



WESTERN NEUROPATHY ASSOCIATION

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Celebrating our 24th Year!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

USE OF BOTOX (Botulinum Toxin) IN THE TREATMENT OF NEUROPATHIC PAIN: A CASE SERIES

Du, X and Patel, D. (2022, May). Use Of Botulinum Toxin In The Treatment Of Neuropathic Pain: A Case Series. *Neurology*, 98(18), 864. https://n.neurology.org/content/98/18_Supplement/864

ABSTRACT

Objective: To report the treatment benefits of botulinum toxin A (Botox) in the treatment of refractory neuropathic pain in both diabetic and idiopathic neuropathy.

Background: Neuropathic pain is a frequent complaint in patients with peripheral neuropathy secondary to diabetes or other causes. Many symptomatic treatments have been studied and proven effective, but a significant number of patients still experience uncontrolled pain or intolerable side effects. A small cross-over trial has suggested efficacy of Botox after one round of injections, but multiple sessions have not been examined and there has not been a large clinical trial.

Design/Methods: Patients were selected based on having a known diagnosis of neuropathy and having failed an adequate trial of 3 standard neuropathic pain medications. They were treated with intradermal injection of Botox at 10 sites on the dorsum of each foot every 3 months. Total of 100U were used for each procedure. The 11-point Likert numeric scale was used to assess their pain before during and after treatment.

Results: 8 male veterans were identified and consented to a trial of Botox for neuropathic pain. Ages ranged from 47 to 90 years. One patient had idiopathic neuropathy while the remainder had diabetes. Average duration of neuropathic pain was 9 years. The treatment duration with Botox ranged from 3 months to 12 years. One patient withdrew after first injection due to inconvenience and less improvement than expected. All other patients reported significant improvement with average reduction of 6.2 points on the Likert scale. The treatment benefits sustained in all responders.

Conclusions: In this case series, intradermal injection of Botox every 3 months offers effective and sustained reduction in neuropathic pain in both diabetic and idiopathic neuropathy and is well tolerated.

Editor's Note – One of the patients in the clinical trial was diagnosed as Idiopathic. This is the first time I've seen such a distinction in a clinical trial participant. Usually participants are diabetic, chemo or other toxin based, or a specific hereditary neuropathy. I find this very encouraging as an Idiopathic Progressive Polyneuropathy diagnosed patient.

On the negative side, only males were included. I don't see this as an adverse indicator as other studies using botox on neuropathic pain have used male and female participants. Results should be the same for us.

And finally, with this treatment you will also have less wrinkles on your feet! (couldn't resist!)

...Katherine

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Katherine Stenzel
Editor

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OCTOBER NEUROPATHY SUPPORT GROUPS SCHEDULE

In-Person Support Group Meetings

October 3 (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

October 20 (Thursday)

Grants Pass OR Support Group

3:30pm PST

Contact David Tally at david@tallymediagroup.com for meeting information.

Virtual Support Group Meetings

(Open your internet browser, go to join.zoom.us, enter the meeting ID and Passcode)

October 8 (2nd Saturday)

11:00am-1:00pm PST/1:00pm-3:00pm CST, Meeting ID: 893 4117 5040 / Passcode: 123557

Host – Katherine Stenzel, klstenzel@hotmail.com

October 19 (3rd Wednesday)

10:00am-11:30am PST/12:00pm - 1:30pm CST, Meeting ID: 863 2548 2422 / Passcode: 609857

Host – Glenn Ribotsky, glenntaj@yahoo.com

October 22 (4th Saturday – Open Discussion)

11:00am-1:00pm PST/1:00pm - 3:00pm CST, Meeting ID: 818 9099 1051 / Passcode: 227946

Host – John Phillips, johnphillips.wna@gmail.com

Attention California Members

There are many members who want to attend California based in-person meetings. Right now, only Auburn has a monthly meeting (see information above). Most of the leaders from groups that met pre-pandemic, and who have led these groups for many years (thank you very much!), have taken this opportunity to step aside so that another member can pick up the leadership role. But alas, **not one person** has volunteered.

It's not an easy job to be a group leader but it's not hard either.

- The WNA can help with sending emails to members that live in your area. You already have a ready-made audience!
- Speakers are not required at meetings to provide education. That is why the WNA has monthly virtual seminars for its members and friends.
- A support group is for sharing between the attendees – sharing what works for reducing your symptoms, sharing your fears about a situation and what to do, sharing the day-to-day anxiety and depression that result from our disease. It's the place where everyone KNOWS about neuropathy symptoms and how those nasty electric shocks zing through your body. You don't need to explain that pain to others – they get it!

If you want advice on how to lead, I'll be glad to share what works for John, Glenn and I during the virtual support groups. We must be doing it right as our attendance keeps climbing each month. And of course, you are welcome to attend any of the virtual support group meetings for a first-hand experience.

Please write me at klstenzel@hotmail.com for more information on leading a peripheral neuropathy support group. I'd love to help you start your own group!

...Katherine

FROM THE PRESIDENT Pam Hart, WNA President

It is with great pleasure that we welcome a new member to our Board of Directors, Martin Price. Some of you may remember Martin from the Discovery Bay Support Group and that he received a Leadership Award from Bev in 2019 at our Annual Meeting. He is very supportive and has great information on supplements. We have even convinced him to host a webinar to review the supplements he has found helpful.

Yes, October...Halloween, cooler weather and, of course, pumpkins. I thought I would remind you of the advantages of pumpkins.

- Highly nutritious and particularly rich in Vitamin A.
- High in antioxidants which may reduce your risk of chronic disease and cancer
- Packed with the vitamins that boost immunity
- Vitamin A, Lutein and Zeaxanthin may protect your eyesight
- Nutrient density and low calorie count may promote weight loss
- Potassium, Vitamin C and fiber may benefit heart health
- Contains compounds that promote healthy skin
- Incredibly versatile and easy to add to your diet

With all of these advantages, I look forward to my fill of pumpkin, not just pumpkin spice added to my coffee.



WEBINARS

Past Webinars on WNA's YouTube Channel (<https://pnhelp.org/resources/audio-and-video>)

July 28, 2022 – Essential Neuropathy Websites by Glenn Ribotsky, WNA Director

August 25, 2022 – What works for Neuropathy, Brad and Bob, Physical Therapists

September 29, 2022 – Adaptive/Assistive Driving

Future Webinars

October 2022 - No Webinar

November 9, 2022 - Beneficial Supplements for Peripheral Neuropathy,
Martin Price, WNA Director

Look in your inbox for a registration email around November 1st

December 2022 – No Webinar



CURABLE – AN APP TO HELP MANAGE PAIN

Curable is like having a reassuring best friend in your back pocket; her name is Clara. Clara, the virtual pain coach, interacts with you by sending text messages, activities, resources, and funny gifs. The app was created by people who suffered from chronic pain themselves, which is why it feels like you're interacting with someone who "gets it."

Using pain psychology and a biopsychosocial approach, the app helps users manage their pain. When you begin, Clara asks a series of questions to get insight into your pain and its causes. She then presents 5-to-20-minute exercises, like guided meditations, visualizations, and activities that help you to better manage your pain. The Curable data indicates that "70 percent of people who use the app for 30 days or more report some physical relief", with half of those saying their pain is "much better" or "completely gone."

The free version of Curable offers 13 introductory audio lessons. Although the app is not a "cure" for chronic pain, its benefits may be worth the small monthly fee giving you access to all of its features.

You can download Curable at <https://www.curablehealth.com/clara>

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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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.

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(888) HMO-2219

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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".

AGING AND MUSCLE LOSS - KEEP YOUR STRENGTH AND STAY INDEPENDENT

Retrieved 8/27/2022 from <https://www.myhealth.va.gov/mhv-portal-web/ss20201023-aging-muscle-loss>

Submitted by Stephen Harvey, Austin, TX

Aging can come with some great benefits, like wisdom, experiences, and memories. But one challenge can include muscle loss. Losing strength as you age can make daily tasks harder and cause you to become less independent. Can it be stopped? By keeping your muscles strong and able, you can stay independent longer and continue doing the things you love without needing much help from others.

Things that accelerate muscle loss

As you age, your body can change in ways that surprise you. One of the most noticeable changes is weakness and less ease of motion. Your lifestyle and overall health play a key role in how fast those changes occur. Factors that can increase muscle loss include:

- Inactive lifestyle
- An unbalanced diet, low in proteins
- Inflammation or swelling
- Medical conditions that cause muscle loss

You can control many of the factors linked to muscle loss. Managing your health conditions and making the right lifestyle changes can help you build and keep your strength.

'Motion is lotion, rest is rust'

We can't stop ourselves from aging, but we can slow down some of its effects. While increased physical activity is important to maintain your overall health and well-being, engaging in strengthening exercises at least 2 to 3 times each week is your best defense against muscle loss. By continuing to use your muscles, you'll be working to keep them strong.

You don't need expensive exercise equipment, a personal trainer, or even a gym membership. Common forms of physical activity and exercise that can help build strength and keep you mobile include:

- Walking, stair climbing, and biking
- Strength training with resistance tubes and bands
- Yard work (mowing, gardening, and planting)

Also consider one of the many varieties of yoga that may also help to maintain muscle strength, as well as relaxation and meditation practices.

MEMBER QUOTES ON EXERCISE HEARD AT VIRTUAL SUPPORT GROUPS

I increased the weights and resistance in my lower body workout. After a couple of months, my wife noticed that my posture is better and my stride is longer and more stable, i.e. I'm walking better. And I feel better too.

– Arthur Fant, Houston, TX

Walking/hiking has increased sensitivity in my feet which in turn has aided my balance and stride. I also have a greater feeling of positive, well-being.

– Stephen Harvey, Austin, TX

Members and Friends - What exercises do you do to help reduce your peripheral neuropathy symptoms? Share your exercise 'secret' with others. Email me at klstenzel@hotmail.com and I'll share the results in the December issue.

...Katherine (Question suggested by Helaine Greenburg, Las Vegas, NV)

HOW CAN I HAVE PAIN AND NUMBNESS?

Realief Neuropathy Centers, <https://realiefcenters.com/am-i-insane-i-have-pain-and-i-feel-like-im-going- numb/> retrieved July 16, 2022.

Peripheral neuropathy, when it is damage to the ends of the nerves, can pick and choose which nerve endings to damage. Your symptoms depend on which nerve endings are damaged.

Think of your peripheral nerves. They have a main cell body coming right off of the spinal cord. Inside they have many individual nerve fibers, like a coaxial cable is made up of many individual wires twined together.

Eventually these individual nerve “wires” end. Some end up and make a muscle fiber fire. Some make you cry like when you read your phone bill. Some tell your glands to squirt hormones into your bloodstream. And some tell you how soft the puppy’s ear that you are petting is.

The ends of the nerves are specialized and basically have one job each. One job! So, if a bunch of the nerves for feeling warmth are damaged, you will have a tough time feeling warmth. If they really get damaged, they can send the sensation of heat when they are not supposed to.

Table 1 from Dartmouth has more detail on the individual nerve endings and what they do.

Which particular nerve endings the neuropathy decides to damage, gives you your symptoms. Look at the chart above, second group, Fiber category A β , Group II afferents. These nerve fibers’ function is touch sensation. If they are damaged, you can get a numb-ish feeling. The bottom group, C Fibers, Group IV afferents, does burning pain. If they are damaged, you can get a burning type pain. If both groups are damaged, then that patient can have both numbness and burning pain.

Fiber category	Size (microns)	Speed (meters/second)	Function
A α Group IA and IB afferents	15	60-100	Large motor axons Muscle stretch and tension sensory axons
A β Group II afferents	12-14	30-60	Touch, pressure, vibration and joint position sensory axons
A γ	8-10	15-30	Gamma efferent motor axons
A δ Group III afferents	6-8	10-15	Sharp pain, very light touch & temperature sensation
B	2-5	3-10	Sympathetic preganglionic motor axons
C Group IV afferents	<1	<1.5	Dull, aching, burning pain and temperature sensation

Table 1. Fiber types and functions (from largest to smallest).

MEDICINAL PLANT HAS HELPED MY NEUROPATHY

WNA member, Houston, TX

I have researched in Pub Med National Library of Medicine, Mayo Clinic and several others seeking help for my crippling peripheral neuropathy. I have found help in nopals, the pads from prickly pear cactus. Before I started using them, I checked with Mark Vorderbruggen, who gave a talk on Medicinal wild plants to the Native Plant Society of Texas in July of this year at the Houston Arboretum. He has written books about it and is an expert. He says that nopals are safe to eat, and have anti-cancer properties in vitro and in animals.

Every day I use 2-3 prickly pear cactus pads in a smoothie. I also sauté chopped nopals with onions, garlic and eggs and add to crisp corn tortillas. And I add them to salads. I buy chopped nopals in the produce coolers at the Fiesta grocery store on Westheimer in Houston. They also have fresh nopal pads in the produce section. In season they also have red tunas (cactus fruit) and I buy many pounds of those and juice them. Warning - you have to remove the stickers/spines on the pads and the hard seeds in the tunas as you cannot consume them.

I have been using nopals for a month now. The sharp pains have stopped and I can feel my feet better. An added benefit is I have GI problems and the nopals have stopped nearly all that. I know this may not help everyone but this is what is working for me.

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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TIPS FOR LIVING WITH CHRONIC (NEUROPATHIC) PAIN

Ratini, M. 2020, September 16. *11 Tips for Living with Chronic Pain.* WebMD. <https://www.webmd.com/pain-management/guide/11-tips-for-living-with-chronic-pain>

(Editor - While the original article is focused on chronic pain, I've modified the content for our neuropathic pain. This topic and tips were submitted by Barbara Montgomery, Las Vegas, NV)

Learn deep breathing or meditation to help you relax.

Deep breathing and meditation are techniques that help your body relax, which may ease pain. Tension and tightness seep from muscles as they receive a quiet message to relax.

Although there are many ways to meditate, the soothing power of repetition is at the heart of some forms of meditation. Focusing on the breath, ignoring thoughts, and repeating a word or phrase -- a mantra -- causes the body to relax. While you can learn meditation on your own, it helps to take a class.

Deep breathing is also a relaxation technique. Find a quiet location, a comfortable body position, and block out distracting thoughts. Then, imagine a spot just below your navel. Breathe into that spot, filling your abdomen with air. Let the air fill you from the abdomen up, then let it out, like deflating a balloon.

Reduce stress in your life. Stress intensifies chronic pain.

Negative feelings like depression, anxiety, stress, and anger can increase the body's sensitivity to pain. By learning to take control of stress, you may find some relief from chronic pain.

Several techniques can help reduce stress and promote relaxation. Listening to soothing, calming music can lift your mood -- and make living with chronic pain more bearable. There are even specially designed relaxation tapes or CDs for this. Mental imagery relaxation (also called guided imagery) is a form of mental escape that can help you feel peaceful. It involves creating calming, peaceful images in your mind. Progressive muscle relaxation is another technique that promotes relaxation.

Boost chronic pain relief with the natural endorphins from exercise.

Endorphins are brain chemicals that help improve your mood while also blocking pain signals. Exercise has another pain-reducing effect -- it strengthens muscles, helping prevent re-injury and further pain. Plus, exercise can help keep your weight down, reduce heart disease risk, and control blood sugar levels -- especially important if you have diabetes. Ask your doctor for an exercise routine that is right for you. If you have certain health conditions, like diabetic neuropathy, you will need to be careful about the types of activities you engage in; your doctor can advise you on the best physical activities for you.

Cut back on alcohol, which can worsen sleep problems.

Pain makes sleep difficult, and alcohol can make sleep problems worse. If you're living with chronic pain, drinking less or no alcohol can improve your quality of life.

Join a support group. Meet others living with chronic pain.

When you're with people who have chronic pain and understand what you're going through, you feel less alone. You also benefit from their wisdom in coping with the pain.

Also, consider meeting with a mental health professional. Anyone can develop depression if they are living with chronic pain. Getting counseling can help you learn to cope better and help you avoid negative thoughts that make pain worse -- so you have a healthier attitude. Asking for help is a sign of strength, not weakness.

Don't smoke. It can worsen chronic pain.

Smoking can worsen painful circulation problems and increase risk of heart disease and cancer.

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SIX GREAT PLANT-BASED FOODS TO FIGHT NERVE PAIN

Dr. Bussell, Loma Linda University Health, March 30, 2021

If you're living with nerve pain, there is a definite benefit to eating healthy, low-inflammatory foods. A plant-based diet offers abundant opportunities for healthier nerves and less pain.

What's also great, is how easy it is to prepare simple meals at home, where you control the ingredients that go into your meals. The convenience of eating out doesn't outweigh the risk of relying on restaurant kitchens to use foods or ingredients that will relieve rather than aggravate your nerve pain.

Incorporate these into your diet every day in half or full cup servings, fresh or frozen. Eat them separately or mix up some appetizing salads. Bon appetit!

1. **Green and leafy vegetables.** Broccoli, spinach and asparagus all contain vitamin B, a nutrient important for nerve regeneration and nerve function. Spinach, broccoli and kale also contain a micronutrient called alpha-lipoic acid that prevents nerve damage and improves nerve function.
2. **Fruits.** Eat at least one fruit daily to help heal damaged nerves. Berries, peaches, cherries, red grapes, oranges and watermelon, among others, are loaded with antioxidants, which help to decrease inflammation and reduce nerve damage. Plus, grapes, blueberries and cranberries have been found to be full of a powerful anti-inflammatory compound called resveratrol.
3. **Zucchini.** A type of summer squash, zucchini is actually a fruit. Like other fruits, it's rich in antioxidants and, therefore, good for nerve cells. It's also a good source of potassium, which promotes effective nerve transmission, and magnesium, which calms excited nerves.
4. **Sweet potato.** This root vegetable offers several nerve health benefits: an abundance of vitamins A and C, which provides antioxidant protection for cells along with natural anti-inflammatory compounds. Animal research has demonstrated that nerve and brain tissue has shown reduced inflammation after eating purple sweet potato extract. And the high fiber content of a sweet potato won't spike your blood sugar because it causes starch to burn slowly.
5. **Quinoa.** Although it's commonly considered to be a grain, quinoa is actually a flowering plant that produces edible seeds. Once a staple food grown in the Andes Mountains for native people of Peru, Bolivia and Chile, quinoa has become a worldwide favorite, grown in more than 70 countries. Quinoa is a great source of potassium, which aids effective conduction of messages through nerves. It's an excellent source of magnesium, phosphorus, manganese and folate. This superfood also contains protein, fiber, iron, copper and vitamin B6.
6. **Avocado.** This unique fruit is full of healthy fats. Like quinoa, it has a healthy dose of potassium, which promotes effective nerve conduction. Avocados also help increase your body's absorption of antioxidants.

Tips For Living With Chronic (Neuropathic) Pain – Continued from page 6

Track your pain level and activities every day.

To effectively treat your pain, your doctor needs to know how you've been feeling between visits. Keeping a log or journal of your daily "pain score" will help you track your pain. At the end of each day, note your pain level on the 1 to 10 pain scale. Also, note what activities you did that day. Take this log book to every doctor visit -- to give your doctor a good understanding of how you're living with chronic pain and your physical functioning level.

Eat a healthy diet if you're living with chronic pain.

A well-balanced diet is important in many ways -- aiding your digestive process, reducing heart disease risk, keeping weight under control, and improving blood sugar levels. To eat a low-fat, low-sodium diet, choose from these: fresh fruits and vegetables; cooked dried beans and peas; whole-grain breads and cereals; low-fat cheese, milk, and yogurt; and lean meats.

Find ways to distract yourself from pain so you enjoy life more.

When you focus on pain, it makes it worse rather than better. Instead, find something you like doing -- an activity that keeps you busy and thinking about things besides your pain. You might not be able to avoid pain, but you can take control of your life.

DISCOUNTS FOR WNA MEMBERS

Continued from page 6

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-better-balance.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.building-better-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 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.



WESTERN NEUROPATHY ASSOCIATION

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RECRUITING SOON FOR PHASE 3 CLINICAL TRIAL – WINSANTOR

WinSanTor recently completed the second study in Canada in patients with diabetic peripheral neuropathy. This study was with their lead drug, WST-057. The recent Canadian study confirmed that WST-057 appears to be preventing and reversing peripheral nerve damage. The results were very positive (statistically significant) in showing repair and regrowth of the intraepidermal nerve fibers of the peripheral nerves.

They are currently preparing to start a Phase 3 global study for diabetic peripheral neuropathy, in which the FDA has requested a relatively large number of patients— 1,500 patients. For more information or to volunteer for the trial, email yillera@winsantor.com.



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Katherine Stenzel, 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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