



WESTERN NEUROPATHY ASSOCIATION

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CELEBRATING OUR 26TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

FDA APPROVES MEDTRONIC'S *INCEPTIV* CLOSED-LOOP SPINAL CORD STIMULATOR

Marco Meglio; *NeurologyLive.com*; April 30, 2024

The FDA's approval of Medtronic's spinal cord stimulator (SCS) makes it the first on the market to offer a closed-loop feature that senses biological signals along the spinal cord and automatically adjusts stimulation in real time for chronic pain, keeping therapy in sync with daily activities of living.

While traditional fixed-output SCS devices deliver constant, mild electrical impulses that disrupt pain signals before they reach the brain, *Inceptiv* SCS constantly maintains the physician's prescribed stimulation that is tailored to the patient's needs. The therapy includes a specialized circuitry and a proprietary algorithm to detect evoked compound action potentials (ECAPs), which are a direct measure of how much nerve tissue is activated in the spinal cord. It then senses the body's response to stimulation 50 times per second and instantly increases or decreases stimulation to maintain prescribed settings.

With the approval, *Inceptiv* becomes the only approved closed-loop SCS that offers full-body 3T MRI access. After already receiving approvals in Europe and in Japan, Medtronic expects *Inceptiv* to be launched in the US in the coming weeks. The treatment is also paired with CareGuidePro, a mobile application web portal that serves as a virtual guide throughout a patient's therapy journey.

At the recent 2024 North American Neuromodulation Society (NANS) Annual Meeting, a late-breaking, EU-based, post-marketing study highlighted the benefits *Inceptiv* brings to patients. The prospective study included 2 parts: in-clinic testing for primary end point assessment at 1 month, and a long-term follow-up for pain outcomes as 3-, 6-, 12-, 18-, and 24-months post device activation. Among the key findings, results showed that the study met its primary objective, with 89% of patients reporting a significant reduction in overstimulation relative to open loop and 86% reporting a preference for closed-loop blinded testing at 1 month. The trial also met its secondary objective, with 86% of participants reporting at least 50% reduction in overall back and leg pain at 3 months.

Additional data from the study showed clinically meaningful improvements in pain, physical function, and quality of life at 3 months. At the same time point, over 80% of patients were able to achieve their stated activity goals for daily living with SCS therapy without fear of pain or therapy adverse effects.

In the post-marketing study, 77% reduction in chronic low back pain at 24 months was observed in *Inceptiv*-treated patients. Additionally, 93% of these individuals were considered responders on leg pain and 95% of patients were satisfied or very satisfied with SCS treatment at 24 months. Furthermore, investigators observed a significant average reduction of more than 26 points on Oswestry Disability Index.

"*Inceptiv* is the most cutting-edge SCS solution available today, with its closed-loop capability, full-body 1.5T and 3T MRI access, compatibility with multiple types of waveforms, and tiny form factor that makes it the smallest and thinnest on the market. These features together make *Inceptiv* the most advanced closed-loop spinal cord stimulator available today," David Carr, vice president and general manager, Pain Interventions within the Neuromodulation business, Neuroscience Portfolio, Medtronic, told *NeurologyLive*®.

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PERIPHERAL NEUROPATHY SUPPORT GROUPS

VIRTUAL AND IN-PERSON FOR JULY 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.*

	<p>Auburn CA Peripheral Neuropathy Support Group (1st Monday of the month) No meetings in July, August and September</p>
<p>Virtual 3 Wednesday</p>	<p>1st Wednesday – Strategies for Singles with Neuropathy Support Group Wednesday, 4pm – 5pm Pacific / 6pm – 7pm Central / 7pm – 8pm Eastern Host – Erika McDannell, contact Erika for the Zoom link</p>
	<p>NEW See page 7</p>
<p>Virtual 8 Wednesday</p>	<p>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</p>
<p>Virtual 13 Saturday</p>	<p>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</p>
<p>Virtual 17 Wednesday</p>	<p>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</p>
<p>In-Person 17 Wednesday</p>	<p>Santa Cruz CA Peripheral Neuropathy Support Group (3rd Wednesday of the odd months) Wednesday, 1pm – 2:30 pm Pacific Trinity Presbyterian Church, 420 Melrose Avenue, Santa Cruz, CA Host - Mary Ann Leer (831) 477-1239</p>
<p>Virtual 17 Wednesday</p>	<p>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</p>
<p>Virtual 27 Saturday</p>	<p>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</p>

VIRTUAL SUPPORT GROUP CONTACTS

Katherine Stenzel kstenzel@hotmail.com
 Glenn Ribotsky glenntaj@gmail.com
 John Phillips johnphillips.wna@gmail.com
 Erika McDannell ejmcdannell@gmail.com

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

FROM THE PRESIDENT Pam Hart, WNA President

Another Great Testimony

I can hardly contain my excitement as I write this article. I love to be able to bring hope and encouragement. At our June Auburn Support Group Meeting, a couple announced that they had recently started taking Low Dose Naltrexone (LDN). They were very happy with their results of less pain, a good night's sleep and the very best news of all...they were able to talk their regular doctor at Kaiser into prescribing it! Not only did Kaiser Medical Group recognize LDN, they are actually stocking it in their pharmacy!! Kaiser Permanente is the largest health care provider in California – what does this tell you.

With Stanford University Medical Services regularly prescribing LDN for Fibromyalgia patients, it sounds like the medical community is embracing the benefits of LDN. With something so helpful, no contraindications with other medications and low cost, it seems the perfect medication to prescribe – at least to see if it will help individuals. Find out more at www.LDNResearchTrust.org or find an online doctor at www.ldndirect.com.

I would love to hear back from those that have tried it. We can keep a running total of successes.

Please be safe and stay cool this summer.

Blessings,

Pam

pamula1@hotmail.com

CHECK IT OUT – WNA MERCHANDISE

Have you heard the exciting news? The Western Neuropathy Association now has t-shirts, hats, mugs, and more available for purchase.

In our support groups, we often emphasize how humor can be a great tool in managing the challenges of living with neuropathy. Our latest items were designed with that in mind, so we hope they bring a little brightness to your day whenever you wear/use them!

To find these items and more on our website, go to pnhelp.org and click “STORE” in the navigation menu.

Join us as we help fund research and spread awareness for neuropathy. For any questions or suggestions about our merchandise, email WNA Director Erika McDannell at ejmcdannell@gmail.com.



TIDBITS FROM THE VIRTUAL SUPPORT GROUP SESSION - JUNE 8, 2024

Katherine Stenzel, Editor

Neuropathy manifests with a variety of different symptoms. During the June 8th, 2nd Saturday Virtual Support Group, several attendees said their toe nails stopped growing entirely or exhibited a sporadic growing pattern. Others talked about the absence of leg hair with Glenn Ribotsky, WNA Director and Support Group Lead, saying this happened more often to women. At least there is no pain or discomfort with these symptoms!

HEALTH CARE CHALLENGES WEBSITES

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
(844) USAGOV1
(844) 872-4681

For those with a disability, learn how government programs and services can help in your daily life.

OFFICE APPROACH TO SMALL FIBER NEUROPATHY – PART 3: TREATMENT

Jinny O. Tavee, MD. (2018). Office Approach To Small Fiber Neuropathy. *Cleveland Clinic Journal of Medicine*, 85/(10), 801-812. DOI: <https://doi.org/10.3949/>

TREATING SPECIFIC DISORDERS

For patients with an identified cause of neuropathy, targeted treatment offers the best chance of halting progression and possibly improving symptoms. Below are recommendations for addressing neuropathy associated with the common diagnoses.

Diabetes, impaired glucose tolerance, and metabolic syndrome

In addition to glycemic- and lipid-lowering therapies, lifestyle modifications with a specific focus on exercise and nutrition are integral to treating diabetes and related disorders.

In the Look AHEAD (Action for Health in Diabetes) study, which evaluated the effects of intensive lifestyle intervention on neuropathy in 5,145 overweight patients with type 2 diabetes, patients in the intervention group had lower pain scores and better touch sensation in the toes compared with controls at 1 year. Differences correlated with the degree of weight loss and reduction of hemoglobin A1c and lipid levels.

As running and walking may not be feasible for many patients owing to pain, stationary cycling, aqua therapy, and swimming are other options. A stationary recumbent bike may be useful for older patients with balance issues.

Vitamin B12 deficiency

As reduced absorption rather than low dietary intake is the primary cause of vitamin B12 deficiency for many patients, parenteral rather than oral supplementation may be best. A suggested regimen is subcutaneous or intramuscular methylcobalamin injection of 1,000 µg given daily for 1 week, then once weekly for 1 month, followed by a maintenance dose once a month for at least 6 to 12 months. Alternatively, a daily dose of vitamin B12 1,000 µg can be taken sublingually.

Sjögren syndrome

According to anecdotal case reports, intravenous immune globulin, corticosteroids, and other immunosuppressants help painful small fiber neuropathy and dysautonomia associated with Sjögren syndrome.

Sarcoidosis

Sarcoidosis-associated small fiber neuropathy may also respond to intravenous immune globulin, as well as infliximab and combination therapy. Culver et al found that cibinetide, an experimental erythropoietin agonist, resulted in improved corneal nerve fiber measures in patients with small fiber neuropathy associated with sarcoidosis.

Celiac disease

A gluten-free diet is the treatment for celiac disease and can help some patients.

GENERAL MANAGEMENT

For all patients, regardless of whether the cause of small fiber neuropathy has been identified, managing symptoms remains key, as pain and autonomic dysfunction can markedly impair quality of life. A multidisciplinary approach that incorporates pain medications, physical therapy, and lifestyle modifications is ideal. Integrative holistic treatments such as natural supplements, yoga, and other mind-body therapies may also help.

Pain control

Antiepileptics, antidepressants, and topical agents are first-line therapies for small fiber neuropathy pain (Table 3). The efficacy of each drug varies among individuals, so initial treatment choice is often based on cost or side-effect profiles. For example, topiramate should be avoided in patients with a history of renal stones but can be beneficial for metabolic syndrome, as it promotes weight loss.

Mexiletine, a voltage-gated sodium channel blocker used as an antiarrhythmic, may help refractory pain or hereditary small fiber neuropathy related to sodium channel dysfunction. However, it is not recommended for diabetic neuropathy.

Combination regimens that use drugs with different mechanisms of action can be effective. In one study, combined gabapentin and nortriptyline were more effective than either drug alone for neuropathic pain.

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Therapy	Dosages (per day)	Common adverse effects
Anticonvulsants		
Gabapentin	300–3,600 mg	Sedation, dizziness, peripheral edema, weight gain
Pregabalin	150–600 mg	Similar to gabapentin
Topiramate	25–400 mg	Weight loss, sedation, cognitive slowing, depression with suicidal ideation, renal stones, paresthesias, glaucoma
Zonegran	100–400 mg	
Antidepressants		
Amitriptyline	20–100 mg	Sedation, weight gain, anticholinergic effects, sexual dysfunction, arrhythmia (side effects most prominent with amitriptyline)
Nortriptyline	20–100 mg	
Desipramine	20–200 mg	
Duloxetine	60–120 mg	
Topical anesthetics		
Lidocaine 5% patch	3 patches for 12 hours	Local edema, burning, erythema
Lidocaine 5% cream or gel	5 g to affected areas up to 20 g total	Local edema, burning, erythema
Capsaicin 0.75%	Apply up to 4 times daily	Burning
Capsaicin 8% patch	60–90 minutes (applied by the clinician)	Burning
Other		
Tramadol	50–400 mg	Sedation, dizziness, seizures, nausea, constipation
Mexiletine	200–600 mg	Nausea, vomiting, abdominal pain, dry mouth (not helpful for diabetic neuropathy)

Table 3 – Pain management for small fiber neuropathy

Inhaled cannabis reduced pain in patients with HIV and diabetic neuropathy in a number of studies. Side effects included euphoria, somnolence, and cognitive impairment. The use of medical marijuana is not yet legal nationwide and may affect employability even in states in which it has been legalized.

Owing to the opioid epidemic and high addiction potential, opioids are no longer a preferred recommendation for chronic treatment of noncancer-related neuropathy. A population-based study of 2,892 patients with neuropathy found that those on chronic opioid therapy (≥ 90 days) had worse functional outcomes and higher rates of addiction and overdose than those on short-term therapy. However, the opioid agonist tramadol was found to be effective in reducing neuropathic pain and may be a safer option for patients with chronic small fiber neuropathy.

Integrative, holistic therapies

Many patients with chronic illness are turning toward complementary and alternative medicine owing to lack of perceived benefit from conventional treatments, medication side effects, or a desire for more “natural” therapies. Limited data from small clinical trials have shown marginal improvement in neuropathic pain with a number of over-the-counter supplements,

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OFFICE APPROACH TO SMALL FIBER NEUROPATHY – PART 3: TREATMENT - Continued from page 5

including acetyl-L-carnitine and alpha lipoic acid (Table 4). In one study, omega-3 fatty acids from seal oil improved corneal fiber density in patients with diabetic neuropathy. Acupuncture, as well as mentholated ointments and essential oils in combination with massage of the feet, may also provide temporary relief. Mind-body therapies such as yoga, meditation, and tai chi may help pain, balance, and quality of life in patients with neuropathy.

Treatments	Dosage	Comments
Oral supplements		
Acetyl-L-carnitine	1,000 mg 3 times a day	Some benefit seen in diabetic and human immunodeficiency virus neuropathy, but may worsen chemotherapy-induced neuropathy
Alpha lipoic acid	600 mg/day	Early studies found benefit with intravenous dosing but no data on optimal oral dose
Glutamine	15 g twice a day	Possible neuroprotective effect in chemotherapy-induced neuropathy with oral dose, pain reduction with intravenous dosing
Curcumin	Dose varies	Some benefit in pain reduction for diabetic and chemotherapy-induced neuropathy
Omega-3 fatty acids	1,000–3,000 g/day	Possible pain reduction seen in mouse models; increased nerve growth in patients with diabetic small fiber neuropathy
Topical products		
Vicks VapoRub	Apply as needed	May cause increased pain on initial contact
Horse liniment cream	Apply as needed	May cause increased pain on initial contact
Frankincense oil	Apply as needed	Reduces neuropathic pain in mice
Hemp cream or oil	Apply as needed	Noncannabidiol form legal in all states

Table 4 – Over-the-counter treatments for small fiber neuropathy

PROGNOSIS

For many patients, small fiber neuropathy is a slowly progressive disorder that reaches a clinical plateau lasting for years, with progression to large fiber involvement reported in 13% to 36% of cases; over half of patients in one series either improved or remained stable over a period of 2 years. Long-term studies are needed to fully understand the natural disease course. In the meantime, treating underlying disease and managing symptoms are imperative to patient care.

BALANCE WEBINAR FROM THE FOUNDATION FOR PERIPHERAL NEUROPATHY (FPN), MARCH 2024

During this webinar, LeeAnn Manoni, DC, presented alternative therapies that enhance balance. She spoke about therapies that can improve communication from the brain to the body to improve balance. She also discussed possible home therapies that can impact your balance and what should you invest your time in daily. The program also touched on what supplements or food can impact neuropathy.

You can find the recorded webinar on the FPN website at www.foundationforpn.org > Patient Resources > Events > Past Webinars.

NEW VIRTUAL SPECIALIZED SUPPORT GROUP!

Strategies for Singles Coping with Neuropathy Support Group

July 3rd, 2024 at 4pm Pacific, 6pm Central, 7pm Eastern

Email Erika McDannell at ejmcdannell@gmail.com for Zoom link

Live alone and have neuropathy? We're excited to share that the Western Neuropathy Association is launching a new **quarterly** support group exclusively for members like you.

Meeting for the first time on July 3rd at 6 PM Central, we'll be focusing on building connections and sharing with each other the helpful strategies we've developed to live life well with neuropathy and other chronic illnesses. This is a great opportunity to get to know each other, expand your support network, and feel encouraged by our awesome WNA community. To join the conversation, email WNA Director Erika McDannell at ejmcdannell@gmail.com for the Zoom link. Note: this specialized support group will be "Members Only."

FEELING OVERWHELMED? TRY THIS SIMPLE PLAN CREATED BY A WNA MEMBER

Kris Langenfeld, WNA member from Houston, Texas, was depressed and felt paralyzed from being so overwhelmed! "There was sooooo much I need/should/could do, but didn't."

She adopted a new system for Monday through Friday. Each day she lists 3 items that she must accomplish that day. If she completes more, that is great. But she does not plan on doing more. Out of those 3 items, only 2 could be medical appointments.

At press time, she was in her 3rd week of the new system. She says "So far it is working quite well. I have a sense of control because I can see that I AM, indeed, getting things done." An example of one of her days is: 1. Clean floors 2. Catch up with my brother 3. Exercise in the pool. And finally, Kris states "What do I love more than making lists? Checking off items in the list!"



STANFORD RESOURCE GUIDE TO CHRONIC PAIN MANAGEMENT

American Chronic Pain Association, 2024

The American Chronic Pain Association (ACPA) believes that people with chronic pain benefit from being well informed about their medications. This knowledge may relieve the fears that can interfere with receiving maximum benefits from medications. The ACPA - Stanford Resource Guide to Chronic Pain Management discusses six broad categories of therapy: (1) medications, (2) interventional procedures, (3) psychological/behavioral approaches, (4) physical rehabilitative approaches, (5) complementary and integrative medicine approaches, and (6) self-help strategies. These are all applied in a person-centric manner to improve the health and well-being of the person in pain. It is not meant to serve as medical advice for your condition or regarding your medication needs. Remember that the best source of information about your health and medication needs is from an open dialogue with your treating doctor.

To view or download the PDF of the Guide, go to acpanow.com/acpa-stanford-guide.html. Note: it is a comprehensive and lengthy document at 226 pages.

ACPA – STANFORD RESOURCE GUIDE To CHRONIC PAIN MANAGEMENT

An Integrated Guide to
Comprehensive Pain Therapies

PATIENT ADVOCATES – WHAT DO THEY DO?

Many large medical offices and hospitals have a Patient Advocate (could also be called a Patient Representative, Patient Navigator or Case Worker) that could be helpful when encountering problems – help with coordinating appointments, seeing a specific specialist, securing medical tests, finding a second opinion, find financial or legal resources, or find support groups or other social support. They may also work with insurance companies, employers, lawyers and others who may have an effect on a patient's health care needs.

Another definition of a Patient Advocate would be someone who helps patients communicate with their health care providers so they get the information they need to makes decisions about their health care.

REFERENCE: National Cancer Institute at the National Institutes of Health, dictionary of terms



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IN THIS ISSUE

The conclusion of “Office Approach to Small Fiber Neuropathy” highlights this issue with Part 3 discussing Treatments. Two excellent tables are included – Table 3 on Pain Management containing both oral and topical medications, and Table 4 which details over-the-counter oral supplements and topicals. Dosage for each is specified along with comments on adverse effects and/or possible benefits.

The front-page article is about another spinal cord stimulator (SCS) that has been recently approved by the FDA. This one is a little different in that it constantly monitors the patient’s response to the electrical signals that disrupt the pain signals and increases or decreases the stimulation as needed to keep it at the doctor prescribed level. Medtronic calls this device *Inceptiv* and the stimulation technique a closed-loop system.

Interested in WNA branded merchandise? Erika McDannell, who recently joined the Board of Directors, has designed t-shirts and hoodies, coffee mugs and travel mugs with a touch of humor. See Page 3 for more details.

May these give you Hope.

..Katherine

klstenzel@hotmail.com



Western Neuropathy Association (WNA)

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tax-exempt corporation.

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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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