

# PN News

Yolo County

VOL. 5, NO. 8

AUGUST 2007

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.00.0.” Henry Ford

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## August Yolo Neuropathy Group Plans

**Woodland Neuropathy Group: Mon., August 6 at 4:30 pm,**  
“Celiac Disease and Neuropathy,” Diane Craig, Celiac Group Leader  
Woodland Community & Senior Center, 2001 East Street  
Contact: Delia Genera at (530) 661-3238

**Davis Neuropathy Group: Wed., Aug 8 at 2:30 pm**  
“Celiac Disease and Neuropathy,” Diane Craig, Celia Group Leader  
Institute for Restorative Health, 1460 Drew Avenue, Suite 300  
Contact: Martha Chandley at (916) 371-1125

**West Sacramento Neuropathy Group: Thurs., Aug 16 at 2 pm**  
“Experiencing Diabetic Neuropathy” Martha Chandley  
A. F. Turner Library, 1212 Merkley Avenue  
Contact: Sandra Vinson at (916) 372-6093

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Our colleague **Diane Craig, leader of the Sacramento Celiac Disease Support Group**, spoke to the West Sacramento Group last year with a most fascinating and enlightening presentation on this gluten intolerance condition that can cause neuropathic symptoms that are familiar to many of us. Some of us who have been diagnosed as having “idiopathic” neuropathy may very well have celiac disease and may wish to ask for a medical evaluation on this possibility. We understand that neuropathic symptoms caused by celiac disease usually disappear with a gluten free diet. Diane will be able to give us a great deal of information about this disorder gained from her many years of personal experience, independent research and leadership of the area support group. As she works in an after school enrichment program during much of the year, we are pleased to have her with us at the Woodland and Davis meetings before resuming her academic year program responsibilities. This is an important issue that PNers need to know about. Do please come to learn and be encouraged.

The August and September meetings in West Sacramento will focus on diabetic neuropathy. Martha will lead a general discussion on “**Experiencing Diabetic Neuropathy**” of typical symptoms and treatments, using an article developed and published by the AGS Foundation for Health in Aging. This article is being sent to those calling the **Neuropathy Hotline** in response to the neuropathy posters. In September, **Elizabeth Yeh, RN**, will present a more technically medical presentation, “**Understanding Diabetic Neuropathy**,” at an extra West Sacramento meeting. If your neuropathy was or may have been caused by diabetes, you may find illumination and hope. But all are welcome...

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**Personal Progress Report** Thanks to all who called or sent cards of encouragement regarding my spinal injuries in the June falls. Healing the L-1 fracture continues slowly, punctuated with some periodic really bad pain, distress, moans, tears and exhaustion for non-restorative sleep. Anodyne therapy has helped in reducing pain levels as a supplement to the Lidoderm pain patches and pills. I'm still struggling to prevent overdoing in sitting, standing, or walking but also know that strengthening my back is moving up the priority scale. Thank God for the principles of the American Chronic Pain Association's "**Ten Steps from Patient to Person**" and their relaxation tapes that have help keep me sane in the process. Handling the **Neuropathy Hotline** calls from bed has worked well, though note taking has often been cumbersome. While the ordeal has very much limited my capacity to take care of business as usual for old and new projects I'd planned for the summer, it has certainly made me more empathetic for those who suffer with PN and other acute and chronic conditions. Whenever I'm tempted to give in to "poor me pity party" sentiments, I am reminded of the much worse difficulties of many of you old-timers and those potential newcomers who have called the Hotline this summer. **While I do hope to be back to relative normalcy this fall, I'll likely need to take it fairly easy for some time.** While I regret this, *it is what it is and I am coming to accept it*, thanks to the nurturing wisdom of **Ilona Ireland**, who gave three wonderful talks on **Caring for the Caregiver** for the Yolo groups in July.

Thanks to John Chandley, my 88 year old Dad, who has been a fabulously patient and helpful caregiver; couldn't have made it without him! Special appreciation is sent to **Sandra Vinson**, who filled in at two meetings and helped in other ways. Thanks to others who helped with mailings, errands to the printer and post office and posting flyers. Thanks to those who wrote copy for the **Neuropathy Action Foundation** event report below, particularly for Donna Russell's medical training that allowed her to capture so much of the rich information presented by the speakers. Extra special thanks to those who sent \$200+ in new or renewing membership checks and generous donations in July to support our PN patient education and advocacy work via the Neuropathy Hotline project. For those who haven't joined or renewed membership in NCCNA for 2007, the new membership form is on page 7 and dues for the balance of the year are only \$10. Please join if you can. **Blessings to all!**

**Neuropathy Hotline Update** If you've dialed 916-371-1125 in recent weeks, you've likely heard, "**Thanks for calling the Neuropathy Hotline; this is Martha, how may I help you?**" In response I've heard tales of woe, frustration, sometimes despair and occasional relief to know there is a name for mysterious conditions and there are some things to help. Some 40+ callers have thus far explained they recognized the symptoms seen on the NCCNA posters and want to know what to do now. The posters are currently on about 300 public transport vehicles and at numerous community and medical facilities in Sacramento, Yolo, Placer and El Dorado counties. Our conversations have reviewed a bit of medical history looking for possible causes, and their futile efforts to secure proper diagnoses and treatments. Most have recounted encounters with maddeningly unresponsive, dismissive and ill-informed doctors, whether at the many public clinics or prominent HMO's and medical groups in our area. Guidance for going forward is offered the callers, encouraging them to find more responsive medical providers if possible, connect with the nearest PN support group and to feel free to call again with questions.

Callers are then sent a simple "Neuropathy 101" package of information about general neuropathy issues (a very brief summary of the NINDS booklet, **Peripheral Neuropathy**), about diabetic neuropathy (as most so far have been diabetic, although many report having spinal problems as well), and two documents developed by the **American Chronic Pain Association** – their really marvelous graphic, "**Nerve Man**," showing the major nerves, as well as their really wonderful holistic guide - "**Ten Steps from Patient to Person**." The new **NCCNA**, **TNA**, and **OriginBioMed** brochures are also sent, along with a list of area support groups' with their meeting times, locations and contact numbers; a "site map" of NCCNA's marvelously evolving [www.pnhelp.org](http://www.pnhelp.org) web site; and a membership form. If our conversation produced a potential specific neuropathy cause, or treatment need, one or more of the NINDS booklets or product/service brochures we make available at the area group

meetings, are also sent. Contact information will soon be sent to the area support group leaders with the hope they too will reach out to potential members in their service areas.

We hope the callers will soon show up at the area groups to find warm welcomes and helpful information awaiting them. Several marvelous new folks have already connected with the Yolo groups and/or are planning to come to the August meetings. We hope many more will soon appear at the Sacramento and Placer area support groups in the coming months. Some calls have led to further contacts with a few of the area social agencies and public clinics, with information packages sent to their onsite “navigators” or program managers, encouraging acquisition of more free NINDS booklets for medical and other patient support staff.

Several callers have explained their work hours and transportation problems make current group meeting schedules and locations impossible for their participation. It would be great to have more groups in several new sites across Sacramento as callers have expressed interest in making participation viable. As we had hoped and anticipated, their geographic and socio-economic diversity has been quite broad – from well-off professional commuters to homeless people, all suffering from various types of neuropathy. A mid-town Sacramento group could be a very legitimate short-term goal, although the **YoloBus 42A** route provides easy access from downtown Sac to our West Sac meeting site for those used to public transit and drivers alike. Several have expressed an interest in a weekend meeting because of their work schedules. At least one other group in the NCCNA network meets on the weekend. We can hope that new leaders and accommodations will arise in the coming months.

When we first began acting on the neuropathy bus poster dream many months ago, we had no idea how it would work. **The Neuropathy Association’s** grant to match that of an **anonymous local donor** underwrote the basic poster development and production costs. Thanks again to our new friends at the Sacramento RT, Yolo and Placer bus districts for their remarkable community partnership support for providing the medium for our message! NCCNA’s neuropathy awareness campaign continues to reach out to hundreds of people in our metropolitan area with our shared neurological disorders. The dream is being fulfilled and bearing fruit for NCCNA’s unique public health neuropathy awareness crusade. The posters’ delightful cartoon logo design has caught the attention of hundreds of folks who’ve never heard of neuropathy. Many clearly saw themselves in the symptom list. Some have called, and hopefully more will continue to call in the future. Working on this project has been a great joy for your coordinator and we hope it has been and will continue to be a real help for many of our brother and sister Pners. But the encounters have also emphasized the desperate need to reach out to the medical community, advocating for the availability of appropriate medical information and much better care for those with neuropathy. We all deserve nothing less, regardless of our socio-economic status or the source of our medical care.

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## **First Annual Neuropathy Awareness Day Conference** **June 26, 2007, Sponsored by the Neuropathy Action Foundation**

I was being dismissed from the UCDMC hospital just as the conference was beginning in San Francisco, sad to know I would miss out on the event. So, I was especially grateful to **Nancy Nix** and **Charlotte Krale** who later dropped off several documents they had gathered for me from the exhibitors and vendors, including the long document prepared by Dr. Phillips, which we’ll be addressing later. All feedback received thus far indicates that Dominick Spatafora, President of the San Francisco based Neuropathy Action Foundation, his board and colleagues did a tremendous job and those attending were most grateful for the total experience. Some Yolo members who rode the bus to San Francisco were invited to submit some reflections on what they learned, what the experience meant to them, or some questions they now have in response to the information provided

in the speeches and at the vendor tables. We're pleased to share some of the submissions from Elizabeth Chaudhry, Dolores Saint and Donna Russell. All three are coping as best they can with their own unique neuropathies.

As a long-time integrated health care advocate, Donna worked for many years as an RN and led a huge fibromyalgia support group in Yolo County. Some of her detailed, lengthy submission contained very technical materials that would likely be incomprehensible for most of us. A very informative long list of institutional health regulation and rights agencies providing consumer oversight services is being with-held for a future issue in the context of planned meeting presentations later in the year. We hope that what remains for this issue will be meaningful for most of our readers. For a copy of her full report, please send an email request to me at [kairoschandley@yahoo.com](mailto:kairoschandley@yahoo.com) and it will be sent via email.

**Elizabeth** was part of the Woodland contingent that caught the bus in Davis. She says, "The program itself was truly first class ALL the way. The many and varied information booths were well stocked and staffed with helpful and knowledgeable persons. There were close to 250 attendees, far greater than the sponsors had dared hoped for! Many highly trained doctors and other professionals shared information, the latest research, showed us movements that assist with balance (feldenkreis), anodyne therapy, traditional Chinese medicine, etc. A wide variety of snacks were provided and truly sumptuous meal was served at the end of the day. It was truly an event to remember and many thanks to ALL who worked so very hard to make it such an overwhelming success. I can't wait for the 2<sup>nd</sup> annual event!" **(Current planning is a Sacramento event on or about June 26, 2008! More on this will be shared in coming months as plans evolve!)**

Downtown Sacramentan **Dolores** boarded the bus in West Sac and reports that she had no particular expectations. Having had neuropathy for several years, she knew little about her condition but was curious to learn about pain management options so she could reduce her medications. She saw the event as a good place to get some answers and was glad to report that it was!! She was very impressed by the vendors and their materials which quickly filled up her tote bag to arm stretching weight. She was delighted to realize that the conference area was easy to get around in, even with a walker or wheel chair, as some had needed. Dolores found answers to some of her questions, and now has some new questions to pursue. She had a really good time and particularly appreciated the opportunity to make the trip by bus and get to know other Pners on the journey.

**Thanks to Donna Russell (530-661-3705) for her special training that captured so much rich medical content from the talks as excerpted below!!!**

**IVIG** (Intravenous Immunoglobulin). Several companies had exhibits, but the most interesting thing I learned from Michelle Greer, R.N., was that since IVIG is a blood product that is collected from different populations with varying immune arrays, if a positive response is not the result then the physician should order the next IVIG from a different batch number from the same company. If there is still no positive result, then the doctor should order the next batch from a different company. She stated that the array and quantity of immunoglobulins contained per batch can vary to a certain degree and between companies the difference can be great. Bottom line: If the first IV doesn't seem to work it may be due to the IV not containing the IG you need, but it may be in another batch or product from another company. I asked if the IVIG companies scanned batches to create an immunoglobulin content list for each batch and the answer was "No" because of the cost involved. In a magazine sample offered at one table I learned about a national support/advocacy group for those with Primary Immune Deficiencies ([www.pid.org](http://www.pid.org)). This reopened my awareness to my

own diagnosis of a gammaglobulinemia and how having that diagnosis on my current Dx list may help me get certain drugs or other services/products that could help me. **Lesson: Make sure that potentially helpful diagnoses from youth are on your current Dx list.**

### **David Phillips, Ph.D., Inventor and CEO of Rebuilder Medical, Inc.,**

Dr. Phillips was a dynamic speaker who dared go where physicians wished for silence. Among his several important inventions was the 'ear thermometer' which eliminated the necessity for inserting a glass rod full of mercury into a baby's rectum. His current invention allows the "Shumann's Natural Frequency of the Earth" [7.34/sec], which also happens to be the frequency for healthy nerve wave form and the one at which the human brain releases endorphins) to be sent through the body via foot baths. He claims that thousands have obtained a decrease in their neuropathy symptoms.

Dr. Phillips said that there were several **causes of neuropathy: PHARMACEUTICALS** (especially the "Statins" (the cholesterol lowering drugs) which damage the myelin sheaths and Neurontin (gabapentin), hypnotic (sleep) medications, and others); **Neurotoxins: Chemotherapy** and radiation treatments for cancers; MSG; aspartame (artificial sweetener "NutraSweet"); fluoride; **black mold** (Stachy botryus toxins); solder fumes; carbon tetrachloride; **Diabetes** mellitus (because higher glucose level decreases blood oxygen levels which alters glucose metabolism and slows nerve impulse transmissions, etc); etc.; **Fear**, as it contracts/shrinks tissues and therefore widens the synaptic junction gaps); **Compression**, e.g., the sciatic nerve compressed by the periformis muscle). His **Rebuilder** device is sold strictly via his website. Medicare said it would have to cost a minimum of \$1400 to get acceptance, but he wanted it to cost below \$900. Physicians can buy it for ½ price for resale. It is contraindicated for those with a pacemaker or other implanted electrical medical device, pregnant women or children under 8 years old. **Rebuilder Medical, Inc., 636 Treeline Dr., Charles Town, WV 25414 Website: [www.rebuildermedical.com](http://www.rebuildermedical.com) Phone: 866-725-2202 Fax: 304-725-4915.** [I was very favorably impressed by Dr. Phillips, as a person and scientist for his extensive practical knowledge, his approachability, his down-to-earth-just-folks commonsense and generosity. I'll let you know if this device works for me in a future article.]

### **Acupuncture: Mark Frost of the American College for Traditional Chinese Medicine**

Frost said that basically acupuncture would stimulate a nerve to decrease local inflammatory response, change brain wave form and release related endogenous steroids. [Many people around the world have found pain relief using acupuncture. Unfortunately, like literally everything, it does not work for everyone. If you have never given acupuncture a try because are afraid of needles &/or worry about infection from unspecialized needles I encourage you to visit a Licensed Acupuncturist (L.Ac.) office and see how it is done.]

**Feldenkries movement:** A systematic method of very gentle minimal movements which enable the body to gain greater flexibility and broader range of motion. [I had heard of Feldenkries but had never seen or experienced it. I was amazed!!! In a room of about 200 Pners, all tired, stiff and in pain, there were many murmurs of shock at the positive results immediately experienced from the tiny shifts which resulted in improved movement without increased pain and often with less pain. I encourage everyone to explore this. If your Parks & Rec Dept. or Senior Center does not already offer it, you might ask/suggest that it be added.]

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### **Jeffery Ralph, M.D., Assistant Clinical Professor, UCSF, Director of The Neuropathy Association's Neuropathy Center at UCSF**

Dr. Ralph gave an overview of "Neuropathy 101" showing many good visuals of anatomy, etc. The spine is divided into four connected areas: [from top (head) to bottom (tail)]: atlas C-1), axis (C-2), Cervical, Thoracic, Lumbar, Sacrum, Coccyx. Axon nerve fibers are sheathed in myelin (the

cholesterol insulation). Impairment of the axon can produce numbness, tingling, impaired perception of sharp stimuli and temperature; impaired perception of joint positions, which can affect balance. Descriptive terms of pain included aching, burning, dull, electric, itching, numbness, sharp, shooting, stabbing, throbbing, tingling, Allodynia pain from non-noxious stimulation. Autonomic neuropathy symptoms can include impaired sweating, urinary tract problems, GI (feeling full too quickly), feeling lightheaded on standing. Sensory functions of light touch, temperature sensitivity, pain sensitivity, vibrational sensitivity (usually tested by a tuning fork), can be impaired. Muscle weakness, often seen in ankles is common for some neuropathies. Classification terms of neuropathology include generalized (polyneuropathy). Axonal polyneuropathy, the most common type, usually in the feet. . Demyelinating polyneuropathy that causes weakness. Focal neuropathy, Trauma, Entrapment. Deficient nerve perfusion in blood flow. Infectious diseases, including HIV and leprosy.

## **Jonathan Katz, M.D., Chief of Neurology Services, California Pacific Medical Center**

The usual causes of neurological conditions include MMN, CIPD, hereditary (diagnosable but untreatable), Diabetes, and idiopathic. Neurological diagnoses are usually relatively easy despite there generally being no one conclusive test. But the cause most often remains unknown and classified as idiopathic some 38 to 50% of the time. Neuropathy usually starts in the fifth and sixth decades of life. Diagnoses are often revealed through recognizing signs and symptoms patterns. There are many things to observe and rarely any clear cut off point as on a spectrum of condition. For example: examination of motor, sensory, sensori-motor, proximal (central or closer to center), distal (further out or more peripheral); timing of progression as acute vs. chronic. Electric diagnostic studies such as EMG and NCV and various lab test results, histology - visual study of the cells are included in diagnostic workups.

Most neurological problems are mild and progress very slowly, so patients should not get caught up in their diagnoses. Very few neurological conditions are treatable beyond symptom management. Treatments for specific neuropathies are often nonexistent or ineffective. He believes that Vitamin B12 and Alpha Lipoic Acid have not been studied so there is no scientific basis for their usage. They should only be taken if there is a proven deficiency as they could create a placebo effect or make the condition worse. "It is not impossible to 'over exercise' [make neurological condition worse by exercising]." A nerve biopsy creates permanent nerve damage, which is the primary reason why it is seldom performed. Increased pain at night is caused by decreased distracting stimuli and fatigue. Some hypertensive [blood pressure] medications can cause nerve damage. Mood and pain are processed by many of the same neurological pathways, so the mind-body medicine benefits pain reduction." "Viral infection can precipitate CIPD (Chronic), a demyelinating condition, but more usually the AIPD or Acute [*more commonly known as Guillain Barre.*] Light weight amino/peptide chains (a component of immune proteins) cause Amyloidosis when deposited in nerve cells. Hepatitis C Neuropathy treated by Retuxan (IV) turns off immune cells- used as secondary treatment. Interferon (IV) decreases Hepatitis C neuropathy. Nerves can regenerate. Varying degrees of damage from chemotherapy can be healed. Surgical nerve damage is often healed. Damage from diabetes rarely gets better. Chronic Length Dependent Neuropathy CLDN) is common and involves a "stocking" distribution of symptoms; numb feet with or without pain and is slowly progressive. Damage in the feet involves the motor nerves; while the sensory nerves are involved with damage up to the knees.

**NOTE: To gain understanding of the neuropathy terms enumerated above, do please purchase a copy of Dr. Norman Latov's book, *Peripheral Neuropathy: When the Numbness, Weakness and Pain, Won't Stop* for only \$10, plus postage. Place orders with Beverly Anderson at (530) 389-2416, or with The Neuropathy Association at (212) 692-0662.**

# Odds and Ends

**Celiac Disease Neuropathy** and **Diabetic Peripheral Neuropathy** are the focus of our August Yolo meetings. Thanks to area Celiac expert **Diane Craig**, who will speak at the August 6 Woodland meeting and the August 8 Davis meeting. Martha Chandley will lead a discussion on **Experiencing Diabetic Neuropathy** on August 16. The first condition is important because many with idiopathic neuropathy may have this gluten intolerance problem and it is reversible. The second condition is important because of the propensity to develop diabetes and diabetic neuropathy as we age, even though they've not appeared earlier. It's important to prevent that development and reverse its development as much as possible.

Our long-time podiatrist friend and Yolo neuropathy group supporter, **Tracy Basso, DPM, Davis Foot and Ankle Clinic** will speak on **Proper Care for Feet with Nerve Damage** at all three regular Yolo meetings in September. Having completed his major leadership responsibilities as head of the state podiatric association, he is finally free to return to us with very important information on how to protect our feet. As most of us experience neuropathy problems mostly in our feet, this is a very important topic for all of us.

With continued apologies to our wonderful speakers over the summer, the September issue of **PN News** will bring us up to date with reports on programs presented since June. Better late than never.

**In the meantime, keep cool, keep moving, keep learning, keep positive and take care of yourself and those you care about. Share what you're learning with others with neuropathy for your mutual benefit and well being.**

**The Neuropathy Hotline is at (916) 371-1125**

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**TO:**