



WESTERN NEUROPATHY ASSOCIATION

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Issue 05

Volume 15

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Antidepressants And Anti-Seizure Drugs Can Effectively Treat Diabetic Nerve Pain, Research Finds

Group Leader Of The Year Awards For 2017

Register To Watch the NAF Conference On Your Computer At No Cost

WESTERN NEUROPATHY ASSOCIATION

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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

OUR ANNUAL CONFERENCE FOR 2017 WAS SUCCESSFUL WITH THREE GREAT SPEAKERS

We were welcomed by Dr. Frederick Gorin, Professor and Chair of the UC Davis Medical Center Neurology Department. The Neurology Department sponsored our conference this year and will again next year. Dr. Gorin, an excellent neurologist and the go to person for neuropathy at the Medical Center, described the advances made and planned for the Neurology Department. They are actively recruiting a neuromuscular neurologist, which will be significant for people with neuropathy as well as other neurological conditions that need their expertise.

Yuen So, MD, PhD, provided some informative facts about neuropathy:

- It is now thought that 10% of the population have neuropathy with 20-30 million in the U.S. More older people have it because nerves can wear out.
- Sensory nerves are responsible for tingling, pins/needles, burning, aching, electric stabbing, electric like pain, and numbness, which is actually a loss of sensations.
- Motor nerves give way to weakness, cramps, muscle atrophy, and high arch.
- Neuropathy is length dependent and starts in the longest nerve. This is why it starts in the feet and moves up to the calf. Then it may start in the fingers.
- There are hundreds of different types of neuropathies.
- Autonomic nerves are responsible for blood pressure, bowels and urinary tract, and sexual response.
- A single nerve might be affected. Such is the case in Multi-Focal Neuropathy.

Kyle Fink, MD, stem cell researcher, spoke on the importance of the process of clinical trials: to ensure medication safety and effectiveness. He cautioned us to carefully research any treatment option we are offered and consult with our own doctors before trying something questionable. People are being permanently damaged by some of the treatments that we are seeing promoted.

Dr. Hammock shared that human clinical trials on his research project medication are likely to start at Duke University by the end of the year. Phase 1 - Is it safe? Does it do no harm? He reminded us that they have done clinical human trials in India with 30 people all of whom were considered successful. This medication is for neuropathy pain relief. It will most likely be helpful for people in arthritis pain. If the form for humans does as much good as the form for cats and horses does, it will be great news for all suffering pain.

Thank you to our attendees and the speakers for the healthy questions and answer periods. More of the speakers' presentations will appear in the next issue of Neuropathy Hope.

Other activities included well received raffle prizes, special silent auction items, and a good lunch served along with coffee, tea, water, and soda available.

In addition to the UC Davis Medical Center Neurology Department, The Occupational Therapy Association was a sponsor with one or more raffle prizes and the morning snacks. Some of the raffle prizes and all of the silent auction items were provided by members of the WNA Board. Sonya Wells, our pharmacist on the Board who sold raffle tickets, obtained the donation of the carved cane and made the encouraging blanket. Darrell O'Sullivan donated his own artwork -- the framed photograph of a unique bridge. It received Best of Show in an art show in 2016,

SCOTT STOKES, LEADER IN SAN RAFAEL'S WORDS OF WISDOM

Scott, one of our Support Group Leaders of the Year, did the video taping of the speakers and also led a stretching time just before lunch. He had planned to do a final stretching to help people warm up to have more energy to get home safely, but people were ready to leave so he put it in writing for everyone. Parting words of encouragement: Quote from Marin Independent Journal article, April 17, 2017, by Dr. Bill Elliott, assistant clinical professor of medicine at UCSF. "We know that regular exercise and fitness later in life protects against dementia as does staying socially and intellectually active. We have suspected that blood vessel and heart health are linked to Alzheimer's disease, but this is the first major study to link obesity as well."

So, what can we do now?

Beyond a healthy diet and regular exercise, striving to keep your weight in a healthy range may protect your brain. A diet high in healthy fats, fresh fruits and vegetables high in antioxidants, limiting sugar as well as limiting portions all can help.

Most importantly, stay active. Try to burn calories every day by exercising and being active. **And finally, stay engaged with others. We know social isolation is a risk for Alzheimer's disease. It turns out that conversation is the best brain exercise of all!!**

Roster of Our WNA Information and Support Groups

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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

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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)
Marty Price (925) 626-7988

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

Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
For information, call:
Bev Anderson (877) 622-6298

Castro Valley

2nd Wednesday, 1:30 PM
First Presbyterian Church
2490 Grove Way (next to Trader Joe)
Joy Rotz (510) 842-8440

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

Costa Mesa

3rd Wednesday, 10:00 AM
Call Martha Woodside
949-573-0056 for the location

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 Thursday, 12:30 PM
Burger Rehabilitation
1301 E. Bidwell St., Folsom
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
Bonnie Zimmerman (559) 313-6140

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

Meeting day and time, call Mito.
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.
Lee Parlett (925) 292-9280

Madera

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

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeiser 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

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

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 (415) 297-1815

Roseville

2nd Wednesday, 1PM - odd numbered months
Sierra Point Sr. Res.
5161 Foothills Blvd.
Stan Pashote (916) 409-5747

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

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

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital
2105 Forest Avenue
SJ DePaul Conf. Rm.
Danielle LaFlash (415) 297-1815

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
Mary Ann Leer (831) 477-1239

Santa Maria

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

Santa Rosa

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

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President's Message By Bev Anderson

What a joy it was to see all the people from near and far that came to this year's Annual Conference. I wished I'd had time to talk to each one individually and share more of my joy to have the conference at The Mind Institute. I was in that building when it was under construction. It now is a world class institution dealing with diseases of the mind, especially autism. A support group of families of autistic children is responsible for precipitating this special institute to help children and adults and do research into the best ways to help.

Chicken Soup for the Soul: Inspiration for Teachers went on sale on April 18 and we sold some at our sales table where I was able to sign them. I wrote one of the 101 stories in the book. It has added book signing to my list of activities as they ask us to participate in promoting the book. If you want a copy, you can send a check for \$18 to WNA, P.O. Box 276567, Sacramento, CA 96928-6567 or go to www.WNAinfo.org. It is \$15 plus \$3 for shipping and handling. It is a good gift for someone, especially a teacher, but all of us are teachers as we teach someone something each day of our life. The books are a fundraiser for WNA to provide more funds to buy the books we are presenting to medical schools to be sure each Resident in Neurology has a reference book for neurology on their bookshelf. You can see a photo of the first presentation of the neurology books in this newsletter.

All of us want to leave a legacy – something that continues to live after we are gone. One way is the form in which we prepare our wills. Yes, you likely want to leave some assets to your family, but there is a way you can do both. I'd honestly not been aware of how to prepare a will so that people/organizations could receive percentages of the total estate value. So, last year, I revised my will – allocating percentages to various people/organizations. My estate is not large but I have assigned a portion to WNA. I'd like to suggest that when you write or update a will that you will think about leaving a legacy portion of your estate to the Western Neuropathy Association so help for people with neuropathy will continue.

Pam Hart gave each person at the conference a sock with a small bar of soap to commemorate Neuropathy Awareness Week, May 7 – 14, 2017. That is the specific week designated on the national calendar, but WNA considers all of May to be Neuropathy Awareness Month. Pam was reminding us of the soap between the sheets at the end of the bed that is supposed to quiet the feet at night and to avoid leg cramps. You might like try it for the month of May and see if it helps you. If it does help you, please share your stories with me.



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".

WNA Information and Support Groups – Continued from page 2

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

First Meeting, May 22
4th Monday, 6:15 – 7:45 PM
The Goebel Adult Community Center
1385 Janss Rd.
Angie Becerra 805-390-2999

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
Vista Room
Karen Hewitt (925) 932-2248

West Sacramento

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

Woodland

First meeting, Tuesday, May 16, 2017
3rd Tuesday, 1:00 PM
Woodland Senior Center
2001 East Street
Sue (530) 405-6304

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
www.grantspass.neuropathysupportgroup.org

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

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 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
WNA Discount: 10% off the regular price shoes.

Elk Grove

Shoes That Fit
8649 Elk Grove Blvd.
(916) 686-1050
WNA 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
WNA Discount: 10% off the regular price shoes.

West Sacramento

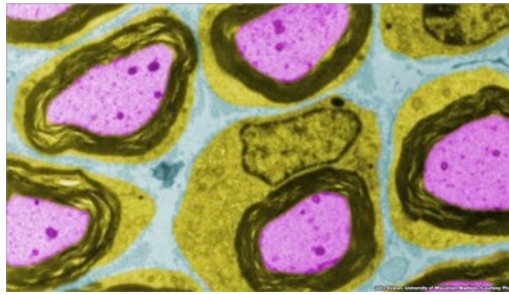
Beverly's Never Just Haircuts and Lilly's Nails
2007 W. Capitol Ave
Hair - (916) 372-5606
Nails - (916) 346-8342
WNA discount: 10% off the regular price.

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NERVE CELLS CAN BE SWITCHED ON TO REPAIR DAMAGE

September 20, 2016 • VOA News

Scientists at the University of Wisconsin have found a way to coax peripheral nerve cells into repairing damaged axons. Peripheral cells extend outside the central nervous system into the arms and legs and are responsible for sensation. They contain long fibers known as axons that transmit impulses from the brain. They can be damaged in diseases such as diabetes, causing pain.



The axons are surrounded by a protective sheath called myelin, a fatty insulation that speeds electrical signals from the brain. Myelin is created by Schwann cells, but researchers have discovered that Schwann cells can also stimulate nerve regrowth.

They conducted an experiment in mice with both intact axons and axons which had been cut. Using a method for switching on genes, they saw Schwann cells become more active, but only in the injured rodents.

They went into a repair mode that stimulated nerve regrowth. This clean-up, as researchers call it, began within days of the injury.

As part of the clean-up process, the Schwann cells send signals that enlist blood cells to help in the repair. During

this time, the myelin begins to dissolve to make room for the axonal repair. After the axons are on the road to recovery, a new myelin sheath begins to form over the regenerated fibers.

The scientists identified a particular pathway that switches the Schwann cells on or off. They suggest drugs may some day be available to activate the repair program.

A report on axonal regeneration was published in *The Journal of Neuroscience*.

Lead researcher John Svaren, a professor of comparative biosciences at the University of

Wisconsin, says it's not clear that this single on-off pathway works to regenerate all axonal nerve cell damage. But he's hopeful that it's a key repair mechanism, not only within the peripheral nervous system but for nerve damage within the brain.

Until now, Svaren says scientists have thought of the Schwann cell as a "static entity," with only one function: producing myelin. But he is excited that the cells can be coaxed to become "first responders" in helping to repair the peripheral nervous system.

Used by permission of Med Page Today

MAY 4TH, 2017, OUR REGION COMES TOGETHER FOR THE 4TH ANNUAL BIG DAY OF GIVING

A program of the Sacramento Region Community Foundation's initiative to grow local philanthropy, Big Day of Giving is a 24-hour online giving challenge that brings together the region's nonprofit community to help raise much needed unrestricted funds and shine a spotlight on the work nonprofits do to make the Sacramento region the place we call home. For the past few years, the giving day has united our community, raising more than \$16 million for local nonprofits from over 36,000 donors from all over the region, the state, the country, and the world.

WNA is excited to participate again this year. There are a lot of changes – such as the date – which is on a Thursday this year, the processing company (due to all the issues last year), and the manner in which you can donate. After April 14th, you will be able to access our donation page and schedule a donation. (<https://www.bigdayofgiving.org/wna>). (This can be a one-time donation, or, you can make it recurring. The minimum donation this year is \$15.00. There are also categories that you can consider when donating, such as:

1) Book Sponsor (\$50.00) – this will purchase two of Dr. Said's books to be given to Neurology Residents –



your name will be added to an honor roll on our website. It can be given in honor of a person or as a memorial as well.

- 2) New Support Group Meeting Sponsor (\$100.00) – this will cover the start-up materials for new groups forming.
- 3) Annual Meeting Sponsor (\$500.00) – this will help us to bring quality speakers to inform and educate us.
- 4) Major Donor (\$1,000 and above) – this lets us know that you appreciate the work that we do and would like to see it continue.

We look forward to this event and hope you will join us in making a difference for Neuropathy in this region.

VITAMIN B3 PREVENTS NERVE PAIN CAUSED BY CANCER DRUGS

February 28, 2017

A new study in rats suggests that nicotinamide riboside (NR), a form of vitamin B3, may be useful for treating or preventing nerve pain (neuropathy) caused by chemotherapy drugs. The findings by researchers at the University of Iowa (UI) were published recently in the *Journal of the International Association for the Study of Pain (PAIN)* and lay the groundwork for testing whether this nutritional supplement can reduce nerve pain in cancer patients receiving chemotherapy.

Although chemotherapies have improved cancer survival rates, many of these drugs also cause debilitating side effects that decrease the quality of life of patients and survivors. In particular, many anti-cancer drugs cause chemotherapy-induced peripheral neuropathy (CIPN)—nerve damage and pain.

“Chemotherapy-induced peripheral neuropathy can both hinder continuation of treatment and persist long after treatment has ended, severely affecting the quality of life of cancer patients,” says Marta Hamity, UI assistant research scientist and first author on the study. “Our findings support the idea that NR could potentially be used to prevent or mitigate CIPN in cancer patients, resulting in a meaningful improvement in their quality of life and the ability to sustain better and longer treatment.”

A recent report from the American Society for Clinical Oncology states that there is an unmet need for treatments that can alleviate CIPN.

The new study, led by Hamity and Donna Hammond, UI professor of anesthesia and pharmacology at the UI Carver College of Medicine, tested the effect of NR in female rats that were treated with paclitaxel, a chemotherapy commonly used to treat breast and ovarian cancer.

The researchers found that paclitaxel given at doses that mimicked the amount a human patient would receive caused peripheral neuropathy in the rats, and the effects lasted at least five weeks beyond the end of the chemotherapy treatment.

The team used a standard test to assess the pain caused by CIPN. They measured the rats’ increased sensitivity to a light foot poke. Untreated rats did not withdraw their foot when light pressure was applied.



However, treatment with paclitaxel made the rats hypersensitive to this light touch and caused them to withdraw their foot.

NR boosts levels of an important cell metabolite called nicotinamide adenine dinucleotide

(NAD+). Previous animal studies, including work from the UI lab of study co-author Charles Brenner, have shown that increasing NAD+ levels with NR can protect against many types of nerve damage. The new study found that the NR supplement increased levels of NAD+ in the rats’ blood by about 50 percent.

Prophylactic treatment with daily doses of NR (200 mg/kg) for seven days before chemotherapy and maintained for 24 days after chemotherapy ceased prevented the hypersensitivity to touch in the rats. This protective effect lasted for at least two weeks after the NR supplementation stopped.

The UI researchers also devised a new method to measure how unpleasant the rats with CIPN found the light touch to be. Rats were given a choice between a dark environment where their feet were repeatedly poked and a brightly lit environment. By nature, rats prefer the dark. The team found that untreated rats tolerated many pokes before they were prompted to leave a darkened area. In contrast, rats with CIPN would leave the dark chamber after fewer pokes and would remain in the light. Rats getting both chemotherapy and the NR supplement behaved more like untreated rats and tolerated more poking before leaving the dark.

“The touch-sensitivity test measures the threshold where a light touch that normally is not painful is now perceived as painful because of the neuropathy. For example, people with CIPN can find the light touch of clothes or typing on a keyboard painful,” Hamity explains. “In the case of the ‘escape’ test, we were trying to mimic how unpleasant a normal stimulus can be because of the neuropathy—and if that would cause you to avoid (that stimulus) even if it means choosing an activity that you don’t enjoy. For example, typing can become so painful that you avoid doing it even if it means not being able to work.”

DISCOUNTS FOR WNA MEMBERS

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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.



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ANTIDEPRESSANTS AND ANTI-SEIZURE DRUGS CAN EFFECTIVELY TREAT DIABETIC NERVE PAIN, RESEARCH FINDS

March 25, 2017

A federal health agency has found certain antidepressants and anti-seizure drugs are among medications that effectively treat diabetic nerve pain. The research is being published simultaneously in the March 24, 2017, online issue of *Neurology*, the medical journal of the American Academy of Neurology (AAN) and in a more comprehensive report by the Agency for Healthcare Research and Quality (AHRQ).

AHRQ is the lead federal agency charged with improving patient safety and the quality of America's health care system.

The Centers for Disease Control and Prevention (CDC) says more than nine percent of the U.S. population has diabetes and an estimated 50 percent of people with diabetes have some form of diabetic peripheral neuropathy, nerve damage caused by high levels of blood sugar, although not all have symptoms. Symptoms can include nerve pain, numbness and tingling in the legs and feet. The longer someone has diabetes, the greater the risk of developing neuropathy, especially for those who have problems controlling blood sugar. Severe neuropathy may eventually lead to the need to consider amputation.

"Providing pain relief for neuropathy is crucial to managing this complicated disease," said Julie Waldfoegel, PharmD, of The Johns Hopkins Hospital in Baltimore, Md., and author of the systematic review. "Unfortunately, more research is still needed, as the current treatments have substantial risk of side effects, and few studies have been done on the long-term effects of these drugs."

A systematic review is an analysis of the results of multiple, carefully designed studies available on a topic.

For this systematic review, researchers looked for studies and other systematic reviews conducted after the American Academy of Neurology's 2011 guideline "Treatment of Painful Diabetic Neuropathy." A total of 106 studies were included in the review.

Researchers found moderate evidence that the antidepressants duloxetine and venlafaxine, which act as serotonin-norepinephrine reuptake inhibitors, were effective in reducing neuropathy-related pain.

They also found weak evidence that botulinum toxin, the anti-seizure drugs pregabalin and oxcarbazepine, as well as drugs classified as tricyclic antidepressants and atypical opioids were probably effective in reducing pain.

Waldfoegel noted that the long-term use of opioids is not recommended for chronic pain due to lack of evidence of long-term benefit and the risk of abuse, misuse and overdose.

Researchers noted that while pregabalin works in the same way as gabapentin—both are often used interchangeably in clinical care—this review found gabapentin was not more effective than placebo. This is contrary to the 2011 AAN guideline, which found gabapentin to be probably effective.

The seizure drug valproate and capsaicin cream, which were considered probably effective in the 2011 AAN guideline, were ineffective in this meta-analysis.

"We hope our findings are helpful to doctors and people with diabetes who are searching for the most effective way to control pain from neuropathy," said Waldfoegel. "Unfortunately, there was not enough evidence available to determine if these treatments had an impact on quality of life. Future studies are needed to assess this."

There were other limitations. One was that all studies were short-term, less than six months, and all studies on effective drugs had more than 9 percent of participants drop out due to adverse effects. Longer-term outcomes should be evaluated in future studies so that side effects and continued effectiveness of the drugs can be assessed.

Source: The American Academy of Neurology Press Release
<https://www.aan.com/PressRoom/Home/PressRelease/1539>

WHAT TO DO ABOUT FRAUD

Many of you saw Dr. Oz's program on the dangers of stem cell clinics and why you should never go to one. So many people are having life altering and limiting experiences that doctors can't treat because the cells grow independently as if developing another body, but without the system through which medication is usually introduced. We are also aware of other groups we questioned who shared about receiving pitches for treatment programs that may or may not help -- and if some do experience results, they are often not long lasting. These treatments are often through a 'hard sell' and are expensive. If you have been caught in what you consider a scam, please report it, and track others you know of who have been scammed as well. It often takes having a critical mass of individuals affected before legal action will be taken.

Dr. Oz ended his program by saying we should write letters to our legislators, state and federal. The January-February AARP Bulletin gave these recommendations to report that fraud. If someone comes to your door, contact local police and your state attorney general or district attorney. You can find the contact information for legislators and state officials on the Internet, http://www.legislature.ca.gov/legislators_and_districts.html

For other frauds or scams:

Federal Trade Commission (www.ftc.gov/complaint 877-382-4357) – Report identity theft, abusive debt collectors, and most types of fraud. When you report, get a reference number to use when you call back for an update. They won't contact you or plead your case, they put it together with other complaints to use in going after the group causing the fraud. You should also file it with your state's attorney general and even law enforcement.

National Do Not Call Registry (www.donotcall.gov 888-382-1222) If your name is not on this list, start by adding your name. After you have been on for 31 days, you can report unwanted calls that have come in. Your information will be put with others to catch ones involved. Remember calls from legitimate charities, survey firms, debt collectors, and political candidates or parties are not covered by this list.

Consumer Financial Protection Bureau (www.consumerfinance.gov/complaint 855-411-2372) This is for complaints about shady business practices and financial products including loans, bank services, credit reporting, ID theft, debt collection, and payment cards. The CFPB forwards complaints to the company, which has 15 days to respond. It is supposed to be resolved within 60 days.

Internet Crime Complaint Center (www.ic3.gov/complaint) This is where you report online auctions, investment and sales fraud, internet extortion, hacking and phishing, and scam e-mails. It is operated by the FBI. The information is forwarded to the appropriate law enforcement or regulatory agencies, but does not directly conduct investigations.

Postal Inspection Service (www.postalinspectors.uspis.gov 877-876-2455) This is where you report scams distributed by U.S. mail, such as bogus lottery and sweepstakes "winnings," chain-letter schemes and deceptive advertisements and mail theft.

(Go to www.aarp.org/fraudwatchnetwork to learn more about identity theft and avoiding scams.)

GROUP LEADER OF THE YEAR AWARDS FOR 2017

At our Annual Conference on April 18, 2017, we awarded four Support Group Leaders the Support Group Leader of the Year Award. It is a nice plaque with a clock imbedded. The following received the award.

MARY ANN LEER – SANTA CRUZ, CA

Mary Ann Leer has been the Neuropathy Support Group Leader in Santa Cruz for about 10 years. The group meets on odd numbered months and has a sizable number of attendees.

She was born in Orange, California, but has lived in Northern California most of her life. She graduated from Wilcox High School, Santa Clara, California, and went on to attend San Jose State College.

After graduation, Mary Ann worked at Stanford University as a computer programmer supporting its business applications. This is where she met her husband 34 years ago. They don't have any children. She enjoys taking walks around beautiful Santa Cruz, gardening, and reading mysteries.

Mary Ann was unable to be at the conference due to the sudden death of her husband in early March. Our heartfelt sympathies are extended to her.

LARRY METZGER – SANTA ROSA, CA

Larry Metzger has been the leader of the Santa Rosa Neuropathy Support Group for three years. He was born on Long Island, New York; when he was two months old, his family moved to Teaneck, New Jersey, which is a suburb of New York City, near the George Washington Bridge. Larry graduated from high school in Teaneck, and graduated from Trinity College in Hartford, Connecticut, where he received a Bachelor of Arts. Later, he earned an MSW (Master of Social Work) from the University of Michigan at Ann Arbor. He also attended Saybrook Institute (now University) where he received a PhD in Psychology.

For more than 20 years Larry had a successful private practice in psychotherapy, and for more than 10 years, he also was on faculty at the University of California, Berkeley, where he had the opportunity to train several thousand professionals and paraprofessionals in their work with addicted individuals. He taught courses on counseling, diagnosis and treatment, addictive disorders, and life transition. For several years, Larry also worked with the Institute for the Study of Social Change at the University of California, Berkeley, researching anxiety experienced during major life transitions.

While working as an addictions specialist and teaching in that specialty, he wrote *From Denial to Recovery: Counseling Problem Drinkers, Alcoholics and Their Families*. The book was published in 1988 and used in many classroom settings and by individual therapists.

Larry is listed in the Who's Who in California and Who's Who in the West. Fairly recently, he and his partner of 14 years married.

ROGER WHITE – ELK GROVE, CA

Roger White has been the Leader of the Elk Grove Neuropathy Support Group since June 2013. He was born in Long Beach, CA, but when he was six months old the family moved to Blythe, CA, and then other communities. He graduated from Roseville High School in Roseville, CA.

Roger was commissioned as a 2nd Lieutenant in the California

Army National Guard after graduating from OCS and worked in electronics at McClellan Air Force Base in Sacramento, CA. He went to a number of classes over the years working in radar, radios, amplifiers and other types of electronics that came along. Roger retired as a Quality Assurance Supervisor at McClellan Air Force Base.

He and his wife, Marion, have three sons. They have lived in Elk Grove, Lone, and Woodland – all in California. All three of their sons are married; between them, Roger and Marion have six grandchildren.

Roger is a member of the Charcot-Marie Tooth Association (CMTA), which gives him added helpful information. He has numbness, but not constant pain that some with different types of CMT experience. At the present time, there is no cure for CMT. Pain seems to be considered more critical to treat even though those with numbness are concerned about their needs as well.

SCOTT STOKES – SAN RAFAEL, CA

Scott Stokes has been the Group Leader for the Neuropathy Support Group in San Rafael, CA for over eight years. He was born in Evanston, IL, but grew up in Winnetka, IL, which is just outside of Chicago. He says he is a Midwest boy at heart. He graduated from New Trier High School in Winnetka in 1965. From there, he went to Brown University and Northwestern University, where he earned a Bachelor of Science in Industrial Engineering – for this he thanks his Mom and Dad. Scott says he held a number of different jobs, but he got to maintain, repair, and instruct in the Pershing Missile System during his years in the U.S. Army.

He married Barbie and has a wonderful grown son who lives in Del Mar, CA. As this is being written, he and Barbie finished their trip to Barcelona, Spain, and have continued their trip into France.

Scott says he has idiopathic neuropathy and shuffles with the worst of them. In the 13 years since diagnosis he has had two full knee replacements. On the trip, he reports, he has been walking about two hours a day. "Mr. Last Person to the Bus" is currently his nickname.



The first set of Peripheral Neuropathy & Neuropathic Pain Into the Light by Gerard Said, MD, FRCP, were presented to the UC-Davis Neurology Department on March 22, 2017. Pictured are Pasha Ansari, MD, Chief Resident in Neurology; Darrell O'Sullivan, WNA Treasurer; and Bev Anderson, WNA President



WESTERN NEUROPATHY ASSOCIATION

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MARK YOUR CALENDAR! BIG DAY OF GIVING Thursday, May 4, 2017

24 Hours To Give!
www.bigdayofgiving.org

– See page 4 for details –

May 7-13, 2017

is Peripheral Neuropathy Awareness Week

FOR NO COST, YOU CAN WATCH THE NEUROPATHY ACTION FOUNDATION (NAF) CONFERENCE VIA COMPUTER BUT YOU MUST REGISTER TO GET THE ACCESS INFORMATION TO SEE IT

The Conference is Friday, June 23, 9:30 AM – 3:30 PM. Register now by calling (877) 512-7262 or on their website www.neuropathyaction.org. If you choose to attend in person and want to register for that, it is \$25 using the phone or their website for patients and their caregivers. \$125 for others. Lunch is included with the registration.

The MC for this conference is Carolyn Johnson, award winning journalist and co-anchor, NBC Channel 4 Southern California News. Cancer survivor, artist, and author, Darryle Pollack will speak during lunch. Other speakers include: Perry Shieh, MD, PhD, Associate Clinical Professor, University of California, Los Angeles (UCLA), will discuss the signs, symptoms, and causes of peripheral neuropathy; Richard Lewis, MD, FAAN, Director EMG Laboratory and Co-Director Neuromuscular Clinic, Cedars-Sinai, will discuss understanding a neurologist's approach to the diagnosis and treatment of peripheral neuropathy; Jeffrey Ralph, MD, Associate Clinical Professor, University of California, San Francisco (UCSF), will discuss current treatment options for peripheral neuropathy; Manny Hernandez, Co-Founder, Diabetes Hands Foundation and Senior Vice President of Livongo Health, will discuss Diabetes and "Why You Are Not Alone;" Jim Romano, Director of Government Relations and Advocacy, Patient Services, Inc. (PSI).

"Neuropathy Action Awareness Day provides patients with a critical forum to help empower themselves to be the most effective advocates for their own care," said NAF President Dominick Spatafora. "As insurance benefit restrictions make it more difficult to access IVIG and other medications, it is more important than ever that the neuropathy advocacy community has a strong voice to protect access to care and ensure that the health care cost debate does not focus on short-term savings at the expense of patient health and long-term costs."



Western Neuropathy Association (WNA)

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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.

This newsletter is designed for educational and informational purposes only. The information contained herein is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. Western Neuropathy Association (WNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.