



WESTERN NEUROPATHY ASSOCIATION

MARCH 2025

Issue 02

Volume 23

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CELEBRATING OUR 27TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

FDA APPROVES FIRST NEW NON-OPIOD PAIN PILL IN DECADES

HealthDayNews @ NeurologyAdvisor.com; February 5, 2025

The U.S. Food and Drug Administration (FDA) has approved *Journavx*, a new pain reliever without the risks of addiction or overdose linked to drugs like Vicodin and OxyContin. The new pill, developed by Vertex Pharmaceuticals, is intended for short-term pain relief following surgery or injury. Unlike opioids, which bind to brain receptors to reduce pain but often lead to dependence and addiction, Journavx works differently. The medication blocks specific proteins that trigger pain signals before they reach the brain.

Studies of more than 870 patients who took *Journavx* after foot and abdominal surgery showed that the drug provided more relief than a placebo but was not more effective than a common opioid-acetaminophen combination pill. "It's not a slam dunk on effectiveness," Michael Schuh of the Mayo Clinic, a pharmacist who was not involved in the research. "But it is a slam dunk in that it's a very different pathway and mechanism of action. So, I think that shows a lot [of] promise."

One major concern is cost. *Journavx* will have a list price of \$15.50 per pill, compared to generic opioids, which cost \$1 or less.

Some reported side effects included nausea, constipation, itching, rash and headache, but no risk of addiction.

Vertex's drug (formerly called VX-548 / *suzetrigine*) has attracted much interest, but the drugmaker's stock took a hit in December after disappointing results in a study of chronic nerve pain. Despite this, the company plans to continue with another late-stage trial in hopes of getting FDA approval for chronic pain treatment.

REFERENCE

The Associated Press media report; January 31, 2025

(Editor - Refer to the January/February 2024 issue of the *Neuropathy Hope* newsletter for details on Clinical Trial results and description of the sodium channel mechanism for pain relief. September 2024 issue notes the New Drug Application submission to the FDA.)

WELCOME TO NEW DIRECTOR, BRIAN LOCKARD!

During the December 2024 Board of Directors meeting, Brian Lockard was unanimously approved as the latest Western Neuropathy Association Director! With this appointment, our Board is at a healthy number of ten members, providing a depth of business experience, creative capability and innovative ideas to lead the organization.

Brian started attending the Houston in-person support group and it's associated virtual group after Covid. He credits the supportive group environment as the reason he continued to seek out medical advice about his neuropathy, finally being diagnosed with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) in 2023. Being treated with IVIG has greatly reduced his symptoms and allowed him to once again enjoy his woodworking hobby. Welcome Brian!

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PERIPHERAL NEUROPATHY SUPPORT GROUPS VIRTUAL AND IN-PERSON FOR MARCH 2025

*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 1 Saturday	Houston TX Peripheral Neuropathy Support Group 1pm – 2:30pm Central Memorial Drive United Methodist Church, 12955 Memorial Drive Room DS100, enter at back (south) of building, follow signs Hosts – Katherine Stenzel, John Phillips and Brian Lockard
In-Person 3 Monday	Auburn CA Peripheral Neuropathy Support Group 12 noon - 1:30pm Pacific Unity of Auburn, 1212 High Street, Auburn, CA Host – Pam Hart, pamhart@pnhelp.org , and Cass Capel, capelkbphd@gmail.com
Virtual 5 Wednesday	Strategies for Singles with Neuropathy Support Group (1st Wednesday of the odd months) 4pm Pacific / 5pm Mountain / 6pm Central / 7pm Eastern (1 hour long) Host – Erika McDannell, contact Erika for Zoom link
Virtual 8 Wednesday	2nd Saturday Peripheral Neuropathy Support Group 11am Pacific / noon Mountain / 1pm Central / 2pm Eastern (2 hours long) Meeting ID: 857 8287 7624 / Passcode: 369333 Host - Katherine Stenzel, contact Katherine for Zoom link
Virtual 11 Tuesday	2nd Tuesday Peripheral Neuropathy Support Group 2pm Pacific / 3pm Mountain / 4pm Central / 5pm Eastern (90 minutes long) Meeting ID: 980 2190 9000 / Passcode: 784590 Host – Shana Phelps, contact Shana for Zoom link (everyone welcome, Colorado focus on healthcare providers)
Virtual 12 Wednesday	2nd Wednesday Chemo-Induced Peripheral Neuropathy (CIPN) Support Group 2pm Pacific / 3pm Mountain / 4pm Central / 5pm Eastern (90 minutes long) Meeting ID: 830 5538 3243 / Passcode: 396320 Host - Glenn Ribotsky, contact Katherine for Zoom link
Virtual 19 Wednesday	3rd Wednesday Peripheral Neuropathy Support Group 10am Pacific / 11am Mountain / Noon Central / 1pm Eastern (2 hours long) Meeting ID: 833 4473 0364 / Passcode: 341654 Host - Glenn Ribotsky, contact Katherine for Zoom link
In-Person 19 Wednesday	Santa Cruz CA Peripheral Neuropathy Support Group (3rd Wednesday of the odd months) 1pm – 2:30 pm Pacific Trinity Presbyterian Church, 420 Melrose Avenue, Santa Cruz, CA Host - Mary Ann Leer (831) 477-1239
Virtual 19 Wednesday	3rd Wednesday CIDP and Autoimmune Support Group 3pm Pacific / 4pm Mountain / 5pm Central / 6pm Eastern (1 hour long) Host - John Phillips, contact John for Zoom link
Virtual 22 Saturday	4th Saturday Peripheral Neuropathy Open Discussion 11am Pacific / noon Mountain / 1pm Central / 2pm Eastern (2 hours long) Meeting ID: 851 7949 9276 / Passcode: 159827 Host - John Phillips, contact Katherine for Zoom link

**NEW – See page 4
for information**

Contact emails in the sidebar Board of Directors listing.

Support Group information can also be found on www.pnhelp.org under the Support Group tab.

FROM THE PRESIDENT Pam Hart, WNA President

As the vibrant colors of spring emerge, we are reminded of the renewal and energy this season brings. It's an opportune time to focus on activities that can aid in managing neuropathy symptoms and enhancing our overall well-being.

Embrace Physical Activity Engaging in regular, low-impact exercises can significantly benefit those with neuropathy. Activities such as walking, swimming, and cycling improve circulation, strengthen muscles, and enhance balance, all of which are crucial for nerve health. I have an electric bike which sounds like cheating, but since you know you have help, you are more likely to use the bike, get outdoors, and pedal when you can

Prioritize Balance and Coordination Improving balance is essential to prevent falls, a common concern for individuals with neuropathy. Simple exercises, like standing on one foot while holding onto a sturdy surface, can enhance stability and confidence in daily movements. Incorporating stretching routines can increase flexibility and reduce muscle tension. Tai Chi or Qi Gong are also low impact, helpful practices.

Manage Stress Effectively Stress can exacerbate neuropathy symptoms. Incorporating relaxation techniques such as deep breathing exercises, meditation, or yoga into your daily routine can help manage stress levels and promote nerve health. Of course, Tai Chi or Qi Gong can also help with this.

Our association continues to offer virtual support group meetings, providing a platform to share experiences, gain insights, and foster a sense of community. Your participation not only benefits you but also offers support to fellow members navigating similar challenges.

As we enjoy the longer days and warmer weather, let's seize the opportunity to engage in these beneficial activities. Remember, small, consistent efforts can lead to significant improvements in managing neuropathy.

Wishing you a healthy and active spring season.

Warm regards,

Pam

pamhart@pnhelp.org

A NOTE FROM THE MERCHANDISING TEAM Erika McDannell, WNA Director

Here at the Western Neuropathy Association (WNA), we talk about all aspects of neuropathy - the tough, the everyday, and, yes, even the joyful. With this design, we wanted to highlight the activities that we can still appreciate and enjoy, despite the challenges of neuropathy. There are countless areas in my life that are beyond my control and having CIDP, NLD-SFN, and autonomic neuropathy is a great example of that. While it's important to process and grieve the ways in which my life has changed, I always look for the joys and I hope that you do as well.

As an all volunteer-run nonprofit, we truly strive to offer you hope here at WNA and we want our designs to remind you that you're not alone.

Thank you for being a part of the Western Neuropathy Association and for wearing our apparel. It's a great way to help others with neuropathy find WNA so that they, too, can find hope and support!



LIVING WITH JOY ONE STEP AT A TIME

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](http://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.

COMBINATION TREATMENTS FOR PERIPHERAL NEUROPATHY

Vicky Herman, Los Angeles, CA

I'm writing to share my journey with peripheral neuropathy, which began approximately three years ago, following a diagnosis of chronic myeloid leukemia (CML). My illness, unfortunately, stemmed from an environmental disaster in my neighborhood, where four people—including myself—contracted leukemia within the same year.

After being diagnosed, I was prescribed Sprycel, a necessary but challenging drug with significant side effects. Among these was the onset of peripheral neuropathy. My toes went numb, and I began experiencing stabbing pain in the balls of my feet, often so severe that it disrupted my ability to function normally.

Driving became hazardous, as I sometimes had to pull over and wait for 20 minutes before the pain subsided. These episodes escalated to monthly neuropathy attacks at night, where my feet would contort and lock in place, accompanied by shooting pain up my legs. The agony left me drenched in sweat and screaming, often lasting 20 minutes.

Determined to find a solution beyond medications, I embarked on extensive research. My first attempts were Calmare therapy, which offered only temporary relief, and a Soft Wave therapy which proved too invasive and unsuitable for cancer patients. I sought advice from my oncologist, who had no suggestions, and a naturopathic doctor, who recommended supplements, but none addressed the root of the problem or helped relieve the pain.

Refusing to give up, I discovered and invested in a combination of therapies that changed my life:

Pulsed Electromagnetic Field (PEMF) Therapy

This therapy stimulated cellular repair, reduced inflammation, and supported my overall well-being.

<https://pemftherapysolutions.com/about-us>

Red Light Therapy

Known for promoting cell regeneration, healing, and anti-aging, red light therapy also improved my skin, mood, and sleep.

<https://exesas.com/>

(Editor – read more about Red Light Therapy on the next page, Page 5)

Leg Compression Therapy (Normatec by Hyperice):

This device provided deep massage and compression, increasing blood and oxygen flow from my feet to the top of my legs.

<https://hyperice.com/>

I have included the websites for each, but there is plenty of information on the internet. If possible, I would always suggest going to a wellness center in your city to try out any of the therapies before you invest. But ultimately, I found that it was much cheaper to buy the equipment. Also, some insurance companies will cover the cost.

With daily use of these therapies—30 to 45 minutes for leg compression, combined with regular PEMF at about 20 minutes per day, plus red light therapy about 20 minutes per day, I have achieved remarkable results. My peripheral neuropathy has improved by approximately 85%. The unbearable pounding pain is gone, the numbness in my toes has decreased by 90%, and the tingling has become an occasional minor sensation. And no more leg cramping at night.

While everyone's journey is different, I believe in the importance of staying curious, advocating for oneself, and pursuing solutions through trial and error. I am deeply grateful for the relief I've found and feel compelled to share my experience in the hope that others might benefit from these therapies.

(Editor – After writing this article for the newsletter, Vicky lost her home in the Pacific Palisades fire in Southern California. We all wish her the best during this challenging time as she rebuilds. We hope she can look forward to a future filled with hope and new possibilities.)

VIRTUAL SUPPORT GROUP ADDED TO WESTERN NEUROPATHY ASSOCIATION SCHEDULE

The 2nd Tuesday of each month will now host a peripheral neuropathy support group! This is WNA's fourth monthly general peripheral neuropathy directed group but will have a Colorado focus with respect to doctors. Contact Shana Phelps, Director, shanaphelps@pnhelp.org, for the direct Zoom link.

■ RED LIGHT THERAPY FOR DIABETIC NEUROPATHY: DOES IT WORK?

Christine Fallabel and Megan Soliman, MD; *Healthline.com*; August 29, 2024

Red light therapy is a drug-free, noninvasive alternative that can be effective in helping people living with diabetic neuropathy. Using this treatment may aid in inflammation and pain reduction. This article explores the effectiveness and feasibility of Red Light Therapy for people managing diabetic neuropathy.

How does Red Light Therapy work?

Red light therapy is also known as low-level light therapy or photo biomodulation. This promising new therapy makes use of specific wavelengths of red and near-infrared light to stimulate cell activity and promote healing. People undergoing red light therapy may lie in a full-body red light pod or be treated with a small device outfitted with red light panels. Either way, the Red Light Therapy is applied to the affected area for a certain amount of time.

When used for diabetic neuropathy, the red light focuses on affected nerve cells to improve their function and reduce inflammation and pain. Session duration can range from 10 to 30 minutes a few days per week for approximately 12 weeks. Depending on the severity of your diabetic neuropathy, you may require more or fewer red light sessions.

While relatively new and results may vary, red light therapy is showing promise at effectively decreasing pain and inflammation for diabetic neuropathy patients.¹ However, more studies need to be done to determine absolute effectiveness, but many patients are finding relief from this new therapy.

It can relieve pain and inflammation in two ways:

- Increasing cellular energy production - Red Light Therapy stimulates the production of adenosine triphosphate (ATP), which provides energy to drive and support many processes of the cell. The increased energy can help promote healing.
- Enhancing blood circulation - Red Light Therapy increases blood flow to the area, facilitating improved oxygen and nutrient delivery to the nerves and promoting regeneration. This can aid in pain relief and reduce inflammation.

Are there any risks associated with this therapy?

Most people tolerate the therapy well and experience no adverse side effects. This is because it's noninvasive and a nonpharmaceutical option. However, any therapy can pose minimal health risks, including the following:

- Eye irritation - Direct exposure to red light can cause eye discomfort. During therapy, you should wear proper eye protection, such as an eye shield, patch, or goggles.
- Skin irritation - If you have particularly sensitive skin, talk with your doctor about starting with shorter sessions. Consider discussing a plan to increase your session time when you're comfortable.
- Complications with other conditions - Talk with your doctor if you have another chronic condition in addition to diabetes and diabetic neuropathy. They can review your current medications to determine potential contraindications you may be at risk of experiencing.

The bottom line

Diabetic neuropathy is a painful and common complication of diabetes, affecting up to half of people who live with the condition. While it isn't a cure, a new therapy that's gaining popularity is Red Light Therapy, which treats the pain and inflammation associated with the condition. While results may vary, this cost-effective option may offer hope to the millions of people affected by painful diabetic neuropathy.

REFERENCE

¹ Hakim A, Sadeghi et al. (2016). Effect Of Infrared Radiation On The Healing Of Diabetic Foot Ulcer. *International Journal of Endocrinol Metabolism*, 14(3):e32444. doi: 10.5812/ijem.32444.

Western Neuropathy Association - Contact Information

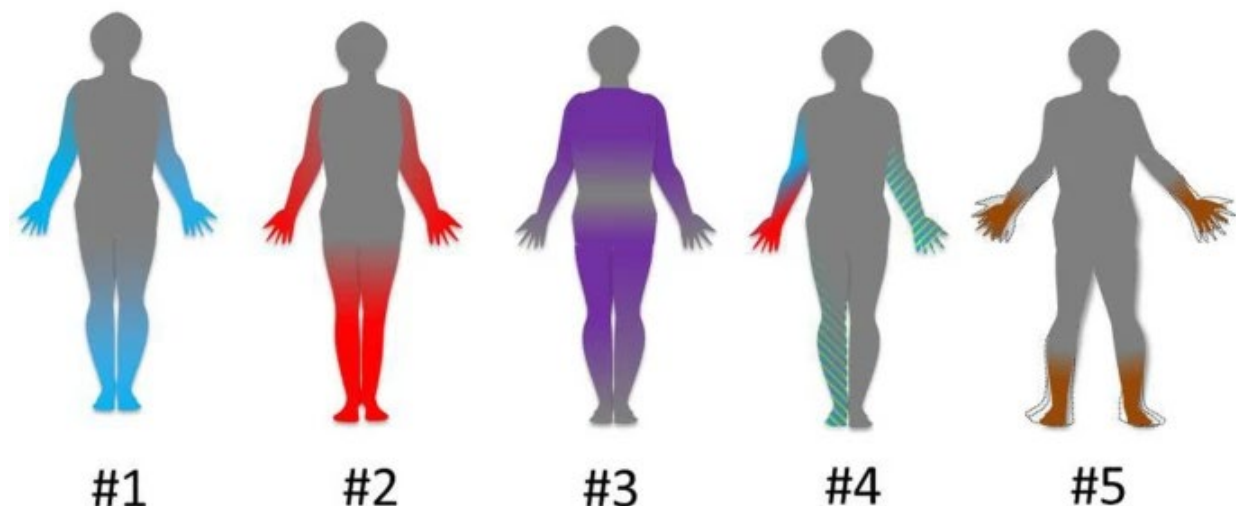
Neuropathy Assistance: (833) 980-4181 • Admin Assistance: (888) 556-3356 or admin@WNAinfo.org

FIVE DIFFERENT PHYSICAL PRESENTATIONS OF PERIPHERAL NEUROPATHY

Recognizing specific clinical patterns is essential to stratify the diagnostic workup in a patient who presents with signs and symptoms of peripheral neuropathy. This workup should include a detailed history and a thorough clinical examination. In our flow chart, we propose five different clinical patterns:

- #1. **Slowly progressive, distal symmetric, predominantly sensory neuropathy:** This most common peripheral neuropathy subtype is often caused by a metabolic condition (diabetes), chronic alcohol consumption, or neurotoxic drugs (chemotherapy). These patients only need limited diagnostic testing unless atypical neuropathy features are present. Exclusion of these causes may lead to the diagnosis of chronic idiopathic axonal neuropathy (CIAP), which usually has a benign course.
- #2. **Slowly progressive, long-standing neuropathy with muscle wasting and foot abnormalities:** Motor predominant, onset in child or adulthood, these patients may be less frequent compared to the other subtypes. Diagnostic workup should be prioritized towards genetic testing for hereditary causes.
- #3. **Neuropathy with subacute onset and/or proximal involvement:** These patients present with clinical features suggestive of an acquired immune-mediated condition. Extensive diagnostic workup, including antibody testing, etc. may be required. Potentially caused by CIDP, MMN (only motor), vasculitis, diabetic plexopathy, and paraneoplastic syndromes.
- #4. **Neuropathy with subacute or rapidly progressive disease course, multifocal symptoms, neuropathic pain, and autonomic dysfunction:** Potentially caused by GBS (acute), vasculitis, amyloidosis, or paraneoplastic syndrome. Patients with this subtype should undergo detailed diagnostic workup.
- #5. **Sensory ataxic neuropathy:** Clinical correlates of sensory neuronopathy or Denny-Brown's syndrome. Patients present with loss of proprioception and vibration sense and may display pseudoathetosis, with relative preservation of muscle strength. Underlying causes that should be explored include autoimmune disorders (i.e., Sjögren), paraneoplastic syndromes, POLG1 mutations and mitochondrial disorders.

These five subtypes should neither be taken as exclusive nor absolute since overlap of these patterns is not uncommon. For instance, some patients with a hereditary neuropathy (i.e., ATTRv amyloidosis) present with a rapidly progressive disease course, and are often misdiagnosed as CIDP. On the other hand, also CIDP patients occasionally present with a slowly progressive disease course.



Color Keys

- Sensory deficits drawn in blue (#1 and #4 arms and legs), motor deficits drawn in red (#2 arms and legs and #4 lower arm), and sensorimotor in magenta color (#3 upper torso and upper legs).
- Painful and / or autonomous dysfunction colored with green lines (#4 arms and legs overlain blue color).
- Loss of proprioception colored brown (#5 hands and feet).

REFERENCE

Lehmann, H.C. et al. (2020). Diagnosis Of Peripheral Neuropathy. *Neurological Research and Practice*, 2(20). <https://doi.org/10.1186/s42466-020-00064-2>

WHICH SUPPLEMENTS CAN HELP WITH NEUROPATHY?

Zawn Villines and Amy Fitzgerald; *MedicalNewsToday.com*; December 17, 2024

Treatment for neuropathy usually involves managing the condition that has caused it and relieving symptoms. Supplements may have fewer side effects than conventional treatments and have other health benefits. This article examines vitamins and supplements that may help reduce symptoms of neuropathy, prevent it from occurring, or even reverse nerve damage.

Acetyl-L-carnitine Acetyl-L-carnitine (ALC) is a popular supplement for treating a wide variety of symptoms. The liver, brain, and kidneys naturally produce it. A 2019 review suggests that ALC may help reduce pain and may improve nerve function in people with neuropathy. Review authors note it may be particularly effective for those with diabetic neuropathy.

B-complex vitamins A 2022 review of research indicates that B vitamins, including vitamin B1 and B12, play an important role in nervous system function and may also ease symptoms of neuropathy. The United Kingdom's National Health Service (NHS) notes that vitamin B12 deficiency is one possible cause of peripheral neuropathy, which people can treat by taking vitamin B12 supplements. People may want to try individual B vitamin supplements or B-complex vitamins, which include all eight types of B vitamins in one supplement. However, they should speak with a doctor before doing so to make sure B vitamins are safe to take for them.

Alpha-lipoic acid Alpha-lipoic acid (ALA) may help reverse free radical damage and intensify the effects of antioxidants, which may slow or stop nerve damage in individuals with diabetic neuropathy. The NHS also notes that ALA is a possible complementary therapy for people with peripheral neuropathy. A 2021 study found that ALA may be safe and effective to treat pain in people with various types of neuropathy.

Magnesium A 2021 review concluded that magnesium may promote peripheral nerve regeneration. Additionally, a 2018 study involving people undergoing chemotherapy found that those who had high levels of magnesium in their diet were less likely to experience chemotherapy-related neuropathy. A 2023 analysis found that both excessive and insufficient intake of magnesium may increase the likelihood of developing peripheral neuropathy. Therefore, they should always seek a doctor's advice before taking any magnesium supplements.

Calcium According to a 2023 analysis, both insufficient and excessive intake of calcium may increase the chances of developing peripheral neuropathy. Therefore, a person should speak with a healthcare professional before taking calcium supplements. Rich dietary sources of calcium include dairy foods, such as milk and cheese, as well as nondairy foods, like almonds and chia seeds.

Glutamine Glutamine is a type of amino acid that may improve many side effects of chemotherapy, including neuropathy. Food sources of glutamine include wheat, barley, peanuts, corn, soybeans, egg whites and milk. Glutamine is also available as a pill or an injection.

N-acetylcysteine N-acetylcysteine (NAC) is present in foods such as lentils, beans, and bananas. NAC may protect the neurological system from inflammation and damage, which may help prevent or treat neuropathy. A 2019 study found that complementary therapy with NAC over 8 weeks was more effective at improving diabetic neuropathy pain than a placebo. Researchers note this may be due to the antioxidant effects of NAC.

Vitamin D A 2020 study suggests there may be a link between vitamin D deficiency and diabetic neuropathy. A 2020 review of previous studies supports these findings. Researchers suggest that vitamin D may help relieve pain in people with diabetic neuropathy.

Vitamin E A 2021 meta-analysis found that vitamin E supplementation may help prevent chemotherapy-related neuropathy. However, a different 2021 meta-analysis notes that while there is some evidence to support the use of vitamin E to prevent and manage the symptoms of chemotherapy-related neuropathy, further high quality research is necessary to confirm these findings.

Caution - Experts recommend people always speak with a healthcare professional before taking any vitamins or supplements for neuropathy to make sure it is safe for them to do so.



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IN THIS ISSUE

Dear Readers,

The most exciting news in this issue is the FDA approval of a new pain reliever that is not addictive and works by blocking the pain signal to the brain. Check out the **front-page article to read about Journavx** and its approved use for acute pain from surgery or injury. The company, Vertex, is continuing with a Phase 3 trial on its use for neuropathic pain so it's not specifically approved for that use currently. I'll keep you updated on that clinical trial as news is released.

Vicky Herman's personal journey with neuropathy and her search for treatment is detailed on **Page 4**. Through research and experimentation, she found a combination of therapies that have worked to eliminate her pain and reduce numbness by 90%. She includes websites for each device for your own individual research.

Lastly, look at the graphics on **Page 6 for 5 patterns of peripheral neuropathy** including potential causes. As the article states, these types are not "exclusive or absolute" but a general guideline. I'm a #1 – the most common type. How about you?

May these give you Hope.

..Katherine

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

All contributions and dues are tax-deductible.

Tax ID # 68-0476041

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

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