



WESTERN NEUROPATHY ASSOCIATION

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Issue 12
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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)

■ HOW IS PERIPHERAL NERVE PAIN TREATED?

By LtCol Eugene B Richardson, USA (Retired) BA, MDiv, Ed.M., MS

Pain signals from an external stimulus like a cut or from an internal broken bone are treated with many well-known treatment options for pain.

Pain signals from damaged nerves which send real, but faulty signals to the brain must be treated with other options which currently are limited until research provides more options at the clinical level.

Options

The majority of patients with neuropathic pain are currently treated with two classes of medication. The anti-depressants and the anti-seizure medications either alone or in combination work for many patients to reduce such pain.

Some of these options would include Nortriptyline in the first class and Lyrica in the second class. Speak to your doctor about the options, but recommend that you first consider the antidepressants as these may have fewer side effects. Both the anti-depressants and anti-seizure medications reduce neuropathic pain, even if the medical community is not totally sure why they work.

This information is from the book by Norman Latov, MD, PhD, of Weill Medical College, Cornell

University. Most patients get about 85% relief and a few are lucky with 100% relief, but until there are better medications developed by research, we are fortunate to have these options. Dr. Latov speaks of these and other medications and they do help many neuropathy patients. However, like all medications sometimes the side effects are worse than the symptoms.

Each patient must decide if they are worth using if

the pain is only at the nuisance level. The dosage and the combinations of these medications must be worked through by the patient with the doctor in a patient doctor partnership of trial and error. As of now, I know of no other way to find what works for you.

Other patients have been prescribed Lidocaine patches for burning pains as noted by Dr. Latov and patients report that these help reduce the burning.

I have found that the burning sensations respond best to compounded topical creams and not to the oral medications. Compounded topical creams are being prescribed more often by doctors and the benefit is that the absorption into the blood is limited and it tends to stay concentrated to the area you need it the most according to neurologist Corey Hunter.

FACT: Neuropathic pain does NOT respond to 'normal' pain medications.

Some of the ingredients physicians use in these compounds include Lidocaine, Ketamine, Gabapentin, and Amitriptyline, mixed by a compounding pharmacy in percentages as prescribed by the physician.

For patients with an immune mediated neuropathy the use of intravenous immune globulin (IVIg) has been very effective in reducing pain in sensory neuropathies while providing more muscle strength in motor neuropathies and protecting the nerves from more damage. It works! Ketamine infusions for chronic pain are sometimes used. (Used by permission)

■ INFORMATION IN E-NEWS FROM THE FOUNDATION FOR PERIPHERAL NEUROPATHY

This is sent to members of The Foundation. To join and read more, you can go to tffpn.org

SAFE IN THE KITCHEN

Peripheral nerves control your sense of touch, how you feel pain and temperature, your muscle strength and balance. People with peripheral neuropathy need to take extra care in the kitchen

to avoid injury. Be sure to clear the floor of rugs and clutter. Use pot holders when you are cooking, and a thermometer to test water temperature before washing dishes. Note: This is a good

Roster of Our WNA Information and Support Groups

Some groups meet in December and some don't. If the group you attend does not appear on this list and you plan to attend, please call the contact person to check whether it is meeting this month.

Groups planning to meet in December: Berkeley-Oakland, CA; Santa Rosa, CA; Davis, CA; Redwood City, CA; Merced, CA; Auburn, CA; Lakeport, CA

Groups that will not meet in December: Grants Pass; OR, Elk Grove, CA; Woodland, CA; Livermore, CA; Walnut Creek, CA; Carmichael-Eskaton, CA; Ukiah, CA; Santa Cruz, CA; Folsom, CA; Roseville, CA; Antioch-Brentwood, CA; Modesto, CA; San Jose, CA; Fresno, CA; Concord, CA; Grass Valley, CA; Monterey, CA; Sacramento, CA; Santa Barbara, CA; Turlock, CA

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

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 daylight 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

Salli Hearn (530) 268-1017

Jackson

For information, call

Bev Anderson (877) 622-6298

Lakeport

Lakeport Senior Center

507 Konocti Ave.

Mito Shiraki (707) 245-7605

Lincoln

For information call:

Bev Anderson (877) 622-6298

Livermore

4th Tuesday, 10 AM

Heritage Estates

900 E. Stanley Blvd.

Sandra Grafrath (925) 443-6655

Madera

For information, call

Bev Anderson (877) 622-6298

Merced

2nd Thursday, 1 PM

Central Presbyterian Church

1920 Canal Street

(The Hoffmeister Center across the street from the church)

Larry Frice (209) 358-2045

Modesto

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 - Cont. on page 3

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

President's Message

By Bev Anderson



Thank you to all of you who attend your support group regularly. You are part of a faithful group that participates no matter the topic, speaker, or no speaker. Your support group leader can depend on you to be there if at all possible. You are among those that make support groups possible.

Support group leaders are regular people with dedication to making a difference for people. This encourages them to use their leadership skills to help those with neuropathy. Your support and encouragement mean much to your leader and to the health of your group. You know that the group is not solely for your benefit but is there to help others who are newly diagnosed and desperate for information or who are going through a rough time. Seeing and talking to other people who know what neuropathy is like makes a huge difference when family can't understand and friends wonder when a person says they can't do something because of neuropathy.

Recently a support group leader said that at the meeting she had conducted recently that it consisted of mostly new people and few regulars. She has worked hard for years and does a great job. My heart hurt thinking of how much time and effort she has given to those that have come to the group only to have them not value it enough to help her help others. Just having a presence there is a big help. Please make it a point to put it on the calendar to be there as often as possible. When an appointment is suggested at that time, unless it is an emergency or critical to your care, ask if another time is available.

If you ever meet someone who you think would be a good group leader and they are interested, I would be delighted to meet them. We always have unreached areas in any region in need of a leader or more

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WNA Information and Support Groups – continued from page 2

San Jose

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

San Rafael

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

Santa Barbara

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

Santa Cruz

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

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

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

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

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

Start a support group in your area:

Contact Bev Anderson at

(877) 622-6298

or info@WNAinfo.org

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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REPORTS FROM MEMBERS AND FRIENDS

Christeen Mulholand of the San Jose Neuropathy Support Group reports that she used a Rebuilder and took ProArgi9 L – Arginine for good results with her neuropathy.

Sharlene McCord, leader of the Auburn Neuropathy Support Group, reports that taking magnesium has helped her get more and better sleep.

Some people in the Auburn Neuropathy Support Group are finding that the bar of soap under the

covers beyond the feet or a stainless steel spoon laid there helps them get to sleep.

Other sleep suggestions from Harvard Medical School: Try “relaxing” distractions – meditation, focus on a peaceful location. Take your pain medication shortly before you go to bed. Reading a book in quietness and a regular sleep schedule helps.

Editor's note: Magnesium is also good for cramps and stiffness. Talk to your doctor for amount to take.

CREAMS TO MOISTURIZE SKIN ON YOUR FEET AND HANDS

It is important to keep your feet moisturized so the skin won't split and cause a sore that can lead to losing your foot. Hands need help too because they are constantly being washed. Here are several choices people with neuropathy make that could be helpful to you, especially in the winter:

A friend of the WNA wanted to let our members know that she was able to find 40% urea cream in a three ounce tube for a reasonable \$23.08 cash price at CVS.

40% urea cream is a skin softener sometimes prescribed to prevent the feet from drying, cracking, and splitting. It is not a Medicare drug, so most Medicare Part D stand-alone plans also will not cover it to any extent. Medicare Advantage plans (Part C) may or may not provide coverage. So a reasonable cash price is crucial. For some reason, inexpensive urea cream has become difficult to find. This

person used to get it for about \$40, but the brand her pharmacy currently carries is now \$160. She contacted a variety of pharmacies, including Costco and Target, and most found a fairly inexpensive version on their listing, but could only order a more expensive version from their particular supplier. Thinking others may also be having this problem, she wanted to share her find with us.

Amlactin, Moisturizing Body Lotion that says it is an Alpha-Hydroxy Therapy is another cream often recommended by podiatrists and dermatologists. There are also generic products that contain the main ingredient in Amlactin which is Ammonium Lactate.

The standby dairy farmers have used for years is Bag Balm. Any farmers that did any hand milking, especially, used this to good effect. However, the process of cleaning the equipment is also hard on hands so Bag Balm is often chosen.

ILLUSTRATION OF A WAY WNA HELPS

E-mail contactor: “Hi, Bev, I really appreciate the recommendation on the neuropathy book. It has sparked a fire in me that I didn't have because of my doctors. I do not believe after reading part of the book that I'm getting the treatment I need. Do you know who, preferably in NorCal, is the best neuropathy doctor?”

Bev: “What medical group is your primary care doctor related to? That makes a difference. Also, your health insurance makes a difference. Are you tied to that group or can you go to any doctor you choose. I can give you some suggestions but you would not be able to go to some depending on your insurance.”

Contactor: “I'm currently with _____; however, I can go wherever my insurance is taken. We have a PPO with _____. I started looking up some doctors yesterday and found a _____. He was on the neuropathy association website, thoughts? Let me know if there's anything else I'm missing. Thanks so much for your help.”

Bev: I don't know this doctor. The chief of neurology at your current health care provider is an expert in neuropathy, but doesn't have the time for many patients due to his administrative, teaching, and research commitments. However, he could recommend someone on his staff. There are others in the area I could recommend, but starting with your current location is probably best. Always check to see if the neurologist has neuromuscular training. If they don't or discount the question, you don't want to see them. Neuropathy is a neuromuscular disease. Not understanding the Peripheral Nervous System and its relationship to the muscles makes a person not one you want to see for neuropathy.

Contactor: I want to thank you so much for the Doctor info. I found Dr. _____'s email and wrote him yesterday morning about my situation and he wrote me back that afternoon telling me someone would be in touch with me to schedule an appointment. So thanks again.

HARVARD MEDICAL SCHOOL'S HEALTH BEAT RECOMMENDS EXERCISE FOR JOINT PAIN

The right exercise can help pain in joints HEALTHBeat says.

- It increases strength and flexibility as developing strength in surrounding tissue that will take pressure off of joints.
- It relieves stiffness.
- It boosts production of synovial fluid, the lubricant inside the joints keeping the joints "well oiled."

- It increases production of natural compounds in the body that help bring down pain.
- It helps you keep your weight under control which can help all your joints.

The Harvard Medical School produces more than 60 special reports on health topics like this. You can see these at <http://www.health.harvard.edu> to think if any are of interest to you.

President's Message – Continued from page 3

people on the leadership team. If you know anyone interested in a group, please let me know as we have the beginnings of groups in places that if there were more people interested we could grow a new support group.

Two of our group leaders have been quite ill recently and are recovering. Monte Schrader in Modesto had a heart condition requiring treatment that initially did not go as well as expected. It is somewhat slow, but he is expected to recover. He is home now after being in convalescent care for a few weeks.

Stan Pashote fell from a ladder (Please raise your right hand and repeat after me, "I will not use a ladder.") and hit his head on concrete. No other bones were broken but he is recovering from a skull fracture and all the problems that can cause for someone whose physical condition is not robust to start with. As of this writing, Stan is now home doing rather well. Actually, it was two hours ago at this point. Both of these guys are presently using walkers to get around.

This newsletter has a variety of short, easy to read articles for the busy season. I hope at least one of them is helpful to you.

Before or after this newsletter, our end of the year letter encouraging you to pay your dues if they are due in December, January or February and/or make a contribution to The Western Neuropathy Association will be coming. If you or anyone you know has funds

they would like to donate to a non-profit organization before the end of the year to aid them in their tax planning, please let them know we would be grateful to receive any amount and promise to put it to good use.

We have a focus on support groups and could have more if we had funds to advertise and communicate in a variety of areas. This goes along with our efforts to make neuropathy known as far and as wide as possible. Currently, we are growing our outreach to the health care community with visits with doctors, especially neurologists, to develop connections between us. Our potential is tremendous. Additional funding is critical to moving forward on much of this. Whatever we can do benefits neuropathy patients in the long run. That is our chief goal – to benefit people with neuropathy.

Happy Holidays,

(Using this term includes all of the many holidays in this season of the year which are celebrated by our members. If I listed them, I might leave one out. I trust you and your family will enjoy and be uplifted by your celebrations and that 2016 will dawn with peace in our hearts and in our world.)

Bew

DISCOUNTS FOR WNA MEMBERS

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

Neuropathy Support Formula

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

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

Additional Discounts

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

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

AMAZON SMILE

Do you ever shop online at Amazon.com? I often do so as do millions of people. Amazon now has a program called "Smile." You sign up for it online, select the nonprofit group that you want to support, and from then on, it automatically gives a portion of your purchase with Amazon to the nonprofit you selected. The price you pay is the same, you don't pay any more. It is Amazon's way to help nonprofit organizations that do so much good. The Western Neuropathy Association is registered so please sign up for Smile before you shop the next time on Amazon.com. Help this group that helps you. Every penny helps. You can tell your friends, neighbors, relatives, etc. about this and they can also sign up, too.



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:

- 15288403 This double blind, placebo controlled study of the effectiveness of pregabalin (Lyrica®) 300mg daily for diabetic peripheral neuropathy demonstrated statistically significantly decreased pain, improved mood and quality of life.
- 15288411 This is a double blind, randomized; placebo

controlled study of 244 adult diabetics with painful neuropathy. At higher doses of venlafaxine (Effexor®) 150mg-225mg, the Visual Analog Pain Relief Scale at week 6 was 44mm vs. 60mm for placebo (p<0.001).

- 16235318 This is a Cochrane Database review of 32 double blind randomized trials utilizing lidocaine anesthetic intravenously or analogs—tocainide, mexitilene or flecainide—orally, to relieve neuropathic pain. These agents were as effective and safe as carbamazepine, amantadine, gabapentin or morphine.
- 17157116 This University of Chicago dose escalation study of dextromethorphan (DM) 45mg/ quinidine 30mg one to four daily resulted in significant pain relief (p=0.001—probability of chance result less than 0.1%). Adverse events occurred as follows: nausea 27.8%, dizziness 25.0% and headache 25.0%. DM is the ingredient found in cough medicine and is an NMDA inhibitor. Quinidine is a cardiac drug used to control arrhythmias and incidentally increases blood levels of DM.
- 20373255 This paper discusses a novel combination drug, Nuedexta®, which contains the NMDA (N-methyl-D-Aspartate) antagonist, dextromethorphan (DM) and quinidine, a cytochrome p450 2D6 enzyme inhibitor that effectively prevents the metabolism of DM, increasing its blood level. DM (commonly used as a cough suppressant in cold medicines) is effective in reducing diabetic neuropathic pain as well as pseudo bulbar affect (uncontrolled emotionality post stroke)

BREAKTHROUGH POTENTIAL FOR A LIMITED HEREDITARY NEUROPATHY

(This is presented to show there are advances in research resulting in possible cures for certain types of neuropathy and allied conditions. It is an international search that takes much time to do the testing to see if it works successfully. This also opens a window to see that there are neuropathies that are not familiar to most of us and likely not to at least some of our doctors. The variety of hereditary neuropathies is further pointed out here. There are some of these that are only found in certain places in the world and people in the United States whose family came from that location can surprise doctors here and have much difficulty being diagnosed. It is not likely this medication will be of value to anyone receiving our newsletter, but one never knows. However, this research may open doors to other knowledge that can help many more.)

Alynam Pharmaceuticals, Inc.. (ALNY) an RNA therapeutics company, announced new results from the ongoing Phase 2 open-label extension studies with patisiran and revusiran, investigational RNAi therapeutics targeting transthyretin or TTR for the treatment of TTR-mediated amyloidosis called ATTR amyloidosis.

Data from the patisiran Phase 2 OLE study provided continued evidence following 18 months of dosing that patisiran has the potential to halt neuropathy progression in patients with Familial Amyloidosis Polyneuropathy or FAP. The familial amyloid neuropathies are a rare group of autosomal diseases wherein the autonomic nervous system and/or other nerves are compromised by protein aggregation and/or amyloid fibril formation.

The company expects to complete enrollment in the APOLLO Phase 3 trial of patisiran over the next three to four months supporting a potential New Drug Application filing in 2017 if the study is positive.

In addition, initial data from the revusiran Phase 2 OLE study showed robust and sustained knockdown of serum TTR. It was found to be generally well tolerated in the majority of patients with TTR cardiac amyloidosis, including patients with Familial Amyloidosis Cardiomyopathy and Senile Systemic Amyloidosis, out to 10 months of treatment. These new clinical data were presented at the 1st European Congress on Hereditary ATTR amyloidosis held November 2-3, 2015 in Paris. (News release)

recommendation when running water for a bath or shower as well. Don't depend on your hands to tell the temperature. The underside of your arm or elbow area or a thermometer can be more accurate.

YouTube VIDEOS ON PERIPHERAL NERVE PAIN MAY MISGUIDE PATIENTS

Researchers who combed YouTube for videos regarding peripheral neuropathy, or nerve damage that causes weakness, numbness, and pain in the hands and feet, found 200 videos, but only about half of them were from healthcare professionals, mostly chiropractors. Alternative medicine was cited most frequently among the treatment discussions, followed by devices and pharmacological treatments. Only a minority of treatment discussions were based on recommendations by the American Academy of Neurology.

"Caution should be exercised when YouTube videos are used as a source of information for the treatment of neuropathy," said Dr. Harsh Gupta, lead author of the Muscle and Nerve study. "With the ever-increasing reach of YouTube to our patients, a stronger presence of neurologists in this social medium is needed."

SHOULD PN PATIENTS GET A FLU SHOT?

Flu season is upon us. At this time of year the Foundation frequently receives inquiries about the safety of getting the flu vaccine if a patient has peripheral neuropathy - especially peripheral neuropathy patients with underlying immune issues. HIV patients tend to be especially skeptical about receiving the vaccine.

According to the Centers for Disease Control there is no evidence that the flu shot will make their neuropathy symptoms worse unless they had a vaccine induced neuropathy associated with Guillain-Barre Syndrome.

Note: When flu shots were first given, it was thought that cases of Gullain-Barre Syndrome increased. If a person has this type of neuropathy, many medical groups advise against getting the shot. Recent testing of current vaccine development indicates that this problem may have been solved. If you have had GBS, check with your doctor before getting a flu shot. The doctor can decide with you if there is any risk for you. Otherwise, unless your doctor tells you differently, be sure to get your flu shot. It can save you from a lot of misery. If you don't get one, be sure to stay far away from babies too young to get the shot

FOLLOW-UP NERVE CONDUCTION STUDIES IN CIDP AFTER TREATMENT WITH IGIV-C: COMPARISON OF PATIENTS WITH AND WITHOUT SUBSEQUENT RELAPSE

Study found that most subjects developed new demyelinating

findings during the active treatment phase of the immune globulin intravenous study even as they were improving clinically. This may reflect ongoing demyelinating activity even as other nerve segments were undergoing repair or remyelination. The appearance of new conduction blocks in patients with CIDP undergoing IVIG therapy has been reported previously. CIDP appears to be a more dynamic disease process than has been appreciated previously, with ongoing demyelination and remyelination, even during periods of apparent clinical remission, similar to what is seen in multiple sclerosis. This might limit the improvement seen in some patients undergoing treatment.

TAKE CHARGE BY KEEPING TRACK!

Recognizing patterns in your experience and documenting them can provide invaluable information about how your lifestyle, habits, and therapeutic treatments are impacting your ability to live well with neuropathy. Take charge by keeping track! Keep a diary of your day:

- when did the pain become more challenging
- how long did you sleep
- what medications did you take and when
- what kind of physical activity did you have
- and maybe even what you ate!

Look for patterns: Does the time of day you take pain medications help you sleep better? Did you have less pain the day after you exercised?

Share this information with your doctor to create your own wellness plan!

* these ideas come from Pain-Tracking: Your Personal Guide to Living Well with Chronic Pain by Deborah Barrett

MEDICATION TIMING

Chronic pain, including the pain and burning of peripheral neuropathy can make getting a good night sleep feel impossible. Many find relief from pain medications but consider this - the timing of when you take your medication can be as important as what and how much you take.

With your doctor's consent, consider taking evening pain medications two to three hours before bedtime, giving the medications time to "kick in" before settling in for the night and maximizing their effectiveness during sleep hours. (These items used by permission.)



WESTERN NEUROPATHY ASSOCIATION

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■ PN Information/Advice ■ Support Group Inquiries

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and help the WNA

continue

to help you!

See page 5 for details.



Happy Holidays from All of Us at WNA!

WNA Art Auction – Help Raise Funds for WNA Activities

Bid online for this fantastic piece of original art, *20 Mule Team*, from WNA Board member Darrell O'Sullivan who is an accomplished landscape and nature photographer. Go to the WNA website at www.pnhelp.org for information.

About 20 Mule Team. In the 1890s in Death Valley, Borax Ore was transported using a 20 Mule Team and wooden wagons. For many miners and prospectors this was a life and death struggle for millions of dollars. This image was created from a photograph of one of the remaining wagons still found in Furnace Flat, Death Valley. This art work is matted (white with light grey speckles) and framed with a nice western style frame.

About the artist: Darrell O'Sullivan is a photographer and artist focusing on nature, landscape, macro-photography and advanced photography printing. He is passionate about revealing nature's beauty and expression in his imagery. Darrell is completely self-taught only taking up photography in the late 1990s, and he prints and frames all of his own art. He began a philanthropic business (OSullivanImages) in 2005 to help support a wide variety of fund raisers and educational causes. He annually contributes fine art images to KVIE Public Television and the KVIE Art Auction. He regularly donates fine art images to many fundraising events - including the UC Davis Children's Hospital, Children's Painting for Miracles, Serotonin Surge, UC Davis Free Clinic Fundraising, Pour for Prevention of Child Abuse, Sunflower Presents, UC Hospice, San Joaquin County Hospice, Cancer Society, etc.

Here is the direct link to the auction where you can get a better view of the print - <https://www.32auctions.com/wna>



Framed Dimensions - 24 3/4" wide X 19 1/25" high



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.

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