CELEBRATING OUR 27TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

WESTERN NEUROPATHY ASSOCIATION

NOVEMBER 2025
Issue 10
Volume 23

WESTERN NEUROPATHY ASSOCIATION
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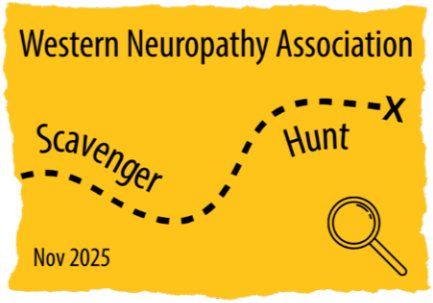
THE SCAVENGER HUNT STARTS MONDAY, NOVEMBER 3!

Katherine Stenzel, Editor

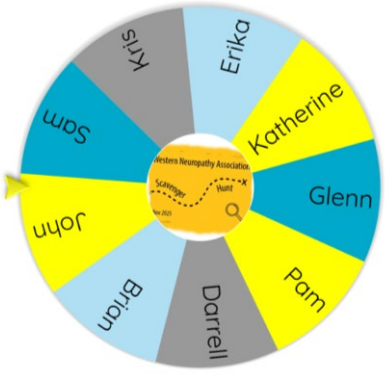


Are you ready to search the WNA website for answers about neuropathy and the Western Neuropathy Association!

On Monday, November 3, noon Central, everyone will receive an email with Part 1 of the Scavenger Hunt. Find and submit the correct answers for the three parts of the Hunt and be entered into the Winners Wheel. It will be the luck of the spin of the Wheel to place for prizes.

PARTICIPATION DETAILS (NOTE: DETAILS HAVE CHANGED SINCE THE OCTOBER ISSUE)

- Monday, November 3 at noon Central, check your inbox for the email to start Part 1 of the Scavenger Hunt. The email contains a link to a form with four questions. After answering, submit the form by Wednesday, November 5, noon Central.



- Participants will receive an email saying if they successfully completed Part 1 (or not…) and may proceed to Part 2 of the Scavenger Hunt.
- Part 2 questions will be sent on Monday, November 10, at noon Central. Again, click on the link and submit answers by Wednesday, November 12, noon Central. Participants will receive an email with their Hunt results.
- Part 3 questions will be sent on Monday, November 17, at noon Central. And again, click and submit by Wednesday, November 19, noon Central. And participants will receive an email with their results.

Winner Announcement

Winners of the 3 Parts of the Scavenger Hunt will have their names entered in the Wheel of Names! During the 4th Saturday Support Group on November 22, at 1pm Central, the wheel will spin to select the names!

Prizes

- First Prize: Choice of Zip Up Hoodie or Sweatshirt
- Second Prize: T-shirt
- Third Prize: Mug or Notebook

Important Dates and Times (10am Pacific, 11am Mountain, Noon Central, 1pm Eastern)

Scavenger Hunt	Start Date & Time (Central)	Submission Deadline (Central)
Part 1	Monday, November 3, noon	Wednesday, November 5, noon
Part 2	Monday, November 10, noon	Wednesday, November 12, noon
Part 3	Monday, November 17, noon	Wednesday, November 19, noon

We hope you enjoy learning more about neuropathy and WNA as you search for answers in the Scavenger Hunt!

Peripheral Neuropathy Support Groups – November 2025 Schedule

Environments of education, empowerment, support and caring for people with neuropathy. Please join a group for yourself and for others. You are always welcome!

	Houston TX Peripheral Neuropathy Support Group 1st Saturday of the last month in each quarter **Next Meeting December 6** Memorial Drive United Methodist Church, 12955 Memorial Drive Hosts – Katherine Stenzel, John Phillips and Brian Lockard
In-Person 3 Monday	**Auburn CA Peripheral Neuropathy Support Group** 1st Monday of the month (no meetings July, August, September) **12 noon - 1:30pm Pacific** Unity of Auburn, 1212 High Street, Auburn, CA Hosts – Pam Hart, *pamhart@pnhelp.org*, and Cass Capel, *capelkbphd@gmail.com*
Virtual 5 Wednesday	**Strategies for Singles with Neuropathy Support Grou**p 1st Wednesday of the odd months **4pm Pacific / 5pm Mountain / 6pm Central / 7pm Eastern (90 minutes long)** Meeting ID: 921 6944 4482 / Passcode: 858258 Host – Erika McDannell, contact Erika for Zoom link
Virtual 8 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 11 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 12 Wednesday	**2nd Wednesday Chemo-Induced Peripheral Neuropathy (CIPN) Support Group** **2pm Pacific / 3pm Mountain / 4pm Central / 5pm Eastern (90 minutes long)** Meeting ID: 830 5538 3243 / Passcode: 396320 Host - Glenn Ribotsky, contact Katherine for Zoom link
Virtual 19 Wednesday	**3rd Wednesday Peripheral Neuropathy Support Group** **10am Pacific / 11am Mountain / Noon Central / 1pm Eastern (2 hours long)** Meeting ID: 833 4473 0364 / Passcode: 341654 Host - Glenn Ribotsky, contact Katherine for Zoom link
Virtual 19 Wednesday	**3rd Wednesday CIDP and Autoimmune Support Group** **3pm Pacific / 4pm Mountain / 5pm Central / 6pm Eastern (2 hours long)** Meeting ID: 943 1735 2429 / Passcode: 579413 Host - John Phillips, contact John for Zoom link
Virtual 22 Saturday	**4th Saturday Peripheral Neuropathy Open Discussion** **11am Pacific / noon Mountain / 1pm Central / 2pm Eastern (2 hours long)** Meeting ID: 851 7949 9276 / Passcode: 159827 Host - John Phillips, contact Katherine for Zoom link
Virtual 26 Friday	**4th Wednesday Autonomic Support Group** **9am Pacific / 10am Mountain / 11am Central / Noon Eastern (1 hour long)** Meeting ID: 981 9504 4615 / Passcode: 840294 Hosts – Dan Kahn and Katherine Stenzel, 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 Glenn Ribotsky, WNA President

How Do I Describe What Neuropathy Is Like?

Neuropathy is a condition with such a variety of symptoms--sensory, motor, autonomic--and such a plethora of potential etiologies (more than three hundred acquired possible causes and who knows how many genetic ones) that describing what one is experiencing, and how one might have gotten it (if one can even determine that) is one of the major challenges of living with the condition. It's a problem that those with cancer or heart disease generally don't have, and it probably contributes to the relative lack of attention that neuropathy gets compared to those and other common maladies.

To give people a little help with this, please see the piece in this month's newsletter titled "How Do I Describe What I Have?". Finding the language for our condition is not only important when we're in health professionals' offices, but also when we're with our family, our friends, maybe even our elected representatives, who we surely want to encourage to vote for more funding and research to understand and produce treatments for this "most common of neurological conditions nobody has heard about".

Of course, there are several other articles here intended to help with various aspects of our neuropathy journeys--peruse them all. And don't forget about our Neuropathy Scavenger Hunt, which will happen in three Parts across the month—letting you demonstrate your knowledge of neuropathy and the WNA website. Hunt through the website, answer the questions correctly and you could be in line for some really delightful prizes.

Here's hoping for a minimally symptomatic Thanksgiving for us all.

Glenn
glenntag@yahoo.com

Five Things Living With A Mobility Aid Does Not Mean

From post "You Are Lazy?!" by coolcrutches on TicTok

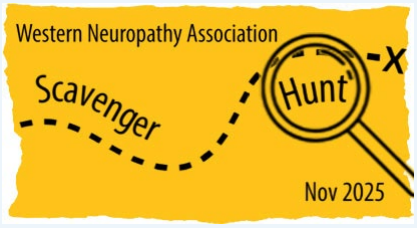
That we're lazy - Using a mobility aid is an active choice to keep moving. Movement is what matters, not how.

That we've given up - Using a daily mobility aid is the opposite of giving up. Giving up would be not using and not moving. By using mobility aids, we are proactively choosing to use tools that will help keep us moving and active!

That we're tragic - There is nothing tragic about mobility aids of any kind. They're tools which bring us freedom and JOY!

That we're sad - While living with a disability can present its own set of challenges, it does not mean that individuals with disabilities cannot experience joy, happiness, and fulfillment in their lives.

That we're not trying hard enough - People with disabilities often demonstrate immense resourcefulness and creativity in navigating their daily lives, and that's something to be proud of!



The Scavenger Hunt Starts Monday, Nov. 3!

Check your email at noon *(Central)*
Monday, November 3 to start Part 1

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.

How Do I Describe What I Have? Support Group Manual, Neuropathy Alliance of Texas

Three examples to help you describe your neuropathy to others.

Short Description

"I have neuropathy, a disease of my nerves/damage to my nerves. In my case it causes _____ (pain, burning, weakness, tingling, a feeling of pins and needles, numbness, loss of sensation, etc.) in my _____ (feet, legs, hands, arms, digestive system, etc.) and affects my _____ (walking, using my hands, energy level, etc.). Currently there is no cure, only symptom management."

30 Second Description

"I have neuropathy, a disease of my peripheral nerves, the ones that go from my spine to my hands and feet. It gives me _____ (pain, burning, weakness, tingling, a feeling of pins and needles, numbness, loss of sensation, etc.) in my _____ (feet, legs, hands, arms, digestive system, etc.). I have had this for _____ years, and it is the result of _____ (chemotherapy, diabetes, an auto-immune disease, toxin exposure, an accident or surgery, etc.) OR the doctors don't know why I have it. Currently there is no cure, only symptom management."

Long Description

"I have neuropathy, a disease of the nervous system. In my case, it causes _____ (pain, burning, weakness, tingling, a feeling of pins and needles, numbness, loss of sensation, etc.) in my _____ (feet, legs, hands, arms, digestive system, etc.). You may have heard of Parkinson's Disease, MS or Alzheimer's Disease. Those involve the Central Nervous System – the brain and spinal cord. My disorder involves the Peripheral Nervous System – nerves from the spine to the extremities. Over 20 million people in the US or 1 in 15 have a form of neuropathy. I've had this for _____ years. It's the result of _____ (chemotherapy, diabetes, an auto-immune disease, toxin exposure, an accident or surgery, etc.) OR the doctors don't know why I have it. There are actually over 100 causes of neuropathy and patients may feel different symptoms depending on which nerves are affected. Currently there is no cure, only symptom management. I was diagnosed through a series of tests (EMG, Nerve Conduction Studies, Nerve Biopsy, Lumbar Puncture, CT, MRI, etc.) and currently see a _____ (neurologist, podiatrist, endocrinologist, pain management specialist). I treat it with _____ (medications, diet, exercise, PT, supplements, Immunoglobulin, Plasmapheresis, steroids, etc.). My neuropathy _____ (is stabilized, has worsened over the past few years, is getting better, etc.). Currently there is no cure, only symptom management."

Drug (*ART26.12*) Designed To Treat Neuropathy Advances In Clinical Trials

https://news.stonybrook.edu/newsroom/press-release/, January 17, 2025

A non-opioid investigational drug with promising pre-clinical results in treating neuropathic pain has passed an important hurdle after the study's safety review committee (SRC) reviewed the data from initial volunteers and recommended to progress into the next dose level in a first-in-human clinical trial.

The drug, **ART26.12**, originally developed at Stony Brook University, is now in clinical development at Artelo Biosciences, Inc, based in Solana Beach, Calif. The technology is based on a class of fatty acid binding proteins (FABPs) inhibitors, including what is now ART26.12, and was licensed to Artelo in 2018 by the Research Foundation for the State University of New York. ART26.12 is being developed for **chemotherapy-induced peripheral neuropathy – specifically Oxaliplatin-induced peripheral neuropathy (OIPN**), which remains a serious adverse problem for patients during cancer therapy and post therapy.

The SRC completed its initial clinical safety review of ART26.12 in early January for the first cohort of eight volunteers. With that, the phase 1 clinical trial of this drug will advance to the next step, which will include more subjects and an evaluation of higher doses of the investigational drug.

Mutations Of The SCN9A Gene

Mutations of the *SCN9A* gene can cause pain conditions such as small fiber neuropathy (SFN) and erythromelalgia (EM). This gene provides instructions for the sodium channel Nav1.7, which is crucial for pain sensation. Variants in *SCN9A* can lead to malfunctioning of these channels, causing them to remain overly active, leading to increased pain signals and neuropathic pain.

Types of SCN9A Related Neuropathies

SCN9A neuropathic pain syndromes (SCN9A-NPS) comprise SCN9A erythromelalgia (EM), SCN9A paroxysmal extreme pain disorder (PEPD), and SCN9A small fiber neuropathy (SFN).

- ***SCN9A*-EM** is characterized by recurrent episodes of bilateral intense, burning pain and redness, warmth, and occasionally swelling. While the feet are more commonly affected than the hands, in severely affected individuals the legs, arms, face, and/or ears may be involved.
- ***SCN9A*-PEPD** is characterized by neonatal or infantile onset of autonomic manifestations that can include skin flushing, harlequin (patchy or asymmetric) color change, tonic non-epileptic attacks (stiffening), and syncope with bradycardia. Later manifestations are episodes of excruciating deep burning rectal, ocular, or submandibular pain accompanied by flushing (erythematous skin changes).
- ***SCN9A*-SFN** is characterized by adult-onset neuropathic pain in a stocking and glove distribution, often with a burning quality; autonomic manifestations such as dry eyes and/or mouth, orthostatic dizziness, palpitations, bowel or bladder disturbances; and preservation of large nerve fiber functions (normal strength, tendon reflexes, and vibration sense).

Treatment Management

Most affected individuals are treated in dermatology clinics, neurology clinics, or pain clinics, or by anesthesiologists specializing in the management of chronic pain.

- ***SCN9A*-EM**. Cooling the extremities reduces pain; note that use of a fan is preferable to prolonged immersion in cold water, which can result in skin maceration, infection, and gangrene. Medications to consider are nonselective sodium channel blockers (e.g., carbamazepine, lidocaine infusion, or oral mexiletine).
- ***SCN9A*-PEPD.** Use of stool softeners and passing stool slowly to reduce the likelihood of triggering an attack. Carbamazepine is the most effective (albeit not completely effective) treatment in reducing the number and severity of attacks. Other anti-seizure medications with varying effectiveness include lamotrigine, topiramate, tiagabine, and sodium valproate.
- ***SCN9A*-SFN.** Lacosamide is associated with reduced pain ratings, improved general well-being and sleep quality, but not with changed overall quality of life or autonomic manifestations.

Agents/circumstances to avoid: Triggers including warmth, standing, alcohol, and spicy foods (*SCN19A*-EM); defecation, cold wind, eating, and emotion (*SCN9A*-PEPD); diabetes mellitus, alcohol, and chemotherapy (*SCN9A*-SFN).

Genetic counseling

SCN9A neuropathic pain syndromes (NPS) are inherited in an autosomal dominant manner. Each child of an individual with an NPS-causing variant in *SCN9A* has a 50% chance of inheriting the variant. Once the *SCN9A* pathogenic variant has been identified in an affected family member, prenatal testing for a pregnancy at increased risk and preimplantation genetic testing are possible.

Reference

Hisama FM, Dib-Hajj SD, Waxman SG. SCN9A Neuropathic Pain Syndromes. 2006 May 6 [Updated 2020 Jan 23]. GeneReviews® [Internet]. Available from: *https://www.ncbi.nlm.nih.gov/books/NBK1163/*

I Finally Found My Groove

Michael Wright, Founder of PERIPHERAEUROPATHY SUCCESS STORIES (Facebook Group), Charlotte, NC

Shortly after my diagnosis of idiopathic sensorimotor peripheral neuropathy, my neurologist looked at me one day and said, "you will eventually find your groove." I hardly believed her, based on the severe pain that I had in my feet and legs. My calf muscles were twitching like crazy and my feet hurt so bad that I could barely walk across my back yard. My usual cheerful approach to life was fading away and I was becoming someone that I barely recognized.

I certainly didn't think I would find my groove, after fruitless trips to the Mayo Clinic and multiple local specialists of every kind. My kitchen cabinet looked like a pharmacy – filled with so many supplements and prescription drugs, even an opioid. I even had a stash of cannabis, as three different specialists suggested that I try it. (Note: I had never used cannabis in any form prior to this time, so this was somewhat radical for me!) I was getting acupuncture, medical massages, red laser light sessions, physical therapy, and even hypnosis! I began swimming, at the recommendation of my neurologist. Unfortunately, nothing was having any lasting positive impact and my disposition was souring quickly.

The breakthrough came for me about seven long and grueling years after my diagnosis. I was seeing a pain specialist regularly, since I was taking an opioid and had to be followed. During one of my appointments, a seasoned physician assistant asked me if I had ever tried **Low Dose Naltrexone**. I told him that I had not, but that I knew about it and would be very willing to try it. He prescribed it and told me that it would take a full ninety days to determine if it would work. I left his office dubious, but hopeful.

So, this was the moment that I was finally on the way to finding my groove! After almost exactly ninety days of taking LDN, I was **pain free and getting my life back**! I stopped taking the opioid and was able to wean off Gabapentin. I stopped taking all supplements, never having been convinced that any of them worked.

Low Dose Naltrexone has seriously been my miracle drug. I started at a very low dose and now take 6mg each day, still considered a low dose. It works so well for me that I was able to walk over 3,025 miles last year! This year, I have been walking about six miles per day and have so many hobbies that I run out of hours in each day. My life is full and happy, but I never lose sight of where I have come from and how I felt just a few years ago.

While I realize that not every treatment modality works for every person, I suggest trying everything possible. What works for you may not work for me, and what works for me may not work for you. We owe it to ourselves to keep trying all the options, I believe. LDN is one option that you might consider. My hope is that you, too, will have a breakthrough moment and find your own groove.

By the way - after my diagnosis, I wanted to connect with others who would understand my plight. I looked at multiple PN support groups on Facebook, but they all seemed negative and less than uplifting. So, I founded **PERIPHERAL NEUROPATHY SUCCESS STORIES**, with the goal of educating, inspiring, and offering positive support to people with neuropathy. I, along with a team of outstanding group moderators, try hard to keep the group different from the others. We monitor every post and stay determined to keep a positive tone in the group. Today, we have almost 48,000 members in over 100 countries across the world. Please join us, if you haven't already!

Michael Wright is a former District Sales Manager for a large pharmaceutical company. He has been retired for nine years and was happy to hang it up a bit early. Michael resides in the Charlotte, NC area with his husband, John, who is a retired pediatrician. Together, they care for Michael's 91-year-old mother and their two-year old Cotonoodle dog, Dudley Doo. When Michael is not out walking, he is either gardening, going to thrift stores, reading, or managing his gazillion Facebook groups.

Positive And Negative Symptoms Of Neuropathy

Sensory symptoms are usually the first symptoms of neuropathy and include positive (burning, pain, walking on cotton wool, band-like sensation on feet or trunk, stumbling, tingling, pins and needles) and negative symptoms (numbness, loss of sensation) in hands and feet. *(Editor - You can think of it as positive symptom is something added and negative is taken away.)*

Reference

Misra, U. K., Kalita, J., & Nair, P. P. (2008). Diagnostic Approach To Peripheral Neuropathy. *Annals of Indian Academy of Neurology, 11*(2), 89–97. *https://doi.org/10.4103/0972-2327.41875*

Men And Women Use Different Biological Systems To Reduce Pain

Miles Martin, *universityofcalifornia.edu*, October 17, 2024 (submitted by Darrell O'Sullivan WNA Vice President)

The experience of pain is a unique combination of physical sensation, state-of-mind, and neurological activity. The brain also helps mediate pain relief, and UC San Diego researchers have found that pain relief processes in the brain differ between men and women.

In a new study evaluating meditation for chronic lower back pain, researchers at University of California San Diego School of Medicine have discovered that men and women utilize different biological systems to relieve pain. While men relieve pain by releasing endogenous opioids, the body's natural painkillers, women rely instead on other, non-opioid based pathways.

Synthetic opioid drugs, such as morphine and fentanyl, are the most powerful class of painkilling drugs available. Women are known to respond poorly to opioid therapies, which use synthetic opioid molecules to bind to the same receptors as naturally-occurring endogenous opioids. This aspect of opioid drugs helps explain why they are so powerful as painkillers, but also why they carry a significant risk of dependence and addiction.

"Dependence develops because people start taking more opioids when their original dosage stops working," said Fadel Zeidan, Ph.D., professor of anesthesiology and Endowed Professor in Empathy and Compassion Research at UC San Diego Sanford Institute for Empathy and Compassion. "Although speculative, our findings suggest that maybe one reason that females are more likely to become addicted to opioids is that they're biologically less responsive to them and need to take more to experience any pain relief."

The study combined data from two clinical trials involving a total of 98 participants, including both healthy individuals and those diagnosed with chronic lower back pain. Participants underwent a meditation training program, then practiced meditation while receiving either placebo or a high-dose of naloxone, a drug that stops both synthetic and endogenous opioids from working. At the same time, they experienced a very painful but harmless heat stimulus to the back of the leg. The researchers measured and compared how much pain relief was experienced from meditation when the opioid system was blocked versus when it was intact.

The study found:

- Blocking the opioid system with naloxone inhibited meditation-based pain relief in men, suggesting that **men rely on endogenous opioids to reduce pain.**
- Naloxone increased meditation-based pain relief in women, suggesting that **women rely on non-opioid mechanisms to reduce pain.**
- In both men and women, people with chronic pain experienced more pain relief from meditation than healthy participants.

"These results underscore the need for more sex-specific pain therapies, because many of the treatments we use don't work nearly as well for women as they do for men," said Zeidan. The researchers conclude that by tailoring pain treatment to an individual's sex, it may be possible to improve patient outcomes and reduce the reliance on and misuse of opioids. "There are clear disparities in how pain is managed between men and women, but we haven't seen a clear biological difference in the use of their endogenous systems before now," said Zeidan. "This study provides the first clear evidence that sex-based differences in pain processing are real and need to be taken more seriously when developing and prescribing treatment for pain."

Simplistic Difference Between Demyelinating Neuropathy And Axonal Neuropathy

AXONAL NEUROPATHY

Pathophysiology: The primary injury is to the nerve fibers (axons) themselves, leading to a decrease in the number of functioning axons.
Clinical Presentation: Symptoms are related to axon loss, such as numbness, burning, and tingling, often affecting longer, distal nerves first. Motor involvement can lead to weakness and muscle atrophy.
Causes: A broad range of systemic illnesses and conditions, such as diabetes and chronic alcohol use.

DEMYELINATING NEUROPATHY

Pathophysiology: The myelin sheath surrounding the nerve fibers is damaged, impairing the ability of the nerve impulse to travel efficiently.
Clinical Presentation: Tends to affect larger nerve fibers first, leading to more prominent muscle weakness and potentially slower progression than axonal damage.
Causes: Can be immune-mediated (like CIDP), toxic, or hereditary.

WESTERN NEUROPATHY ASSOCIATION
A California public benefit, nonprofit, tax exempt corporation

P.O. Box 4740, Auburn, CA 95604

Call WNA using our toll free phone number:
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www.pnhelp.org

With Hope from the Western Neuropathy Association

In This Issue

Dear Readers,

A good example (or maybe a bad example?) of how slowly research progresses is the **Page 4** article about **drug ART26.12.** The drug was developed at the State University of New York, then licensed for development to Artelo in 2018. A Phase 1 clinical trial was completed this year in January – seven years later. Research and development does more slowly – but it moves. This drug is for pain from chemotherapy-induced peripheral neuropathy.

A **genetic cause of peripheral neuropathy** is discussed on **Page 5**. The gene *SCN9A* provides instruction to Nav1.7, a sodium channel for pain sensation. When this gene is mutated, the channel malfunctions causing more pain. ***SCN9A* mutations** can also lead to erythromelalgia and paroxysmal extreme pain disorder.

For another success story with **Low Dose Naltrexone**, on **Page 6** read Michael Wright's (Founder of Peripheral Neuropathy Success Stories on Facebook) journey to becoming **pain free** after trying numerous treatments to alleviate his symptoms. Note it took him a full 90 days before he started experiencing results!

May these give you Hope.
..Katherine
klstenzel@hotmail.com

Western Neuropathy Association (WNA)
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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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