

PN News

Yolo County

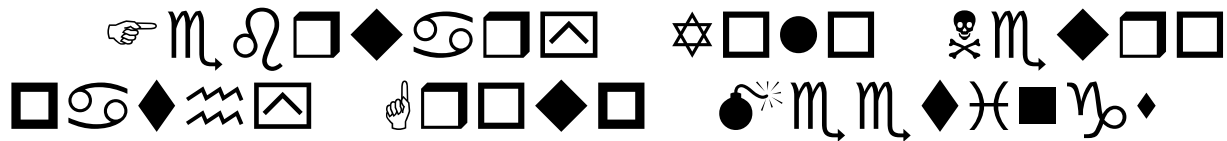
VOL. 6, NO.2

FEBRUARY 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



Come to be encouraged and learn some tools for living well with PN!

Woodland: Monday, Feb. 4 at 3:30 pm (Note time change)

Woodland Community and Senior Center, 2001 East St.

Sue Marie Mozzoni, CMP, CNHP (530-669-5853)

“Awakening Wellness: Massage & Wellness Consulting Services”

Contacts: Delia Genera at 530-661-3238 or Donna Russell at 530-661-3705

Davis: Wednesday, Feb. 13 at 2:00 pm

Institute for Restorative Health & Physical Edge, 1460 Drew Avenue, Classroom

Don Walk, MD, “Dealing with Depression Associated with Neuropathy & Other Chronic Pain Conditions”

Contacts: Martha Chandley at 916-371-1125 or Donna Russell at 530-661-3705

West Sac: Tuesday, Feb. 19 at 2:00 pm (Note day change)

A. F. Turner Library, 1212 Merkley. Conference Room

Don Walk, MD, “Dealing with Depression Associated with Neuropathy & Other Chronic Pain Conditions”

Contacts: Martha Chandley at 916-371-1125 or Sandra Vinson at 916-372-6093

Preview for March Meetings:

Kayvan Haddadan, MD, a psychiatrist formerly with the **Institute for Restorative Health** and now on the pain management team of **Woodland HealthCare**, will speak with the Woodland group on Monday, March 3 on a range of pain management options, such as Medtronic’s high-tech implant systems. Dr. Haddadan’s specialty is pain management for musculoskeletal problems. Naturopath **Marco Vespignani, ND**, at the **Institute** will be speaking on nutrition and

supplement issues, including food plans for those with diabetic neuropathy, in response to a group request. Meeting plans for the March West Sacramento group are pending.

About our February Topics and Speakers

Sue Marie Mazzoni, CMP, CNHP has been a certified massage professional for eight years, and a nutrition/wellness counselor for two years. She currently works out of **Cut-N-Loose**, 702 Lincoln, Woodland, with in-home appointments available as well. Her presentation to the Woodland group will involve talking about using massage and essential oils for relieving PN symptoms, and looking at nutrition habits toward balancing one's PH (Acid/Alkalinity) to reduce inflammatory pain. She comes with an enthusiastic referral from long-time member Beverly Matteoli, who loves Sue's wonderful VitaFlex foot massages. Her services are designed to help us with stress, headaches, chronic fatigue, chronic pain, and diminished immune system functioning.

Massage is great therapy for most of us with neuropathy as it increases the blood and oxygen flow to our damaged nerve cells, helping to restore sensation in areas of numbness and relieving PN pain and distress. Her line of therapeutic grade essential oils can help with pain relief. Foot massage could well become a favorite and essential treatment for your PN symptoms, whether done by another or yourself on a regular basis. But, how about treating yourself and significant other(s) with a Vita-Flex foot massage as a very special Valentine Day treat!

Don Walk, MD, is a semi-retired psychiatrist friend and colleague from my church who is very much looking forward to meeting with us for an interactive presentation on dealing with depression associated with neuropathy and other chronic pain conditions. Dr. Walk has had a long career in the US Navy, various community mental health settings, corrections programs and private practice. He currently works part-time evaluating applications for mental health disability benefits for the Social Security Administration. On hearing last year about our PN groups and our difficulties with disabling conditions, he readily offered to come share his expertise with us. That time has come at last!

Many of us PNers are prescribed **tri-cyclic anti-depressants** to help calm our symptoms and help us sleep. Some of us have protested, "Hey, I'm not depressed, so what's with that?" We still don't clearly understand why the TCAs diminish our PN and distress, but they do for some of us. PN's symptoms are enough to make most of us depressed at some point, thus complicating our efforts to live with neuropathy. Having PN can significantly reduce the quality of our lives, and intermittent grief over treasured life capacity losses are an appropriate part of coming to terms with our conditions. The intensity of our depressive symptoms may or may not directly correlate with the intensity of our pain/distress levels, but they may well do so. It's very important that we own these realities and, working with our doctors, find appropriate medications and/or other treatment options to effectively deal with our emotional and cognitive difficulties associated with our physical distress. Dr. Walk will be talking about:

The pain/depression catch 22 cycle dynamic and what can trigger our depressive responses and thought patterns that tend to sustain them. Various types of anti-depressant and/or anxiety medications – what, how and why they do and don't work for us and the negative side effects we need to watch for. How we can intervene with ourselves and one another in mutual support to re-establish positive, empowered feelings, thoughts and life style choices so that, in spite of all, we CAN live well with neuropathy and other chronic pain conditions. These are very important issues and we hope many will take advantage of these great opportunities to benefit from Dr. Walk's caring expertise. And may we more and more come to support one another in good times and bad.

If we do need some extra help, remember the really excellent Institute for Restorative Health's six week Integrative Pain Management Program starting on Wednesday, February 13; call 530-458-4474 for details. Here you'll learn to turn off your pain, using the neurobehavioral techniques developed by clinical psychologist John Leonard, Ph.D. And check the yellow pages for other public and private mental health resources in our communities.

More on the Neuropathy Pain and Depression Link

So what’s so depressing about neuropathy? Each of us would likely have our own answers, depending on such factors as our neuropathy causes (known or unknown), time with the disease, treatments offered and tried, relationships with medical and family care givers, our positive or negative orientation to life’s exigencies, our effectiveness in grieving over lost capacities and opportunities, as well as the body/mind interactions with other concurrent chronic health problems, etc.

A Google search on the relationship came up with a fascinating article from a 2005 report in **Diabetes Care (28:2378-2383)** you might find of interest and relevant to your own situation. **“Diabetic Peripheral Neuropathy and Depressive Symptoms”**, by Loretta Vilekyte, MD, PhD, et.al. (<http://care.diabetesjournals.org/cgi/content/full28.10.2378>)

The multi-site study’s objective was to examine the association between the severity of peripheral neuropathy and depressive symptoms and the potential mediators of the association. The researchers involved 494 DPN patients with a mean age of 72, using a variety of well established subjective questionnaires on emotional status and objective diagnostic neuropathy scales, and the ADL (activities of daily living) and Social Self-Perception quality of life surveys.

Results: Depression scores were most strongly associated with unsteadiness (balance and gait problems), perceptions of symptom unpredictability, lack of treatment control, frustrating restrictions in ADL capacity, and sense of being a burden to others. Surprisingly, the presence of foot ulcers – many of which could result in amputations – was not strongly related to depressive states. These findings are most significant, as they suggest reasonably accessible real potential interventions for physical treatment and emotional support by our medical teams and personal social support systems.

That was the good news. Here’s the bad news: In January, FDA announced their completed analysis of placebo controlled **anti-epileptic** studies showing a high risk of suicidal **behavior and ideation** (thoughts) as early as the first week and continued throughout the 24 weeks of the studies considered. Among the commonly prescribed meds for various types of neuropathy showing these findings included Neurontin, Lyrica, Topamax, Lamictal, and Depakote. See the **2008 Med-Watch Safety Summary** for more updated info on drug safety issues at <http://www.fda.gov/medwatch/safety/2008/08.1>

Some more good and bad news to know: A Northwestern University based study report appearing in a recent issue of the **Journal of Neuroscience** (2008, 28:1398-1403) entitled, **“Beyond Feeling: Chronic Pain Hurts the Brain, Disrupting the Default Mode Network Dynamics”** by Norman I. Baliki, et. al. This ground breaking research proved that Brain scans of people in chronic pain show a state of constant activity In areas of the brain that should be at rest while undertaking a task.....a finding that could help explain why patients have higher rates of depression, anxiety, sleep disturbances and attention disorders.

While this finding might have been assumed intuitively, it’s good to know there is actual physical evidence confirming what has otherwise been observed with pain patient problems. Perhaps especially so with neuropathic pain. But it may well point the way for future treatment options to quiet our brain’s intense activities so we can get some rest from our distress.

Supplements for Reducing Neuropathy Symptoms

Knowledgeable old-time Pners know from the **John Senneff** books that Vitamins B-6, B-12 and the anti-oxidants like Alpha Lipoic Acid are very important for nerve health. Many of us have taken the old and now discontinued **NeuroHelp Supreme** or newer **NeuroHelp Essential** for years most grateful to acknowledge they have improved our neuropathy distress. (The Essential product is available via

www.originbiomed.com or call 1-888-894-7256 for orders, though the Citrus Heights Elliott's Natural Food Store may still be carrying the product. In any event, **Alpha Lipoic Acid** remains an essential supplement for many, many PNers.

Neuropathy and other patients at the **Institute for Restorative Health** are offered a special broad mix of multi-vitamins, minerals and anti-oxidants similar to the original Supreme product, but with some specially added powerful ingredients, such as N-Acetyl-Cysteine developed by IRH naturopath Marco Vespignani, ND and compound pharmacist Jerra Banwarth, RPh. You may call IRH at 530758-4474 or Ms. Banwarth's pharmacy in Woodland, **Prescription Specialists** at 530-669-7038 for more information.

A few years ago we heard of some chemo-induced PNers in Alabama successfully taking a physician-prescribed form of glutamine to reduce neuropathy symptoms. As an amino acid, **Glutamine*** (**see below**) helps with immune support and maintaining muscle mass. (The Neuropathy Association reports having partially funded a study of the product some years ago at Weill Medical College in NYC, but repeated efforts to secure a status report or final results of the research have been futile.)

Analysis of two year-long multi-center randomized, placebo-controlled studies involving Canadian and American chronic diabetic neuropathy patients was published in *Diabetes Care* (**28:89-94**) with some very encouraging results. Participants taking thrice-daily 500 or 1,000 mg dosages of **Acetyl-L-Carnitine (ALC)** experienced markedly enhanced symptoms. "The studies demonstrate that ALC treatment is efficacious in alleviating symptom, particularly pain, and improve nerve fiber regeneration and vibration perception in patients with established diabetic neuropathy." Would similar results occur with other types of neuropathy? Very possibly, but it should be noted that ALC is particularly deficient in diabetics.

An article published in the July-August 2007 issue of the *Journal of Practical Pain Management* reported on a small study of 30 patients with neuropathy, primarily from diabetes. The study treatment product was **NeuropathyRX**, a compound of **L-Carnitine, Selenium, Vitamin C, Alpha Lipoic Acid, and N-Acetyl-Cysteine**, the most effective nutrients for reducing neuropathy symptoms identified from an analysis of some 4000 studies [*many of which were likely discussed in Senneff's book, Nutrients for Neuropathy*]. The product had earlier been shown to be effective for reducing neuropathy symptoms of cancer patients.

Participants in the new study were monitored for changes over three months on symptoms of pain, numbness, loss of physical function, and mental sharpness. The results showed a consistent and progressive reduction in pain and numbness and improvement in mental sharpness over the three months, suggesting that symptom improvements would likely increase with continued use. It also explains why the ingredients are so important in fighting free radicals and the linkage between **glutamine*** with **cysteine** for cell protection. The company warns that some people may have problems with diarrhea with product use; whether this is more or less significant than warnings on many of our medications is not known. But they have found that consuming two rather than four capsules a day is usually sufficient to resolve the problem.

NeuropathyRx is a patent pending combination of natural nutritional supplements developed by Mark Gostine, MD and Lawrence Pawl, MD. **Neuropathy Solutions™** proudly markets the product, proclaiming, "Our Mission at Neuropathy Solutions™ is to help alleviate the burning and numbness in your hands and feet!" A 30-day supply of the product is available for \$30+ at www.neuropathysolutions.com, or call 1-877-243-6633. A limited supply of brochures and reports from the company will be available at the Davis and West Sacramento meetings.

Spinal Damage and Neuropathic Pain

Members paying \$35 annual dues to The Neuropathy Association receive two types of newsletters: thrice-a-year hard copy, patient friendly "magazines," and the bi-monthly, more technical **Neuropathy-E-News** via email. Both publications are worth your investment and you are urged to join TNA to receive them. The latest issue of E-News included a short article on **spinal stenosis** by **Peter D. Donofrio, MD**, Professor of Neurology and Director of the Neuro-muscular Division of the Department of Neurology at Vanderbilt University Medical Center. As many of us are suffering neuropathic pain from stenosis and

other spinal damage problems, the following is shared with an encouragement to learn more.

Spinal stenosis refers to a spinal canal that is too narrow for the spinal cord to function properly. It afflicts many with neuropathy, in fact their primary and often unbearable neuropathic pain may indeed be emanating from the upper, middle or lower back. A patient's symptoms depend on the location of the stenosis. Pain may be radiating across the back and down the arms or legs, spasticity or stiffness in the legs, muscle weakness in the arms and legs, and tingling or numbness in the legs, as well as autonomic neuropathy symptoms of problems with bowel, bladder or sexual function. Symptoms can be worse on one side. Sciatica is common with damage to the L5 and S1 nerve roots at the spine and may be connected to spinal stenosis.

[The NINDS booklet, Low Back Pain, is one of the gratefully received patient education materials made available at our meetings and sent to appropriate callers to the NCCNA Neuropathy Hotline, in addition to other materials on peripheral neuropathy.]

The above information is shared in anticipation of upcoming presentations at all Yolo neuropathy support groups about the "pain pacemaker" relieving help for some of **neurostimulation implants**. Thanks to Davisite Retta Gilbert and the TNA E-News for calling our attention to a **New York Times** January 8 article "**Pain Relief for Some, With an Odd Tradeoff**" by Tara Parker-Pope and the West Sacramento library for displaying a July 2007 issue of **Reader's Digest** featuring an article, "**Back Pain Breakthroughs**" by Michael J. Weiss about this treatment alternative.

As the NYT article explained, implantable stimulators blunt pain with electrical impulses with a tradeoff of living with a constant buzzing sensation in place of the pain. The devices are implanted near the spine with lead wires extended to the spine to direct the impulses up the canal. The implant is very expensive, rarely completely solving pain problems and doesn't work for everyone. But they can be life changing options for some who want an alternative to life nullifying constant bed rest or extremely sedating pain medications. As noted on page 1, Kayvan Haddadan will soon be presenting information about the implantable stimulators and other pain treatment alternatives at upcoming Yolo meetings.

Health Care Rights for Californians

The focus of two of our November Yolo PNER meetings and the December NCCNA Leadership min-conference began to address a myriad of issues on the topic of health rights for Californians. The following is a brief review of these remarkable presentations. We were most blessed to hear from **Shauntay Davis**, MPH, of the **Health Rights Hotline** at the West Sac meeting and **Dominick Spatafora, MPA**, founder and president of the **Neuropathy Action Foundation** (see the NAF site at www.neuropathyaction.org) at the Davis meeting.

As the Davis Enterprise featured a lengthy article on his presentation on Dec. 21, 2007 and, as we'll have some up to date information on Dominick's proposed legislation for a California Neuropathy Task Force, to be reported below, we'll pass over his Davis presentation. Except to say that, if we think we have problems now, we need to understand that it's going to get much worse before it gets better. (See the editorial toward the end of this issue.)

Dominick organized and facilitated the wonderful December NAF/NCCNA event, "**Championing Healthcare Rights for Yourself and Others – An Advocacy Education Summit**," with these additional speakers: **Michelle Vogel, MPA** of the **Alliance for Plasma Therapies**; **Margaret Reilly, Health Insurance Counseling and Advocacy Program**, and **Paul Deiro, Chief of Staff of CA State Senator Sam Aanestad of Redding**. Audio tapes of these presentations will soon be made available to all the NCCNA groups. If you'd like to hear them at future Yolo meetings, please let Martha or Delia know.

Shauntay Davis (Health Rights Hotline, 916-551-2191) is "one of us" with chronic pain associated with Lupus and has suffered through chemotherapy for kidney disease, experiencing her own difficulties with getting appropriate care from a sometimes unresponsive the medical system.

As the HRH's **Health Education and Outreach Coordinator** she is out and about the region, meeting with all kinds of community groups concerned with helping their members on health care issues.

HRH is part of the **Legal Services of Northern California**, serving a diverse client population, regardless of income in the four county area of metro Sacramento. HRH's multi-lingual staff speaks Spanish, Hmong, Russian and English. They work to solve all kinds of medical care problems with established state regulatory and advocacy agencies, private insurers, public providers, medical groups and hospitals. They have three attorneys working on public policy issues and litigating systemic problems. They are particularly interested in expanding access and options. Other staff do the main Hotline services advising consumers on how to navigate the health care systems, file grievances and appeals, and develop new health rights education materials. Some work full time on Medicare/MediCal issues. Common issues are denial of care and benefits, denial of specialty referrals, coverage disputes or wrongful financial charges, help in choosing plans, etc. Most importantly, they can help with appeal procedures. If you're seeking HRH help, be sure to call around 9 am, M-F as the "early bird gets the worm, as it were."

It's very important that we clearly understand the contents of our Medicare booklets and the HMO/PPO Evidence of Benefits - EOB booklets, which we tend to ignore upon receipt and beyond, as they are the key to what is and isn't available to us and under what circumstances, etc. It's essential that we develop partnership relationships with our doctors and not be intimidated by them. We need to learn as much as we can about our medical conditions from a variety of sources, maintain well-organized medical records of lab reports and x-rays, etc., as well as good notes from our doctor visits. All will help should disputed issues arise. We need to know our **Responsibilities** as well as our **Rights**. The structure of our medical care is a two way contractual relationship and we need to maintain integrity from our side to better hold the other side accountable should problems arise.

Many of those calling the **Neuropathy Hotline** in response to the bus posters are either on MediCal or have no established medical care. Among the many resource materials provided by Ms. Davis were two brochures on medical care resources available in Yolo, Sacramento and Placer Counties, which have been sent to some of our callers. She also explained that in addition to county clinics, Yolo MediCal patients are enrolled in Partnership plans that connect patients with private medical groups. In Sacramento County, MediCal patients are required to connect with specific geographically based managed care programs unless pregnant or disabled.

Another resource she provided was the extremely informative booklets published by the Office of the Patient Advocate, such as the **California HMO Guide for Seniors**, chock full of information on critical issues and the state and federal agencies that have regulatory and/or advocacy responsibilities for a very broad range of needs. For coping with health care issues, the OPA Guide is clearly an essential resource to keep alongside of the most updated county Senior Resource Guides and the Yellow Pages. Just a few examples -

Health Insurance Counseling and Advocacy for Medicare issues:	1-800-494-0222
California Registry for long term care facility referrals	1-800-777-7575
Family Caregiver Alliance	1-800-445-8106
California Office of Patients' Rights (hospitalized mentally ill	1-916-575-1610
Protection and Advocacy, legal help for the disabled	1-800-776-5746
Medicare D Prescription program	1-800-633-4227

If you'd like to order a free copy of the guide, call OPA at 1-866-466-8900 or go to www.opa.ca.org.

Knowledge of health care problems and rights advocacy by Shauntay and her colleagues at the Health Rights Hotline is enormous and we are most blessed to have access to her caring time with us. Thanks so much, Shauntay, for educating us and so many others!

Last year we learned of **Michelle Vogel, MPA**, with the **Alliance for Plasma Therapies** as we sought to help the lady in the Boston area who'd been denied access to IVIG treatments for her neuropathy. Michelle opened our December Summit meeting via a terrific power point presentation and

long distance conference call from Washington D.C where she works, as she needed to be there for a special legislative hearing later that day. Her topic was **Health Insurance: Friend or Foe?** She helped demystify lots of terms we'd all heard but may not have had a clue as to their meanings or significance for us in our search for better health care for ourselves and our families. Thank goodness we'll be able to listen to the complexities on the forthcoming audio tape, but here's is a brief summary list of the topics she covered:

Most of us are choosing "managed care plans" that are administered through several types of health insurance coverage plans (e.g. Managed Care Plans, HMOs, PPOs, Indemnity Plans, and Point of Service Plans). Figuring out which is best for your budget and care needs can be a hassle, but understanding the pros and cons of each types can be very important.

Group health insurance plans carry essential protections against non-discrimination limitations on exclusions and pre-existing conditions, guarantees of renewability, and no cancellations if you get sick. Small employer group coverage can be rather restrictive in the midst of some protections. Leaving one's employer plans give you access to HIPAA and COBRA for continued coverage. Very careful planning is essential to protect yourself from exhausted benefit status. Appeal processes are available for a variety of denied therapy circumstances. The basic rules for appealing adverse decisions are reading and understanding your Policy Booklets (Explanation of Benefits); carefully documenting all conversations; be persistent – the squeaky wheel gets greased; and if at first you don't succeed, try, try again [and call for HRH help!]

You'd do need to establish and maintain a relationship with a **Case Manager** – All patients who have chronic illnesses should have a consistent, permanent Case Manager at your insurance company, including Medicare, assigned to them. You should not have to call an 800 number and talk to someone different each time you call.

Michelle provided some information on federal and state health care resources that are less relevant to our readers, but it was good to know there are some alternatives; though they are generally not good or just in terms of coverage and costs. Someday.....

Thanks Michelle for being with us via long distance and thanks for all the very wonderful and difficult advocacy work you do on behalf of those seeking dependable access to IVIG treatments for their neuropathies.

Spatafora/NAF Proposed Legislative Task Force on Peripheral

At our November and December meetings, **Dominick Spatafora**, our dear friend, health advocate extraordinaire and Founder/President of the Neuropathy Action Foundation, mentioned plans to propose a bill to establish a Legislative Task Force on Peripheral Neuropathy. He has since shared content of the now filed Assembly Concurrent Resolution, No. 87, about which we'll be hearing more in the coming months.

Although ACR 87 is far from perfect, it does address some very significant issues and preliminary remedies that are long overdue. The currently negotiated language leaves much to be desired as writing legislation is too much like making sausage, as Dominick explains, Highlights of the ACR 87 document follows.

The measure would establish a body consisting of 22 specified members representing various consumer, medical, academic and governmental research interest groups and physicians specializing in neuropathy. The task force would suggest ways to promote public and physician awareness of peripheral neuropathy, promote understanding of the importance of early diagnosis and proper treatment and management, create programs to promote public and physician awareness of various treatments to improve patient care, and determine how many people are affected by the various types of neuropathies. The task force would be authorized to use existing funds and assets to support its activities, but should be allowed to solicit funding from public and private foundations and make use of available federal funds.

There will be opportunities for individual and organizational advocacy efforts to improve upon the resolution's contents and we'll continue to keep our readers informed along the way. But thanks to Dominick and the NAF board's efforts to mobilize the neuropathy community to get the process started. You'll be hearing more about ACR 87 in the coming months. If you'd like a copy, please call or email Martha.

Present and Future Health Care Issues that Really Matter

(An editorial by Martha Chandley)

A Message from the American Medical Association: Appearing in the latest (Feb. 11) issue of *Newsweek* is a full page advertisement that merits our attention and hopefully our positive response. A picture of an obviously distressed middle-aged woman is surrounded by these assertions:

*"1 out of 7 isn't just a statistic. It's a woman who chooses her blood pressure meds over Parkinson's meds because she can't afford both..... 47 million uninsured. It's not just a number on a graph in a report. It's people all around you. Like a friend. A neighbor. A relative. People who are suffering. And you can do something about it. One out of seven of us doesn't have health insurance, but we all have access to a voting booth. Please vote with this issue in mind. (Emphasis added.) To learn more and share your voice about this issue, visit **VoiceForTheUninsured.org**. Because 1 out of 7 is 47 million too many."*

Super Tuesday has come and gone and our next concrete chance to make our preferences known will be November 2. There are very many critical issues at stake in this year's election process, but the most important (*regardless of what the current polls may say*) may well be the proposed models for health care reform articulated by the remaining presidential candidates and various special interest spokespersons and groups from the right or left. Do please begin researching currently proposed plans; the following web site resources across the spectrum are offered as a beginning point to help in the process:

<http://www.ama-assn.org/ama1/pub/upload/mm/478/2008brochure.pdf>

(American Medical Association)

<http://www.amsa.org/alc/reponseama.cfm> (Am. Med.Stud.Asso.)

<http://www.pnhp.org/news/2007august/ama-plan-wontcure-pnhp>

(Physicians for a National Health Plan)

<http://www.johnmccain.com/healthcare>

<http://www.barackobama.com/issues/healthcare>

<http://www.hillaryclinton.com/feature/healthcareplan/summary.aspx>

Recent articles about several health insurance companies operating in our state have reported on their systematically dropping whole classes of past or potential subscribers because of specific health problems and/or denying claims on presumed actual benefits because of rising costs, mismanagement, and commitments to maximizing profits. Relevant state agencies have taken them to task for their unethical, if not illegal practices; but whether that really will make a big difference in the long run has yet to be seen. The Jan. 30 Business section of *The Sacramento Bee* featured news of **Pacific Care** being fined \$3.5 million after finding that 30% of their HMO claims were denied and 29% of the disputes with doctors were handled incorrectly. Earlier this year international attention was drawn to **Cigna's** role in a child's death because they refused to cover a valid transplant that would have saved her life. The national negative PR was substantial and the child's "death by profit margin" was ruled unconscionable by progressive bloggers.

A Firedoglake columnist sardonically observed, “Let’s start with a fundamental truth. Insurance companies are in the business of not paying claims. By not paying your claim, they get to keep all those premiums you pay. Maximizing their benefit [*rather than ours*] by minimizing their risk.” (www.firedoglake.com, December. 23, 2007.) The issue is already a huge factor in current insurance policies, but will also have a huge role in defining the scope and dynamics of any possible national or state health care legislation that may emerge in 2009.

Many of us have our own experiences of being unable to get specific services we and our doctors know would likely help us, but our HMO/PPO plans or their service contracts will not cover what we want or need. Frequently the reason given for a denial is “**We do not cover experimental, investigational and unproven services.**” It really doesn’t matter how effective a particular treatment may have proven to be, even via gold standard clinical trials whose reports have appeared in peer reviewed medical journals. If the **establishment** medical industry can’t make a profit on a product/service and/or we’re not rich, forget about getting the kinds of medical care we need. Those who castigate “socialized medicine” argue that it will result in rationed services, refusing to recognize the very real and very highly unjust rationed medical care system that is the result of their beloved private market forces.

Cases in point – The Neuropathy Association and other patient organizations, such as the Neuropathy Action Foundation, have been struggling with Medicare and private insurers for years to ensure accessibility and affordability of IVIG care for a variety of disease states for which it has been proven to be a very effective treatment. Medicare and our commercial plans will pay umpteen thousands of dollars for amputations but will not pay for anodyne therapy, which has pretty much nullified the need for many, if not most amputations. Medicare and our commercial plans will gladly pay for expensive name brand medications approved for neuropathy but will not pay for basic nutraceuticals (vitamins, minerals and anti-oxidants supplements, etc.) that have been shown to significantly reduce neuropathic symptoms. In spite of thousands of “failed back surgeries” insurance continue to pay for surgeries for chronic spinal problems, but won’t consider alternative treatments that could give significant relief. There is very real rationing of health care in both private insurance policies and public service programs that deny people over 70 or with significant disabilities surgical procedures that could increase significantly their quality of life. Age and disability discrimination are alive and well as are more and more excluded from treatment options.

Then there is the reality that FDA approval is no guarantee of product integrity or safety. In the last few years, we have seen FDA approved products being recalled, special danger warnings being reluctantly fixed to labels, and advertised benefits have often been a sham. FDA approvals and marketing campaigns have often been based on incomplete or erroneous data, with only the positive data being published

A recent analysis of 74 clinical trials of commonly prescribed anti-depressants (Prozac and Paxil) were found to be only marginally more effective than placebos when ALL the data were re-examined, as per a Jan. 17th **New York Times** article, entitled **Antidepressant Studies Unpublished.**” Another NYT article on Jan. 30th, **In Spinal Device Research, Questions on Conflicts**, disclosed that spinal surgeons at half of the study centers testing the Prodisk product, designed to replace spinal fusion procedures, had financial interests in the product’s success. The Prodisk study results submitted to the FDA did not include data on the many patients who had fared poorly in the trials.

But it doesn’t stop there; as UCD medical professor, Dr. Michael Wilkes, reminded us in his most recent Sunday **Sacramento Bee** column, “**Good chance that statins aren’t for you.**” The pharmaceutical industry has many ways to maximize sustained profits on product lines, whether their products are really needed or not. For instance, follow-up studies on **Vytorin** have

shown that this dual product is no more effective than **Zocor** alone; while Vytorin costs \$100/month versus Zocor at \$30/month. Wilkes further disclosed that members of disease treatment guide-line panels are likely to have financial ties to the pharmaceutical companies whose products they are not only promoting but whose use they are attempting to mandate, whether really needed or not.

Our president has twice vetoed the SCHIP bills that would have extended medical care to 10 million more children. We claim to have the best medical care system in the world, but it is clearly the most costly and least effective on many levels. Our presidential candidates have offered a variety of new health care plans, some with quite dubious value, depending on one's personal or business interests. In dialogue with legislative leaders, our governor sought to develop a carefully crafted "bipartisan" plan that would cover most uninsured Californians with support from a broad range of the health industry, business and consumer interest groups. By Jan. 29th, the hope was gone as the Senate committee backed off amid fears of budget deficits, opposition of the tobacco industry to the proposed tax increase on cigarettes, and refusal to pursue other means for raising funds for the proposed program. The Bush and Schwarzenegger budgets seek to cut Medicare and Medicaid programs leaving the state and county-run medical programs with no choice but to further limit desired and essential medical services for thousands.

Why should we care? Because it really matters. It really matters to the predominantly low-income folks calling the NCCNA Neuropathy Hotline, desperate to find some relief from their neuro-pathic pain, frustrated by their total lack of or inadequacy of appropriate care, and are astounded to learn that anyone should care about them. It really matters to the more affluent among us who wandered from doctor to doctor over many years, desperately seeking diagnosis, treatment and consolation for their suffering. It really matters to our doctors who really would like to help us but don't have the knowledge, tools or medical delivery systems to do so. It really matters to the many general and specific health advocacy organizations working to make the way better. It really matters to our families and friends who feel helpless to help us and we may be overwhelmed with taking care of them on top of our own health care crises. It really matters to us, because sometimes it's just too hard to deal with the symptoms when our "medically legitimated" treatments are largely ineffective and we're too exhausted from the non-restorative sleep, the pain or the burning or the numbness, or, or, or..... and we too easily slip into anxiety and depression until some relief or reassurance comes to buck us up.

**Why should we care?
Because, God help us,
it really does matter!!!**



The Northern California Chapter of The Neuropathy Association

Hope through caring and education

PO Box 6985, Auburn, CA 95604 (877) 622-6298

www.pnhelp.org

info@pnhelp.org

First Name _____ Last Name _____

Honorific (i.e., Mr./Mrs./Ms./Dr., etc.) _____ Sex M F Full name as you would like it on your membership card _____

Optional: Spouse or other household member if you want that person included in addressed mail _____ Relationship _____

Address _____ City _____ State _____ Zip _____

() _____ Home Work Cell _____
Primary Phone Number

() _____ Home Work Cell _____
Alternative Phone Number

E-Mail Address _____ Occupation (if retired, please also state your previous occupation) _____

Please indicate: New member Renewal for _____ (enter year)

Please indicate which support group you attend: _____
OR No specific group (Member at Large)

How would you like to receive the newsletter? By E-Mail (address required) Through Standard Mail
(e-mailing helps us reduce printing and mailing costs)

Are you a member of The Neuropathy Association (our national organization)? Yes No

Tax-deductible dues are \$24 a year, pro-rated at \$2 per month for new members joining during the year.
Please make checks payable to NCCNA and give your check or cash with this form to your group treasurer
or mail (please, no cash) to the Membership Chair at the address above. Dues is per household.

\$ _____ + \$ _____ = \$ _____
Total Dues Optional contribution Total tax-deductible amount enclosed

Please provide the following information so we may serve you better
(NOTE: This information is used only to help us provide useful information and address member concerns.
No information is shared with third parties, except some aggregate data used for grant applications or research)

Are you diabetic? Yes No

What are your primary symptoms? (check all that affect you frequently)

- Burning Numbness Coordination problems Sharp, stabbing pain
- Cold Pins and needles Difficulties walking or standing Electrical sensations
- Weakness in limbs Tingling Sensitivity to touch or pressure General pain
- Sensation of glove or stocking Other: _____ Not personally afflicted

What caused your neuropathy?

- Diabetes Infections Nutritional deficiencies Immune system disorders
- Hormonal Diseases Trauma Drugs, alcohol or toxins Cancer/Chemotherapy
- Impaired Circulation Tumors Gluten intolerance (celiac sprue) Idiopathic
- Heredity/Genetics Unknown Other: _____ Not personally afflicted

How did you hear about the Northern California Chapter of the Neuropathy Association?

- Brochure Internet Magazine or Newspaper National Association
- Poster Event Radio or Television Health care provider
- Friend/Other Person Other: _____

What do you hope to receive by being involved in NCCNA? (check all that apply)

- Information Support Understanding of my situation Provide aid to group or others
- Treatment ideas Friendship Other: _____ Not personally afflicted
- Coping strategies Sympathy

2008-02

Odds and Ends of Interest

Dr. Tracy Basso, DPM, reports that many people have signed up for the **Walking for Wellness Study** and are still accepting applications for participation. Interested? Call **530-758-1810** for a preliminary eligibility screening. The **NCCNA membership cards** will be sent out the third week of February and members will then be able to take advantage of the **15% discount prices** on specialty shoes at **Shoes 'n' Feet** in North Natomas, generously provided by owner Tracy Basso, DPM for our NCCNA members.

If you've not yet paid your **NCCNA dues for 2008**, please do so, sending your **\$24** check and completed form on page 11 of this newsletter to the NCCNA address, so you can continue receiving both the ever improving Yolo and NCCNA newsletters in the coming months. Your financial support is urgently needed for our ongoing mission of educating and empowering PN patients in our service areas.

From the January issue of *Neuropathy Hope*, our regional NCCNA newsletter:

In each county, there is a service to help low-income seniors and disabled persons make home modifications that help with safety repairs. Grab bars, ramps, stair rails, level door knobs, Smoke and fire detectors can be installed. In the Sacramento area (including Yolo County), call Rebuilding Together at (916)455-1880, or go to www.rebuildingtogether.org.

**Yolo Neuropathy Groups
c/o Martha Chandley
1399 Sacramento Ave. Unit 108
West Sacramento, CA 95605**

TO: