



WESTERN NEUROPATHY ASSOCIATION

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Volume 14

- WNA Spring Conference Speaker - Leonard Chuck, M.D.
- We Honor Three Support Group Leaders
- WNA Support Groups
- President's Message
- PN Literature Review
- Eric Clapton Has PN
- B6 Needed But Too Much Can give You Neuropathy
- PainMedicine News
- D.C. Week: Two Novel Opioids Win Tepid Backing from FDA Panel
- What Is A Neurologist?

WESTERN  
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# Neuropathy Hope

*Hope through caring, support, research, education, and empowerment*  
A newsletter for members of Western Neuropathy Association (WNA)

## ■ WNA SPRING CONFERENCE SPEAKER – LEONARD CHUCK, MD: "HOW IS RESEARCH CONDUCTED?" Notes By Mary Sprifke

Dr. Chuck is medical director at Diablo Research in Walnut Creek, CA. His career path is specializing in internal medicine and peripheral neuropathy. He noted that he would address how we define research, including types, stages and rules that apply. But first he asked, "What is a scientist?" And he answered 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.



Dr. Leonard Chuck

### 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, covering 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) and axons, including the myelin sheath, which signal 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 in peripheral neuropathy.

– Continued on page 7

## ■ WE HONOR THREE SUPPORT GROUP LEADERS

Each year at our Annual Conference, we honor support group leaders. This year we honored three. Each received a commemorative plaque with a clock in it with their name and honor engraved on the plaque. It is a very nice piece to put on a desk or a mantel or other display place. The three honored this year were **Marvin Arnold**, Leader of

the Fresno Neuropathy Support Group; **Ron Patrick**, Leader of the Napa Neuropathy Support Group; and **Monte Schrader**, recently retired Leader of the Modesto Neuropathy Support Group. Their photos and biographies appear in this newsletter on page 4.

– Continued on page 4

# Roster of Our WNA Information and Support Groups

## 2016 WNA Board of Directors

**Bev Anderson**  
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**Sandra Vinson**  
Emeritus

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Emeritus

Please contact  
your group leader  
or check your  
local paper to  
find out about  
the topic/speaker  
for the upcoming  
meeting.

**Bev Anderson**  
Editor

Newsletter Design by

 **Diane Blakley**  
Designs

## CALIFORNIA

### Alturas

For information, call:  
Bev Anderson (877) 622-6298

### Antioch-Brentwood

3<sup>rd</sup> Wednesday, 2 PM-odd numbered months  
Next meeting Sept. 21  
Antioch-Kaiser  
AMC-1H2 (from hospital lobby)  
Sandra (925) 443-6655

### Auburn

1<sup>st</sup> Monday, 11 AM  
Next meeting, Oct. 3  
Woodside Village MH Park  
12155 Luther Road  
Sharlene McCord (530) 878-8392

### Bakersfield

For information, call  
Bev Anderson 877-622-6298

### Berkeley-Oakland

3<sup>rd</sup> Wed., 3-4 PM  
North Berkeley Senior Center  
1901 Hearst Ave.  
Kathleen Nagel (510) 653-8625

### Carmichael - Eskaton

2<sup>nd</sup> Tuesday, 1:30 PM  
Eskaton, 3939 Walnut Ave.  
Karen Robison (916) 972-1632  
*Call Karen before coming as it is a gated  
community and sometimes the day/time  
changes. She welcomes newcomers!*

### Carmichael - Atria

3<sup>rd</sup> Tuesday, 3:30 PM  
Atria - Carmichael Oaks  
8350 Fair Oaks Boulevard  
Tanysha (916) 944-2323  
Community members welcome

### Castro Valley

2<sup>nd</sup> Wednesday, 1:30 PM  
First Presbyterian Church  
2490 Grove Way (next to Trader Joe)  
Joy Rotz (510) 842-8440

### Clearlake

For information, call  
Bev Anderson (877) 622-6298

### Concord

3<sup>rd</sup> Thursday, 1:30 PM  
Next meeting, Sept 15  
First Christian Church  
3039 Willow Pass Road  
Wayne Korsinen (925)685-0953

### Crescent City

For information, call:  
Bev Anderson (877) 622-6298

### Davis

2<sup>nd</sup> Tuesday, 3:30-5:00 PM  
Davis Senior Center  
646 A Street  
Mary Sprifke (530) 756-5102

### Elk Grove

2<sup>nd</sup> Tuesday, 1 PM  
Elk Grove Senior Center  
8830 Sharkey Avenue  
Roger White (916) 686-4719

### Eureka

For information, call:  
Earlene (707) 496-3625

### Folsom

1<sup>st</sup> Thursday, 12:30 PM  
Berger Rehabilitation  
1301 E. Bidwell St., Folsom  
Bev Anderson (877) 622-6298  
<http://folsom.neuropathysupportgroup.org/>

### Fort Bragg

For information, call:  
Bev Anderson ((707) 964-3327

### Fresno

3<sup>rd</sup> Tuesday, 11:00 AM  
Denny's Restaurant  
1110 East Shaw  
Marvin Arnold (559) 226-9466

### Garberville

For information, call:  
Bev Anderson (877) 622-6298

### Grass Valley

2<sup>nd</sup> Monday, 1:30 PM  
Next meeting, Sept. 12  
GV United Methodist Church  
236 S. Church Street  
Bev Anderson 877-622-6298

### Jackson

For information, call  
Bev Anderson (877) 622-6298

### Lakeport

March meeting day and time, call Mito.  
Lakeport Senior Center  
507 Knocoti Ave.  
Mito Shiraki (707) 245-7605

### Lincoln

For information, call:  
Bev Anderson (877) 622-6298

### Livermore

4<sup>th</sup> Tuesday, 10 AM  
Heritage Estates  
900 E. Stanley Blvd.  
Sandra Grafrath (925) 443-6655

### Madera

For information, call  
Bev Anderson (877) 622-6298

### Merced

2<sup>nd</sup> Thursday, 1 PM  
Next meeting, Sept. 8  
Central Presbyterian Church  
1920 Canal Street  
(The Hoffmeiser Center across the  
street from the church)  
Larry Frice (209) 358-2045

### Modesto

3<sup>rd</sup> Monday, 10:30 AM  
Next meeting, Sept. 19  
Trinity United Presbyterian Church  
1600 Carver Rd., Rm. 503  
Ray (209) 634-4373

### Monterey

3<sup>rd</sup> Wed., 10:30 AM-odd numbered months  
First Presbyterian Church  
501 El Dorado Street  
Dr. William Donovan (831) 625-3407

### Napa

1<sup>st</sup> Thursday, 2 PM  
Napa Senior Center  
1500 Jefferson Street  
Ron Patrick (707) 257-2343  
bonjournapa@hotmail.com

### Oxnard

For information, call:  
Bev Anderson (877) 622-6298

### Placerville

For information, call  
Bev Anderson (877) 622-6298

### Quincy

1<sup>st</sup> Thursday, 1 PM  
Our Savior Lutheran Church  
298 High St.  
Stacey Harrison (530) 283-3702

### Redding

For information, call:  
Tiger Michiels (530) 246-4933

### Redwood City

4<sup>th</sup> Tuesday, 1 PM  
Sequoia Hospital Health and  
Wellness Center  
749 Brewster Avenue  
Danielle LaFlash (415) 297-1815

### Roseville

2<sup>nd</sup> Wednesday, 1PM - odd numbered months  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Bev Anderson (877) 622-6298

### Sacramento

3<sup>rd</sup> Tuesday, 1:30 PM  
Next meeting, Aug. 16  
Northminster Presby. Church  
3235 Pope Street  
Charles Moore (916) 485-7723  
<http://sacramento.neuropathysupportgroup.org/>

### Salinas

Contact Bill Donovan (831) 625-3407

### San Francisco

4<sup>th</sup> Thursday, 10 AM  
UC-San Francisco Med Ctr.  
400 Parnassus Avenue  
Amb. Care Ctr. 8th Flr., Rm A888  
Y-Nhy (e nee) Duong  
Nhy-y.duong@ucsf.edu

### San Jose

3<sup>rd</sup> Saturday, 10:30 AM  
O'Conner Hospital  
2105 Forest Avenue  
SJ DePaul Conf. Rm.  
Danielle LaFlash (415) 297-1815

### San Rafael

3<sup>rd</sup> Wednesday, 1 PM  
Lutheran Church of the Resurrection  
1100 Las Galinas Avenue  
Scott Stokes (415) 246-9156

### Santa Barbara

4<sup>th</sup> Saturday, 10AM - odd numbered months  
The First Methodist Church  
Garden & Anapamu  
Shirley Hopper (805) 689-5939

# President's Message

By Bev Anderson



Has this year seemed to fly by for you like it has for me? It seems like just yesterday that I was rejoicing on the longest night of the year, December 21, and that the days would be getting longer and be staying light later. Now, about the time you get this newsletter, June 21 will have passed and when the days start getting shorter we start toward winter a few minutes at a time.

I thought I might use this passage of time to strongly encourage you to be sure your "Advance Health Care Directive" is completed, copies made, and given to your doctors, the hospital you are most likely to go to in an emergency, and members of your family mentioned in it. The last thing you want is to have something happen and no one has permission to make decisions for you if you are not able to make them yourself. You fall, injure your head and are in a coma, who signs for the treatments needed to restore you to health? Whether you live or die or get treatment that will make it easier for you to recover can depend on there being someone to sign for the treatment. You can get a form from your doctor's office, an attorney, stationery store, drug store, etc. Ask, and if they don't have a usable form, they can tell you where to get it. You fill it in and have it witnessed. It may ask for a notary to do this and it may not. It is a gift you can give yourself. Be sure others in your family have them prepared as well.

Having a will is another necessity. Doing it with an attorney is best so you cover all the bases, but there are forms on line and you can write out your wishes and have it notarized. I belong to a church

- Continued on page 7

## WNA Information and Support Groups – continued from page 2

### **Santa Cruz**

3<sup>rd</sup> Wednesday, 1PM- odd numbered months  
Trinity Presbyterian Church  
420 Melrose Avenue  
For information call  
Bev Anderson (877) 622-6298

### **Santa Maria**

For information, call  
Bev Anderson (877) 622- 6298  
or Mary (805) 344-6845

### **Santa Rosa**

1<sup>st</sup> Thursday, 10:30 AM  
Next meeting, Sept. 1  
Santa Rosa Senior Center  
704 Bennett Valley Road  
Larry Metzger (707) 541-6776

### **Sonoma**

For information, call  
Bev Anderson (877) 622-6298

### **Sonora**

For information, call  
Bev Anderson (877) 622-6298

### **Stockton**

For information, call  
Bev Anderson (877) 622-6298

### **Susanville**

For information, call:  
Bev Anderson (877) 622-6298

### **Thousand Oaks Region**

For information, call  
Bev Anderson (877) 622-6298

### **Truckee**

For information, call:  
Bev Anderson (877) 622-6298

### **Tulare-Visalia**

For information, call  
Bev Anderson (877) 622-6298

### **Turlock**

3<sup>rd</sup> Monday, 1 PM- odd numbered months  
Covenant Village Adm. Bldg. Classroom  
2125 N. Olive St.  
Joanne Waters (209) 634-0683

### **Ukiah**

Last Tuesday, 5:30 PM  
Next meeting, Sept. 27  
North Coast Opportunities (NCO)  
413 N. State St.  
Carole Hester (707) 972-2795

### **Walnut Creek**

4<sup>th</sup> Friday, 10 AM  
Rossmoor, Hillside Clubhouse  
Vista Room  
Karen Hewitt (925) 932-2248

### **West Sacramento**

No meeting until new leader is found  
Sandra Vinson (916) 372-6093  
slvins11@gmail.com

### **Woodland**

For information, call  
Bev Anderson (877) 622-6298

### **Yreka**

For information, call  
Bev Anderson (877) 622-6298

### **Yuba City-Marysville**

For information, call  
Bev Anderson (877) 622-6298

### **NEVADA**

#### **Reno-Sparks**

For information, call  
Bev Anderson (877) 622-6298

### **OREGON**

#### **Brookings**

For information, call  
Robert Levine (541) 469-4075

#### **Grants Pass**

3<sup>rd</sup> Wednesday, 2:00 PM  
No meeting in August  
Club Northwest  
2160 N.W. Vine St.  
Carol Smith (541) 955-4995  
www.grantspass.neuropathysupportgroup.org

#### **Medford**

For information, call  
Bev Anderson (877) 622-6298

#### **Portland**

For information, call  
Bev Anderson (877) 622-6298

#### **Salem**

For information, call  
Bev Anderson (877) 622-6298

### **Help With Health Care Challenges**

If the number is not in your area, call the one listed and ask for the right number.

#### **Medicare**

www.Medicare.gov

...

#### **The Affordable Health Care Act**

For current information go to  
www.HealthCare.gov

...

#### **HICAP**

#### **Health Insurance Counseling**

for seniors and people with disabilities.  
www.cahealthadvocates.org  
/HICAP/  
Call (800) 434-0222 to ask a question or to make an appointment.

...

#### **Health Rights Hotline**

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.  
Tollfree (888) 354-4474  
or TDD (916) 551-2180.  
In Sacramento, (916) 551-2100.  
www.hrh.org.

...

#### **HMO Help Center**

Assistance  
24 hours a day, seven days a week.  
(888) HMO-2219  
or (877) 688-9891 TDD

...

#### **DRA's Health**

**Access Project** Free publications about the health care, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

Start a support group in your area:

Contact Bev Anderson at (877) 622-6298 or [info@pnhelp.org](mailto:info@pnhelp.org)

## PERIPHERAL NEUROPATHY LITERATURE REVIEW By William B. Donovan, M.D.

### DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA a discount to WNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your PCNA/WNA Membership Card and claim the discount.

#### Anodyne Therapy

Infrared Light Therapy equipment - **\$50 off Model Freedom 300 (single leg at a time) and \$50 discount on Model 120 that does both legs at the same time.** Contact: 800-521-6664 or [www.anodynetherapy.com](http://www.anodynetherapy.com)

**HealthLight** Infrared Light Therapy equipment - **10% off Single Boot System and Dual boot system.** Contact: 888-395-3040 or [www.healthlight.us](http://www.healthlight.us)

#### Auburn

**The Footpath**  
825 Lincoln Way  
(530) 885-2091  
[www.footpathshoes.com](http://www.footpathshoes.com)  
**PCNA Discount: 10% off the regular price shoes.**

#### Elk Grove

**Shoes That Fit**  
8649 Elk Grove Blvd.  
(916) 686-1050  
**PCNA Discount: 20% off the regular price shoes.**

#### Fortuna

**Strehl's Family Shoes & Repair**  
Corner of 12th & Main  
1155 Main Street  
(707) 725-2610  
Marilyn Strehl, C.PED  
is a Certified Pedorthic  
**PCNA Discount: 10% off the regular price shoes.**

#### Sacramento

**Midtown Comfort Shoes**  
3400 Folsom Blvd.  
(916) 731-4400  
**PCNA discount: 15% on the regular price.**

– Continued on page 5

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over 100 medical articles a month written on PN.

I review these references and select articles that would appear to be most interesting to us neuropathy sufferers. This is the link to **PubMed** that will take us to the **NLM: [www.ncbi.nlm.nih.gov/sites/entrez](http://www.ncbi.nlm.nih.gov/sites/entrez)**

If you are reading this article on the computer, just click on the above link to go there. If you are reading the print edition of the newsletter, type this link into the address bar of the browser on a computer. If you don't know how, get a librarian or friend to help you.

After you get to **PubMed**, you will see a line that says "**Search PubMed**" followed by "**for**" and a space. Every article in the **NLM** is given a **PMID**, an eight digit identification number. I will give you **PMID** numbers of the selected articles. Type the **PMID** into the space after the "**for**" and click on "**Go**" at the end of the space, or press the ENTER key on your keyboard. You will then see a one paragraph abstract of the article appear, as well as links to related articles.

This month's PMIDs:

- 25843054 This University of California San Diego, randomized double-blind controlled crossover study compared the effects of different concentrations of aerosolized cannabis

(THC) on pain and impairment with 16 patients with diabetic neuropathy. Significant pain relief was dose dependent. There was significant impairment only at the highest dose.

- 26245776 This Mayo Clinic study performed a pilot test of Scrambler®, an electroneurostimulation device, on 37 patients suffering from chemotherapy-induced peripheral neuropathy pain (CIPN). In this uncontrolled trial there was a 53% reduction in pain score, 44% reduction in tingling, and 37% reduction in numbness.
- 25118789 This study tested a portable thermal-metered-dose marijuana inhaler (MDI) on a cohort of 8 patients with chronic neuropathic pain. A 45% reduction in pain intensity was noted 20 minutes post inhalation, returning to baseline in 90 minutes. The only adverse event was tolerable lightheadedness.
- 25345609 This paper reviews experimental data that reveals that neuropathic pain not only results from injury to the nerves, but from the reaction of the immune system to the cytokines and chemokines released by the injured nerves. Neuropathy is an inflammatory autoimmune condition. Solutions addressing this system can hopefully reduce chronic neuropathic pain.
- 25234478 In a review of 16 randomized controlled trials the authors found evidence for the effectiveness of vasodilators, NMDA analogs and bisphosphonates (increase calcium) in the early treatment of complex regional pain syndrome.

## We Honor Three Support Group Leaders – continued from page 1

### MARVIN ARNOLD

#### Leader, Fresno Neuropathy Support Group

Marvin Arnold was born 84 years ago in Fresno, CA. He graduated from Fresno High School and went on to earn his B.A. in business at California State University at Fresno, then called Fresno State College. During this time he worked in his dad's gas station. As he remembers, gas was 17 cents a gallon; ethyl was 20 cents. He also worked in a grocery store.

After college, Marvin enlisted in the U.S. Air Force where he served for two years, first in St. Louis, MO, and later in Goose Bay, Labrador, on the east coast of Canada. Following his military service, he worked for AAA for three years and then Merrill Lynch from 1960-1986. He became a certified financial planner through a two-year course sponsored by U.S.C. Marvin and his wife, Nadia, had three children, a daughter and two sons. He now has five grandchildren and one great-grandchild.

When interviewed for this award, Marvin spoke highly of a vacation he and Nadia took recently to Cambria Pines Lodge in Cambria near Hearst Castle in San Simeon, CA. He said they had gotten a discount so the price was quite

reasonable for lodging in a beautiful facility with three delicious daily meals. The views of the ocean were beautiful as were those of the grounds and they could easily access Hearst Castle tours. He highly recommends it as a get-away place.



Marvin Arnold (left) and L.D. Wright (right),  
Bev Anderson standing and laughing

When asked about his neuropathy, Marvin said that he noticed problems developing in his feet a long time ago. Over 10 years ago, he talked to his doctor who sent him to a neurologist who referred him to U.C. – San Francisco for full diagnosis, which was peripheral neuropathy. Since his father exhibited the same symptoms and

his brother reports he does too, they realize it is hereditary. His is diagnosed as Charcot Marie Tooth (SMT). He says his legs are "dead" up to his knees and now he has problems with his fingers as well. He started using a cane, graduated to a walker, and now uses a scooter. He had his van modified so he can carry his scooter with him.

Marvin has led the Fresno Neuropathy Support Group for a number of years. His active promotion and welcoming of new people has grown the group. They meet over lunch in a separate room in a local Denny's. Marvin is also active in a variety of other local activities near where they live.

– Continued on page 5

## We Honor Three Support Group Leaders – continued from page 4

### RON PATRICK

#### Leader, Napa Neuropathy Support Group

Ron Patrick was born in Amsterdam, New York, where he attended a Catholic elementary school taught by Polish nuns. His Catholic high school was taught by Irish nuns and French was part of his high school curriculum. So at an early age he learned to pick up languages.

After graduating from high school, he was employed by General Electric (G.E.), where he worked for 10 years. During this time he earned a B.A. in mechanical engineering at Union College in Schenectady, N.Y. It took him six years – four years at night after work paid for by G.E. and then two years full-time. Later, he received his M.B.A. from the University of Santa Clara in California. Several years were spent in Germany with G.E. where he also picked up the German language “with a Polish accent,” he said. He finished his career in 1995 after 30 years with IBM which included being an engineering manager.

On vacation in Acapulco, he met his wife, Martine, a French-speaking young woman from Switzerland. She had been an ampere in San Francisco and stopped to vacation in Acapulco on her way home to Switzerland. After they met she decided to return to the United States. They married and have two daughters who are fluent in French and doing well in their careers.

His neuropathy started in 2001 as a result of the toxic products he dealt with at G.E. and IBM. The exposure was constant and he was in close contact as an analyst, walking daily through departments with toxic fumes. Thirteen of the 15 men he worked with died of cancer. This was before OSHA established strict standards that have saved many lives. Now all such toxic materials are basically sent out of the country, Ron stated.

Ron has led the Napa Neuropathy Support Group very ably for some years. One of his most memorable neuropathy achievements happened when he and his wife attended her family reunion in Geneva, Switzerland. At that time, WNA had helped a lady in Geneva start a support group and shipped her neuropathy materials. What a delight it was to set up a meeting with her when Ron and Martine were there. They had a great visit with all speaking fluent French. She reported she enjoyed their visit very much and thought it quite special. She died some months after their visit. Ron and Martine were sad about her passing but glad that she had had a memorable visit tying us together with our international group. She appreciated that through this connection she was not alone in her struggles with neuropathy.



Ron Patrick with Board Member Pam Hart



Monte Schrader



Monte Schrader's Award

### MONTE SCHRADER

#### Leader, Modesto Neuropathy Support Group

Monte Schrader was born on March 5, 1930, in St. Agnes Hospital, Fresno, CA. He graduated from Theodore Roosevelt High School a few years ahead of WNA Founder and President Bev Anderson and he attended Fresno State College, now called California State University at Fresno.

Monte enlisted in the Army, where he was trained as an MP (military police) at Fort Ord, CA, and was sent to Korea to guard prisoners of war (POW). There were 400 U.S. soldiers and a number of South Korean troops as well guarding 76,000 POWs.

On his return home, he lived in Modesto and worked for Turner Hardware at first part-time, but soon was working full-time. He became manager of one store and then became manager of 11 stores throughout the area. He earned his real estate license to become a real estate broker and he worked for Wolverine Real Estate. Monte was also a member of the McHenry Village Association and the local chamber of commerce.

In 1987, he and his wife moved to Missouri to be near family. Their son designed a house they had built there. It included a small guest house where company could stay when they came to visit. After only three years there, his wife died and he returned to Modesto. They had two sons. One passed away. They adopted three girls and there were two stepchildren. He said that at last count, he had 34 grandchildren and since that count several more have been added. They live all over the country including California.

While still in Missouri one day he had trouble getting his shoe off. He saw a nail in his shoe holding it onto his foot and realized he hadn't felt it much. The doctors blamed it on pre-diabetes but he remembers that after he was kneed in the

lower back as a teenager, he sprained his ankle a lot. He estimates 20-30 times. Fairly recently, Monte had a heart attack and bypass surgery. It has been a slow recovery; he doesn't have the strength he used to. However, he considers that he has had a fortunate life and there are many people worse off than he is.

Monte has led the Modesto Neuropathy Support Group for some years and has grown it to one of the larger groups in the Western Neuropathy Association. Although he is well-known for the jokes he had for each meeting, he is not able to continue. The good team that he developed is carrying on in his place but they are looking for a new leader. Many of the responsibilities are covered by the team of volunteers in place so the group leader position should be fairly easy.

### DISCOUNTS FOR WNA MEMBERS

*Continued from page 4*

**West Sacramento Beverly's Never Just Haircuts and Lilly' Nails**  
2007 W. Capitol Ave, West Hair-(916) 372-5606  
Nails-(916) 346-8342  
**PCNA discount: 10% off the regular price.**

#### Neuropathy Support Formula

(1-888-840-7142) is a supplement that a sizable number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back.

**Free DVD on "Coping with Chronic Neuropathy"**, introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at [www.neuropathysupportnetwork.org/order-neuropathy-dvd.html](http://www.neuropathysupportnetwork.org/order-neuropathy-dvd.html)

#### Additional Discounts

Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail [info@pnhelp.org](mailto:info@pnhelp.org).

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

## ERIC CLAPTON REVEALS HE HAS NEUROPATHY

Eric Clapton, noted rock guitarist, says, “I’ve got a lot of pain over the last year. It started with lower back pain, and turned into what they call – peripheral neuropathy – which is where you feel like you have electric shocks going down

your leg.” He says it also makes it hard to play his guitar. He attributes his neuropathy to his addictions to cocaine, heroin, prescription drugs, and alcohol. He is grateful to be alive given what he has done to his body over the years.

## B6 NEEDED BUT TOO MUCH CAN GIVE YOU NEUROPATHY

Recently I (Bev Anderson) was given a supplement to review that someone brought to a meeting. I would have taken it to our compounding pharmacist advisor, but I didn’t have to as it was obvious not to recommend it. It listed 35mg of B6 and instructed to take two tablets a day. This would be 70mg of B6 – we have had people start having symptoms around 50 mg. Many foods we eat contain B6 so if you took this supplement you could be near or over 100mg, which could be a toxic level. Here are examples of foods with high levels of B6, with the ones with the most B6 at the top.

### B6 Foods

1. Sunflower Seeds
2. Pistachio Nuts
3. Fish (tuna, cooked)
4. Turkey (light meat)
5. Lean Pork (sirloin, cooked)
6. Dried Fruit (prunes)
7. Lean Beef (rib, cooked)
8. Bananas
9. Avocados
10. Spinach (cooked)

## PAINMEDICINE NEWS

Painmedicine News reporting on Clinical Pain Medicine says that Olanzapine (Zyprexa, Lilly) shows analgesic properties and may help reduce chronic pain. It is a drug chiefly used by psychiatrists to treat psychosis, mood, sleep, anxiety, etc. From studies conducted, it was found that a lower

dose than usually prescribed may indirectly modulate pain. It might be something to talk to your doctor about and let them investigate through their channels. It seems to have some positive side effects rather than negative.

## D.C. WEEK: TWO NOVEL OPIOIDS WIN TEPID BACKING FROM FDA PANEL

by Shannon Firth, Washington Correspondent, MedPage Today

WASHINGTON – A Federal Drug Administration (FDA) panel recommends a new abuse-deterrent opioid for treating severe pain, while stressing the need for stronger outcomes measures to show deterrence.

FDA Advisors OK Abuse-Deterrent Opioid, Despite Concerns

A joint FDA advisory committee voted 14 to 3 to recommend approval of an abuse-deterrent formulation of extended-release hydrocodone (Vantrela) to treat severe pain, but also wished for better ways to evaluate abuse-deterrence.

Both committees -- the Anesthetic and Analgesic Drug Products Advisory Committee (AADPAC) and the Drug Safety Risk Management Advisory Committee (DSaRM) -- were asked to consider a proposed indication of pain severe

enough to require daily, around-the-clock, long-term opioid treatment for which alternative treatment options are inadequate.

Many of the committee members said their “yes” votes on approval came with some hesitation -- while Teva’s product may be an incremental step in the right direction, there needs to be better outcome measures for reductions in abuse resulting from reformulations, as well as improved outcomes for the treatment of pain, they said.

Meeting a second day, the same panel also voted 9 to 6 to “recommend” approval of a different abuse-deterrent product, this one combining extended release oxycodone with naltrexone (Troxyca). The slim margin is often seen as a null recommendation. (Used with permission)

## ACTIONS BY CONGRESS ON OPIOIDS HAVEN'T INCLUDED LIMITING THEM

For now, Washington appears ready to allow opioid prescriptions to remain widely accessible, a victory for pharmacies, drug makers, and lawmakers say, customers – and instead focus on the treatment of addiction, not its source.

### **Symptoms – What You Tell the Doctor:**

Vague, general descriptions don't help much. But common symptoms are pain, numbness, tingling, analgesia, hyperalgesia (excessive sensitivity, 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-Barre Syndrome, MS, Rheumatoid Arthritis, Lupus, Sjorgen's
- Infection, e.g., Lyme Disease, Shingles, Polio, Leprosy
- Metabolic dysfunction, e.g., diabetes, alcoholism, thyroid
- Toxins, e.g., chemotherapy, insecticides, Hggt, 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<sup>++</sup>, 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](http://www.clinicaltrials.gov).

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## **President's Message** – Continued from page 3

with membership files. I wrote a note indicating what I'd want included in a memorial service and had it put in my membership file. I may change it a bit but it gives some guidance to people who would be the ones to plan it. I will amend the name of our corporation so they have it correct to list for contributions in lieu of flowers. If each member and friend of the Western Neuropathy Association listed our organization for memorial contributions, it could be a significant help in our long-term sustainability in supporting neuropathy sufferers. The daughter of a couple in the Los Angeles area recently did this and a number of people have given memorials in their honor. We send a receipt to the donor and a list of the names of the donors to the family.

Some of you watched the FDA Meeting Webinar on June 10. It was an encouraging time with the FDA asking in-depth questions about symptoms and how they affect us and our responses to treatments we have tried. A full report will come out after August

as the docket is open until August 10 for additional information people may send in. It is our hope that all of this information will make a difference.

This newsletter has additional information from our Annual Conference. The photos in this issue were taken by Ray Nichols, Interim Leader of the Modesto Neuropathy Support Group. The photos last month were taken by Anne Trim, member of our Board of Directors, and others.

A number of groups will not meet in July and/or August with Auburn also not meeting in September because of Labor Day.

I hope you have a wonderful enjoyable and safe summer. Please take care of yourself.

*Bea*



# WESTERN NEUROPATHY ASSOCIATION

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### WHAT IS A NEUROLOGIST?

(Just in case you'd like a definition)

A neurologist is a physician who diagnoses and treats disorders of the nervous system that is comprised of the brain, spinal cord and nerves. These doctors do not perform surgery, but refer patients to neurological surgeons when they determine that surgical intervention is necessary.

Some of the conditions that neurologists diagnose and treat are epilepsy, aneurysms, hydrocephalus, Parkinson's disease, multiple sclerosis, stroke, spinal disc herniation, and spinal disease.

In addition to using diagnostic tests like MRI, CT scans, EEG and EMG, neurologists also employ neurological testing to gauge muscle strength and movement, balance, reflexes, sensation, memory, speech, and other cognitive abilities.



Vanessa Kettler, presenter of "Balance Techniques That Help" led us in a fun time of learning activities that help us keep in shape.

She has videos available for use at home or in a support group.

Annual Conference at the Jelly Belly Factory in Fairfield.



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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.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

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