



Neuropathy Hope

Hope through caring, support, research, education, and empowerment
A newsletter for members of Western Neuropathy Association (WNA)

January/February 2023 Issue 01 Volume 21

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WESTERN NEUROPATHY ASSOCIATION

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GREEN LIGHT EXPOSURE MAY HELP REDUCE PAIN

Jeffrey Kluger, Time.com, October 27, 2022

Researchers are exploring a potential alternative to drugs for pain relief and it is safe, affordable, and comes with few or no side effects and no risk of addiction: green light exposure. Though the science is young and the research is by no means conclusive, in recent years, studies have found that exposing people to light across the green wavelength—either by having them sit in a dark room illuminated by green LED light strips or by giving them green-tinted glasses to wear—can reduce both their severity of pain and the frequency of episodes of migraines, fibromyalgia, and chronic musculoskeletal pain. It can also relieve the anxiety and fear associated with chronic pain.

In a study presented October 23, 2022 at the annual meeting of the American Society of Anesthesiologists in New Orleans, Dr. Padma Gulur, vice chair of the department of anesthesiology at Duke University, reported on an experiment she conducted in which 34 fibromyalgia patients were assigned to wear tinted glasses of different shades, four hours per day for two weeks. Ten of the patients wore glasses with blue lenses, 12 wore clear ones, and another 12 wore green. At the end of the study period, the people who wore green glasses were four times likelier than those in either of the other two groups to report that their anxiety over their pain had declined, as had their reliance on opioids.

Gulur used commercially available glasses for the study and tested each with a spectrophotometer to ascertain exactly which wavelength of green light each pair produced. She also tested each person's pair of eyeglasses at the end of the study to confirm which person got which wavelength. "What struck us the most was that at the end of the study, the patients were so pleased with the results, they didn't want to return the green glasses," she says.

Though small, Gulur's study is not the only one of its kind. At the University of Arizona, Dr. Mohab Ibrahim, professor of anesthesiology, neurosurgery, and pharmacology; along with other colleagues have published half a dozen papers in the past four years demonstrating the power of green light to reduce pain.) In one paper, published in 2021 in the journal Pain Medicine, Ibrahim recruited 21 fibromyalgia patients, exposed them to one to two hours of green LED lights—which the university provided people to set up in their homes—every day for 10 weeks in an otherwise dark room and found that people who reported their pain as an eight out of 10 when they were exposed to white light dropped their rating to below five when they were exposed to green.

"There are neural pathways that start from the eyes and can be traced back to several brain regions," says Ibrahim. "Some of these regions are heavily involved in pain modulation." Through a mechanism that's not yet fully understood, the green light appears to interrupt this connection, providing relief without medication, or at least not as much.

"This is such a simple approach," Ibrahim says. "There's still some skepticism, and rightfully so. When you make an extraordinary claim, you have to have extraordinary evidence. But the more studies and research that get funded, the closer we get to reaching a critical mass of evidence that says, OK, something is really happening here."

For more information on how green light relieves pain, please read the full article at Time.com.

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PERIPHERAL NEUROPATHY SUPPORT GROUPS JANUARY AND FEBRUARY SCHEDULE

Encourage, inform, share, support, and hope.

Join a meeting to help others, learn something new, and/or share experiences.

In-person or virtual – connect to others with peripheral neuropathy

In-Person Support Group Meetings

January 2 (Monday)

Auburn CA Support Group

11:00 am PST, Woodside Village Mobile Home Park, 12155 Luther Road Contact: Sharlene McCord (530) 878-8392, Kathy Clemens (916) 580-9449, kaclemens@earthlink.net

February 6 (Monday)

Auburn CA Support Group

11:00 am PST, Woodside Village Mobile Home Park, 12155 Luther Road Contact: Sharlene McCord (530) 878-8392, Kathy Clemens (916) 580-9449, kaclemens@earthlink.net

Santa Cruz area CA Support Group

Starting meetings. Contact Mary Ann Leer at (831) 477-1239 for meeting information.

Virtual Support Group Meetings

Contact Katherine Stenzel at klstenzel@hotmail.com for the Zoom link or open your internet browser, go to **join.zoom.us**, enter the meeting ID and Passcode

** All NEW IDs and Passcodes for 2023 **

January 14 (2nd Saturday)

11:00am-1:00pm PST/1:00pm-3:00pm CST, Meeting ID856 7106 1474 / Passcode: 114963 Host – Katherine Stenzel, klstenzel@hotmail.com

January 18 (3rd Wednesday)

10:00am-11:30am PST/12:00pm - 1:30pm CST, Meeting ID: 833 4473 0364 / Passcode: 341654 Host – Glenn Ribotsky, glenntaj@yahoo.com

January 28 (4th Saturday – Open Discussion)

11:00am-1:00pm PST/1:00pm - 3:00pm CST, Meeting ID: 851 7949 9276 / Passcode: 159827 Host – John Phillips, johnphillips.wna@gmail.com

February 11 (2nd Saturday)

11:00am-1:00pm PST/1:00pm-3:00pm CST, Meeting ID: 856 7106 1474 / Passcode: 114963 Host – Katherine Stenzel, klstenzel@hotmail.com

February 15 (3rd Wednesday)

10:00am-11:30am PST/12:00pm - 1:30pm CST, Meeting ID: 833 4473 0364 / Passcode: 341654 Host – Glenn Ribotsky, glenntaj@yahoo.com

February 25 (4th Saturday – Open Discussion)

11:00am-1:00pm PST/1:00pm - 3:00pm CST, Meeting ID: 851 7949 9276 / Passcode: 159827 Host – John Phillips, johnphillips.wna@gmail.com

FROM THE PRESIDENT Pam Hart, WNA President

The Happy New Year rings again as the old year resigns itself to history. We look forward to a great New Year and try to find positive steps we can take to benefit each other. Often our family members wonder what they can do to help with our neuropathy. Well...I have an idea – give blood! January is National Blood Donor month and the blood supply is still recovering from the pandemic. You may still donate blood, platelets or plasma after receiving a COVID-19 vaccine. Knowing the name of the manufacturer of the vaccine is important in determining your blood donation eligibility. If an individual has tested negative for COVID-19 or has recently recovered from COVID, he or she needs to wait for minimum 14-17 days from the resolution of symptoms according to the Red Cross.

Blood and blood products such as plasma are especially helpful for certain neuropathy sufferers. Here are two examples of blood products used in neuropathy treatments:

Platelet-Rich Plasma (PRP) uses growth factors naturally found in your blood platelets to promote healing and trigger new tissue growth.

Ivlg or IVg (Intravenous gamma globulin) are concentrated antibodies collected from the blood of healthy individuals which are put in a sterile solution and injected directly into a vein to help fight illness borne neuropathy. Although this is a helpful treatment, it is very expensive, mainly because of the shortage of plasma to make the IVg.

Even if you just donate whole blood, the potential for helping others is very satisfying. I have my 10-gallon pin from our local Blood Donation Center. I encourage my son and his wife to donate regularly also.

WNA is celebrating 2023 as our 25th year of getting the word out about peripheral neuropathy and what we can do to calm symptoms, talk to our doctors and encourage others. In 1998 Bev Anderson started the group with Grant Whitney and Joe Nicosia and had about 35 others at their first meeting in Auburn, California. It went on to be called the Northern California Chapter of the Peripheral Neuropathy Association. As we expanded, we changed the name to the Pacific Chapter of the Neuropathy Association. After the dissolution of the Neuropathy Association, we changed the name to the Western Neuropathy Association – and we are sticking with that name as we expand, just defining Western as the Western Hemisphere.

We are very thankful to all of our supporters, no matter where you are, and hope we can be of assistance in this New Year.

Peace to All,

Pam Hart

UPCOMING WEBINARS

Assisted Driving - January 26, 2023, Thursday at 1pm Pacific, 3pm Central

For those with feet numbness, adapting your car for hand controls allows you to regain independence and be in control of your own transportation. This webinar will give information on the process of installing hand controls so you can use your hands instead of your feet. WNA member Lynn Carpenter will discuss her personal experience with transitioning to hand controls.

Orientation to WNA - February 23, 2023, Thursday at 1pm Pacific, 3pm Central

Want to know more about the Western Neuropathy Association? Meet the President and Board of Directors? Learn more about information on our website? Find out about the support groups? Ask questions? Then attend this webinar for a better understanding of the WNA, what we do and what we offer neuropathy sufferers.

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. Toll free (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 https://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% 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 the regular price.

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■ IN-PERSON SUPPORT GROUP NEWS

Auburn, CA Support Group

Pam Hart, President of WNA, attended the November meeting of the Auburn group. While the turnout was small, it allowed the one new attendee to get personal attention to all their questions. Meetings continue on the first Monday of each month. Refer to Page 2 for contact information.

Santa Cruz, CA Support Group

The November meeting had a great turnout of 35 attendees due to having the notice published in the local paper. A local podiatrist provided a presentation and answered audience questions. The group is still in the initial stages of forming and will publicize a permanent time and place when determined. Refer to Page 2 for contact information.

Houston, TX Support Group

The 4th quarter meeting was held at the start of December and included a White Elephant Christmas Gift Exchange. After starting the meeting with attendee sharing of doctor and acupuncture experiences, gifts were exchanged and re-exchanged until everyone was happy! Meetings will continue quarterly in 2023 on the first Saturday of March, June, September and December.

SUPPLEMENTS: VITAMIN B-1 (Benfotiamine)

Martin Price, WNA Director

Thiamine, also called vitamin B1, enables the body to convert carbohydrates, fats and protein into energy, or glucose. Vitamin B1 is necessary for keeping the liver, skin, hair and eyes healthy and essential for glucose metabolism. It also plays a key role in nerve, muscle, and heart function. We should ensure we get enough B vitamins to enhance our nerve health.

Thiamine is classified as a water-soluble vitamin. Vitamins are classed via the materials they dissolve in. Water-soluble vitamins are carried thru the blood stream. Whatever the body does not use is eliminated via urination within 4-5 hours. This is where the additional benefits of Benfotiamine come in as the body can store greater amounts of Benfotiamine as it is low water soluble.

Benfotiamine is a synthetic or lab made type of thiamine used to treat diabetic nerve related damage, to protect against Alzheimer's, alcohol abuse and alcoholic depression. Because it is lab produced it is more effective than thiamine as it is not eliminated via urination but digested and absorbed more readily into the body. Benfotiamine supplements increase the body's level of thiamine storage five times greater than a similar dosage of thiamine.

Natural sources of B-1 include nuts, eggs, potatoes, oranges, meat, and breakfast cereals. When supplemented in tablet form, dosage is most effective in the range from 300mg to 600mg per day divided into two equal doses. Side effects may include nausea, low blood pressure and dizziness.

Deficiency of vitamin B-1 commonly leads to beriberi - a condition that features problems with the peripheral nerves and wasting, weight loss, anorexia development and mental disorders including confusion and short-term memory loss. Muscles may become weak and cardiovascular symptoms can occur.

I have not found a great deal of benefit from taking Benfotiamine for neuropathy but have found it has given benefit for other issues. I feel/think that neuropathy progresses faster if you do not take it. However, it did not help much with the burning sensation in my feet which has progressed to my knees. Perhaps a grater dosage level would help? I have tried increasing my dosage for several months but found it too difficult to tell if it helped more or less with the burning sensation versus my medication.

As with most vitamin supplements, short term use does not appear to be beneficial. It could take months to years depending on age and physical condition.

Reference

Seward, M. February 16, 2018. 5 Proven Health Benefits of Benfotiamine. Healthy Focus.org. https://healthyfocus.org/health-benefits-benfotiamine/

CALIFORNIA AND TEXAS RESIDENTS - VIRTUAL SUPPORT GROUP MEETINGS

One topic that always is discussed in support group meetings is doctors – which doctor have you seen, which doctor is good, which doctor is bad, which doctor has helped you, etc. And along with this is a doctor's location as many want a doctor a reasonable distance from and/or close to their home. Physical therapists are another medical professional that is often mentioned as are acupuncturists.

With the virtual support groups, people attend from all over the country, and finding someone in the same geographical location as you can be difficult. To help with this, WNA will start having virtual local support groups with California and Texas being the first two locations.



WNA California Residents Virtual Meeting

February 16, 2023 (Thursday) 1:00 PM Pacific Time, 3:00 PM Central Time Join Zoom Meeting:

https://us06web.zoom.us/j/84747923326?pwd=UEE3dC9ac2dMRyttY1N6Uk1qMTVidz09

Meeting ID: 847 4792 3326

Passcode: 115483



WNA Texas Residents Virtual Meeting

February 22, 2023 (Wednesday) 1:00 PM Pacific Time, 3:00 PM Central Time Join Zoom Meeting:

https://us06web.zoom.us/j/81808399765?pwd=N3pQdmFYTStwaGVwNHpjdG84T0prZz09

Meeting ID: 818 0839 9765

Passcode: 505631

We will have these meetings every six months but that is subject to change depending on the attendees. Let's just start them and see how it all goes!

If you want a reminder email, please send your name to me.

If you already receive emails from me about the monthly virtual groups, note that I will be using the same list for these meetings so you do not need to contact me.

And if you want to send me an email with a comment or question, I read and answer them all.

...Katherine (klstenzel@hotmail.com)

SIT AND BE FIT!

Many attendees of the virtual support groups have suggested the 'Sit and Be Fit' programs that are shown on public television. One person wrote to me after a recent meeting: "There is an excellent tv exercise group called 'sit and be fit' for those with limited ability and/or in a chair. Very doable for the most reluctant of us."

If viewing on television doesn't work for you, their website at sitandbefit.org has other options. DVDs were made of most of the TV seasons but prices are expensive. But one DVD listed is titled 'Neuropathy Workout' with the description: "If you struggle with neuropathy, this DVD is for you! Features educational segments with Podiatrist and Human Movement Specialist, Dr. Emily Splichal." Price is \$18.95.

In addition, they have a steaming service where you get access to their full library of programs. A monthly charge of \$7.99 let's you watch from any of your devices, at any time, where ever you are.

The cheapest option is to view on their YouTube channel. You can access free video exercise segments only. And the last uploaded segment was two years ago.

(Note this is for information purposes only. WNA does not endorse or receive any payment from this company.)

DISCOUNTS FOR WNA MEMBERS

Continued from page 4

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 buildingbetter-balance.com 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 888-556-3356 or email admin@ WNAinfo.org.

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

■ KEEPING A DAILY LOG Kris Langenfeld, Houston, TX

Keeping a daily log is tedious work. I understand. It is hard to remember another item on the To Do List. And even more difficult to jot down notes every single day. I am horribly unreliable at keeping a journal, but love making lists (or even better, checking items off the list). But data does not lie. It has brought to light many correlations in my symptoms. Especially if the symptoms are not immediate and take 4-8 weeks to take effect.

I try to keep my daily log simple from the perspective of filling out. Therefore, there are lots of columns and less super descriptive note taking. If I make this daily task simple, I am more likely to accomplish it.

I started out with the basics: Date, Medications, Sleep, Peripheral Neuropathy Symptoms and Additional Notes. This quickly grew into too many boxes that I needed to fill out in more than a few words. Subsequently, the log was edited to include subcategories and more metrics to document. The following list includes the column headings with subcategories that I am currently using in my daily log.

DATE

MEDICATION

Subcategories: each medication's dosage and if there is a change in supplements.

SLEEP

Subcategories: Time Asleep, Number of instances I Woke Up and time I got Out of Bed.

The time I go to bed is different than when I actually fall asleep. Plus, the time I wake up may be different than when I physically get out of bed. I used to have insomnia, so this distinction was important as well as how many times I was waking up during the night.

ACTIVITIES

Subcategories: Physical Therapy and Other Activities.

I include how long and what area I focused on for the physical therapy column. For the other activities I record walking our dog, cleaning house, yardwork and activities that require physical exertion.

FOOD

Subcategories: Ultra-Processed Food, Gluten and Unhealthy Sugars/Fats.

This helps keep me making healthy nutrition decisions. Every now and then I will have food that falls into one of these categories; however, it holds me accountable if I see that there are several entries within a short time period.

ALCOHOL CONSUMPTION

Similar to food, helps keep me accountable and decreases the likelihood of making poor choices on a regular basis.

PERIPHERAL NEUROPATHY SYMPTOMS

Subcategories: Numbness, Tingling, Pain, Dizziness and Other.

SOCIALIZATION

This may seem like an odd category, but I have been in lockdown for about 4 years due to various ongoing medical issues. As a result, I started to get panic attacks even driving to the grocery store. I added this metric to motivate me to move in small steps toward being able to handle being in public again. I can see how much progress I have made.

MOOD/EMOTIONAL STATE

It is important to record how I feel overall each day. I use a scale of -5 to +5 and a very brief description of why I chose that number. This helps me on a cognitive level see if I am falling back in the pit of depression, climbing out of the pit or just having a bad day.

WEIGHT

- Continued on page 7

WNA DONATION THANK YOU!

(In response to the WNA donation of \$10,000 to Dr. Hammock, University of California at Davis, for his research on the pain relief medication EC5026, https://www.eicosis.com/)

November 28, 2022

Dear Pam and Darrell,

It took the University of California a pound of paper and a month to process your donation. But it appears to be done.

I want to thank you two for pushing this through the system. The financial support is so important for the fundamental work we are doing on control of neuropathic pain. Beyond the financial support, the continued confidence from the Western Neuropathy Association and the individual members is a continual boost to the morale of the scientists and a feeling that we are truly helping.

The basic work continues. The movement of the drug through the FDA seems terribly slow to us who are involved, but in reality, we have gotten amazingly far with very limited resources. Our investigational new drug candidate should enter Phase 1b human safety trials in early winter. We are scheduled for an FDA meeting on this in late December. So far, the drug is unique in its large safety profile. Pain remains the focus, but studies from this and other laboratories indicate that the target we have selected is promising for a variety of chronic CNS disorders including Parkinson's, Alzheimer's, and depression. Recently the NIH has selected our investigational new drug candidate for a long-term mouse study on longevity. There will be no results for over two years, but this does show confidence in the studies we are doing.

I so much appreciate your support, and please say hello to the group.

Bruce

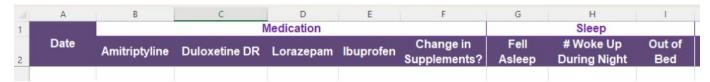
Bruce D. Hammock

KEEPING A DAILY LOG – continued from page 6

ADDITIONAL NOTES

Anything that does not fall into one of the other columns is entered in this box. If I see a trend of the same symptom, I then make that item into its own category/subcategory. For instance, I used to have crying spells in some deep depression episodes. My doctor told me how my mood has changed in the positive direction. I did not see it until I started documenting how many times a day I cried. Data does not lie. The trend was the daily crying spells were lessening.

To visualize the categories and subcategories, here is a snippet:



About every six months I will insert a row that includes the average current state of each category. I find it useful to summarize my health and wellbeing a couple of times a year.

The following are two examples of how useful this daily log was in finding a correlation between medication and symptoms.

Last year I was able to pinpoint a probable cause of gaining seventeen pounds in six weeks. There were no changes in diet or exercise, so I assumed hormones given that I am a 50+ woman. After researching my medications, I learned that one of the prescriptions can cause sudden weight gain after six months of continuous usage. The weight increase occurred around that six-month period.

A more recent observation is my decrease in grip strength and increase in numbness and pain in fingertips. For one of my medications, I had reduced the dosage amount. This medication usually needs between four and eight weeks to see effects. Analyzing my log, I could see that six weeks prior I had lowered the dosage. The only other variable was the drop in temperature. Hence, two weeks ago I increased back to the amount where I was successful and entered in the Additional Notes box the correlation. I am hoping that in a couple of weeks I will be back to being able to write and type with more intention and less fumbling around the keyboard.

Trying to remember when a symptom started, medication dosage changed, and other important information is difficult. Although tedious, keeping a daily log is an essential tool in managing my health and wellbeing.



WESTERN NEUROPATHY ASSOCIATION

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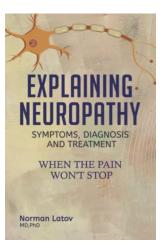
Explaining Neuropathy: Symptoms, Diagnosis and Treatment - When the Pain Won't Stop

By Norman Latov, MD, PhD; published October 23, 2022; \$19.50 through Amazon

(15% of the net revenues generated from the sale of this book will be donated to the Foundation for Peripheral Neuropathy in support of their research activities.)

This book is an updated 2022 edition that was previously published as the American Academy of Neurology Quality of Life Guide "Peripheral Neuropathy, When the Numbness, Weakness and Pain Won't Stop". It is based on over 40 years of experience in caring for, addressing the concerns, and advocating for people with neuropathy. Topics that are covered include: how the nerves work, understanding the symptoms of neuropathy, the many causes of neuropathy and their

treatments, the evaluation and diagnosis of neuropathy, treatment of the motor, sensory and autonomic symptoms, monitoring the neuropathy, caring for your feet and sharing stories and experiences.





Western Neuropathy Association (WNA)

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WNA Headquarters: admin@WNAinfo.org

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

Dues - \$30 a year All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

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