



JUNE 2025

Issue 05

Volume 23

Can Gene Therapy Treat Chronic Pain?

Shana Resigns Her Position On The Board Of Directors

Peripheral Neuropathy Support Groups – June 2025 Schedule

From The President

Types Of Diabetic Neuropathy

Distinguishing Fibromyalgia Syndrome From Small Fiber Neuropathy

Evening Primrose Oil Benefits and Risks

Letter to the Editor

June Webinar - Cannabinoids

Communication Guide For Your Next Clinical Visit

In This Issue

Platinum Transparency 2024

Candid.

Awarded by GuideStar®
2024 Guidelines
Certification

WESTERN
NEUROPATHY ASSOCIATION
P.O. Box 4740
Auburn, CA 95604
888-556-3356
info@pnhelp.org
www.pnhelp.org

CELEBRATING OUR 27TH YEAR!

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

CAN GENE THERAPY TREAT CHRONIC PAIN?

Carmen Leitch; lapboots.com; December 22, 2024

Sometimes pain is a necessary warning signal; for example, if we touch something very hot and it burns, we know to move our hand away. But chronic pain can destroy a person's quality of life, and it can be extremely challenging to get relief. Some researchers have been searching for ways to deactivate pain receptors, so the body no longer feels the neural signals of chronic pain. Using mouse models of acute inflammatory pain, scientists have shown that it is possible to deactivate pain receptors with genetic engineering tools. The work has been reported in *Cell*.

"What we have developed is potentially a gene therapy approach for chronic pain," said senior study author Bryan L. Roth, MD, PhD, a distinguished professor at the University of North Carolina (UNC) School of Medicine, among other appointments. "The idea is that we could deliver this chemogenetic tool through a virus to the neurons that sense the pain. Then, you could just take an inert pill and turn those neurons off, and the pain will literally disappear."

This study took advantage of chemogenetic technology, which was applied to the peripheral nervous system in a major breakthrough. The researchers based this effort on the hydroxycarboxylic acid receptor 2 (HCA2), which has been associated with inflammation. These receptors are only expressed in the peripheral nervous system, and they can typically bind to vitamin B3.

In this work, the scientists made alterations to HCA2 receptors so they would instead bind only to a molecule called FCH-2296413. This compound is meant to have no effect, and act only in the peripheral nervous system. The intent is to disrupt the action of pain receptors and make it more difficult for pain signals to move from sensory neurons in the peripheral nervous system to the spinal cord and brain. The mHCA2 system reduces the chemical and electrical signals coming from sensory neurons, and stronger signals are then needed to cause pain to be perceived. This was achieved using an adeno-associated virus (AAV), which infects cells not to cause harm or disease, but in this case, to deliver the therapeutic mHCA2 into the proper neurons.

This study was only a proof-of-concept, and more research will be needed to show that it could be safe and effective in humans. But it is a very important step on the path to treating chronic pain in a totally new way, which aims for the pain receptors themselves. This research is also a small part of an effort to learn more about all of the different types of neurons in the peripheral nervous system.

REFERENCE

Kang, Hye Jin et al. (2024) Structure-Guided Design Of A Peripherally Restricted Chemogenetic System. *Cell*, 187(26), 7433 - 7449. DOI: 10.1016/j.cell.2024.11.001

SHANA RESIGNS HER POSITION ON THE BOARD OF DIRECTORS.

Due to medical issues, Shana (Phelps) has resigned her position on the Board of Directors. The Board thanks her (along with Erika and Brian) for leading the website transition to give our digital presence a clean, new look. Shana also brought our new support group, 2nd Tuesday, into the WNA community when they needed help with their meeting platform. She will be greatly missed in the support groups with her quick typing in Chat and wealth of knowledge about neuropathy. The Board, WNA members and support group attendees wish her the best with her doctor appointments, tests and treatments. Warm hugs from us all!

**2025
WNA BOARD
OF DIRECTORS**

PAM HART
PRESIDENT
pamhart@pnhelp.org

DARRELL O'SULLIVAN
VICE PRESIDENT AND TREASURER
dosully@comcast.net

GLENN RIBOTSKY
SECRETARY
glennrtaj@gmail.com

KATHERINE STENZEL
DIRECTOR, EDITOR
klstenzel@hotmail.com

JOHN PHILLIPS
DIRECTOR
johnphillips@pnhelp.org

ERIKA MCDANNELL
DIRECTOR
ejmcdannell@pnhelp.org

SAMANTHA FIELDS
DIRECTOR
samanthafields@pnhelp.org

KRIS LANGENFELD
DIRECTOR
kris.langenfeld@gmail.com

BRIAN LOCKARD
DIRECTOR AND MEMBERSHIP
brianlockard@pnhelp.org

ADMINISTRATION
info@pnhelp.org

EMERITUS COUNCIL

BEV ANDERSON

MICHAEL GREEN

SHANA PHELPS

MARTIN PRICE

WNA ASSISTANCE LINE
833-980-4181

KATHERINE STENZEL
EDITOR

Newsletter Design by
Diane Blakley Designs

PERIPHERAL NEUROPATHY SUPPORT GROUPS – JUNE 2025 SCHEDULE

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

	1st Wednesday Strategies for Singles with Neuropathy Support Group 1st Wednesday of the odd months, next meeting July 2 Host – Erika McDannell, contact Erika for Zoom link
In-Person 2 Monday	Auburn CA Peripheral Neuropathy Support Group 12 noon - 1:30pm Pacific Unity of Auburn, 1212 High Street, Auburn, CA Host – Pam Hart, pamhart@pnhelp.org , and Cass Capel, cassbrownncapel@me.com
In-Person 7 Saturday	Houston TX Peripheral Neuropathy Support Group 1st Saturday of the last month in each quarter 1 – 2:30pm Central Memorial Drive United Methodist Church, 12955 Memorial Drive Room DS100, enter at back (south) of building, follow signs Hosts – Katherine Stenzel, John Phillips and Brian Lockard
Virtual 10 Tuesday	2nd Tuesday Peripheral Neuropathy Support Group 2pm Pacific / 3pm Mountain / 4pm Central / 5pm Eastern (90 minutes long) Meeting ID: 980 2190 9000 / Passcode: 784590 Contact Katherine For Zoom link (everyone welcome, Colorado focus on healthcare providers)
Virtual 11 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 14 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 18 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 18 Wednesday	3rd Wednesday CIDP and Autoimmune Support Group 3pm Pacific / 4pm Mountain / 5pm Central / 6pm Eastern (1 hour long) Host - John Phillips, contact John for Zoom link
Virtual 28 Saturday	4th Saturday Peripheral Neuropathy Open Discussion 11am Pacific / noon Mountain / 1pm Central / 2pm Eastern (2 hours long) Meeting ID: 851 7949 9276 / Passcode: 159827 Host - John Phillips, contact Katherine for Zoom link

Contact emails in the sidebar Board of Directors listing.

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

FROM THE PRESIDENT Pam Hart, WNA President

Say Something Nice Day: Spreading Kindness One Word at a Time

In a world where the hustle and bustle of daily life can sometimes feel overwhelming, it's easy for people to forget how much the simple act of kindness can mean. When I came across this listing, I was excited. This is just what we need. Celebrated annually on June 1st, Say Something Nice Day, can serve as a reminder to pause, reflect, and spread positive words. But why limit it to one day a year?

The Power of Words

Words are powerful. They have the ability to build, inspire, heal, and uplift. A kind word at the right moment can make someone's day, change their perspective, or even alter the course of their life. Think about it—how often have you been in a difficult situation and someone said something to you that gave you the strength to push through? That's the magic of kindness in words.

Words are powerful.
They have the ability
to build, inspire, heal,
and uplift.

Conversely, words can also hurt. A sharp comment or a negative remark can stay with someone long after the conversation ends. Say Something Nice Day reminds us that words, when used with care, can leave a lasting impact—just like a kind gesture or a thoughtful action. When was the last time you told your significant other, "I Love You"?

As a person on their second marriage, I have learned that communication is the key. After my first husband died, I couldn't imagine 'interviewing' a new prospect. We started our relationship with a question a day that we both had to answer – even write down. One of the questions was "what do you fear most in this new relationship?". I answered, "saying the wrong thing at the wrong time, being too curt and condescending". Even then I knew that criticism and judgement often shared in the name of humor can sometimes go too far.

Why Celebrate Say Something Nice Day?

Here are a few reasons why celebrating Say Something Nice Day is important:

- 1. Boosts Mental Health** Receiving kind words can boost self-esteem and improve overall mental health. It shows others that they are seen and appreciated, which can foster a sense of belonging. For those who are struggling, a kind word can be a powerful source of comfort.
- 2. Strengthens Relationships** Positive reinforcement strengthens the bond between friends, family, colleagues, and even strangers. Taking the time to acknowledge someone's good qualities or to compliment their efforts can deepen relationships and make individuals feel valued. Just acknowledging that the other person is 'appreciated' goes a long way.

How to Celebrate Say Something Nice Day

Celebrating Say Something Nice Day doesn't require grand gestures—sometimes, the most impactful things are the smallest. Here are a few ideas to get started: compliment a stranger, write a thoughtful note, put a shout-out on social media, thank someone, encourage others.

The next time you're faced with a choice of whether to speak or remain silent, remember: it only takes a moment to say something nice, but the impact can last a lifetime.

Thank you for being members of WNA. You are appreciated.

Cheers,

Pam

pamhart@pnhelp.org

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](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.

TYPES OF DIABETIC NEUROPATHY

HealthCentral.com, February 19, 2021

(Editor – these descriptions can also apply to other forms of neuropathy.)

Diabetic neuropathy can be broken into several types. This is because we have different kinds of nerves in our bodies that serve different functions. Your symptoms and treatments depend on which type of diabetic neuropathy you have.

There are four types of diabetic neuropathy:

- **Peripheral neuropathy** (also called **diabetic nerve pain** and **distal polyneuropathy**)
- **Proximal neuropathy** (also called **diabetic amyotrophy**)
- **Autonomic neuropathy**
- **Focal neuropathy** (also called **mononeuropathy**)

Peripheral Neuropathy

Peripheral diabetic neuropathy goes by various names: peripheral diabetic nerve pain and distal polyneuropathy. Peripheral neuropathy is the most common form of neuropathy caused by diabetes. It affects **nerves leading to your extremities**—to your feet, legs, hands, and arms. The nerves going to your feet are the longest in your body. After they branch off the spinal cord in the lumbar region (low back), they have to go all the way down your legs and into the feet—quite a distance.

Because the nerves leading to your feet are so long, it's most often these nerves that are damaged; there's more of them to be damaged. This nerve damage can lead to the foot problems often associated with diabetes, including deformities, infections, ulcers, and amputations.

Proximal Neuropathy

Proximal neuropathy can also be called diabetic amyotrophy. That *myo* in the word means muscle, so this is a form of neuropathy that can cause **muscle weakness**. It specifically affects the muscles in the upper part of your leg(s), buttocks, and hips. Sometimes, proximal neuropathy can also involve nerve pain, especially pain that shoots from the low back and down the leg. The technical medical term for that is radiculopathy, although most people refer to it as sciatica. If there's also shooting nerve pain involved, this form of neuropathy can be called polyradiculopathy-diabetic amyotrophy.

Proximal neuropathy is the second most common type of diabetic neuropathy (second only to peripheral diabetic neuropathy). It usually affects elderly people with diabetes; as opposed to peripheral neuropathy, it usually resolves with time or treatment.

Autonomic Neuropathy

Autonomic nerves are supposed to **keep your body running as it should**. There are many functions that happen in your body without you thinking about them: your heart pumps, you breathe, and your stomach digests food. Those actions are controlled by the autonomic nervous system; it's also sometimes called the automatic nervous system. The autonomic nervous system should maintain your body's homeostasis, which is its normal, balanced state. If the autonomic nerves are damaged by the effects of diabetes—autonomic diabetic neuropathy—then your body may have trouble maintaining homeostasis.

Autonomic neuropathy can seem daunting because it can affect so many of your body's systems, from your digestive tract to how well you can see. However, remember that your symptoms depend on what specific nerves in the autonomic nervous system are damaged.

Focal Neuropathy

All of the types of diabetic neuropathy above—peripheral, autonomic, and proximal—are examples of polyneuropathy. *Poly* means that they affect many nerves. Focal neuropathy, by contrast, affects one specific nerve; it's *focused* neuropathy. It can also be called **mononeuropathy**. Focal neuropathy, which comes on suddenly, most often affects nerves in the head (especially ones that go to the eyes). It can also affect the torso and legs.

When focal neuropathy affects the legs, it has different symptoms than proximal neuropathy, which can also affect the legs. Proximal neuropathy causes muscle weakness in the legs, and it may also cause shooting pain down the leg. Focal neuropathy, however, causes pain in very specific locations on the legs.

DISTINGUISHING FIBROMYALGIA SYNDROME FROM SMALL FIBER NEUROPATHY

(Editor - Refer to the digital version of this newsletter to view Figure 1 in color or send me an email and I will email you the color page.)

Introduction Fibromyalgia syndrome (FMS) and small fiber neuropathy (SFN) are distinct pain conditions that share commonalities and may be challenging as for differential diagnosis.

Objective To comprehensively investigate clinical characteristics of women with FMS and SFN to determine clinically applicable parameters for differentiation.

Methods We retrospectively analyzed medical records of 158 women with FMS and 53 with SFN focusing on pain-specific medical and family history, accompanying symptoms, additional diseases, and treatment. We investigated data obtained using standardized pain, depression, and anxiety questionnaires. We further analyzed test results and findings obtained in standardized small fiber tests.

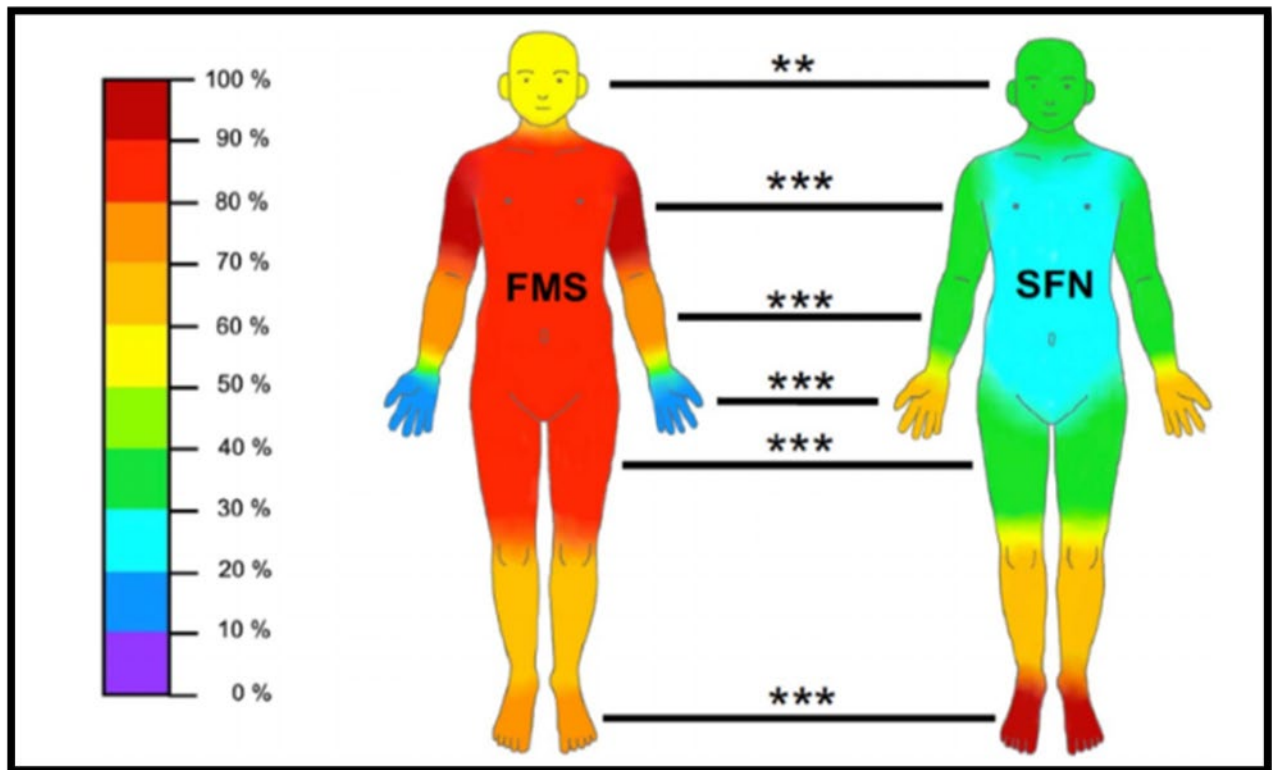


Figure 1. Proportion of patients who reported pain in distinct body areas. The graph depicts the frequency of pain reported in distinct body areas in relation to the FMS and SFN patient groups.

Results

- FMS patients were on average ten years younger at symptom onset, described higher pain intensities requiring frequent change of pharmaceuticals, and reported generalized pain compared to SFN.
- Pain in PFM was generalized and variable, while mainly focal and constant in SFN.
- Pain in FMS was accompanied by irritable bowel or sleep disturbances, and in SFN by paresthesias, numbness, and impaired glucose metabolism.
- Family history was informative for chronic pain and affective disorders in FMS and for neurological disorders in SFN patients.
- Small fiber pathology in terms of skin denervation and/or thermal sensory threshold elevation was present in 110/158 (69.7 %) FMS patients and 39/53 (73.6 %) SFN patients.
- FMS patients mainly showed proximally reduced skin innervation and higher corneal nerve branch densities whereas SFN patients were characterized by reduced cold detection and prolonged electrical A-delta conduction latencies.

Conclusions Our data show that FMS and SFN differ substantially. Detailed pain, drug and family history, investigating blood glucose metabolism, and applying differential small fiber tests may help to improve diagnostic differentiation and targeted therapy.

REFERENCE

Sarah Jänsch, S. et al. (2024). Distinguishing Fibromyalgia Syndrome From Small Fiber Neuropathy: A Clinical Guide. *PAIN Reports* 9(1):e1136. DOI:10.1097/PR9.0000000000001136

EVENING PRIMROSE OIL BENEFITS AND RISKS

Carla Eisenstein, PharmD; *verywellhealth.com*; March 17, 2025

Evening primrose oil is extracted from the seeds of *Oenothera biennis*, a plant native to North America and South America. It gets its name from its yellow blossoms, which bloom in the evening. The oil contains linoleic acid, gamma-linolenic acid (GLA), and other omega-6 fatty acids. The evidence for using evening primrose oil as a treatment is supported by small, preliminary studies and reviews of those studies.

Diabetic Neuropathy

In a 12-week study, 73 participants with diabetic neuropathy took GLA, alpha lipoic acid, or a placebo. Both treatment groups reported decreased pain and total symptoms compared to the placebo group. However, there was not a statistically significant difference between the two treatment groups.

Another 12-month study used vitamin E and evening primrose oil to treat 80 people with painful diabetic neuropathy. The researchers concluded that evening primrose oil combined with vitamin E improved pain in 88% of the participants.

These studies were small and used combination treatments rather than just evening primrose oil, so the results are not significant enough to prove that evening primrose oil on its own can treat diabetic neuropathy.

Side Effects

Shorter studies have noted some side effects such as upset stomach, bloating, headache, nausea and altered taste, diarrhea, and seizure. Most of the side effects are mild and get better on their own once the treatment is stopped.

Precautions

Evening primrose oil may increase the risk of bleeding. If you have a bleeding disorder, be very careful if you use evening primrose oil. If you are having surgery, tell your provider who might want you to stop taking evening primrose.

When choosing a supplement, look for independently tested products and consult a healthcare provider, registered dietitian nutritionist (RD or RDN), or pharmacist. It's important to always tell your healthcare provider about all the supplements you take. They can help make sure they won't interact with any medications or conditions you have.

LETTER TO THE EDITOR

Hello Katherine,

I want to thank you for the article "Magnesium And Gabapentin" in the August 2024 issue of *Neuropathy Hope*.

The thing is I thought I was OK taking my Gabapentin at night before bedtime. The instructions about Gabapentin only referenced antacids as having magnesium in it. So, no problem since I rarely take antacids. Then recently, I was reading the label of my Glucosamine & Chondroitin supplement and saw that it contains Magnesium! I have been taking this supplement with my Gabapentin for the last 5 years. So it's no wonder that I would wake up 2 - 3 times in the night and my feet were so agitated (and I would go rock in my rocking chair for about 20 min). I immediately switched to taking the Glucosamine & Chondroitin with my mid-day supplements. And guess what? I am sleeping pretty darn solid through the night with only 1 wakeup to use the toilet. And I can get back to sleep without my feet bothering me. It's been about 3 weeks now. I needed to tell you how much this article has made such an impact on my life and quality of sleep.

Keep up the good work. I appreciate you and all that you do.

Karen C. Hewitt
January 30, 2025

JUNE WEBINAR - CANNABINOIDS

Join us on June 26 to learn how cannabinoids can improve neuropathic pain.

"A recent review of 14 randomized clinical trials (published November 2024) found that cannabis-based medicines are a potentially effective emerging drug class in the treatment of peripheral neuropathy via reducing neuropathic pain and related symptoms."

Reference: Choi, J., et. al. (2024). The Use Of Cannabinoids In The Treatment Of Peripheral Neuropathy And Neuropathic Pain: A Systematic Review. *The Journal of Hand Surgery*. <https://doi.org/10.1016/j.jhsa.2024.09.015>

Communication Guide... for your next CLINICAL VISIT

Learn



Document



Communicate



Plan



Adhere

I would like to discuss _____
(#1 health concern)

1. List your 3 main symptoms of your #1 health concern?

- Symptom 1 _____
- Symptom 2 _____
- Symptom 3 _____

2. My current treatment(s) are... (Circle One)

1. working
2. need improvement. Why? _____
3. completely unsatisfactory. Why? _____
4. I don't have a treatment or can't access treatment.

3. What is our treatment goal(s)?

4. Shared Decision-Making Speaking Points

1. I appreciate us working together to form a healthcare plan.
2. I am ready to adhere to the plan.
3. I will do my part by...
 1. exercising and eating healthy
 2. documenting progress and concerns
 3. Other: _____

5. When do you want to schedule a follow-up visit?

- ____ / ____ / ____

TheACPA.org



ACPA®
American Chronic Pain Association





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:

(888) 556-3356 • info@pnhelp.org

www.pnhelp.org

June 26th Webinar:

• CANNABINOIDS •

See page 6 for more information

IN THIS ISSUE

Dear Readers,

Research for chronic pain IS happening. This month's **front-page article** highlights the University of North Carolina's School of Medicine's study on **deactivating the body's pain receptors** so a person will not actually feel the chronic pain. This concept was tested on mouse models with positive results! While more research is needed to show it could be safe and effective for humans, the mouse model is the first step for a proof-of-concept of a totally new way to treat pain.

Last month's issue described the difference between Peripheral Neuropathy and Multiple Sclerosis. This month the descriptive analysis is between Small Fiber Neuropathy and Fibromyalgia. **Page 5 has a colored body graphic depicting the frequency of pain from both diseases.** Typically Small Fiber Neuropathy pain is focused in the feet, then legs and hands. For Fibromyalgia, the trunk and upper arms have the most pain.

Page 7 has a new form to use for talking with your healthcare team. This guide from the American Chronic Pain Association (theacpa.org) is simple with only 4 items to detail. To download the form, you can either print the page if you have the digital newsletter version or find the form on the website at www.pnhelp.org, hover over Resources and click on Peripheral Neuropathy Patient Toolkit. After the page opens, click on the plus sign by Dialogue with Health Care Team, and look for Communication Guide. OR – send me an email!!

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

P.O. Box 4740, Auburn, CA 95604

(888) 556-3356

www.pnhelp.org

WNA Headquarters: info@pnhelp.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.