



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)

■ REPORT FROM THE NEUROPATHY ACTION FOUNDATION CONFERENCE, PART ONE

Livestream Notes from the 12th Annual Neuropathy Action Awareness Day - 6/22/18
By Barbara Montgomery, Group Leader, Las Vegas, NV

Congrats to our own Bev Anderson: Founder/president of the Western Neuropathy Association. She was presented the **2018 Neuropathy Action Awareness You Are Our Hero Award!** Bev mentioned our Las Vegas group from the podium. Bev is our leader and our group is blessed to be under her wonderful Association! We need to support her by joining the Western Neuropathy Association and receiving her newsletter.

Presentation Notes:

Topic: The Whole-Body Experience: Neuropathy from Head to Toe

Todd Levine, MD, co-director, GBS/CIDP Center of Excellence at Phoenix Neurological Associates and clinical associate professor of neurology, University of Arizona School of Medicine.

Nerves send signals like a phone wire. We don't know where the phone connection is going wrong: at the phone itself, the city, the wires... Different diseases that affect the nervous system are like these telephone wires.

How long does it take to be diagnosed with peripheral neuropathy (PN)? Do I have to worry about a wheelchair or dying? Best predictor of future is your past. If in the last 20 years you have been walking around, you are OK. CIDP or Guillain-Barre Syndrome are serious and you can end up in a hospital immediately. Burning/numbness can take years. Intense pain can be in your back and/or your feet. You have to find localization and find out 'where' the problem is. Some have inherited PN.

Cognitive behavioral therapy/neuropsychologist and hypnotism are some types of treatments.

How can we function better? Not only more medications, but to learn how to function better. Most insurance won't pay. Ten sessions are enough to use for rest of your life. Pain clinics can help.

Sleep problems: Cycle gives more pain. Increase sleep, reduce pain.



If pain is bad enough, try medications. If not working, or causes side effects, try something else. Then if nothing works, try non-medical approaches.

Dizzy, dopey, stupid with anticonvulsants? Make a change.

There is a place for opiates. It is not about whether pain went from an 8 level to a 6, but could you sit at a movie, play golf, think as well as you did before? If not, then best to do something else. You don't want up and down cycles. Take Percocet then ok, then take Percocet. We want to make you level ... not up and down.

Try to understand where the problem is coming from.

Are you worse off or on the meds? Most times they are NOT WORSE.

Diet, water exercise, spiritual, cognitive therapy are possibilities to ease your suffering.

Different Diseases that affect the Nervous System

Central: Brain/Spinal Cord

Peripheral: Any nervous system outside the brain and spinal cord.

Numbness could be spine, nerve, brain. You have to figure it out.

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Roster of Our WNA Information and Support Groups

Some groups continue meeting all summer months but some don't. If the meeting you attend does not have any changes in its listing, it likely meets through the summer. If you want to be sure, call the leader at the number given.

2018 WNA Board of Directors

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President

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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

Antioch-Brentwood

Next meeting, Sept. 19
3rd Wednesday, 2 PM (odd numbered months)
Antioch-Kaiser, Deer Valley Rooms 1 & 2
Marty Price (925) 626-7988

Auburn

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

Berkeley-Oakland

Next meeting Sept. 19
3rd Wed., 3-4 PM
North Berkeley Senior Center
1901 Hearst Ave.
Kathleen Nagel (510) 653-8625

Carmichael - Atria

Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
For information, call:
Ryan Harris 916-342-8440

Castro Valley

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

Concord

Next meeting, Sept. 20
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

Davis

Next meeting, Sept. 10
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

Folsom

Special Meeting, Thursday, July 26, 12:30 PM
Burger Rehabilitation
1301 E. Bidwell St.
Bev Anderson (877) 622-6298
Special Speaker: Lindsay Fosler
Hereditary ATTR Amyloidosis PN

For information on groups in the following areas or any other place you are interested in finding out about a support group, call Bev Anderson at (877) 622-6298. She is actively trying to open new groups and re-open closed groups. Check with her about a group in your area especially if you would volunteer to be the leader.

California: Alturas, Bakersfield, Clearlake, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, Salinas, San Francisco, Santa Maria, San Rafael, Sonoma, Sonora, Stockton, Susanville, Truckee, Tulare-Visalia, Turlock, West Sacramento, Weed, Ukiah, Woodland, Yreka, Yuba City-Marysville. **Nevada:** Reno-Sparks. **Oregon:** Brookings, Medford, Portland, Salem.

Fresno

3rd Tuesday, 11:00 AM
Denny's Restaurant
1110 East Shaw
Bonnie Zimmerman (559) 313-6140

Grass Valley

Next meeting, Sept. 10
2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church Street
Bev Anderson 877-622-6298

Livermore

4th Tuesday, 10 AM
Heritage Estates, 900 E. Stanley Blvd.
Lee Parlett (925) 292-9280

Merced

Next meeting, Sept. 13
2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(Hoffmeister Center across from the church)
Larry Frice (209) 358-2045

Modesto

Next meeting, Sept. 17
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 St.
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Placerville

Next meeting, Sept. 11
2nd Wednesday, 1 PM
El Dorado Senior Center
937 Spring Street
John McCoy (530) 642-8511

Redwood City

Next meeting, Sept. 25
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

Next meeting, Aug. 21
3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Charles Moore (916) 485-7723

San Francisco

Please contact Bev at 877-622-6298
if you would like to attend a SF meeting.
There may be a meeting fairly soon.

San Jose

Next meeting, Sept. 15
3rd Saturday, 10:30 AM
O'Conner Hospital, 2105 Forest Avenue
SJ DePaul Conf. Rm.
Danielle LaFlash (415) 297-1815

Santa Barbara

4th Saturday, 10AM (odd numbered months)
St. Raphael Catholic Church
5444 Hollister Ave., Conference Room
Shirley Hopper (805) 689-5939

Santa Cruz

3rd Wednesday, 12:30 PM (odd numbered months)
Trinity Presbyterian Church
420 Melrose Avenue
Mary Ann Leer (831) 477-1239

Santa Rosa

1st Wednesday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Judy Leandro (707) 480-3740

Thousand Oaks - Westlake Village

2nd Monday, 2:30 - 4 PM
United Methodist Church of Westlake Village
1049 S. Westlake Blvd.
Angie Becerra (805) 390-2999

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse
Vista Room
Karen Hewitt (925) 932-2248
Special Speaker: Lindsay Fosler
Hereditary ATTR Amyloidosis PN

NEVADA

Las Vegas

3rd Thursday, 1 PM
Mountain View Presbyterian Church
8601 Del Webb Blvd.
Barbara Montgomery (818) 400 0296

OREGON

Grants Pass

Next meeting, Sept. 19
3rd Wednesday, 2:00 PM
Club Northwest
2160 N.W. Vine St.
Carol Smith (541) 955-4995



Celebrating our 20th Year – Upcoming events will be announced next month.

We heard that many watched the Neuropathy Action Foundation (NAF) Conference in Los Angeles on June 22 via live e-streaming. We received a set of notes of each of the speakers except the last from Barbara Montgomery, leader of the Las Vegas Neuropathy Support Group. Her set detailing the talk by Dr. Todd Levine, neurologist in Phoenix, AZ, are included in this issue. Dr. Levine is also the lead author of the recent book on small fiber neuropathy – Small Nerves, Big Problems. Notes from other speakers will be included in future newsletters.

Pam Hart, Darrell and Mary O'Sullivan, and I flew to the Los Angeles International Airport on June 21, spent the night, attended the Conference on Friday and flew back Friday evening. (Our flight and lodging were paid by the Neuropathy Action Foundation for which we are grateful.) During the Conference, we had a table with information and visited other exhibitors in addition to being present at each of the speaker's presentations. You will see a photo of my receiving the Neuropathy Action Foundation's You Are Our Hero Award 2018 from Dominick Spatafora, NAF's president. I was thrilled to receive this recognition.

My speech following the award is also included in this newsletter. It resulted in three volunteers to lead a support group that I am following up on to be sure that they are still interested. I've also received volunteers for another group in the area where the Conference is held -- that is a major award in itself, I feel. That interest came as a result of the five minutes I was given to respond to receiving the award. I felt there were many there that didn't know our organization more than just seeing it on the program so being able to provide them an overview was helpful. Maybe it will help you better understand the organization to which you belong as well.

You will soon receive our midsummer letter reminding people about their dues and asking for a contribution. We appreciate any amount people are able to give. You may have had times in your life, seldom or often, when the income didn't quite cover your expenses. WNA is managing OK but we too experience times when our expenses exceed our income for the month. This is our 20th Anniversary coming up in November. It is time to celebrate and have a very great year.

Over the next months, Lindsay Fosler of Alnylam Pharmaceuticals, Inc. will be speaking at a number of our groups about Understanding Hereditary ATTR Amyloidosis. An article telling you about it was in the June 2018 issue. It is a fairly rare neuropathy but there are likely more cases than are commonly known. It is definitely not one you want to have. Knowing about it, that there is a test for it, and a new medication and how that happened is good information and can give us hope. Her presentation will likely tell you more about neuropathy than you knew when you came to the meeting. I recommend you get to a meeting if there is one in your area. She will be listed at the number of groups she will speak to in September. Two groups will hear her at the end of July.

Bev

MARIJUANA FOR NERVE PAIN OFFERS HOPE FOR NEUROPATHY SUFFERERS

Medical marijuana has been found to be effective in treating a whole host of conditions and disorders. In fact, as scientists continue to investigate the plant, more medical uses are being discovered. One of the conditions medical marijuana is found to be useful for is neuropathy. The nerves are damaged and pain is the result. According to several studies, medical marijuana is very effective for treating the condition, regardless of its cause, and many are now using marijuana for nerve pain. (Jessica Leone September 19, 2018) Used by permission.

DR. ARTHUR AVLIN - CANCER EXPERT OF SAN RAFAEL, CA, HAD NEUROPATHY

Dr. Arthur Avlin, a leading pediatric oncologist, died Aug. 14, 2017 at his home in San Rafael after an illness. He was 90.

Family members and colleagues remembered him as a man with insatiable curiosity. He would encourage students to examine the different coloration of his feet to understand a disease that wasn't critical to why he was being admitted, but he'd say, "This is a rare opportunity to understand the effects of neuropathy. This is why my foot is shaped this way. This is why I have to walk this way. He used himself as a diagram," said Debbie Avlin, his wife of 63 years.

(The article from which this comes was sent to us by Isabella Lively of Rocklin.)

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 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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Physical exam, talking, what does it sound more like. EMG nerve conduction study. Only tests the peripheral system to see if it is injured. They break that down to three nerve groups.

1. Sensory: Transmits signals from specialized receptors in the skin, joints and inter organs. Feeling, numbness, burning, stabbing most common 90%.
2. Autonomic: Control involuntary functions. Most meds that are good are focused on heart symptoms, raise blood pressure. Don't have meds to move food through the stomach. Erythromycin, antibiotic works, or teach people to eat differently. All automatic behaviors: heart rate, blood pressure, digestion, sweating. These can also be damaged and very disabling. Poor treatment for this.
 - a. Bladder is different. We have meds for that.
 - b. Sweating/temp regulation, overheating or can't sweat, nothing we can do. Consider a cooling vest.
3. Motor: Controls muscles, and voluntary movement.

Disease that damages sensory nerves ... some are dead nerves, numbness, but if not dead, some are on their way to being dead. Yes or no, travels up to brain and a response may give feeling of burning.

Causes of Dysphagia: Difficulty swallowing (dysphagia) means it takes more time and effort to move food or liquid from your mouth to your stomach.

• Head and Neck Surgery	36%
• Stroke	29%
• Closed Head Injury	7%
• Spinal Cord Injury	6%
• Neuromuscular Disease	6%
• Vocal Cord Problem	4%
• Zenker's Diverticulum	2%
• Anxiety	2.5%

Variability in neuropathy symptoms. Rare to have it stay at one level. Hot, cold, gluten, carbs, sugar ... all effect people differently. All are reasonable, but it's individual. Keep a diary. Sleep, stress, diet to see when it is worse and what you were doing.

Lack of sleep increases pain.

Spinal cord stimulators: Phone wire analogy, put impulse to keep wires from sending wrong signals. Physician can do a trial for about a week. Ask self "did it help?" If so GREAT ... no side effects for trying.

Not something I would recommend. It's a hit or miss. Judge each trial. If you tried everything, then maybe try something that seemed better than the rest as a longer trial.

Caffeine: Raises blood pressure ... better than meds if you have low blood pressure. Used for autonomic. Neurologist wants more blood to the brain. Low blood pressure, want to raise it? Eat more salt if blood pressure too low.

Balance difficulty: Weak muscles; don't know where our foot is. Sensory nerves damaged; have problem with balance.

Treatment:

- Nerves generate electricity (+-) to generate signal. Can feel like a pin through big toe, for no good reason. Some medications block the +sodium channels. But these same channels effect the heart.
 - o Anticonvulsant; Gabapentin, Lyrica
 - o Antidepressants: Cymbalta stops perception of pain.
 - o Pain Meds: Narcotics. They can be effective. Improve level of function.
- Pain will be taken away but life style will be affected and side effects.
- Nutritional Supplements: Strong advocates/less advocates. Body is trying to regrow. Diet and exercise will help. Not one particular diet works for all. But good nutrition is best for all.
- Infrared Light Therapy
- Electrical Stimulation
- Magnetic Stimulation

Autonomic: All automatic behaviors. Heart rate, blood pressure, digestion, sweating. These can also be damaged and very disabling. Poor treatment for this.

Exercise is important.

Sleep Problems: Cycle gives more pain. Increase sleep, reduce pain.

If pain bad enough, try med if not working, or causes side effects, try something else...then if it doesn't work, try non-med possibilities.

Two types problems; Numbness and Pain. Biggest problem is numbness. Amputation is mostly from numbness because you can't feel the pain. Always check feet.

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Take care of feet:

- Leg symptoms
- Walking Vs Resting
- Many other things cause leg pain
- Radiculopathy/Stenosis
- Often asymmetric
- Vascular Claudication When are your symptoms worse?
- Worse at night and when resting
- Restless Leg Syndrome
- Periodic Limb Movements
- Libido is generally not affected
- Men/women may be less sensation
- Bladder: urinary incontinence
 - o Not every symptom is PN

Gut system:

- o Autonomic nervous system controls the peristalsis in the gut
- o Gastric stasis...can occur causing severe symptoms
- o Many other causes
- o Gi Evaluation (leads to nutrition issues)

Cardio symptoms: impaired heart rate

- o Lightheadedness
- o Syncope
- o Fatigue
- o Palpitations *need cardiologist and neurologist. Test autonomic testing; autonomic dysfunction is a strong predictor of increased mortality particularly with diabetes
- o Tilt table test
- o Treatment: Increase baseline blood pressure; stop anti hypertensives; increase flow

Swallowing problems/dysphagia: choking; weight loss; worse with liquids

- Required evaluation by GI. Numerous causes.

Emotional Side Effects:

Depression/Anxiety:

- As many as 30% of chronic PN patients develop depression.
- Treatment options
 - o Cognitive behavioral therapy/ neuropsychologist, hypnotism, counseling
 - o Exercise
 - o Medications
- SNRI-Cymbalta
- SSRI
- TCA

Cognitive Therapy: How can we function better? Job is not to give more meds, but to teach you to function better. Most pain clinics have a therapist.

Exercise is important.

Sleep Dysfunction: Very high percentage of patients have sleep problems associated with their neuropathy

- Restless legs syndrome
- Pain
- Disrupted sleep architecture
- Other causes of sleep problems
 - o Sleep apnea
 - o Insomnia
 - o Need for sleep study to decide on therapy
- Sleep Problems: When not on a regular cycle gives more pain. Increase sleep, reduce pain.

Medication Side Effects:

- Antidepressants
 - o Mood change
 - o Nausea
 - o Thinking differently
- Anticonvulsants
 - o Dizziness
 - o Sleepiness
 - o Weight gain
 - o Lower extremity edema
- Opiates
 - o Addiction/Tolerance
 - o Thinking differences
 - o Constipation
 - o Endocrine side effects

Conclusion:

Not every symptom is always related to your neuropathy.

Individual symptoms can be managed and treated.

They need to be diagnosed accurately.

Many can be managed without additional medications and therefore without additional side effects.

DISCOUNTS FOR WNA MEMBERS

Continued from page 4

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.

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.

BEV ANDERSON'S SPEECH AT THE CONFERENCE UPON RECEIVING THE SPECIAL AWARD

I want to thank Dominick Spatafora and the Board of the Neuropathy Action Foundation for this spectacular honor. Dominick and I met in the beginning stages of the organization (Neuropathy Action Foundation) and have encouraged each other along the way. This strategic foundation has made a major difference in the knowledge of neuropathy especially in the medical community, which still has a long way to go in knowing neuropathy.

The Western Neuropathy Association started in November 1998 so we celebrate our 20th year this November. We started as the Placer-Nevada County Neuropathy Association. With the encouragement of Mary Ann Donovan, a founder of The Neuropathy Association, we incorporated in 2001 and affiliated with that organization as The Northern California Chapter of The Neuropathy Association. We specialize in support groups and had one support group meeting within driving distances of most people above a line from Fresno to Monterey including those cities.

There were two groups in Southern California. Neither exists today. We asked to become the Pacific Chapter of The Neuropathy Association to start trying to spread south. It was granted and new groups started with currently four groups meeting regularly. We also have groups in Grants Pass, Oregon and Las Vegas, Nevada.

(I'd like to give a shout out to our Las Vegas group here and where they are watching the live e-streaming and the San Jose and Redwood City groups and others from other groups in Palo Alto doing the same.)

We would have many more groups if we could find people willing to lead a group. We say we want people to know about neuropathy and the best way to get the word out to people and motivate them to do the same is through a support group. However, even though we help people who lead groups so they don't feel alone, getting and keeping leaders is our biggest challenge.

When The Neuropathy Association dissolved in December, 2014, we continued as the independent organization we had always been as our incorporation is as a California Public Benefit Corporation. We had to change our name again and became The Western Neuropathy Association with emphasis on California, Nevada, and Oregon.

As I said, our chief focus is getting information out with an emphasis on support groups. However, we have special projects that gain member interest.

We thought carefully about how we could make a difference in what doctors, especially neurologists know about neuropathy. We decided that getting a

book from a leading neuropathy authority into the hands of those training to be neurologists would be effective. We delivered them to one medical center training neurologists and had a good response. We have books for two more that will be delivered soon. We need to raise the funds to keep going until every training site receives the books. The neurology residents are there for three years. If they go for the neuromuscular designation most needed by people with neuropathy, it is four years. We are presenting *Peripheral Neuropathy & Neuropathic Pain – Into the Light* by Dr. Gerard Said (Paris, France), considered one of the world's authorities on neuropathy. It makes it so no U.S. person is seeming in any competition with others. The book covers neuropathy in depth but is readable and not lengthy. It is commissioned by the Neuropathy Trust in the United Kingdom. We are dealing with a British company with U.S. collaborator to get a good price for the books.

One thing I could mention here is the amazement I had one night sending an e-mail to Dr. Said and being invited into a phone conversation between him and a leading neurologist in London. My late hours coincided fine with their day. When I had a request from a lady in northern England for a neurologist that knew about neuropathy, I contacted the London neurologist. He explained that with their medical system, doctors are trained in areas of need and are in communication. He gave me the name and contact information for a neurologist to the north of her small town and one to the south.

We have been working with a research group from the University of California at Davis for over three years now. Their proposal for a pain medication has won competition at the National Institutes of Health (NIH) goes to human trials in early 2019. We are very excited about it.

If you are a member of WNA, just \$30 a year, you receive a monthly newsletter. You can pick up a sample at our booth. Lately, it has featured articles about new medications and treatments every month with the UC Davis pain medication providing regular reports.

If you would be willing to lead a group by yourself or better with at least someone else you know, we would be glad to help you get started. We have copies of our basic guide to starting and developing groups available at our booth at the back of this room. Come by and Pam or Darrell or I will be glad to get acquainted and exchange contact information. You have our brochure in your bag or can pick up one at the Information Desk outside or at our booth. My card is also on our table. We would be glad to welcome you to the exciting world of telling people about neuropathy.

Thank you for your attention. Have a wonderful day and weekend.

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 connect 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.

The reader can also go to the WNA website www.pnhelp.org, click on the RESOURCES tab and select MEDICAL LITERATURE

REVIEW from the menu to review the archive of summaries that have appeared in this column over recent years.

This month's PMIDs:

- 28067783 This paper explores stem cell transplantation to effect peripheral nerve regeneration. The problem of harvesting the stem cells is the donor site morbidity. The stem cells become Schwann-like cells that secrete neurotropic factors that promote axonal growth and remyelination.
- 28084646 This Cochrane systematic review of all treatments of chronic inflammatory demyelinating polyneuropathy (CIDP) finds little evidence for a significant difference among intravenous immunoglobulin (IVIG), plasmapheresis, high dose corticosteroids and azathioprine. There is a need for more long-term randomized controlled cost benefit studies.
- 28092909 The authors share their experience of three patients who were treated with autologous hemopoitin stem cell transplantation following which, in clear temporal association, developed immune mediated neuropathies.

NEW DISCOVERY MAY LEAD TO NEW APPROACH TO TREATING NEUROPATHY PAIN

MAY 31, 2018

Blocking the Pathway of Neuropathy Pain

An international collaboration between Indiana University in Bloomington, Indiana, and the Turku Center for Biotechnology in Finland made early inroads into a new approach to reducing neuropathy pain.

The researchers identified the correlation between the formation of a certain protein in the cell (NOS1AP) and the transmission of neurological pain. By disrupting the formation of this protein and the resultant biological pathway, pain is reduced. The researchers were able to demonstrate that an experimental molecule with this modified pathway was able to reduce the pain as a result of nerve damage and certain chemotherapy treatments in rodents.

A Better Nerve Blocker

The current research also seems to suggest that this treatment may be feasible without the severe side effects attributable to current drugs designed to block the pain receptors or alter the biological pathway.

Next Steps

The formation of the NOS1AP protein and its contribution to chronic pain warrants more study in the quest for chronic pain relief.

More information on this research can be found in this announcement from the University of Turku.

<http://www.utu.fi/en/news/news/Pages/International-Collaboration-between-U.S.-and-Finnish-Researchers-Identifies-New-Approach-for-Treating-Neuropathic-Pain.aspx>



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PAIN MEDICATION RECOMMENDATIONS

Notes From Darrell O'Sullivan

At this year's Neuropathy Action Foundation Conference there was an excellent presentation on "Non-Opioid Treatments for Neuropathy". The presentation was by Steve Richeimer, MD, Professor of Anesthesiology and Psychiatry, Chief, Division of Pain Medicine, University of Southern California (USC). In his talk, he outlined the following treatments:

NMDA Receptor Antagonists

Ketamine	10% topical gel
Memantine (Namenda)	10mg p o bid
Amantadine	100 mg
Methadone	variable amounts
Dextromethorphan	(cough syrup)
Oxytocin	20 - 80 IU

Behavioral Approaches

Bio-feedback
Hypnosis
Relaxation Therapy
Cognitive Restructuring

Book: "Confronting Chronic Pain"



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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.

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