



WESTERN NEUROPATHY ASSOCIATION

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Issue 7
Volume 13

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WESTERN
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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ INITIAL REPORT FROM THE NEUROPATHY ACTION FOUNDATION CONFERENCE

WNA Secretary, Pam Hart, and I attended the Neuropathy Action Awareness Conference put on by the Neuropathy Action Foundation. It was an excellent conference. We enjoyed having lunch with Stan and Deanna Pashote and Tiger and Susan Michiels. Stan was awarded the You Are Our Hero Award for 2015. We were glad to be there to applaud and listen to his words of acceptance, which were well said. Tiger is getting ready to restart the Redding Neuropathy Support Group soon.

We met and talked with many people from Southern California. There is an excellent chance that a group may be forming soon in Pasadena

and another in Newport Beach. If you live near either of these communities or know people with neuropathy that do, please send the name, address, phone number and e-mail address to me. All of the information is wonderful but the name and one way to contact the person(s) is a good start.

The conference was live streamed so many of you saw all or part of it. The material will be divided out into the different speaker segments and put on the website of the company that did the livestreaming with it linked to the NAF website. We will develop the way that group leaders will be able to access these to show at group meetings.

■ PERIPHERAL NEUROPATHY (PN) PRESCRIPTION CHOICES II

By William B. Donovan, MD

In May 2015 my first article in this series appeared in Neuropathy Hope.

As you may recall, I was searching for a solution to my increasing evening pain and insomnia due to worsening of my PN in the lower extremities. The meta-analysis reviewed at the time indicated the following medications in decreasing order of net benefit: gabapentin (Neurontin®), venlafaxine (Effexor ER®), pregabalin (Lyrica®), and duloxetine (Cymbalta®) in combination with gabapentin.

My neurologist concurred with my discontinuing gabapentin that I had gradually increased to 800 mg daily, but still had little pain relief. Because of somnolence we had tapered the dose down to 100 mg daily, but even at that dose concern was expressed by family and friends that, "Bill seems out of it." During that time, without warning, I briefly dozed off while driving. Needless to say that was the end of the gabapentin!

I shared the last article with my neurologist who acknowledged it, but felt the evidence in favor of duloxetine was more "robust," and wrote me a prescription for duloxetine 30 mg daily (cost for 90 over \$400). Taking the medication daily before bedtime resulted in incomplete relief of pain and

insomnia. Somnolence was less of a problem, but comments were still being made that, "Bill doesn't seem to be his usual energetic self." Because of lower urinary tract symptoms (LUTS), we decreased the dose of duloxetine to 20 mg daily. LUTS can include incontinence, difficulty voiding, urgency, diminished stream, urinary retention, and difficulties with erection and ejaculation. The duloxetine 20 mg continued to cause troublesome though diminished side effects, but with little relief of the pain and insomnia.

My neurologist concurred with the plan of switching to venlafaxine ER 37.5 mg daily (cost of 90 under \$50). The evening pain markedly diminished and the LUTS became tolerable. The insomnia currently requires trazodone (Desyrel®) 12.5 mg (1/4 of a 50mg tablet) two hours before bedtime to achieve sleep through the night, in addition to zolpidem (Ambien®) 2.5mg (1/4 of a 10 mg tablet) under the tongue to get to sleep.

I am continuing to review over a 100 articles on PN monthly looking for the "perfect" solutions for us. Articles on venlafaxine as a treatment for PN are listed [on page 7].

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Roster of Our WNA Information and Support Groups

2015 WNA Board of Directors

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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
Bev Anderson (877) 622-6298

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

No meeting in July
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

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

May 4, 10 AM
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

No meeting in July
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 Fl., 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

No meeting in July
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 first thing to remember when you are reading this issue is that diabetes is a cause of neuropathy, but if your neuropathy is from a different cause remedies listed for diabetic neuropathy might well help you, too. Six to 10 percent of the population (depends on the state) has neuropathy. Seventy to 80 percent of those will get neuropathy. That is a lot of people and since they are so numerous, there seems like there would be a level playing field for research as their neuropathy is from the same cause. Most studies are done on diabetics that have neuropathy.

Diabetic neuropathy is caused by a toxin build up in the body. That is true of many other types of neuropathy. The whole nervous system is attacked by the toxin. The response starts in the longest nerves which are the ones to the feet. If the response spreads up to the knees, it may start in the hands. Sometimes, it may start in the hands first.

Small fiber neuropathy may be present but your doctor may tell you that you don't have neuropathy because it may not show up in the usual tests. Eugene Richardson gives links to information about the Skin Biopsy Test for Small Fiber Neuropathy mentioned in the article. Here they are: <http://neuropathyjournal.org/small-fiber-neuropathy>, <http://neuropathyjournal.org/skin-biopsy/>

In the new Leader Handbook (binder) your Support Group Leader will have brochures from Therapath that performs this test if you are interested in asking your neurologist about it. Your primary care physician may even be able to do this test. You would want to also consult with your health care plan. If there are not enough brochures for those that want them, Group Leaders may ask for more to be sent or obtain the information from the Web.

In this issue is a personal experience article as follow up to the first one published in the May issue from William B. Donovan, M.D. who spoke at our 2014 Conference. He is a retired pain specialist

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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

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
newsforsalem@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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NeuroMetrix TO EXHIBIT AT AMERICAN DIABETICS ASSOCIATION 75TH SCIENTIFIC SESSIONS

Quell™ Wearable Pain Relief and DPNCheck® Neuropathy Test to be Featured

June 02, 2015 02:51 PM Eastern Daylight Time

WALTHAM, Mass.--(BUSINESS WIRE)--NeuroMetrix, Inc. (Nasdaq: NURO), an innovative health care company that develops wearable medical technology and point-of-care tests to help patients and physicians better manage chronic pain, nerve diseases, and sleep disorders, reported today that it will exhibit at the American Diabetes Association (ADA) 75th Scientific Sessions. The ADA Scientific Sessions will be held June 5-9 at The Boston Convention and Exhibition Center in Boston, Massachusetts.

Diabetes is one of the leading causes of chronic pain and nerve disease throughout the world. Diabetes has always been a core market for NeuroMetrix, and continues to represent a major focus for the Company. The ADA Scientific Sessions meeting represents a key opportunity for the Company to engage with thought leaders in the prevention and treatment of diabetes and its complications, and to interact with other companies in the space. Key highlights of the upcoming meeting include:

- Quell™ will be featured. This over-the-counter wearable device utilizes proprietary non-invasive neurostimulation technology to provide relief for chronic pain. The device is designed for people with conditions such as diabetic nerve pain, which affects over one-quarter of people with diabetes. It is lightweight and can be worn during the day while active, and at night while sleeping. Users have the option of using their smart phone to track and personalize their pain therapy through the Quell Relief app. The Company recently initiated shipments to healthcare professionals and plans full commercialization during June.

- DPNCheck® will also be featured. This rapid, quantitative and cost effective point-of-care test allows physicians to accurately detect diabetic peripheral neuropathy (DPN), even at very early stages. DPN is the most common complication of diabetes, affecting over half of people with diabetes. DPN causes significant morbidity including loss of sensation, pain, increased risk of falling in the elderly, and is the primary trigger for diabetic foot ulcers which may require lower extremity amputations. DPNCheck is directly mar-

keted by NeuroMetrix in the U.S. and by Omron Healthcare in the major markets of Asia.

- The Company's scientific advisory board, representing international leaders in the detection, management, and treatment of the neurological complications of diabetes, will have its annual meeting.

The following scientific presentations will present new data demonstrating the accuracy and clinical utility of the DPNCheck test.

- Combined Large and Small Fibre Assessments Using Novel Point of Care Devices Provide More Accurate Diagnostic Classification of Diabetic Neuropathy (Poster 636, June 8, 12:00 - 2:00 PM). Study conducted at Sheffield University, UK, in the laboratory of Professor S. Tesfaye.

- Effect of Intensive Weight Reduction on Neuropathy Progression in Patients with Diabetes: A 1-Year Controlled Clinical Trial (Oral Presentation 196, June 7, 4:00 - 4:15 PM). Study conducted at Joslin Diabetes Center, Boston, US, in the laboratory of Dr. O. Hamdy.

Representatives of the Company, including Shai N. Gozani, M.D., Ph.D, President and CEO; Frank McGillin, GM Consumer, Michael MacDonald, SVP Commercial Operations, and Tom Higgins, CFO, will be available for business discussions. Attendees are encouraged to visit NeuroMetrix at booth #1305.

About NeuroMetrix

NeuroMetrix is an innovative health-care company that develops wearable medical technology and point-of-care tests that help patients and physicians better manage chronic pain, nerve diseases, and sleep disorders. For more information, please visit <http://cts.businesswire.com/ct/CT?id=smartlink&url=http%3A%2F%2Fwww.NeuroMetrix.com&sheet=51115938&newsitemid=20150602006819&lan=en-US&anchor=www.NeuroMetrix.com&index=1&md5=4f8d6e5e1ac96a770c89bb379ac71a8a>.

Contacts

NeuroMetrix, Inc.

Thomas T. Higgins, 781-314-2761

SVP and Chief Financial Officer

neurometrix.ir@neurometrix.com

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DIABETIC NEUROPATHY – OBESITY AND NEPHROPATHY

By: Sonya Wells, Pharm.D., MPH

Diabetic neuropathy is mainly nerve damage that occurs when you have diabetes. Typically, high blood sugar levels can affect the nerve fibers throughout your body. The increased prevalence of obesity runs in parallel with an increased prevalence of diabetes. Obesity makes the body resistant to insulin so it is not able to utilize the insulin properly and isn't able to direct it to the cells, thereby increasing the level of sugar in blood and causing diabetes. In the type II diabetes group, about 80 to 90 percent are also diagnosed as obese. (A Diabetic Life, 2011)

Nearly one-third of patients with diabetes develop diabetic nephropathy (Diabetic nephropathy is kidney damage that occurs when diabetes affects the kidneys. Anatomy of the Kidney. Copyright © Nucleus Medical.) Most of this damage in diabetic neuropathy is due to the damage of blood vessels that filter the blood to make urine. Hypertension, or high blood pressure, is believed to contribute most directly to diabetic nephropathy and is a characteristic manifestation of diabetes. Diabetic nephropathy can occur in both types of diabetes – Type 1 and Type 2. (A Diabetic Life, 2011)

One hallmark of obesity is high body mass index (BMI) which has been reported to be related with increased diabetic neuropathy. BMI is an indicative of obesity, whether or not you are obese, to some extent can be determined by its Body Mass Index (BMI). It measures the body fat based on height and weight that applies to adults. $BMI = \text{Weight (kg)} / (\text{Height (m)} \times \text{Height (m)})$ (Stevens, 2015)

Obesity is associated with the most rapid increase in nephropathy globally. Regular evaluation of weight and monitoring of glucose level is important for the patients with Diabetic Neuropathy. The aim of weight loss in Diabetic Neuropathy patients is to significantly decrease urinary protein excretion as the increase in body weight may relate to the increase the protein content in urine; therefore weight control remains an important target of control in overweight Diabetic Neuropathy patients. The onset and progression of diabetic nephropathy can be slowed down by intensive management of obesity and diabetes. (Stevens, 2015)

To minimize the risk of obesity induced diabetic nephropathy; take a look at the following-

Eat healthy food. Exercise regularly:

A healthy diet along with exercise is the best way to reduce weight. Prefer foods that are low in calories and avoid the sources rich in fat and calories. Some

best fat burning foods are oranges, oats, grapefruit, and mushrooms. Some other fat burning foods include lentils, pears, tomatoes, pine nuts, egg white, broccoli, lean meats, spinach, green tea and cinnamon. (Stevens, 2015)

Intensive blood glucose control:

Clinical trials have consistently demonstrated that controlling the sugar level may decrease the risk for manifestations of diabetic nephropathy in type 1 and type 2 diabetic patients. One keystone in the prevention and management of diabetic nephropathy is tight glycemic control. Strict glycemic control is important; glycemic control reduces the rate of development of proteinuria. Eating a low-fat diet, taking drugs to control blood cholesterol, and getting regular exercise can slow down or prevent nephropathy. To control sugar level eat healthy foods, get regular exercise and check your blood sugar level as often as instructed and keep a record of your numbers. (Stevens, 2015)

Blood pressure control:

Treatment of hypertension dramatically reduces the risk of cardiovascular events in patients with diabetes. Hypertension is common in diabetic neuropathy patients. Blood pressure targets patients with diabetes lower (130/80 mmHg) than those patients who don't suffer from diabetes. (Stevens, 2015)

Conclusion:

Referral to a nephrologist should be considered if you are facing a severe filtration problem or any discomfort in Diabetic Neuropathy and the abdomen. Fluctuating blood pressure, hyperkalemia, or rising protein level in urine, the increased sugar level may also prompt a referral. Joint National Committee guidelines recommend that blood pressure in diabetics should be reduced to less than 130/80 mm Hg. Specific use of agents that appears to be inflaming Diabetic Neuropathy or increasing the sugar level should be avoided for Diabetic Neuropathy and general health. (Stevens, 2015)

References:

“Diabetic Neuropathy Tingling, Nerve Pain and Amputation”, A-Diabetic-Life.com website, 2011. Retrieved from:<http://www.a-diabetic-life.com/diabetic-neuropathy.html>

Stevens, Allison, “Obesity& Foot & Toe Pain”, Livestrong website, February, 2015. Retrieved from:<http://www.livestrong.com/article/517002-obesity-foot-toe-pain/>

DISCOUNTS FOR WNA MEMBERS

Continued from page 4

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.

FOOD AS MEDICINE: IMPROVE HEALTH, INCREASE VITALITY & LIVE LONGER!

Speaker: Melina Jampolis, M.D. Celebrity Internist and Board Certified MD Nutrition Specialist. In 2005, Dr. Melina hosted a program on the Discovery Network's FIT TV titled "Fit TV's Diet Doctor" and she currently serves as the diet and fitness expert for CNNHealth.com

Dr. Jampolis views food as medicine, a large percentage of disease is caused by poor diet and conditions that develop from a poor diet. She says that genetics loads the gun and lifestyle pulls the trigger. The four critical supports for good health and lack of disease, especially earlier in life are

1. Best diet
2. Never smoked
3. BMI < 30
4. Exercise

Choose healthy eating as opposed to the fad diets and the haphazard way many make food choices. She recommends 5 servings of vegetables, 3 servings of fruit which fills you up with fewer calories. One serving of nuts (can include peanuts) or soy eaten daily. Nuts are the preferred choice. Beans are an excellent part of your diet.

You don't have to give up red meat but do have it at a 4-1 ratio. This means white meats and fish to one of red meat. Red meat twice a week is a good plan.

Cereal fiber is important. It should be two servings a day and preferably whole grain. This includes bread.

Reduce sugar and refined carbs. Watch out for hidden sugar and high sugar corn syrup. Trans fats are being phased out completely. There is no safe level. Avoid partially hydrogenated products. Choose butter/margarine and mayo that says they have a minimum or less of these.

Omega 3 fatty acids are vital. Fish two times a week and nuts, especially walnuts, have this nutrient. Vitamin D is being found very helpful. Many people are deficient in this vitamin.

There should be a low amount of alcohol consumption but some of any kind can be helpful. It isn't just red wine and dark chocolate that have the healthy flavonoids.

Dr. Jampolis recommended turmeric which is used in many medicines and food flavorings. It is best you check with your doctor before using this in any quantity as WebMD cautions against using it if you are pregnant, have stomach or gall bladder problems, have diabetes as it can lower the sugar blood levels, interfere with blood clotting, reduce testosterone count, and slow the absorption of iron which would be a concern of those dealing with anemia.

STAN PASHOTE - WHAT A LIFE HE LEADS!

*Stan Pashote was awarded the **Our Hero Award** by the Neuropathy Action Foundation at the Neuropathy Action Awareness Conference in Los Angeles on June 18. This is the article that appeared in NEUROPATHY HOPE's February 2012 edition a number of months after he was awarded the Support Group Leader of the Year Award. Stan is still leading two groups – San Jose and Redwood City. Would you expect anyone with his health issues to even lead one group? Would you expect a retired welder to do this? Anyone who has a heart for people and is able to be out and about can successfully lead a support group if they put their mind and energy into it. Stan is proof.*

Stan is the Regional Coordinator for the Peninsula and South Bay Region, Leader of the San Jose Neuropathy Support Group, and is leading the Redwood City and Morgan Hill start-up groups that need leaders of their own. He was given the Support Group Leader of the Year Award at our 2011 Annual Meeting. Does this sound like a dynamic guy with robust energy?

Stan was born in San Jose and had no siblings. He was raised in Newark and graduated from high school there in 1971. Stan received an AA Degree in Welding Technology from Chabot Community College in Hayward. He worked in the metal trades as a journey-level welding technician. He married his wife Deanna and they had two children. Jennifer and Kevin were born a few years apart. Both are now grown. Jennifer made Stan a grandfather to Emily in 2008.

In 1987 Stan started to become ill with pneumonia and blood infections. He was finally diagnosed with Common Variable Immune Deficiency at Stanford Medical Center. He started what will be a lifelong habit of taking IVIG infusions every two weeks for IgG anti-body replacement. (The Auto-immune issues include Raynauds Phenomenon, Osteo-arthritis, Alopecia, muscle atrophy and Osteoporosis.) The family moved to Fremont 19 years ago. Stan had to quit work as he just couldn't get through a full shift and they wanted him to work overtime. He was put on State disability benefits which went into Social Security Disability after a year. Wanting to do something, Stan

became a Meals On Wheels volunteer to have something to do that didn't take a lot of time, but it proved too much due to the stairs he had to climb. He was looking for a volunteer job when he discovered the San Jose Support Group.

In 2001, Stan was diagnosed with neuropathy. About this time, he was also diagnosed with nutritional deficiency due to malabsorption due to permanent damage to the intestines and related inflammation and started on TPN (Total Parenteral Nutrition) infusions and hydration IVs. He does this several nights of one and several nights of the other while he sleeps six days of the seven. A home care nurse comes every Monday to access his implanted IV port and do any blood draws. He takes the new Neuropathy Support Formula and thinks it helps.

In 2006 Stan became a TNA and PCNA (NCCNA at that time) volunteer at the San Jose Support Group and a little while later its leader. He became Regional Coordinator in 2010. He says he enjoys making friends and assisting patients at the support groups. The atmosphere is good - non judgmental and not a lot of pressure. Stan likes handyman work, like home repair and gardening, and spending time with family. He says he quit doing work for others as keeping up at home is a challenge. He likes to be busy but can't over do it so he schedules activities with that in mind.



This is the link to **PubMed** that will take us to the **NLM: www.ncbi.nlm.nih.gov/sites/entrez**

- 17943857 In a Cochrane Database study of 61 trials of antidepressants for neuropathic pain, it was concluded that venlafaxine (Effexor®) and tricyclic antidepressants are effective.
- 18413214 Venlafaxine (Effexor®) is a combination norepinephrine-serotonin uptake inhibitor like duloxetine (Cymbalta®), the latter approved for use with peripheral neuropathy by the FDA. This study found venlafaxine to be safe, effective and well tolerated as a treatment for the pain of distal symmetrical sensorimotor polyneuropathy.
- 12187335 This is the first case report (year 2002) Of venlafaxine (Effexor®) being effective against cancer chemotherapy-induced neuropathic pain. The patient, a 69 year -old woman on a course of paclitaxel was given 37.5 mg of venlafaxine twice daily and made a dramatic recovery in two days.
- 21427067 This is a randomized, double blind, placebo controlled study of venlafaxine ER (Effexor ER ®), 50mg IV before and 37.5 mg twice daily from days 2-11 following oxaliplatin with cancer chemotherapy patients. Full relief was obtained in 31.3% versus 5.3% with placebo.
- 21497321 This article reviews the literature on efficacy of medications as well as non-pharmacological treatment for painful diabetic neuropathy according to the American Academy of Neurology criteria. Pregabalin (Lyrica ®) was established as effective (A), and the following as probably effective (B): venlafaxine (Effexor®), duloxetine (Cymbalta®),

amitriptyline (Elavil®), gabapentin (Neurontin®), opioids and capsaicin.

- 23978467 This animal study demonstrates that antidepressants [norepinephrine-serotonin reuptake inhibitors] used to treat neuropathic pain—nortriptyline (Pamelor®) and venlafaxine (Effexor®) –work by inhibiting the cytokine, tumor necrosis factor alpha (TNF-a). The potent, expensive TNF-a inhibitors (Enbrel®, Remicaid® and Humira®) are used to treat rheumatoid arthritis, psoriasis and low back pain.
- 2452178 This double blind, randomized, placebo controlled study demonstrates that venlafaxine (Effexor®) used preventively resulted in significantly less acute neurotoxicity from oxaliplatin based chemotherapy. Similar effect was found with duloxetine (Cymbalta®).
- 24577146 This is a review of the literature indicating that the norepinephrine- serotonin reuptake inhibitors (SNRIs), duloxetine (Cymbalta®) and venlafaxine (Effexor®) decrease pain and relieve numbness and tingling associated with chemotherapy induced peripheral neuropathy (CIPN).
- 24983280 This is an Iranian double blind, randomized, parallel group clinical trial of three agents for the treatment of diabetic peripheral neuropathy showing the following Visual Analog Scale Scores at the conclusion of the study: venlafaxine (Effexor®)-46.4%; carbamazepine (Tegretol®) 39.6%; and pregabalin (Lyrica®)-33.4%. Although all three agents resulted in diminished pain, pregabalin was the most efficacious.

President's Message – Continued from page 3

who has neuropathy, is a member, and is Assistant Leader in the Monterey Neuropathy Support Group. Also included is the second article by Sonya Wells, Pharm.D., MPH, the pharmacist that is speaking to groups in the greater Sacramento area. She made a special trip to the Turlock Neuropathy Support Group on Monday, June 15. It made a good field trip for her children out of school for the summer as Turlock has some interesting sites to see like the cheese factory and air museum. (I shouldn't mention it, I know, but their spectacular, huge, Swedish Bakery is a worthwhile, but costly visit. It is hard to choose just one.) Sonya has neuropathy and fibromyalgia. Some of you met her at the Conference.

Be sure to check the listing for your support group on the list in this newsletter. Some are taking a break in the summer and some are not. If you are in town, be sure to show up for your sake, that of others in the group, and the encouragement of your group leaders. We all want attention paid to neuropathy so there is research that will hopefully find cures. We hold the key in our hands but many people with neuropathy don't seem to realize it.

The more people that attend support groups and join neuropathy organizations, the more those that fund research and other activities think it might be valuable and those that would buy their product or service. When a support group leader is discouraged or even quits saying that attendance is

down and people don't seem to care, it hurts deeply. Those people are throwing a major opportunity to make a difference away and it hurts us all. Support group leaders are jewels and should be treated as such. They are hard to find and quite valuable.

Please remember a support group's primary purpose is not entertainment, but association with people who understand what you are going through and with whom you may talk freely about what helps or doesn't help you. We need many more support groups so that those who call or write to me asking for a support group near them, will find there is one.

Yay! Support Groups!

Bev

P.S. Please do not make copies of the June newsletter or send it to anyone else. For the first time in 16 years of compiling the newsletter, I have a withdrawal of permission. The group from whom I got the lead article is saying that I didn't use the right version of the permission statement so I didn't have permission to use the one I did. So please use it for your information as it is a tremendous article, but don't distribute it. If a new version comes by e-mail, it will have the correct information and can be used. The new one is the version that will be on the website.



WESTERN NEUROPATHY ASSOCIATION

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HELPFUL RECOMMENDATIONS BY PEOPLE WITH NEUROPATHY

Dottie Macchia in Sun Valley, CA (near Burbank) said that she got the Dr. Scholl's clear gel insoles and found them very helpful. She bought them in a local drug store.

Don Bethe can't attend the Grass Valley Neuropathy Support Group often as he has a conflicting meeting on that day. He joined WNA and receives the newsletter so he still gets some monthly support. He attended a meeting when Bev Anderson spoke. He had been taking a low dose of Alpha Lipoic Acid and raised it to 400 mg in the morning and 400 mg in the evening with meals. (Bev recommends 300 mg each time. Some large of stature people have reported taking 900 mg a day.) Don said he has had tremendous positive results which he is very happy about.

GOOD HEALTH SNACKING SUGGESTIONS

1. Whole grains – tortilla chips, whole grain cereals
2. Breakfast foods – cereal, toast with low sugar jam, granola
3. Peanut butter, celery sticks, apple slices, whole grain crackers
4. Unsalted nuts and seeds of any type
5. Cheese and whole grain cracker, nuts and grapes
6. Think about what you are eating. Don't just eat without noticing it.



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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.

Dues - \$30 a year

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