



WESTERN NEUROPATHY ASSOCIATION

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# Neuropathy Hope

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

## ■ SUPPLEMENTS CAN BE DANGEROUS OR OF NO VALUE

Supplements do not receive any Food and Drug Administration (FDA) approval. They are categorized as food. They can end up on store shelves due to special interests getting Congress to give them a 'pass'. It was thought they were so insipid it didn't matter. They aren't and it does. Supplements are subject to far less oversight than even over the counter (OTC) drugs and hardly any next to prescription drugs. So we have no real confidence what it is we are taking and if any of the claims they make are true. Many reports of health problems, a sizable number of deaths, and many injuries and illnesses have been reported to the FDA. Many more are likely not identified as such and/or are not reported.

The companies that make and sell supplements are not required to prove they do what the labels

say they do – they are also not held accountable. Supplements can be contaminated with microbes or heavy metals, dangerously mislabeled, or intentionally spiked with illegal or prescription drugs. They can also interact negatively with prescription or OTC medications you may be taking. We have samples given to us checked by our compounding pharmacist advisor but he/she goes by what the label says is in it. If manufacturers put something in the supplement that is not on the label, he/she has no way of knowing and doesn't have the time or resources to test each sample to be sure of what is in it.

Is this the scam of the unsuspecting? Billions of dollars are made each year from the sale of questionable supplements. This began in 1970

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## ■ YOUR PHARMACIST CAN BE A BIG HELP

Your pharmacist can do a lot to help you better understand your medications and any drug and supplement interactions that you should be aware of. The list you give your pharmacist for review should include any drugs, supplements, and over the counter medications you are taking. You should also share the list with your doctor.

Knowing what ingredients that you would or may have an adverse reaction to is critical, as well as identifying where those ingredients might pop up. For example, some juice bar stores include supplements (herbs, vitamins) in their drinks. Although mostly that might seem like a good-health idea, or at minimum no harm, some do experience adverse reactions to these added ingredients. Ask preparers about all ingredients in your order. Checking the ingredients of all items that you ingest is recommended even if they are noted as 'health' and/or 'natural' products in health promoting stores.

Below is an example of a list of medications that was presented to an experienced pharmacist for review for possible adverse interactions (not my list).

### **MEDICATION LIST** (example):

Liquid Potassium  
 Lorazepam and Valium (Lorazepam and Valium are not supposed to be taken together.)

- Benicar
- Fluconazole
- Furosemide
- Crestor
- Bisoprolol Fumerate
- Zegerid OTC
- Travatan

### **MEDICATION INTERACTIONS** (example pharmacist report):

- Level 1 - Severe - None
- Level 2 - Moderate
- Zegerid OTC may lower the absorption of Crestor
- Fluconazole increases the effect of Valium
- Fluconazole increases ?? with Flurazepam which is similar to Valium (but is not Valium). You aren't taking Flurazepam based on your medication list. (I think this interaction was included by the pharmacist for completeness. Don't worry about this.)

Zegerid OTC increases the effect of Valium.

(Bev Anderson, Editor)

## Roster of Our WNA Information and Support Groups

### 2016 WNA Board of Directors

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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  
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  
First Christian Church  
3039 Willow Pass Road  
Wayne Korsinen (925)685-0953

#### Costa Mesa

3<sup>rd</sup> Wednesday, 10:00 AM  
Call Martha Woodside  
949-573-0056 for the location

#### 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  
GV United Methodist Church  
236 S. Church Street  
Bev Anderson 877-622-6298

#### Jackson

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

#### Lakeport

Meeting day and time, call Mito.  
Lakeport Senior Center  
507 Konocti 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  
Central Presbyterian Church  
1920 Canal Street  
(The Hoffmeister Center across the  
street from the church)  
Larry Frice (209) 358-2045

#### Modesto

3<sup>rd</sup> Monday, 10:30 AM  
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](mailto: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  
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 Fl., Rm A888  
Y-Nhy (e nee) Duong  
[Nhy-y.duong@ucsf.edu](mailto: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

# President's Message

By Bev Anderson



**By now, you should have received my letter asking for donations and contributions so that we continue to have programs and people in place when I am no longer president.** My goal is to have someone in each of the various areas who is already in the process of reaching out to others and building support groups. My vision is for a network of passionate individuals who will be effective in achieving our goals as well as someone near our headquarters office to coordinate the network/support groups. Our goal is to reach each person with neuropathy, bringing hope through caring, support, research, education, and empowerment. Our chief avenue for this is the development of support groups and communication via e-mail and standard mail. Some teleconference groups are also planned.

**There are new developments in areas with great need.** A new group started in Costa Mesa on Sept. 21. This is so exciting as it is a member and her daughter-in-law that are coordinating and they are bringing together friends and neighbors. An article will be forthcoming and I will be contacting people who have contacted me from Orange County. If you happen to live in that area and want to attend, call Martha Woodside at 949-573-0056 for the location.

This newsletter goes to members and other interested organizations and people. The donation/contribution letter you received went to our total database. **There were three groups that received it with each a different P.S. after the signature.** The one that most of you received said 'thank you for being members'. Another said that your dues are due in the next month or two. Please renew.

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

### Santa Barbara

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

### 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  
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  
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)

## 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.**

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## WE NEED YOUR STORY

This is your opportunity to have your story on file. We want it so we get to know you better, but we also want to have descriptions of a number of kinds of neuropathy that exist in the population we serve. We are asked from time to time for certain information and sometimes researchers want to talk to people who have certain types of neuropathy. If we don't know basics about people we actually know, we can't consult you. We are seeing possibilities where there will be research trials with people other than diabetic neuropathy. We will never share information on #1 below with anyone else. This is so we can contact you in the event your information is needed and a researcher wants to interview you. We will contact you. They will not have any contact information unless you personally give it to them.

So here is what we want to know. You can write a story including the answers to the questions or just answer the questions. If you write it in story form, please don't write a book – 600 maximum words through #12. There is no limit on #13 and #14. I say that because I listened to a caller recently who told me what he thought caused his neuropathy. As he spoke, he realized his symptoms started with an unusual experience that produced similar symptoms that had never really gone away. I'm asking questions that may bring memories that give you an "aha" moment but also some location questions that sometimes give some information that can be surprising. Like the person whose neurologist said, you have the symptoms of a neuropathy only found in a specific site in Russia, which is \_\_\_ and he named it. She said, "My mother was born and raised there and then came to America as a young adult."

1. Your name and contact information – address, phone, e-mail (if you have one)
2. Where and what year were you born? Where did you grow up? Where did you graduate from high school?

3. If you went to college? Which? Where located?
4. How many siblings did you have? (brothers, sisters)
5. At what age did you first have symptoms of neuropathy?
6. At what age were you diagnosed? If not actually diagnosed how did you decide that was what you have?
7. What symptoms did you have then? What symptoms do you have now?
8. Do any family members especially parents and/or siblings have symptoms of neuropathy?
9. Have you seen a neurologist? Have you seen any other doctors besides your primary care doctor?
10. Do you have an idea of the cause or causes, if so what do you and/or your doctors think caused it?
11. What are you doing to help yourself cope with neuropathy?
12. Are you attending a support group? Has this helped you?
13. What else would you like someone to know about your neuropathy?
14. What question(s) would you like to ask about neuropathy?

When you finish writing your story, please e-mail it to [lindsayc@pnhelp.org](mailto:lindsayc@pnhelp.org) and [info@pnhelp.org](mailto:info@pnhelp.org) or mail it to WNA, P.O. Box 276567, Sacramento, CA 95827-6567. Lindsay is our administrative associate so it can be sure to be in the file at our office and not just on my computer. If I'd like to use any of what you send in the newsletter or other publication, I will be in contact with you to ask for permission first.

(Bev Anderson, Editor)

## NEW GROUP STARTING IN COSTA MESA (ORANGE COUNTY)

Martha Woodside assisted by Patty Woodside (her daughter-in-law) had their first meeting on Wednesday, September 21, at 10 AM. It will continue on the 3rd Wednesday of each month. If you would like to attend, please call Martha at 949-573-0056 for the location.

## PERIPHERAL NEUROPATHY LITERATURE REVIEW By William B. Donovan, MD

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:

- 25792176 This is a study of post herpetic neuralgia (PHN) patient's refractory to current therapy including antidepressants, capsaicin, gabapentin and oxycodone. Two weeks after

intravenous ketamine 1mg/kg, 10/15 had over 50% reduction in pain; magnesium sulfate 30mg/kg had a similar effect with 7/15

- 25843054 This University of California San Diego, randomized double-blind controlled crossover study compared the effects of different concentrations of aerosolized cannabis (THC) on refractory pain and impairment in 16 patients with diabetic neuropathy. Significant pain relief was dose dependent. There was significant relief only at the highest dosage (7% THC).
- 25955980 This randomized, placebo-controlled, double-blinded crossover trial at the Massachusetts General Hospital evaluated the effect of 1.5% topical diclofenac (Voltaren®) on the neuropathic pain of postherpetic neuralgia and complex regional pain syndrome. It was effective in reducing pain scores at the level of  $p=0.04$ .
- 26049773 This is a 30-year review of the literature of deep brain magnetic stimulation (DBS) as a treatment for chronic pain. Effectiveness is greater in those who have failed extra cranial methods, including failed back surgery, phantom limb pain and peripheral neuropathy.
- 26141332 This is a very complete Mayo Clinic monograph on the management of peripheral neuropathy from causes to differential diagnosis and evaluation to treatment.

### DISCOUNTS FOR WNA MEMBERS

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**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.

## TAKING CONTROL OF YOUR DISEASE

The August/September issue of NEUROLOGY NOW has more information and help for neuropathy in that issue more than usual. Cedric the Entertainer talks about his father's diabetic nerve pain and even mentions that it is peripheral neuropathy, which the Lyrica commercial doesn't claim. It is an article worth reading. If you don't already get NEUROLOGY NOW, you can sign up at [www.neurologynow.com](http://www.neurologynow.com) or call 800-422-2681 (Mon-Fri 8:30 am - 5 pm EST) which is 5:30 am - 2 pm PST (our time) so call early. Tell them you are a neuropathy patient or caregiver and the magazine comes to you without cost. It is a great magazine on neurological conditions so if you know someone with a central nervous system disease like MS or Parkinson's Disease or some other neurological disease, be sure to encourage them to call or go online to request it too.

Some articles relate to us even though they may be written with another disease in mind. Melissa Armstrong, MD, MSC, FAAN, wrote an article on **5 Ways to Take Control of Your Disease** for people with Parkinson's Disease, but I thought you should have the essence of her article.

She first reminds people that not learning about their disease and taking a proactive stand to do what you can to help yourself is a mistake. Missing

medication and treatments because you are angry about having the disease isn't helpful. "Those who believe they can take charge of their situation function better and report better health and more satisfaction with their lives. They also are more physically active and less depressed and report less pain," she says.

Here are the five ways:

1. Be informed. Learn about your disease.
2. Be connected. Put together a network of family, friends, doctors and others that are your support. She says to investigate support groups. I say, if there is one in your area, join it. If not, see if you can get help to form one. WNA is always willing to help you with a support group.
3. Be involved. Take responsibility for managing your health life. Keep track of symptoms and medications and be sure to take what is prescribed as it is prescribed so you can report to your doctor accurately.
4. Be active. Exercise regularly. Move throughout the day. Advocate for yourself with others involved with your health.
5. Be positive. Focus on possibilities, not challenges. Evaluate options. Talk to people.

(Bev Anderson, Editor)

## PLEASE EXERCISE CAUTION WITH "NEUROPATHY CLINICS"

Clinics promising cures or at least much relief from neuropathy are popping up everywhere. A clinic in one part of the country that has had success will open a facility in another part of the country. They actively tell you they are concerned about helping people and they are there for the good of those they serve. They may appear to be caring people with clean, up to date offices and equipment. The names sound appropriate, too. They offer free initial exams and consults. "We never pressure people," I'm told when contacted. However, a person who contacts the same clinic may be told they must take these treatments or they will lose a foot or leg or at least be in a wheelchair.

Some of them approach our group leaders and want to speak to the group or invite them to a dinner or some such overture. Please don't open the doors of your group to these clinics or whatever they call themselves. The usual rate is now \$5,000-\$10,000 up front without a guarantee or money back if it doesn't help. For that sum a patient could buy the same equipment to use at home on an ongoing basis and other treatments with the first \$1,000 or so and save the rest. They will help you with a long term loan which you may not live long enough to pay off which they call "easy payment loans." There are treatments like

massage, acupuncture, and exercise that can be helpful, but they too must be continued, but for much longer with the amount of money charged by the clinics. Also a person can quit these other alternative treatments if it wasn't helping.

If we had members who reported great improvement that lasted beyond a few months, we might be more supportive. A few notice some residual relief that takes longer to recede. We got excited about one clinic for a while as it seemed like things were changing drastically for people, but when the treatments ended, the help faded as well. That has happened in major clinical trials with some of the equipment as well. For example, we know that infrared light treatments with Anodyne, Health Light or Big Foot does do wonders for some people. However, you have to be able to keep up the treatments for the rest of your life and the best way is with a home unit available from either of the first two listed here. Some of the "clinics" call them Low Level Lasers, but they are not lasers. You can find these in the discount column in this newsletter as they offer discounts to members.

(Bev Anderson, Editor)

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### Supplements Can Be Dangerous Or Be Of No Value – Continued from page 1

when Linus Pauling, a chemist who had won two Nobel Prizes in his field declared that taking 3,000 mg. of vitamin C every day would abolish the common cold, which it didn't. Others came up with other theories. When the FDA started to regulate, a group of industry leaders came together to claim that the supplements were safe because they were "natural" products and testing them would drive the cost up and deprive people of alternative choices. They are required to test for safety but not for results or to report what is in each. In 2013 in Hawaii, for example, there was an outbreak of liver injuries that resulted in 47 hospitalizations, three transplants, and one death, which was traced to a new ingredient in a diet supplement that wasn't reported.

There is an extensive, well written article in the September 2016 issue of Consumer Reports that I recommend you read. It reports what not to do and when you might actually need a supplement. There are some supplements that are helpful. Your doctor and/or your pharmacist can assist you in choosing which ones in the event a diagnosis calls for vitamin support.

To understand why and what the risks are, read the article or talk with your pharmacist, but here are the 15 ingredients in a supplement that they say you should always avoid: (aka = also called)

- Aconite aka Aconti, tuber, aconitum, augustifolium, monkshood, radix aconti, wolfsbane
- Caffeine Powder aka 1,3,7-trimethylxanthin
- Chaparral aka Creosote bush, greasewood, larrea divaricate, larrea tridentate ferreastat Coltsfoot aka coughwart, farfarae folium leaf, foalswort, tussilago farfara
- Comfrey aka blackwort, bruisewort, slippery root, symphytum officinale

- Germander aka teucrium, chamaedrys, viscidum
- Greater Celandine aka celandine, chelidonium majus, chelidonii herba
- Green Tea Extract Powder aka camellia sinensis
- Kava aka ava pepper, kava kava, piper methysticum
- Lobelia aka asthma weed, lobelia inflata, vomit wort, wild tobacco
- Methylsynephrine aka Oxilofrine. p-hydroxyephedrine, 4-HMP
- Pennyroyal Oil aka hedeoma pulegioides, mentha pulegium
- Red Yeast Rice aka monascus purpureus
- Usnic acid aka beard moss, tree moss, usnea
- Yohimbe aka johimbi, pausinystalia yohimbe, yohimbine, corynanthe johimbi

The risks are chiefly to liver, breathing, and heart function problems that they can produce. The following are indicated their use could possibly cause death: Aconite, Caffeine Powder, Chaparral, Comfrey, Kava, Lobelia, Pennyroyal Oil, Yohimbe.

Consumer Report reference: <http://www.consumerreports.org/vitamins-supplements/supplements-can-make-you-sick/>

The best advice is to know what you are taking and why. List everything on your medication list so your doctor knows if something they think of prescribing will conflict with something you are taking. It is also a reason you want all your prescriptions with one pharmacy. Your doctor or a doctor on call may not have checked your list but your pharmacist is likely to see any conflict with a medication you take.

(Bev Anderson, Editor)

## REMINDER FOR VIETNAM VETS

The Department of Veterans Affairs has reversed its denial of Agent Orange-related disability benefits. The decision was due to the illness of an Air Force lieutenant colonel who was gravely ill. It said, "The preponderance of the evidence suggests that you were exposed to herbicide onboard U.S. Air Force C-123K aircrafts. Reasonable doubt in regards to the exposure to certain herbicide to include Agent Orange, as a result of occupational hazards onboard C-123K aircrafts is resolved in your favor." In a further statement it indicated

that cases that were denied may well be approved due to this ruling. "Where cases are not clear cut, reasonable doubt is always decided in the claimant's favor." 8/8/2013

If you are a vet that came into contact with Agent Orange, made a claim that was denied or haven't made a case for your neuropathy coming from your service connection, now is the time to appeal or start a claim.

## STATINS SHOWN TO CAUSE FATIGUE

In a study of more than 1,000 adults, researchers at the University of California, San Diego, found that individuals taking cholesterol-lowering statin drugs are more likely than non-users to experience decreased energy, fatigue upon exertion, or both. The researchers suggest that these findings should be taken into account by doctors when weighing risk versus benefits in prescribing statins.

<http://health.ucsd.edu/news/releases/Pages/2012-06-11-statins-cause-fatigue..> 3/31/2015

Note. It is known that statins can cause neuropathy in some people. If you get neuropathy soon after starting statins, stopping the statins sometimes clears up the neuropathy. (Bev Anderson, Editor)

## President's Message – Continued from page 3

The third one asked the person to become a member. We have over 3,000 entries in the data base. We'd really like to increase the number of members. We were close to breaking 1,000 at one time and then the recession came along. We are not near that now. It helps so much with budgeting, viability when applying for grants, and when advocating for members in legislative affairs when we are asked how many people we are representing.

### **Our 2017 Annual Conference in April will be sponsored by the U.C. Davis Medical Center Neurology Department.**

Darrell O'Sullivan, director on our Board of Directors, and I met with the director of that Department, Dr. Fred Gorin, recently to secure this sponsorship. It is not decided yet whether it will be on the Medical Center campus in Sacramento or the University campus in Davis. Actually, it is a two-year commitment that we are quite excited about. It will involve patients, as usual, but will also involve Residents training to be neurologists. When doctors graduate from medical school they may choose a specialty then or practice for a while and come back to qualify for a specialty later, like neuropathy. U.C. Davis is one of the institutions that trains neurologists. This Conference will give them an opportunity to talk and get acquainted with our organization and with actual neuropathy patients. Knowing people that have neuropathy should give them a greater understanding of neuropathy.

The first year we will be bringing in leading neurologists that we know are committed to working with people with neuropathy that these residents probably have not heard about. By the second year, U.C. Davis is planning to make a major commitment to people with neuropathy by bringing in a neuromuscular neurologist to be on the faculty and see patients.

### **One of the Board's major goals is to find ways to impact the training of neurologists so they are better prepared to treat people with peripheral neuropathy.**

So many times they are trained almost totally on central nervous system diseases and don't connect well with people with peripheral nervous system diseases of which there are over 150 forms of neuropathy. Even in these, subtypes are being discovered that make the number even larger. We have heard from you about your experiences that neurologists are not as prepared to deal with people with neuropathy as they should be and want to do something about it. We thought that if we found a way to impact them at the point they are being trained, it might make a difference.

### **We will be starting with U.C. Davis neurology residents to give them a copy of Peripheral Neuropathy & Neuropathic Pain – Into the Light by Gerard Said, M.D.**

This is the new book from one of the world's leading experts on neuropathy. We want to give one to every neurology resident being trained in California and Oregon but will start with U.C. Davis. We will start contacting organizations for funding help to expand this to others.

**Caregivers.** If you are a caregiver or you have a caregiver, either family member or someone else, be sure to care for them and make sure they have some time away. There are support groups for caregivers. In some communities, like Grass Valley, the local hospital or other agency provides classes and respite opportunities as well as care for the one they care for so they can get away for a time.

Have a delightful October,

*Bev*



# WESTERN NEUROPATHY ASSOCIATION

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tax exempt corporation

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Call WNA using our toll free phone numbers:

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■ PN Information/Advice ■ Support Group Inquiries

**(888) 556-3356** ■ Email: [admin@WNAinfo.org](mailto:admin@WNAinfo.org)

■ Membership Information/Inquiries ■ Sponsorships

■ General Organizational Inquiries ■ [www.WNAinfo.org](http://www.WNAinfo.org)

## ZIKA VIRUS CAUSING NEUROPATHY AS WELL AS BIRTH DEFECTS

Dr. John England, professor and chair of Neurology at LSU Health, New Orleans School of Medicine, and colleagues in Honduras and Venezuela have reported a new neurological complication of infection with the Zika virus. They described the first confirmed case of Zika-associated sensory polyneuropathy in a paper published online by the Journal of the Neurological Sciences.

It also has been found that the Zika virus can precipitate cases of Gullian Barre Syndrome (GBS) and other neurological conditions.

(Bev Anderson, Editor)

### Planning on doing some online shopping? We recommend AmazonSmile.

AmazonSmile is an easy and automatic way for you to support WNA every time you shop, at no cost to you. When you shop at [smile.amazon.com](http://smile.amazon.com), you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that AmazonSmile will donate a portion of the purchase price to the Western Neuropathy Association!!! Make sure you type in our organization.



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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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