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#### 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)

## ENDOCRINOLOGY > TYPE 1 DIABETES

FDA Says 'Yes' to Short-Acting Insulin Admelog Final approval for Sanofi follow-on to Humalog confirms September 2017 tentative okay By Kristen Monaco, Staff Writer, MedPage Today December 11, 2017

The Federal Drug Administration (FDA) granted full approval for the first "follow-on" version of short-acting insulin lispro, to be sold as Admelog and indicated for improving glycemic control, the agency announced Monday.

The approval covers use in adults with type 2 diabetes, as well as in adults and children at least three years old with type 1 diabetes. Typically administered prior to meals, the insulin can be given via injection, through an insulin pump, or by intravenous infusion.

Admelog, developed by Sanofi, is a follow-on to

Eli Lilly's insulin lispro sold as Humalog and was therefore reviewed under the abbreviated 505(b)(2) pathway, which is separate from the FDA's so-called biosimilar pathway although functionally there is little to distinguish them. Sanofi's insulin lispro had been tentatively approved in September with final approval withheld while patent issues were resolved.

Admelog's approval was also based on two phase III clinical trials involving around 1,000 patients. During the clinical trials, the most commonly reported adverse events included hypoglycemia, itching, and rash.

## SMALL NERVES, BIG PROBLEMS:

## A Comprehensive Patient Guide To Small Fiber Neuropathy

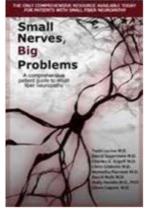
Written by eight neurologists representing some of the leading experts on this disease from across the country, Small Nerves, Big Problems arms patients and caregivers with the latest information available today about small fiber neuropathy – what causes it, what the common signs and symptoms are, how it's diagnosed and ways to manage the disease and minimize pain.

### **About the Authors**

- Todd Levine, MD, Phoenix Neurological Associates (Phoenix, AZ) and University of Kansas (Kansas City, KS)
- David Saperstein, MD, Phoenix Neurological Associates and University of Arizona (Phoenix, AZ)
- Charles Argoff, MD, Albany Medical College and Albany Medical Center (Albany, NY)
- Christopher Gibbons, MD, MMSc, FAAN, Harvard Medical School, Joslin Diabetes Center Neuropathy Clinic, and Beth Israel Deaconess Medical Center Neurocutaneous Laboratory (Boston, MA)
- Mamatha Pasnoor, MD, University of Kansas (Kansas City, KS)
- David Walk, MD, University of Minnesota, (Minneapolis, MN)
- Holly Hendin, MD, PhD, Phoenix Neurological Associates (Phoenix, AZ)
- Glenn Lopate, MD, Washington University (St. Louis, MO)

ISBN=9780998328201; FORMAT=Paperback; \$19.95 Order through your favorite place to buy books or office of the publisher at 219-922-4868.

Editor Bev Anderson's Note: I have been reading this book and have found it to have excellent information. Given the



quality of the authors, it would be expected. The chapter titles give an idea of the scope of information: What Is Peripheral Neuropathy? What is Small Fiber Neuropathy? Diagnosing Small Fiber Neuropathy? Oher Symptoms of Small Fiber Neuropathy, What Causes Small Fiber Therapy for Small Fiber Neuropathy, Neuropathy? Managing Pain Associated with Small Fiber Neuropathy, Managing the Psychological Aspects of Pain. A sizable variety of approaches to treatments and pain management are presented, which would be helpful to anyone with neuropathy. There are some approaches to information that are a bit different than we usually present them but it is a way of seeing that which may be helpful to some. For example, I usually present sensory, motor, and autonomic as separate peripheral nervous systems. They indicate autonomic as coming along with sensory and/or motor neuropathy. This is basically true but it is possible for autonomic to be the dominant one. I highly recommend this book.

### 2018 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

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## **Roster of Our WNA Information and Support Groups**

CALIFORNIA Antioch-Brentwood

3<sup>rd</sup> Wednesday, 2 PM (odd numbered months) Antioch–Kaiser, Deer Valley Rooms 1 & 2 Marty Price (925) 626-7988

Auburr

1st Monday, 11 AM Woodside Village MH Park 12155 Luther Road Sharlene McCord (530) 878-8392 Nov. Speaker: Bev Anderson, WNA President

Berkeley-Oakland

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

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

Concord

3rd Thursday, 1:30 PM First Christian Church 3039 Willow Pass Road Wayne Korsinen (925)685-0953

Costa Mesa

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

Davis

2<sup>nd</sup> Tuesday, 3:30-5:00 PM Davis Senior Center, 646 A Street Mary Sprifke (530) 756-5102

**Elk Grove** 

2<sup>nd</sup> Tuesday, 1 PM Elk Grove Senior Center 8830 Sharkey Avenue Roger White (916) 686-4719

Folsom

1st Thursday, 12:30 PM (odd numbered months) Burger Rehabilitation 1301 E. Bidwell St., Folsom Bev Anderson (877) 622-6298 http://folsom.neuropathysupportgroup.org

<u>Fresno</u>

3<sup>rd</sup> Tuesday, 11:00 AM Denny's Restaurant 1110 East Shaw Bonnie Zimmerman (559) 313-6140 **Grass Valley** 

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

Livermore

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

Merced

2<sup>nd</sup> Thursday, 1 PM Central Presbyterian Church 1920 Canal Street (The Hoffmeiser Center across the street from the church) Larry Frice (209) 358-2045

Modesto

3<sup>rd</sup> 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** 

2<sup>nd</sup> Wednesday, 1 PM El Dorado Senior Center 937 Spring Street John McCoy (530) 642-8511

Redwood City

4th Tuesday, 1 PM Sequoia Hospital Health and Wellness Center 749 Brewster Avenue Danielle LaFlash (415) 297-1815

Roseville

2<sup>nd</sup> 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/

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

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

Santa Cruz

3<sup>rd</sup> Wednesday, 1PM (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

NEVADA Las Vegas

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

OREGON Grants Pass

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

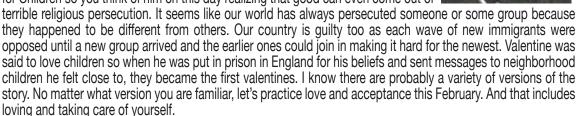
For information on groups in the following areas or any other place you are interested in finding out about a support group, call Bev Anderson at (877) 622-6298. She is actively trying to open new groups and re-open closed groups. Check with her about a group in your area especially if you would volunteer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

## President's Message By Bev Anderson

It is always sort of a puzzle when I write my column as I am always writing forward. This one is for February, but I'm writing it on January 7, the day after the 12th Day of Christmas. However, the stores are very helpful in keeping on track with where I am in the future, not where I am in the present. I was in a store last Thursday and Valentine's Day was much in evidence. How kind of them to help us remember. Right?

Maybe your parents read the story of St. Valentine to you from the Childcraft Books for Children so you think of him on this day realizing that good can even come out of



We are reminding you in this issue of the Annual Conference at The Mind Institute on the campus of the U.C. Davis Medical Center in Sacramento (just off Highway 50) on April 17. I usually come in from I-80 which is easy, once you know the way. Registration will start at 9:30 AM and the conference at 10 AM. We will be out at approximately 3:30 PM. The morning speakers will be from U.C. Davis Neurology Department introducing new personnel making U.C. Davis Medical Center a center for the treatment of neuropathy. We hope to have names and bios soon. We hope that Frederic Gorin, MD, who spoke briefly last year and received good reviews will also participate. We have plans for the afternoon that include a report from Bruce Hammock, PhD, on the human trials of his medication for neuropathy pain.

CVS has a rather pricy machine called Quell. They had a special on it for Christmas and offered it as a gift for loved ones with chronic pain. If you obtained one, please report the results for you. It won't be the same for everyone. They ask users to make recommendations for improvement so newer models will likely be somewhat different. It is hard to keep up with all the products coming out. If you try something and find it works for you, please let us know.

Setting up a legacy gift can start earlier that some can imagine. If you decide that when your time to leave this earth comes and you want to leave a gift to WNA or another group or both, you can start now and add to it over the years. The first thing to do is consult with an attorney that does wills and trusts and talk over what you want to do. He/She can set it up in a way that it could change over the years. It is a good idea to have your Power of Attorney for Health Care set up at the same time so everything coordinates. You never know when that would be very important. If you have a medical episode, you may recover completely but for a short time you may not be able to make sound medical decisions. The ability for you to recover may hinge on a person being able to give the doctors permission to do the needed treatment for you. From the time you are 18, it is a critical need to have this Power of Attorney for Health Care in place.

I wish you a Happy Valentine's Day,

## **SACRAMENTO GROUP AUGUST NOTES** By Charles Moore

On Tuesday, August 15, thirteen members of the Sacramento Peripheral Neuropathy Support Group were fortunate to attend Debbie Eernisse's presentation on the "Top Ten Exercises to Get You Moving." Debbie has taught balance and fitness classes for some 13 years and works out of the Davis Senior Center. Last year she presented a really fine presentation to our support group entitled "Building Balance." This month she prepared a power point presentation with 10 slides illustrating the 10 exercises of the title. In each case, she explained how the exercise would be helpful in developing good form for the exercise. In this report, I will sample a few of the exercises.

Debbie began by having the group participate in breathing exercises. She distributed a stretchy resistance band to each member present and had us tie the band around our waists so that we could be aware of the effect of inhaling and exhaling. Slide #10 shows a sketch of a prone woman who has inhaled and then exhaled.

Slide #9 is called "Lower Your Shoulder Blades" and illustrates good seating posture. Debbie noted that your feet should be flat on the floor. Crossing your knees is simply not good posture. She further added that we tend to sit for too long a time reading, working at the computer. One should get up at least once an hour to do anything at all.



#### **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

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the regular price.

## 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:

- 9153445 In an NIH randomized placebo controlled double blind crossover study of 13 patients with painful diabetic neuropathy, a decrease of 24% was obtained with a mean daily dose381 mg dextromethorphan (DM commonly found in cough medicine).
- 10741812 This is an uncontrolled open label study of 22 patients with neuropathic pain who decreased their pain scores from 6.7 to 5.3 after 8 weeks on bupropion SR (Wellbutrin SR®) 150mg twice a day.
- 11706096 This is a double blind, randomized, placebo controlled, crossover study of 41 patients with neuropathic pain. They received bupropion SR (Wellbutrin SR) 150mg daily for a week, followed by twice a day for another 5 weeks during which their pain score decreased from 5.7 to 4.0 (p<0.001).</li>
- 20447305 This Israeli study assessed the effectiveness of agmatine sulfate (decarboxylated arginine) with lumbar disc related sciatic pain. Compared to baseline agmatine improved pain from 26.7% to 70.8%, whereas the placebo group improved from 6% to 20%.
- 25655006 This demonstrates the effectiveness of sublingual fentanyl for the treatment of breakthrough neuropathic pain. The average pain reduction was 3.30 points from baseline (p< 0.0001).

## EXERCISE CAN TREAT TINGLY HANDS AND FEET AFTER CHEMOTHERAPY

February 17, 2017

Researchers have discovered a simple and inexpensive way to reduce neuropathy in hands and feet due to chemotherapy — exercise.

Scientists for the study, which included more than 300 cancer patients, directly compared the neuropathic symptoms in non-exercisers to the pain among patients who took part in a specialized sixweek walking routine with gentle, resistance-band training at home.

The exercisers reported significantly fewer symptoms of neuropathy — which includes shooting or burning pain, tingling, numbness, and sensitivity to cold — and the effects of exercise seemed to be most beneficial for older patients.

The lead author, Ian Kleckner, is a biophysicist and research assistant professor in the University of Rochester Wilmot Cancer Institute's Cancer Control and Survivorship program.

Not all chemotherapy drugs cause neuropathy, but 60 percent of people with breast cancer and other solid tumors who receive taxanes, vinca alkaloids, and platinum-based chemotherapies will likely suffer this type of side effect, Kleckner says.

Neuropathy is more commonly associated with diabetes or nerve damage. No FDA-approved drugs are available to prevent or treat chemotherapy-induced neuropathy, he adds. A previous randomized, controlled study of 619 patients showed that Wilmot's EXCAP (exercise for cancer patients) program reduced chronic inflammation and cognitive impairment among people receiving chemotherapy.

Kleckner's study involved a subset of patients from that trial, which is the largest phase 3 confirmatory exercise study ever conducted among cancer patients during chemotherapy. "Exercise is like a sledgehammer because it affects so many biological and psycho-social pathways at the same time — brain circuitry, inflammation, our social interactions — whereas drugs usually have a specific target," says Kleckner.

"Our next study is being designed to find out how exercise works, how the body reacts to exercise during cancer treatment, and how exercise affects the brain."

## Thank You For Your Contribution To WNA

We thank the individuals listed here for giving a contribution to the Western Neuropathy Association in 2017 beyond their dues to help the organization fulfill its mission and to make possible help and hope for more people who suffer with neuropathy. Our members' dues aren't enough to sustain and grow the organization. There are other individuals who donated but asked for anonymity. We thank them as well.

Beverly Anderson Jane Anderson Dorothy Asmus Ina Atchison Georgia Augugliaro Carol Bailey Barbara Balbo Mary Barnewitz Loretta Bayse Jane Bennett Randall Berger Shirlee Berger Barbara Bernhart Margaret Berry Elaine Bianco Breda Boran-Sears Frances Borok Gillian Bowman **Donald Burchard** Warren Burke Stanley Butolph Paula Cairo Phyllis Calechman Luciana Capecci Steve Carey Valerie Castor Elizabeth Chaudhry Einer Christensen Albert Christenson Kathleen Clemens Toney Coffey Jeannine Cogley Donald Craghead Thomas Cramblet Kathie Cravalho Geraldine Craver Jerrie Cruess Chuck Currey Henry Davis Mary Dehennis Shirley Dhillen William Donovan Gerri Dows Audrey Drynan Marjorie Early Babs Eggleston Jeryldine Elliott Charles Ellis Cheryl Engel Troyl Epley Lydia Fabela Shirley Farnsworth Tanya Ferguson

**Edwin Flinn** 

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Richard Long

Mayrebelle Lukins Harold Lustin Barbara Lyons Ernest Maag Richard Manke Lee Mathewson **Peder Matthews** Cynthia McAlexander Barbara McArn John McCov Jacqueline McDow Claudia McHenry Linda McKay Marilyn McMasters Charles Metro Lawrence Metzger **Tiger Michiels** Roberta Millard Brian Mock **Edward Mock** Frederick Mohr John Money Nancy Moresco Katherine Morris Richard Morrison Judith Moss Kathleen Nagel David Newman **Raymond Nichols** Gary Nickerson William Oldson Kathryn Orsini Alfred Osborne Darrell O'Sullivan Marie Padveen Werner Paster Bronislaw Paszek Richard Perkins Nils Peterson Fred Pillsbury Karen Polastri Ronald Potter Joann Pourroy Teresa Pusser Paulette Quam **Dolores Reckers** Frank Rhodes Maxine Richards Georgia Richardson Wilma Rodricks Doris Roe

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## 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.

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.

#### **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.

## DRIVING WITH PERIPHERAL NEUROPATHY – LIFESTYLE, LIVING WELL, STORIES

### Staying Safe And Independent And Continuing To Drive With Peripheral Neuropathy

"It was dark out as I pulled into the driveway. My wife and I were discussing the news story being broadcast on the radio. As I turned toward the garage, I took my foot off the accelerator and moved toward the brake. But I couldn't do it! I couldn't feel where my foot was. The car kept creeping toward the garage door and I still couldn't get my foot onto the brake. And then, BANG! The car hit the garage door and came to a stop."

This frightening story is shared by Jack Miller who suffers from idiopathic peripheral neuropathy. The lack of feeling he describes in his feet is a common symptom of this often-debilitating condition. Symptoms such as experiencing weakness or not being able to hold something, not knowing where your feet are, and experiencing pain that feels as if it is stabbing or burning in your limbs can make driving difficult and even dangerous.

"The first thought I had was, 'What if that had been a woman pushing a baby across the street in a buggy? I'm not going to drive anymore until I get hand controls on my car." Jack is referring to just one of many emerging technologies that broaden opportunities for people with disabilities to drive vehicles with hand controls and adaptive automotive products and devices. In recent years, technological advances have introduced automotive adaptive devices which reduce the physical effort required to control and/or operate a vehicle or alter the way in which driver control initiatives are applied to the vehicle control systems. With these tools and systems people with disabilities can once again enjoy the freedom and independence associated with being able to drive.

"The next morning, I got on the computer and a brief internet search of 'car hand controls' led me to a number of companies and eventually to the name of an instructor." Driver rehabilitation specialists perform comprehensive evaluations to identify the adaptive equipment most suited to a person's needs. The use of this

equipment usually requires the driver to take and pass a special training class which educates on the nuances of driving with the controls. Jack felt that it was important to get a system that had a "lock out" feature so he could disable it when others drove the car in the regular manner. "I didn't want the possibility that they could accidentally hit the hand control and accelerate and cause an accident."

Unfortunately, the freedom Jack found does come at a price that for some may be prohibitive. The good news is that funding assistance to purchase new adaptive vehicles or to retrofit existing vehicles is becoming increasingly available. Medicaid assistance varies by state. Medicare may pay for adaptive equipment following a specialty evaluation performed by a qualified practitioner. There are additional programs through Social Security, state vocational agencies and non-profit organizations including local "Centers for Independent Living" that can provide additional information. A number of automobile makes are also stepping up to provide persons with disabilities a wide range of rebates and incentive programs. Check with your auto dealer for those details. Finally, often sales-tax exemptions on equipment purchases and other out-of-pocket expense can qualify for tax deductions as medical expenses. Contact your tax adviser or review the IRS tax code for medical equipment.

Jack is enjoying his regained freedom and confidence that with these adaptations he, his passengers and those on the roads with him are all safe: "So after two months of having to depend on others to take me places, I once again had the freedom that my own 'wheels' gave me and without the fear that my peripheral neuropathy could cause me to have a serious accident that could cause damage or death to others. It truly was a great solution.

Used with permission of the Foundation for Peripheral Neuropathy. (Be sure to also look at www.wnainfo.org under Resources for more information about hand controls.)

## WELCOME TO NEW LEADER IN SANTA ROSA

We are delighted to announce that Judy Leandro has stepped up to lead the Santa Rosa Support Group upon the retirement of current leader, Larry Metzger. What an inspiration this is to all who know her situation. She did not want to see the group disappear so in spite of losing the house she was living in because of the recent fire and now renting a house in Sebastopol, she stepped forward. She said they woke up at 2:30 AM smelling smoke. Embers from neighbors' homes were falling on their roof and the house was partly on fire. They found

shoes and additional clothing and got out of the house with little more than what they were wearing. She said she wished she had grabbed her laptop with all her pictures but the full reality of what was happening hadn't set in. However, if they had stopped to save any possessions, they might not have gotten out alive. As it was, they were able to save their car by escaping when they did. One amazing thing was that the large tree under which their truck sat was spared and it protected the truck that wasn't even singed. Let's give Judy applause for her positive attitude, wish her well, and show her support with a strong attendance at the support group meeting.

## Sacramento Group August Notes - Continued from page 3

I think my favorite exercise that Debbie presented is #3 "Clock Step." Imagine a large clock face sitting on the floor. Your left leg is in the middle of the clock; you then take a wide step for each hour of clock. For example, at 3:00 your left foot is in the middle and your right foot has moved to a spot where 3 is on the clock face. At 6:00, your left foot is still in the middle, but your right foot is directly behind you where 6 occurs on the clock face. After traveling through the various times with your left foot in the center, change and put your right foot in the middle of the clock face and move your left foot

through each of the clock hours. You should challenge yourself by taking a wide step as you move around the clock. This exercise is particularly good to prevent a fall and to improve your balance and proprioception (the ability to know where your feet are in space).

Debbie's presentation lasted about an hour and a half and was filled with excellent advice and actual practice. The overall focus was on balance and flexibility and strength, which are useful in fall prevention.

Used with permission from PN News, the newsletter from Davis and Sacramento Support Groups.

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#### WESTERN NEUROPATHY ASSOCIATION

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

ur mission is to provide support, information and referral to people with neuropathy and to those who care about then to inform and connect with the health care community, and to support research.

Date: Tuesday, April 17, 2018

Time: 9:30 AM to 3:30 PM

Pre-register By: Tuesday, April 3, 2018

Seating is limited. Must register in advance.

**Registration Fee: \$25.00** 

Location: UC Davis Mind Institute
UC Davis Medical Center
2825 50th Street, Sacramento, CA

Questions?
Toll-free: (888) 556-3356
E-mail: lindsayc@pnhelp.org



## Western Neuropathy Association 2018 Annual Conference

## **New Help for Neuropathy Patients**

9:30 am Registration check-in

(must register in advance; limited seating)
Morning snacks and coffee included

10:00 am Announcements and Introductions

10:30 am **Fredric Gorin, M.D., Ph.D.** – Professor and Chair, Department of Neurology

Will describe the new opportunities for neuropathy patients at U.C Davis. He will introduce neurologists who will speak about their background and their views on treating neuropathy. There will be time for Q & A.

Noon Catered Lunch

1:00 pm Program in Development

2:00 pm Karen Wagner, Ph.D. She will be bringing a report from Bruce Hammock, Ph.D. and describing her role in the research done in his lab. She is a member of his research team. He will be traveling possibly involving the neuropathy pain medication which we hope will be in Phase 1 Human Trials by then. We will be hearing up to date information.

#### 3:00 pm Closing Activities

- Evaluations
- Door Prizes and Silent Auction
- Closing Announcements

More information in the next newsletter.



Mail registration fee and form to:

WNA PO Box 276567 Sacramento, CA 95827

Name				
Address				
City / State / Zip				
E-mail				
Support Group				At Large Member
If you need a special diet, please indicate:	□ Vegetarian	☐ Gluten Free		□ Other
☐ I am enclosing my check for the \$25 registration fee (includes lunch and morning spacks).				



## WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit, tax exempt corporation

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

Call WNA using our toll free phone numbers: (877) 622-6298 Email: info@WNAinfo.org

■ PN Information/Advice ■ Support Group Inquiries

(888) 556-3356 · Email: admin@WNAinfo.org

- Membership Information/Inquiries Sponsorships
- General Organizational Inquiries www.WNAinfo.org

## WNA ANNUAL CONFERENCE

April 17, 2018 • 9:30 AM – 3:30 PM
THE MIND INSTITUTE
UC DAVIS MEDICAL CENTER in SACRAMENTO

\$25 per person. Registration form on page 7 of this newsletter or register online at www.WNAinfo.org – Registration includes morning snacks, lunch, and all-day beverages.

The full program will be in the next newsletter. It will be chiefly neurologists so get any questions you have ready. We hope to also have an up to date report from Bruce Hammock, PhD, on the medication for neuropathic pain that is to go into human trials very soon.

## CROSSING YOUR LEGS CAN CAUSE NEUROPATHY

One of the attendees at our Folsom Neuropathy Support Group reported she had met with a neurologist who included leg crossing as one cause of neuropathy. We all laughed. It surely couldn't be true, we thought. I sent Peter Skaff, MD, FAAN, Neurologist, Mercy Medical Group, an e-mail asking him about it. Here is his reply: "I am writing in response to your inquiry with regard to medical references for compression neuropathy caused by chronic leg crossing. The first reference I could find was from 1929, and can be accessed at the online site of JAMA (Journal of the American Medical Association). https://jamanetwork.com/journals/jama/article-abstract/269594?redirect=true The focal neuropathy has been described extensively since. Try using the term "leg crosser's palsy" or "peroneal nerve palsy" or "peroneal neuropathy" in the text box of your favorite search engine."

If you have been in a support group meeting and have seen the DVD we have of Dr. Skaff speaking to our Eskaton group in Carmichael, you are aware of his knowledge about neuropathy and his positive attitude toward its treatment. Our library of DVDs is available at \$5 per DVD. They are listed on our website. We hope to soon distribute the three DVDs from the 2017 Annual Conference.



www.facebook.com/Neuro







#### Western Neuropathy Association (WNA)

A California public benefit, nonprofit, tax-exempt corporation.

Bev Anderson, Editor

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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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