

VOL. 13, No. 3 MARCH 2017

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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 - NO MEETING IN MARCH

(TUESDAY, <u>APRIL</u> 11, 3:30 - 5:00 p.m.)

Program: DVD: Forks Over Knives: a documentary of two doctors and their research on healthy eating.

Davis Senior Center 646 A Street, Davis, 95616

> Contact: Mary Sprifke (530) 756-5102 or Retta Gilbert at (530) 747-0186

SACRAMENTO

4th TUESDAY, MARCH 21 - 1:30-3:30

Program: Speaker, Eskaton dietician Shannon Guthrie, also teaches nutrition at Los Rios Community colleges

Northminster Presbyterian Church 3235 Pope Avenue Sacramento, CA 95825 Contact: Charles Moore (916) 485-7723



Spring is on the way!

MEETING RECAPS



DAVIS FEBRUARY NOTES

By Mary Sprifke

On February 14 we viewed a DVD available from Western Neuropathy Association WNA), titled "Peripheral Neuropathy: What It Is and What Can Be Done About It." (2008) featuring Peter T Skaff, M.D.

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. A copy is available for check out at a meeting.

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 sheathe 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.

Some Causes:

- Diabetes and pre-diabetes cause 50% of PN (alcohol 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, and high triglycerides
- Heredity
- Gastrointestinal, e.g., Crohn's or Celiac disease
- Heavy metal poisoning

- Autoimmune disorders
- Carpel Tunnel or Radiculopathy pinched nerves
- Infections acute, chronic and/or postinfection e.g, HIV/AIDS, Hepatitis C, Lyme disease, GBS or Shingles.
- Cancer
- Vasculitis
- Amyloidosis
- Paraproteinemia
- Toxins

So, what's up, Doc?

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The Doctor Visit:

A **clinical history** will be taken and physical tests ordered.

Lab tests for blood and urine, including a 2-hour oral glucose (sugar) tolerance tests are ordered. Thyroid and B12 levels are also checked.

Other tests may include Electrical EMG/NCV (Electromyography and Nerve Conduction Velocity) to help locate the PN. Imaging studies to locate pinched nerves near the spine (Radiculopathy). Other possible tests are a lumbar puncture or MRI or a muscle or nerve (or skin) biopsy.

TREATING PN (there are LOTS of options!)

1) Treat the underlying cause and remove the insult to the nerve to aid healing (nerves can regenerate).

Peter Skaff, M.D.



2) Treat the symptoms:

- Improve body functions
- Healthy diet
- Regular exercise regimen
- Normalize blood sugar
- Wear protective footwear
- Self-exam legs and feet daily
- Maintain a healthy body weight
- Get diabetic education

Normal pain medications, Nociceptive or traditional include **NSAIDS** (Ibuprophin, Voltaren); Tylenol; **Opiates** (Vicadin, Norco, Hydrocodone; Topical Analgesics: Lidocaine patch or cream, or Naproxin [Voltarin or Diclofenac]

PN pain medications for injured nerves change the way the body processes pain signals. They often take 2-4 weeks to kick in and need to be given at least that much time to work. Antidepressants (older class) tricyclic can be given to start with a low dose of 10-15 mg, checking for tolerance.

Newer class **antidepressants (SNRI)** are Cymbalta (Duloxetine) and Venlafaxine (Effexor). These may have side effects such as nausea, dry mouth, constipation, diarrhea, fatigue, drowsiness, difficulty sleeping, loss of appetite, and dizziness. These are not taken at the level of treating depression.

Less common are **Anti-convulsants** including 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. Anti-hypertensive 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
- Massage
- Acupuncture
- Join a support group

Invasive Treatments:

- Surgery for pinched nerve or arthritis in the spine
- Radiculopathy and Entrapment PN needed to relieve pressure
- Nerve blocks can numb specific areas of pain

BE PREPARED FOR YOUR DOCTOR VISIT: (and request a referral to a neurologist)



- ✓ Write down your own description of your symptoms: what, where, how long, come and go, worse in the morning, or at night? What activity affects your pain. How long has it been at the current level? Has it changed over time? Does it run in your family?
- Provide a complete list of all medications and supplements and their dosages; list all doctors who treat you for other issues.
- ✓ Relax and be honest the doctor wants to help you!
- ✓ Those with persistent problems should see their doctor.

End notes and audience Q/A.

Blood sugar levels for pre-diabetes should be under 110 fasting, and below 140 for the 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.

In 2008, between 15-20 million were affected in the U.S. Most causes are treatable.

Muscles tighten with pain and massage or acupuncture can bring relief.

Nerves regenerate when the injury/insult is removed.

Insomnia from nerve pain is worst when there's been no activity.

PN is not caused by poor circulation. Your GP should be aware of PN, since some symptoms can be similar. A physical examination can tell the difference.

SACRAMENTO FEBRUARY NOTES

By Charles Moore

The Sacramento Peripheral Neuropathy (PN) Support Group featured presenter Mallory Tomei, Resource and Information Specialist with Eskaton, Sacramento. At our meeting, Ms. Tomei outlined Eskaton's Community Outreach, known as Telephone Reassurance (TA). The TA program serves seniors, 62 and older, in Sacramento and surrounding counties (including Amador). It consists of three parts: Telephone contacts, transportation, and information. The program was previously designated as TLC.

In the telephone portion, volunteers call seniors who request set phone times. The calls serve a variety of purposes: to be sure that the recipient is well, that medications are followed, that personal contact is maintained.

The TA presently serves about 658 people. Trained volunteers place calls seven days a week to older adults who live alone. The calls serve as a "wellness check," plus they provide an opportunity to socialize.

Caring volunteers, who are partnered with homebound older adults based on common interests and location, provide companionship two to four times a month. All volunteers have passed a background check.

If you are interested in receiving TA services or in volunteering, you need only **call**Mallory Tomei at 916-334-1072. She will then set up the schedule of calls and determine the nature of the contact.

A sub-set of the telephone reassurance program is the home visit. As a volunteer you might be able to help plan phone calls and home visits.

Transportation is another important part of the TA program. It offers free service to the community for people earning less than \$25,000 per year. Transportation to doctor appointments or other errands twice a month cost the senior only \$5 of the \$25 cost; Eskaton pays the remaining \$20. The driver will remain with you for up to three hours. Tomei's presentation was filled with useful information about navigating life without a car.

The Information function of TA provides a list of care-giving agencies. Call Eskakton's free Resource Specialist (Ms. Tomei) for assistance with housing, senior care services, transportation options, assistive technology and equipment, professional services (attorneys home maintenance), support groups, dementia resources. For local services, dial 211.

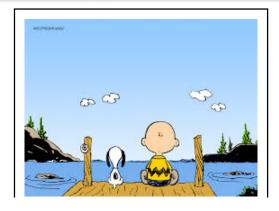
Also,

The WESTERN NEUROPATHY ASSOCIATION WILL HOLD ITS ANNUAL CONFERENCE ON TUESDAY, APRIL 18, AT THE UC DAVIS M.I.N.D. INSTITUTE, UCD MED CENTER, 2814 50TH STREET. SACRAMENTO.

The cost is \$25 for lunch and morning snacks and coffee.

I will be forwarding to you the registration form and directions to the Mind Institute shortly. Since the conference will take place when our support group usually meets, we will meet a week later on April 25. A reminder will follow.

Our support group meeting on March 21 will feature Eskaton dietician Shannon Guthrie, who also teaches nutrition at Los Rios Community colleges.







GREAT TRUTHS THAT LITTLE CHILDREN HAVE LEARNED:

- 1) No matter how hard you try, you can't baptize cats.
- 2) When your Mom is mad at your Dad, don't let her brush your hair.
- 3) If your sister hits you, don't hit her back. They always catch the second person.



- 4) Never ask your 3-year old brother to hold a tomato.
- 5) You can't trust dogs to watch your food. 6) Don't sneeze when someone is cutting your hair. 7) Never hold a Dust-Buster and a cat at the same time. 8) You can't hide a piece of broccoli in a glass of milk. 9) Don't wear polka-dot underwear under white shorts. 10) The best place to be when you're sad is Grandma's lap.



GREAT TRUTHS THAT ADULTS HAVE LEARNED:

- 1) Raising teenagers is like nailing Jell-O to a tree.
- A
- 2) Wrinkles don't hurt.
- 3) Families are like fudge...mostly sweet, with a few nuts.
- 4) Today's mighty oak is just yesterday's nut that held its ground.
- 5) Laughing is good exercise. It's like jogging on the inside.
- 6) Middle age is when you choose your cereal for the fiber, not the toy.

GREAT TRUTHS ABOUT GROWING OLD:

- 1) Growing old is mandatory; growing up is optional.
- 2) Forget the health food. You need all the preservatives you can get.
- 3) When you fall down, you wonder what else you can do while you're down there.
- 4) You're getting old when you get the same sensation from a rocking chair that you once got from a roller coaster.
- 5) It's frustrating when you know all the answers but nobody bothers to ask you the questions.
- 6) Time may be a great healer, but it's a lousy beautician.
- 7) Wisdom comes with age, but sometimes age comes alone.





THE FOUR STAGES OF LIFE:

- 1) You believe in Santa Claus.
- 2) You don't believe in Santa Claus.
- 3) You are Santa Claus.
- 4) You look like Santa Claus.

It's To Laugh . . .

SUCCESS:

At age 4 success is . . . Not piddling in your pants.

At age 12 success is . . . Having friends.

At age 17 success is . . . Having a driver's license.

At age 35 success is . . . Having money.

At age 50 success is . . . Having money.

At age 70 success is . . . Having a driver's license.

At age 75 success is . . . Having friends.

At age 80 success is . . . Not piddling in your pants.



WESTERN NEUROPATHY ASSOCIATION

Hope through caring, support, research, education, and empowerment Our mission is to provide support, information and referral to people with neuropathy and to those who care about them.

Date: Tuesday, April 18, 2017

Time: 9:30 AM to 3:30 PM

Pre-register By: Tuesday, April 4, 2017 Seating is limited. Must register in advance.

Registration Fee: \$25.00

Location: UC Davis Mind Institute
UC Davis Medical Center
2825 50th Street
Sacramento, CA

Questions?
Toll-free: (888) 556-3356
E-mail: lindsayc@pnhelp.org



Western Neuropathy Association 2017 Annual Conference

Neuropathy Today & Tomorrow

9:30 am Registration check-in (must register in advance; limited seating)
Morning snacks and coffee included.

10:00 Announcements and Introductions

10:30 Yuen So, M.D, Ph.D.—Professor, Neurology & Neurological Sciences; Associate Chair, Clinical Services; Chief, Neurology Clinic; Stanford University Medical Center; oversees clinical trials. "What is a neuro-muscular neurologist?" "Why is this type of neurologist often recommended for treating people with neuropathy?"

Noon Catered Lunch

1:00 pm Stem Cell Researcher—Invited

"What is a stem cell?" "What does the research consist of?" "What does the future possibly hold for the impact of stem cells in the treatment of neuropathy?"

2:00 pm **Bruce D. Hammock**, Ph.D.— Distinguished Professor Department of Entomology & UCD Comprehensive Cancer Center, Director, NIEHS-UCD Superfund Research Program PI, NIH Biotechnology Training Program "Report on the progress of his current neuropathy treatment"

research and how soon human clinical trials begin."

3:00 pm Closing activities:

- Evaluations
- Door Prizes and Silent Auction
- Closing Announcements

3:30 pm Adjournment



Mail registration fee and form to:

Name	
Address	
City / State / Zip	
E-mail	
	□ At Large Member

UPCOMING MEETINGS



2nd Tuesday, April 11, 3:30-5:00 (Mary Sprifke 530-756-5102) Davis Senior Center 246 A Street, Davis

Sacramento

4th Tuesday, April 25, 1:30-3:00 (Charles Moore 916-485-7723) Northminster Presbyterian Church 3235 Pope Avenue, Sacramento

Woodland

Seeking new leaders



WNA ANNUAL CONFERENCE Tuesday, April 21 9:30 a.m. – 3:30 p.m.

M.I.N.D. Center, 2814 50th Street UC Medical Center Sacramento

(see p. 7)

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.

Yolo Neuropathy Groups c/o Mary Sprifke, Editor 1121 Decatur Ct. Davis, CA 95618