

# NEUROPATHY NEWS

The Newsletter of The Northern California Chapter of The Neuropathy Association  
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*Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.*

Vol. 2, No. 3 “Neuropathy, a term for all disorders of peripheral nerves” March, 2007  
American Medical Association Home Medical Encyclopedia

## 6<sup>th</sup> ANNUAL CALIFORNIA NEUROALLIANCE CONFERENCE March 26-27, 2007 Sheraton Grand Hotel Sacramento, California

If you have any interest in the legislative side of addressing the needs and concerns of people with neurological diseases, this is the conference for you. Besides educating the legislators, you get to meet active, involved people suffering from other neurological diseases.

On the first day, you hear legislators and legislative assistants as well as experts in the topics of the four bills chosen for focused attention. This year's dinner keynote speaker is Assembly Health Chair Mervyn Dymally. The day will also feature a panel of presenters discussing healthcare reform. Representatives from the Governor's Office, Senate, and Assembly, including both the Governor's Plan and the Republican plan are due to be present.

On the second day, those willing to participate are put in teams of 3-4 people to visit every legislator in Sacramento. Each team visits with four legislators. I did this for the first time with this group last year and enjoyed it. We met with some legislators themselves but otherwise we met with their staff person assigned to health issues.

There is room for 10 from NCCNA. The registration fee is \$90. This includes breakfast both mornings, lunch and dinner on Monday, March 26, and all handouts. If you decide to stay at the hotel, rooms are \$165 for this conference. If you want to go but need financial help or have any

question about the conference, please contact Bev Anderson (530)389-2416. The CalNeuroAlliance offers limited help to a few.

## ANNUAL MEETING AND GROUP LEADERS GATHERING Tuesday, April 10, 2007 10 a.m. – 1:30 p.m. Sierra Health Foundation 1321 Garden Highway, Sacramento

Sierra Health Foundation is a new site for this gathering. It is in a lovely setting on the banks of the Sacramento River. It is just off I-5. Plan to take the portion of I-80 that goes around Sacramento, not Business 80. Take I-5 toward downtown Sacramento. Soon, you will take the Garden Highway exit and turn right. In a short way, you will see a row of office buildings along the riverfront and find that one of the first is 1321. Park in the lot in front of 1321 and to the left of it. The other part of the lot is for the offices in the buildings to the right of 1321. If necessary, there is street parking.

We will have an opportunity to get more acquainted, to hear and interact with the Annual Report and Strategic Plan, as well as to hear a speaker yet to be confirmed.

We need to know you are coming so Sandra Vinson can plan the amount of food to prepare. She will have a lovely array of light finger food to keep us going through to 1:30 p.m. The Sierra Health Foundation provides coffee, tea, and water. Please call Sandra (916)372-6093 or Bev (530)389-2416 to make a reservation.

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

Group/Date/ Time	Place	Program	Contact
Auburn-Day 1 <sup>st</sup> Monday, 1:30 PM	Woodside Village MH Park 12155 Luther Rd., Auburn	Come and enjoy!	Terri Stennes, 916-663-3108 bridget@infostations.net
Auburn-Eve 1 <sup>st</sup> Monday, 7 PM	Sutter Auburn Faith Hospital 11815 Education Street, Auburn	William Gilbrech, DPM Auburn podiatrist “PN Discoveries”	Bev 530-389-2416 <a href="mailto:bj@foothill.net">bj@foothill.net</a> , Grant 530-887-9881
Berkeley 3 <sup>rd</sup> Monday, 6-8 PM 1 <sup>st</sup> Month of each quarter	Lutheran Church of the Cross 1744 University Ave., Berkeley	<b>No Meeting in March</b>	Alan Dampsey, 510-527-3568 adampsey@comcast.net
Concord, 3 <sup>rd</sup> Tuesday, 1:30 PM	First Christian Church 3039 Willow Pass Rd., Concord	Come and enjoy!	Ernette Rivera, 925-889-2484 ernette5712@sbcglobal.net
Davis 2 <sup>nd</sup> Wednesday 2 PM	Institute for Restorative Health, 1460 Drew Ave. across from Kaiser	Come and enjoy!	Martha Chandley, 916-371-1125 kairoschandley@sbcglobal.net
Elk Grove 2 <sup>nd</sup> Tuesday, 2 PM	Elk Grove Senior Center 8830 Sharkey Ave, Elk Grove	Come and enjoy!	Michael Colozzi, 916-421-8103 Susi Watson 916-354-0483
Folsom 2 <sup>nd</sup> Tuesday, 3:30 PM	Creekside Oaks Retirement Residence 1715 Creekside Drive.	Come and enjoy!	Lorraine 916-983-4023, Beverly 916- 984-4302
Grass Valley 2 <sup>nd</sup> Monday, 1:30 PM	GV United Methodist Church 236 S. Church St., Grass Valley	Come and enjoy!	Bev 530-389-2416 Betty Gears 530-432-7774
Jackson 3 <sup>rd</sup> Tuesday, 10 AM	Amador County Senior Center 229 New York Ranch Rd. Jackson	Call Darlene for meeting information.	Laurie 209-223-0442 Darlene 209-296-1760
Lincoln 3 <sup>rd</sup> Tuesday, 1 PM	Raley's Event Center 765 S. Hwy 65, Lincoln	Come and enjoy!	Joe Facha 916-408-2007 Lavern 916-408-2007
Livermore 4 <sup>th</sup> Tuesday, 10 AM	Heritage Estates 900 E. Stanley Blvd.	Come and enjoy!	E. Lorene Stack 925-447-6158
Monterey Not chosen yet	First Presbyterian Church 501 El Dorado St.	<b>Call Don or Ann to learn meeting schedule.</b>	Don & Ann Trout 831-372-6959
Napa 1 <sup>st</sup> Thursday, 2 PM	Napa Senior Center 1500 Jefferson St., Napa	Come and enjoy!	Ron Patrick 707-257-2343 bonjournapa@aol.com
Placerville 4 <sup>th</sup> Weds., 1:30 PM	Placerville Senior Center 937 Spring St., Placerville	Come, be encouraged	Arlene Middlebrook, 530-626-1098 Dan Hudgins, 530-622-5188
Rancho Cordova, 2 <sup>nd</sup> Tuesday, 7 PM	Mather Field Veterans Hospital Bldg. #728, Hospital Way, MF	<b>Next meeting in March or April. Watch this box for news.</b>	Bev Anderson 530-389-2416 Charlie Green 916-363-1052
Redding, Restarting soon		Call Sandi Deome (530)365-7081 for info	Bev Anderson (530)389-2416
Redwood City, 1 <sup>st</sup> Tuesday, 2 p.m.	Bakers Square Restaurant 949 Veteran's Blvd., Rdwd Cty	Come and enjoy!	Annette Devost 650-595-2478
Reno, NV 2 <sup>nd</sup> Tuesday, 6:30 PM	Fire Station #11 7105 Mae Anne Ave., Reno	Video of Jeffrey Reinking, M.D. Pain Specialist	Marsha Campbell 775-851-0499 <a href="mailto:LadyJane2b@sbcglobal.net">LadyJane2b@sbcglobal.net</a>
Roseville 2 <sup>nd</sup> Tuesday, 7 PM	Point West Sr. Res., 5161 Foothills Blvd., Roseville	Come and enjoy!	Marilyn Larson 916-771-8435 Helen Astill 916-782-6208
Sacramento 3 <sup>rd</sup> Tuesday, 1:30 PM	Northminster Presby. Church 3235 Pope Street, Sacramento	Harold Kuphaldt with Gentiva. Presenting special programs available	Anne Fletcher 916-391-3317 Myke Taylor 916-487-2903
San Francisco – Wed. Jan. 10, 10-11:15 a.m.	UC-San Francisco Med Ctr. Amb. Care Ctr. 8th Flr. , Rm A888, San Francisco	Come and enjoy!	Amy Mahoney, 415-353-2312 <a href="mailto:amy.Mahoney@ucsfmedctr.org">amy.Mahoney@ucsfmedctr.org</a>

Group/Date/ Time	Place	Program	Contact
San Jose 3 <sup>rd</sup> Saturday, 10:30 AM	O'Conner Hospital, 2105 Forest Ave, SJ DePaul Conf. Rm., San Jose	Come and enjoy!	Ann Louie, 408-282-0780 Glenda Whiteside, 408-378-6691
Santa Cruz – Call Mary Ann for date and time.	Life Oak Senior Center, 1777 Capitola Rd., Santa Cruz	Come and enjoy!	Mary Ann Leer. 831-477-1239 <a href="mailto:MALEER@SURFNETUSA.COM">MALEER@SURFNETUSA.COM</a>
Santa Rosa, 1 <sup>st</sup> Thursday, 10:30 AM	Santa Rosa Senior Center 704 Bennett Valley Rd, SR.	Come and enjoy!	Ginger Minnich, 707-829-2934
Sonora. Meeting, Oct. 30 Last Monday, 2-4 PM	Sonora Regional Medical Center Conference Room	Come and enjoy!	Ed Minium (209)586-3702
Stockton 3 <sup>rd</sup> Tuesday, 4 PM	Central United Methodist Church 3600 Pacific Avenue.	Come and enjoy!	Mary & Case Klooster (209)463-5985
Walnut Creek	Rossmoor, Hillside Clubhouse Vista Room, Walnut Creek	<b>Time, place, and program to be announced</b>	Ginny Olson, 925-947-3158 <a href="mailto:riowwo@comcast.net">riowwo@comcast.net</a>
West Sacramento 3 <sup>rd</sup> Wednesday, 2:00 PM	AF Turner Branch, Yolo County Library, 1212 Merkley Ave. WS	<b>Note new day and time.</b> Come and enjoy!	Sandra Vinson, 916-372-6093 <a href="mailto:slvins11@charter.net">slvins11@charter.net</a>
Woodland 1 <sup>st</sup> Monday, 4:30 p.m.	Woodland Senior Center 610 Lincoln Ave, Woodland	Come and enjoy!	Delia Genera 530-661-3238
Yuba City 2 <sup>nd</sup> Monday, 7 PM	Sutter Estates 1230 Plumas Street, Yuba City	Come and enjoy!	Nancy Escudero, 530-673-3608 <a href="mailto:nancychristina1@yahoo.net">nancychristina1@yahoo.net</a>

**Please realize that even though a speaker is not listed, it doesn't mean there won't be one. It is hard to know far enough ahead to meet the deadline for this publication. Some of the best meetings, however, are sharing and discussion meetings. Local e-mail, news flyers, newspaper, and phone calls may be used to inform you more about the meeting but any time the group meets, it is worth being there.**

**PRESIDENT'S REPORT  
by Bev Anderson**

**MEMBER SURVEY  
FOR STRATEGIC PLANNING**

Your Board of Directors is developing and writing a Strategic Plan to give us a road map for the next three years. This is guided by our Mission Statement and Vision Statement. If you lay out the trip and have an idea of where you are going, it is easier to make adjustments along the way. If you have no knowledge of where to go, you may not leave home. We want NCCNA to have a plan.

You are receiving, in a separate mailing, a questionnaire so you can give us input that will serve to give guidance for the final plan. The nearly final plan will be presented to the Group Leaders Gathering on Tuesday, April 10. By "leaders" we mean anyone helping or interested in helping to lead their group. This is also our Annual Meeting so any member is welcome.

**WE MADE A BIG MISTAKE  
WITH THE  
CALIFORNIA NEUROALLIANCE  
INTERNET SURVEY  
YOUR HELP IS NEEDED**

We find that it is impossible for us to fill out the California NeuroAlliance questionnaire on-line without more information than we put on the original survey we sent out with the newsletter. Some questions, you probably noticed, are not listed. We thought they had been dropped but it was because we answered "no" for the question before these blanks. If you answer "yes," then the other questions appear to clarify your "yes" answer. We also didn't get the full information needed at the beginning of the survey. So we are not going to keep trying to do this impossible task but instead ask your help.

If you sent in a paper survey, please go on line yourself or have a friend, relative, neighbor, or friend of any of these help you. You can do it

over the phone with them if they have a separate line or will use their cell phone to talk to you.

Here is what you do: Go on line to <http://www.calneurosurvey.com> and follow the directions. When they ask for the last 4 digits of your Social Security Number, just put in any 4 random digits. However, do write what you used down where you can find it if there is ever a question they need to get back to you on so you can verify it is you they are talking to. There is an ultra slim chance of this. This is the only reason they needed the numbers. However, with so much of our computer data being available just with those last four digits of our Social Security Number, it is probably wise not to use them unless you deal with the company on a regular basis and you trust them to protect it.

**THE FOLSOM NEUROPATHY GROUP  
HAS A NEW MEETING PLACE  
STARTING IN MARCH**

Starting with its meeting on March 13, 2007, the Folsom Neuropathy Group will move to Creekside Oaks, Gracious Retirement Living, 1715 Creekside Drive, Folsom, CA 95630. The meeting time will change to 3:15 – 4:30 p.m.

This facility is a block or so beyond Mercy Hospital on Creekside Drive. Creekside is off of E. Bidwell just south of Blue Ravine Rd.

**FREE HELP FOR YOUR  
HEALTHCARE SERVICES PROBLEMS**  
HICAP – Health Insurance Counseling for seniors and people with disabilities. Call Seniors First/Senior Link at 1-800-878-9222 to make an appointment.

Health Rights Hotline, serving people in Sacramento, Yolo, Placer or El Dorado Counties regardless of where you receive your health coverage. Every county has one of these. If you can't find the one for your county, call this number and they can guide you. In Placer, El Dorado or Yolo Counties call toll free (888)354-4474 or TTY/TDD (916)551-2180. In Sacramento, call (916)551-2100 [www.hrh.org](http://www.hrh.org)

HMO Help Center: Assistance is available 24 hours a day, seven days a week. Call (888) HMO-2219 or (877)688-9891 (TDD)

**RENO GOLF TOURNAMENT  
RAISES FUNDS FOR  
THE NEUROPATHY CENTER  
ALL GOLFERS WELCOME**

The Annual David Loeb Memorial Golf Tournament is Friday, June 22, 2007, starting at 12:30 p.m. The Championship Hale Irwin Hills Course at The Resort at Red Hawk, a private golf course, is the prestigious site for the event.

This golf tournament funds The Neuropathy Center in San Francisco where some of our members have received help. Having The Neuropathy Center at the University of California-San Francisco Medical Center has greatly increased access for those with neuropathy, especially members of NCCNA.

Registration is \$300. This includes a really nice lunch, an afternoon of golf at an exclusive club, and an incredible dinner. Spouses or significant others are welcome to come to the dinner at no extra charge. Others who would like to attend the dinner may do so at a cost that will be announced shortly. The dinner will feature a silent auction, musical entertainment, and the comedian Rocky LaPorte who has appeared on the Jay Leno Show.

Detailed information is available in the Invitation. To receive an invitation, call Heidi Loeb (775)321-5901 or e-mail to [hloeb@resortatredhawk.com](mailto:hloeb@resortatredhawk.com) Invitations will be sent out at the end of April.

Here is our opportunity to help raise funds for The Neuropathy Center but also to have an enjoyable time. Please tell anyone you know who plays golf about this opportunity. You might write Heidi's name and contact information on a card or sheet of paper and give this to anyone you find that is interested. If you use a computer, just copy this announcement, paste it to your word processing program, and print it out to give to golfers.

**CHECK OUT THE WEBSITE FOR  
THE JACK MILLER CENTER  
FOR PERIPHERAL NEUROPATHY  
<http://millercenter.uchicago.edu>**

There are numerous articles of interest from various publications and links for information.

## **ARE YOUR \$24 DUES PAID?**

This is the last newsletter people who have not paid their dues for 2007 will receive until the dues are received. **Please remember that if you paid dues in 2006, your 2007 dues are \$24. The prorated dues are for new members as they were not present to receive the services the dues provided prior to their joining.** We have gotten some odd amount payments that indicate there is some confusion here. Please send your check to NCCNA, P.O. Box 6985, Auburn, CA 95604.

## **MEMBERSHIP CARDS COMING WITH THIS NEWSLETTER**

If you are a member with 2007 dues paid, you are receiving a 2007 Membership Card. We are asking that you put your name on it the way you want it with or without initial. You might have someone whose hands are not affected with neuropathy print your name on it.

Since we are using a mailing service and sending the newsletter at bulk mail rates, it would be almost impossible to match the card inside with the name outside. We send them an Excel file by e-mail with all the names and addresses. By the miracle of modern technology, they ink jet the names and addresses on the envelopes or newsletters along with the bar code that is supposed to expedite the handling by the post office. So when we deliver them, there is no label on them.

## **GENE THERAPY STUDIES**

The Jack Miller Center for Peripheral Neuropathy reports The University of Chicago, Northwestern University, and the University of Illinois at Chicago will provide a core facility to promote gene therapy studies for varied neurological disorders, including genetic diseases (e.g. inherited forms of peripheral neuropathy), neurodegenerative diseases, and injuries to the nervous system.

## **PRACTICE HOME SAFETY**

- Install grab bars in the bathroom,
- Never use towel racks for grab bars.
- Use floor mat and rugs with non skid backing.
- Exercise to help with balance
- Don't use deep pile carpet

## **JUNE 26 IN SAN FRANCISCO AN EVENT NOT TO BE MISSED PLAN NOW TO ATTEND**

Sponsored by the Neuropathy Action Foundation and actively involving The Northern California Chapter of The Neuropathy Association, this event will be at the new UC-SF Conference Center at Mission Bay in San Francisco where we understand there is ample parking. Full directions to the site will be in next month's newsletter.

- A health fair including the following will start at 1 p.m.: FREE Massage Booth – UCSF, Nu Factor, The Northern CA Chapter of the Neuropathy Association (NCCNA), Crescent HC, GBS/CIDP International, American Diabetes Association, Anodyne Infrared Therapy, CMS – Medicare, Dr. David Phillips (Rebuilder) Pfizer, Lilly, CA Department of Insurance and more.

During the Health Fair, there will be seminars led by a variety of people. The day will conclude with a very special Dinner featuring awards, presentations, and speakers. There will be at least one celebrity guest. The Neuropathy Action Foundation very much wants a sizable crowd of patients to interact with the exhibitors, doctors, community leaders, and others expected.

## **SPECIAL NEWS FOR THOSE ALONG THE I-80 CORRIDOR**

A 47 passenger tour bus with amenities has been rented to take that many people to San Francisco. It will leave Auburn at 10 a.m. and make stops along the way depending on the reservations received. Those who live a distance from I-80 but choose to take the bus from one of these locations rather than drive to San Francisco, are welcome. Currently stops are expected in Roseville, Sacramento, and Davis but these will be adjusted depending on the response.

There will be a charge for the Dinner but not for the bus. We will start taking reservations in April but please be planning now to take this opportunity for an exciting and informative day. The bus will leave immediately after the Dinner to return. It is expected to arrive in Auburn between 10 and 11 p.m.

**ANOTHER WAY TO OBTAIN THE  
PERIPHERAL NEUROPATHY**

**BOOK BY NORMAN LATOV, M.D., Ph.D.**

Last month, we had the excellent review from Martha Chandley of this new book by Norman Latov, M.D., Ph.D. He is one of the founders of The Neuropathy Association. It is available from the publisher for \$19.95 plus shipping. Amazon now has it for \$13.57.

Here is a suggestion: If you buy more than \$25 worth of books from Amazon.com, you receive free shipping. So for not much more than the cost of the book from the publisher, you can buy two - one for you and one for your doctor. If you don't have Internet access, you most likely have someone in your family, neighborhood, or circle of friends who does. Some groups are collecting for the book at meetings and someone, with Internet access, is buying them all at once.



**MARTHA'S CORNER**

News from Martha Chandley, PN resource  
extraordinaire

**Gluten Intolerance, Celiac Disease  
and Neuropathy**

**Speaker: Diane Craig, Support Group Leader of  
the Celiac Sprue Association, Chapter 24,  
P.O. Box 2873, Carmichael CA 95609  
(916)483-8546 [dcraig101@hotmail.com](mailto:dcraig101@hotmail.com)**

Ms. Craig is a wonderful and delightful model for coming to terms with any serious chronic illness, and especially **Celiac Disease (CD)**, one of whose 300 known symptoms is neuropathy. Having had the disease for 40 years, she was finally diagnosed some twenty years ago and has worked hard to educate herself and hundreds, perhaps thousands of others, about the mysterious condition through the Sacramento support group and many outreach activities at health fairs, etc. She was a great delight to get to know at the January meeting of the West Sacramento Neuropathy Support Group meeting. The following report is based on her report, a CSA brochure she provided and other materials from internet resources.

We now know that CD is a genetically linked autoimmune disorder triggered by eating grain-based proteins (such as wheat, rye, barley and possibly oats), causing gluten sensitive enteropathy. This is damage to the villi that helps with nutrient absorption in the

small intestine. The conditions afflict one in 130 undiagnosed Americans of all ages. The damage leads to malnutrition and other complications such as neuropathy, presumably because of nutritional deficiencies.

Because the symptoms are so diverse, there is no one typical celiac profile. In fact, there may be no symptoms at all, according to the CSA brochure, which also states that "The type and severity of symptoms seems to be related to the level of intestinal damage and length of time nutrient absorption has been abnormal." The symptoms can be physical or emotional and may also be found in many other chronic disease conditions.

**Following is a partial list of CD's physical**

**symptoms:** Abdominal/cramping/bloating or distention, Anemia, Appetite changes, Constipation, Decreased ability to clot blood, Decreased fat padding in the feet, buttocks and hands (common with some neuropathies), Dehydration, Delayed puberty, Diarrhea, Edema, Electrolyte imbalance, Fatigue, Flatus (passing gas), Gluten ataxia (failure of muscle coordination), Infertility/miscarriages, Mouth sores or cracked lips, Muscle cramping in hands and legs, night blindness, Osteopenia/osteoporosis, Pain in bones and joints, Smooth tongue, Stools that are foul smelling with abnormal color (ray or tan), Very dry skin, Weakness, Unexplained weight loss or gain. Emotional symptoms include depression, disinterest in usual activities, irritability, mood changes, and inability to concentrate. Some people with CD may also have Dermatitis Herpetiformis (DH) occurring on the skin and appearing as small, itchy burning blisters found at pressure points, such as ankles/feet, buttocks, elbows, face/neck, knees, sacra, scalp and shoulders.

CD tends to be the more common among those with autoimmune diseases such as Lupus (Erythematosis, Type 1 Diabetes, Rheumatoid arthritis, Autoimmune Thyroid Disease, and Microscopic Colitis., Some of the symptoms are common with Irritable Bowel Syndrome, Chronic Fatigue Syndrome and Fibromyalgia. Ms. Craig reported on a Kaiser Permanente physician who had discovered that some of his CD patients had the markers for Type 1 Diabetics but no diabetes, once they had gone off glutes, the markers disappeared. However, she also reported that some five percent of diabetics have CD and five percent of celiac.

If you are experiencing some of the above symptoms, and particularly if you've been diagnosed as having "idiopathic" neuropathy or have one of the

autoimmune diseases noted above, you may want to talk with your primary physician about initiating a diagnostic process, beginning with a complete physical exam and blood tests for gluten antibodies (specifically EMA and TTG) A second step might involve a small bowel biopsy, or skin biopsy in the case of suspected DH, to further confirm the condition.

**The only effective treatment is maintaining a gluten-free diet.** There is no real “going back” in the sense that a permanent life style change requires remaining free of all forms of gluten, whether obvious or “hidden” as in processed foods, medications, and personal care products. The good news is that the food industry has discovered a sizable niche market, producing many gluten-free products (even beer) in recent years that are increasingly found in major supermarkets and health food stores, such as Elliotts. Corn, rice and buckwheat, flax seeds, quinoa and millet are suitable grain alternatives. The extra costs of maintaining a gluten-free diet can be deducted on income tax as a valid medical expense! And once a gluten-free diet is initiated, the damaged villi in the small intestine can recover within 6 weeks, thus some, perhaps many of the CD symptoms can be reversed.

**Could CD related neuropathy symptoms also be reversed?** That’s probably not yet fully known, but it appears to be an ongoing research issue. **If one “googles” celiac disease and neuropathy**, one will find several articles, one of which is a presentation made by **Norman Latov, MD** (whose new book on neuropathy was reviewed in the January issue) **at the February 3, 2002 meeting of the Westchester Celiac Sprue Support Group**, Dr. Latov reported on his research he was conducting at the time, indicating that some 20-25% of those CD patients in his small sample had neuropathy. One of Dr. Latov’s research questions is whether those with CD and neuropathy who have maintained a gluten-free diet for an extended period of time would experience improvement in their neuropathy symptoms. One study of celiac and neuropathy patients given extra vitamin supplements found that they really didn’t get better. He also noted that textbooks on neuropathy do not mention celiac disease. The then recently formed Neuropathy Association published an article on the link in one of its early newsletters. The organizers were delighted to begin receiving many calls requesting more information from both patients and neurologists. The dialogue had begun!

Another good internet resource is a December 14, 2006, article from The Mayo Clinic which states that untreated CD can lead to such complications as malnutrition, loss of calcium and bone density, lactose

tolerance, cancer (especially intestinal lymphoma and bowel cancer), and neurological complications including seizures and peripheral neuropathy. The article had some excellent information on meal planning options and adapting recipes to become gluten-free.

Our fibro SGL/Advocate colleague, Sue Alexander, forwarded a fascinating article by Scot Lewey, MD regarding additional research done by Dr. H. finding TTG antibodies in the intestines and brains of blood test-negative CD. He concludes that gluten ataxia is a brain disorder characterized by balance disturbances not explained by any cause than ingestion of gluten. The disorder responds to a gluten free diet if irreversible brain damage has not already occurred. Dr. H has called for a new paradigm to be accepted where CD is no longer considered primarily as an intestinal disease.

Dr. Lewey states that many of his patients with gluten sensitivity describe symptoms of balance difficulty, concentration problems, “brain fog,” headaches, neuropathy and sensations of “bug crawling” and strange “muscle twitches.” He has found that these symptoms improved with a gluten-free diet and return with resumption of gluten exposure. (Those with idiopathic PN with the underlined symptoms might especially pursue CD diagnostic procedures.)

**Thanks so much, Diane Craig, for your fascinating presentation and your mission of educating people about Celiac Disease. Perhaps some of our PNers will soon be contacting you about your support group meetings. Thanks also for stimulating our further inquiries into the “celiac disease and neuropathy” connection.**

**(Note to Group Leaders: Diane will be available to speak to groups during the summer months. She is an after school daycare provider so not available for meetings during the school year. She spoke to the West Sacramento Neuropathy Group during a vacation week.)**

## **DIABETES RESEARCH**

A December 19 issue of **Diabetes in Control** had a fascinating article from the December 14 issue of the journal Cell reporting on a possible new way to prevent and reverse diabetes in mice. The Canadian researchers learned Type 1 Diabetes may be a disease of the nervous system and not just an autoimmune disease as had long been assumed. They found that pain receptors in mice don’t secrete chemical elements found in the brain to keep insulin producing pancreating islets working normally. By supplying the chemical element to diabetic prone mice, the research group learned how to treat the abnormally and even reverse established diabetes in mice!

