

PN News

Yolo County

VOL. 5, NO. 11

NOVEMBER 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.” Henry Ford

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

Woodland Neuropathy Group: Monday, November 5, at 4:30 pm
“The Woodland Neuropathy Group Shares Together “
Woodland Senior Center, 2001 East
Call Delia Genera at 530-661-3238

Davis Neuropathy Group: Wednesday, November 14 at 2.00 pm
Dominick Spatafora, MPA, President, Neuropathy Action Foundation, San Francisco
“Knowing Your Health Rights in California
Institute for Restorative Health & Physical Edge, 1460 Drew Avenue,
Call Martha at 916-371-1125

West Sacramento Neuropathy Group: Thursday, November 15 at 2 pm
Shauntay Davis, MPH, Health Rights Hotline, Sacramento 916-551-2191
“Knowing Your Health Rights in California”
A. F. Turner Library, 1212 Merkley Avenue
Call Sandra, at 916-372-6093

About our November Meetings

Woodland. The Woodland Neuropathy Group members will have a sharing time led by Delia Genera. This group has been particularly wonderful in sharing information about how members are doing, what’s working for them, what they need from the group in the way of support and the topics and issues they want to know more about. And Delia really is a remarkably gifted group process leader!

Davis. Some of us got to meet and hear **Dominick Spatafora, MPA, President of the Neuropathy Action Foundation (NAF)**, at the June NAF Neuropathy Awareness Day Conference in San Francisco. We are very pleased to bring him to Davis for a presentation on “Knowing Your California Health Rights.” With a Masters in Public Administration, Dominick has worked in a variety of governmental and private sector health care environments and teaches Health Care Administration at the University of Phoenix. This incredibly dynamic

and creative young man is one of us Pners, having finally been diag-nosed with **Multifocal Motor Neuropathy (MMN)**, a rather rare condition that requires IVIG treatments. Because of insurance problems, he had to go without treatments for three months, causing him to lose use of one of his hands. As a long-time and very knowledgeable health industry professional, he became a persistent and formidable advocate for himself, finally prevailing in the dispute. The costly treatments were restored and he regained use of his hand.

He founded the Neuropathy Action Foundation because of his commitment to educating the public about neuropathy and helping other Neuropathy patients obtain and maintain appropriate individualized care. He'll be speaking about NAF's mission and what's happening in California's health rights world. We have much to learn from him and are honored to have him with us.

West Sacramento. Shauntay Davis, MPH, is another extraordinary person, serving as the Health Education and Outreach Coordinator for the **Health Rights Hotline** since 2004. *(HRH provides free assistance and information about health care rights in our region. Some of us have benefited from HRH trained volunteer **HICAP** counselors at Yolo Senior Centers on health insurance issues.)* HRH staff answers general questions about health care coverage issues and help consumers resolve specific problems with their plans. No matter how consumers get their coverage and regardless of their plans, HRH can help. Like many of us, Shauntay has to deal with chronic pain issues herself, crediting her religious faith and commitment to serving others for keeping her going. She very much understands and appreciates some of our health care dilemmas. She earned her Masters in Public Health in South Africa and worked several years as a health educator, developing social marketing campaigns on public health issues. She is knowledgeable about the laws regulating health care industry practices in California and will bring a great deal of printed and oral information about private insurance policies and MediCal program issues to address our concerns.

Two years ago, the Yolo Neuropathy Groups hosted Health Rights Hotline staffers to help prepare us for participating in Medicare D and how to begin choosing between competing health plans. We learned a lot about our health care rights from those experiences, as well. With so many newcomers in our midst, it's time for an update for reviewing on our health rights. Please make a special effort to attend these very valuable Davis and/or West Sacramento presentations this month.

Dominick Spatafora has organized a terrific **health care advocacy training summit** in Sacramento on December 5th for NCCNA support group leaders and special guests like our colleagues Diane Craig (Celiac Disease Leader) and Sue Alexander (Fibromyalgia and Chronic Fatigue Syndrome advocate.) The event is being jointly sponsored by NAF and NCCNA to equip us for better helping our members in successfully dealing with health care rights issues. We are allocated two people from each group for the event. (If you are not in a leadership role but would like to attend, you may call Bev Anderson at 530/389-2416 to get on a waiting list for potential openings.)

Becoming a Member of TNA and NCCNA

Enclosed with this newsletter are the new TNA and NCCNA brochures for your information and hopefully use. On the next to the last page of this extended catch-up newsletter, you will find the new **Northern California Chapter of The Neuropathy Association's (NCCNA) new membership form.**

Members of **The Neuropathy Association (TNA)**, our national organization, have been receiving the increasingly informative and helpful **Neuropathy News** published **3-4 times a year.**

Recent issues have included a list of the 120 current support groups with contact information across America and the world, illustrating something of the breadth of TNA’s impact. There are more and more articles about living well with neuropathy both in the newsletter and at the constantly evolving web site at www.neuropathy.org.

As with other national health organizations, **TNA** very much needs our **membership dues of \$35/year**. As TNA’s new Executive Director, Tina Tockarszewsky said in the latest issue of *Neuropathy News*, if the current 50,000 members recruited two new members, the membership base would grow to 150,000 members and TNA would have raised \$3.5 million to fund research, offer more comprehensive support group operations, launch additional Neuropathy Centers, etc.

Members receive the printed and mailed newsletter. For those with internet and email access, you can also receive the new monthly emailed newsletter with even more information. If you’re not now a TNA member, this is a great time to join with the thousands of Pners across the world who are supporting TNA’s mission and activities. TNA’s many activities include expanding public awareness, developing patient education materials, advocating for policy changes and funding before Congress and the health insurance industry. They also support the local groups across the world and are expanding the number of **Neuropathy Centers** at major universities (including UCSF). And always they are helping to fund research studies on the causes of and treatments for various neuropathies. If each of us became a member and encouraged membership by others with neuropathies, TNA could expand its program efforts. You can also use the membership form on the brochure to order the marvelous Dr. Latov book on neuropathy, which is available for \$10 each, plus postage. You can also order the classic John Senneff books from the TNA store on the www.neuropathy.org web site.

We have a large supply of these new brochures and need your help in taking packets of 10 brochure/flyer sets to your own doctors, libraries, community centers, etc. to introduce people to our national, regional and local activities. The packages will be available at the November meetings and we ask you to report on where you took the materials and whether they would like more.

We are grateful that some of you have already paid NCCNA’s \$24 dues for 2008 or special donations for 2008. Because the Yolo groups are particularly active, \$9 of the annual dues will be returned to us in support of the printed and emailed newsletters and other special outreach activities. For those of you living outside of Yolo County, but identifying with the Yolo groups, you would receive both the Yolo and NCCNA newsletters each month. Your membership helps to support NCCNA’s growing programs, now located in 30 population centers across Northern California. **We hope you will join as a new or renewing member by the end of this year so we can begin the new year with funds on hand for producing regularly expanded issues of *PN News*.**

Living Better with Neuropathy with the Help of Others

One of the goals of the **Yolo Neuropathy Groups** has been that we all become capable of and willing to give and receive mutual support in living with neuropathy. Here are some vignettes illustrating how that’s working in our national, regional and local neuropathy networks.

National network: Some of the Support Group Leaders (SGLs) across the country are in touch with one another, sharing general and specific information via newsletters, e-mails and phone calls for the sake of empowering ourselves and our group members. One such recent call came from Elizabeth, a retired teacher who had been referred by the SGL in the Boston area. Elizabeth very much needed counsel on finding health insurance to cover her desperately needed ongoing IVIG treatments for her **CIDP** neuropathy – **Chronic Inflammatory Demyelinating Polyneuropathy**. She explained that she had been told by Medicare officials that the program was no longer covering

IVIG infusions. Furthermore, she had spoken with many health insurance companies who also said they were not covering the treatments. She had been receiving IVIG treatments five times a week and was now down to one every other month. While she anticipated a time of not needing infusions, she knew her need would continue for a few more months. IVIG treatments are horrendously expensive and, because of her colon cancer surgery history, she could no longer take prednisone for her CIDP as an alternative as she had for years before beginning the IVIG treatments. What was she to do? Where could she go? Was any health insurer covering IVIG treatments for CIDP?

Wow! Hadn't a clue, but knowing that access to IVIG can literally be a matter of life and death or severe disability for CIDP patients; I knew there were some folks in the network who would know where to go and what to do. One immediate email was to our colleague, Dominick, who also had been once dependent upon IVIG treatments for his MMN condition. Dominick immediately contacted a colleague in Washington DC who handles IVIG advocacy cases for the **NAF**. Within a couple of hours of the first email, **Michelle Vogel (Executive Director of the Alliance for Plasma Therapies (who will speak at the NAF/NCCNA December 5 training event))** had already called Elizabeth with immediate assurances that neither Medicare nor private Medicare supplemental health care insurers could deny her IVIG coverage. Michelle pledged to contact her again with further information on how to resolve her problem. Our talk the next day found Elizabeth more at peace and very grateful for the interventions made possible through the neuropathy network.

Regionally: A woman formerly active in the Sacramento group recently moved to the foothills area. She had suffered for many years with an "idiopathic" neuropathy that kept her literally living on her belly in bed because she could barely sit, stand or walk. Sharon called to report that she now had a new neurologist and was really excited because she finally had had a thorough diagnostic work-up. The result was a diagnosis of CIDP and she assumed she'd be starting IVIG treatments in the near future. She wanted others to know about her find: **Rosalind Hsia, MD**, (pronounced Shaw) with **Neurological Associates**, is at 3319 J Street, Sacramento, CA 95816, 916-358-9101. As she appears to be an expert on diagnosing diffi= cult neuropathies, we hope to have her come speak to a Yolo meeting about diagnosing diverse neuropathies early in 2008.

Turns out Dr. Hsia's office sends their Medicare CIDP patients to the **Sutter Infusion Center** 916-454-6585 all the time, encountering no Medicare coverage problems with proper diagnoses of autoimmune disorders, such as CIDP. This was confirmed by the head of the billing department, who reported they've had no problems with any of the region's HMO's and PPO's, such as PacifiCare, HealthNet, Aetna and Cigna medicare products. (This was great news indeed and immediately relayed to Elizabeth, our new PNER friend, who planned to make follow-up calls to their offices in the Boston area.)

And a million thanks to our friend **Sue Alexander** for arranging for a **Neuropathy Table** next to her **Fibro/CFS Table** at the **Diabetes Walk and Health Fair** at the Capitol on October 27th. Some 60 folks from across the region stopped by the PN table, learning that they, their relatives and friends with PN are not alone; hope and help are available through the support groups. They took away nearly all the materials I'd brought, including the TNA and NCCNA brochures, articles about diabetic and other neuropathies, lists of the support groups in the metropolitan area and the NINDS PN booklets in English and Spanish. In between there were opportunities for visiting with other organizational representatives, some of whom are willing to make presentations to area PN groups in the new year or providing some excellent educational materials for our future meetings, particularly a really marvelous booklet, the **Foot Owner's Manual**, published by the **Institute for Preventive Foot Health**, which we hope to have for the Yolo groups in the new year in conjunctions with one or two more presentations by Davis podiatrists since most of us have PN problems with our feet.

One of the vendors was **Sierra Clinical Research**, which is currently administering a **diabetic neuropathy study** at their Orangevale facility at 8680 Greenback Lane, Suite 250. Volunteers may receive compensation for time and travel costs. SCR plans to open an office in Roseville soon. It is also conducting studies on high blood pressure, fibromyalgia, and overactive bladder, osteoarthritis of the knee, obesity, diabetes and COPD. **Interested? Call 916-988-2079** for a preliminary eligibility interview.

We have long encouraged our members to participate in area clinical trials for the development of new PN treatment options. Some studies will provide some compensation for time and travel costs. Unfortunately most studies available in our area are designed for those with Diabetic Neuropathy. Other types of neuropathy research tend to occur at universities settings. If and when the test medication is approved by FDA, it may well be prescribed for other neuropathies, as been the case of Lyrica.

Locally: I recently shared with a dear PNER cancer survivor friend that when I tried to function outside the bed in recent months, I remained in serious pain and exhaustion for many, many hours, and sometimes days. Whether that was from the spinal fracture or fibromyalgia, I didn't know. But it was an unwelcome barrier I had to learn to live with, and go over, around or through, to continue functioning, just as many of you do. Thank God those times are now shorter for me. But my friend Marta shared the following counsel, which I found helpful and hope it will help you:

Don't stress (not too easy for active people); and don't exhaust yourself by doing what your body is not able to do. What I do during my "trials" is to do what I can with my "working parts" by gently stretching my neck from side to side, stretching my fingers and toes, or rotating my ankles; gently shaking my fingers, hands and arms. Keep moving, working any part that is not giving you grief; just keep the flow going. And, BREATHE! I find yoga breathing very helpful. I send the breath to the grieving, non-functioning parts. I am actually able to relieve some pain in this manner.

Finally, our October meetings featuring **Sue Alexander** on **fibromyalgia** and **chronic fatigue syndrome** brought many new folks to the meetings and calls from others who were unable to come but wanted more information. One was from a lady with some traditional neuropathy symptoms in her feet and balance problems, for which she was told about some treatment alternatives. Dana also had a serious case of **Sjogren's Disease**, one of the rare neuropathies, whose primary symptoms are dry mouth and eyes. Those on pain meds for neuropathy and/or fibromyalgia and many other medications for other conditions experience dry mouth a lot. Sue's very generous fibro/CFS presentation info bags included samples of the **Biotene** dry mouth products, "the long lasting oral lubricant for dry mouth relief." Dana explained she has used Biotene, but her dry mouth had really damaged her teeth, so much so that she had to have some teeth pulled and replaced with implants. **(It would help if our doc-tors would let us know about such serious side effects!)** She now uses a prescribed product called **Evoxac** that has helped a great deal. So thanks to a newcomer who shared a problem **and** a remedy to share with others in the network. And welcome to the Davis PN community, Dana.

What are your problems and solutions? What are your stories? Each of us has wisdom that can help others. Please share your experience with the PN community through our newsletter, at our Yolo group meetings AND with the NCCNA web site at www.pnhelp.org!

The Glucophage/Metformin, Vitamin B-12 Deficiency & PN Connection

One of the great benefits we have in the PN community is that some of us are medically trained, retired nurses, current internet researchers and/or natural born health educators, willing to share their knowledge with the rest of us. Woodlanite Donna Russell is one of those jewels. She once led a huge fibromyalgia group in Davis and recently reported on the June NAF conference talks for us. She's preparing a series of articles on a variety of neuropathies and neuro-pathy issues as part of our patient education program. Her first choice was Vitamin B-12 as nutritional deficiencies and particularly Vitamin B-12, are one of the most common causes of neuropathy. B-12 deficiencies may be found with alcohol and celiac disease related neuropathies, as well as gastric by-pass surgery patients, as all involve malabsorption problems. Some diabetics are particularly at risk because their use of metformin can seriously deplete their B-12 levels, potentially causing some very serious health problems, of which neuropathy is only one. So, welcome again Donna to **PN News** and thanks for the following helpful information.

Glucophage (Metformin) Causes Vitamin B-12 Deficiency

By Donna Russell, 530-661-3705

Disclaimer: This information is given for the purpose of increasing consumer knowledge, thereby empowering each person to make informed decisions about their health, which should include discussing various points with their physicians. It may also alert people to some preventable harmful side effects.

Metformin (generic name for Glucophage), is prescribed to modulate glucose levels in Type II diabetes. While this drug has clear benefits, like other pharmaceuticals, it also has a list of negative side effects (some of which are very dangerous), contraindications and cautions.

Counter indications (those who should NOT take Metformin): Those with kidney disease (which many diabetics have) and heart failure, aka CHF (Congestive Heart Failure)

Side effects: Life Threatening: Lactic acidosis. This risk increases if any alcohol is consumed. One initially common side effect is GI (gastro-intestinal) upsets that usually go away within a month. A few people find these symptoms severe and unrelenting.

Vitamin B-12 Deficiency (leading to Pernicious Anemia): Depletion of B-12 is gradual. It can cause **peripheral neuropathy** and diminished mental acuity. The signs and symptoms, such as fatigue, shortness of breath and anemia, are common with many other medical problems, but some may be dismissed as being "all in your head." Other symptoms include

Decreased immune function.

Nerve damage: tingling, burning, weakness, numbness -- mostly in hands and feet, leading to difficulty in sensing vibrations or interpreting them, causes unstable walking.

Dysfunctional proprioception – not properly sensing where one's body parts are in relation to the environment, resulting in poor coordination.

Depression and mental 'fuzziness', confusion, poor memory -- may be mistaken for early onset of Alzheimer's Disease.

'Burning' tongue.

Cautions: Proton Pump Inhibitors (PPI's) like Nexium, Prilosec, Prevacid, Protoxix, Aciphex for "acid reflux" can all destroy vitamin B-12! Avoid consuming guar gum, found in many frozen desert and low-cal items as it decreases absorption and effectiveness of Metformin. Avoid alcohol (ETOH) as even very small amounts destroy both Vitamins B-6 and B-12, whose deficiencies can lead to increase homocysteine levels which are correlated to increased risk of heart disease.

Diagnosis: The best blood test for Vitamin B-12 is MMA (methylmalonic acid), rather than a simple B-12 level. High MMA and low cobalamine indicate a vitamin B-12 deficiency needing corrective action.

Treatment: Oral B-12, works well. Shots can be painful and usually unnecessary.

Do you have a particular interest in a specific neuropathy that you'd like to see featured in future issues of *PN News*? Please give Donna a call and let her know.

Diane Craig, Celiac Disease Educator & Advocate, Chapter #24, Celiac Sprue Asso.
P. O. Box 2873, Sacramento, CA 95609 916/483-8546 dcraig101@hotmail.com
"The Celiac Disease & Neuropathy Connection"

Diane Craig's long awaited August presentations in Woodland and Davis was most welcome and informative. She's been dealing personally with Celiac Disease (CD) for 20+ years. Her CD-related PN symptoms began to disappear during her fourth year of gluten-free eating. She very well knows that even minor deviations from that life style can trigger a return of CD-related PN distress. She and her family are committed to a strict gluten-free life, with appropriate supplements to make up for missing nutrients. She specifically noted that people particularly need folic acid, B vitamins and omega 3 foods.

As the leader of the Sacramento area CD support group, Diane has done a very great deal to educate the non-medical CD community over the years about the disease and how to eat gluten-free. She explains that is getting easier now as food manufacturers and restaurants are beginning to appreciate the buying power of a sizeable niche market. After all, an estimated one in 133 Americans (about two million people) have undiagnosed celiac disease. It's believed that 97% of all persons with the disease have not been properly diagnosed! Diane's delightful oral presentation was aided by her informative display and copies of the Celiac Sprue Association's brochure, which is quoted below.

"Celiac Disease is a genetically linked autoimmune disorder that can affect both adults and children. For Celiacs eating certain types of grain-based proteins sets off an immune response that causes damage to the small intestine, interfering with its ability to absorb nutrients found in food, leading to malnutrition and other complications. The **offending proteins** are commonly called gluten and are found in **wheat, barley, rye**, and, to a lesser degree, **oats – WBRO**.

Celiac disease is a genetic, inheritable disease (and not a food allergy or an Idiosyncratic reaction to food proteins typified by rapid histamine type reactions.) CD is commonly diagnosed and characterized by damage to the mucosal lining of the small intestine, known as villous atrophy. CD is responsible for the malabsorption of nutrients resulting in malnutrition, but is reversible in most cases when WBRO is excluded from the diet. Sometimes CD manifests in skin blisters called Dermatitis Herpetiformis (DH).

The Symptoms of Celiac Disease vary so widely among people that there is no such thing as a "typical" Celiac. The type and severity seems to be related to the level of intestinal damage and the length of time nutrient absorption has been abnormal. Some people with CD report having no symptoms at all. Adults and children can experience any combination of the following symptoms. **(Diane said that anyone having two or more of these symptoms should consider being tested, using blood tests for gluten antibodies; see below.**

PHYSICAL SYMPTOMS:

*abdominal cramping/bloating/distention * anemia * appetite changes * constipation * diarrhea * abnormal stools, such as unusually loose or hard, small or large, foul smelling, light tan or gray or frothy * decreased ability to clot blood * decreased fat padding on feet, buttocks or hands* dehydration * delayed puberty * edema * electrolyte imbalance * fatigue * flatulence – passing gas, * gluten ataxia – failure of muscle coordination * infertility or miscarriages * mouth sores or cracked lips * muscle cramps in hands and legs * night blindness * osteopenia or osteoporosis * pain in bones or joints * smooth tongue * very dry skin * weakness* and unexplained weight loss or gain.

EMOTIONAL SYMPTOMS:

depression * disinterest in normal activities * irritability * mood changes* inability to concentrate.

DIAGNOSING CELIAC DISEASE The three major steps are:

1. A thorough physical examination, including blood tests for gluten antibodies - EMA and TT - Quest Lab codes #23280. These tests were developed in 1998.
2. A small bowel biopsy or a skin biopsy will be done for persons with DH
3. Implement the gluten-free diet.

The process is complete when symptoms subside and the intestinal lining normalizes. **To ensure an accurate diagnosis, the gluten-free diet should begin only after the first two steps are completed.**

TREATMENT

At the present time the only treatment for CD and DH is the life-long commitment to a strictly gluten-free life-style. This means avoiding any contact with the offending proteins, found in wheat, barley, rye and oats, or their derivatives. Many of these grains or their derivatives are found in processed foods, medications (prescribed and OTC) and personal care products.

Self management is the key to a living gluten-free life style. Working with a gastro-enterologist and registered dietitian who are well versed in the specifics of CD and DH is important, Meeting and sharing with others who live gluten-free helps increase both knowledge and confidence when transitioning into a gluten-free lifestyle. “

Diane said that development of CD is triggered by such factors as 1) possessing the genetic markers for CD; 2) having been exposed to viral infections, 3) a history of eating high gluten foods, such as “fast foods” and 4) experiencing a high stress event, when subtle symptoms first begin to appear.

She gave us several startling historical facts about CD that merit passing on: While the diagnostic blood tests for CD were finally developed in 1998, Hippocrates described CD some 2,500 years ago! It became more commonly known during World War II when pediatricians began to see chronically ill children getting well and the only explainable factor was the substitution of potatoes for wheat products! However, contemporary medical students will have no more than an hour of training on CD.

Her **CD support group** has done a great deal of “field research” in identifying restaurants with gluten-free foods. She encouraged us to check out the CSA website, for a list of gluten-free commercial products now available, including beer; go to www.csaceliacs.org or call 877-CSA-4-CSA. For information about the Sacramento area CD support group contact Diane at the phone or her email address noted above.

PS. The September 17, 2007 issue of Newsweek featured a wow article on CD. **Dr. Peter Green**, director of the **Celiac Disease Center at Columbia University**, explains the consequences of the auto-immune disease aspect of CD: *“In launching its assault on gluten, the immune system generates antibodies against an enzyme called tissue transglutaminase.... But because the enzyme is also found throughout the body – in the skin, heart, thyroid, bones and nervous system - antibodies that attack it can direct their fire at any of these other organs too.”*

Another web site for CD information is at www.celiac.org for the **Celiac Disease Foundation**. It's patient brochure asks, **“Are You the One?”** That is are you the one in 133 Americans with undiagnosed celiac disease? It also adds discolored teeth as a common CD symptom; and notes these co-morbidities: Type I diabetes, Chronic Fatigue Syndrome, Fibromyalgia, Irritable Bowel Syndrome, Sjogren's Disease, Peripheral Neuropathy and Thyroid Disease. It recommends four specific blood tests: EMA-IGA, tTG-IgA, IgA and AGA-IgA and. AGA-IgA. If the results are positive, your doctor may recommend a small bowel biopsy, which is performed endoscopically. Samples of the small intestine lining will be studied under a microscope to look for damage and inflammation. When both the blood tests and biopsy are positive, a presumptive diagnosis of Celiac Disease can be made. Should the tests be uncertain, a genetic test may be done indicating whether one is high or low risk for Celiac Disease.

Thanks Diane for a most enlightening presentation and the CD brochure, for your very caring group leadership in the CD community, and for so often staffing area health fairs to teach the general public about CD!

**Elizabeth Yeh, RN, BSN, MSW, Long Term Care Ombudsman
Ombudsman Services for Northern California, www.osnc.net, 530- 668-5775
“ Understanding Diabetic Peripheral Neuropathy”**

Thanks to **Elizabeth (Liz) Yeh** for purchasing an LCD for her extremely helpful power point presentation at the West Sacramento group meeting in September! Wow, that's some dedication! Although she did explain that she'll use the LCD for other presentations she does in her other volunteer community work. (**This report will replicate her very excellent power point presentation.**) One of her roles is as an ombudsman, investigating problems at Yolo long term care facilities and being an advocate for residents and their families. She is one of nine such volunteers with the OSNC, which meets monthly for mutual support and ongoing training. Her long-time professional work in that world and her strong advocacy for its patients and their families particularly equips her for a powerful and thorough performance of that role. If you know of a patient problem in a Yolo facility, be sure to contact Elizabeth at the above for a prompt investigation and help. The following is from her power point talk which she provided for all present.

“Diabetic Peripheral Neuropathy (DPN) is from damage to the sensory, motor and autonomic nerves (to skin, muscles and organs) potentially affecting any part of the body, from head to toe. It is a common complication of patients with diabetes and is generally cause by high levels of glucose (blood sugar) and poor cardiovascular circulation. This is a debilitating disorder affecting some 50% of diabetics. I

DPN is most frequently found among those with Diabetic Mellitis (DM - Type II form), is a complex metabolic disease that is life long that is usually not curable, but it can be well controlled by medications, diet, and exercise. With DM the body cannot properly process glucose, protein and fats. Our cells and nerves need glucose to function, but its processing most affects glucose.

The role of Insulin in diabetes: The pancreatic beta cells secrete insulin. There may be an absolute or relative deficiency of insulin or an ineffective insulin uptake. In the absolute case, beta cells may not produce enough insulin (Type I). With Type II, the body's nerve cells' insulin receptor sites are fewer in diabetics than a normal person calling for an increase in insulin production or resisting it, thus keeping the glucose in the bloodstream. DPN is most likely to occur in people who have a long history of diabetes, difficulty in controlling their glucose (unstable diabetes), high levels of food fats (cholesterol), and damage to the blood vessels, which supply nutrients and oxygen to the nerves.

Prevalence of DPN: No racial or ethnic group has a complete monopoly on developing DPN, but it is more common among males over 40 years of age who are overweight and smokers. The American Diabetic Association estimated that after 15 years of living with diabetes, some 60-70% of diabetics have DPN.

Damaged nerves are unable to transmit signals to the brain correctly. The result is impaired sensation, motor function, or organ regulatory functions. Common symptoms are pain, numbness, burning, weakness and sexual dysfunction. The nerve injuries may be focal or multiple (i.e. involving a single nerve or many nerves), unilateral or bilateral - although usually the latter with DPN, temporary or permanent, and the symptoms may change over time.

Neuropathy types: peripheral neuropathy affects the upper and lower limbs. Autonomic neuropathy affects the heart rate, breathing, digestion, perspiration, blood pressure, sexual, bladder and bowel functions. Focal neuropathy affects a single nerve, most often in the face, hands or feet. Proximal neuropathy mainly affects the hips, thighs and buttocks. Neuropathy can affect some or all of the senses (such as touch, sight and hearing); some or all of the digestive, endocrine, neurological, respiratory, reproduction and elimination systems.

The signs and symptoms of diabetic neuropathy follow a "natural history" of potential progressively worsening condition. Early symptoms are tingling, numbness, burning, loss of balance and coordination, impaired sleep and fatigue. The onset is gradual and symptoms are worse at night. Symptom may progress as follows: sensitivity to touch, muscle weakness, serious infections, gangrene and amputation. The signs and symptoms of autonomic neuro-pathy, with a gradual onset, are dizziness, low blood pressure, excessive sweating, and poor bladder control. The progressing symptoms are fainting, heart rate irregularities, bladder & bowel problems, sexual dysfunction, stomach problems like nausea and poor digestion, and hypoglycemia unawareness. The signs and symptoms of focal neuropathy are initially blurred vision, mild facial weakness, ankle or foot weakness. The onset can be sudden or gradual. The symptoms progress to double vision and facial paralysis.

Treatments for DPN. Treating the underlying condition is a priority; i.e. controlling blood sugar, as measured by an A1C value less than 6. The second focus is on symptom relief of symptoms with nerve pain medications and topical ointments; physical therapies for a variety of symptoms; and alternative treatments such as acupuncture, acupressure and massage, etc.

Preventive measures for DPN: Carefully manage any medical condition that put you at risk, including blood pressure and cholesterol. Avoid any repetitive motions, cramped positions and toxic chemicals. Reduce weight. Stop smoking. Control the blood glucose. Exercise to reach target heart rate. Check your feet daily for cuts and bruises.

QUESTIONS FOR YOUR DOCTOR:

Do I have or am I at risk of developing diabetic peripheral neuropathy?

What else might be causing my pain, tingling, numbness or other symptoms?

What tests for neuropathy might I undergo and what do they involve?

What do my test results show? What type or types of neuropathy do I have?
 Is my neuropathy exacerbated by a condition other than diabetes?
 How can my neuropathy affect me?
 If lifestyle improvements, glucose control and medications don't help, is surgery an option?
 What is the expected course of my condition?
 Will I need to see a neurologist or other specialist?
 What can I do to prevent or reduce my risk of neuropathy?
 Can I do anything to avoid complications of neuropathy such as sexual dysfunction of foot problems (*that could lead to amputations*)?
 Are there any recent breakthroughs in gene therapy or other research into diabetic neuropathy that could benefit me?"

(HOW CONSIDERATE OF LIZ TO GIVE US THESE REALLY TERRIFIC QUESTIONS THAT ARE PERTINENT TO DPN AND OTHER NEUROPATHIES!!! IF YOU DON'T KNOW THE ANSWERS TO THESE QUESTIONS, YOU MIGHT WANT TO DO SOME RESEARCH.)

LIZ, THANKS SO MUCH FOR YOUR WONDERFUL PRESENTATION ON DIABETIC NEUROPATHY!! And thanks for your current service to OSNC and your many years of advocacy in geriatric medicine.

**TRACY L. BASSO, DPM, FACFAS, DAVIS FOOT & ANKLE CENTER
 635 Anderson Road, Ste. 4, 530-758-1810 DrBasso@dcn.org.
 "The Value of Walking"**

Dr. Basso's CV is most impressive. He is certified by the American Board of Podiatric Surgery and the American Board of Podiatric Orthopedics and is a fellow of the American College of Foot and Ankle Surgeons. He is the immediate past president of the California Podiatric Medical Association, one of whose achievements during his tenure was insuring that MediCal patients are covered for podiatric care. He is also vice chair of the Podiatric Medical Education Advisory Committee to the California School of Podiatric Medicine at Samuel Merritt College. An athlete himself, he is the team podiatrist of the UC Davis Cycling Team. And is owner of Shoes 'n' Feet store in north Natomas, whose dynamic manager has spoken to Yolo groups in the past. He has been a long-time supporter of the Yolo neuropathy groups, having spoken twice to the Davis group in the past and whose office staff provided printing services of our newsletter for several months last year. We are grateful for the generosity of his time in presenting his power point lecture on "The Value of Walking" (on which this report is based) at all three of our groups in the last month

He sees walking as an essential and optimal prescription for health because it is easy, safe and inexpensive, is physically (and emotionally) rewarding, easy to include in one's daily routine. It's not age dependent but can be done almost anywhere. Studies show that older people who continue active lifestyles experience less health problems as they age. Every minute of walking adds two minutes to your life, while physical inactivity contributes to 300,000 preventable deaths each year in the US.

Walking is a sure way to fitness by strengthening one's heart and lungs; improves circulation, prevents or rehabs heart attacks and strokes, reduces obesity and hypertension, boosts one's metabolic rate and reduces stress and tension. A British survey concluded that walking is an ideal, low impact form of exercise for overweight people. American studies have found that briskly walking 12 miles a week yields meaningful aerobic fitness gains and reduces the risk of cardiovascular disease in at-risk populations. Mortality is halved in retired men who walk more than

two miles per day. Regular walking can help to strengthen bones and therefore reduce the risk of osteoporosis and associated fractures; and brisk walking reduces bone loss in post-menopausal women.

Beginning walkers should remember to go at a steady pace on level ground with head erect, straight back and swinging arms. Simple warm-up and cool down stretches are important. Proper clothing and shoes are essential. Take along a heart rate monitor, a pedometer and a bottle of water. Listening to music or meditating while walking can be helpful. Begin with an easy pace, gradually building up to twenty minutes of uninterrupted exertion along a premeasured route. A pedometer counts your steps of walking through the day, but shoot for reaching 10,000 steps per day at least 4-5 times a week. Keep an activity log to track your progress. Walking can burn 297 calories per hour!

Be on the lookout for **foot problems** such as heel and forefoot pain, bunions, hammer-toes, neuromas, blisters, Athlete's foot, warts, excessive sweating. Common sports-related injuries include ankle sprains, muscle strains, tendonitis, plantar fasciitis, nail injuries, runners knees and shin splints. Stress and traumatic bone fractures may occur. Treatments should include RICE – rest, ice, compression and elevation. But see your podiatrist to treat any acute or chronic injuries and problems.

Choosing shoes for proper Footwear for walking and other sports wear is essential for preventing injuries. Choose good construction quality, proper fit for both length and width, firm heel counters, removable insoles, arch supports or orthotics as needed. Trying on shoes in the afternoon will help insure proper length and width. As to length, there should be a thumb nail's length at the end of the longest toe, fit to the largest of the two feet, try on shoes in the after-noon to insure the best fit. A proper last insures that the shape of the shoe must match the shape of the foot. **Proper style** will vary with the type of sports use and should have proper control, stability and shock absorption; with the most appropriate materials, e.g. leather or neoprene or nylon for varying usage.

The staff of Shoes 'n' Feet at 4740 Blvd., Ste 130 (916-419-0040) is highly trained to insure you will have the best possible fit from the wide selection of the shoes carried at the store. Dr. Basso showed us pictures of some of the smart and stylish shoes available that are especially designed to solve difficult fit problems and yet are not "old ladies shoes."

APMA Walking Study: *The American Podiatric Medical Association's press release begins this way:* "What if someone told you, you could walk your way to health? With 65 % of American adults considered to be overweight or obese, walking may be one way to battle the bulge. However, if you lack motivation, a prescription to walk may be just what the doctor ordered. That's the premise behind a 48 week pilot walking program conducted by 16 member physicians of the APMA.

Dr. Basso is one of the 16 podiatrists in California and Florida participating in a study sponsored by the American Podiatric Medical Association for which Dr. Basso is recruiting participants. The Inclusion Criteria are that one must be 18 years or older, NOT currently on another exercise program, have a Body Mass Index of 27 or greater, and cleared by one's primary care provider for the walking exercise. The Exclusion Criteria includes presence of significant coronary vascular difficulties, significant neuropathy (numbness) symptoms. Once chosen, a participant will be randomly selected into two different test groups. Regardless of the test group, all participants will receive these **benefits:** a free pair of shoes, a free pedometer, monitoring of cholesterol, blood pressure, weight, and two blood tests, including HgA1c for diabetics, and overall improvement of one's health. **If you're interested, give Dr. Basso's office a call (530-758-1820) to begin the eligibility evaluation process. If you're outside of Yolo, ask about the other podiatrists in the metropolitan area also participating in the study**

Thanks so much, Dr. Basso, for the Walking lecture, for providing Anodyne services at the Center for bringing the Shoes 'n' Feet store to Sacramento, being part of the APMA walking study and all the ways you and your staff have helped the Yolo Neuropathy Groups over the years.

Some Neuropathy Odds and Ends

Those who came for Sue Alexander's October presentations on fibromyalgia and chronic fatigue syndrome were no doubt overwhelmed by the generous bags of patient education hand-outs and product samples she provided for the many in attendance. It will take awhile to review and digest all that great information; so the report on her presentation must await the next issue of **PN News**. **THANKS SO MUCH, SUE, FOR ALL YOU DID FOR US THIS MONTH!**

Those who are taking duloxetine (Cymbalta) for their DPN pain need to know that prolonged usage can significantly increase one's **A1c** levels, according to findings of Eli Lilly researchers after reviewing data from three clinical trials. Secondly, in an FDA a letter to Lilly dated September 21, Lilly was asked to immediately stop using promotional materials that are "false or misleading in that it **overstates the efficacy** of Cymbalta and omits some of the most serious and important **risk information** associated with its use,, including **sometimes fatal reactions** if combined with monoamine oxidase inhibitors. If you're diabetic and/or taking Cymbalta and MAOIs, you probably need to talk with your doctor about these developments.

Some of us with a variety of Neuropathies may experience intense **burning sensations** in our feet and legs, but our usual pain medications don't help much. **Artalgia** is a homeopathic product developed by **Todd Horton**, a podiatrist in Florida. One places several drops of the liquid, which is made up of 16 herbs, under one's tongue. While there is a terrible taste for a few seconds, the burning quickly disappears for several hours. The one ounce bottle contains 36 drops which can last for several days/weeks, depending on how many drops are used each time. You can order the product by sending your check for \$17 for each bottle (which includes shipping costs) made out to Todd Horton, DPM; his address is 3304 Brigadoon Drive, Clearwater, FL 33759. Artalgia is shipped immediately upon receiving your check and has a 100% refund guarantee if you're not satisfied. You may also pay by Pay Pal. Go to his informative web site at www.burningneurophy.com to read some of the many testimonials and his helpful explanation of various neuropathies.

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