



WESTERN NEUROPATHY ASSOCIATION

OCTOBER 2024

Issue 10

Volume 22

- A New Psychotherapeutic 'Gold Standard' For Chronic Pain?
- Peripheral Neuropathy Support Groups Virtual And In-Person For October
- From The President
- University of California - San Francisco Clinical Trials
- Neuromuscular Training Cuts Onset And Reduce Symptoms Of Chemo-Induced Peripheral Neuropathy
- Sensorimotor Balance Training Program (Example)
- Whole Body Vibration Machine – How To Use For Balance Improvement
- Investigating GSK3858279 in treating Diabetic Peripheral Neuropathic Pain (DPNP)
- Neurosarcoidosis: A Very "Cryptogenic" Neuropathy Possibility
- Low Dose Naltrexone in Patients with Cryptogenic Small Fiber Neuropathy – Abstract
- The Role of Neurotropic B Vitamins in Nerve Regeneration
- In This Issue



Awarded by GuideStar®
2024 Guidelines
Certification

WESTERN
NEUROPATHY ASSOCIATION
3620 American River Dr., Suite 230
Sacramento, CA 95864
888-556-3356
admin@WNAinfo.org
www.WNAinfo.org

CELEBRATING OUR 26TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ A NEW PSYCHOTHERAPEUTIC 'GOLD STANDARD' FOR CHRONIC PAIN? Alicia Ault; *Medscape Medical News*; June 19, 2024. Submitted by Darrell O'Sullivan, WNA Director

A single course of treatment with **emotional awareness and expression therapy (EAET)** was associated with a significantly greater reduction in chronic pain severity than cognitive-behavioral therapy (CBT), the current psychotherapeutic gold standard, a new study suggested. Two thirds of the patients who received EAET reported at least a 30% reduction in pain compared with 17% of those who received CBT. The randomized clinical trial also showed that individuals with depression and anxiety responded more favorably to EAET, a novel (*Editor: new*) finding. The study is one of only a few to directly compare EAET with CBT.

"Most people with chronic pain don't consider psychotherapy at all," study investigator Brandon C. Yarns, MD, a staff psychiatrist at the VA Greater Los Angeles Healthcare System, and clinical professor of health sciences at the Department of Psychiatry and Biobehavioral Sciences, UCLA Health, told *Medscape Medical News*.

Although patients were allowed to continue medication for pain and other comorbidities during the study, those who received EAET "had larger improvements in pain, depression, and anxiety," Yarns said. "That suggests that the effect was due to the EAET."

'Gold Standard'

EAET was first used in the early 2010s. In the therapy, patients are asked to recall a difficult or traumatic memory, engage in experiencing how the related emotions feel in the body, express those feelings in words, and release or let them go. They are taught that the brain's perception of pain is strongly influenced by the evasion of grief, fear, rage, or guilt, Yarns said. This contrasts with CBT — considered the current gold standard for chronic pain — which teaches patients to improve the ability to tolerate pain through guided imagery, muscle relaxation, and other exercises and to adapt their thinking to change how they think about pain.

The trial enrolled 126 veterans (92% men; 55% Black or African American) aged 60-95 years with at least 3 months of musculoskeletal pain. More than two thirds of patients had a psychiatric diagnosis, with about one third having posttraumatic stress disorder (PTSD). Almost all had back pain, and many had pain in multiple locations. Half underwent CBT, while the other half received EAET. Each patient had one 90-minute individual session and eight additional 90-minute group sessions.

Patients were asked to rate their pain using a 0-10 scale in the Brief Pain Inventory (BPI) before starting treatment, at the end of the nine sessions (at week 10), and 6 months after the sessions ended.

- Baseline BPI score for both groups was a mean of around 6.
- Post-treatment, people in the EAET vs CBT group had a mean two-point reduction vs 0.60 reduction, respectively, on the BPI scale. A clinically significant reduction in pain — defined as $\geq 30\%$ decrease — was reported in 63% of EAET patients vs 17% of CBT patients,
- At 6 months, the mean reduction was 1.2 for the EAET group compared with 0.25 for the CBT group, and 40% of the EAET group reported a clinically significant reduction in pain.
- A little more than **a third (35%) of veterans receiving EAET reported at least a 50% reduction in pain at 10 weeks** compared with 7% of those receiving CBT. At 6 months, 16% of the EAET arm reported a halving of their pain.
- EAET was also superior to CBT in reducing anxiety, depression, and PTSD symptoms at the 10-week mark.

The study demonstrated that the evocation and expression of emotions is superior to the mere cognitive discussion of these emotions in therapy of patients with chronic pain. More research is needed on how to personalize patient treatment.

**2024
WNA BOARD
OF DIRECTORS**

PAM HART
PRESIDENT

DARRELL O'SULLIVAN
VICE PRESIDENT AND TREASURER

GLENN RIBOTSKY
SECRETARY

KATHERINE STENZEL
DIRECTOR, EDITOR

JOHN PHILLIPS
DIRECTOR, MEMBERSHIP
CHAIRPERSON

ERIKA MCDANNELL
DIRECTOR

SHANA PHELPS
DIRECTOR

LINDSAY CAMPOY
WNA ADMINISTRATION
(888) 556-3356
admin@pnhelp.org

EMERITUS COUNCIL

BEV ANDERSON

MICHAEL GREEN

KAREN POLASTRI, IOM

MARTIN PRICE

**WNA Neuropathy
Assistance Line
833-980-4181**

Katherine Stenzel
Editor

Newsletter Design by
Diane Blakley Designs

PERIPHERAL NEUROPATHY SUPPORT GROUPS

VIRTUAL AND IN-PERSON FOR OCTOBER 2024

*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.*

	Strategies for Singles with Neuropathy Support Group (1st Wednesday of the odd months) Next meeting November 6, 2024 Host – Erika McDannell Santa Cruz CA Peripheral Neuropathy Support Group (3rd Wednesday of the odd months) Next meeting November 20, 2024 Host - Mary Ann Leer (831) 477-1239 Houston TX Peripheral Neuropathy Support Group (1st Saturday in each quarter) Next meeting December 7, 2024 Host – Katherine Stenzel and John Phillips
In-Person 7 Monday	Auburn CA Peripheral Neuropathy Support Group Monday, 12 noon - 1:30pm Pacific Beecher Room at the Auburn Library, 350 Nevada St., Auburn, CA Host - Pam Hart, pamula1@hotmail.com, and Cass Capel, capelkbphd@gmail.com
Virtual 9 Wednesday	2nd Wednesday Chemo-Induced Peripheral Neuropathy (CIPN) Support Group Wednesday, 2pm - 3pm Pacific / 4pm - 5pm Central / 5pm - 6pm Eastern Meeting ID: 830 5538 3243, Passcode: 396320 Host - Glenn Ribotsky, contact Katherine for Zoom link
Virtual 12 Saturday	2nd Saturday Peripheral Neuropathy Support Group Saturday, 11am - 1pm Pacific / 1pm - 3pm Central / 2pm - 4pm Eastern Meeting ID: 856 7106 1474, Passcode: 114963 Host - Katherine Stenzel, contact Katherine for Zoom link
Virtual 16 Wednesday	3rd Wednesday Peripheral Neuropathy Support Group Wednesday, 10am - Noon Pacific / Noon - 2pm Central / 1pm - 3pm Eastern 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 Wednesday, 3pm - 4pm Pacific / 5pm - 6pm Central / 6pm - 7pm Eastern Host - John Phillips, contact John for Zoom link
Virtual 26 Saturday	4th Saturday Peripheral Neuropathy Open Discussion Saturday, 11am -1pm Pacific / 1pm - 3pm Central / 2pm - 4pm Eastern Meeting ID: 851 7949 9276 / Passcode: 159827 Host - John Phillips, contact Katherine for Zoom link

VIRTUAL SUPPORT GROUP CONTACTS

Katherine Stenzel	klstenzel@hotmail.com	Erika McDannell	ejmcdannell@pnhelp.org
Glenn Ribotsky	glenntaj@gmail.com	Shana Phelps	shanaphelps@pnhelp.org
John Phillips	johnphillips@pnhelp.org		

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

FROM THE PRESIDENT Pam Hart, WNA President

Heartfelt Thanks for Your Incredible Support!

I hope this message finds you well. As I reflect on the incredible journey we've shared over the past 26 years, I wanted to take a moment to express my deepest gratitude for your unwavering support and dedication. Fall is a time of harvest and counting our blessings, and that is what I am doing!

I especially want to thank our Board of Directors whose dedication has been nothing short of inspiring. Whether they've contributed time, resources, or expertise, every effort has significantly impacted our mission. I especially want to thank and encourage our younger members who are not afraid to speak up and help WNA slide into the 21st century. I know that many lament the loss of in-person support groups, but our online groups are very productive and our community has seen real, positive change.

I understand that the success of our organization relies heavily on the generosity of individuals like you. Your enthusiasm, participation, and compassion have not only fueled our progress but have also strengthened the sense of community we cherish so much. The response to our latest fundraising effort was fantastic. Every donation we receive is cherished.

We are also so very thankful for Thrifty Bargain (Thrift Stores) for donating a monthly allotment. Knowing that a set amount is coming to us allows us to plan for the future. Thank you Brian and Ted Mock. (see page 7 for store locations)

Once again, thank you from the bottom of my heart for your incredible support. I am truly grateful for your dedication and look forward to continuing this journey with you.

With heartfelt appreciation,
Pam
pamula1@hotmail.com

UNIVERSITY OF CALIFORNIA - SAN FRANCISCO CLINICAL TRIALS August 7, 2024

Doctors and researchers at UCSF look for new ways to prevent and treat diseases by conducting clinical trials which are used to see if a treatment works and is safe for people. As a world class research center, UCSF has hundreds of clinical trials, many of which are done at the UCSF Medical Center, one of the best hospitals in the country. Currently UCSF has 14 pain clinical trials in progress with 10 of those open to eligible people (i.e. recruiting). Of those, the ones below are relevant to either refractory pain or neuropathic pain. (*More information at <https://clinicaltrials.ucsf.edu/pain>*)

Closed-Loop Deep Brain Stimulation for Refractory Chronic Pain Using Summit RC+S A study on Spinal Cord Injury, Nerve Injury, Postoperative Pain, Postherpetic Neuralgia, Complex Regional Pain Syndrome, Post-Stroke Pain, Brain Injury, Post Radiation Plexopathy, Nerve Root Avulsion, Deep Brain Stimulation, and Pain. Open to eligible people ages 22-80.

Random Clinical Trial (6 weeks duration) of a Weighted Blanket to Reduce Chronic Pain in Veterans A study on Pain and Sleep Disorders. Open to eligible people ages 18 years and up.

Pilot Trial of Longitudinal Repetitive Transcranial Magnetic Stimulation (rTMS) for Chronic Neuropathic Pain A study on Pain, Post-Stroke Pain, Trigeminal Neuralgia, Nerve Injury, Spinal Cord Injury, Postoperative Pain, Complex Regional Pain Syndrome, Postherpetic Neuralgia, Nerve Root Avulsion, and Transcranial Magnetic Stimulation. Open to eligible people ages 18-80.

Transcutaneous (non-invasive) Spinal Cord Stimulation for Chronic Low Back Pain A study on Back Pain, Lower Back Pain and Pain. Open to eligible people ages 21-85.

The following two clinical trials are in progress and not accepting new patients:

Closed-loop Deep Brain Stimulation to Treat Refractory Neuropathic Pain A study on Pain, Post Stroke Pain, Amputation, Phantom Limb, Spinal Cord Injury, and Deep Brain Stimulation using "as needed" stimulation.

Mindfulness Based Pain Reduction A developmental study on Back Pain, Lower Back Pain and Pain develop and test an 8-week Mindfulness-Based Pain Reduction (MBPR) program.

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.medicarights.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.

■ NEUROMUSCULAR TRAINING CUTS ONSET AND REDUCE SYMPTOMS OF CHEMO-INDUCED PERIPHERAL NEUROPATHY

HealthDay News; July 29, 2024

Neuromuscular training reduces the onset of chemotherapy-induced peripheral neuropathy (CIPN), according to a study published online July 1 in JAMA Internal Medicine.

Fiona Streckmann, Ph.D., from the University of Basel in Switzerland, and colleagues examined whether **sensorimotor training (SMT) and whole-body vibration (WBV) training** reduce symptoms and decrease onset of CIPN among patients undergoing treatment with oxaliplatin or vinca alkaloids. A total of 158 patients were randomly assigned into three groups: SMT (55 patients), WBV (53 patients), and treatment as usual (TAU; 50 patients). The researchers found that the incidence of CIPN was significantly lower in SMT (30%) and WBV (41.2%) groups compared with TAU (70.6%).

For balance control bipedal with eyes open, bipedal with eyes closed, monopedal, vibration sensitivity, sense of touch, lower leg strength, pain reduction, burning sensation, chemotherapy dose reductions, and mortality, improvements were seen in favor of SMT versus TAU.

“We were able to show that SMT can decrease CIPN, as well as maintain and improve subjective and objective outcomes, such as vibration sensitivity, sense of touch, lower leg strength, pain, burning sensation, and balance control,” the authors write. “WBV showed a reduced incidence of CIPN and improved balance in a bipedal stance.

■ SENSORIMOTOR BALANCE TRAINING PROGRAM (EXAMPLE)

There are three stages: static, dynamic, and functional. Each exercise is repeated 3–5 times during a session and with enough periods of rest between each set of exercises as needed. The exercises graduate from easy to more difficult and the patient was not progressed to a more difficult stage until performing the easier one according to the following protocol:

1st and 2nd weeks: First phase (Static)

- Standing upright position (30 s) on a firm surface, then on a soft surface (a mat).
- Single leg stance with closed eyes for 10 s on a firm surface, then on a soft surface (a mat).
- Half-step position for 10 s.
- One-leg balance for 10 s.

3rd and 4th weeks: Second stage (Dynamic), in addition:

- Forward stepping lunge.
- T-band kicks exercise.

5th and 6th weeks: Third phase (Functional), in addition:

- Walking exercise on a firm surface, then on a foam surface:
 - o Toe skipping with toes straight ahead for 20 minutes, toes pointing outward for 20 minutes and toes pointing inward for 20 m.
 - o Heel skipping with toes straight ahead for 20 m, toes pointing outward for 20 m and toes pointing inward for 20.
- Squatting exercise:
 - o Against a wall and away from the wall.
 - o One leg squats.
- Balance exercise on wobble board:
 - o Multidirectional rolling movement from sitting.
 - o Multidirectional rolling movement from standing on both legs between parallel bars with eyes open, then eyes closed.
 - o Multidirectional rolling movement from standing on one leg between parallel bars with eyes open, then eyes closed.
 - o Balance with two legs, eyes open, multidirectional, then eyes closed.
 - o Balance with one leg, eyes open, multidirectional, then eyes closed.

REFERENCE

Ahmed, A. F. (2011). Effect Of Sensorimotor Training On Balance In Elderly Patients With Knee Osteoarthritis. *Journal of Advanced Research*, 2(4), 305-311. <https://doi.org/10.1016/j.jare.2011.02.001>

■ WHOLE BODY VIBRATION MACHINE – HOW TO USE FOR BALANCE

IMPROVEMENT Generated by Google AI using “how to use a whole body vibration machine for balance”

Using a whole-body vibration machine, also known as a vibration plate, for balance improvement involves utilizing the destabilizing effect of the vibrations to challenge your body's stability mechanisms.

General Approach

- **Setup:** Ensure the machine is on a flat, stable surface. Stand on the platform with feet shoulder-width apart and slightly bent knees.
- **Warm-up:** Allow your body to adjust to the vibrations for 30-45 seconds before starting exercises.
- **Exercise Selection:** Focus on exercises that challenge your balance and stability, often incorporating single-leg movements or dynamic shifts in weight distribution.

Specific Exercises

- **Standing Balance:** Simply stand on the platform, maintaining a stable posture while the vibrations work to destabilize you.
- **Single-Leg Balance:** Stand on one leg, holding the other slightly off the platform, and challenge your balance.
- **Squats with Variation:** Perform squats with a slightly wider stance, focusing on maintaining stability throughout the movement.
- **Tiptoe to Heel Shifts:** Alternate between standing on tiptoes and heels, forcing your body to adjust to the changing center of gravity.
- **Dynamic Movements:** Incorporate arm movements or torso twists while standing to further challenge your balance.
- **Progression:** As you become more comfortable, increase the vibration intensity or add additional challenges like holding a light weight or closing your eyes.

Important Considerations

- **Start Slow:** Gradually increase the duration and intensity of your sessions to avoid injury.
- **Proper Form:** Maintain proper posture and alignment throughout exercises to maximize benefits and minimize risk.
- **Consult a Professional:** If you have any health concerns, consult a medical professional before using a vibration machine.

■ INVESTIGATING GSK3858279 IN TREATING DIABETIC PERIPHERAL NEUROPATHIC PAIN (DPNP) www.neptune17study.com

The study drug GSK3858279, from GlaxoSmithKline, is a type of medicine called a monoclonal antibody. Previous research has shown that GSK3858279 blocks the activity of a protein called CCL17 and may reduce pain. It is hoped that blocking CCL17 may reduce pain in people with DPNP.

GSK3858279 has been previously studied in approximately 100 people in a clinical trial (NCT03485365, Phase 1, 98 participants).

The NEPTUNE-17 clinical trial (NCT05838755, Phase 2, Recruiting) will continue testing GSK3858279 in adults with DPNP. However, GSK3858279 is not an approved treatment. What is learned in this trial may help future DPNP patients.

NCT05838755 – Phase 2 - A Study to Evaluate Efficacy and Safety of GSK3858279 in Diabetic Peripheral Neuropathic Pain (NEPTUNE-17)

Brief Summary - This is a multicenter randomized, double-blind, placebo-controlled phase 2 study to evaluate efficacy, safety, tolerability, pharmacokinetics, and target engagement of GSK3858279 in adult participants with chronic Diabetic Peripheral Neuropathic Pain (DPNP). The primary objective of the study is to assess the efficacy of GSK3858279 in participants with DPNP who have been unable to sufficiently manage their pain.

Primary Outcome - Change from baseline in the weekly average of average daily pain intensity at Week 12, assessed on the Numeric Rating Scale (NRS).

Among the many categories of neuropathy etiologies are those that result from immune reactions, in which, for whatever reason, antibodies are produced and erroneously directed against components of peripheral nerve. Many have heard of conditions such as Guillan Barre syndrome or CIDP (chronic inflammatory demyelinated polyneuropathy), in which these antibodies are directed against the myelin sheath, or a number of the autoimmune collagen vascular conditions such as lupus, Sjogren’s syndrome, and others, in which antibodies are directed against the axons—the actual nerve fibers. There are also various conditions in which antibodies produced for other reasons interact with and damage nerves, such as monoclonal gammopathies, which are often associated with various blood diseases.

One of the more unusual autoimmune conditions that affects nerves, which can affect tracts in both the central and peripheral nervous systems, is **neurosarcoidosis**. This condition is usually considered a subset of the range of reactions that result from sarcoidosis, a mysterious autoimmune reaction in which immune complexes are deposited in various bodily tissues. These complexes, termed granulomas, are composed mainly of inflammatory lymphocytes (white blood cells) that bunch up and create granules that can settle into and disrupt almost any organ—lungs, heart, kidneys, skin, and, of course, nerves.

Unfortunately, sarcoidosis is, like many autoimmune conditions, hard to pin down and diagnose—unless the deposits are in the skin, where they can easily be biopsied, it is difficult to find them except through advanced imaging, and the symptoms they produce mimic many other conditions. Even laboratory testing is not always helpful—the only lab test that is reliably consistent with sarcoidosis involves elevated levels of angiotensin conversion enzyme (ACE), and even this is not as specific and sensitive as clinicians would like; other conditions can cause rises in ACE, and there are wide variations in levels even among those with biopsy-proven sarcoidosis.

Because these granulomas can collect anywhere in the body, people with **neurosarcoidosis** can experience neuropathies in varied locations and patterns; the “stocking-glove” distribution not being as common with this condition as it is with many metabolic neuropathies. Cranial neuropathies are frequent, as are multiple mononeuropathies, in which various distinct nerve tracts are affected. More diffuse small-fiber neuropathies are also not uncommon.

Though sarcoidosis is one of many autoimmunities that can experience either spontaneous remission or a relapsing-remitting pattern, the difficulty in pinning down the diagnosis often means that significant damage to organ systems is done by the time the condition is verified. Treatment for sarcoid is similar to that for many autoimmune conditions, involving immune modulating treatments such as steroids or immune modulating monoclonal antibodies (the latter are often medications ending in “-mab”); these are used to help arrest the ongoing organ damage, though they cannot “cure” the condition.

The greatest worry for those with sarcoid is usually for involvement of organs other than nerves—those with peripheral nerve involvement often also have central nervous system involvement, and almost always have lung involvement, along with frequent granulomas in lymph nodes and even the heart. In the most advanced and refractory cases, damage to lungs or heart can be so severe that transplant may even be considered.

There is apparently some genetic aspect to sarcoidosis, some 10 percent of people with it have a first degree relative likewise afflicted, and there are clusters of the condition among both Nordic and Afro-Caribbean populations. The true genesis of sarcoidosis—how environmental exposures combines with genetic susceptibility to start the process—remains very much a mystery.

Certainly, clinicians confronted with people experiencing neuropathies don’t generally have **neurosarcoidosis** high up on the list of potential causes. But for people of certain backgrounds, especially those experiencing diffuse small fiber, cranial, or mononeuropathy multiplex presentations, it should be part of the differential diagnosis investigation, with, at the least, an ACE lab result, chest/lung x-ray, and extensive skin exam undertaken.

REFERENCES

- Bradshaw, M.B. et al. (2021). Neurosarcoidosis Pathophysiology, Diagnosis, And Treatment. *Neurology Neuroimmunology & Neuroinflammation*, 8(6). <https://doi.org/10.1212/NXI.000000000000010>
- Gabriel Bucurescu, MD, et al, Neurosarcoidosis, *Medscape.com*, July 15, 2024.
- Pirau, L.FI. (2023). StatPearls [Internet]. Neurosarcoidosis. *StatPearls Publishing*, 2024 Jan. <https://www.ncbi.nlm.nih.gov/books/NBK534768/>
- Soto-Gomez, N., et al. (2016) Diagnosis And Management Of Sarcoidosis. *American Family Physician*, 93(10), 840-850. PMID: 27175719.
- Zheng, S. et al. (2023). Re-Evaluation Serum Angiotensin-Converting Enzyme In Sarcoidosis. *Frontiers in Immunology*, 14. <https://doi.org/10.3389/fimmu.2023.950095>

■ LOW DOSE NALTREXONE IN PATIENTS WITH CRYPTOGENIC SMALL FIBER NEUROPATHY – ABSTRACT

Ahmed, S. et al. (2024). Use Of Low Dose Naltrexone In A Cohort Of Patients With Cryptogenic Small Fiber Neuropathy. *Neurology*, 102(17-supplement 1). <https://doi.org/10.1212/WNL.0000000000206418>

(Editor – this is the first time I have seen the word Cryptogenic. It is another word for Idiopathic – meaning the cause of the neuropathy is unknown. This is also used in the title of Glenn’s article on Neurosarcoisodid on the previous page.)

Objective - To explore the efficacy of low dose naltrexone (LDN) in a group of patients with biopsy-confirmed cryptogenic small fiber neuropathy (SFN).

Background - SFN affects somatic and autonomic fibers and can present with disabling pain and autonomic symptoms. Management involves a multimodal approach with rehabilitation, optimal treatment of co-morbid conditions, and pharmacological treatment using antidepressants, anticonvulsants, and topical agents. LDN, an opioid receptor antagonist, has emerged as a potential treatment option for diabetic neuropathy and management of chronic pain in fibromyalgia. However, limited evidence exists regarding the efficacy of LDN in management of patients with cryptogenic SFN.

Design/Methods - In a retrospective analysis, 44 patients with biopsy-confirmed cryptogenic SFN were identified in a university neuropathy clinic. Of these, the outcomes of patients started on LDN were further analyzed. In these patients, LDN was titrated to doses ranging as high as 4.5mg. The Small-fiber Sensory Survey (SSS) was administered prior to LDN initiation and at varying intervals in order to assess for symptomatic response to LDN.

Results - Out of the 84 patients who underwent biopsies, 44 had positive findings confirming SFN, and 13 patients were started on LDN. Adequate follow up SSS screenings were obtained from 8 patients who completed two surveys separated by 6 to 24 months. Follow up surveys indicated a decrease in all 5 composite scores on the SSS including “sensory”, “circulation”, “gastrointestinal”, “pelvic”, and “miscellaneous” scores. The largest mean decrease was noted in “sensory” composite scores and the smallest decrease was noted in “pelvic” composite scores.

Conclusions - Our study reveals a potential role for LDN in the management of cryptogenic SFN. Results are confounded by limited sample size along with variable LDN dosing and survey intervals. Nevertheless, follow up studies may be beneficial in establishing the benefit of LDN in SFN using larger sample sizes and assessing for response over a longer interval.

■ THE ROLE OF NEUROTROPIC B VITAMINS IN NERVE REGENERATION

Damage and regeneration naturally occur in the peripheral nervous system. The neurotropic B vitamins thiamine (B1), pyridoxine (B6), and cobalamin (B12) are key players, which maintain the neuronal viability in different ways. Firstly, they constantly protect nerves against damaging environmental influences. While vitamin B1 acts as a site-directed antioxidant, vitamin B6 balances nerve metabolism, and vitamin B12 maintains myelin sheaths. However, nerve injury occurs at times, because of an imbalance between protective factors and accumulating stress and noxae. This will result in the so-called Wallerian degeneration process. The presence of vitamins B1, B6, and B12 paves the way out to the following important regeneration by supporting the development of new cell structures. Furthermore, vitamin B1 facilitates the usage of carbohydrates for energy production, whereas vitamin B12 promotes nerve cell survival and remyelination. Absence of these vitamins will favor permanent nerve degeneration and pain, eventually leading to peripheral neuropathy.

All of the three highlighted B vitamins may create the necessary environmental conditions for successful nerve regeneration, each of which via individual modes of action.

- Vitamin B1 essentially facilitates the energy production needed for the process and acts as a site-directed antioxidant
- Vitamin B6 is vital for neurotransmitter synthesis and for inhibiting the release of neurotoxic glutamate
- Vitamin B12, on the other hand, largely promotes nerve cell survival and is strongly and directly involved in remyelination and the maintenance of myelin sheaths.

However, to elucidate molecular mechanisms, prove nerve-regenerating functions, and investigate neuroprotection, further experimental in vitro and in vivo studies with the individual B vitamins and the combination are needed.

REFERENCE

Baltrusch, S. (2021). The Role Of Neurotropic B Vitamins In Nerve Regeneration. *BioMedical Research International*, 2021(1). <https://doi.org/10.1155/2021/9968228>



WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit,
tax exempt corporation

3620 American River Drive, Suite 230
Sacramento, CA 95864

Call WNA using our toll free phone number:
(888) 556-3356 • Email: admin@WNAinfo.org

IN THIS ISSUE

Dear Readers,

Most sufferers of peripheral neuropathy use medication, diet, and/or exercise to help with pain. Those are physical treatments or either a pill, food or using your body. But what about using your mind to help with pain? The front-page article on a clinical trial using a new type of psychotherapy, **Emotional Awareness and Expression Therapy (EAET)**, found a 30% decrease in pain with some participants having a 50% decrease. EAET also helped reduce anxiety and depression.

Many of our members live in California as that is where the organization originated. The **University of California at San Francisco** is currently recruiting eligible people for four clinical trials on chronic pain related to neuropathic pain. Your participation could help prove these treatments for all of us. Find more information on **Page 3**.

Most clinical trials are conducted on diabetic peripheral neuropathy and chemotherapy induced peripheral neuropathy. The question is do those results also apply to peripheral neuropathy that is idiopathic. **Page 7** summarizes a clinical trial using Low Dose Naltrexone (LDN) on patients with Cryptogenic (Idiopathic) Small Fiber Neuropathy. Finally – a clinical trial that applies to those of us (*me included*) with no cause to our neuropathy. And using LDN! The results describe the most decrease in sensory symptoms with decreases also noted in circulation, gastrointestinal, pelvic and miscellaneous symptoms. Another **positive clinical trial for LDN treatment**.

May these give you Hope.

...Katherine

klstenzel@hotmail.com



Western Neuropathy Association (WNA)

A California public benefit, nonprofit,
tax-exempt corporation.

Katherine Stenzel, Editor
klstenzel@hotmail.com

3620 American River Drive, Suite 230
Sacramento, CA 95864
(888) 556-3356
www.WNAinfo.org

WNA Headquarters: admin@WNAinfo.org

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.

This newsletter is designed for educational and informational purposes only. The information contained herein is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. Western Neuropathy Association (WNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.