

PN News

Yolo County

VOL. 12, No. 6

JUNE 2016

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Contributors:

Charles Moore
 Mary Sprifke



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 14, 3:30 – 5:00 p.m.

Program: Dr. Kene Ofili, Podiatrist

Davis Senior Center
 646 A Street, Davis, 95616
 Contact: Mary Sprifke (530) 756-5102 or
 Retta Gilbert at (530) 747-0186

WOODLAND

No Meeting – No leader(s)

SACRAMENTO

TUESDAY, JUNE 21 1:30-3:30

Program: View and Discuss PN DVD

Northminster Presbyterian Church
 3235 Pope Avenue
 Sacramento, CA 95825
 Contact: Charles Moore (916) 485-772



The *PN News*
 is taking a break.

We'll be back in
 September.

MEETING RECAPS



DAVIS APRIL NOTES

By Mary Sprifke

On April 11 we viewed a DVD available from Western Neuropathy Association, titled **Peter T. Skaff, MD: "Peripheral Neuropathy: What It Is and What Can Be Done About It." (2008)**

In our group, we call this 'PN 101.' It is down to earth and full of detail about symptoms, treatments and how to best talk to our doctors.

First, how our bodies are 'wired.' *Peripheral* refers to nerves away from the center, which start in the spine and go down legs and arms. We have three types of nerves: motor, sensory and autonomic (e.g., lungs, heart, blood pressure, intestines).

Peripheral nerves are like a long wire, with insulation around it called "myelin" and axons inside. Damage to one or both can be neuropathy.

Symptoms: Altered sensations, e.g., numb feet and/or hands, tingling, pins & needles, creepy-crawly feelings. **Pain** may present as burning, stinging, or electrical stabbing. **Imbalance** may lead to unsteady walking, less steadiness or dizziness. **Weakness or atrophy** of muscles.

Organ system dysfunction, e.g., bowel, bladder, sexual organs.

Causes:

- Diabetes and pre-diabetes cause 50% of PN
- Alcoholism is 2nd most common cause in the USA
- Vitamin deficiency, e.g., B12, B6 and folate
- Medications such as Amidorone, Chemo, Nitrofurantoin
- Metabolic dysfunction e.g., thyroid, kidney, high triglycerides
- Carpel Tunnel or Radiculopathy pinched nerves
- Infections – acute, chronic and/or post-infection e.g, HIV/AIDS, Hepatitis C, Lyme disease, GBS or Shingles.
- Cancer
- Vasculitis
- Amyloidosis
- Paraproteinemia

The Doctor Visit

A **clinical history** will be taken and a physical exam.

Lab tests for blood and urine, including a 2-hour glucose tolerance test. Thyroid and B12 levels are checked.

Other tests:

-- EMG/NCV (Electromyography and Nerve Conduction Velocity) help locate where the PN is located.

-- Imaging Studies – may find pinched nerves near the spine (Radiculopathy).



- Lumbar Puncture
- Muscle or nerve (or skin) biopsy

TREATING PN

First treat the underlying cause and remove the insult to the nerve to aid healing.

Second, treat the symptoms:

- Improve functions
- Healthy diet
- Exercise regimen
- Normalize blood sugar
- Wear protective footwear
- Self-exam legs and feet daily
- Maintain a healthy body weight



Normal pain medications, nociceptive, traditional include NSAIDS (Ibuprophen, Voltaren); Tylenol; Opiates (Vicadin, Norco, Hydrocodone; Topical Analgesics (Lidocaine patch or cream)

PN pain medications for injured nerves must change the way the body processes pain signals. They often take 2-4 weeks to kick in. Antidepressants (older class) tricyclic can start at 10-25 mg, checking tolerance.

Newer class **antidepressants** (SNRI) are Cymbalta (Duloxetine), Venlafaxine (Effexor). These may have side effects such as nausea, dry mouth, constipation, diarrhea, fatigue, drowsiness, difficulty sleeping, loss of appetite, and dizziness.

Anti-convulsants include Gabapentin (Neurontin) and Pre-Gabalin (Lyrica). Their side effects are listed online and commonly include dizziness, nausea and blurred vision.

Anti-hypertensives may also be considered: They are a class of drugs that are used to treat hypertension. Antihypertensive therapy seeks to prevent the complications of high blood pressure, such as stroke and myocardial infarction.

Non-RX Approaches:

- Physical Therapy – very important to address balance issues
- Balance and gait training
- Physical conditioning
- Electrical stimulation
- Adaptive devices: cane, walker, wheelchair, walking sticks

- Surgery for pinched nerve or arthritis in the spine
- Radiculopathy and Entrapment PN – need to relieve pressure
- Nerve blocks –can numb specific areas of pain
- Join a support group

- Massage
- Acupuncture

BE PREPARED FOR A DIAGNOSIS

Write down your own description of your symptoms: what, where, how long, come and go, worse in the morning, or at night?

Provide a complete list of all medications and supplements and their dosages; list all doctors who treat you.

Relax and be honest – the doctor wants to help you!

Those with persistent problems should see their doctor.

End Notes from DVD audience Q/A.

Blood sugar levels for diabetes should be under 110 fasting, and under 140 for 2-hour glucose test.

A fasting level of 110-140 indicates pre-diabetes; a 2-hour test score of 140-200 indicates diabetes.

Peripheral neuropathy is often a first signal of pre-diabetes, or diabetes.

With circulation issues, a good history and physical exam can tell the difference between PN and other problems.

DAVIS MAY NOTES

By Mary Sprifke

This meeting centered on **RX compounding** and lots of other input during our round-table discussion. We had no formal speaker, but covered lots of ideas. Here are the notes as taken.

Retta shared a 9-page packet covering northern California pharmacists who provide compounding. Also included was an article from a Los Angeles group, Melissa Hoyt, entitled, "Help from Compounding



Medications,” an article on risk of NSAIDs for heart issues indicating topical may be better than oral dosing, a Davis Enterprise article about Kin Sing Lee winning a NIH K99 award for studies on neuropathy, an excerpt from Mims Cushing *You Can Cope With Peripheral Neuropathy* outlining several topicals, and a sample order form for compounded pain management. We read the material aloud and commented as we went.

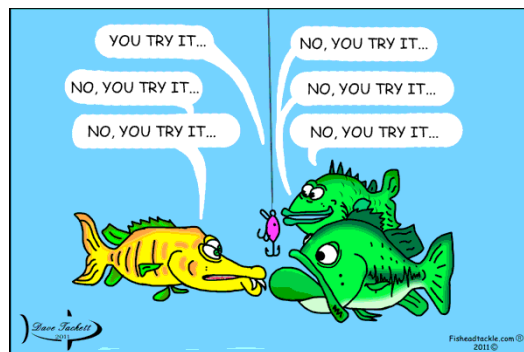


Some Davis Group suggestions: (Too many for The Toolkit!)

- Cover topicals with plastic and keep an airtight seal
- Ask at your pharmacy about which doctors prescribe compounded RX’s. (Dr. Mould in Davis does.)
- An over-the-counter, Aspercreme, works for some.
- The downside of NSAID’s such as Ibuprophen, aspirin and Aleve is that the formula can attack mitochondria, reducing cellular ability to produce energy, which is a stroke risk. Scientists compared Naproxen (‘the safest NSAID’) with meclomate sodium which RX may be worse than the OTC product.
- Before taking an NSAID, take an antioxidant such as vitamin C. A topical suggestion is to break a capsule and add some water or oil, mix, and apply to the skin.
- If you notice your indigestion is becoming ‘long term’ take note and consult your doctor.
- Mims Cushing, author of *You Can Cope With Peripheral Neuropathy* suggests the topical, Neuragen.
- Another product is Aspercreme, which contains lidocaine, with anesthetic properties.
- Consider Nikken infrared socks or thermo-skin ‘booties.’
- Got a muscle cramp and can’t stretch it, rub it or release it? Just pinch your upper lip, with your thumb inside the lip, and the index finger on the outside top. Pinch it as hard as you can.... it won’t hurt you, and just hold it for 30-60 seconds. Wow, right?

Most of us have tried some of the following products:

- Capcasin
- Gold Bond Foot Cream
- Bio freeze
- Icy Hot
- Super Blue Stuff
- Miracle Ice
- Blue Ice
- Vicks Vaporub
- Ben Gay



- L-Arginine Cream
- Biotone Peppermint massage cream
- Bach’s Original Flower Essences
- Arnica – for bruises, joint pain and PN
- Aloe - a top choice to smooth onto the skin
- Hyland’s Leg Cramps crème/oil
- Neuragen

The key here is to be careful and include your doctor in your decisions. Diabetics are encouraged to consult an endocrinologist.

SACRAMENTO MAY NOTES

By Charles Moore

To structure the PN meeting of May 17, I distributed a lightly edited copy of from the on-line *Neuropathy Journal*. I then read aloud most of the article, stopping to discuss points of

particular interest. Of the 11 group members in attendance, most contributed comments on their own diagnoses of neuropathy. Not surprisingly,

most had faced a rocky path leading to diagnosis.

When my podiatrist used a tuning fork to test the pain and numbness in my toes, he said, "You have lost vibratory sensation; you have peripheral neuropathy."

That was my first diagnosis; my primary care doctor did not know to what kind of specialist he should refer me. I think that it is still common to find that doctors may be

find that doctors may be

Let me briefly mention the topics of our fall meetings starting in August:



- In August the topic will be Medical Marijuana and Neuropathy Pain.
- September will cover Fitness and Balance.
- October will feature Dr. Ryan Armour, Neurologist with Mercy Medical Group.
- November will feature John Richards, compounding pharmacist on pain medication.

I hope to see you at our future meetings on the 3rd Tuesday of each month excluding July.



The 10th Conference will be held at the Intercontinental In Los Angeles on **Thursday, June 23**. Visit the Web site at <http://www.neuropathyaction.org> to register and see topics, speakers and full-day agenda.

- A limited number of rooms have been reserved at the InterContinental Hotel. To take advantage of the special NAF room rate of \$269 (exclusive of taxes) per night, you must reserve your room *before* **May 27, 2016**. Please remember to tell the reservation agent that you are part of the "Neuropathy Action Foundation" Courtesy Block to receive the special rate. Book your room on-line at the following direct link: **INTERCONTINENTAL LOS ANGELES** and select "BOOK NOW" or call the Toll-Free Reservations number at (866) 329-1010 or (310) 284-6500.

10th ANNUAL
ACTION
AWARENESS DAY

JUNE 23, 2016

LOS ANGELES

Note: The NAF will pay for up to 10 flights and hotel rooms for the night of the event or the night before the event for patients from out of the Los Angeles region who have a financial hardship. The NAF does not want a single patient to miss this event due to cost.

Western Neuropathy Association (WNA) SPRING CONFERENCE SPEAKER –

Leonard Chuck, MD: “How is Research Conducted?”

Notes by Mary Sprifke

Dr. Chuck is Medical Director at Diablo Research, Walnut Creek. His career path is specializing in internal medicine and peripheral neuropathy. He noted that he'll address how we define research, including types, stages and rules that apply. But first he asks, “What is a scientist?” And he answers with a smile, “A person who doesn't know and is trying to find out.” Basic research involves ‘out of the box’ thinking followed by clinical applications to humans, involving safety, efficacy and duration of action.



Non-human clinical research phases:

0. – Pharmacodynamics, pK, bioavailability, T12
1. Number of subjects 20-100, efficacy, dose range, safety
2. 100-300, efficacy, toxicity
3. 1000-2000, efficacy, safety leading to FDA approval
4. After-market safety (extremely important, e.g., thalidomide)

(A side-note: for a diabetic drug, coverings steps 1-3, the cost can be \$800m - \$2.6b for just one compound.)

STUDY RULES

- Information must be correct and thorough
- Drug administration specific
- SEC Commission approved
- Goal of clinical practice

Areas of study can look at nerve systems, structures and transmitters.

The **nerve system** comprises the central brain and spinal cord; PN, the spinal cord to end organs; somatic system voluntary connections, of the body; autonomic – involuntary e.g., a gland; sympathetic division, arousing; parasympathetic, e.g., bowel, bladder, blood pressure, temperature.

The **neuronal structures** include the cell body (with nucleus, organelles, trophic substances). Also included are the axons, including the myelin sheath which signals transmissions; synapses that provide information on whether the information is transferred or not; and dendrites that receive information from the synapses.

Neuronal transmitters are chemical messengers such as Glutamate, Aspart, Serotonin, Histamine, Dopamine and Norepinephrine. Acetylcholine is an organic chemical that functions in the brain and body of many types of animals, including humans, as a neurotransmitter—a chemical released by nerve cells to send signals to other cells that may aid with PN.

Symptoms – What You Tell the Doctor:

Vague, general descriptions don't help much. But common ones are pain, numbness, tingling, analgesia, hyperalgesia (excessive feeling, such as cannot walk on conglomerate pebbles), allodynia (very cold), weakness or paralysis. Be quantitative: pain can be sharp, jabbing, aching, burning, or nocturnal.

Autonomic neuropathy can cause:

- Orthostatic hypotension – dizziness upon standing
- Anhidrosis – inability to sweat
- Erectile dysfunction
- Constipation
- Diarrhea
- Bowel or Bladder incontinence
- Difficulty swallowing

Signs and Tests

- Deep tendon reflexes
- Vibration
- Proprioception – sense of body position
- Pinprick
- Charcot-Marie-Tooth (CMT) is hereditary – skin changes in the feet (calluses, fissures, ulcers)

Causes

- Trauma caused by pressure
- Immunologic such as Guillain-Barré Syndrome, MS, Rheumatoid Arthritis, Lupis, Sjorgen's
- Infection, e.g., Lyme Disease, Shingles, Polio, Leprosy
- Metabolic dysfunction, e.g., diabetes, alcoholism, thyroid
- Toxins, e.g., chemotherapy, insecticides, Hg^{tt}, solvents
- Congenital causes, e.g., CMT, Freidrich's ataxia
- Nutrition deficiency, e.g., vitamins B12, B1 and E

Treatments

- Central Nervous System: opioids, anesthetics, serotonin (5-HT), histamine, CGRP (Calcitonin gene related peptide).
- PNS/GABA Agonists: the GABA receptors in the PNS are potential therapeutic targets in a variety of diseases and conditions; T-type Ca⁺⁺, channel blockers
- Trophic Factors: 'Relating to the feeding

habits of different organisms in a food chain or web.' Affecting regrowth of the myelin sheath are anti-NGF, DNA plasmids

- Synaptic in the Dorsal Horn. Afferent nociceptive fibers (those that send information to, rather than from the brain) travel back to the spinal cord where they form **synapses** in its **dorsal horn**. This nociceptive fiber (located in the periphery) is a first order neuron. (From *Wikipedia*)

Diabetic Peripheral Neuropathy Symptoms:

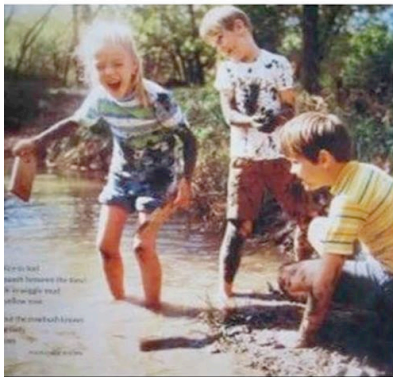
- Bilateral and symmetric distribution
- Length dependent (tight stocking or glove sensation)
- Hyperalgesia – heightened sensitivity to pain
- Allodynia - refers to central pain sensitization (increased response of neurons) following painful, often repetitive, stimulation. Often cold feet. Allodynia can lead to the triggering of a pain response from stimuli that do not normally provoke pain.
- Nocturnal amplification – worse at night.

Dr. Chuck noted that stem cell research is still in early stages and asks 'where is the proof?' He said, "not everything written is correct" and he suggests visiting www.clinicaltrials.gov. His contact information is Address: 2255 Ygnacio Valley Rd # M, Walnut Creek, CA 94598, Phone: (925) 930-7267



It's To Laugh . . .

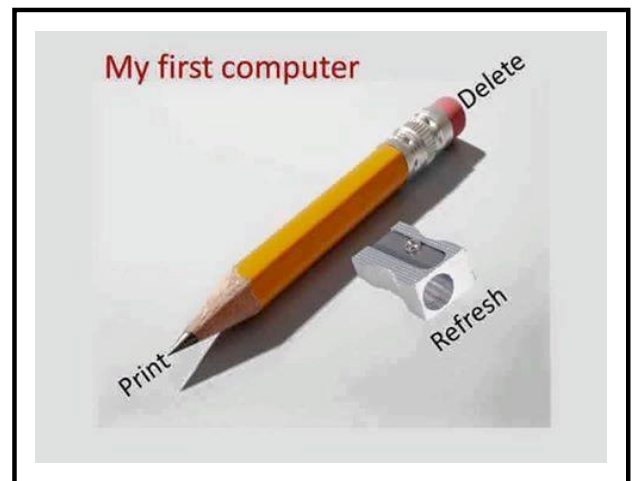
SO GLAD I GREW UP



DOING THIS



NOT THIS



UPCOMING MEETINGS

Summer Schedule

2nd Tuesday, September 13, 3:30-5:00

(Mary Sprifke (530-756-5102)

Davis Senior Center

246 A Street, Davis



10th ANNUAL
ACTION
AWARENESS DAY

JUNE 23, 2016

See Pg. 5

Sacramento

3rd Tuesday, August 16, 1:30-3:00

(Charles Moore 916-485-7723)

Northminster Presbyterian Church

3235 Pope Avenue, Sacramento

Woodland

Cancelled, pending new leadership

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

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 (a national organization)**
 - **Western Neuropathy Association (WNA) (formerly PCNA) – www.pnhelp.org or toll-free (877) 662-6298**
 - **www.diabetes.org**
 - **www.neuropathyjournal.org**
 - **www.neuropathysupportnetwork.org**
 - **Neuropathy Journal at 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.

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