



WESTERN NEUROPATHY ASSOCIATION

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Issue 8
Volume 13

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WESTERN
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www.pnhelp.org

Neuropathy Hope

Hope through caring, support, research, education, and empowerment

A newsletter for members of Western Neuropathy Association (WNA)

■ DRIVING WITH HAND CONTROLS By Bev Anderson

Many of you know that this past year my neuropathy advanced to the point that I decided to get hand controls for my car. I wanted to make this a separate story so it would be one you could refer to and send to others you may find that need to know the information. Leaders can make copies to have as resource for their group attendees.

My neuropathy is hereditary but responds much the same as neuropathy from other causes. This is rather common as neuropathy symptoms can be similar to others even though the cause is different. Whatever the cause, it damages the Peripheral Nervous System. The Peripheral Nervous System responds in much the same ways no matter the causal agent. It is like a cut on the skin. There

are numerous ways for it to happen but you have basically the same experience with the result. The neuropathy I have has progressed rather slowly over the years with different symptoms taking the lead at different times of my life.

In the past several years, I noticed I was not as comfortable driving with this past year becoming rather challenging. My right foot could find the gas pedal but it became more and more of a problem on the brake. It got so I might find the brake and feel the pressure but I would lose comprehension of pressure. The longer I had to wait at a stop light, the worse it was. I got so I used the emergency brake (hand brake) to hold the car until I was ready to start again.

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■ WHAT ABOUT THE ADS SAYING THEY CAN CURE NEUROPATHY?

By Bev Anderson

A number of people have asked me about the big ads, chiefly by chiropractors, that say they can cure neuropathy. These ads are a highly persuasive approach that is often accompanied by strong sales tactics once you give them an opportunity. A large amount of money is usually requested up front, and there usually aren't guarantees of the services or money back offers if it doesn't work for you. The average up front amount I've heard about lately is \$8,000. If you are not able to pay it, you would most likely be offered a credit opportunity to make payments, which likely will continue longer than you would receive treatments. I know for sure of this happening to one person.

Over the years since this approach started, we have had people in our groups try the products. Sometimes a person feels there is help for a while, but it doesn't last*. Some of our people have finished the treatments with no noticeable difference with no money refunded. Others have actually been hurt. I talked to one couple who had each paid \$7,500 who received cuts and bruises from some of the equipment used in their treatment. They said they were actually worse off after the treatments concluded.

I have spoken to the Attorney General's office. They said that if a person has a problem with this kind of a group, they should retain their own attorney to

sue. One Sacramento practitioner has patients join a religious group he has formed and then has them promise not to go to legal authorities, but submit to the tribunal of the religious group if they have a problem. Since the owners of the practice also own the religious group, the person has relinquished rights to protection. The Attorney General of each state now has a complaint form. If you have tried any of these people/treatment and have not gotten permanent relief, go to the website of the Attorney General office of your state and file a report form or call and ask that a form be sent. If you have any of these pop up in your area, please cut out the ad from your paper and send it to me. I am putting together a collection/report. Use the address on the back page of this newsletter.

On another note, we have found lately some companies are claiming to have a "medical supervisor." An M.D. is listed as the responsible person. He or she may be in another state and visits the 'clinic' from time to time. We had experience with one that initially had Medicare coverage. People who started the treatments reported feeling much better and we thought we had finally found an effective treatment. Medicare stopped covering the service requiring patients to pay out of pocket for the treatments. The service converted to requiring

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Roster of Our WNA Information and Support Groups

2015 WNA Board of Directors

Bev Anderson
President

Karen C. Polastri, IOM
Vice President

Pam Hart
Secretary

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Treasurer

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Emeritus

Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.

Bev Anderson
Editor

Newsletter Design by

 Diane Blakley
Designs

CALIFORNIA

Alturas

For information call:
Bev Anderson (877) 622-6298

Antioch-Brentwood

3rd Wednesday, 2 PM- odd numbered months
Antioch-Kaiser
AMC-1H2 (from hospital lobby)
Bev Anderson 877-622-6298

Auburn

Next Meeting Oct. 5
1st Monday, 11 AM
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

Bakersfield

For information call
Bev Anderson 877-622-6298

Berkeley-Oakland

3rd Wed., 3-4 PM
North Berkeley Senior Center
1901 Hearst Ave.
Kathleen Nagel (510) 653-8625

Carmichael - Eskaton

2nd Tuesday, 1:30 PM
Eskaton, 3939 Walnut Ave.
Karen Robison (916) 972-1632
*Call Karen before coming as it is a gated
community and sometimes the day/time
changes. She welcomes newcomers!*

Carmichael - Atria

3rd Thursday, 6 PM
Atria, El Camino Gardens
2426 Garfield, Ave.
Tanysha Kaye (916) 488-5722

Castro Valley

2nd Wednesday, 1:30 PM
First Presbyterian Church
2490 Grove Way (next to Trader Joe)
Judson Leong (510) 581-6697

Clearlake

For information, call
Bev Anderson (877) 622-6298

Concord

Next meeting Sept. 17
3rd Thursday, 1:30 PM
First Christian Church
3039 Willow Pass Road
Wayne Korsinen (925)685-0953

Crescent City

For information call:
Bev Anderson (877) 622-6298

Davis

Next meeting Sept. 8
2nd Tuesday, 3:30-5:00 PM
Davis Senior Center
646 A Street
Mary Sprifke (530) 756-5102

Elk Grove

2nd Tuesday, 1 PM
Elk Grove Senior Center
8830 Sharkey Avenue
Roger White (916) 686-4719

Eureka

For information call:
Earlene (707) 496-3625

Folsom

3rd Monday, 1:00 PM- odd numbered months
Journey Church
450 Blue Ravine Rd.
Bev Anderson (877) 622-6298

Fort Bragg

For information call:
Bev Anderson ((707) 964-3327

Fresno

3rd Tuesday, 11:00 AM
Denny's Restaurant
1110 East Shaw
Marvin Arnold (559) 226-9466

Garberville

For information call:
Bev Anderson (877) 622-6298

Grass Valley

Next meeting Sept. 14
2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church Street
Salli Hearn (530) 268-1017

Jackson

For information, call
Bev Anderson (877) 622-6298

Lakeport

Lakeport Senior Center
507 Konocti Ave.
Mito Shiraki (707) 245-7605

Lincoln

For information call:
Bev Anderson (877) 622-6298

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
Sandra Grafrath (925) 443-6655

Madera

For information, call
Bev Anderson (877) 622-6298

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeister Center across the
street from the church)
Larry Frice (209) 358-2045

Modesto

Next meeting, Sept. 21
3rd Monday, 10:30 AM
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Monte Schrader (209) 531-3838

Monterey

Next meeting, Sept. 16
3rd Wed., 10:30 AM-odd numbered months
First Presbyterian Church
501 El Dorado Street
Don & Ann Trout (831) 372-6959

Napa

1st Thursday, 2 PM
Napa Senior Center
1500 Jefferson Street
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Oxnard

For information call:
Bev Anderson (877) 622-6298

Placerville

For information, call
Bev Anderson (877) 622-6298

Quincy

1st Thursday, 1 PM
Our Savior Lutheran Church
298 High St.
Stacey Harrison (530) 283-3702

Redding

For information call:
Tiger Michiels (530) 246-4933

Redwood City

4th Tuesday, 1 PM
Sequoia Hospital Health and
Wellness Center
749 Brewster Avenue
Stan Pashote (510) 490-4456

Roseville

Next meeting September 9
2nd Wednesday, 1PM - odd numbered months
Sierra Point Sr. Res.
5161 Foothills Blvd.
Carol Brosk (916) 531-2752

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Charles Moore (916) 485-7723

Salinas

Contact Bill Donovan (831) 625-3407

San Francisco

4th Thursday, 10 AM
UC-San Francisco Med Ctr.
400 Parnassus Avenue
Amb. Care Ctr. 8th Flr., Rm A888
Y-Nhy (e nee) Duong
Nhy-y.duong@ucsf.edu

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital
2105 Forest Avenue
SJ DePaul Conf. Rm.
Stan Pashote (510) 490-4456

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Avenue
Scott Stokes (415) 246-9156

Santa Barbara

4th Saturday, 10AM- odd numbered months
The First Methodist Church
Garden & Anapamu
Shirley Hopper (805) 689-5939

Santa Cruz

3rd Wednesday, 1PM- odd numbered months
Trinity Presbyterian Church
420 Melrose Avenue
Mary Ann Leer (831) 477-1239
maleer@comcast.net

President's Message

By Bev Anderson



The last changes in moving from our former name to The Western Neuropathy Association are now accomplished. New copies of most materials are now out. Any place that you still see The Pacific Chapter or PCNA listed, please let us know. Group leaders have received new brochures and updated information including a copy of our letter from the IRS tax exemption letter with the new name.

If you or someone you know are on Facebook or Twitter, be sure to connect with the WNA sites. Board Director Pam Hart keeps up the Facebook page at www.facebook.com/neuro. Board Director Johnathan Istilart converses with people @Neuropathy_WNA. He has some medical personnel who follow him so you may find the interaction very interesting. I suggest you give it a try. (If you aren't on Facebook or Twitter, ask your grandchildren to help you get started.)

You will soon be receiving a letter from me as will everyone on our data base. The P.S. under my signature lets you know what membership status you currently hold.

- You will likely receive the one that congratulates you on being a paid member and being a great help to The Western Neuropathy Association. It will also encourage you to make a donation if you are able to do so. Many times people give to a variety of agencies or a favorite one and forget that this organization survives on the contributions of members and friends. Once in a while we receive a small grant. We receive no funds from governmental agencies.

- If your dues are due in July, August, or September, you will receive a reminder so you can renew and, if you choose, make a donation along with it.

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WNA Information and Support Groups – continued from page 2

Santa Maria

For information call
Bev Anderson (877) 622- 6298
or Mary (805) 344-6845

Santa Rosa

1st Thursday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Larry Metzger (707) 541-6776

Sonoma

For information, call
Bev Anderson (877) 622-62988

Sonora

For information, call
Bev Anderson (877) 622-6298

Stockton

For information, call
Bev Anderson (877) 622-6298

Susanville

For information call:
Bev Anderson (877) 622-6298

Thousand Oaks Region

For information, call
Bev Anderson (877) 622-62988

Truckee

For information call:
Bev Anderson (877) 622-6298

Tulare-Visalia

For information call
Bev Anderson (877) 622-6298

Turlock

Next meeting Sept. 21
3rd Monday, 1 PM
Covenant Village Adm. Bldg. Classroom
2125 N. Olive St.
Joanne Waters (209) 634-0683

Ukiah

Next meeting, Sept 29
Last Tuesday, 5:30 PM
North Coast Opportunities (NCO)
413 N. State St.
Shirley Blattner (707) 621-0208
Carole Hester (707) 972-2795

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse
Las Trampas Room
David Woods (925) 287-8100

West Sacramento

No meeting until new leader is found
Sandra Vinson (916) 372-6093
slvins11@gmail.com

Woodland

Next meeting, Sept. 8
2nd Tuesday, 1:00 PM
Woodland Comm & Senior Center
2001 East Street
Elizabeth Chaudhry (530) 661-3859

Yreka

For information call
Bev Anderson (877) 622-6298

Yuba City-Marysville

Next meeting, Sept. 8
2nd Tuesday, 10:30 AM
St. Andrew Presbyterian Church
1390 Franklin Rd.
(next to Winco Shopping Center)
Ken Lux (530) 673-3479

NEVADA

Reno-Sparks

For information call
Bev Anderson (877) 622-6298

OREGON

Brookings

For information, call
Robert Levine (541) 469-4075

Grant's Pass

No meeting in August
3rd Wednesday, 10:30 AM
Three Rivers Medical Center
500 S.W. Ramsey Ave.
Carol Smith (541) 955-4995

Medford

For information, call
Bev Anderson (877) 622-62988

Portland

For information call
Bev Anderson (877) 622-6298

Salem

Next meeting, Sept. 21
3rd Monday, 6:30 PM
Community Health Education Center
Salem Hospital Campus, Bldg. D
890 Oak Street SE
Michael (503) 857-3508
newsofsalem@gmail.com

Help With Health Care Challenges

If the number is not in your area, call the one listed and ask for the right number.

Medicare

www.Medicare.gov

•••

The Affordable Health Care Act

For current information go to www.HealthCare.gov

•••

HICAP Health Insurance Counseling

for seniors and people with disabilities.
www.cahealthadvocates.org/HICAP/
Call (800) 434-0222 to ask a question or to make an appointment.

•••

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.
Tollfree (888) 354-4474
or TDD (916) 551-2180.
In Sacramento, (916) 551-2100.
www.hrh.org.

•••

HMO Help Center

Assistance
24 hours a day, seven days a week.
(888) HMO-2219
or (877) 688-9891 TDD

•••

DRA's Health

Access Project Free publications about the health care, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA a discount to WNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your PCNA/WNA Membership Card and claim the discount.

Anodyne Therapy

Infrared Light Therapy equipment - **\$50 off Model Freedom 300 (single leg at a time) and \$50 discount on Model 120 that does both legs at the same time.** Contact: 800-521-6664 or www.anodynetherapy.com

HealthLight Infrared Light Therapy equipment

- **10% off Single Boot System and Dual boot system.** Contact: 888-395-3040 or www.healthlight.us

Auburn

The Footpath

825 Lincoln Way
(530) 885-2091
www.footpathshoes.com
PCNA Discount: 10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
(916) 686-1050
PCNA Discount: 20% off the regular price shoes.

Fortuna

Strehl's Family Shoes & Repair

Corner of 12th & Main
1155 Main Street
(707) 725-2610
Marilyn Strehl, C.PED
is a Certified Pedorthic
PCNA Discount: 10% off the regular price shoes.

Sacramento

Midtown Comfort

Shoes

3400 Folsom Blvd.
(916) 731-4400
PCNA discount: 15% on the regular price.

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VITAMINS & SUPPLEMENTS – 10 DANGERS THAT MAY SURPRISE YOU

(Summary of article from Consumer Reports Foundation, September 2012)

More than half of American adults take vitamins, minerals, herbs, or other nutritional supplements. Some of these products aren't especially helpful, but that aside, don't assume they're safe because they're all natural. They may be neither, as a matter of fact. Here are 20 hazards that we've distilled from interviews with experts, published research, and our own analysis of reports of serious adverse events submitted to the Food and Drug Administration, which we obtained through a Freedom of Information Act request. Read and be warned.

1. Supplements are not risk free. Protect yourself: Type the name of the supplement you're interested in into the search box at www.fda.gov to see whether it has been subject to warnings, alerts, or voluntary recalls. If you suspect you're having a bad reaction to a supplement, tell your doctor. You can also report your problem to the FDA at 800-332-1088 or www.fda.gov/medwatch.

2. Some supplements are really prescription drugs.
3. You can overdose on vitamins and minerals.
4. You can't depend on warning labels.
5. None are proven to cure major diseases.
6. Buy with caution from botanicas.
7. Heart and cancer protection is not proven.
8. Betcha can't guess this commonly reported problem – Feeling of choking on a supplement pill. Take a swallow of water first. Put the pill on your tongue. Drink enough to get it started and the rest of the water to get it down. For actual choking where a pill or other object goes into the windpipe, the Heimlich Maneuver or emergency surgery is necessary.
9. Some natural products are anything but.
10. You may not need supplements at all.

Be sure to list all supplements you take on the list your doctor has and presents when you come for an office visit. It helps them know if something you take conflicts with something they prescribe. They can also advise if they have heard any report on that supplement.

PERIPHERAL NEUROPATHY LITERATURE REVIEW By William B. Donovan, M.D.

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over 100 medical articles a month written on PN.

I review these references and select articles that would appear to be most interesting to us neuropathy sufferers. This is the link to **PubMed** that will take us to the **NLM: www.ncbi.nlm.nih.gov/sites/entrez**

If you are reading this article on the computer, just click on the above link to go there. If you are reading the print edition of the newsletter, type this link into the address bar of the browser on a computer. If you don't know how, get a librarian or friend to help you.

After you get to **PubMed**, you will see a line that says "**Search PubMed**" followed by "**for**" and a space. Every article in the **NLM** is given a **PMID**, an eight digit identification number. I will give you **PMID** numbers of the selected articles. Type the **PMID** into the space after the "**for**" and click on "**Go**" at the end of the space, or press the ENTER key on your keyboard. You will then see a one paragraph abstract of the article appear, as well as links to related articles.

This month's PMIDs:

- 23691937 This meta-analysis of seventeen studies comprised of 5,975 subjects with chronic peripheral neuropathic pain revealed the most pain reduction with duloxetine (Cymbalta®) 120mg, and

pregabalin (Lyrica®) 600mg.

- 23703408 Sixty-two patients with refractory unilateral lumbar radiculopathy were randomly assigned to either transforaminal steroid injection with or without a Fogarty balloon catheter. During 52 weeks follow-up the balloon group experienced significant improvement in pain and distance walked before claudication pain commenced.
- A study of eight patients with chronic intractable neuropathic pain who were treated with a neurosurgical procedure – stereotactic central lateral thalamotomy (CLT). They experienced significant improvement in both pain and depression.
- 23794648 This article describes the "pathway" for care of neuropathic pain developed by the British Pain Society for non-specialists. It includes initial assessment; topical treatment as indicated with lidocaine (Xylocaine®) patch and capsaicin 0.075% cream; initial prescription of gabapentin (Neurontin®) or pregabalin (Lyrica®) – carbamazepam (Tegretol®) in trigeminal neuralgia; possible use of tricyclic antidepressants – duloxetine (Cymbalta®) are also mentioned; tramadol (Ultram®) for pain; followed, if necessary, by the judicious use of strong opioids to prevent the development of chronic pain. Multi-disciplinary referral is employed in refractory cases.

STATINS SHOWN TO CAUSE FATIGUE

June 11, 2012

In a study of more than 1,000 adults, researchers at the University of California, San Diego, found that individuals taking cholesterol-lowering statin drugs are more likely than non-users to experience decreased energy, fatigue upon exertion, or both. The researchers suggest that these findings should be taken into account by doctors when weighing risk versus benefit in prescribing statins.

Statin drugs are among the bestselling and most widely used prescription drugs on the market. Recently, increasing attention has focused on statins' side effects, particularly their effect on exercise. While some patients have reported fatigue or exercise intolerance when placed on statins, randomized trials had not previously addressed occurrence of fatigue-with-exertion or impaired energy in patients on statins relative to placebo. In the June 11 issue of Archives of Internal Medicine, Beatrice Golomb, MD, PhD, associate professor of medicine at UC San Diego School of Medicine, and colleagues present randomized trial data which show that these side effects were significantly greater in persons placed on statins than those on a placebo.

More than 1,000 adults from San Diego were randomly allocated to identical capsules with placebo, or one of two statins at relatively low potencies: pravastatin (Pravachol) at 40mg, or simvastatin (Zocor) at 20mg – chosen as the most water-soluble and most fat-soluble of the statins, at doses expected to produce similar LDL (“bad cholesterol”) reduction. According to the researchers, the cholesterol reduction would be similar to that expected with atorvastatin (Lipitor) at 10mg, or rosuvastatin (Crestor) at 2.5-5mg.

Persons with heart disease and diabetes were excluded. Neither subjects nor investigators knew which agent the subject had received. Subjects rated their energy and fatigue with exertion relative to baseline, on a five-point scale, from “much worse” to “much better.”

Those placed on statins were significantly more likely than those on placebo to report worsening in energy, fatigue-with-exertion, or both. Both statins contributed to the finding, though the effect appeared to be stronger in those on simvastatin. (Simvastatin led to significantly greater cholesterol reduction.)

“Side effects of statins generally rise with increasing dose, and these doses were modest by current

standards,” said Golomb. “Yet occurrence of this problem was not rare – even at these doses, and particularly in women.”

The magnitude of the effect observed can be seen in the research findings if, for example, 4 of 10 treated women on simvastatin cited worsened energy or exertional fatigue; 2 in 10 cited worsening in both, or rated either one as “much worse”; or if 1 in 10 study participants rated energy and exertional fatigue as “much worse.”

“Energy is central to quality of life. It also predicts interest in activity,” said Golomb. “Exertional fatigue not only predicts actual participation in exercise, but both lower energy and greater exertional fatigue may signal triggering of mechanisms by which statins may adversely affect cell health.”

For these reasons, the researchers state that decreases in energy, and increases in exertional fatigue on statins represent important findings which should be taken into account in risk-benefit determinations for statins. According to Golomb, this is particularly true for groups for whom evidence does not support mortality benefit on statins – such as most patients without heart disease, and women and those over 70 or 75, even if heart disease is present.

Additional contributors to the paper include Marcella A. Evans, Department of Anatomy and Neurobiology, UC Irvine; Joel E. Dimsdale, MD, UC San Diego Department of Psychiatry; and Halbert L. White, UC San Diego Department of Economics.

This study was funded by the National Heart, Lung and Blood Institute, part of the National Institutes of Health, # RO1 HL63055; and supported by the UCSD General Clinical Research Center, NIH # MO1 RR00827.

(Judged as public information given the source and the funding of the research)

<http://health.ucsd.edu/news/releases/Pages/2012-06-11-statins-cause-fatigue>

...3/31/2015

Another research article indicating statins linked to muscle side effects is found at

<http://health.ucsd.edu/news/releases/Pages/2012-08-22-potency-of-statins-lit>

... 3/31/2015

DISCOUNTS FOR WNA MEMBERS

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West Sacramento Beverly's Never Just Haircuts and Lilly' Nails
2007 W. Capitol Ave, West Hair-(916) 372-5606
Nails-(916) 346-8342
PCNA discount: 10% off the regular price.

Neuropathy Support Formula

(1-888-840-7142) is a supplement that a sizable number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back.

Free DVD on “Coping with Chronic Neuropathy”, introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at www.neuropathysupportnetwork.org/order-neuropathy-dvd.html

Additional Discounts

Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail info@pnhelp.org.

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

THIAMINE AND NEUROPATHY

Thiamine, or vitamin B1, is a part of the B vitamins, a group of water soluble vitamins involved in various metabolic processes in the body. Thiamine is important in the function of nerves and muscles, in the processing of carbohydrates, and in the production of stomach acid. Being a water-soluble vitamin, the body does not have large stores of it, so thiamine deficiency can occur in as little as two weeks without proper nutrition. One of the symptoms of thiamine deficiency is neuropathy or nerve damage.

There are two types – primary and secondary – of thiamine deficiency. Primary happens when a person doesn't get enough thiamine in their diet which can happen with too many refined sugars and white rice. Secondary is when a person's body has an increased demand for thiamine such as in a case of prolonged diarrhea. Thiamine deficiency is common among alcoholics due to their lack of a balanced diet and impaired absorption of any they do have.

It can cause beriberi that attacks the myelin sheaf around the nerves. Other symptoms include vomiting, difficulty walking and mental confusion. Some foods high in thiamine include lentils, peas, and cooked brown rice. Supplements by mouth or injection

are given to build the level. If it has caused neuropathy and help is given quickly, the neuropathy may go away. But usually, it can be helped but not cured.

<http://www.livestrong.com/article/395326-thiamine-and-neuropathy/>

Note: The Neuropathy Support Formula has thiamine in it. It is Benfotiamine. This is a fat soluble type. The difference is that regular B1 is water soluble so that any extra is excreted from your body. If it is fat soluble, it builds up in your body. There is some concern about this, but thousands of people are using it in the Neuropathy Support Formula and other products with no reported ill effects. There is some research data as well.

I, personally, have taken 100 mg. of B1 daily for many years, which a doctor prescribed. It used to be on the shelf with other vitamins. Now, I have to ask the pharmacist for it. Sometimes they have to order it if they are out of it as some doctors prescribe it. If you are not taking supplemental thiamine, talk to your doctor about checking the level you have. For some people, this could be the cause of your neuropathy. (Bev)

10 ENEMIES OF SOUND FOOTING

(This is a summary of information found in a USA TODAY article from Thursday, April 22, 2004. I thought it points out conditions we may not have considered as being so much a problem to our balance. We think of things we can rearrange or do so as not to be tripped. These are physical conditions.)

1. Achilles tendinitis – Inflammation or irritation of the calf muscle to the back of the heel bone.
2. Bunions – Enlargement of the joint at the base of the big toe. It moves the joint and a painful bump occurs.
3. Hammertoes – Toes bent upward in a slight claw
4. Heel spurs – Boney growths on the underside of the heel bone
5. Ingrown toenails – Nails whose corners dig painfully into the skin
6. Plantar fasciitis – An inflammation of the band of fibrous connective tissue (fascia) running along the bottom surface (plantar) of the foot from heel to toe.
7. Shin splints – Pain on either side of the shin bone from inflammation of muscle or tendon
8. Neuromas – Benign growths of nerve tissue usually between the third and fourth toes and can be painful
9. Sesamoiditis – Sometimes called the “ball bearings” of the foot, sesamoids are two small bones on the underside of the forefoot

10. Stress Fractures – Incomplete cracks in the bones caused by over use or loss of bone strength

Be sure to be in good communication with your podiatrist if any of these are a problem for you. If you think you have any of these and don't have a podiatrist, make it a point to work with your Primary Care Physician to be referred to one. It is a good idea for anyone with neuropathy to be seen at least once a year. If you have foot numbness and are on Medicare or other insurance that covers it, you can have your toenails cut by a podiatrist or a nurse specially trained to do this depending on your medical group's policy every three months. On the first visit, they will likely check the extent of numbness, but most people with neuropathy with numb feet being a symptom will qualify. It isn't just for diabetic neuropathy. If you get this response, your doctor's referral should be enough to get you evaluated for it.

5 BRAIN NUTRIENTS FOUND ONLY IN MEAT, FISH, AND EGGS

(This is a summary of an article in Healthy Eating, May 13, 2013 by Kris Gunnars. A few comments from other sources are included.)

The human brain is the most complex object in the universe. It consumes the most energy compared to its weight – It is only about 2 percent of the body weight but uses 20 percent of the energy. Here are five nutrients that are very important for the brain and only found in animal foods:

1. **Vitamin B-12** – It is a water soluble vitamin that is necessary in the function of every cell in the body, in the formation of blood and the function of the brain. Being deficient can cause poor memory, depression, and fatigue. It is also a cause of neuropathy. Be sure to have your level checked when blood work is done. There are supplements,

but they are not as effective as the source.

2. **Creatine** – It is the most popular muscle building supplement in the world. It functions to form an energy reserve that is drawn upon by the body including the brain.

3. **Vitamin D3** – Vitamin D is produced out of cholesterol in the skin when it is exposed to ultraviolet rays from the sun. A deficiency of Vitamin D is linked to all sorts of diseases including cardiovascular disease and cancer. It may help treat Type 2 Diabetes, reduce pain, and combat depression in women*. It is abundant in fatty fish. Otherwise a supplement is recommended.

– Continued on page 7

Driving With Hand Controls - Continued from page 1

I have a friend who has driven with hand controls for years. So I'd seen them in action and knew it was possible. I went to a company she recommended in Rancho Cordova called Driving Specialties listed under van and truck conversions. They installed the equipment and required that I go to the driving school they contracted with until I was comfortable enough with the equipment that they could trust me to use it on my own. It probably took longer for me as I had gotten very nervous about driving so my confidence was in tatters.



I learned not to be too confident even when I finally graduated and was fully on my own. I tell myself to do one thing at a time especially when backing out of the garage and changing into drive to leave the property. Stop to do the movement to close the garage door after you have gotten ready to drive away (be sure to have your car in park before you get out to close the garage door).

Parking proved to be the part of working out the process to be the most challenging. For a time, I parked where I could drive through to the opposite space and go out forward when I returned to the car. Then, I parked only where there would

be no car in front of me. Now, I've graduated to parking in any configuration I would have tried when I had confidence in my driving. Although this did not ever include parking on the edge of a cliff or drop off, for example. Living in the Sierras as I do, this is sometimes hard to avoid. But, as many people with neuropathy experience, my great fear of heights kicks in mightily.

I hear you asking about where you would go to get hand controls installed and the training needed to drive safely. I recently got a reference that said to check the NMEDA.org website for companies that did this. I checked a few cities. In Modesto I found one as well as one in the Sacramento area. In the Greater Bay Area, there were quite a few. Sometimes a distance might need to be traveled to find one. For example, there is one in Modesto and one in Fresno but none listed in between. That doesn't mean there aren't any. It just means they are not listed on this organization's website. You can always check the Van Conversion listing for your area.

Check www.pnhelp.org under Resources, Practical Help, Driving Assistance for more information. The controls can be on the right or the left. Bev has them on the right.

What About The Ads Saying They Can Cure Neuropathy? - Continued from page 1

a large amount up front with a credit account to support it; they hired a chiropractor to operate their financing program. People with minimal neuropathy were told they would get drastically worse if they didn't have the treatments. People that had treatment and were finished were finding that any benefit they thought they had received was not lasting. The company folded. It is the old adage of "Let the buyer beware." If it looks too good to be true, it probably is.

*Initially, sometimes there is a feeling of relief because one of the machines many use is HealthLight which like Anodyne is an infrared light treatment. These have been found quite helpful by a sizable number of people, but not all. The treatments have to be continued for the result to last. People have bought a home unit to use regularly as often as needed to continue to get that help for a lot less than having it administered. These two home unit machines are listed in this newsletter with a discount to our members and a free trial period.

President's Message - Continued from page 3

• If you are not a member, we will ask you to join. This is when some people who attend support group meetings choose to join. A handy self-addressed envelope helps encourage this. If you know someone who is not a member but has neuropathy, I ask you to encourage them to join whether they get the letter or not.

The address to use is on the back of this newsletter.

According to the signs I see in the woods around me, I'm trusting for a winter that breaks the drought. One sign is that we have had few sugar pine cones the past few years. This year the trees are loaded with them. Let's all keep our fingers crossed that the lakes get filled and wells are replenished.

Bev

5 Brain Nutrients Found Only In Meat, Fish, And Eggs - Continued from page 6

4. **Carnosine** - It is a very important nutrient that you may never have heard of before. It is created out of two amino acids and is highly concentrated in both muscle tissue and brain. This nutrient can reduce damage caused by elevated blood glucose and may have strong anti-aging effects.

5. **Docosahexaenoic Acid (DHA)** - These are the Omega-3 fatty acids that are extremely important. The human body can't make them. They must come from our diet. There are two forms

EPA and DHA. DHA is the most abundant and it is critical for normal brain development. Plant sources produce ALA which has to be converted to DHA and humans don't do a good job of this. The best source is fatty fish.

People who choose not to eat meat, fish, or eggs need to carefully supplement or end up being sick and having a brain that doesn't function properly. An ongoing lack of B12 can lead to death.



WESTERN NEUROPATHY ASSOCIATION

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■ PN Information/Advice ■ Support Group Inquiries

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HOW IS YOUR ARSENIC LEVEL?

Jean Salmon from the San Jose Neuropathy Support Group sent a note to Stan Pashote, Group Leader, saying, "I was recently re-tested for my arsenic level as a possible cause of idiopathic peripheral neuropathy. It tested high – twice the allowable level despite my avoiding rice and apples. Has anyone else had their arsenic level tested? It has been suggested that veggies grown here are high in pesticides, including arsenic-rich chicken manure. My guess is that most people don't think to have their arsenic level tested. It would be interesting to know other's experiences."

If anyone has their level tested, could you let me know at info@pnhelp.org or 877-622-6298 and we'll see if others had the same experience as Jean, or not. It will be interesting to see if there is a difference in where you live.



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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.

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