

# PN News

Yolo County

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<https://www.FoundationforPN.org>

Webmd.com



**FYI – Davis will not meet in March due to surgery.**

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. The Western Neuropathy Association (WNA) and the Yolo Neuropathy Groups (PN News) do not endorse any treatments, medications, articles, abstracts or products discussed herein.



Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no help at all.

Dale Carnegie

## DAVIS

**TUESDAY, FEBRUARY 14, 3:30 – 5:00 p.m.**

**Program:** DVD: *Peripheral Neuropathy: What it is and What Can Be Done About It.* Featuring Peter. T. Skaff M.D.

Davis Senior Center

646 A Street, Davis, 95616

Call: Mary Sprifke (530) 756-5102 or

Retta Gilbert at (530) 747-0186

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**WOODLAND – NO MEETING, NO LEADER(S)**

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## SACRAMENTO

**TUESDAY, FEBRUARY 21, 1:30-3:30 p.m.**

**Program:** Mallory Tomei, Information and Resource Specialist with Eskaton, will highlight "Community Resources."

Northminster Presbyterian Church

3235 Pope Avenue, Sacramento, CA 95825

Call: Charles Moore (916) 485-7723



## MEETING RECAPS



### DAVIS JANUARY NOTES

By Mary Sprifke

Sometimes a good meeting just can't be captured in note form. In our group, two new attendees had great questions and the flow felt more like a friendly dinner conversation, with each participating. Two suggestions for future meetings were to ask Debbie Eernise to return with her engaging program on exercise and balance and also to once again show the DVD: *Forks Over Knives*. Empathy and humor plus hints for life-style changes were the take-away gifts. If you missed it we hope to see you next time.

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### SACRAMENTO JANUARY NOTES

By Charles Moore

Dr. Karen Romines, podiatrist, shared practical advice for living with PN, including shoes with deep toe boxes and Edema Care Shoes. She also recommended SAS shoes and Foot Smart Shoes online and Power Steps orthotics also online. She suggested urea creams with salicylic acid and lamb's wool between toes.

She reviewed a new book called *Walking Well Again: Neutralize the Hidden Causes of Pain*, by Stuart Goldman, DPM and introduced his claim that spinal stenosis is a principal cause of peripheral neuropathy. This intrigued me because a recent X-ray of my spine revealed that I have spinal stenosis in at least one or two places, so I bought the book and now present my own report.

Goldman makes many claims that seem to be doubtful. With spinal stenosis patients, he has them lean forward to alleviate pain by causing "lumbar sacral flexion" or opening the spine. He says using a walker, a grocery cart or a treadmill can bring very quick relief from stenosis; however the opposite is true for me. I find that my pain increases if I lean forward and hold that position for any length of time.

Spinal stenosis is a narrowing of the open spaces within your spine, which can put pressure on your spinal cord and the nerves that travel through the spine to your arm and legs. It occurs most often in the lower back and the neck and is most commonly caused by wear-and-tear related to osteoarthritis. Clearly spinal stenosis is a very likely cause of peripheral neuropathy.

He describes varying symptoms using confusing terms he's coined, such as 'PseudoStenosis' or PS. He says that many patients may exhibit either Spinal Stenosis SS or PS or both. PS is caused, at least partly, by anatomic changes or function in the lower extremities (and thus outside the spine), which lead to positional changes inside the spine. This is not clearly explained.

I think it is a serious defect that his book lacks documentation of other sources of information. At the very least, such a book should reference other studies. He also offered a 'pain scale' that is nothing short of 'Greek' to the reader.

Dr. Goldman, in order to make his points more persuasive, resorts to numerous "Story Time" examples of patients he has cured. Each is a narration that typically shows that the patient has unequal leg length, often as little as 1/8" to 1/4" (which is a very slight difference). He then offers a lift in the shorter leg and has the patient use a walker or grocery cart.

I do not recommend this book for someone who suffers from peripheral neuropathy and wants a clearer understanding of the cause of the problem.

Karen A. Romines, DPM  
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# Scrambler Therapy for Treating Neuropathic Pain

by Dr. Thomas J. Smith and Dr. Charles Loprinzi

From <https://www.FoundationforPN.org>

**Scrambler therapy** (sometimes Calmare scrambler therapy or Calmare Therapy) involves the use of electronic stimulation on the skin with the goal of overwhelming pain information with non-pain information. In a therapy session, "electrocardiographic-like pads are placed around the area of pain".

Scrambler therapy - Wikipedia -

[https://en.wikipedia.org/wiki/Scrambler\\_therapy](https://en.wikipedia.org/wiki/Scrambler_therapy)



## What is neuropathic pain, from the non-expert oncologist's point of view?

The way we think of it, pain is about the most protective instinct and impulse known to humans! If you touch a hot plate, you retract your hand even before you actually feel the pain. Then, the pain comes – very localized – such that you can plunge the hand into cold water. After that, usually the pain goes away and you can then blame your son-in-law for leaving the hot plate on. But sometimes, the pain signal gets stuck in the “on” position, even though your hand has healed. There has been some damage to the nerve endings, and they are continuing to send the “pain” impulse when it is not doing you any good. The pain pathways in the spinal cord and the brain actually get bigger and more active; neurologists call this “wind-up.”

Pain has come to the attention of most oncologists because we CAUSE it with chemotherapy agents; we call it **chemotherapy induced peripheral neuropathy (CIPN)**. For the unfortunate 40-70% of chemo patients who get CIPN, it can range from being a nuisance to being life-destroying. Our patients describe constant burning or pins-and-needles pain, with numbness and tingling. It starts in the

longest nerves that go to the hands and feet first, then progresses upstream. For many people it is just an inconvenience, and goes away in between chemo cycles and abates after treatment. But for others it persists for years.

Preventing or treating CIPN has been frustrating. We both were part of the American Society of Clinical Oncology panel that made national clinical practice guidelines for CIPN. There are no drugs proven to prevent it, and alpha-lipoic acid, Vitamin A, natural products, L-carnitine – things that help in other neuropathies – were no better than placebo. Only one drug is proven to help, duloxetine (Cymbalta), with a reduction in pain of about 1 point on a 10 point scale.

Of course, there are other neuropathic pains that oncologists know all too well. The pain from a pinched nerve leaving a collapsed or damaged vertebra, shooting down the leg. The pain after shingles, “post-herpetic neuropathy” that can last for years. The pain after chest surgery, or mastectomy, or radiation.

## What is Scrambler Therapy, and How Does it Work?

Scrambler Therapy (marketed as Calmare™ therapy in the United States) is a new type of pain relief that uses a rapidly changing electrical impulse to send a “non-pain” signal along the same pain fibers that are sending the “pain” stimulus. We got interested in Scrambler Therapy because we thought it MIGHT help CIPN patients, and Scrambler Therapy appeared to be non-toxic. It had been cleared for safety by the FDA in 2009.

We were skeptical, but we did a trial of Scrambler Therapy. We treated 16 patients with refractory CIPN (present for at least 6 months, and refractory to medications); the group had a 60% reduction in their CIPN pain – in 10 days of treatment. Of the 16 patients we treated, essentially all reported some benefit, including 4 whose pain resolved to “0.” Function improved in most

patients including less interference with walking and sleeping, for at least 3 months.

The setup is simple as shown in Figure 1 (Tom Smith’s legs). EKG electrodes are used to transmit the electrical impulses from a colored electrode to a black one, back and forth. The treatment is given for 30-45 minutes for up to 10 days in a row (excluding weekends). Our patients report a feeling like being bitten by electrical ants, or bee-stings. If the treatment is working, the sensation will change to a “hum” in the nerve and go to the ends of the nerve. We have to start above the painful area – remember, we are trying to replace the pain with a “non-pain” stimulus, and sometimes can work progressively down the legs and arms as pain relief occurs.

### Figure 1: A typical setup to treat “stocking and glove neuropathy”

Colleagues at Mayo Clinic were skeptical and repeated the study in a larger group of people with CIPN. Pachman, Loprinzi and colleagues at Mayo reported about a 50% reduction in pain, numbness and tingling lasting at least 3 months. Of note, there appeared to be a learning curve, with the later patients getting better and longer lasting pain relief.

We will be the first to note that Scrambler Therapy lacks the “Good Housekeeping Seal of Approval” of cancer treatments – the well-designed, large, high statistical power, randomized controlled trial. We are both doing randomized trials, comparing Scrambler Therapy to “sham” (electrodes in the wrong place” and to TENS (trans-cutaneous electrical stimulation).

That said, we are interested in treatments that might work and don’t cause side effects.

A recent review of at least 20 scientific reports noted no harm in any trial, with most reporting a substantial relief of pain. The two randomized trials comparing “sham” to real Scrambler Therapy showed a 50% reduction in low back pain, and a 91% reduction in pain from failed back syndrome, post herpetic neuropathy, and spinal cord stenosis. In all the trials, pain relief – if it happened – was obvious in the first 3 days, continued to get better, and usually lasted several months.

There are additional reports of Scrambler Therapy having success in cancer somatic pain including bone and visceral metastases, complex regional pain syndrome, pediatric cancer chest wall pain, and others (see list below). The US Military has 17 Scrambler Therapy machines for treating both wounded warriors and civilians.

## Some types of pain for which Scrambler Therapy has been used:

Pancreas and abdominal cancer pain

**Chemotherapy induced peripheral neuropathy**

Non cancer pain such as neuropathic back pain

Post-herpetic pain (shingles pain)

Bone metastase

Spinal cord stenosis

“Failed back syndrome” – after surgery, the back hurts worse

Complex regional pain syndrome

Post-mastectomy pain



## Is Scrambler Therapy Related to Anything Similar?

Scrambler Therapy looks superficially likes

**TENS** therapy. TENS applies similar electrodes on the skin and passes a pulse of electrical current between them. TENS is a completely different type of on-off current, and, classically, the effect wears off as soon as the electrodes are removed. When Scrambler Therapy works, it seems to reset or reboot the system for an extended period of time.

Spinal cord stimulation appears to have a same effect on pain that Scrambler Therapy appears to have. However, it involves putting electrodes on the spinal cord, and implantation of a pulse generator, similar to a pacemaker. It is also expensive – typically near \$100,000 for a trial, then surgery and the equipment. It can last for years.

## Is Scrambler Therapy Covered by Insurance?

Quick answer, no, not very well yet. They are waiting for more traditional evidence (unlike the U S Military!) Some places are doing it for free on the clinical trials listed on [clinicaltrials.gov](http://clinicaltrials.gov). There is a list of certified centers on the **Calmare website**. An increasing number of insurers are paying for Scrambler if the person and their doctor appeals with lots of evidence from the trials

above.

The machines themselves are expensive (\$105,000 was the last quote we got) but can be used for a new person each hour, and last for years. The electrodes cost \$4-15 dollars per person for a course of treatment. A person with training can do the treatment supervised by a physician with knowledge of the nervous system.

## What research needs to be done before Scrambler Therapy is proven effective, and reimbursed if it is?

We have been using Scrambler Therapy routinely at our centers, and believe there is benefit to some patients. At the same time, we are humbled by the many therapies that have shown promise in phase

II trials only to be no better than placebo or sham in Phase III trials. We need bigger randomized trials, sponsored by the NIH or someone who is not trying to sell the machines.

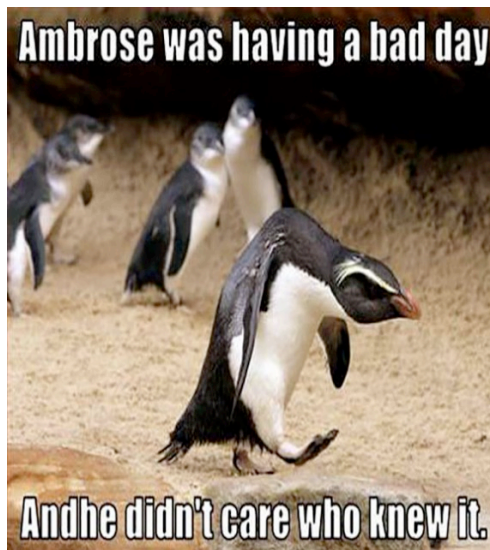
*Dr. Thomas Smith is the Director of Palliative Medicine, Harry J. Duffey Family Professor of Palliative Medicine, Johns Hopkins Sidney Kimmel Comprehensive Cancer Center*

*Dr. Charles Loprinzi is Regis Professor of Breast Cancer Research, Mayo Clinic*

It's To Laugh . . .



Even flooding has some quirky moments ...



## SENIOR TRYING TO SET A NEW PASSWORD

**WINDOWS:**

Please enter your new password.

**USER:**

cabbage

**WINDOWS:**

Sorry, the password must be more than 8 characters.

**USER:**

boiled cabbage

**WINDOWS:**

Sorry, the password must contain 1 numerical character.

**USER:**

1 boiled cabbage

**WINDOWS:**

Sorry, the password cannot have blank spaces

**USER:**

50damnboiledcabbages

**WINDOWS:**

Sorry, the password must contain at least one upper case character

**USER:**

50DAMNboiledcabbages

**WINDOWS:**

Sorry the password cannot use more than one upper case character consecutively.

**USER:**

50damnBoiledCabbagesShovedUp  
YourAssIfYouDon'tGiveMeAccessNow!

**WINDOWS:**

Sorry, the password cannot contain punctuation.

**USER:**

ReallyPissedOff50DamnBoiled  
CabbagesShovedUpYourAssIfYouDont  
GiveMeAccessNow

**WINDOWS:**

Sorry, that password is already in use.

## ??? DID YOU KNOW ??? - - The TOOL KIT



As helpful ideas or PN-related information become available we will try to include them.

- Hepatitis C can cause neuropathy and so can the antibiotic *Levaquin*.
- B6 maximum dosage: 50mg\day.
- Alpha Lipoic Acid (ALA) dosage: between 600-1200mg per day.
- Cinnamon may be helpful for diabetes: take 1 tsp. of cinnamon and 2 tbsp. of honey, add to hot water. Drink 2x per day. (Cinnamon from Ceylon is recommended.)
- Got muscle cramps? Take potassium and magnesium. For instant relief, pinch your upper lip between thumb and index finger, pressing hard. Hold until the cramp releases. And always stay well-hydrated.
- Anti-depressants Cymbalta and Nortriptyline aid in regeneration of the nerve sheath.
- Be careful in responding to full-page ads that promise aid for PN. Some have proven to be financial rip-offs.

### Coping with Diabetic PN - from [www.webmd.com](http://www.webmd.com)

When you live with [nerve pain](#) from [peripheral neuropathy](#) caused by [diabetes](#), it's normal to feel down sometimes. You'll probably have to deal with fear, anger, denial, disappointment, guilt, or loneliness. But there's room for hope, because the right treatment and lifestyle changes can bring you relief.

Talk to Your Medical Team. Your doctor may prescribe [medications](#) that treat [depression](#). These drugs can pull double duty, easing the physical pain and its emotional effects.

Talk with your [diabetes doctors](#) before you take this kind of drug, though. Some of these meds can cause [weight](#) gain, which could make it harder to control your [blood sugar](#). Also consider trying [psychotherapy](#) if you're diagnosed with [depression](#). Talking with a therapist will let you sort out problems or events in your life that may have led to [depression](#). This can help you solve problems, regain a sense of control over your life, and help you enjoy it again.

#### Techniques to Try:

Here are more ways to handle the emotions related to your [diabetes](#) and [nerve pain](#):

- Learn how to relax. Try deep breathing and other relaxation techniques like [meditation](#).
- Set reachable goals. Don't try to overdo things on good days. Learn to pace yourself.
- Don't put yourself down. If you do, just notice that you're being harsh, and think of something positive about yourself instead.
- Make time for de-stressing. You need [exercise](#) and relaxation every day.
- Join a [chronic pain](#) support group. It often helps to share your feelings.
- Don't drink alcohol. Pain often disrupts [sleep](#). So does alcohol.
- [Quit smoking](#) . Research shows that smokers are at higher risk for pain in general. Also, [smoking](#) worsens peripheral neuropathy.
- Find a Support Group
- [The American Pain Society and the National Pain Foundation](#) both offer local support groups in many areas.
- You can meet people facing the same challenges as you. Plus, you can learn what pain-relieving tricks work for them. For example, some people say wearing socks to bed can help. You can also ask them if they've taken medications that have helped.
- Open Up to Your Partner
- If you're in a relationship, be candid with your partner. Discuss any fears you have about [intimacy](#), be it fear of rejection, or pain from [sex](#). Also discuss what's good, and be frank about your needs.

## UPCOMING MEETINGS



### **Davis – Cancelled this month**

~~2<sup>nd</sup> Tuesday, March 14, 3:30-5:00~~

~~(Mary Sprifke (530-756-5102)~~

~~Davis Senior Center~~

~~246 A Street, Davis~~

### **Sacramento**

**3<sup>rd</sup> Tuesday, March 21, 1:30-3:00**

Charles Moore (916-485-7723)

Northminster Presbyterian Church

3235 Pope Avenue, Sacramento

### **Woodland - Cancelled**

A special thank you to everyone who receives this newsletter via e-mail. It helps save a lot of postage,

Call the editor if you would like to change to electronic mail:

530-756-5102

### **RESOURCES:**

1. Norman Latov M.D., Ph.D. – *Peripheral Neuropathy: When the Numbness, Weakness and Pain Won't Stop*
2. Harry J. Gould, III, M.D., and Ph.D. – *Understanding Pain: What It Is, Why it Happens and How It's Managed*
3. Alexander McLellan N.D. and Marc Spitz D.P.M. – *The Numb Foot Book – check Amazon.com -- Out of Print*
4. Mims Cushing & Norman Latov, MD – *You CAN Cope With Peripheral Neuropathy 365 Days a Year*
5. John Senneff – *Numb Toes and Aching Soles: Coping with Peripheral Neuropathy*
6. John Senneff – *Numb Toes and Other Woes: More of Peripheral Neuropathy*
7. John Senneff – *Nutrients for Neuropathy: How to use natural supplements to treat the severe pain of PN*
  - **The Foundation for Peripheral Neuropathy- [www.foundationforpn.org](http://www.foundationforpn.org) (a national organization)**
  - **Western Neuropathy Association (WNA) (formerly PCNA) – [www.pnhelp.org](http://www.pnhelp.org) or toll-free (877) 662-6298**
  - **[www.diabetes.org](http://www.diabetes.org)**
  - **[www.neuropathysupportnetwork.org](http://www.neuropathysupportnetwork.org)**
  - **Neuropathy Journal at [www.neuropathyjournal.org](http://www.neuropathyjournal.org)**
  - **Eugene B Richardson MDiv, MSM, EdM, MS, Patient Educator in the DVD “Coping with Chronic Neuropathy”**

To send *PN News* to others or if you no longer wish to receive this newsletter, please contact (530) 756-5102.

*Yolo PN News*

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