A publication of the Western Neuropathy Association

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Neuropathy Hope

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

RESEARCH

WinSanTor Update, December 2025 THE NEUROTRANSMISSION Investor Update, Volume 10, December 2025

2025 HIGHLIGHTS: SCIENTIFIC AND STRATEGIC PROGRESS

Peer-Reviewed Clinical Publication

WinSanTor's proof-of-concept Phase 2a trial results were published in eBioMedicine (December 5, 2025), part of the renowned The Lancet family of medical journals. The study demonstrated peer-reviewed evidence that WST-057 (topical pirenzepine) demonstrated both symptomatic improvement and nerve regeneration in patients in this trial with diabetic peripheral neuropathy.

Strategic and Licensing Discussions

WinSanTor signed a structured, multi-year agreement with a strategic partner providing for up to $105 million over three years to support their diabetic peripheral neuropathy program, contingent on defined development milestones, in exchange for IP rights in the UK, India, and Africa. Funding is milestone-based and expected to be received in portions over time as development milestones are met, consistent with standard industry practice.

Separately, a non-binding agreement was reached in principle with a large global pharmaceutical company regarding potential commercial rights in Canada. The parties are aligned on key terms and are working toward a definitive agreement. In parallel, the company continues discussions with other parties regarding additional regional commercial rights.

Manufacturing & Clinical Readiness

The company authorized the manufacture of additional drug supply to support planned Phase 3 clinical trials and Compassionate Use / Early Access Programs. This operational milestone positions the company to advance efficiently as funding and regulatory activities progress.

THE ROAD AHEAD: 2026 AND BEYOND

Looking ahead, their focus is on continued regulatory engagement and evaluating opportunities to expand patient access. Discussions are continuing with regulatory advisors, including former FDA officials, to assess potential accelerated development and regulatory review pathways for WST-057. In parallel, they are evaluating Expanded Access and Compassionate Use programs in select markets, including the U.S. and Europe, subject to regulatory approval and program execution, which may allow for early patient access and limited revenue in 2026. They are also assessing potential conditional approval pathways in multiple countries, based on regulatory feedback, data requirements, and execution readiness.

Why This Matters

Peripheral neuropathy affects hundreds of millions of people worldwide, yet there are currently no approved therapies that reverse the underlying condition. WST-057 has the potential to regrow peripheral nerves and restore function, which could meaningfully change the treatment paradigm for diabetic peripheral neuropathy and, over time, other neuropathic conditions. With WST-057 now in late-stage development, WinSanTor has the opportunity for their work to translate into real-world impact.

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WESTERN NEUROPATHY ASSOCIATION

OPENING NOTES

From The President Glenn Ribotsky, WNA President, *glenntaj@yahoo.com*

Do We Have a Terminology Problem?

Any of you who are familiar with my history in this space knows that I've been trying to get a lot more attention focused on the condition of neuropathy—"the most common neurologic condition that nobody's ever heard of"—for more than two decades, with somewhat haphazard and frustrating results. It's especially frustrating as attention does tend to translate into research monies and eventually treatments, and in that regard neuropathy lags well behind the much better known entities of multiple sclerosis, Parkinson's, myasthenia gravis—conditions that afflict significantly fewer people.

Many have speculated as to why we have this state of affairs; some have said that since neuropathy doesn't kill you (generally) the impetus isn't quite as urgent, or that we simply haven't had the equivalent of a Michael J. Fox or an Annette Funicello to draw attention to the condition (there are famous neuropathy sufferers, but they tend to be quiet about it), or that neuropathy is generally considered secondary to some other condition that gets more play, such as diabetes. All of these may have some merits, but does it explain the loud yawn reaction to a condition that one in every fifteen people will experience at some point?

Recently, one person mentioned that maybe the terminology is too confusing—people speak of neuropathy (literally, from Latin, "feelings from nerve"), peripheral neuropathy (the "peripheral", from the Greek for "around" or "outside", merely indicated nerves beyond the brain and spinal cord are involved), polyneuropathy (the "poly" just means "many", as opposed to a "mononeuropathy" that involves injuries to one nerve) "axonal" vs. "demyelinating" (the first term means the nerve shaft itself is involved; the second, that the fatty covering that helps maintain signal conduction is damaged), or even small vs. large fiber (the first involves microscopic unmyelinated sensory and autonomic nerves; the second larger sensory nerves that deal with mechanical touch, vibration, and position sense, and also with motor nerves). This person argued that this variety in terminology causes a lot of eyes to glaze over; it lacks the oomph of saying one has "cancer" or even "Parkinson's", which are a lot easier to explain (though, of course, many experts believe even these to not be one disease entity but actually numerous ones).

What do you all think? Would just saying we have "nerve damage" make it easier explaining things to the press, grant-making foundations, legislative committees, and your families? Would that generic term be too nonspecific to get monied interests to pony up for research into treatments, though? How do we get to the point at which when you say, "I have neuropathy", people nod knowingly and empathize, and put neuropathy organizations on their charity list?

Glenn

In This Issue Katherine Stenzel, Editor, *klstenzel@hotmail.com*

Dear Readers,

Early last year was when the new medication **Journavx** (suzetrigine) was approved for acute pain. Many thanks to WNA member Lynn Carpenter for reminding me that Journavx is also under evaluation for peripheral nerve pain which is more of a chronic pain. **Page 4** summarizes 3 approved **clinical trials for neuropathy** with two unfortunate conditions – they are being evaluated only for diabetic peripheral neuropathy with completions estimated throughout 2027. Luckily, they are all Phase 3 trials which is the last phase in the approval process. Let's hope for positive results!

The chart on **Page 5** lists drugs that are commonly used to treat **sensory peripheral neuropathy**. It is very detailed with information on initial dosage, maximum dose and a whole bunch of side effects for every drug!

Director Erika McDannell introduced me to the **Tightrope Concept (page 6)** during our preparation for the April Workshop. It's another way (besides Spoon Theory – July 2022 Neuropathy Hope issue) to describe to friends and family how neuropathy limits our daily abilities, activities and/or energy. Both Spoon Theory and the Tightrope Concept provide good physical analogies of the limitations we experience from our invisible disease of neuropathy.

May these give you Hope.

...Katherine

TREATMENT

These Devices Can Bring Relief Consumer Reports, September + October 2025 issue

Editor: From the article titled "How to Really Stop PAIN", this section on devices has good, understandable descriptions. Note in the online version of Consumer Reports, consumerreports.org, their report titled "What Really Works for Nerve Pain", was on the front page of the May 2025 issue of Neuropathy Hope. More evidence that nerve pain is getting attention in the mainstream media.

The signals that tell your brain that you're feeling aching, stabbing, or tingling are essentially electrical currents. One expanding area of pain treatment, called neuromodulation, uses mild electrical pulses to target specific nerves and block pain signals – like a small, precise electric shock.

Some neuromodulation devices are surgically implanted in the body, similar to a pacemaker. Others are noninvasive and over-the-counter, and don't require a medical procedure. Here are a few key types and how they might help.

Transcutaneous Electrical Nerve Stimulation (TENS)

A TENS unit is a non-invasive device that you can probably find in your local drugstore or online for about $30 to $80. They're also used at some doctor's offices and pain clinics. TENS delivers low-voltage electrical currents to the skin through stick-on electrodes applied to the painful area. Studies have shown this can relieve pain for people with fibromyalgia, knee osteoarthritis, and nerve pain. There is little risk of serious side effects: however, the benefits of TENS tend to decrease over time.

Interferential Current Therapy (IFC)

This looks similar to a TENS device, but it uses medium-frequency electrical currents to target deeper tissues. Though IFC machines can also be used at home, they tend to be more expensive. They are frequently used by physical therapists. IFC therapy is most helpful for people with muscle and joint pain, including discomfort in the neck and lower back.

Spinal Cord Stimulation (SCS)

Some neurosurgeons offer this treatment, which uses an implantable device – consisting of a battery pack and two wires – that stimulates the spinal cord. It is designed to replace the feeling of pain with light tingling (or in the case of some new SCS devices, no feeling at all). Evidence is mixed, but research has shown that it is most promising for people with nerve pain. Since implanting this device requires a serious surgery with general anesthesia, it's generally considered only after less invasive options have failed.

Peripheral Nerve Stimulation (PNS)

To target nerves outside of the spinal cord and brain, small wires call electrodes are implanted under the skin near the site of pain. (Some newer devices are wireless.) This can be an effective treatment for people with pain in a particular nerve. A 2021 review found good evidence to support the use of PNS for pelvic, lower back, and shoulder pain.

MEDICATION

Bondlido® Topical System Approved For Postherpetic Neuralgia

Diana Ernst, RPh; *neurologicaladvisor.com*; October 6, 2025

The Food and Drug Administration (FDA) has approved Bondlido® **(lidocaine topical system 10%)** for the relief of pain associated with postherpetic neuralgia (long-lasting nerve pain occurring after a shingles outbreak) in adults.

Bondlido® is a drug-in-adhesive topical delivery system containing 200mg of lidocaine, an amide local anesthetic. Each topical system is 10cm × 14cm × 0.066cm and is applied to the skin to cover the most painful area. Bondlido® is supplied in a carton containing 28 topical systems. The product is expected to be available in the first half of 2026.

Clinical Trials For Suzetrigine / Journavx

Journavx was approved by the FDA on January 30, 2025 for the treatment of acute pain. At the time, the company said they were continuing to evaluate Journavx for chronic pain and neuropathy. Journavx/brand name – suzetrigine/ generic drug - is being developed by Vertex Pharmaceuticals Inc.

The clinical trials listed below are current as of November/December 2025. The first two are 12 week studies comparing suzetrigine to placebo or pregabalin/placebo. The third is a year long study with only suzetrigine.

Evaluation of Efficacy and Safety of Suzetrigine for Pain Associated With Diabetic Peripheral Neuropathy (Phase 3)

ClinicalTrials.gov ID NCT06628908 **RECRUITING**

The study has 76 locations. Some hospitals have completed the study, some recruiting. California is recruiting. Study compares **suzetrigine to pregabalin (Lyrica) to placebo over 12 weeks**. Study started November 1, 2024 with completion estimated to be May 31, 2027. Enrollment estimated at 1100.

Evaluation of Efficacy and Safety of Suzetrigine (SUZ) for Pain Associated With Diabetic Peripheral Neuropathy (Phase 3)

ClinicalTrials.gov ID NCT07231419 **NOT YET RECRUITING**

No location data. Study participants to receive **suzetrigine or placebo for 12 weeks.** Study estimated to start on November 17, 2025 with completion estimated at April 6, 2027. 734 participants are estimated to be enrolled.

Evaluation of the Long-term Safety and Effectiveness of Suzetrigine (SUZ) in Participants With Painful Diabetic Peripheral Neuropathy (DPN) (Phase 3)

ClinicalTrials.gov ID NCT06696443 **ENROLLING BY INVITATION**

This study has 65 locations. Participants must have completed the final visit of the treatment period in NCT07231419 or NCT06628908 (described above). Study participants will receive **suzetrigine once daily for up to 52 weeks**. Study started December 18, 2024 with completion estimated to be January 25, 2027. 300 participants are estimated to be enrolled.

Epigenetic Regulator (ST-503) Fast Tracked For Small Fiber Neuropathy

Jaymin Kang, PharmD; *neurologyadvisor.com*, December 19, 2025

The Food and Drug Administration (FDA) has granted Fast Track designation to ST-503 for the treatment of small fiber neuropathy (SFN), a chronic neuropathic pain disorder.

ST-503 is an intrathecally administered, investigational epigenetic regulator that specifically targets and silences the SCN9A gene, thereby preventing the encoding of Nav1.7 sodium channels, known for pain signaling. By **reducing the expression of these sodium channels, ST-503 is expected to reduce pain hypersensitivity** in SFN patients.

In preclinical models, ST-503 demonstrated strong, selective, and durable repression of SCN9A for up to 6 months in nonhuman primates, while also maintaining a favorable safety profile. Additionally, it did not induce changes in nerve conduction velocity, heart rate or blood pressure at 6 months after administration.

ST-503 will be evaluated in a randomized, double-blind, sham-controlled, dose escalation phase 1/2 study (STAND; ClinicalTrials.gov Identifier: NCT06980948) in adults with SFN who have pain that has been refractory to first line therapies for at least 6 months. According to Sangamo, the first patient is scheduled to receive the therapy in the coming months.

"We are very pleased to receive FDA Fast Track designation for ST-503," said Nathalie Dubois-Stringfellow, PhD, Sangamo's Chief Development Officer. "This designation underscores the high unmet patient need in SFN and the urgency to develop safe and effective nonopioid treatment alternatives."

Related Articles in Previous Issues of Neuropathy Hope:

- November 2026 – SCN9A Mutations
- April 2025 – First article on ST-503
- September 2022 – Fast Track Designation description

Table Of Commonly Used Drugs In Sensory Neuropathy

Gomatos EL, Dulebohn SC, Rehman A. Sensory Neuropathy. [Updated 2024 Feb 25]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan. *https://www.ncbi.nlm.nih.gov/books/NBK559020/*

DRUG	MECHANISM	INITIAL DOSE	MAXIMUM DOSE	ADVERSE EFFECTS
Gabapentin	Calcium channel alpha-2-delta subunit blocker	300 mg/day	3600 mg/day in divided doses	– Dizziness – Drowsiness – Peripheral edema – Constipation – Dry mouth – Flatulence – Hypertension – Insomnia – Memory loss
Pregabalin	Calcium channel alpha-2-delta subunit blocker	150 mg/day in 2-3 divided doses	600 mg/day in 2-3 divided doses	– Dizziness – Drowsiness – Peripheral edema – Sexual dysfunction – Impaired concentration – Diarrhea – Vision disorders
Duloxetine	Serotonin-norepinephrine reuptake inhibitor	30 mg/day	60-120 mg/day	– Nausea – Somnolence – Anxiety – Yawning – Constipation – Dry mouth
Amitriptyline	Tricyclic antidepressant	10-25 mg at bedtime, dose increased in steps of 10-25 mg every 3-7 days in 1-2 divided doses	100 mg at bedtime; doses above 100 mg should be used with caution in older adults, with maximum per dose of 75 mg	– Dry mouth – Constipation – Blurred vision – Anticholinergic syndrome – QT interval prolongation – Breast enlargement – Cardiac disorders – Conduction disorders – Galactorrhea – Hepatic disorders – SIADH
Carbamazepine	Sodium channel blocker	100 mg twice daily	800-1600 mg/day	– Dizziness – Drowsiness – Nausea – Hyponatremia – Leukopenia movement disorders – Thrombocytopenia – Vision disorders – Weight gain – Edema – Skin reactions
Oxcarbazepine	Sodium channel blocker	300 mg twice daily	2400 mg/day in divided dosages	– Dizziness – Drowsiness – Nausea – Agitation – Abdominal pain – Ataxia – Emotional lability – Skin reactions – Vertigo – Vision disorders – Vomiting

The Tightrope Concept: An Alternative To Spoon Theory

Clare Marie Edgema; *www.medium.com*; February 3, 2018

Spoon Theory is an analogy started by Christine Miserandino (*www.butyoudontlooksick.com*) to help explain the limitations of having a chronic illness, in her case, Lupus. She was sitting at a diner with a friend when first offering up this analogy and used what she had available to her to try to explain: spoons.

Basics of Spoon Theory

The basic idea is that spoons represent energy and capacity to get things done. Those who are not chronically ill have unlimited spoons to spend throughout the day for things like getting up, brushing their teeth, cooking breakfast, cleaning the litter box, getting dressed, etc., etc., etc. The chronically ill, however, have a limited number of spoons and must choose how to use them. On a good day you might have 20 spoons, but on a bad day you may have 5.

The Tightrope Concept

I presented the idea that most people are walking through life as if it is a wide-open parking lot floating above the ground. There may be obstacles, and if they get too crazy people might approach the edge and risk falling off, but they have a lot of space to move and run and even maybe do some gymnastic tricks.

Instead of having the breadth of a parking lot to play, I explained, having a chronic illness is like walking on a tightrope. Some days it's windy, or the tightrope is a bit wobbly, or I'm a bit tired, and suddenly it is all I can do to cling to the damn thing. There are days when I can do careful cartwheels along the length of my tightrope, but there are also days when I just have to clutch to it in a gale force wind and it takes 90% of the energy of my day just to manage to not fall off.

While 'normal,' non-chronically ill people might have a parking lot to play in, chronically ill people have a sidewalk. There's still quite a lot of room to move and get creative, but they have to be mindful of the edges, they're a lot closer than they are for many of our peers.

Why the Tightrope, Sidewalk, and Parking Lot?

I like the analogy of the tightrope, sidewalk, street, parking lot, etc. because it can take into account my mastery of my chronic illness, but also my complete lack of control over it on some days.

I acknowledge that this analogy may not resonate with everyone and may not at all be applicable to your chronic condition that I don't have an embodied understanding of living with each day. However, I present it as my analogy, and perhaps my answer to some of the problems that have arisen as people without chronic illnesses have co-opt Spoon Theory for their own lived experiences of exhaustion, burnout, and emotional labor.

The Tightrope Concept is for everyone. I will challenge, however, that if you'd like to take it and make it your own, please be mindful that your perception of what you define as a tightrope might be challenged when you meet someone who is battling cancer as a single mother and suddenly you realize that perhaps you have a sidewalk, or at least a small path, instead.

However big you feel your path to walk and run and play is, the point is to understand that the tightrope, sidewalk, slack-line, etc. is not visible to those around you. They might assume you have a parking lot, as they do, particularly if your disease or condition is invisible as Diabetes, Lupus, Chronic Fatigue, and Fibromyalgia *(Editor – or neuropathy)* often are.

If the Tightrope Concept resonates with you, take it, run with it — or cling to it, depending on your day.

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

The Michael J. Fox Foundation for Parkinson's Research holds Third Thursday Webinars via Zoom. Many of their topics are also applicable to those suffering from neuropathy. For example, the topic for December was "Stress and Parkinson's: Strategies to Manage the Strain" which is applicable for most people with chronic pain as too much stress can impact physical and emotional health. February's webinar focused on approaches to decision-making about care and sharing strategies to keep a care partnership resilient as needs and symptoms change.

Their webinars are free, but as with WNA, you must register beforehand. You can find additional information at www.michaeljfox.org.

Navigating Social Security Disability While Living With Chronic Pain

Michael Liner with Liner Legal, ACPA Winter Chronicle 2025, page 6

Living with chronic pain isn't just physically exhausting, it can also be emotionally and financially draining. Applying for Social Security Disability (SSD) benefits becomes a necessary step toward stability. However, proving chronic pain to the Social Security Administration (SSA) can be one of the biggest challenges applicants often face. While chronic pain may not be a "visible" illness, it can be debilitating and affect abilities to keep and maintain employment.

KEY QUALIFICATIONS FOR A SOCIAL SECURITY DISABILITY CLAIM

Understand How SSA Views Chronic Pain

The SSA doesn't approve claims based on pain alone. They look for medically determinable impairments, something such as fibromyalgia, rheumatoid arthritis, or degenerative disc disease, that cause the pain. Simply stating that you are living in pain is not enough, unfortunately. You will be required to provide clear medical documentation that demonstrates a diagnosed condition responsible for your chronic pain symptoms.

Consistent Medical Treatment is Key

One of the most common reasons Social Security Disability claims are denied is apparent gaps in medical treatment. If you are living with chronic pain, it is crucial to actively see your doctors and follow all recommended treatments, even if they do not fully relieve your symptoms. Regular appointments create a visual representation that supports your claim.

Symptom journal: Bring your own documentation of your pain symptoms to your appointments. It helps your doctor (and your case file) reflect the day-to-day impact of your chronic pain.

Be Specific in Descriptions

When filling out your Social Security Disability forms or speaking with doctors, do NOT just say that "I am in pain." Describe how the pain affects your life.

For example:

- I can only sit for 10 minutes before the pain becomes unbearable.
- I wake up multiple times at night due to sharp pain.
- I drop items because of numbness and pain in my hands.

These specific details help paint a bigger and clearer picture for the SSA of your functional limitations, which is a critical factor in their decision making.

Note Effects Physical Pain has on Mental Condition

Chronic pain often leads to secondary and "invisible" conditions, like anxiety, depression and/or sleep disorders. If you are experiencing any mental health conditions as a result of your chronic pain, ensure that those are documented and that you are seeking treatment for those conditions as well. Mental health conditions are just as valid in a Social Security Disability claim.

Work with a Social Security Disability Attorney

The Social Security Disability process is notoriously complex and claims involving chronic pain are among the most difficult to win, due to their "invisible" qualities. A qualified and esteemed disability attorney can help:

- Gather and organize medical records
- Prepare you for your hearing (when denied)
- Communicate with the SSA on your behalf
- Maximize your chances of approval

Knowing what the SSA is looking for and how to best present your case ensures a higher chance of approval.

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P.O. Box 4740, Auburn, CA 95604

TREATMENT

How To Manage Neuropathy Symptoms With Dry Brushing

Retrieved Feb 4, 2026 from *https://todayusahealth.com/news/how-to-manage-neuropathy-symptoms-with-dry-brushing*

A lesser known but effective method for managing neuropathy symptoms is dry brushing. By stimulating the skin and underlying tissues, dry brushing can improve blood flow to the affected areas, which may help reduce numbness and tingling. Additionally, the exfoliating action of dry brushing can help remove dead skin cells and improve the overall health of the skin, which is essential for individuals with neuropathy, as they may be more prone to skin issues due to decreased sensation.

To effectively manage neuropathy symptoms with dry brushing, choose a high-quality dry brush with stiff, natural bristles. Before dry brushing, ensure that your skin is dry and free of any lotions or oils. Begin brushing gently in long, sweeping motions towards the heart, starting from the feet and moving upwards. Avoid brushing over sensitive or irritated areas and always be gentle to prevent skin damage. Consistency is key, so aim to dry brush at least once a day for optimal results. However, be mindful of your skins sensitivity and adjust the frequency and pressure of brushing as needed.

"If many remedies are prescribed for an illness, you may be certain that the illness has no cure." – Anton Chekhov

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Western Neuropathy Association (WNA)
A California public benefit, nonprofit, tax-exempt corporation.
P.O. Box 4740, Auburn, CA 95604
Toll Free: (888) 556-3356 | *www.pnhelp.org* | *info@pnhelp.org*
Dues - $30 a year | Tax ID # 68-0476041
Editor: Katherine Stenzel, *klstenzel@hotmail. com*

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