

PN News

Yolo County

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Webmd.com

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, JUNE 11, 3:30-5:00 p.m.

Program: John Cole Hall and Rob Reed from the Davis "F Street Dispensary" will share current information about CBD (medical cannabis) use.

Davis Senior Center

646 A Street, Davis, 95616

Contact: Mary Sprifke (530) 756-5102

SACRAMENTO

**TUESDAY, JUNE 25, 1:30-3:00 p.m.
(4th Tuesday)**

WNA PRESIDENT BEV ANDERSON LEADS.

Anyone wanting this group to continue to meet should plan on attending. We will talk about any concerns or questions people have about neuropathy and see a video on UC Davis' Dr. Hammock's pain medication that goes into clinical trials this summer. The video includes the amazing clips of animals experiencing the results of the medication. We can talk about what this medication may mean to people with neuropathy.

Northminster Presbyterian Church

3235 Pope Avenue, Sacramento

Contact: Bev Anderson (877) 622-6298

MEETING RECAPS



DAVIS MAY NOTES

By Mary Sprifke

Dottie Pendleton shared relaxation techniques and guided imagery visualization with her personal warm and affirming style. I was somewhat taken aback when just one member attended, but Dottie was actually delighted that guiding just two of us allowed for more time and options for our personal requests.

Centering Meditation: (About 5 minutes)

Have another read this to you, speaking slowly and repeating several phrases.

Close your eyes.

Relax and with palms up if comfortable, exhale your breath all the way out if possible. Don't force or change it, just let it happen. Put your attention to the process of breath flowing in and out.

On your exhale, make a decision to let go of tension of everything from the past, and be aware of just the present moment as you inhale. Exhale, let go of past and the future. Enjoy several slow breaths, quietly.

As you breathe out, your body may respond, possibly with a softer belly or awareness of particular tension. Just note any sensations, acknowledge and release tension if you feel it. Take in this special moment.

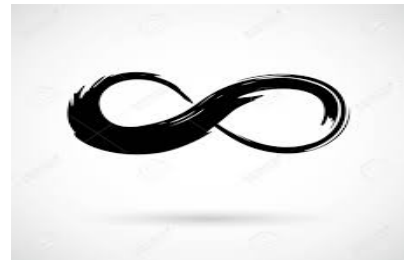
Think of our beautiful earth, the source of all life, our sustenance. Earth has supported us in all we've done. Imagine the energy of the earth; possibly imagine the color of the earth. Imagine that this energy/color enters your feet, rises and continues out through the top of your head. Breathing in, the life force energy rises; exhaling, our breath fills this room with the energy of the group. Sparkling, beautiful, radiant energy passing through your body. Invite energy into your feet and up through your body; drink in the life force, then let it go. Feel and visualize the color. Here in this moment, we receive the life force, reviving and filling us.

Turn your palms down toward the earth, relax for several moments.

Dottie says, "The hard part of this exercise is remembering to do it." Soon you will remember the affirmations while breathing and not need prompting.

We had a brief discussion personal about being grateful and feeling joy in the midst of pain or tension. We're learning to name and celebrate the healthy parts of our body and to affirm ourselves.

Standing, we learned a yoga movement, using an infinity sign (sideways, figure-eight). Breathing in through the nose; breathing out through the mouth, traveling one side of the sign with our hands, then breathing out following the other side of it. An in – out pattern was followed. This doesn't have to be a large movement; even just with our hands or fingers can help with release.



We ended with a guided imagery meditation (10 minutes). Mind and body join together during this sort of exercise. Dottie provided suggestions and we followed individually.

I'm sorry not to have notes, but I enjoyed this trip to my special place in nature.

Email to the Editor received recently:

(Reprinted with permission)

Dear Mary,

I am one of those 300 who have been on your list for years but never attend the meetings. Please allow me to continue as a silent participant! I live in fear and dread of the time when my diagnosed peripheral neuropathy becomes more pronounced and I am greatly comforted by your monthly news and humor.

Best wishes for the continuation of your Davis group!
Carol



Dear Carol,

Your letter raised my sagging spirits and renewed my faith that what we do and share makes a difference in someone's life. You are not alone in your fear and trepidation about PN and what may come. I hope you've found a doctor to trust and chosen some of the many possibilities for physical and mental relief that we've talked about. This is my 15th year as a group leader and editor and I, too, am uncertain what my future holds. I'm hoping a small team may join me to focus on programs and possibly co-chair meetings.

Thanks for taking time to get in touch and to lend your support!
Mary





On May 28, 2019 the *Sacramento Bee* ran a lengthy article by Jane E. Brody (*New York Times*).

Entitled: **GABAPENTIN A POPULAR PAIN DRUG, BUT IT MAY NOT WORK**

Since we often discuss Gabapentin (Neurontin/Lyrica), I hope you might find excerpted parts of her article interesting.

Brody notes, “Gabapentin, is being taken by millions of patients despite little or no evidence that it can relieve their pain. “The drug was initially approved 25 years ago to treat seizure disorders, but it is now commonly prescribed off-label.”

Off-labeling allows a medical provider to legally prescribe any drug that has been approved by the FDA for any condition, not just the ones for which it was approved. Patients aren’t usually scientists or doctors, so deciding when to use a particular drug can be difficult. A third drug, gabapentin encarbil, or Horizant, is now approved only for restless leg syndrome and postherpetic neuralgia.”

Drs. Christopher W. Goodman and Allan S. Brett of South Carolina School of Medicine, recently reviewed these drugs, called gabapentinoids for their efficacy. Quoting Goodman, “There is very little data to justify how these drugs are being used and why they should be in the top 10 in sales. Patients and physicians should understand that the drugs have limited evidence to support their use for many conditions, and there can be some harmful side effects, like somnolence, dizziness and difficulty walking. ... furthermore, for patients prone to substance use disorders, like an opioid addiction, the gabapentinoids, although they are not opioids, are potentially addictive.”

“Gabapentin and Lyrica, have been approved by the FDA to treat only four pain problems: postherpetic neuralgia, diabetic neuropathy, fibromyalgia and spinal cord injury. Evidence for relief offered by the drugs is hardly dramatic, Drs. Goodman and Brett reported in JAMA Internal Medicine online.

In many well-controlled studies they found there was less than a one-point difference on the 10-point pain scale between patients taking the drug versus a placebo, a difference often clinically meaningless. For example, among 209 patients with sciatica, Lyrica did not significantly reduce the intensity of leg pain when compared with a placebo, and dizziness was more commonly reported by the 108 patients who took the drug.”

Following Neurontin’s approval, its then-producer “Warner-Lambert engaged in what the government claimed was an illegal marketing campaign that resulted in sales exceeding \$2 billion a year before its patent expired in 2004. Still, the campaign succeeded in bringing gabapentin to the attention of many doctors who treat patients with persistent life-disrupting pain.”

As Dr. Michael E. Johansen, of Columbus, Ohio, put it, “I use gabapentin clinically and try to stay close to the approved indications, but occasionally we run out of options when faced with patients who hurt. It’s rare that these drugs eliminate pain, and I don’t tell patients their pain will go away. If there’s any benefit, it’s probably marginal.”

Despite the limited evidence of benefit, Dr. Johansen found that the number of people taking gabapentinoids more than tripled from 2002 to 2015, with more than four in five taking the inexpensive generic, gabapentin.”

In 2016,
64 million
gabapentin
prescriptions were
written, up from
39 million in 2012

“Dr. Johansen cited several serious concerns about overuse of gabapentinoids, including “a dearth of long-term safety data, small effect sizes, concern for increased risk of overdose in combination with opioid use, and high rates of off-label prescribing, which are associated with high rates of adverse effects.”

How doctors interpret the term “neuropathic pain” defined as pain caused by a lesion or disease of the nervous system, may lead to the belief that if it works for one type of neuropathic pain, it is effective for all types.

Dr. Johansen pointed out that “there is no recipe book” for treating pain with gabapentinoids. “Doctors need to work with one patient at a time and figure out what works and what doesn’t work,” he said. He noted that many times pain resolves with “the tincture of time” but patients and doctors may attribute improvement to the prescribed drug. For those taking a gabapentinoid, he suggested that patients’ doctors readdress its use after two or three months.

But Dr. Goodman warned against stopping the drug suddenly, because there can be unpleasant withdrawal symptoms.

Jane Brody is the Personal Health columnist, a position she has held since 1976. She has written more than a dozen books including the best sellers “Jane Brody’s Nutrition Book” and “Jane Brody’s Good Food Book.”



MEDICAL MARIJUANA

Some information from **WebMD.com**

Since the Davis program for June is about marijuana for pain, here is some basic information to think about in advance.



Marijuana has chemicals called cannabinoids. Medical researchers usually focus on the health effects of two in particular: delta-9-tetrahydrocannabinol (THC) and Cannabidiol (CBD).

- ✚ THC is the substance that makes you high.
- ✚ CBD doesn't have mind-altering effects.

There are a variety of ways to take the drug. You can inhale a vaporized spray, smoke the leaves, take a pill or liquid, or bake it into foods. All of the types differ in terms of how often you should use them, how they'll affect your symptoms, and side effects you may feel.

State laws differ on the conditions that you can legally treat with medical marijuana. But you might be allowed to use it if you have Alzheimer's, ALS, cancer, Crohn's disease, epilepsy, seizures, hepatitis C, AIDS, glaucoma, multiple sclerosis, posttraumatic stress disorder, chronic pain, or severe nausea. But scientists aren't sure that it helps all of these conditions. The research is most clear that it works as a painkiller, to stop vomiting during chemotherapy, to relieve some MS symptoms, and to treat a few rare forms of epilepsy.

Is Cannabidiol safe? (From **Harvard Medical School**, Peter Grins Peter Grinspoon, MD Contributing Editor)

Side effects of CBD include nausea, fatigue and irritability. CBD can increase the level in your blood of the blood thinner Coumadin, and it can raise levels of certain other medications in your blood by the exact same mechanism that grapefruit juice does. A significant safety concern with CBD is that it is primarily marketed and sold as a supplement, not a medication. Currently, the FDA does not regulate the safety and purity of dietary supplements. So you cannot know for sure that the product you buy has active ingredients at the dose listed on the label. In addition, the product may contain other (unknown) elements. We also don't know the most effective therapeutic dose of CBD for any particular medical condition.

The bottom line on Cannabidiol

Some CBD manufacturers have come under government scrutiny for wild, indefensible claims, such that CBD is a cure-all for cancer, which it is not. We need more research but CBD may prove to be an option for managing anxiety, insomnia, and chronic pain. Without sufficient high-quality evidence in human studies we can't pinpoint effective doses, and because CBD is currently mostly available as an unregulated supplement, it's difficult to know exactly what you are getting. If you decide to try CBD, talk with your doctor — if for no other reason than to make sure it won't affect other medications you are taking.

It's To Laugh . . .

The *Washington Post's* Style Invitational asked readers to take any word from the dictionary, alter it by adding, subtracting, or changing one letter, and supply a new definition. Here are this year's winners:

1. Bozone (N.): The substance surrounding stupid people and that stops bright ideas from penetrating. The bozone layer, unfortunately, shows little sign of breaking down in the near future.
2. Cashtration (N.): The act of buying a house, which renders the subject financially impotent for an indefinite period.
3. Giraffiti (N): Vandalism spray-painted very, very high.
4. Sarchasm (N): The gulf between the author of sarcastic wit and the person who doesn't get it.
5. Inoculatte (V): To take coffee intravenously when you are running late.
6. Hipatitis (N): Terminal coolness.
7. Karmageddon (N): It's like, when everybody is sending off all these really bad vibes, right? And then, like, the earth explodes and it's like, a serious bummer.
8. Decafalon (N.): The grueling event of getting through the day consuming only things that are good for you.
9. Glibido (V): All talk and no action.
10. Dopeler effect (N): The tendency of stupid ideas to seem smarter when they come at you rapidly.
11. Arachnoleptic fit (N.): The frantic dance performed just after you've accidentally walked through a spider web.
12. Beelzebug (N.): Satan in the form of a mosquito that gets into your bedroom at three in the morning and cannot be cast out.



Now I've seen it all!



UPCOMING MEETINGS

2nd Tuesday, Sept 10, 3:30 p.m.
Davis Senior Center, 246 A Street
(Mary Sprifke 530-756-5102)



The mission of the Yolo Neuropathy Groups is to ensure through information, empowerment and mutual support, that all may have hope and that no one will face their peripheral neuropathy alone.

SACRAMENTO

No Meeting Scheduled
Seeking New Leader

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*
8. Dr. Valerie Monteiro & Dr. John Coppola: *Defeat Neuropathy Now ... In Spite of Your Doctor*
9. Todd Levine, M.D., *Neuropathy Hope? Small Nerves, Big Problems*
10. **The Foundation for Peripheral Neuropathy-** www.foundationforpn.org (a national organization)
11. **Western Neuropathy Association (WNA)** – www.pnhelp.org or toll-free (877) 662-6298
12. www.diabetes.org
13. www.neuropathyjournal.org
14. www.neuropathysupportnetwork.org
15. Eugene B. Richardson MDiv, MSM, EdM, MS, Patient Educator: DVD "Coping with Chronic Neuropathy"
16. DVD's: "Forks Over Knives" and "What the Health?"

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

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