Celebrating our 25th Year!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

WESTERN NEUROPATHY ASSOCIATION

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WESTERN NEUROPATHY ASSOCIATION
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NEW LOMA LINDA UNIVERSITY HEALTH (LOMA LINDA, CA) RESEARCH DISCOVERS TREATMENT FOR DIABETIC NEUROPATHY

Molly Smith, Loma Linda University Health, September 22, 2022

Intraneural Facilitation (INF) treatment effectively restores blood flow to damaged nerves, decreasing pain caused by diabetic peripheral neuropathy (DPN), according to a new study conducted by researchers at Loma Linda University Health. The study shows the quantitative results positively affect diabetes mellitus patients' quality of life whose previous pain treatment option was medication utilization.

The previous treatment for DPN consisted of glycemic control, foot care, and pain management. The American Diabetes Association recommends medication utilization for the relief of painful DPN. Despite ongoing research, only modest benefits from pharmacology have been shown to slow disease progression and reduce pain associated with DPN.

Mark Bussell, DPT, developer of INF treatment and one of the lead researchers in this study, hypothesized that INF would decrease perceived pain, and improve balance, ambulation, quality of life, and protective sensory function in patients with moderate-to-severe DPN.

Reduced blood flow impacts DPN, and INF utilizes three holds or positions which widen tiny openings in arteries surrounding nerves and improves blood flow to targeted nerves. The improved blood flow in these nerves stimulates healing and reduces or even stops nerve pain.

"There hasn't been treatment to consistently reverse painful symptoms caused by Type 2 diabetes," Bussell says. "It's previously been said that there is no cure for DPN. We wanted to go for something that some people said could never be done."

This single-blind, randomized clinical trial enrolled patients with Type 2 diabetes mellitus and moderate-to-severe DPN symptoms below the ankle. Patients were randomly assigned to receive INF or sham treatment. In the INF group, trained INF physical therapists provided therapy for 50 to 60 minutes, three times a week for three weeks. Sham treatment consisted of patients believing they received therapy for three weeks. Pre- and post-treatment data were compared between the two groups for quality of life, balance, gait, protective sensory function, and pain outcome measures.

A total of 28 patients were enrolled in the study: 17 in the INF group; 11 in the sham group. Researchers found a significant decrease in the overall pain score in both the INF and sham groups over time, but the decreased pain was greater in the INF group; 1.11 versus 0.82. Between-group comparisons demonstrated significant differences in unpleasant pain and protective sensory function. The INF group showed post-treatment improvements in protective sensory function and composite static balance score. There were no significant differences in the baseline characteristics of age, height, weight, and sex between the two groups.

"We've just discovered a new process towards manipulating the underappreciated vascular system," Bussell says. "This is just the pilot study. We are thrilled to conduct further research showing success in treating other types of neuropathies with INF."

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Katherine Stenzel
Editor

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PERIPHERAL NEUROPATHY SUPPORT GROUPS MAY 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

May 1 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

May 24 Santa Cruz CA Support Group
1:00 pm PST, Trinity Presbyterian Church, 420 Melrose Avenue
Contact: Mary Ann Leer (831) 477-1239

Virtual Support Group Sessions

May 13 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

May 17 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

May 27 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

PLANT-DERIVED CANNABIS OILS EFFECTIVE FOR SYMPTOM MANAGEMENT IN OLDER PATIENTS WITH TREATMENT-RESISTANT NEUROLOGICAL DISEASES NORML, March 16, 2023

The use of plant-derived cannabis oils containing balanced ratios of THC and CBD is generally safe and effective for patients suffering from neurological diseases, according to observational trial data published in the Journal of Clinical Medicine in which Australian researchers assessed the sustained use of cannabis extracts in 157 patients with treatment-resistant neurological, musculoskeletal, autoimmune, or anti-inflammatory disorders.

Investigators reported that patients age 65 or older and/or those suffering from neurological disorders, such as Parkinson's disease, peripheral neuropathy, and multiple sclerosis, perceived the greatest overall benefits from cannabis therapy. Their findings are consistent with those of several other studies reporting health-related quality of life benefits among older patients who consume cannabis.

Subjects were most likely to report cannabis to be effective for improving sleep and for reducing pain – findings that are consistent with other studies.

Authors concluded: "This retrospective medical record review describes the population characteristics of patients using medicinal cannabis at a clinic in Sydney, Australia and provides data on the effectiveness and safety of medicinal cannabis treatment on patient conditions and indications. … [Its findings] indicate that medicinal cannabis, in a balanced formulation, may address a variety of non-cancer conditions and indications concurrently and can be safely prescribed by a medical doctor."

FROM THE PRESIDENT Pam Hart, WNA President

It is exciting to realize that we are already into May – and Neuropathy month! I know that neuropathy doesn't seem like something to celebrate, but if we don't bring attention to it, and the numerous people it affects, who will? We encourage you to wear your "Ask About My Neuropathy" pin. If you don't have one, contact us to get one. All of us are ambassadors.

We celebrate the research being done and the people who think of us when they find accessory benefits to drugs that were not originally designed to help neuropathy. At the Auburn CA Peripheral Neuropathy Support Group meeting in April, we were treated to such news from Janell Jones, PharmD, from Gold Country Compounding. As a compounding pharmacist, Janell helps to formulate medications in different doses and forms to accommodate individual patients. Over the years Janell has seen the results of such medications and she was excited to share her observations about Low Dose Naltrexone (LDN). As she spoke, I couldn't help but think of what a miracle drug this sounds like as it mitigates the effects of a number of auto-immune conditions such as Parkinson's, Fibromyalgia, Multiple Myeloma and Grave's Disease, just to mention a few. And, yes, it can even help with peripheral neuropathy conditions. Janell cautioned that in her experience it only helped in about 50% of the cases of neuropathy, but it is certainly worth a try! At a clinic in Ireland, they are even using it for infertility treatment!

This is a medication that would need to be prescribed by a physician and it is not covered by insurance, but it is such an 'old' drug, that a monthly supply is around $30.00. More information regarding this drug can be found at www.ldnresearchtrust.org, the website for the LDN Research Trust charity in the UK. And check out Page 7 in this issue of Neuropathy Hope for summaries of two review papers on LDN and chronic pain, and the result of a 2021 Clinical Trial on LDN for Painful Diabetic Neuropathy (PDN).

Cheers,
Pam

During **Peripheral Neuropathy Awareness Week** – May 7 through 13 – and during the entire month of May, enjoy the offerings of the other neuropathy organizations in their educational outreach programs. For example, the GBS|CIDP Foundation International is having their 2023 Virtual Summit titled "Life After Diagnosis" on Saturday, May 20, 2023, from 10am to 3pm Eastern. Last year they also sponsored several Walks for Neuropathy to further awareness. Check out their website at www.gbs-cidp.org for additional information.

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

Western Neuropathy Association

Virtual Gala

Save the Date!

Saturday, July 22, 2023

11:00am – 1:00pm Pacific, 1:00pm – 3:00pm Central

(in lieu of 4th Saturday Virtual Support Group)

Put on your fancy hats, caps and tiaras and join us for an afternoon of fun!

There will be contests, dancing, a scavenger hunt, awards, speeches and a little fundraising.

WNA members and friends, support group attendees and family – everyone is welcome!

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-benefits-insurance
(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)
FDA approved 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)
FDA approved 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)

THE #1 EXERCISE TO DO AS YOU GET OLDER

AARP Webletter, January 5, 2023

If you only have time for one exercise, fitness experts say, make it a squat.

Squats strengthen all of the muscle groups in your legs, including your glutes, hamstrings, quadriceps and calves, as well as muscles in your lower back and core. Those muscles provide the foundation for most activities of daily living, such as getting off the toilet, climbing a set of stairs and simply standing up from a chair.

Squats can also help protect your joints, improve your balance and prevent falls, says Denise Austin, health and fitness expert and creator of DeniseAustin.com. "Squats are one of the best overall exercises," she says. "they strengthen the major muscles of the lower body we need to keep strong and also protect two joints we need help with on a regular basis — our knees and our hips."

Here's how to get started with squats:

1. **Get in position**

If you're new to squats, choose a spot where you can hold on to the kitchen counter, a table or another steady surface. Holding on for stability makes it easier to focus on your form without worrying about your balance, Austin says.

Set your feet about shoulder-width apart or a little wider. (If you have hip issues, it's OK to have your legs a little farther apart.) Toes should face slightly outward.

2. **Lower into a squat**

Keeping your back straight, chest up and heels planted, push your hips back like you are sitting in a chair.

Try to keep your weight evenly distributed on both feet as you do the exercise, with your weight mostly on your heels, not your toes, says Lori Michiel, founder of Lori Michiel Fitness, which specializes in senior fitness in the home.

Make sure your knees do not extend forward over your toes, because that can hurt your knees.

If you have knee or hip issues, you don't need to do a deep bend. The coming-up part of the exercise is what really builds strength, Austin says.

3. **Repeat**

Aim for two sets of eight to 10, at a tempo of two seconds down, two seconds up. Inhale on the way down and exhale on the way up. As your body tires at the end of the set, make sure you're not hunching over or letting your knees cave in.

For the best results, do the exercise two or three times a week.

4. **Get your arms in play**

As you start to build strength, you can try doing your squats without holding on to anything. For balance, let your arms rise parallel in front of you on the downward part of the squat, then drop them to your sides when you stand up, Austin suggests.

Another option is to cross your arms across your chest. That can help keep you upright if you tend to hunch over.

5. **For a greater challenge, add resistance**

Once you can do two sets of 15 without feeling any muscle soreness afterward, you're ready to add some weight.

The easiest way is to hold a pair of dumbbells. Start with low weights and build up.

PATIENT TO PERSON: 10 STEPS TO REGAIN YOUR LIFE

Pain Management & Injury Relief, November 6, 2012; modified by Katherine Stenzel, Editor

Being diagnosed with peripheral neuropathy is scary. You may feel like you are the only one with this condition, which can be isolating and lonely. You may not know who to turn to or where to go for help. What do you do?

The American Chronic Pain Association (ACPA) found this same situation with their chronic pain sufferers and created the following 10 steps to help them look beyond themselves as simply a chronic pain patient. These steps are just as applicable to those of us suffering from peripheral neuropathy, whether we have pain or not.

I have adjusted the wording slightly for us neuropathy patients. If you don't have pain, you can substitute that word with your particular symptoms or neuropathy in general.

STEP 1: Accept the Pain

Spend time learning about your condition, and gathering all the informational resources you can (visit our website at pnhelp.org). Accept that pain is a part of your life, and that there may be no cure for your condition.

STEP 2: Get Involved

Speak with your physician about what you can do outside of the office to take an active role in treating your pain. Understand that being involved in your pain management plan increases its success.

STEP 3: Learn to Set Priorities

Make a list of things that are most important to you outside of your pain condition. Making priorities will help you begin living the life you want.

STEP 4: Set Realistic Goals

Set goals which are accomplishable, and then break those goals into smaller steps. Work with your physician to set pain goals that are manageable and realistic for you.

STEP 5: Know Your Basic Rights

"We all have basic rights. Among these are the right to be treated with respect, to say no without guilt, to do less than humanly possible, to make mistakes, and to not need to justify your decisions, with words or pain," states the ACPA.

STEP 6: Recognize Emotions

Understand that your mind and body are interconnected, and your emotions affect your physical well-being. Take the steps necessary to acknowledge your feelings and decrease your stress, which may in turn reduce your pain.

STEP 7: Learn to Relax

"Pain increases in times of stress," states the ACPA. Learn some relaxation techniques such as deep breathing and visualization. By taking time to relax your mind and body, you will be better equipped to manage the pain.

STEP 8: Exercise

While exercise can seem scary or impossible when you're in chronic pain, it can actually help to relieve your pain. Speak with your physician or therapist about implementing an exercise regimen that works for you and your lifestyle.

STEP 9: See the Total Picture

Realize that pain does not need to control your life. By following the steps above, you can regain control over the pain you feel, and experience life the way you want to and the way you deserve it. The ACPA states, "You will grow stronger in your belief that you can live a normal life in spite of chronic pain."

STEP 10: Reach Out

Over 100 million people suffer from chronic pain in the United States and over 20 million suffer from peripheral neuropathy. When you have taken control of your life and managed your symptoms, let those around you learn from the steps you have taken. Reach out to others through support groups sponsored by our organization, Western Neuropathy Association, and/or through the American Chronic Pain Association.

Peripheral Neuropathy Treatment Drug Classes

(continued from page 4)

Combination therapy

gabapentinoid with a TCA

gabapentinoid with a SNRI

∞

Topicals

5% lidocaine

8% capsaicin (Qutenza) *FDA approved for neuropathic pain associated with diabetic peripheral neuropathy in the feet of adults.*

∞

Botulinum

BTX-A SC

∞

Opiods

Tramadol

Tapentadol extended-release FDA approved to treat severe neuropathic pain in diabetics.

∞

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

HOW LONG IT TAKES GABAPENTIN TO WORK (PLUS 5 TIPS FOR TAKING IT) Kevin Le, PharmD, BCPS, BCPPS and Christina Aungst, PharmD; GoodRX.com; September 23, 2022

Gabapentin (Neurontin) is one of the most commonly used medications in the U.S. It treats a variety of medical conditions, including certain types of nerve pain and seizures.

What's gabapentin?

Gabapentin immediate-release (IR) is FDA approved to treat certain types of seizures and a type of nerve pain from shingles - postherpetic neuralgia. It's also used for many conditions that is not FDA approved – called off label use. This includes alcohol use disorder, fibromyalgia, and other types of nerve pain.

Gabapentin is also available in two extended-release (ER) forms: Gralise and Horizant. Gralise is approved for postherpetic neuralgia. Horizant is approved for postherpetic neuralgia and restless leg syndrome.

It's not exactly clear how gabapentin works to treat these conditions. Gabapentin mimics a chemical in the brain called gamma-aminobutyric acid (GABA). GABA calms down the activity of your brain and nerves. This is thought to relieve pain, cause drowsiness, and treat seizures.

Knowing the best way to take gabapentin is important. Here are the five commonly asked questions about gabapentin.

1. How long does gabapentin take to work?

Most people feel the effects of gabapentin (like pain relief) within the first week. But it can take up to a month or longer for some people to see significant improvement. And the dose of gabapentin varies significantly from person to person with some people needing higher doses than others. Gabapentin has a wide dosing range, and sometimes it takes a while to find the dose that works for you.

If you don't feel pain relief after a couple weeks of taking gabapentin, talk to your provider. They might consider increasing your dose. But don't make any changes without talking to them first. Taking too much gabapentin can be dangerous.

2. What time of day should I take gabapentin?

Depending on what you're using gabapentin for, your healthcare provider may recommend taking it once a day to start. And it's a good idea to take it at night as one of gabapentin's most common side effects is drowsiness. And while gabapentin has been used off-label to help people with sleep problems, it's also one of the most common reasons people stop taking gabapentin.

Most people will end up taking gabapentin 2 to 3 times daily, so it's best to space the doses evenly throughout the day. Doing so helps make sure a steady level of gabapentin is in your body throughout the entire day.

Gralise is only taken once a day with your evening meal. And Horizant is taken once in the evening, or twice a day depending on what you're taking it for.

3. Should I take gabapentin with food?

You can take gabapentin with or without food but it's best to take it the same way each time. This is because taking gabapentin with food may have a slight effect on how well gabapentin is absorbed. For example, foods that are high in protein may help gabapentin be better absorbed. Even though these effects are minimal, it may still be a good idea to be consistent with whether you take gabapentin with food or not.

If you're taking one of the ER versions of gabapentin (Gralise or Horizant), you should take them with food. Gralise is usually taken once a day with your evening meal. Horizant is usually taken more than once a day with meals. Taking these formulations with food helps improve how well they're absorbed by the body.

4. What if I miss my dose of gabapentin?

If you miss a dose of gabapentin or Gralise, take it right when you remember. But if your next scheduled dose is coming up soon after you remember, skip your missed dose. Then take your next dose of gabapentin or Gralise according to your usual dosing schedule. It's important not to double up on your doses. If you miss a dose of Horizant, skip it. Wait for your next scheduled dose.

5. What can I do if I experience side effects from gabapentin?

People taking gabapentin may experience side effects with the most common ones being dizziness and tiredness. These side effects may feel most intense when you first start taking gabapentin, and they may improve over time.

If you experience drowsiness or dizziness, avoid doing any activities that require alertness until these side effects improve. This includes driving a car, or operating heavy machinery. Other possible gabapentin side effects include fluid buildup (edema), dry mouth, uncontrollable eye movements, double vision and tremors. If any of these side effects occur and don't improve, contact your healthcare provider. They may be able to adjust your dose of gabapentin, or try another medication altogether.

LOW-DOSE NALTREXONE (LDN) REVIEW PAPERS AND CLINICAL TRIAL RESULT

Low-Dose Naltrexone for Chronic Pain – 2014 Review Paper

Abstract

Low-dose naltrexone (LDN) has been demonstrated to reduce symptom severity in conditions such as fibromyalgia, Crohn's disease, multiple sclerosis, and complex regional pain syndrome. We review the evidence that LDN may operate as a novel anti-inflammatory agent in the central nervous system, via action on microglial cells. These effects may be unique to low dosages of naltrexone and appear to be entirely independent from naltrexone's better-known activity on opioid receptors. As a daily oral therapy, LDN is inexpensive and well-tolerated. Despite initial promise of efficacy, the use of LDN for chronic disorders is still highly experimental. Published trials have low sample sizes, and few replications have been performed. We cover the typical usage of LDN in clinical trials, caveats to using the medication, and recommendations for future research and clinical work. LDN may represent one of the first glial cell modulators to be used for the management of chronic pain disorders.

Reference

Younger, J., et al. (2014). *The Use Of Low-Dose Naltrexone (LDN) As A Novel Anti-Inflammatory Treatment For Chronic Pain*. Clinical Rheumatology, 33(4), 451–459. doi: 10.1007/s10067-014-2517-2

Low-Dose Naltrexone for Painful Diabetic Neuropathy – 2021 Clinical Trial Results

Abstract

Previous clinical trials on low-dose naltrexone (1-5 mg/d) showed efficacy and safety in certain chronic painful conditions, but not in painful diabetic neuropathy. Hence the present study was planned.

Sixty-seven participants with painful diabetic neuropathy were randomized to receive either 2 mg naltrexone or 10 mg amitriptyline daily following a 2-week run-in period. The participants were followed up every 2 weeks for a total of 6 weeks. Up-titration was done (to 4 mg naltrexone or 25/50 mg amitriptyline) if the pain reduction was less than 20% on the visual analog scale (VAS) during the next follow-up visit.

Results: The difference (confidence interval) in the change in VAS score between groups from baseline was 1.64 (-0.92 to 4.20) in per-protocol analysis and 1.5 (-1.11 to 4.13) in intention-to-treat analysis. Eight and fifty-two adverse events were reported in the naltrexone and amitriptyline groups, respectively ($P < .001$). The most common adverse events were mild diarrhea with naltrexone and somnolence with amitriptyline.

Conclusions: Low-dose naltrexone exhibited similar efficacy and a superior safety profile compared with amitriptyline in painful diabetic neuropathy.

Reference

Srinivasa, A., et al. (2021). *Efficacy And Safety Of Low-Dose Naltrexone In Painful Diabetic Neuropathy: A Randomized, Double-Blind, Active-Control, Crossover Clinical Trial*. Journal of Diabetes, 13(10), 770-778. doi: 10.1111/1753-0407.13202.

Low-Dose Naltrexone for Chronic Pain – 2020 Clinical Review

Abstract

Purpose of review: The purpose of this review is to evaluate and explain our current understanding of the clinical use of low-dose naltrexone in the treatment of chronic pain.

Recent findings: Recent pre-clinical uses and clinical studies further elucidate the use of low-dose naltrexone in the treatment of chronic pain. Low-dose naltrexone (LDN) has shown promise to reduce symptoms related to chronic pain conditions such as fibromyalgia, inflammatory bowel conditions, and multiple sclerosis. The mechanism of LDN appears to be modulation of neuro-inflammation, specifically, the modulation of the glial cells and release of inflammatory chemicals in the central nervous system. These effects appear to be unique at low dosage compared to dosage for food and drug administration approved use for alcohol and opioid dependence. We review the evidence that LDN has shown more than promise and should be further investigated in clinical practice.

Reference

Kim, P., et al. (2020). *Low-Dose Naltrexone For Chronic Pain: Update And Systemic Review.* Current Pain and Headache Reports, 24(10), 64. doi: 10.1007/s11916-020-00898-0.

WESTERN NEUROPATHY ASSOCIATION
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DIAGNOSIS OF PREDIABETES/DIABETES

MedlinePlus, https://medlineplus.gov/prediabetes.html

All neuropathy sufferers should be aware of their glucose numbers as developing prediabetes or type 2 diabetes could increase your neuropathy symptoms.

How is prediabetes/diabetes diagnosed?

There are a few different blood tests that can diagnose prediabetes and diabetes. The most common ones are:

F**asting plasma glucose (FPG) test**, which measures your blood sugar at a single point in time. You need to fast (not eat or drink) for at least 8 hours before the test. The results of the test are given in mg/dL (milligrams per deciliter):

- A normal level is 99 or below
- Prediabetes is 100 to 125
- Type 2 diabetes is 126 and above

A1C test, which measures your average blood sugar over the past 3 months. The results of an A1C test are given as a percentage. The higher the percentage, the higher your blood sugar levels have been.

- A normal level is below 5.7%
- Prediabetes is between 5.7 to 6.4%
- Type 2 diabetes is above 6.5%

You can delay or prevent developing prediabetes or type 2 diabetes through lifestyle changes: losing weight, regular physical activity, and a healthy eating plan.

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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.

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