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WESTERN NEUROPATHY ASSOCIATION

June 2023 Issue 05 Volume 21

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WESTERN NEUROPATHY ASSOCIATION 3620 American River Dr., Suite 230 Sacramento, CA 95864 888-556-3356 admin@WNAinfo.org www.WNAinfo.org Hope through caring, support, research, education, and empowerment A newsletter for members of Western Neuropathy Association (WNA)

**Neuropathy Hope** 

# SPINAL CORD STIMULATION MAY HELP PAINFUL DIABETIC NEUROPATHY

American Academy of Neurology, MedicalXpress.com, February 28, 2023

People with painful diabetic neuropathy may be able to get relief from high-frequency spinal cord stimulation, according to a preliminary study released today, February 28, 2023, that will be presented at the American Academy of Neurology's 75th Annual Meeting being held in person in Boston and live online from April 22-27, 2023.

"Diabetic neuropathy often results in poor quality of life, depression, anxiety and impaired sleep, and the available medications can be ineffective for many people or have side effects that people can't tolerate," said study author Erika Petersen, MD, of the University of Arkansas in Little Rock. "These results are exciting because there is an urgent need for more effective therapies."

The study involved 216 people who had painful diabetic neuropathy symptoms for at least one year that were not responding to medications. Half of the people received spinal cord stimulation plus regular medical treatment for six months. Half received only regular medical treatment. After six months, people had the option to switch to the other treatment. People were followed for a total of two years.

Spinal cord stimulation involves a device that is implanted under the skin. The device delivers electrical stimulation to the spinal cord to cut off pain signals to the brain.

After six months, the people who received stimulation reported 76% decrease in their average pain amount, while the people who did not receive stimulation had a 2% increase in their average amount of pain. In tests of their motor function, sensation and reflexes, improvements were seen in 62% of those receiving stimulation compared to 3% of those receiving medication only.

After two years, people reported 80% improvement in their average pain amount, and 66% continued to have improvement in motor function, sensation and reflexes.

None of the participants had their devices removed because they were not effective. Eight people had infections related to the device. Three of those cleared up, and five people, or 3%, had their devices removed due to infection, which Petersen said is within the range reported for people receiving spinal cord stimulation for other conditions.

Petersen also noted that the high-frequency stimulation appears to provide greater pain relief than low-frequency stimulation. High-frequency stimulation also does not create the "pins and needles" sensation that comes with low-frequency stimulation.

"This study demonstrates that high-frequency stimulation provides long-term pain relief with acceptable safety," Petersen said. "The improvements in motor function, sensation and reflexes suggest that this therapy could have disease-modifying potential."

Petersen said, "Confirmation of results through studies in larger groups of people could further strengthen our understanding of this spinal cord stimulation therapy for the treatment of painful diabetic neuropathy."

(Editor: The March issue front-page article on spinal cord stimulation was a review of 17 clinical trials published between 2003 and 2021. This is a single clinical trial with high-frequency spinal cord stimulation.)

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# PERIPHERAL NEUROPATHY SUPPORT GROUPS JUNE 2023 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 June 3 Houston TX Support Group – Quarterly Meeting 1:00pmCST – 3:00pm CST, Memorial Drive United Methodist Church 12955 Memorial Drive, Houston, TX 77079, Room DS100, enter at back (south) of building Contact: Katherine Stenzel at kIstenzel@hotmail.com

Auburn CA Support Group – No meetings in July, August and September Contact: Sharlene McCord (530) 878-8392, Kathy Clemens (916) 580-9449, kaclemens@earthlink.net

Santa Cruz CA Support Group – Meetings in odd months Contact: Mary Ann Leer (831) 477-1239

#### Virtual Support Group Sessions

#### June 10 2nd Saturday Support Group

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

#### June 21 3rd Wednesday Support Group

10:00am-noon PST/12:00pm-2:00pm CST, Meeting ID: 833 4473 0364 / Passcode: 341654 Host – Glenn Ribotsky, glenntaj@yahoo.com

#### June 24 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

> Contact Katherine Stenzel at klstenzel@hotmail.com for the Zoom link Or go to join.zoom.us and enter the meeting ID and Passcode

## CANNABINOIDS MAY IMPROVE SLEEP QUALITY AND PAIN INTENSITY IN CHRONIC NEUROPATHIC PAIN

Jessica Nye, PhD, Neurology Advisor.com, March 21, 2023

Cannabinoids may improve sleep quality, pain intensity, and patient global impression of change (PGIC) among patients with chronic neuropathic pain, according to results of a systematic review and meta-analysis published in Regional Anesthesia & Pain Medicine.

A team of Canadian investigators searched publication databases for studies evaluating cannabinoid use among patients with neuropathic pain published between 1995 and 2021. A cutoff of tetrahydrocannabinol (THC) 100 mg was used to identify high and low dose treatments. Their search yielded 8 studies conducted in Canada and Europe that included data from 1051 patients.

Study authors concluded, "Cannabinoids are useful agents for treating neuropathic pain as evidenced by significant improvement in sleep quality, pain, and PGIC. However, these benefits were noted at the expense of increased daytime somnolence, dizziness, and nausea. With the advent of new agents and more refined cannabis formulations, further research is needed to comprehensively explore treatment effectiveness."

# FROM THE PRESIDENT Pam Hart, WNA President

I hope everyone is enjoying their June weather. I always look forward to the warmer weather to be able to be more active outside. When I think of being more active, I think of mobility and what it takes to get my body to a place of comfort.

I can't help but remember the webinar that one of our Directors (Marty Price) gave regarding vitamins and supplements. I would like to remind everyone about the B vitamins and how helpful they can be in a one-month process. It takes a long time for your body to re-organize itself for healing.

Vitamin B1 assists in healing damaged peripheral nerves in the body. Two forms are available, benfotiamine and thiamine, however benfotiamine is more bioavailable in the body.

Watch out for the correct form of Vitamin B6. It should be in the form of Pyridoxal 5 Phosphate (P-5-P) and not Pyridoxine HCL. Pyridoxine HCL can be toxic to the nerves in high doses, whereas, P-5-P can be taken in very high doses without any toxicity and is extremely bioavailable for nerve use and function.

One of my favorites for all-around good health is Vitamin B12. It is best taken in the form of Methylcobalamin and not Cyanocobalamin. Methylcobalamin is the most active form of B12 and is better absorbed and retained in our tissues in higher amounts than the synthetic cyanocobalamin. Methylcobalamin is also used much more efficiently by the nervous system, liver, and brain.

Vitamin B9 (Folic acid/Folate) should be in the form of 5-MTHF (5-methyltetrahydrofolate). This is the active form that folic acid must be broken down into before being absorbed by cells.

The other supplement that is available (and is an ingredient in so many other 'treatments') is Alpha Lipoic Acid (ALA). R-Alpha lipoic acid, or R-lipoic acid, is more effective for decreasing insulin resistance and repairing peripheral nerves because it is better absorbed in the body due to its chemical composition.

I hope these reminders are helpful, as we tend to try so many things. Just remember that it takes time to heal. Until then, we value your input as to what has helped you and your comments to help others.

Cheers, Pam

The Directors of the Western Neuropathy Association are pleased to announce our first Virtual Gala!



Health Care Challenges Websites (updated)

SHIPs State Health Insurance Assistance Programs www.shiphelp.org (877) 839-2675

Help for navigating the complexities of Medicare. Search the website for your specific state program.

Medicare Rights Center

www.medicarerights.org (800) 333-4114

Non-profit that works to ensure access to affordable health care for older adults and people with disabilities.

Medicare

www.medicare.org (800) MEDICARE (800) 633-4227

Get started with Medicare, options, news.

Benefits and Insurance for People with Disabilities www.usa.gov/ disability-benefitsinsurance (844) USAGOV1 (844) 872-4681

For those with a disability, learn how government programs and services can help in your daily life.

#### Peripheral Neuropathy Treatment Drug Classes

Gabapentinoids gabapentin (Neurotin)

pregabalin (Lyrica) <u>FDA approved</u> for neuropathic pain associated with diabetic peripheral neuropathy and postherpetic neuralgia.

∞

TCAs tricyclic antidepressants nortriptyline (Pamelor)

amitriptyline

∞

SNRIs serotonin and norepinephrine reuptake inhibitors duloxetine (Cymbalta) <u>FDA approved</u> for neuropathic pain associated with diabetic peripheral neuropathy.

> venlafaxine (Efexor)

> > ∞

Unless specifically noted "FDA Approved", all others are off-label usage for peripheral neuropathy.

(continued on page 5)

# HOW TO KNOW IF CLINICAL TRIALS ARE RIGHT FOR YOU

Cleveland Clinic - Urinary & Kidney, February 13, 2023

#### Reasons to join a clinical trial

Clinical trials are designed in a variety of ways, but the core of many of these experiments is to determine the effectiveness of various treatments. Think of how we've developed targeted therapies for rare cancers or how vaccines must go through clinical trials before they're given to the public. Without the use of clinical trials, we'd never have a way to fully understand how these conditions work and we'd never have access to safe, ethically sourced treatments.

Before a medication makes it to market, it must go through several clinical trial phases in which the medication is tested for safety and effectiveness. Based on the results of those clinical trials, it must then be approved for use by the U.S. Food and Drug Administration (FDA) before it's made publicly available.

Most clinical trials are randomized and double-blinded, meaning for the first part of the trial, you and the researchers won't know if you're getting the actual treatment that's being studied or if you're receiving a placebo instead.

Placebos can come in the form of sugar pills or saline and water injections. The point of using placebos is to compare the outcome of treatments against non-treatment options, and to ensure the team of researchers isn't holding on to any biases during the clinical trial.

You still may be given the new treatment that's being studied, and the possibility of it working may be good considering the number of times it might have gone through other clinical trials. In some cases, even people who are given a placebo may experience a placebo effect, where their body responds positively despite not receiving any new treatment that's being studied. But regardless of the outcome, taking part in a clinical trial can help push science forward to develop new and more effective ways to treat rare and challenging conditions.

If you have a particularly rare condition and/or other treatment options aren't as effective as you'd hoped, joining a clinical trial is a personal choice that comes down to making sure you're comfortable and committed to exploring new possibilities not yet available to the general public.

#### How to find a clinical trial

You can join a clinical trial by speaking to your healthcare provider, who then puts in a referral to the research team working on the study. But if you're curious, you can also search clinicaltrials.gov, which has a helpful tool to locate and find clinical trials that have been completed, as well as clinical trials that are currently recruiting new participants.

#### Risks of joining a clinical trial

Some people worry about the risk of not receiving the treatment that's being studied and ending up with a placebo instead. Others may worry about how the clinical trial will work and whether or not it'll have a lasting impact on their current condition.

But ultimately, the choice to join a clinical trial is up to you. If you have questions about how a clinical trial may work, or if you explore the clinical trials that are out there and would like more information, it's always good to check in with your healthcare team to address some of the fears and concerns you may have. Remember that you are consenting to a clinical trial and you can take away that consent whenever you want.

I just want the PN nation to know that they have a lot more control over this perceived "monster" than they believe and they should expect to never relinquish the control.

#### Fight like hell, play like crazy, meditate. This is your story. Write it like you would like.

Dana Delgado, WNA Member, Austin, TX

# INTRAVENOUS IMMUNOGLOBULIN (IVIG) TREATMENT AND CIDP: WHAT TO KNOW

#### What are immunoglobulin and IVIg?

Immunoglobulins are antibodies, which are proteins the body makes to protect itself against infections. They are part of the immune system and present in plasma, which is an amber-colored liquid that comes from blood.

Doctors can use immunoglobulins as a treatment therapy in the form of Intravenous immunoglobulin (IVIg). To make it, a laboratory separates plasma from the blood of thousands of healthy donors and then combines it, creating a concentrate. Doctors then administer this concentrate intravenously, which means into a person's veins.

There are several classes of immunoglobulins. The most abundant in human blood, and in IVIg, is immunoglobulin G (IVG). The composition of IVIg is very similar to the naturally occurring immunoglobulins in blood plasma, with IVG comprising more than 90% of the concentrate.

#### Why might someone need IVIg?

IVIg treats a variety of autoimmune and inflammatory conditions. Low doses of IVIg may help a person with an immunodeficiency to build an immune response against infections, while high doses may help relieve an inflammatory or autoimmune condition as they decrease inflammation. They can also help block the immune system from attacking a person's own cells, which is what happens in autoimmune diseases.

Some conditions may take longer to respond to IVIg than others. Researchers are still continuing to learn about how effective it is for different autoimmune and inflammatory disorders.

The infusion may take about 3 hours, and it generally does not cause pain. Depending on a person's condition, they may need infusions throughout their life.

#### Other treatments

For people with immunodeficiencies, subcutaneous immunoglobulin (SCIg) may be a suitable alternative. This involves injecting purified immunoglobulin into the fatty tissue just beneath the skin, such as in the buttocks or thigh.

The decision between IVIg and SCIg is based on many factors such as long-term side effects, autonomy, disease severity, comorbidities, venous access and patient preference. IVIg is associated with systemic side effects, including rare but serious adverse events. SCIg requires no venous access and has fewer systemic side effects compared with IVIg. Switching to self-administered SCIg for maintenance therapy can be more convenient for some patients.

#### Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) is an immune-mediated neuromuscular disease characterized by proximal and distal weakness associated with sensory loss and areflexia. Pathophysiology is predominantly demyelinating, but if untreated, can progress to secondary axonal loss resulting in irreversible motor deficit. CIDP typically follows a progressive course but may have a relapsing-remitting pattern.

#### **CIDP Treatment**

Immunoglobulin (Ig) therapy is recommended in guidelines for the treatment of various neurologic diseases and is a first-line treatment for chronic inflammatory demyelinating polyneuropathy (CIDP), Guillain-Barré syndrome (GBS), multifocal motor neuropathy (MMN), and rescue therapy for worsening myasthenia gravis (MG).

Ig mechanisms of action in immune-mediated neuropathies are poorly understood but thought to encompass several pathways including Fc receptor blockade, Fcy receptor modulation, anti-idiotypic antibody binding to autoantibodies, complement neutralization, and cytokine regulation. In the absence of disease-specific biomarkers, monitoring serum Ig concentrations has been explored to aid dose optimization by establishing a patient's Ig trough level and tracking this in relation to clinical outcome.

#### References

Beydown, S.R., et al. (2021). *Individualizing Therapy in CIDP: A Mini-Review Comparing the Pharmacokinetics* of *Ig with SCIg and IVIg*. Frontiers in Neurology, 12. doi.org/10.3389/fneur.2021.638816 Goodwin, M., M.D., West M. (2022, November 3). *Intravenous Immunoglobulin (IVIg) Treatment; What To Know*. Medical News Today. https://www.medicalnewstoday.com/articles/ivig (continued from page 4)

#### Combination therapy gabapentinoid with a TCA

gabapentinoid with a SNRI

∞

#### **Topicals** 5% lidocaine

#### 8% capsaicin (Qutenza) <u>FDA approved</u> for neuropathic pain associated with diabetic peripheral neuropathy in the feet of adults.

~

#### Botulinum BTX-A SC

DIN-A JU

∞

#### **Opiods** Tramadol

Tapentadol extended-release <u>FDA approved</u> to treat severe neuropathic pain in diabetics.

∞

Unless specifically noted "FDA Approved", all others are off-label usage for peripheral neuropathy.

# **IMPROVE BALANCE WITH A STABILITY BALL**

John Hanc, Brain and Life, August/September 2022

Balance is complex and involves three different sensory systems, says Fay B. Horak, PhD, professor of neurology at Oregon Health & Science University in Portland. The most important one, she says, is proprioception—the body's ability to sense movement and action and its location in space. The vestibular system, located in the inner ear, is responsible for providing the brain with information about head position and motion in relation to gravity. The other system used in balance is vision, which helps us anticipate obstacles and place our feet when walking.

Maintaining balance requires combining information from all three sensory systems, and their input may vary depending on the environment, Dr. Horak says. "If you're walking on a soft sand beach, for example, it's harder to use proprioception to know where the center mass of your body is, because the surface is unpredictable. You have to rely more on vision and vestibular function to stay upright and walking."

Fortunately, improving balance is possible. "Lots of studies have shown this," says Dr. Horak. "It's probably because of redundancy and plasticity in the nervous system. If you damage one neural network, you can compensate by using a different one." But like any kind of training, it takes consistency and dedication. "The more you work on your balance, the better you'll get," she says.

#### 4 Stability Ball Exercises to Improve Balance

A stability ball is an effective tool for engaging the three sensory systems—proprioception, vestibular, and vision—involved in balance. A 2020 study in the Journal of Exercise Rehabilitation found significant improvements in balance among stroke survivors who had followed a regimen that included stability ball exercises. "The best part about stability ball exercises is how accessible they are for just about anyone," says Bob Phillips, a personal trainer in Melville, NY, who uses the ball with many of his older clients. "You can easily do them at home."

Before starting any physical activity, check with your neurologist or physical therapist. You can find balance balls on Amazon or at any sporting goods store for about \$20. For those with neurologic conditions, a larger ball is recommended for greater stability. Wear comfortable, loose-fitting clothes; have a pen or pencil and a small rubber ball handy as props; and, depending on your level of fitness, ask a friend to assist or spot you. Once you're ready, try these exercises—designed by Brian DeKuiper, a personal trainer in Columbia, TN—to improve balance.

#### 1...Bounce

Sit on the ball with feet shoulder-width apart and flat on the floor. Gently bounce up and down using small pelvic movements. This improves proprioception—a sense of where your body is in space—by reinforcing balance and postural control, says DeKuiper. To stimulate the vestibular system, hold (or have a partner hold) a pen or pencil at arm's length and look at the letters or logo along its side. "Stay focused on it while bouncing," says DeKuiper. Bounce for 10 seconds to start, and gradually build up to 30 seconds. "It's activating your brain, especially when you include the vision part," says DeKuiper. "It seems simple, but it's effective."

#### 2...Bounce and Toss

Once bouncing feels comfortable, up the challenge by throwing a small rubber ball to a partner a few feet away or throwing it in the air to yourself. Introducing a moving target further challenges the visual component of balance, says DeKuiper. Continue for one minute. "This could be a 10- to 20-minute training session in and of itself," he adds.

#### 3...Head Turn

While seated on the ball, turn your head gently left to right and back as you try to keep an object—the pencil at arm's length or something on a wall in front of you—clearly in sight. Turning the head helps activate the inner ear canals, which contribute to better balance, says DeKuiper. Repeat two or three times at first; stop if you feel dizzy. Work up to doing this for 30 to 60 seconds.

#### 4...Side-to-Side

With your feet firmly on the floor and your butt pressed into the ball, use your hips and torso to slide the ball under you from left to right and back. The ball should move only slightly. The goal is to get the hips and torso moving. "Aim for a smooth motion," says DeKuiper. Feel your hips open as you do this. Again, focus on an object—either the pen or a picture on the wall. "You're working both your vision and vestibular systems with this exercise," he says. Start with 20 seconds at a time and build to three to 10 repetitions of 20 seconds each. "Moving and looking at objects while on the ball work together to trigger beneficial adaptations," says Lawrence Indivigiia, a personal trainer in San Diego, who works with clients over 55.

# **REGENERATIVE MEDICINE THERAPIES - FDA PATIENT**

# **INFORMATION** FDA, June 3, 2021

Unapproved products considered regenerative medicine therapies that are intended for the treatment or cure of a wide range of diseases or medical conditions continue to be marketed, even though they do not have the required FDA licensure/approval and FDA oversight of a clinical trial. These unapproved products, whether recovered from your own body or another person's body, include stem cells, stromal vascular fraction (fat-derived cells), umbilical cord blood and/or cord blood stem cells, amniotic fluid, Wharton's jelly, ortho-biologics, and exosomes. FDA has received reports of blindness, tumor formation, infections, and more, detailed below, due to the use of these unapproved products.

Currently, the only stem cell products that are FDA-approved for use in the United States consist of blood-forming stem cells (also known as hematopoietic progenitor cells) that are derived from umbilical cord blood. These products are approved for use in patients with disorders that affect the production of blood (i.e., the "hematopoietic" system) but they are not approved for other uses.

If you are being offered any of these products outside of a clinical trial for which FDA has oversight, please contact FDA at ocod@fda.hhs. gov. Additionally, contact FDA if you are considering treatment with any of these products and have questions, or if you have been treated with these products and wish to report any adverse effects or file a complaint. We take these reports seriously and want to hear from you.

Please know that if you are being charged for these products or offered these products outside of a clinical trial, you are likely being deceived and offered a product illegally. Likewise, FDA is aware that patients and consumers are being referred to clinicaltrials.gov, or are told that a product is registered with FDA, as a way to suggest that the products being offered are in compliance with FDA laws and regulations. This is often false. The inclusion of a product in the clinicaltrials.gov database or the fact that a firm has registered with FDA and listed its product does not mean the product is legally marketed.

# GABAPENTIN WITHDRAWAL SYMPTOMS, FACTORS AND

SCHEDULE Dan Wagener, M.A., September 15, 2022, American Addiction Centers

Gabapentin (marketed under the trade names Neurontin, Gralise, and Horizant) is an anticonvulsant medication used to treat partial seizures, postherpetic neuralgia, and other types of neuropathic pain. The Horizant extended-release formulation is approved for the treatment of restless leg syndrome.

#### **Gabapentin Withdrawal Syndrome**

Even those who take gabapentin as prescribed may develop some physical dependence. When discontinuing use, withdrawal symptoms may resemble that of alcohol and benzodiazepine withdrawal. This similarity may be due to the fact that gabapentin and these other substances all act on gamma-aminobutyric acid, or GABA, which is an inhibitory neurotransmitter in the brain.

#### Primary withdrawal symptoms

- Anxiety
- Fatigue
- Dizziness Headache

- Agitation Insomnia
- Restlessness Irritability
- Light sensitivity
- Sweating
  - Irregular heartbeat
- Nausea

Withdrawal usually occurs within 12 hours to 7 days after quitting the medication. Though a withdrawal timeline hasn't been clearly documented, some studies have noted symptoms that last up to 10 days.

#### Factors that can affect withdrawal

Age

Length of time

Concurrent use of other drugs or alcohol

Dose

Medical or mental health problems

Withdrawal schedule

Experts recommend gradually smaller doses of gabapentin to wean a person safely and comfortably off the medication. Such tapering schedules are commonly used with medications like gabapentin that have the potential to produce adverse withdrawal effects when being discontinued. Gabapentin use can be phased out over a period of one week, but the exact schedule will depend on the person's particular situation. Slower tapers may allow for a safer discontinuation of the drug. Experts recommend reducing the daily dose at a maximum rate of 300mg every 4 days.



### WESTERN NEUROPATHY ASSOCIATION

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### **IN THIS ISSUE**

Katherine Stenzel, Editor

Hello readers and welcome to the June issue!

Did you notice a change in the side panels on page 4 and 5 in the last issue? I've included them in this issue also as they contain important information - the commonly recommended medications for neuropathic pain (NP) associated with diabetic peripheral neuropathy. Not all of these are FDA approved for NP – only Lyrica (pregabalin), Cymbalta (duloxetine), Qutenza (8% capsaicin), and tapentadol extended-release. The others are off-label use for symptoms of peripheral neuropathy.

Of interest on page 7 is the FDA's statement of regenerative medicine therapies – i.e., stem cells. I have been asked increasing about the use of these products in advertised 'cures' for peripheral neuropathy. I am NOT a medical professional, so I can only get my information from reliable sources (FDA), and those say that stem cells are ONLY approved for treating "disorders that affect the production of blood". And that is not peripheral neuropathy. But as with many treatments, it may give you temporary relief. Proceed with caution – the treatment could also harm your body and your wallet!

And for balance, try a stability ball. Page 6 includes a series of four exercises that build your balance ability step-by-step and all while keeping your feet on the floor.

Happy Reading,

Katherine

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#### Western Neuropathy Association (WNA)

A California public benefit, nonprofit, tax-exempt corporation. Katherine Stenzel, Editor klstenzel@hotmail.com

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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 <u>All contributions and dues are tax-deductible.</u>

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

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