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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)

WNA ANNUAL CONFERENCE PRESENTED VIRTUALLY – MAY 12-14, 2021, 1-3 PM PDT / 3-5 PM CDT

Each day, the first hour will be a speaker with current information. The second hour will be less formal with a topic of the day or demonstration led by a facilitator.

Wednesday, May 12

Jan A. Nolta, Ph.D., Director, Stem Cell Program and Gene Therapy Center Scientific Director, UC Davis GMP Facility Institute for Regenerative Cures, University of California Davis Health, Sacramento, CA, USA. She will talk about what everyone should know about stem cells.

2nd Hour – Please be ready with the name of your city, town, or village and a sentence about what it is positively known for. No downers here.

Thursday, May 13

Manisha Kak Korb, M.D., Neuromuscular Attending Physician, Neurology, School of Medicine, University of California, Irvine, CA. Dr. Korb's topic will be listed closer to the conference. She received her neurologist training at the University of Chicago Medical School where she was Chief Resident of her class.

2nd Hour – What do you do for your neuropathy that helps. Please stay short and to the point so we can get all the answers in. If time remains, Q & A's about the ones you want to know more about.

Friday, May 14

Barbara Montgomery, Nutritionist, has been the Leader of our Las Vegas Neuropathy Support Group. Barbara has had extensive training in nutrition and recently completed an intensive course. She will be speaking on Nutrition and Neuropathy.

2nd Hour – Yoga by Julie Falligant of the Houston Neuropathy Support Group. Julie presents one new yoga activity in each group meeting when she is able to be there.

REGISTER FOR THE CONFERENCE: Send an email to lindsayc@pnhelp.org or leave a message at (916) 932-2218 or (888) 556-3356 stating your email address and phone number. If you do not have a computer, smart phone, or tablet with access to the internet, you can still call in to the meeting. You can hear but not see the activity. We will endeavor to call or send directions on how to do this. The earlier you register, the better. If you are using only your phone, we need to receive your request by Wednesday, May 5 so we can get instructions in the mail to you in time for you to receive them for the conference.

BIG DAY OF GIVING – MAY 6, 2021

Between now and the Big Day of Giving, WNA can accept your donations by checks and credit card on our website (www.pnhelp.org or www.WNAinfo.org.) That week, we will send out via email, the number to call on May 6 if you would like to place your donation on the Big Day of Giving site. It opens at midnight so if you can call immediately after this, a prize might be won that adds \$500 to our total. The same is true for the last few minutes before midnight that night.

2021 WNA Board of Directors

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Lindsay Campoy WNA Administration (888) 556-3356

Please contact
your group leader or
check your group
page on the
WNA website www.WNAinfo.org
to find out about the
topic/speaker for the

upcoming meeting.

Bev Anderson Editor

Newsletter Design by



WNA MAY TELECONFERENCES AND ONLINE ZOOM SCHEDULE

Everyone is welcome to join any of the following calls. We encourage you to join in this opportunity to be on a call with other people that know about or experience neuropathy.

May 10 (Monday) 6:30pm PDT 8:30 pm CDT
 May 15 (Saturday) 10:30am PDT 12:30pm CDT
 May 18 (Tuesday) 1:30pm PDT 3:30pm CDT
 May 19 (Wednesday) 1:00pm PDT 3:00pm CDT

HOW TO CALL IN TO TELECONFERENCES

At the meeting time, call this number: 1-877-366-0711. You will hear an automated voice ask for the pass code to join the conference call. Using your telephone keypad, dial 36199447# A notification sound will chime in the "conference room" so we know someone has joined the call, and we will welcome you.

ZOOM MEETINGS - Everyone is invited to join in on any of the online meetings. Contact the leader for the link to join the meeting.

 Wednesday, May 19, 10:30am-11:30am PDT / 12:30pm-1:30pm CDT: Monterey, CA Neuropathy Support Group. Sign-in opens at 10:00 AM. For Zoom link – email Bill Donovan MD at seabreezex0@ gmail.com, giving name, address, telephone number and email address. Do this even if you have done it before. He may have a new link to give you.

Thursday, May 20, 1:00pm PDT / 3:00pm CDT: Nevada Neuropathy Support Group. For Zoom link
 – email Bev Anderson at faith95@colfaxnet.com, giving name, address, telephone number and email
 address. You will also receive a telephone number you may call if you want to participate by voice only.

• Saturday, May 29, 11:00am-12:30pm PDT / 1:00-2:30pm CDT: Houston, TX Neuropathy Support Group. For Zoom link – email Katherine Stenzel at klstenzel@hotmail.com, giving name, address, telephone number and email address. The Houston, TX group won't have its regular meeting in May but they are starting a second meeting late in the month. So, this is their meeting for May.

Support groups are not meeting in person unless a leader notifies the group that they are. If in doubt, call your leader.

CALIFORNIA

Auburn

Sharlene McCord (530) 878-8392 Kathy Clemens (916) 580-9449

Castro Valley

Joy Rotz (510) 842-8440

Concord

Wavne Korsinen (925) 685-0953

Davis

Mary Sprifke (530) 756-5102

Elk Grove*#

Bev Anderson (877) 622-6298 faith95@colfaxnet.com

Folsom*#

Bev Anderson (877) 622-6298 faith95@colfaxnet.com

Fresno

Bonnie Zimmerman (559) 313-6140

Grass Valley*#

Bev Anderson (877) 622-6298 faith95@colfaxnet.com

Merced

Larry Frice (209) 358-2045

Modesto

Harkaman Ghag (209) 541-5404

Monterey*

Dr. William Donovan (831) 625-3407 seabreezexo9@gmail.com

Napa

Ron Patrick (707) 257-2343 boniournapa@hotmail.com

Placerville

Bev Anderson (877) 622-6298 faith95@colfaxnet.com

Roseville

Stan Pashote (916) 409-5747

Sacramento #

Sonya Wells (916) 627-0228

San Diego

Chhattar Kucheria (858) 774-1408

San Francisco

Merle (415) 346-9781

San Jose*#

Bev Anderson (877) 622-6298 faith95@colfaxnet.com

Santa Barbara

Nancy Kriech (805) 967-8886

Santa Cruz

Mary Ann Leer (831) 477-1239

Santa Rosa

Judy Leandro (707) 480-3740

Judy Leandro (/

South San Diego Jacklyn (858) 228-7480

Walnut Creek*#

Bev Anderson (877) 622-6298 faith95@colfaxnet.com

Westlake Village - Thousand Oaks Angie Becerra (805) 390-2999

NEVADA

Las Vegas

Barbara Montgomery
Ivneuropathygroup@gmail.com

OREGON Grants Pass

David Tally 541-218-4418

<u>TEXAS</u>

Austin

Marty Meraviglia RN, ACNS-BC

(512) 970-5454 • mgmeraviglia@gmail.com

Houston*

Katherine Stenzel klstenzel@hotmail.com

* Leader of online Zoom Meeting(s) # Leader of Teleconference(s)

For information on new groups or other online teleconferences or Zoom meetings, call Bev Anderson at (877) 622-6298. Once we are safe for in-person meetings, new leadership will be needed in the following areas and others: California: Alturas, Antioch-Brentwood, Bakersfield, Berkeley – Oakland, Carmichael, Clearlake, Costa Mesa, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Livermore, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, Redwood City, Salinas, 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.

President's Report By Bev Anderson

We need more April showers to bring on the May flowers. We can get rain on the West Coast on into the first of June and we sure could use some in California. I remember one summer when the classroom wing in which I taught had its roof totally off the fourth of July week with no thought of moisture happening. Surprise! There was a heavy storm. They knew my classroom was in trouble as water was running out of it onto the outside sidewalk. The workmen were finishing it up the first week of school and thought it great fun to entertain the students while teachers were trying to get the school year off to a good start with calmness and order.



Annual Conference – May 12 – 14. Each day of the conference will be a two-hour webinar. The first hour will be a notable speaker. The second hour will be more interaction with opportunity to talk with each other. We hope many of you will be able to participate at least one day. Plan to be present in all three days, if at all possible.

Support Groups: We are starting to see the possibility of support groups meeting in person again this fall. I've had a couple of leader Zoom meetings and will contact the rest. We need some new leaders as some are choosing to retire, but others are excited about the new opportunities as there will be quite a few new people looking for them. Some Zoom meetings will continue and we may add more. There will continue to be at least two teleconferences as well. People who do not live near a support group are finding they can participate in a group in either of those opportunities. Things will never be the same as they were before the pandemic, but in some ways, they will be better.

Informative Letter: WNA is in the first fundraising drive of the year. It is a time when dues can be paid and/or donations can be made. The 'P.S.' at the end of the informative letter alerts you to know if you are a member in good standing, your dues are due, or you are a friend who has not joined and is invited to join now. We hope you will do what you can to help. The first \$2,500 raised will pair with a matching fund to support the research we have been following for several years for the pain medication now in clinical trials from the campus of the University of California at Davis. The first Clinical Trial 1a was held in Austin, Texas. It is possible the second one will be there as well.

Webinar with Vanessa Kettler: We had a webinar featuring Vanessa Kettler and exercises that can help us. In this issue, there is an article by Vanessa on Conscious Walking that comes out of a tragic fall that is limiting her activity during the healing process from breaking bones. The fall happened from losing focus for a few moments. Being conscious all the time on the environment and our personal actions in focus is vital.

I hope you will make a point of showing us you are there with your response to our letter, the teleconferences, Zoom meetings, and the Annual Conference this month. Let's be there for each other.



TELECONFERENCE AND ZOOM MEETINGS OPEN TO ALL

Please remember that you can attend any of the meetings listed on the schedule. It also can mean you attend more than one in a month. Some people attend more than one and say they do this as each is different and they are looking for ideas of what can be done to help themselves with their neuropathy. We have a variety of people attending with different information so it is quite possible to learn something new in each discussion at the meeting. Personally, I learn something new regularly so I'm sure others do too.



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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

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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 - 12%

equipment - 12% off all home units. Contact: 800-521-6664 or www.anodynetherapy.com

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.

CONSCIOUS WALKING

BALANCE NEWS by Vanessa Kettler, April 5, 2021 Vanessa led a webinar on April 8. The recording is available on WNA's website.

As some of you may know, I recently had a bad fall, breaking my shoulder and shattering my wrist. It has been a painful recovery, during which I had plenty of time to think about what I had to do to never have another fall like that ever again. The answer was to develop my senses in such a way that I walked consciously all the time.

The cause of my fall was something stupid, so often the case. I was walking around the neighborhood with my friend, staying 6 feet apart. I turned around to talk to him about something exciting and kept on walking. The sidewalk had a significant crack in it which I did not see because I was not looking where I was going. I tripped and fell. Nothing could save me this time. Usually, I was pretty good at catching myself misstepping but not this time. I knew immediately that I had broken bones and managed to get myself home and then to the ER.

Two other memorable incidents were caused by similar things: 1) Years ago I fell when someone called my name and I turned to see who it was without noticing the pot hole nearby, tripped and fell. 2) Our neighbor fell just 2 weeks ago when a car with a bad exhaust was nearby, so my friend speeded up his walking to get past the exhaust while looking at the car instead of the sidewalk. He tripped and fell.

Conscious Walking describes solutions in detail.

Conscious Walking describes the most important things to do to never fall again while walking. The article includes details on several subjects each which merit great interest, especially if you are prone to dizziness or disorientation or if you have peripheral neuropathy of the feet or are starting to experience foot numbness or tenderness.

- Where to look when you walk: This is the ageold question everyone has, especially those who have had a fall. We should be looking straight ahead in the direction we are going but if we do, how do we see the tree roots and sidewalk cracks that are right in front of us? Good question, great answer.
- 2. Beware of head movement: The secret to stability in our older years is to limit how much we move or tilt our head.
- 3. Improving proprioception: This article is a jewel for those with neuropathy of the feet. That painful/difficult condition can be helped by improving the connection we have between our feet and the ground. This article details so many helpful hints, all in one place.

You can find links to all these references within this month's featured BALANCE NEWS article.

COVID-19 Update

Many of us have had both COVID-19 vaccinations. Some wonder why it is necessary to still wear a mask, stay six feet apart, and avoid indoor gatherings. The answer is to protect all those who are not vaccinated. Masks have always been necessary to protect others rather than ourselves. Even though vaccinated, we can still carry the virus and therefore potentially infect others who are vulnerable. Until more is known, take all precautions.

Mask Danger

So little is said about how dangerous masks are! Most masks cut off your downward peripheral vision. This is an essential skill used in walking safely and consciously. When you wear a mask, in order to see what is near your feet you have to tilt your head downward, a bad idea because you can no longer be looking where you are going. My advice during this intense use of masks is to take extra time before walking to survey the territory you will be moving through. Stop periodically to reevaluate. Be even more careful than normal to walk consciously.

Pain and Emotion

One of the realizations I had during my recuperation was the incredibly strong effect emotion has on pain. The fractures I sustained, especially in the shoulder, are among the most painful. Drugs couldn't take it away so I had to deal with a certain level of pain all the time. Whenever I would get upset about something I noticed my pain level would jump through the roof. And calming down had a better effect on the pain than the drugs themselves. It is a good argument for the benefits of skills like Mindfulness Meditation in the management of chronic pain or anxiety.

Visit Vanessa's website for more information if you have any questions: www.building-better-balance.com

The BALANCE NEWS page on my website has been reorganized. The 80+ articles are now arranged into chapters of what will ultimately become a subscription service. For now, access to these thorough and thoughtful treatments of aspects of the aging process is available for free. Eventually that will become subscription only so get your free information now before it is too late.

Thank You For Your Generosity In 2020 Donating To The Western Neuropathy Association

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DISCOUNTS FOR WNA MEMBERS

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Neuropathy Support Formula/Nerve Renew (1-888-840-7142) is a supplement that a 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. They now have Nerve Renew Fast Acting Cream at \$20 for WNA members. It reportedly takes the edge off numbness.

Building Better Balance DVD, Developing Spine Health - The DVDs are \$30 each. The price of a full set (4 DVDs) is \$100 (that's a 20% discount). You can order the DVDs by going to the website www.building-betterbalance.com. Shipping is free. You can also order the DVDs over the phone using a credit card. Call (707) 318-4476 and leave a message" Vanessa Kettler, Balance and Fall Prevention www.buildingbetter-balance.com (707) 318-4476

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.

WESTERN NEUROPATHY ASSOCIATION ANNUAL REPORT FOR 2021

2020 was a year like no other. It started out with rumors of a virus that might make a huge impact, but no one thought it would affect our country so dramatically and with so many deaths. It was recognized in March with everything we were doing suddenly shut down. It was unbelievable how many were sick, hospitalized, and dying. January had started on a fairly positive note for WNA. Support groups were meeting and plans were being made for a grand Annual Conference at KVIE in Sacramento. By February, we had selected our speakers, and by March, we even had the caterer contracted for an event in May. During our March Board of Directors meeting, it was decided to cancel, but to reformat it so information could be made available.

Our Board of Directors met virtually via Zoom to plan how we were to proceed. Support groups are our central focus so we started there deciding to have teleconferences where people could call in and talk together like they were in a support group. Some people did call in but many never participated. We were sorry about the low participation, but people were coping as they could depending on family and location. Dr. Bill Donovan started a Zoom group that has grown. Katherine Stenzel started a Zoom group in Houston that is quite popular.

One thing we have found out is that these groups open up an opportunity of participation no matter where you live. If you don't have a support group near you, you do have a phone and/or a computer, smart phone, or tablet and you can be in a group. We will likely have Zoom groups continuing because they have people from across the country participating in them. It also means you can have speakers from any location as anyone in the world can call into a Zoom meeting.

The Board decided to experiment with holding a monthly webinar open to anyone to participate. All but one was recorded; the recordings are on our website. It was decided in 2021 that we would try to make copies of these so that they would be available if people wanted a home copy or a support group could use them when they started meeting in person again.

One major event happened early in the 2020 year and has enriched our work for the ensuing months. We accepted and welcomed the Neuropathy Alliance of Texas support groups in Austin and Houston. Almost immediately, however, the COVID-19 curtain came down. They, like everyone else, were sheltered in place trying to stay virus free. In 2021, Katherine Stenzel, the Houston leader, became a member of the Board. We have gotten used to scheduling events with both Pacific and Central Time zones.

We weathered the year with active planning and will see what happens when groups start meeting again. Some groups need new leaders. Others have leaders that can hardly wait to welcome people back to meetings. At least a few will be doing Zoom groups. We may have new groups in a variety of places with Zoom groups instead of meeting in person. It is so much easier for many people to be at home rather than having to drive to a distant location.

2021 goals include:

- Getting as many support groups as possible meeting either in person, by Zoom, or by teleconference.
- Getting a longer list of neurologists that know about neuropathy for people looking for a neurologist that can help them.
- Adding new members to the Board of Directors.

Financial Information

Tammy Hitchcock, our bookkeeper, provided these pie charts of our financial information for the year. We are solvent, our bank account balance is consistent, and we are able to pay our bills without worry thanks to the support of Western Neuropathy Association's members and friends. You are the reason WNA is alive today. Thank you very much.





Thank You For Your Generosity In 2020 Donating To The Western Neuropathy Association - Continued from page 5

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WESTERN NEUROPATHY ASSOCIATION

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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

■ FUNDRAISER FOR RESEARCH

We have a matching grant for the first \$2,500 of the funds coming in at this time of the year and for the Big Day of Giving. This \$5,000 is to be given to the research project through Dr. Bruce Hammock's lab at the UC Davis campus in Davis. This is a tremendous pain medication that will make a major difference when it is finally approved. It is in clinical trials now and due to have Clinical Trial 1b very soon. The National Institutes of Health (NIH) had put it on a fast track but it got put on a side track while the COVID-19 trials were going on for medications and viruses. They had to go through the same channels but at as high a speed as possible. You can be sure that NIH did not let anything get through without their usual scrutiny that has saved many lives over the years. The process for new vaccines and medications can be maddening, but we have not had the trauma that some countries have had with medications that damaged and/or killed people because they were not tested sufficiently.

There are items related to the trials that may not be costly but can't be paid for by the development and testing grants. Some of these are the very forms and certificates needed to actually make the medication available to patients like allowing doctors to prescribe it. Although \$5,000 is not a huge amount in comparison to the total cost, it is still highly helpful. Please choose to donate something above your dues if you are able.



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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