



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. 8

Hope through caring and education

August, 2007

NEUROPATHY AWARENESS DAY

JUDGED A GREAT SUCCESS

Dominick Spatafora, President of the Neuropathy Action Foundation, announced at the closing dinner that approximately 250 people attended the afternoon Health Fair. It was beyond his hopes and expectations. This was chiefly because members of NCCNA came from near and far to hear the speakers and to see the exhibits. Six people joined NCCNA at the NCCNA table.

Most comments about the day were glowing. People said "It was a great day." "I learned a lot about neuropathy." "I met so many people with neuropathy from other areas. There truly are a lot of us." "I found help in the exhibits that I will follow up on." Both Group Leaders and group members gained helpful information.

One question that came up regularly was "When will there be another such day." On or about June 26, 2008, will be the next Neuropathy Awareness Day. This time, it will be in Sacramento. NCCNA will be teaming with NAF to produce this conference. June 26, 2008, is a Thursday. Assemblymember Mary Hayashi has a bill going through the processes in the legislature to designate June 26, 2008, as Neuropathy Awareness Day.

HEALTH CARE RIGHTS

A SPECIAL EMPHASIS

The Neuropathy Action Foundation wants you to know they recognize how difficult it is for persons to navigate the health care system in today's complicated environment. The Neuropathy Action Foundation believes it is important that all persons with medical conditions understand that they have

many health care rights under the law to promote their ability to receive optimal medical care. Here is a summary:

Access to Care – You have the right to choose your physician and, if not satisfied, change to another provider, within your health plan's network of providers. You have the right to a timely appointment when you need one.

If you are in a Knox-Keene plan (HMOs and most Blue Cross and Blue Shield PPO's) you have the right to a standing referral to a specialist where your primary care physician and your plan's medical director believe that it is necessary. If the specialist that you want to care for you is not listed as being part of your health plan's network, you have the right to ask your plan for approval to see that specialist and have the plan cover the medical expenses you incur for such visits.

Continuity of Care – If your physician is no longer part of the plan or if you join a new plan that does not include your physician, you may be entitled to continuity of care with that physician depending upon your condition. Contact the plan to see how the law may apply to you.

Protection Against Drug Switches – If you are in a Knox-Keene plan, then you are protected from drug switches. The law provides that such plans may not limit or exclude coverage for a drug for an enrollee if the drug was previously approved for coverage for the enrollee's medical condition, if the patient's doctor continues to prescribe that drug for the enrollee, and

(continued to page 5)

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 st Monday, 1:30 PM	Woodside Village MH Park 12155 Luther Rd., Auburn	Neuropathy Info & Help Speaker: Bev Anderson	Terri Stennes, 916-663-3108 bridget@infostations.net
Auburn-Eve 1 st Monday, 7 PM	Sutter Auburn Faith Hospital 11815 Education Street, Auburn	Heather Perry, Auburn Chiropractor Anodyne & Chiropractic	Bev 530-389-2416 bj@foothill.net , Grant 530-887-9881
Berkeley 3 rd Monday, 6-8 PM 1 st Month of each quarter	Lutheran Church of the Cross 1744 University Ave., Berkeley	No meeting this month	Alan Dampsey, 510-527-3568 adampsey@comcast.net
Concord, 3 rd Tuesday, 1:30 PM	First Christian Church 3039 Willow Pass Rd., Concord	Neuropathy Help	Ernette Rivera, 925-889-2484 ernette5712@sbcglobal.net
Davis 2 nd Wednesday 2 PM	Institute for Restorative Health, 1460 Drew Ave. across from Kaiser	Diane Craig Celiac Sprue/Gluten Intolerance Sacramento Area Leader	Martha Chandley, 916-371-1125 kairoschandley@sbcglobal.net
Elk Grove 2 nd Tuesday, 2 PM	Elk Grove Senior Center 8830 Sharkey Ave, Elk Grove	Neuropathy Help r	Michael Colozzi, 916-421-8103 Susi Watson 916-354-0483
Folsom 2 nd Tuesday, 3:15 PM	Creekside Oaks Retirement Residence 1715 Creekside Drive.	Diane Craig Celiac Sprue/Gluten Intolerance Sacramento Area Leader	Lorraine 916-983-4023, Beverly 916- 984-4302
Grass Valley 2 nd Monday, 1:30 PM	GV United Methodist Church 236 S. Church St., Grass Valley	Neuropathy Help	Bev 530-389-2416 Betty Gears 530-432-7774
Jackson 3 rd Tuesday, 10 AM	Amador County Senior Center 229 New York Ranch Rd. Jackson	Neuropathy Help	Laurie 209-223-0442 Darlene 209-296-1760
Lincoln 3 rd Tuesday, 1 PM	Raley's Event Center 765 S. Hwy 65, Lincoln	Diane Craig Celiac Sprue/Gluten Intolerance Sacramento Area Leader	Joe Facha 916-408-2007 Lavern 916-408-2007
Livermore 4 th Tuesday, 10 AM	Heritage Estates 900 E. Stanley Blvd.	Neuropathy Help	E. Lorene Stack 925-447-6158
Monterey 3 rd Wednesday, 10:30 AM of odd numbered months	First Presbyterian Church 501 El Dorado St.	No meeting this month	Don & Ann Trout 831-372-6959
Napa 1 st Thursday, 2 PM	Napa Senior Center 1500 Jefferson St., Napa	Neuropathy Help	Ron Patrick 707-257-2343 bonjournapa@aol.com
Placerville 4 th Wednesdays., 1:30 PM	Placerville Senior Center 937 Spring St., Placerville	Love Miller CA Telephone Access	Arlene Middlebrook, 530-626-1098
Redding, Restarting soon			Bev Anderson (530)389-2416
Redwood City, 1 st Tuesday, 2 p.m.	Bakers Square Restaurant 949 Veteran's Blvd., Rdwd Cty	No meeting this month	Annette Devost 650-595-2478
Reno, NV 2 nd Tuesday, 6:30 PM	Fire Station #11 7105 Mae Anne Ave., Reno	Neuropathy Help	Marsha Campbell 775-851-0499 LadyJane2b@sbcglobal.net
Roseville 2 nd Tuesday, 7 PM	Point West Sr. Res., 5161 Foothills Blvd., Roseville	Diane Craig Celiac Sprue/Gluten Intolerance Sacramento Area Leader	Marilyn Larson 916-771-8435
Sacramento 3 rd Tuesday, 1:30 PM	Northminster Presby. Church 3235 Pope Street, Sacramento	Celiac Sprue Experience & Research Speaker: Myke Taylor	Anne Fletcher 916-391-3317 Myke Taylor 916-487-2903
San Francisco - Call Amy Mahoney to be sure of the meeting day and time.	UC-San Francisco Med Ctr. Amb. Care Ctr. 8th Flr. , Rm A888, San Francisco	Neuropathy Help	Amy Mahoney, 415-353-2312 amy.Mahoney@ucsfmedctr.org

Group/Date/ Time	Place	Program	Contact
San Jose 3 rd Saturday, 10:30 AM	O'Conner Hospital, 2105 Forest Ave, SJ DePaul Conf. Rm., San Jose	Neuropathy Help	Stan Pashote (510)490-4456
Santa Cruz - Call Mary Ann for date and time.	Life Oak Senior Center, 1777 Capitola Rd., Santa Cruz	Neuropathy Help	Mary Ann Leer. 831-477-1239 MALEER@SURFNETUSA.COM
Santa Rosa, 1 st Thursday, 10:30 AM	Santa Rosa Senior Center 704 Bennett Valley Rd, SR.	Neuropathy Help	Ginger Minnich, 707-829-2934
Sonora. Meeting 4th Monday, 2-4 PM	Sonora Regional Medical Center Conference Room	Neuropathy Help	Ed Minium (209)586-3702
Stockton 3 rd Tuesday, 4 PM	Central United Methodist Church 3600 Pacific Avenue.	No Meeting in July or August	Mary & Case Klooster (209)463-5985
Walnut Creek 4 th Friday, 10 AM	Rossmoor, Hillside Clubhouse Las Trampas Room, Walnut Creek	Dr. Jonathan Katz, by video	Nancy Ostrander (925) 930-9524
West Sacramento 3rd Wednesday, 2:00 PM	AF Turner Branch, Yolo County Library, 1212 Merkley Ave. WS	Diabetic Neuropathy Speaker: Martha Chandley	Sandra Vinson, 916-372-6093 slvins11@charter.net
Woodland 1 st Monday, 4:30 p.m.	Woodland Senior Center 610 Lincoln Ave, Woodland	Neuropathy Help	Delia Genera 530-661-3238
Yuba City 2 nd Monday, 7 PM	Sutter Estates 1230 Plumas Street, Yuba City	Neuropathy Help	Nancy Escudero, 530-673-3608 nancychristina1@yahoo.net

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

One of the best experiences for those that traveled to the Neuropathy Awareness Day in San Francisco on the bus that started in Auburn was meeting those on the bus. People from the groups in Auburn, Roseville, Sacramento, Placerville, West Sacramento, and Davis boarded. Ideas and helps were exchanged and friendships developed.

**JUST A FEW TICKETS LEFT
TO THE RIVER CATS GAME
ON SUNDAY, AUGUST 5**

Here is another opportunity to meet people with neuropathy and those that care about them. For an evening of entertainment and fun, send your check for \$15 to NCCNA, P.O. Box 6985, Auburn, CA 95604. You may have friends or family that

would enjoy this game, taking advantage of the \$2 discount on the ticket. It starts at 6:05 p.m. and takes approximately 3 hours to play. (The \$2 has been paid by an NCCNA member. It will go to The Neuropathy Association for research.)

The River Cats Stadium is unique in its commitment to build and maintain this facility as handicap accessible. It has accommodations specially designed to make it convenient for people in wheelchairs and scooters, for example. We honor them by choosing to come to take advantage of these. They show their appreciation by listing us in the program and putting our name on their flash screen that lets people know who is there. We hope to also display our bus posters to be sure people know how to contact us.

This is something that is happening in Sacramento. We encourage groups in other areas to get together with one or more groups for a fun event. If it can raise some funds for research, so much the better.

(President's Report Continued)

On June 22, I had the pleasure of having dinner with Tina Tockarschewsky, Executive Director of The Neuropathy Association and Dr. Norman Latov, New York neurologist, co-founder of The Neuropathy Association and current member of the Board of Directors as well as the author PERIPHERAL NEUROPATHY. This was at The Inn at Red Hawk in Sparks, Nevada, site of the David Loeb Memorial Golf Tournament. This annual event helps support The Neuropathy Center at the University of California at San Francisco. A check for \$50,000 was presented prior to the receipts from the silent auction and the regular auction of major items being totaled.

Tina has served as Interim Executive Director for some months and was just that week hired by The Neuropathy Association Board of Directors as the Executive Director. She was born in New York City, grew up in New Jersey, and currently lives in New York, is relatively young, and quite energetic. Her background is marketing for the banking industry. A more complete bio will be available soon.

PERIPHERAL NEUROPATHY

by Dr. Norman Latov

SOON AVAILABLE FOR \$10

At the dinner, Dr. Latov told me that he was receiving quite a few books from the publisher and would give us 100 to sell at \$10 each to assist our organization. I delightedly accepted as this is a very helpful book. It is especially good for giving to doctors and placing in libraries as it is written by a neurologist who specializes in peripheral neuropathy.

These books are due to arrive soon. As soon as they do, they will repose in the back of my vehicle for sale wherever I go. For a check for \$12 each, I'll even ship a copy. These books are available for \$10 plus shipping on The Neuropathy Association website www.neuropathy.org as well. They are in the Bookstore.

As I've told a good number of people, with 17 pages of the book being given to listing the causes of peripheral neuropathy, it is worth the \$10 for the information available there alone. It is information that may awaken physicians to the

prevalence of peripheral neuropathy and diagnoses they are unfamiliar with. I encourage individuals and or support groups to buy these to place in public libraries and medical libraries in their area. Individuals will want to buy one for themselves and possibly for one or more doctors they see.

THE NEUROPATHY ASSOCIATION'S NEW BROCHURE IS INCLUDED THIS MONTH

Once a year, we like to include the brochure of our parent organization and encourage those that are able to join The Neuropathy Association as well. Their newsmagazine comes out about 4 times a year. TNA's focus is on support for support groups, especially unincorporated groups that are basically on their own otherwise. However, they are chiefly known for funding research projects that are showing promise and testifying at Congressional Committee hearings relating to distribution of funds for research and other relevant topics.

NCCNA'S NEW BROCHURE INCLUDED WITH THIS NEWSLETTER

You will also notice a copy of our new brochure using the graphic from the bus poster. It also uses one of the shades of red on the poster. This is your copy but be free to give it away if you find someone who needs it. A small supply has been sent to each group leader.

We ask each group to think of the many places in your area that these can be placed and come up with an amount that would be needed to do this. We plan to write a grant that will hopefully come through and fund enough brochures to accomplish this distribution.



(Continued from page 1)
the drug is appropriately prescribed and considered safe and effective for treating that condition.

In this case, you are protected to have continuity of care. If your plan tries to switch drugs, you can protest that with a letter as along the lines of the “Getting Your Medications” listing on the NAF website.

Second Opinions – You have the right to have the health plan pay for a second opinion by and “appropriately qualified health care professional” when appropriate, such as where you question a diagnosis or treatment plan for a serious chronic condition.

Consent – You have the right to consent to all medical treatment prior to it being performed. Further, you have the right to meaningful information to make that consent informed. Thus, except for “simple and common procedures” involving risks that are commonly known, prior to being treated, your physician must explain to you all material information to your decision as to whether to proceed. This includes:

- The nature of the recommended treatment
- The risks, complications and expected benefits of the recommended treatment, including the likelihood of success, and
- Any alternatives to the recommended treatment, including the alternative of no treatment and their risks and benefits.

Medical Information – You have the right to obtain a copy of your medical records, though your provider may charge you for the copying. You have the right to confidentiality with respect to your medical information though the law does provide some necessary exceptions.

Appeal – If your plan will not cover a service or drug you need or, even places the drug in a co-payment tier that makes it unaffordable to you to obtain, you can appeal that decision, or ask your physician to appeal to the plan on your behalf. Depending on the plan, this can be done by phone, fax or even the plan’s website.

Ask For an Independent Medical Review – You have the right to ask for an independent external medical review of any plan decision to deny, modify or delay treatment based on lack of medical necessity. There is no fee that you will be required to pay when seeking this review.

Complain to the Regulator – If your plan is not providing the rights that by law you are entitled to, you may wish to complain to the appropriate regulatory body. If the plan is a Knox-Keene plan, it is regulated by the Department of Managed Health Care. The department has a toll-free telephone number (888) HMO-2219 and a TDD line (877) 688-9891. The department’s internet website has complaint forms and instructions as to how to lodge a complaint with them. See http://www.dmhc.ca.gov/dmhc_consumer/pc/pc_complaint.asp

The current Department of Insurance complaint program includes a toll-free number dedicated to the handling of complaints and inquiries. Dial (800)927-HELP (4357) for all areas of California except area codes 213, 310, and 818 for which you should dial (213) 897-8921; the TDD line is (800) 482-4833. The Department also provides a simple standardized complaint form. This form is available online at www.insurance.ca.gov/docs/FS-RFA.htm.

For further information about advocacy for your medical patient rights go to www.neuropathyaction.org

The Northern California Chapter of The Neuropathy Association’s chief focus is developing support groups, providing information, connecting with the health care community to bring them information about neuropathy, and encouraging research. The Neuropathy Action Foundation’s chief focus is patient advocacy, informing the decision makers about neuropathy the need for and patient care and protection, and direct education of physicians about neuropathy. We can team together to make a difference.

Have leg or foot cramping? Eat more bananas. They contain magnesium that may help ward off the cramping.



MARTHA'S CORNER

News from Martha Chandley, PN resource
extraordinaire

Nutrition for Health Aging

Kevin Mould, MD, Woodland Healthcare,
2330 West Covell Blvd., Davis, 530-756-2364
Diplomate of American Board of Family Practice,
B.S in Nutrition and Food Science

Dr. Mould's marvelous May talk in Woodland provided an excellent introduction to critical nutrition issues for those of us who are aging. We are most grateful for his nutrition 101 lecture and sharing his power point presentation for this report. It's certainly refreshing to have access to a general physician who knows and cares about nutrition issues. Such is rare indeed, much to our detriment.

Our bodies undergo some critical changes as we begin to age that cause problems for and with our food consumption. Being less active slows our metabolism and we experience bone density losses.

Our tastes and appetite may change and we may have dental problems compounding proper eating problems. Gastrointestinal motility decreases as does our stomach acid production. Depending on our activity levels, our need for calories decreases, as with a low for women of 1600 and 2000 for men; or 2200 for active women and 2800 for active men. But for overall good health we all need to remain physically active as much as possible.

If we have specific chronic conditions like diabetes or heart problems, we will likely need individualized dietary considerations with special eating plans. But virtually everyone will need to emphasize high fiber whole grains; dark green, orange or yellow vegetables; whole fruits (rather than juices); low-fat dairy products; lean meats, skinless poultry and fish; and main dishes of beans, grains and vegetables.

We need a great variety of foods in our meals, but we generally need to lessen our intake of sugar, salt and alcohol, foods with refined sugars and high levels of saturated fats, and cholesterol.

Fats are a major contributor of obesity and are the major risk for heart disease and stroke. Too

much salt elevates our blood pressure and fluid retention. We need no more than 1500 mg, or about 2/3 of a spoonful per day. (*We can get half that much with just one cup of **most canned soups!***) Learning to read canned and packaged food labels alerts us to problem areas on these issues. The answer is to maximize use of herbs and spices in cooking and avoiding processed foods, whether canned or packaged.

Lots of fluids, preferably water is essential. Indeed the base of the Food Guide Pyramid for Persons 50+ prescribes eight glasses of water per day. And we should consider taking supplements of calcium, Vitamin D and Vitamin B12. Because our aging stomachs produce less acid, nutrients from our food are poorly absorbed, causing a B12 (and B6) deficiency that is a major cause of neuropathy. But there are other deficiencies we need to be concerned about:

Vitamin A – poor vision, night blindness, dry eyes

Vitamin C – scurvy and anemia

Vitamin D – osteoporosis, muscle weakness (we need 1200 mg/day of calcium and Vitamin D to increase absorption)

Vitamin E -- peripheral neuropathy, muscle weakness

Vitamin K – impaired blood clotting

Folate – anemia, possible relationship to Alzheimer's disease

Niacin – high cholesterol, atherosclerosis

Selenium – muscle weakness

Zinc – eczema, poor wound healing.

Aside from taking multi-vitamins/minerals on a daily basis, eating a broadly varied diet of whole grains, fresh fruits and vegetables, beans and lean meats can help avoid these deficiencies and their life style limiting and health denying consequences.

Because gastro-intestinal problems are common with the aging, and particularly for those with autonomic neuropathy, constipation is a constant problem for some. Insufficient fluid and fiber intake slows the GI tract's processing our foods and elimination of waste materials. So we have fewer bowel movements, experience bloating and other abdominal discomforts. Common first line treatments include sufficient fluid and fiber intake, stool softeners and stimulants as needed. Anyone taking several pain medications to keep going, needs all the help they can get with this chronic problem.

GENE THERAPY OFFERS NEW HOPE FOR TREATMENT OF PERIPHERAL NEUROPATHY

Abstract

Researchers from the University of Pittsburgh School of Medicine report that they have successfully used gene therapy to block the pain response in an animal model of neuropathic pain, a type of chronic pain in people for which there are few effective treatments. These findings were being presented at the 10th Annual Meeting of the American Society of Gene Therapy, held May 30 to June 3 at the Washington State Convention & Trade Center, Seattle.

Complete Article

11 Jul 2007

Neuropathic pain is the result of damage to nerve fibres caused by injuries or diseases, such as diabetes and cancer. These damaged nerve fibres continue to send signals to pain centres in the brain even after the surrounding tissue has healed. Unfortunately, neuropathic pain often responds poorly to standard pain treatments and occasionally may get worse instead of better over time. For some people, it leads to serious, long-term disability and dependence on pain medications that have a variety of unwanted side effects, including addiction.

The Pitt research team, led by Joseph Glorioso, III, Ph.D., chair of the department of biochemistry and molecular genetics, University of Pittsburgh School of Medicine, used a genetically engineered herpes simplex virus (HSV) to deliver the gene for part of the human glycine receptor (GlyR), a receptor found primarily on the surface of nerve cells in the spinal cord and the lower brain but not in the nerves in the limbs, to the paws of rats. A group of control rats received only the HSV vector without the inserted gene. After the delivery of the therapeutic gene or empty vector (for the control group), the researchers injected the same paws of each rat with formalin, an irritant known to simulate the symptoms of a peripheral neuropathic pain at the site of injection. Following formalin injection, the rats were then given an injection of glycine to activate the GlyR receptor.

Both control and GlyR-HSV-infected rats showed a typical pain response to formalin. However, the application of glycine eliminated the pain response in GlyR-HSV infected animals, while it had no effect on animals infected with vector only. This alleviation of the pain response in GlyR-HSV-treated mice was reversed by the subsequent addition of low concentrations of strychnine, a strong GlyR-specific inhibitor, or antagonist.

According to Dr. Glorioso, these findings suggest that

HSV-directed expression of GlyR in peripheral neurons and subsequent selective activation by glycine has the potential to be used therapeutically not only for neuropathic pain management but a variety of pain syndromes.

"The inability to effectively manage neuropathic pain associated with injuries and illnesses is a growing national and international problem. Gene therapy offers a more targeted, less toxic approach for effectively managing this condition. It also is our hope that targeted transgene delivery of GlyR may have even broader implications for managing a number of chronic pain syndromes, including pain resulting from shingles, arthritis and cancer," explained Dr. Glorioso.

In addition to Dr. Glorioso, others involved in the study included Michael Cascio, Ph.D., James Goss, Ph.D., David Krisky, M.D., Ph.D., and Rahul Scrinivasin, M.D., Ph.D., all with the department of molecular genetics and biochemistry, University of Pittsburgh School of Medicine.

(Source: 10th Annual Meeting of the American Society of Gene Therapy: University of Pittsburgh Medical Center: July 2007)

AARP OFFERS DRIVING CLASS

55 Alive is a special course for those age 55 or older. It reviews portions of the current DMV Driver Handbook and provides a number of ways to improve driving skills and driver safety. Knowledgeable volunteers teach the course. It can also be taken on line at www.aarp.org/drive but one needs more than a dial-up connection or it loads too slowly.

Besides the good information and encouragement, it can produce a sizable deduction in one's auto insurance premium. One other portion that is presented is a look at the point in time that one best chooses not to continue to drive. No specific application is made to anyone so it is as comfortable as that subject can be. It actually can be encouraging.

To find out where the course is or will be given in your area, call 1-888-227-7669 or visit the website www.aarp.org/drive

If you are paying for a medication with no insurance help, always check the COSTCO price. You don't have to belong to use the pharmacy. They usually have the lowest price.

Diane Craig reports she read that 51% of celiacs also have nerve disease and/or PN.

THE GLUTEN CONNECTION: How Gluten Sensitivity May Be Sabotaging Your Health: And What You Can Do to Take Control NOW (published 2007 -ISBN-13: 978-1-59486-387-5)

Author: Shari Lieberman, PhD, CNS, FACN, a practicing clinical nutritionist and current board member of the Certification Board for Nutrition Specialists. www.drshari.net with Linda Segal award-winning writer and editor.

Foreword: Stephen T. Sinatra, MD, FACC, FACN, CNS, specialist in preventive and metabolic cardiology

Report by Myke Taylor-- Co-leader Sacramento Peripheral Neuropathy Support Group

This book published in 2007 is a real eye-opener even though I have been on a gluten free diet for approximately 10 years. Even though a laboratory test at Kaiser didn't indicate I had Celiac Disease, I've adhered to the diet, by eliminating wheat, oats, barley and rye because my digestive symptoms disappeared. (Oats do not contain gluten but are processed by machines that also process the gluten grains.) It turns out that Celiac Disease is the end stage of Gluten Sensitivity and does not show up on blood test until Celiac Disease is full blown.

The book is well documented with many studies of this affliction. Some of the interesting information follows: Silent inflammation is the main factor in the development of cardiovascular disease, gastrointestinal problems, diabetes, cancer, Parkinson's disease, and other neurodegenerative diseases as well as insidious food intolerances such as "leaky gut," "irritable bowel," Chron's disease type syndromes that cause immune-system dysfunctions, such as lupus and rheumatoid arthritis, as well as osteoporosis, multiple sclerosis, chronic fatigue syndrome, and some forms of dermatitis and psoriasis that can slowly undermine our health--all of which affect the heart.

Many of our medical professionals sadly are not as aware as one might hope. Most doctors think in terms of Celiac Disease being a rare disease rather than the final stage of Gluten Sensitivity. Another

clue is that it's genetic and it has been observed that women are more vulnerable than men. Northern Europeans have a higher incidence of celiac disease than African Americans or Asians. Researchers have discovered that Celiac Disease afflicts just under 1% of the population in the USA but that 29% of the population are Gluten Sensitive-- nearly 3 out of 10 people!

The author, Shari Lieberman, also gives a brief history of the development of Gluten Sensitivity. Unfortunately, the human genome hasn't changed. And with the arrival of the industrial revolution, modern man refined wheat and added "vital gluten" so that the food we get at the grocery store today is processed to contain more gluten than at any time in history.

In our digestive process, food is churned in the stomach and mixed with gastric juices into a sloppy kind of soup, which then passes into the small intestine where it is absorbed by finger like projections called villi, which in turn pass the nutrients to the bloodstream. That which cannot be absorbed passes to the large intestine and is eliminated. If you are Gluten Sensitive, your digestive system does not have the ability to break down gluten into soluble proteins (amino acids). When the gluten gets into your bloodstream in this "raw" form your body forms antibodies to combat it. As your body valiantly but unsuccessfully tries to break down the invader gluten, the lining of the intestine becomes inflamed and the villi become flattened and the antibodies that formed to fight the gluten also pass into the bloodstream. Unfortunately, this does not show up in the currently commonly used blood test until you actually have Celiac Disease. And is not routinely used by most American doctors to screen their patients (Chapter 10).

The author devotes a chapter to explaining the difference between an allergy and an intolerance to explain that Gluten Sensitivity is not an allergy but a food intolerance. A major difference is that while an allergic reaction can sometimes evoke a violent effect it does no long-term damage to organs. Food intolerance reactions, on the other hand, are insidious, and the long-term effects on organs throughout the body can be devastating, even leading to premature death.

HAVE YOU SEEN OUR WEBSITE LATELY? Penni Smith, Webmaster

Have you visited the NCCNA website—www.pnhelp.org—recently? On June 25, the entire site was revised with a new look and new content. In addition to aesthetic changes, including incorporating NCCNA's new graphic, font, and slogan, the site features many new areas of content, and will be expanding over time.

Some of the key features of the new site include:

- A section devoted entirely to our support groups

There is a revised page with current meeting times, locations, and contacts for all our support groups, so newcomers can easily find one near them. Also, groups can submit their upcoming events, such as speakers or other activities, so both members and new people can find out what is happening.

- Current and recent events

See what's going on for the NCCNA, and check out recent events. Take a look at the photos and overview of the Neuropathy Action Awareness Day event that many of us attended, for example.

- A solid overview of neuropathy

This should be a good reference for people to gain a basic understanding, a place you may want to send your family and friends to look at. This may expand over time.

- Availability of all NCCNA documents

Access or download our new brochure, common handouts, and older copies of our newsletter.

- Other resources

Links and references to other good sources of information are available on the Resources page.

- Key NCCNA information

Find out about how the NCCNA came to be, who is on the board of directors, our vision, and our association with other organizations.

Some of our future plans include providing some articles about ways to handle the challenges of life with neuropathy, and portraits of how people are overcoming obstacles; in short, anything that will provide inspiration and hope to people struggling with neuropathy. If you know of someone who could be profiled, please pass on that information. And don't be bashful—if you think you have something helpful or inspirational about yourself, that's great too.

We are also looking for more information on things people find helpful, any research or news about neuropathy, and other general information. If you have ideas or information, please pass it along. (Please note that all material will be reviewed for appropriateness, and posting will be subject to approval by the Board. Also, items may be edited for content or consistency.)

So visit our new site, and come back frequently to see what's new. Refer your family and friends to it, and remind people of it in your meetings. Also, we'd love to hear your thoughts on the site and any ideas you may have. Send comments to webmaster@pnhelp.org or use the contact form on the site.

The Northern California Chapter of The Neuropathy Association

(a California public benefit, non profit,
tax exempt corporation)

P.O. Box 6985, Auburn, CA 95604
(530)389-2416 info@pnhelp.org
www.pnhelp.org

Dues - \$24 a year (due each January)
(prorated for new members at
\$2 per each month left in the year)

Board of Directors

Bev Anderson	Laura Niznik
Penni Smith	Sandra Vinson
Dick Ward	Grant Whitney

**We are supported by dues paying members,
contributions by members and friends, and,
occasionally, small grants.**

All contributions are tax deductible.