



WESTERN NEUROPATHY ASSOCIATION

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Issue 2
Volume 14

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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)

■ COULD IT BE LEPROSY?

By Bev Anderson using PERIPHERAL NEUROPATHY & NEUROPATHIC PAIN Into the Light by Gerard Said, M.D., one of the world's leading experts, as reference.

We think of diabetes being the greatest single cause of neuropathy, but on the world scene, leprosy is likely the disease producing the greatest number of neuropathy cases. We never give thought to leprosy as we consider it a disease of the past.

L. Nolen of the Centers for Disease Control and Prevention reported on October 31, 2014 that between 1994-2011 there were 2,323 new cases of leprosy or Hansen's disease (HD) in the United States. In the U.S. it is chiefly caused by the bacterium from armadillos, which exist in certain southern states and may be in zoos in other areas. Leprosy still occurs in the U.S., but because it is rare, clinicians in the U.S. are often unfamiliar with it. The disease can be disabling. Although it can be cured, the disablements remain to be managed. If you have ever come in contact with an armadillo and touched it and later diagnosed with neuropathy, it would be a good idea to have this checked. Evidence of infection may appear years or even decades after initial contact with the bacteria.

"Leprous neuropathy, which is due to the infection of nerve cells by Mycobacterium leprae, still infects millions of people in many developing countries." "Failure of early detection of leprosy often leads to severe disability in spite of the eradication of the mycobacterium at a later date."

Symptoms include hypopigmented skin lesions with loss of sensation, thickening of peripheral nerves, and skin-smear positivity for the acid-fast bacilli. Skin and

nerve biopsies are the only way to be sure of either of the forms of leprosy – lepromatous leprosy and tuberculoid leprosy – separating them from something that might look similar. (We usually suggest you limit having a nerve biopsy, but for leprosy, it is usually required to be sure of the extent and type, and needs to be read by someone who can recognize leprosy.)

Leprosy is covered in the chapter called Infectious Neuropathies. Others included are Lyme Disease, Human Retrovirus Infection which includes human immunodeficiency virus (HIV) which causes AIDS and less often (HTLV-1) the causal agent of tropical myeloneuropathy, and others.

This book by Dr. Said is excellent, but is may be a difficult read for many neuropathy patients. However, there is a good glossary and the Internet is a good reference for word definitions. So if you want to give it a try, it could be a great learning adventure. I highly suggest that patients buy the book for their doctor that they see most often and would be first to be dealing with your neuropathy. If you also see a neurologist, you could give it to them as well. If every doctor had this book, their understanding and concern for patients with neuropathy might be much improved. WNA will be looking for contributions and grants in our effort to get a copy into the hands of doctors in training to be neurologists. There will be copies available at the Annual Conference on April 20, 2016.

WNA 2016 Annual Conference: Exploring Neuropathy Research Options

| | |
|---------|--|
| 9:30am | Registration and Morning Snacks |
| 10:00am | Announcements and Introductions |
| 10:10am | Keynote - Dr. Bruce Hammock, Distinguished Professor, Department of Entomology & UCD Comprehensive Cancer Center, Director, NIEHS-UCD Superfund Research Program, PI, NIH Biotechnology Training Program, University of California - Davis. |
| 11:00am | Break |
| 11:10am | Leonard Chuck, M.D., Medical Director of Diablo Research, Walnut Creek: "How is Research Conducted?" |
| Noon | LUNCH |
| 1:00pm | Small Group Development of Research Ideas |
| 1:30pm | Compiling a list of what groups propose |
| 2:00pm | Vanessa Kettler: "Balance Techniques that Help" |
| 2:45pm | Door Prizes; Closing Announcements |
| 3:00pm | Adjournment |

**Registration Form
on page 7**

Roster of Our WNA Information and Support Groups

2016 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)
Sandra (925) 443-6655

Auburn

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 Tuesday, 3:30 PM
Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
Tanysha (916) 944-2323
Community members welcome

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

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

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

1st Tuesday, 12:30 PM- odd numbered months
Journey Church
450 Blue Ravine Rd.
Bev Anderson (877) 622-6298
<http://folsom.neuropathysupportgroup.org/>

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

2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church Street
Bev Anderson 877-622-6298

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

3rd Monday, 10:30 AM
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Ray (209) 634-4373

Monterey

3rd Wed., 10:30 AM-odd numbered months
First Presbyterian Church
501 El Dorado Street
Dr. William Donovan (831) 625-3407

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
Danielle LaFlash (650) 593-6758

Roseville

2nd Wednesday, 1PM - odd numbered months
Sierra Point Sr. Res.
5161 Foothills Blvd.
Bev Anderson (877) 622-6298

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Charles Moore (916) 485-7723
<http://sacramento.neuropathysupportgroup.org/>

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.
Danielle LaFlash (650) 593-6758

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
For information call
Bev Anderson (877) 622-6298

President's Message

By Bev Anderson



What a difference an El Nino can make to a year's weather. We seem to be getting a steady stream of storms. What a great blessing although great tragedy can result. I hope all of you are safe and dry. Of course, there are some that are rejoicing in the rage of the storms for a variety of sports excitement. I live within sight and sound of I-80 as it ascends the Sierras. Skiers have packed the roads after each storm to get to the first excellent powder they have seen in years.

We need a positive 'El Nino' in WNA to build the membership numbers to what it was some years ago. Many have been members, but haven't renewed over the years. Others may come to meetings, but haven't joined. In order to sustain our operations and make a major difference for people with neuropathy, we need to pull together and be supportive. I'm so delighted with the ones who are renewing and the many that are contributing above their dues. One member contributed \$1,000 through her trust just before the end of the year. Others have done this in the past as well.

We have covered articles in this newsletter about one area of great concern – prescription drug abuse. In the hue and cry over deaths due to overdoses of prescription drugs, the medical profession in its reversal to reduce prescription abuse may be guilty of pushing people with chronic pain into suicide. People who don't know anyone with chronic neurological pain may have no comprehension of the intensity of the pain. Physicians may assume that low level pain killers are enough and deny opiate-based prescriptions of any kind or at least not to the level needed. In California, Nevada, and Oregon, there seems to be some comprehension of the difference between temporary and chronic pain.

I spent more than hour on the phone with a caller from Wisconsin. Her prescription on which she had done well for years was reduced by half. Doctors were previously permitted to prescribe it, but now they aren't. She goes to the emergency room in major diabetic neuropathy pain and they call her

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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) 622-6298

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- odd numbered months
Covenant Village Adm. Bldg. Classroom
2125 N. Olive St.

Joanne Waters (209) 634-0683

Ukiah

Last Tuesday, 5:30 PM
North Coast Opportunities (NCO)
413 N. State St.
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

For information call
Bev Anderson (877) 622-6298

Yreka

For information call
Bev Anderson (877) 622-6298

Yuba City-Marysville

For information call
Bev Anderson (877) 622-6298

NEVADA

Reno-Sparks

For information call
Bev Anderson (877) 622-6298

OREGON

Brookings

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

Grants Pass

3rd Wednesday, 2:00 PM
Club Northwest
2160 N.W. Vine St.
Carol Smith (541) 955-4995

Medford

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

Portland

For information call
Bev Anderson (877) 622-6298

Salem

For information call
Bev Anderson (877) 622-6298

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".

Start a support group in your area:

Contact Bev Anderson at (877) 622-6298 or info@pnhelp.org

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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RESPONSES TO THE JANUARY ISSUE

Several people responded to articles in last month's issue of NEUROPATHY HOPE with pertinent information to add.

Cynthia McAlexander (Santa Barbara, CA Neuropathy Support Group) sent a few additional suggestions to Lots of Falls Happen in Parking Lots by Vanessa Kettler:

1. Apply for and use a handicap placard. If parking handicap spaces close to entrances are available, dangerous hazards such as holes, moving vehicles, or speed bumps may be avoided.

2. Push shopping carts while in parking lots and when inside stores to assist with balance, carry articles, i.e., purses, tote bags, and packages, from already purchased items.

Bev Anderson's addition: Watch out for the cement car stops as they sometimes stick out beside cars and you can trip especially if you walk between two cars. My husband had a bad fall from one of these.

Carole Hester (Leader of the Neuropathy Support Group in Ukiah, CA) suggests Hyland's Leg Cramps. She carries a bottle with her as you can use it anyplace. She uses the bottle that contains 100 quick (under

the tongue) tablets. There are also caplets to swallow but they are not as fast-acting. They are manufactured in Los Angeles. You can get them at pharmacies, Target, and online.

Vicki Anderson (Reno, NV) actually called while I was at this point in the newsletter to say that she had found taking potassium and eating bananas had helped her. She also said that she kneaded the cramp and it did help her, but might not work for others.

Previously published, but in case you missed it, Walfredo De Los Reyes (Concord Neuropathy Support Group) suggests a pain cream recipe manufactured by a local compounding pharmacist. He says it works really well. If you want to try it, you would need to give it to your doctor so the doctor can write a prescription for it as compounding pharmacists also work via prescriptions. The 'recipe': amitriptyline/baclofen/bupivacaine/gabapentin 2%2%1%6%. He has it made at Scriptworks in Walnut Creek, which is a compounding pharmacist that your compounding pharmacist may contact if they have any question. You can also call Walfredo if you have a question (925) 683-7580.

SEE SOMETHING, SAY SOMETHING

We see and hear this often. However, I always wonder who you tell. I had reason to say something recently and consulted Kathy Park a reporter at KCRA Channel 3 in Sacramento. If it is a police matter, you call the jurisdiction involved. If it is an emergency, of course you call 911. However, if it isn't an emergency, you call the non-emergency number. If it is something you wonder could involve terrorism in some way, call the State Threat Assessment Center. In California, it is (916) 874-1100 (Monday-Friday 8:00 am-5:00 pm) but you can call and leave a message as well or send an e-mail to STAC@caloes.ca.gov the website is <http://www.caloes.ca.gov/cal-oes-divisions/state-threat-assessment-center>. In

Oregon, it is <http://www.dhs.gov/fusion-center-locations-and-contact-information>. In Nevada, it is http://dem.nv.gov/homeland_security/Nevada_Fusion_Centers/

I don't expect any of us to have the need to heed 'see something, say something' but it's always good to be prepared. The people in the neighborhood in San Bernardino might have called about all the deliveries to the small apartment if they had had any idea there was a region-wide Homeland Security confidential number they could have called – it may well have made a difference. It is the little things that sometimes make a great difference.

WNA 2016 ANNUAL CONFERENCE

Wednesday, April 20, 2016

Jelly Belly Factory Conference Center • Fairfield, CA

Registration form on page 7

CHOOSING A DIAGNOSTIC TEST FOR TYPE 2 DIABETES

By Mark Abrahams, M.D.

Reviewed by Clifton Jackness, M.D., Attending Physician in Internal Medicine, Lenox Hill Hospital and the Mount Sinai Medical Center, New York, NY

Take Note

- A1C with a cutoff of 6.5% identifies one-third fewer people with diabetes than a FPG of ≥ 126 mg/dL.
- While more expensive, the use of both A1C and FPG may increase diagnostic yield.

The process of diagnosing type 2 diabetes has undergone significant change in the last few decades. Initially, the American Diabetes Association (ADA) and the World Health Organization (WHO) both defined diabetes as either a fasting plasma glucose (FPG) ≥ 140 mg/dL or an oral glucose tolerance test (OGTT) with a 2-hour plasma glucose level of ≥ 200 mg/dL. In 1997, the FPG criterion was lowered to ≥ 126 and subsequently lowered (by the ADA) to 100 to 125 for persons at increased risk.¹ The OGTT, while a more sensitive test than FPG, has significant drawbacks, notably inconvenience, high cost, and low reproducibility. As a result, the OGTT is not widely used for routine diagnosis in the United States.²

Measurement of glycosylated hemoglobin (A1C) is widely used to monitor existing diabetes because of its correlation with average glucose levels over the preceding two to three months. Before 2009, the lack of appropriate standardization kept A1C from being a recommended choice for diagnosis of diabetes. With improvements in global standardization, however, A1C is now universally accepted as a diagnostic tool, with a cutoff of 6.5%.^{2,3}

The advantages of using FPG include extensive experience and availability. However, the inconvenience of the fasting requirement is significant, and is perhaps a primary reason for the increased use of A1C since its standardization.⁴

A1C, despite its convenience and high degree of clinician familiarity, does have limitations. Artificially low values may occur in patients with hemoglobinopathies like sickle cell and thalassemia, those with conditions with increased red-cell turnover like hemolytic anemia, and patients with late-stage kidney disease. Conversely, artificially high values may occur in iron deficiency or other conditions of low red-cell turnover. For more information about the effects of abnormal hemoglobins on the A1C assay, the ADA recommends consulting the NGSP website (The mission of the NGSP, which is partially funded by the National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK] is to standardize A1C results to the Diabetes Control and Complications Trial [DCCT] and United Kingdom Prospective Diabetes Study [UKPDS]).

Other concerns about using A1C to diagnose diabetes include the fact that certain racial groups, African Americans for example, have somewhat higher A1C levels than non-Hispanic white individuals at a given fasting or postglucose load glucose level.⁵ Further, it's unclear how age affects A1C diagnosis in children and teens.³

Perhaps the most clinically significant aspect concerning the use of A1C for diagnosing diabetes is that it appears to be less sensitive than FPG—and will miss the diagnosis of diabetes in many individuals. A recent ADA report

suggests that using A1C with a cutoff of 6.5% identifies one third fewer patients with diabetes than a FPG of ≥ 126 mg/dL.⁶ One report found that A1C identified diabetes in 5.2% of screened individuals, while FPG identified 7.1%. Furthermore, individuals diagnosed via A1C were more likely to be African American compared with those diagnosed via FPG.¹

The use of both A1C and FPG to increase diagnostic yield has been proposed. Whether performed concurrently or sequentially, this dual approach is likely to identify more individuals with diabetes. However, cost is a consideration. Regardless, a large, appropriately designed study to investigate the best approach may be required to reach a definitive conclusion.²

Regardless of the test or tests used to diagnose diabetes, the ADA recommends the following course of action:

- If a test, FPG or A1C for example, is positive, the test should be repeated immediately with a new blood sample to confirm.
- The diagnosis is also confirmed when 2 different tests have positive results.
- When tests have discordant results, the one with the positive result is repeated in a sort of diagnostic tiebreaker.

Early and accurate diagnosis of type 2 diabetes represents an opportunity to prevent a significant amount of morbidity and mortality. Treatment of overt diabetes has been proven to reduce risk of both microvascular and macrovascular damage. Similarly, identifying individuals with prediabetes allows for the institution of lifestyle modifications in order to reduce the risk of conversion to overt diabetes. Until more definitive evidence exists to aid in the choice of which diagnostic test(s) to use, this remains an important clinical judgment left up to each healthcare provider.

Published: 09/09/2015

References:

1. Malkani S, Mordes JP. Implications of using hemoglobin A1C for diagnosing diabetes mellitus. *Am J Med.* 2011;124:395-401.
2. Inzucchi SE. Clinical practice. Diagnosis of diabetes. *N Engl J Med.* 2012;367:542-550.
3. American Diabetes Association. Classification and diagnosis of diabetes. Sec. 2. In *Standards of Medical Care in Diabetes--2015.* *Diabetes Care* 2015;38(Suppl. 1):S8-S16
4. Backholer K, Chen L, Shaw J. Screening for diabetes. *Pathology.* 2012;44:110-114.
5. Saudek CD, Herman WH, Sacks DB, et al. A new look at screening and diagnosing diabetes mellitus. *J Clin Endocrinol Metab.* 2008;93:2447-2453.
6. Picon MJ, Murri M, Mu-noz A, et al. Hemoglobin A1c versus oral glucose tolerance test in postpartum diabetes screening. *Diabetes Care* 2012;35:1648-1653.

Used with permission from MedPage Today, Diabetes Management Resource Center where there are a variety of articles for people dealing with diabetes.

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.

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:

- 21044263 This systematic review of 28 studies of NMDA receptor agonists for the treatment of neuropathic pain including complex regional pain syndrome, postherpetic neuralgia and postamputation pain. Oral memantine was ineffective for all groups, and intravenous ketamine was effective only in postamputation pain.

- 22314263. This 13 week Baylor randomized, placebo-controlled trial of dextromethorphan (DM) 45mg/quinidine 30mg, an NMDA inhibitor marketed as Nuedexta® and its lower dose form, DM 30mg/quinidine 30mg, found reduced diabetic neuropathic pain and insomnia as well as increased activity level. Both dosage forms were statistically better than placebo, but the higher dosage was statistically more significant than the lower.
- 23664235 Combination therapy of intravenous lipoic acid (300-600mg) and methylcobalamine (B12 500-1000mg intramuscularly or intravenously) daily for 2-4 weeks improved nerve conduction velocities significantly better than methylcobalamine alone.
- 23733756 This is a multicenter 24-week randomized controlled trial of 409 women receiving taxane-based chemotherapy given acetyl-L-carnitine (ALC) or placebo. The ALC failed to protect against chemotherapy induced peripheral neuropathy (CIPN). The ALC group's neurotoxicity score was, in fact, 10% worse.
- 24148742 This article discusses the contribution of neuroinflammation and immune response to the development of neuropathic pain. Nerve damage results in the increase of cytokines and chemokines that mediate this process. Hopefully new drugs will be developed to interrupt these agents
- 24612455 this study demonstrates that these males treated with pregabalin (Lyrica®) 300mg daily for three months had a significant improvement of erectile function, orgasm function and overall satisfaction as measured by the International Index for Erectile Function Questionnaire.

President's Message – *Continued from page 3*

a druggie just begging for drugs. They refuse to help. In some states, marijuana is available and is helpful to many in pain. In others, not even the medical marijuana is allowed. This caller that I talked to said she didn't have financial ability to move to a state that would offer treatment and the only way out she could see is suicide, but she doesn't know how she would do that. When she cannot get medical help because of this anti-opiate campaign, what do physicians expect her to do?

Several people contacted me during the month with sympathy and suggestions to help me with my major response to the level of magnesium I took early last month. I was thinking I couldn't make the trip to be with family for Christmas. A few days before the pain set in, I was at my wits end and suddenly thought of the ads on TV for the pro-bionic Yacult. I got some and almost miraculously my bowels calmed and started the journey back to normal. I was able to make the trip and enjoy being with family. Some comments and suggestions I received are in another article in this newsletter.

The theme for this year's Annual Conference is "Exploring Neuropathy Research Options." The program is taking shape. Registrations start with the receipt of this newsletter as you will see a registration form is included on page 7. The cost per person is \$25 prepaid with the registration. There are a limited number of registrations available due to the capacity of the space. Holding the event at the Jelly Belly Factory received positive feedback

so we will be returning to that venue. Attendees gave a high rating for the facility, the food, and the program. The facility and food will be the same this year and we hope the program is even better.

We are excited to announce that Dr. Bruce Hammock, UC-Davis Professor, whose research company was recently awarded a \$4 million grant from the National Institutes of Health to further research and do clinical trials of a new medication targeting neuropathic pain that is showing promise in animals, will be our Keynote Speaker. Further information about this project will be featured in next month's newsletter. Our other speaker, Dr. Leonard Chuck, Medical Director of Diablo Research in Walnut Creek, will educate us about the research process. We will have discussion in small groups and expand the ideas to the whole group in the afternoon. The closing event will be Vanessa Kettler presenting on improving balance and mobility. She is well received by the WNA support groups she has visited. We want everyone to have the opportunity to meet her and participate in one of her entertaining events. Opportunity for a tour of the Jelly Belly Factory will be available at the end of the conference.

Thanks to all, especially those that attend a support group and encourage their leaders,

Bruce

■ INHALED CANNABIS FOR NEUROPATHIC PAIN: RESULTS FROM FIRST-OF-KIND STUDY

Inhaled cannabis had a significant effect on neuropathic pain that appears to be dose-dependent, in the first published research on cannabinoids for painful diabetic neuropathy in humans.

- In a study appearing in *The Journal of Pain*, researchers from the University of California, San Diego conducted a randomized, double-blind, placebo-controlled crossover study of 16 patients with painful diabetic neuropathy to evaluate the short-term efficacy and tolerability of inhaled cannabis. Each participant was exposed to four single dosing sessions of low (1% tetrahydrocannabinol [THC]), medium (4% THC), or high (7% THC) doses of cannabis, or placebo. Baseline spontaneous and evoked pain were measured, and cognitive testing was performed; the participants then received aerosolized cannabis or placebo and the pain intensity and subjective "highness" score was measured at 5, 15, 30, 45, and 60 minutes and then every 30 minutes for an additional three hours. Cognitive testing was performed at 5 and 30 minutes and then every 30 minutes for an additional three hours.

RELATED: Evidence Supports Cannabinoids for Some Pain, But Not Other Conditions

- A dose-dependent reduction was seen in diabetic peripheral neuropathy pain in patients with treatment-refractory pain, with significant differences in spontaneous pain scores between doses, a significant effect of the high dose on foam brush and von Frey evoked pain, and a significant negative effect (impaired performance) on two of the three neuropsychological tests. However, in measuring the impact of inhaled cannabis impact on cognition, the researchers found modest effects with no dramatic declines or impairments.
- Despite all subjects experiencing euphoria or somnolence, which may limit the acceptability of cannabis as an analgesic, the authors conclude that cannabis could still provide benefits in neuropathic pain syndromes that include treatment-refractory diabetic neuropathy.
- For more information visit www.AmericanPainSociety.org

Date: Wednesday, April 20, 2016

Time: 9:30am to 3:00pm

Preregister by April 14, 2016

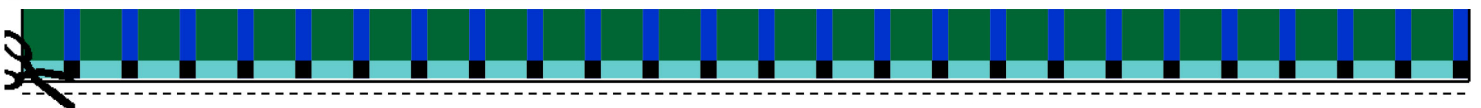
Registration Fee: \$25.00

**Jelly Belly Factory Conference Center
1 Jelly Belly Lane
Fairfield, CA**

**Questions:
Toll Free: (888) 556-3356
Email: admin@WNAinfo.org**



2016 Annual Conference Exploring Neuropathy Research Options



Mail registration fee and form to:

WNA Conference
P.O. Box 276567
Sacramento, CA 95827-6567

Name _____

Address _____

City / State / Zip _____

E-mail _____

Support Group _____ At Large Member

If you need a special diet, please indicate: Vegetarian Gluten Free Other

I am enclosing my check for the \$25 registration fee.

I am interested in taking a tour of the Jelly Belly Factory after the Conference.



WESTERN NEUROPATHY ASSOCIATION

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P.O. Box 276567, Sacramento, CA 95827-6567

Call WNA using our toll free phone numbers:

(877) 622-6298 ■ Email: info@WNAinfo.org

■ PN Information/Advice ■ Support Group Inquiries

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• MARK YOUR CALENDAR NOW •

THE 2016 ANNUAL CONFERENCE

Wednesday, April 20, 2016

Jelly Belly Factory Conference Center in Fairfield, CA

• See page 7 for Registration Form •

WAYS TO STAY MENTALLY ALERT

“Focus, focus, focus,” you may say to yourself when you notice something you have passed by. Some ways to keep sharp include:

- Getting regular physical exercise.
- Getting enough sleep.
- Keep learning and using what you have learned – The more a person knows, the more they are apt to use it.
- Keep actively involved with other people.
- Keep in touch with at least several people.
- Find ways to be in a regular small group setting. (Attending your nearest neuropathy support group is a help to your brain as well as your neuropathy.)
- If you are able, find a volunteer opportunity that stretches you a bit. Most support groups have something you could do that will get you more involved in life. There are always things in church or community that would be delighted to welcome you, too.



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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

All contributions and dues are tax-deductible.

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

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