WESTERN NEUROPATHY ASSOCIATION

CELEBRATING OUR 27TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

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WESTERN NEUROPATHY ASSOCIATION
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TRANSCRANIAL MAGNETIC STIMULATION FOR CHRONIC NEUROPATHIC PAIN – PILOT TRIAL BASED AT UNIVERSITY OF CALIFORNIA AT SAN FRANCISCO

Dates Study started April 2022, completion around January 30, 2025
Principal Investigator Julian Motzkin, Assistant Professor, Neurology, School of Medicine
Last update March 2024

Summary Chronic neuropathic pain is defined as pain caused by a lesion or disease of the somatosensory nervous system. Current available treatments have low efficacy, high side effect burden, and are prone to misuse and dependence. Emerging evidence suggests that the transition from acute to chronic neuropathic pain is associated with reorganization of central brain circuits involved in pain processing. **Repetitive transcranial magnetic stimulation (rTMS)** is a promising alternative treatment that uses focused magnetic pulses to non-invasively modulate brain activity, a strategy that can potentially circumvent the adverse effects of available treatments for pain.

(rTMS) is FDA-approved for the treatment of major depressive disorder, obsessive-compulsive disorder, and migraine, and has been shown to reduce pain scores when applied to the contralateral motor cortex (M1). However, available studies of **(rTMS)** for chronic neuropathic pain typically show variable and often short-lived benefits, and many aspects of optimal treatment remain unknown, including ideal **(rTMS)** stimulation parameters, duration of treatment, and relationship to the underlying pain etiology.

The investigators propose:

- To evaluate the efficacy of high frequency **(rTMS)** to M1, the region with most evidence of benefit in chronic neuropathic pain.
- They will use **functional magnetic resonance imaging (fMRI)** to identify alternative **rTMS** targets for participants that do not respond to stimulation at M1.
- Central aim:
  – evaluate the pain-relieving efficacy of multi-session high-frequency M1 TMS for pain.
- Secondary exploratory analyses:
  – investigate patient characteristics that are predictive of response to M1 **(rTMS)**
  – identify viable alternative stimulation targets in non-responders to M1 **(rTMS)**

Details

The investigators will recruit 20 patients diagnosed with chronic neuropathic pain for a randomized, single-blind, 2-arm crossover pilot TMS treatment trial (NCT05593237).

Patients will be randomized to one of two stimulation frequencies:

- high frequency (10Hz) excitatory repetitive transcranial magnetic stimulation **(rTMS)**)
- low frequency (1Hz) inhibitory repetitive transcranial magnetic stimulation (**(rTMS)**)

Each treatment visit of 30 minutes will consist of either:

- thirty 10-Hz stimulations to the target brain regions at 90% RMT (each lasting 10 s with 50 s between stimulations, for a total of 3,000 pulses per visit) or
- thirty 1-Hz stimulations to the target brain regions at 90% RMT (total of 300 pulses per visit).

Participants will be followed for 6-months to evaluate the duration of benefit with follow up assessments at 1 week, 1 month, and 6 months.

(Editor: Results will be included in a future issue when they are made public.)

Peripheral Neuropathy Support Groups – July 2025 Schedule

Join a meeting to help others, learn something new, and/or share experiences.
In-person or virtual – connect to others with peripheral neuropathy.

Auburn CA Peripheral Neuropathy Support Group
No Meetings in July, August and September
Next Meeting October 6
Host – Pam Hart, pamhart@pnhelp.org, and Cass Capel, cass-browncapel@me.com

Houston TX Peripheral Neuropathy Support Group
1st Saturday of the last month in each quarter, 1 – 2:30pm Central
Next Meeting September 6
Memorial Drive United Methodist Church, 12955 Memorial Drive
Hosts – Katherine Stenzel, John Phillips and Brian Lockard

Virtual 2 Wednesday	**1st 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 Tuesday	**2nd Tuesday Peripheral Neuropathy Support Group** **2pm Pacific / 3pm Mountain / 4pm Central / 5pm Eastern (90 minutes long)** Meeting ID: 953 2710 6263 / Passcode: 613899 Host – Jeff Creech, contact Erika for Zoom link (everyone welcome, Colorado focus on healthcare providers)
Virtual 9 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 12 Saturday	**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 16 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
Virtual 16 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 26 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

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

A Time of Transition

The Board of the Western Neuropathy Association meets monthly to review our programs, financials and strategic plan. In June we met for an Annual Meeting, which is usually a time for change. And, we know that the only thing constant in life is change! With many new Board members, we felt it was time to shake things up a bit and give them a chance to contribute in a more meaningful manner.

After much reflection, I have made the decision to step down from my role as President. This has not been an easy choice, but it is the right time—for me personally and for the continued growth of the organization.

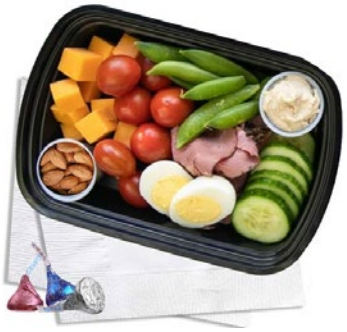
Serving this community has been one of the greatest honors of my life. Together, we've expanded our reach, deepened our impact, and remained true to our mission of bringing support to those who suffer from neuropathy. I am so proud of what we've accomplished and incredibly grateful to have shared this journey with such a passionate and committed team of board members, volunteers, and supporters.

I want to assure you our organization is in very good hands. Our leadership team is strong, our strategic vision is clear, and the board is actively guiding a thoughtful transition process. I have full confidence in their ability to carry this work forward—and to take it even further.

This is not goodbye to the cause or the community. I will continue as the treasurer and advocate for the important work we do, and I look forward to seeing what comes next with excitement and pride.

Thank you for your trust, your collaboration, and your continued belief in what we can achieve—together.
With heartfelt gratitude,
Pam
pamhart@pnhelp.org

The Tray Method Katherine Stenzel, Editor



Years ago, I read what someone did when they were sick and too weak to cook: they kept a tray of ready-to-eat food in the fridge. The tray should have edges so the items will not go traveling and handles for easy use. Keep utensils and paper napkins on the tray so everything is all in one place.

Choose items that need no heating and are easy to grab:

- Protein: packets of tuna or chicken with crackers, hard-boiled eggs, peanut or nut butter.
- Fresh fruit: apples, bananas, precut fruit.
- Canned fruit: small cans of your favorite fruit, individual cups of applesauce.
- Fresh vegetables: baby carrots, baby tomatoes, precut celery.
- Add some sweet treats like Hershey's kisses to end the meal.

For hot food, use an electric boiling pot and have instant meals like oatmeal, mashed potatoes, or soups ready to mix in a big mug.

I hope this approach will help others make eating easier when you have no energy to prepare a meal.

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.

What Is The Difference Between GABA And Gabapentin

Elizabeth Millard; *www.healthcentral.com*; June 17, 2024

In part because they share the same mode of action, and because there's a similarity in how they're named, GABA and gabapentin may sound like synonyms, or at least a shorthand form. However, while there are some similarities, these two things are different from each other.

In short, **GABA** is a naturally occurring neurotransmitter that works with your nervous system to keep it regulated, while **gabapentin** is a type of medication widely used to treat nerve pain and seizures (as well as other off-label uses). Let's take a closer look at the details of each, and what to be aware of if you're prescribed gabapentin for your medical condition.

What Is GABA?

Short for gamma-aminobutyric acid, GABA is an amino acid that functions as the primary neurotransmitter for the central nervous system. It helps regulate nervous system function to prevent overactivity, but when GABA is too low, that can throw off the balance and seizures may occur as a result. Too much GABA can lead to mood issues like anxiety, says Daniel Friedman, M.D., the director of the NYU Langone Comprehensive Epilepsy Center in New York City.

How Neurotransmitters Like GABA Work

Let's break down what that all means: your central nervous system is a network of nerves that send and receive electrical signals from nerve cells, and they produce neurotransmitters to do this work more effectively.

Neurotransmitters are the body's chemical messengers, carrying instructions from one nerve cell to the next. These messages relate to a breadth of functions including blood pressure, breathing, digestion, hearing, heartbeat, hormone regulation, memory formation, muscle movements, sense of hunger and thirst, sight, sleep quality, stress response, and touch and taste.

GABA is best known for producing a calming effect. Because GABA can reduce nerve cell hyperactivity, it's able to alleviate fear, anxiety, and stress. This can have a ripple effect on your overall health, such as improving the quality of your sleep. Many medications have been developed that act on GABA receptors; these include certain types of sedatives, mood stabilizers, and anti-seizure drugs. However, that list of meds does not include gabapentin.

What Is Gabapentin?

Sold under the brand names Horizant, Gralise, and Neurontin, gabapentin is a prescription medication that was originally created as an analogue [meaning a similar structure] to naturally occurring GABA. In other words, it mirrors the effects of that neurotransmitter, explains Dr. Friedman.

Because of that, there's a misperception that gabapentin is the manufactured version of GABA. However, Dr. Friedman adds, gabapentin doesn't act on GABA receptors or affect GABA neurotransmission at all.

"Instead, gabapentin acts on calcium channels, a protein in neuronal membranes which influences cell excitability and neurotransmitter release," Dr. Friedman says. That means it has a similar action to GABA but doesn't affect how GABA operates in the body.

Uses of Gabapentin

The Food and Drug Administration (FDA) has approved gabapentin for various nerve pain disorders, including diabetic neuropathy and post-herpetic neuralgia (a type of pain that occurs after you've had shingles or herpes zoster, which can both cause nerve damage). A long-acting form of gabapentin is approved for restless leg syndrome, says Dr. Friedman. It's also approved for the treatment of partial seizures in people over 3 years old, he adds.

The medication is used off-label for numerous conditions that include pain, says Dr. Friedman. (As a reminder, "off-label" means the FDA has not approved the medication for that specific use, but it's not illegal or inappropriate for a physician to prescribe a drug in this way.) These include such issues as alcohol withdrawal symptoms, anxiety, bipolar disorder, essential tremor, hot flashes in perimenopause and menopause, insomnia, irritable bowel syndrome, and PTSD.

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My Exercise Journey

Julie Scroggins, Houston, TX

The thought of exercising with neuropathy can be a daunting idea. For me, the cancer, chemo and resulting neuropathic pain took away my ability to walk and balance, with the pain pills, including gabapentin, ineffective in restoring something positive from my past. My excuse for not exercising was "I can't walk or balance so how can I exercise!" But after being so frustrated with using a rollator everywhere for 4 years, I decided to try.

My physical therapist with a heart said: let's do toe taps while you are seated. Next, add knee lifts. She continued to include foot pumps, heel to toe, and toe to heel. After that, she held my rollator and continued to teach me similar techniques while standing as I stabilized on the rollator. The bottom line is that she pushed forward to have me walking along kitchen counters, forwards, backwards and sideways, all to improve my balance. And it worked. In a couple of months, I started using a cane again, accomplishing a huge gain through routine simple exercises.

My favorite exercise is leaning forward toward a door with arms stretched and feet apart. Just lean into the door and use your arms to push yourself away from the door. It is like a standing push-up, and you can feel it everywhere. As you lean in bending your arms, try to touch your nose to the door. The push back to vertical is invigorating. These small sets of exercises assist your body to wake up and build muscles that allow you to do more.

I still use my rollator when fatigued but having options is a great choice for many of us that have had limited mobility. Best wishes for a better life. Sometimes it's the small things!

What Is The Difference Between GABA And Gabapentin - Continued from page 4

Thus you don't always need to be experiencing pain to be prescribed gabapentin, says Dr. Friedman. For example, it may be prescribed for sleep issues or addiction management. However, the medication does tend to be considered most when there's nerve involvement and pain as primary symptoms, he says.

Side Effects of Gabapentin

Like any medication, gabapentin comes with risk of side effects, which can range from mild and uncomfortable to severe enough that you'll need to discontinue the medication. According to Daniel Kim, D.O., a family medicine physician with Medical Offices of Manhattan in New York City, the most common include back or joint pain, diarrhea, dizziness, drowsiness, dry mouth, ear pain, fever, flu-like symptoms, headache, heartburn, increased appetite, memory issues, nausea, red and itchy eyes, and weight gain.

What if You Miss a Gabapentin Dose?

Since gabapentin is usually taken at least a couple of times a day, it can be easy to forget a dose when you're busy, or if you're taking other medications as well. "If you miss a dose of gabapentin, take it as soon as possible," says Dr. Kim. "If you are close to your next dose, though, just take that dose instead of doubling up."

If possible, talk with your physician in advance about what to do about missed doses, suggests Dr. Friedman. "Often, simply taking the next scheduled dose is sufficient, but there may be situations where your doctor may want you to make up for the missing dose," he says.

Bottom Line

Although gabapentin was developed using the model of how GABA operates in the body, the medication isn't the same as GABA and doesn't work by using those neurotransmitters or their receptors. That said, gabapentin does have similar actions to GABA, such as preventing minor seizures and alleviating pain. If you're struggling with issues related to pain management and nerve difficulties, talk to your doctor about whether gabapentin may be an option for symptom relief.

Antidepressants: Another Weapon Against Chronic Pain

MayoClinic.com; September 7, 2019

Some of the more effective and commonly used medications for chronic pain are drugs that were developed to treat other conditions. Although not specifically intended to treat chronic pain, antidepressants are a mainstay in the treatment of many chronic pain conditions, even when depression isn't recognized as a factor.

Types Of Pain Relieved

Antidepressants seem to work best for pain caused by arthritis, **nerve damage** from diabetes (diabetic neuropathy), **nerve damage** from shingles (postherpetic neuralgia), **nerve pain** from other causes (peripheral neuropathy, spinal cord injury, stroke, radiculopathy), tension headache, migraine, facial pain, fibromyalgia, low back pain, pelvic pain, and pain due to multiple sclerosis.

The painkilling mechanism of these drugs still isn't fully understood. Antidepressants may increase neurotransmitters in the spinal cord that reduce pain signals. But they don't work immediately. You may feel some relief from an antidepressant after a week or so, but maximum relief may take several weeks. People generally experience **moderate pain relief from antidepressants.**

Medications from other drug classes with distinct mechanisms of pain relief (such as anticonvulsants) may be used in combination with antidepressant class medications if pain relief with antidepressants is incomplete.

Antidepressants are classified based on their chemical structure and how they work. One of the most effective groups of antidepressants for pain is known as the tricyclics.

Tricyclic Antidepressants

Tricyclic antidepressants are the most common type of antidepressant used for pain. They include:

- Amitriptyline, nortriptyline (Pamelor), protriptyline (Vivactil), doxepin (Silenor), imipramine (Tofranil), clomipramine (Anafranil), desipramine (Norpramin)

Side Effects Of Tricyclic Antidepressants

Side effects of tricyclic antidepressants may include blurred vision, drowsiness, dry mouth, nausea, lightheadedness on standing up due to a drop in blood pressure (orthostatic hypotension), weight gain, difficulty thinking clearly, constipation, difficulty urinating, heart rhythm problems, and problems having sexual intercourse.

To reduce or prevent side effects, your doctor will likely start you at a low dose and slowly increase the amount. Most people are able to take tricyclic antidepressants, particularly in low doses, with only mild side effects. The **doses that are effective for pain are generally lower than the doses used for depression.**

Other Antidepressants That May Help

Other classes of antidepressants have become more popular because they have fewer side effects. These drugs may also be used to help relieve chronic pain:

Serotonin and norepinephrine reuptake inhibitors (SNRIs)

- Some SNRIs, such as venlafaxine (Effexor XR), duloxetine (Cymbalta, Drizalma Sprinkle), milnacipran (Savella) and desvenlafaxine (Pristiq), may help relieve chronic pain.

  – Duloxetine (Cymbalta) is the only SNRI that is approved by the FDA to treat pain.

  – Milnacipran is used to relieve fibromyalgia pain and can cause side effects such as nausea and drowsiness. However, it has shown only limited effectiveness in relieving other types of pain.

- People with chronic pain often develop depression along with their chronic pain. Venlafaxine and duloxetine offer the advantage of being effective for depression and anxiety at the same dosages useful for treating pain.

  – Venlafaxine can cause drowsiness, insomnia or elevated blood pressure, and may worsen heart problems.

  – Duloxetine can cause side effects, such as drowsiness, insomnia, nausea, dry mouth, dizziness, constipation or excessive sweating.

Selective serotonin reuptake inhibitors (SSRIs)

- SSRIs, which include drugs such as paroxetine (Paxil) and fluoxetine (Sarafem, Prozac), may help relieve certain types of pain, but there's a lack of evidence that they help alleviate nerve pain.
- SSRIs may boost the painkilling effects of some tricyclic antidepressants by increasing the levels of tricyclic antidepressants in your blood. If your doctor prescribes both medications, they should be used with caution. If you have any concerns, talk with your doctor.

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In Conversation Podcast from *MedicalNewsToday.com* "Health misinformation and disinformation: How to avoid it

Maria Cohut, Ph.D.; *MedicalNewToday.com*; February 21, 2025

In the age of viral content and fast and furious social media communication, disinformation and misinformation, including about health matters, are spreading more widely than ever. Why is this the case exactly, and how can we learn to spot inaccurate and even malicious health information? Why do we fall so easily for false health info, and how can we update our mistaken beliefs?

Nowadays, thanks to the widespread availability of internet access, almost any piece of information we may want is just one click away. While this is generally a positive development, it can also mean that we become exposed to untrustworthy, unchecked information on any topic, including health.

According to a report issued by the International Panel on the Information Environment (IPIE) in 2024, communication experts are currently most concerned "about the threats to the information environment posed by the owners of social media platforms."

Such platforms regularly circulate a varied array of videos, articles, and posts on topics including health. However, in the absence of strict rules and regulations around the information shared on social media, there is a clear danger that at least some of what we see being shared online amounts to misinformation or even disinformation.

Misinformation occurs when communication is laden with inaccuracies, either because the original information was misinterpreted or misunderstood or because someone picked up a piece of erroneous information by mistake and kept sharing it.

Disinformation is an even more concerning phenomenon. It occurs when a bad actor disseminates fake information on purpose, manipulating their audience to support a hidden agenda.

This episode of the ***In Conversation podcas***t looks at why health misinformation and disinformation spread, how we can identify mis- and disinformation, and what it takes for people to update their views after they have assimilated incorrect information.

Our special guest is Prof. Stephan Lewandowsky, PhD, Chair in Cognitive Psychology at the School of Psychological Science, University of Bristol, United Kingdom, and Project Lead of PRODEMINFO (Protecting the Democratic Information Space in Europe) at Potsdam University in Germany.

Prof. Lewandowsky is a cognitive scientist with an interest in computational modeling who has extensively studied decision-making processes, the persistence of misinformation in society, the ways in which myths and misinformation can spread, and how people update their memories if the notions they believe in turn out to be false.

We also hear from our trusted expert, Jenny Yu, MD, FACS, Chief Health Officer at RVO Health, the parent company of Medical News Today and Healthline. Dr. Yu advises on key strategies to ensure we are accessing the most accurate and trustworthy sources of health information.

Please listen to the podcast episode in full below or on your preferred streaming platform.
https://megaphone.link/RVOHE1279115527 (Please type this address in your search browser)
Or Search for *"In Conversation Podcast"*, click on the link, then search for the podcast title under Episodes.

Antidepressants: Another Weapon Against Chronic Pain - Continued from page 6

- SSRIs generally don't work as well as tricyclic antidepressants for pain, but they often produce fewer side effects. Fluoxetine can cause certain side effects, such as insomnia and dizziness.

Suicidal Thoughts

It's important to note that antidepressant medications are associated with a slightly increased risk of suicidal thoughts or actions. Talk to a doctor or counselor promptly if you feel depressed or suicidal.

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In This Issue

Would you have your brain zapped with magnetic pulses to help your pain? That is the focus treatment detailed on the **front page this month – transcranial magnetic stimulation.** This technique is approved for depression, obsessive-compulsive disorder and migraines but has had variable and short-lived benefits for chronic pain. This pilot trial at University of California at San Francisco is hoping to fine tune the stimulation parameters to evaluate the efficacy of this technique.

During a recent session of the Chemo-Induced Peripheral Neuropathy support group, Julie Scroggins discussed how she was able to stop using her rollator – and start using a cane again – just by exercising! She details on **page 5** some the exercises she used to **improve her balance and increase her mobility.** Thanks for writing this, Julie!

If you notice that some articles sound familiar – well they are! Personally, I cannot learn something by reading it once – I need to study it again and again over time. The article on **Page 6 on antidepressants** is such an article but I found that this one made it easier for me to understand how and why these drugs are used for **pain relief.** May it also add to your understanding of this potential treatment for your pain.

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

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