcomed into this most remarkable community of very caring, knowledgeable and committed folks this year, culminating in a very special, celebratory event on the evening of November 13 – a **Yolo County Philanthropy Day Awards Ceremony** at the Heidrick Ag History Center in Woodland.

Among the organizations honoring their special donors and volunteers were the Yolo Literacy Council, the Yolo Arts Council, the WAVE (the Woodland community access television station), the Yolo Family Resource Center, the YCF itself, **AND** your very own Yolo Neuropathy Groups. Testimonies about the good works of the honorees were inspiring expressions of how societal good comes about through the committed, imaginative, compassionate, and generous giving of time, talent, treasure and other resources and services for the benefit of the many who are served in so many ways.

The YNG was represented by Coordinator/Leader Martha Chandley; Delia Genera and Donna Russell, co-leaders of the Woodland group; and Sandra Vinson, co-leader of the West Sacramento group and NCCNA Board member, who were introduced to the 80 or so "Yoloites" attending the event. Chandley shared something of the mission, history and achievements of the YNG and presented lovely framed certificates of appreciation, designed by Penni Smith, NCCNA Secretary and computer expert, par excellence, to two of our honorees who were able to come:

Eric I. Hassid, MD, CEO and Medical Director of the **Institute for Restorative Health** in Davis. He has been the primary neurologist for many of us, as well as our primary patient educator, provider of special services to support our work, generously allowing his treatment staff to also be our educators, while also sharing IRH facilities for our Davis meeting home.

Terry Bassett, Executive Director of the **Yolo County Transportation District** in Woodland. He allowed us to display the neuropathy posters on **Yolo Buses** as part of our ongoing regional neuropathy public health awareness campaign and for providing supportive regular and para transit services for disabled PNers needing public transportation services.

Unable to attend the event were our four other honorees:

Mathew Moore, MPT, co-owner of **Physical Edge**, for our Davis meeting space, for educating us about exercise issues and providing excellent physical therapy services for many of us.

Tracy Basso, DPM, **David Foot and Ankle Center** and owner of the **Shoes 'n' Feet Store** in Sacramento, for his podiatric care services for many of us, for providing printing services for our newsletter last winter, for being a long-time supporter of YNG's efforts; and sharing his knowledge at our meetings.

Maria Lucchesi, Resource Specialist at the **Woodland Senior Center**, has faithfully been our friend and coordinated our use of the facilities for our Woodland group for several years.

Eric Maldonado, Manager of the **UPS Store** in West Sacramento, who has provided great printing services at significantly discounted rates for our **PN News** and other printing needs.

We are extremely grateful for all the many ways they have so generously supported, cared for and served the Neuropathy Community in Yolo County and beyond in recent years. But we also deeply appreciate and salute our new friends - the ever-gracious and helpful Cath Posehn, as YCF's Executive Director, and Maggie Burns, President of the YCF Board of Directors, for their affirmation of and encouragement for our work in, for and with the neuropathy community in Yolo County and beyond.

Davis Enterprise Article Features Spatafora Talk!

While health issues are frequently in the news these days, it's difficult to get media coverage about specific conditions and critical health rights service problems. Thanks to **Linda DuBois**, our wonderful colleague at the **Davis Enterprise**, information about the monthly Davis neuropathy meetings have been regularly presented to the public. We were especially grateful to Linda and honored to have **Emily Levin**, Enterprise Correspondent, with us at our November meeting with **Dominick Spatafora**, founder and president of the **Neuropathy Action Foundation**. Her most informative feature article on his dynamic personal testimony appeared on December 21 as a very special holiday gift to the Yolo neuropathy community, for which we are most grateful! (Go to <http://www.davisenterprise.com/story.php?id=501.5> for the article and delightful picture of Spatafora and his fuzzy Australian friends.)

We were inspired by Spatafora's testimony about his struggles to secure appropriate diagnostic and IVIG treatment services for his rare form of multiple motor neuropathy most intriguing. His personal crisis led to his commitment to develop education and advocacy services to help other PNers learn more about their conditions and obtain the medical help they need in spite of health delivery systems designed to minimize services, even for the well insured. We were discomfited to hear him say, the problems will only get worse. Somehow we've got to become equipped to become advocates for ourselves and one another – hence the desperate and moral necessity for collaborative efforts of such organizations as NAF, NCCNA and TNA.

Several Yolo PNers attended the December 5th **NAF/NCCNA** co-sponsored education advocacy summit: **Championing Healthcare Rights for Yourself and Others**, that was well summarized in the January issue of NCCNA's *Neuropathy Hope*. Spatafora had developed the excellent event for us with presentations by some of his Sacramento area colleagues. There will be more about the November health rights presentations to the Davis and West Sacramento groups and the December summit in the next newsletter.

Thanks also to all of you, our members, subscribers, donors, and friends, for your support of the **Yolo** groups, the **NCCNA** groups across the region and our national organization, **The Neuropathy Association**. We are united in our invitation to affirm and act upon the proposition - **Together, we can beat this disease!** Thanks to the folks in West Sacramento and Woodland who helped stuff the TNA brochures with Yolo support group flyers and helped prepare the info packages about neuropathy or the January distribution to Yolo doctors to share with their patients. **And thanks to all for your patience during my slow but ongoing recovery** from the summer's spinal injuries that delayed newsletters and progress on several planned projects to further educate and support PNers and inform doctors and the public about our PN groups and services.

Sue Alexander, Sacramento Area Fibro/CFS Educator/Activist/Advocate and Video presentation by **Russell Rothenberg, MD**, "**The Diagnosis and Current Treatment of Fibromyalgia**" at the January 2004 Symposium of the National Fibromyalgia Partnership in Chevy Chase, MD.

Our Davis and West Sacramento groups were delighted to welcome numerous newcomers to Sue's great presentations to and very generous informative handouts and product samples for those attending our October meetings! And her display of incredible patient education resources accumulated over the years was truly amazing. With colorful pictures from the family "victory album," Sue shared how they had once maintained very active athletic life styles, competing in multiple sports arenas, until overcome with the disabling symptoms common with Fibromyalgia and Chronic Fatigue Syndrome. How in the world had she been able to maintain her rather phenomenal services with support groups and frequent exhibits at regional health fairs over the years?

She'd done it because she knew it really mattered to other sufferers and had learned to take balanced care of herself to prevent debilitating relapses.

Besides, **fibromyalgia** is finally, at long last, being seen by the scientific and medical community as a very real malady to be taken quite seriously and whose patients are not to be discounted as the "depressed woman's hypochondria" as had been the norm for many years. The October 29 issue of *US New and World Report* contained an article (pp. 52-53) reporting that fibromyalgia is now seen as a problem of the central nervous system, rather than peripheral nervous system as with neuropathy. Rather than being "whiners" those with fibro suffer from being "exquisitely sensitive to pain" possibly from "imbalanced neurotransmitters." But there are also increasing indications that Fibro/CFS and Neuropathy are often linked in functional realities of co-morbidities; indeed, many with fibro experience neuropathic manifestations such as tingling, numbness, burning or twitching

And then you see Pfizer's **Lyrica** ads in magazines and on television; lo and behold, FDA has approved Lyrica for treatment of both chronic pain conditions. And of course, Lilly is seeking FDA approval for **Cymbalta** as an alternative for the estimated 6 million US fibro patients. But readers were reminded that medication effectiveness is usually minimal and variable. And some advocates argue that life style changes, like moderate exercise, like tai chi and yoga, restorative sleep plans and other body-mind self-management techniques could well prove much more significant than the new drugs.

Rothenberg's video lecture begins with the **classic definition** that fibro is a "chronic widespread musculoskeletal pain present for three or more months with no other condition present causing the pain.... and an involuntary painful response to at least 11 out of 18 tender points...." He then lists 12 associated findings that many of us experience, such as facial and head aches, emotional and cognitive difficulties, disorders of the parasympathetic system (e.g. irritable bowel and bladder problems we might associate with autonomic neuropathies), hypotension, chemical sensitivities and nonrestorative sleep. And his causes include genetics, neuroendocrine disorders, neurological disorders (including peripheral neuropathy and disorders balance), associated with rheumatic diseases (e.g. arthritis or myofascial pain).

Traditional pharmaceutical and "alternative" treatments for Fibro/CFS pain pretty much mirror those for neuropathy and associated conditions. For the former - various anti-depressants, sleep medications, anti-convulsant drugs, muscle relaxers, Substance P inhibitors, NMDA receptors, and treatments for concurrent diseases and conditions. For the latter, nutritional enhancements (e.g. supplementation of B and D vitamins, magnesium and calcium), acupuncture, low impact aerobics, stretching exercises, hot and cold packs, warm water aquatic exercises, multiple forms of physical therapy, ergonomics, psychological treatments, conservation of energy and work/life style accommodations. Because the causes and manifestations of Fibro/CFS are so complex, it's important for our doctors to understand the need for combined modalities to maximize functional effectiveness, including a probable need for strong pain meds. We need to become alert to new symptoms that might be wrongly attributed to fibromyalgia with consequent delayed treatments. "Hands on" and listening doctors are essential for proper treatment approaches for central (and peripheral) nervous system disorders.

When asked what worked for her, Sue mentioned using the **Sore No More** pain relieving gel and magnesium tablets for relieving muscle spasms. She's learned how to "pace" herself by not over exerting her body to prevent pain flares, getting good rest, relaxation and sleep. And while no longer leading support groups, she attends them to maintain her support system and keep up to date on diagnostic and treatment developments.

Thanks again to Sue for her wonderful help to the neuropathy and Fibro/CFS community over the years!

Neuropathy Odds and Ends

One of our members recently inquired about securing vehicles able to accommodate scooters/wheelchairs and/or hand controls to compensate for driving dangers with numb feet. Last year we'd had a presentation by **Omar Magana** of **Sacramento Van Conversion and Mobility Services** at the Davis Senior Center regarding their state reimbursable programs to accommodate various disability conditions. Time to provide that contact information again: SVC is at 5821 Florin Road in South Sacramento and can be reached at 916-381-8267 or 800-795-0888. This long-time family owned company has been providing exceptional services for people across the region for many years and are highly commended to those needing special help.

Sacramento is fast becoming a center for multiple kinds of **clinical trial studies** at UCDCM and several private firms as well, as evidence by the frequent appearance of advertisements in The Sacramento Bee. As many of us suffer from **low back pain**, a recently advertised study caught my attention. A Fair Oaks company, **Med Investigations**, has been recruiting participants for a randomized, double-blind placebo-controlled study to test the safety and effectiveness of **BTDS, a transdermal patch with an opioid analgesic**, for treating moderate to severe chronic low back pain. While the FDA has approved the drug's use in the US, the present study investigates its potential for treating chronic pain. If you'd like to learn more about the study and a preliminary eligibility interview, call Susan Mullins at 916-966-7452.

We've long known that various **chemo and radiation therapies** for several forms of cancer are likely to cause neuropathic symptoms, which may or may not diminish once these therapies are ended. In the absence of specific alternative medications, **neurontin** has been commonly prescribed for a broad range of neuropathies, but rarely tested for efficacy for specific types. A September 12, 2007 online issue of *Cancer* reports on a six week study that broadly concluded "This trial failed to demonstrate any benefit to using gabapentin (neurontin) to treat symptoms caused by chemotherapy induced peripheral neuropathy," although the trial involved **oxaliplatin** treatments for colorectal cancer. Whether a longer trial and/or with other chemo induced neuropathies would produce the same results is unknown. But there is certainly a need to minimize, if not end this neuropathy cause.

Two West Sacramentan Pners reported experiencing **blurred vision with neurontin** use that improved with cessation of the medication. As TV commercials and magazine advertisements note this side effect for some Lyrica users, we are once again confronted with the dilemmas of good and bad consequences for product use. Actually, blurred vision is a common side effect for numerous medications for chronic conditions.

An Indian study published in the December 2007 issue of **Diabetes Research and Clinical Practice** found that **yoga postures and breathing exercises** were helpful in reducing the clinical and biochemical changes associated with metabolic syndrome. Participants experienced reductions of waist circumference, blood pressure, and triglycerides and higher HDL measures with their yoga practices. (Yoga classes free to the public are typically found at local senior centers. Some of us Pners in West Sacramento are benefiting from the low cost gentle yoga classes conducted by Mae Denman. Interested? Give her a call at 916-374-9704.)

Charcot foot, a once rare diabetes foot complication is becoming more common according to the American College of Foot and Ankle Surgeons. Charcot is a sudden softening of the foot's bones caused by severe neuropathy that can trigger an avalanche of serious problems including joint loss, fractures, collapse of the arch, massive deformities, ulcers, amputations and even death. Suddenly appearing symptoms of warm, red skin, swelling and pain requires emergency medical care because they can also be caused by deep vein thrombosis or an infection. Do see your podiatrist if you have the above symptoms for corrective treatment, including reconstructive surgery if needed.

Ten Questions to ask your Neurologist (or Primary)

My worst problem is pain, but nothing I take helps, what can I take for pain?

What are the side effects from taking the medications prescribed?

Besides prescription medications, is there anything I can do to relieve the pain?

What can I do to improve my balance? What are the other neuropathy symptoms?

Will I be able to continue driving my car and can I continue to work with my symptoms?

Are there any alternative medicines or treatments that can help my numbness and tingling?

I would like to meet other people with neuropathy to see how they are handling their disease?

Will I continue to get worse and become wheelchair bound?

Is neuropathy hereditary? Will my children develop some form of neuropathy?

How can I find out about clinical trials when new treatments might be available?

(Thanks to Irene Beer at The Neuropathy Association's website, www.neuropathy.org)

**Yolo Neuropathy Groups
C/O Martha Chandley
1399 Sacramento Ave. Unit 108
West Sacramento, CA 95606**

TO: