



WESTERN NEUROPATHY ASSOCIATION

August 2017

Issue 08

Volume 15

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Neuropathy Hope

Hope through caring, support, research, education, and empowerment

A newsletter for members of Western Neuropathy Association (WNA)

■ CAN MDs EVER BE COMFORTABLE WITH 'ALTERNATIVE MEDICINE'?

Unconventional Remedies Versus Science-Based Treatments

By Alexandria Bachert MPH, Staff Writer, MedPage Today June 30, 2017

MedPage Today's F. Perry Wilson, MD, recently met up with Yale's Steven Novella, MD, a noted critic of alternative and complementary medicine. While physicians like Novella are clearly skeptical of unconventional remedies that lack robust evidentiary support or prior plausibility, many patients continue to experiment with supplements and homeopathic remedies, while still seeing their regular doctors.

We reached out to experts from a variety of specialties to get their thoughts on alternative medicine and whether it creates challenges in caring for patients.

Do you make a habit of asking patients about unconventional remedies they are taking, and how well does that work? Are patients usually honest about what they use?

David Spiegel, MD, Stanford University: Yes, and it works well. Patients are usually proud about the extra efforts they are making to augment their health.

Mikhail Kogan, MD, George Washington University School of Medicine and Health Sciences: All providers should ask all patients what remedies they are taking, whether they are herbal, supplements, or homeopathics. Patients often don't disclose this information to their physicians out of concern that they will be judged. Expressing understanding and interest in natural products not only will help to minimize risk of interactions and side effects but will improve patient doctor alliance.

Aaron Michelfelder, MD, Loyola Medicine: It is crucial that physicians know about all therapies a patient is utilizing so that we can think very holistically about a patient's care. I ask patients about other remedies and treatments routinely, and I phrase it in a way that lets patients know I am open to alternatives. An example is, "Sometimes people use herbal therapies to help lower their blood pressure, have you tried herbal or any other types of therapies for your condition?"

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■ GRANT WHITNEY CO-FOUNDER OF THE WESTERN NEUROPATHY ASSOCIATION PASSES

By Bev Anderson

In 1998 I was on the Auburn Interfaith Food Closet Board of Directors as secretary. Barbara Whitney was president. We were asked by Placer County to move our organization. The Board asked Barbara and I to check to see if we could fit in another building. She brought along her husband, Grant, a retired architect. He measured and assured us we could fit into the other building.

When I got out of the car that day, I had my cane to walk. I said, "I use a cane because I have peripheral neuropathy."

He said, "I do, too. Have you joined The Neuropathy Association?" I'd not heard of it but joined online that night and received their information. I saw that

there were support groups here and there across the country but none near us. So I asked Grant if he were game to see if there were people in our area interested in having a support group. He agreed. We found we could use Baker's Square (now Black Bear Diner) on the first Monday. We thought a few might come that first Monday in November 1998, I made 12 copies of the handouts.

The Auburn Journal put it at the top of the FYI column on the front page and people responded. Thirty-three people showed up. I started the meeting while Grant went to Kinkos to make more copies. At the end, the people had enjoyed

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WESTERN NEUROPATHY ASSOCIATION

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www.WNAinfo.org

Roster of Our WNA Information and Support Groups

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**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
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CALIFORNIA

Antioch-Brentwood

3rd Wednesday, 2 PM (odd numbered months)
Antioch-Kaiser, Deer Valley Rooms 1 & 2
Marty Price (925) 626-7988

Auburn

Next meeting Oct. 2, 2017
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

Berkeley-Oakland

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

Carmichael - Atria

Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
For information, call:
Ryan Harris 916-342-8440

Castro Valley

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

Concord

No meeting in August
First Christian Church
3039 Willow Pass Road
Wayne Korsinen (925)685-0953

Costa Mesa

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

Davis

No meeting in August
Davis Senior Center, 646 A Street
Mary Sprifke (530) 756-5102

Elk Grove

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

Folsom

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

Fresno

3rd Tuesday, 11:00 AM
Denny's Restaurant, 1110 East Shaw
Bonnie Zimmerman (559) 313-6140

Grass Valley

No meeting in August
GV United Methodist Church
236 S. Church Street
Bev Anderson 877-622-6298

Livermore

4th Tuesday, 10 AM
Heritage Estates, 900 E. Stanley Blvd.
Lee Parlett (925) 292-9280

Merced

No meeting in August
Central Presbyterian Church
1920 Canal Street
(The Hoffmeier Center across the street from
the church)
Larry Frice (209) 358-2045

Modesto

No meeting in August
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Ray (209) 634-4373

Monterey

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

Napa

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

Placerville

Organizational Meeting
1:00 PM, Wednesday, Aug. 9
El Dorado Senior Center
937 Spring Street
Bev Anderson 877-622-6298

Redwood City

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

Roseville

2nd Wednesday, 1PM (odd numbered months)
Sierra Point Sr. Res., 5161 Foothills Blvd.
Stan Pashote (916) 409-5747

Sacramento

No meeting in July
Northminster Presby. Church
3235 Pope Street
Charles Moore (916) 485-7723
<http://sacramento.neuropathysupportgroup.org/>

San Jose

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

San Rafael

No meeting in August
Lutheran Church of the Resurrection
1100 Las Galinas Avenue
Scott Stokes (415) 246-9156

Santa Barbara

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

Santa Cruz

3rd Wednesday, 1PM (odd numbered months)
Trinity Presbyterian Church
420 Melrose Avenue
Mary Ann Leer (831) 477-1239

Santa Rosa

No meeting in August
Santa Rosa Senior Center
704 Bennett Valley Road
Larry Metzger (707) 541-6776

Thousand Oaks Region

To be announced
Daytime meeting
Angie Becerra 805-390-2999

Ukiah

Oct. 3 meeting
1st Tuesday, 1:30 PM
Ukiah Senior Center
499 Leslie St.
Carole Hester (707) 972-2795

Walnut Creek

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

Woodland

3rd Tuesday, 1:00 PM
Woodland Senior Center
2001 East Street
Sue (530) 405-6304

OREGON

Grants Pass

No meeting in August
Club Northwest
2160 N.W. Vine St.
Carol Smith (541) 955-4995
<http://grantspass.neuropathysupportgroup.org>

For information on groups in the following areas or any other place you are interested in finding out about a support group, call Bev Anderson at (877) 622-6298. She is actively trying to open new groups and re-open closed groups. Check with her about a group in your area especially if you would volunteer to be the leader.

California: Alturas, Bakersfield, Clearlake, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Lodi, Madera, Mt. Shasta, Oxnard, Placerville, Quincy, Redding, Salinas, San Francisco, Santa Maria, Sonoma, Sonora, Stockton, Susanville, Truckee, Tulare-Visalia, Turlock, West Sacramento, Weed, Yreka, Yuba City-Marysville. **Nevada:** Reno-Sparks. **Oregon:** Brookings, Medford, Portland, Salem.

President's Message By Bev Anderson



I hope you are having an enjoyable summer – visits from friends near and far that you may be haven't seen for some time and/or gardening and reaping the rewards of harvesting fruit and vegetables. Relaxation, friendships, fresh fruits and vegetables – all good for our physical and mental well-being.

Speaking of good for you foods – yogurt pops. If you eat yogurt, here is a summer treat I enjoy. I'm a Raley's customer so I buy the Sunnyside yogurt, but you can use any other kind of regular yogurt in the small tubs. It takes buying a box or bag of popsicles and collecting the sticks or you can also buy just the sticks. You can also try plastic spoons, but be sure to use the sturdier ones. Take a popsicle stick (or spoon) and put it down in the middle of the yogurt and place the yogurt in the freezer. The next day or later, run some warm water over the side of the carton to loosen the popsicle away from the container. Pull the container away. Enjoy.

NAF Conference. WNA Board members Darrell O'Sullivan and Brad Livingood and their wives, Mary and Denise, respectively, and I attended the Neuropathy Action Foundation Conference in Los Angeles on June 23. A report will be in the September newsletter. Always a wealth of knowledge to be found there.

WNA goods. Remember that we have WNA t-shirts on sale. They are good for summer wear and promoting awareness. There are also books and videos in our store. You can purchase online with a credit card or send in a check. You can also call our administrative coordinator, Lindsay, toll-free at 888-556-3356. She can take your order over the phone if you don't have access to a computer or just want the additional assistance.

A little bit each month goes a long way. Did you know that you can support the work of the Western Neuropathy Association by sending in a monthly contribution instead of one large check? Some supporters mail in a monthly check. Some arrange with their bank to have an amount deducted monthly from their checking or savings account and sent in. Others sign up online via our website. Their dues are paid out of this monthly donation so they are assured of always having a current membership.

Please take care of yourself. You are precious to many.

Bev

SHORT EDITORIAL NOTES

Causes of Neuropathy: I came across an article from 1983 that reminded me of another cause for neuropathy. Multiple myeloma has neuropathy as an uncommon complication. Most of the time it is a large fiber neuropathy, which means it affects the axons. However, in a few cases, it produces small fiber neuropathy. When I hear about people diagnosed with idiopathic neuropathy, I wish that I could walk them through a number of causes and listen for the "aha" of someone realizing the cause of their neuropathy. In our July issue, Lyme disease was featured. I wondered how many people who are or were hunters, hikers, and/or dog owners thought they should ask their neurologist or primary care physician about up to date blood and urine tests for Lyme disease to see if by some chance that is the cause of their neuropathy. It only takes one tick bite of the right kind to cause the disease. Symptoms can

easily be attributed to something like a light case of the flu until it becomes chronic and produces more problems that are, then, called neuropathy. If it is a young tick, the person may not even realize a tick had bit them.

I remember the day I was speaking to a group and mentioned that oil painting can cause neuropathy if the paint is not cleaned off quickly – the red and yellow pigments are especially toxic. This can also be true of people who do ceramic painting and firing. The hand painted pottery that used to be so popular is not done now as the people painting it were dying early. Neuropathy along with other toxin reactions were impacting their health.

We now know that nicotine is a toxin and heavy smoking can cause neuropathy as does heavy alcohol consumption.

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".

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 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

HealthLight Infrared Light Therapy equipment - 10% off Single Boot System and Dual boot system.

Contact: 888-395-3040 or www.healthlight.us

Auburn

The Footpath

825 Lincoln Way
(530) 885-2091
www.footpathshoes.com
WNA Discount: 10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
(916) 686-1050
WNA 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
WNA Discount: 10% off the regular price shoes.

West Sacramento

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

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MORE INFORMATION ON TICKS AND LYME DISEASE

If you've been bitten, don't panic. Save the tick if you can. And most importantly, watch for symptoms.

Lyme disease has three stages. While each stage and its symptoms usually progress into the next, the rate at which Lyme disease spreads varies significantly.

1. Early Localized Stage

Lyme symptoms usually appear days or weeks after infection. At this stage Lyme is the easiest to cure. Symptoms can include:

- Skin rash, commonly — but not always — a circular or bullseye rash around the bite area
- Headaches or stiff neck
- Flu-like ailments, including fever or chills
- Muscle and joint pain
- Profound fatigue or lack of energy
- A small bump or redness at tick bite
- Swollen lymph nodes

2. Early Disseminated Stage

If untreated, the Lyme infection can expand throughout the body causing a wider range of symptoms. These symptoms usually appear weeks or months after infection and can include:

- Expanding skin rash (more or larger rashes covering more parts of the body)
- Pain or numbness in arms and legs
- Extreme joint pain
- Profound fatigue
- Headaches and lack of energy
- Fainting
- Bell's palsy (facial paralysis)
- Poor memory or inability to concentrate
- Heart palpitations

3. Late-Stage Lyme

Symptoms of late-stage Lyme can appear months or even years after infection. For some, these symptoms may be the first sign of Lyme disease, making it even more difficult to diagnose. Symptoms in this later stage of infection are more severe and include:

- Arthritis, particularly in the knee or near the point of infection
- Nervous system problems including numbness and tingling in hands, feet, or back
- Severe headaches or migraines
- Problems with memory, hearing, and vision
- Stiff neck due to swollen tissues
- Chronic fatigue
- Problems with mood or sleep
- Inflammation of the brain
- Inflammation of the heart

It is important to note that you could have some, and not all, of the symptoms at every stage. If you suspect you may have Lyme disease, talk to your doctor.

Should you get tested for Lyme disease?

The current laboratory diagnostic tests for Lyme disease are blood tests to detect the antibodies created by your body to fight and kill the bacteria

that causes Lyme. This bacteria is called *Borrelia burgdorferi*, or Bb.

However, with early-stage Lyme your antibodies may not have had time to develop in your body. Therefore a blood test at this time will often appear negative. It can take your body up to two months to develop enough antibodies to be detected by these tests. In other words you could have Lyme but the test results will still come up negative.

What does this mean for you? By all means, if your doctor recommends a test, get the test. But don't rely on it completely. Trust your body and trust your homework. Monitor your symptoms. Ask questions.

How do doctors test for Lyme disease?

Lyme disease is typically assessed based on clinical diagnosis, in combination with laboratory tests. There is much debate over the accuracy and reliability of the laboratory tests and the likelihood of false positives and false negatives. The following tests are FDA-approved for diagnosis:

- The Enzyme-linked immunosorbent assay or ELISA is the first step. This test detects antibodies to *B. burgdorferi* and, if positive, is followed up by the Western Blot test.
- The western blot is usually run as a second-stage to confirm the diagnosis following a positive ELISA result. The Western blot detects antibodies to several proteins of *B. burgdorferi*. Together these tests are known as the ELISA/Western Blot.
- Alternatively, the polymerase chain reaction (PCR) is a highly sensitive test that detects DNA from the *Borrelia* bacteria in fluid drawn from an infected joint (typically synovial or cerebrospinal fluid). It is much less commonly used as the bacteria are most likely to bind to joint and nerve tissues and more difficult to detect.

Testing for late-stage Lyme disease

If you suspect you are experiencing symptoms of late-stage Lyme disease, it makes sense to talk to your doctor about getting tested. The test is the same regardless of the stage of Lyme disease. Again, don't rely on it completely. Trust your body and do your homework. Ask questions.

For further information access the website below and/or get in touch with this organization. All this information was borrowed from their website. Thanks to the research done by Roger White, leader of the WNA Elk Grove Support Group.

Bay Area Lyme Foundation
884 Portola Road, Suite A7
Portola Valley, CA 94028
Tel: 650.530.2439
Fax: 855.229.5963
info@bayarealyme.org

Can MDs Ever Be Comfortable With 'Alternative Medicine'? – Continued from page 1

Richard Bedlack, MD, PhD, Duke ALS Clinic: I make it clear from day one that I do not have a way to stop or reverse ALS, and that I am personally trying to find this through research. Some folks cannot get into any studies, and some don't want to put up with the burdens associated with them. Thus, I mention to every new patient that I am open to discussing their self-experimentation with alternative therapies.

Joep Perk, MD, Linnaeus University: I do whenever I suspect they do. It does work fairly well as I tend not to be accusing. Honest? I am afraid many patients remain silent about it.

What do you say to patients who say they want to try alternative medicine instead of science-based treatments that you recommend?

Perk: I try to explain what science-based treatment represents and if it concerns vital medication I make quite an effort to convince and usually engage a nearest relative. My message is clear: I will not take any responsibility if they start on alternative treatment.

Steven E. Nissen MD, Cleveland Clinic Foundation: I strongly advise patients not to take any of these products. I explain that supplements are not regulated by the FDA, may or may not contain the ingredients claimed, and may adversely interact with prescription products.

Spiegel: I advise them to carefully consider the risks and benefits, and to discuss their decisions with the doctors caring for them. There are risk/benefit tradeoffs in scientific medical care as well as "alternatives." I prefer the term "integrative" to "alternative" medicine to indicate that most of the time patients can do both.

Andrew T. Pavia MD, University of Utah: I think of non-traditional medicines in two groups. One is those likely to be safe, not terribly expensive, and used to complement traditional medicines that may be needed. They may or may not be helping but are not likely to harm the patient's body or pocket. As long as we talk about the use of these products, I am generally supportive. The other group are remedies that are of unknown composition and safety and are very expensive. They are making someone rich but the patient poor. These usually are sold with extravagant and unproven claims.

Bedlack: I try to make sure my patients have as much available information about the alternative therapy as possible. I make suggestions on which alternative therapies have more plausible mechanisms, better pre-clinical data, more believable anecdotes and better safety. I tell them what I think; that is really the best I can do. I will always support patients and

reassure them that I will continue to be their doctor even if they do things that I personally do not agree with.

Kogan: I like to find out why they want to do it. If I know that the modality they are going to try is safe, possibly helpful, and they don't waste time not using a possibly much more effective treatment, I never restrict them. It matters to be patient-centered. We look at healing as a journey where a patient's intuitive selection of modalities is often a critical component of finding the best approach.

Michelfelder: If the alternative therapies are inexpensive and safe, and the condition does not need immediate action, then there is no harm in trying an alternative therapy, and I say "why not?" Many of our current medications have come from herbal therapies, and there is much to be learned about alternative therapies. I can help patients decide when to use alternative therapies, and when conventional medical therapies are necessary. We are a much better team when a doctor and a patient have open and honest conversations about all possible therapies for a condition.

Do you support more regulation of supplements and "natural" medicines, including their marketing as well as their production?

Michelfelder: I support more regulation of supplements to ensure that the products contain the advertised ingredients, do not contain harmful contaminants, and contain consistent levels of the advertised ingredients. I also support testing of natural medicine for safety. I also think that all people who make recommendations to others about treating health conditions should be trained and licensed.

Bedlack: I think it would be great to have a way to hold the proponents of alternative therapies accountable for the claims they make.

Spiegel: We do want to be sure they contain what they are supposed to, which is not always the case, and that claims made about them have some basis in fact.

Pavia: An overarching issue is the lack of standards in the production, content, or quality of supplements and nutritional products. Patients and their care team need to know what is actually in the bottle. In the world of HIV medicine, we

DISCOUNTS FOR WNA MEMBERS

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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

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.

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

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always ask about supplements and non-traditional therapies. Some have important interactions with HIV medicines and there are potentially dangerous combinations.

Kogan: Absolutely. The current status quo is a wild, wild west where any company can produce a product that may not even contain the active ingredients listed on the label. Most of Europe regulates supplements very similar to medications, and that is what we need to do in U.S. Better regulations will assure better quality of supplements even if the cost will rise. Having a market saturated with cheap, poor quality retail brand supplements that have little to no therapeutic value continues to create “bad rap” for the industry that has some very high quality brands that try to do the right thing.

Perk: Yes, the rules here in Sweden are quite stiff and the Swedish Medical Agency keeps a close critical eye on it, but occasionally misleading marketing slips through. Our problem is that the SMA has no real authority on internet marketing from abroad so we have a stream of potentially harmful substances that are imported via postal delivery.

Editor's Note: Besides the treatments advertised by big ads in newspapers that cost thousands of dollars to leave you basically the same as you were prior to using them or worse, there are over-the-counter concoctions of many kinds that are touted as being helpful neuropathy when in fact they are worthless or cause damage. The key is to be convinced enough that you can achieve a placebo effect, which can be as much as 50% improvement because you believe so strongly in it. But when reality sets in and you realize there is no difference or you don't feel as well, you know it was not for you.

Neuropathy Support Formula (now called Nerve Renew) is available over-the-counter. We had our compounding pharmacist advisor check it out. It was reported as not containing harmful ingredients. A sizable number of people in our support groups tried it and said it helped them. Now, regularly, some other Nerve Renew clone product is released. We also want to check out these out as well. Some are basically the same product with one new ingredient introduced so it can be classified as different. However, sometimes that new ingredient is a problem.

At the Neuropathy Action Foundation Conference I was given a packet of dietary supplements having 14 pills or capsules – to be taken one pill, twice a day so it was a week's supply. It is called Nutrition For Nerves. I recommend extreme caution in the use of this product; I myself would not use it. The product has 30 mg of Vitamin B6. If you also take a multivitamin and eat

something, you could likely be ingesting over 50 mg which puts you in danger of getting neuropathy. Here are some foods that have lots of B6: fortified breakfast cereals, pork, turkey, beef, bananas, chickpeas, potatoes, pistachios. You get B6 if you eat much at all so fortification is not usually needed. The product also lists 250 mg of alpha lipoic acid and does not indicate which kind it is. It is likely the standard type which requires 300 mg twice a day to be a viable dose. Some of the other dosages look out of scale as well. Be careful of what over the counter help you choose. Also seek the advice of your physician.

While we are all humans, there is a wide range of how each of us reacts to medications or over-the-counter products or even foods (for example, foods with gluten). One product might help one person's conditions, but not their neighbor's same condition. For neuropathy sufferers, this consistency may be due to the type of neuropathy we have. I encourage people to try alpha lipoic acid. It helps me a great deal. I took it for some months and rejoiced that certain symptoms were gone and others much better. I forgot to put it in my morning pills for two weeks and the symptoms started to return. I caught it and added it back in my morning pill routine; the symptoms that my doctor and I were despairing of trying to treat went away again and have stayed away.

I have HSAN (Hereditary, Sensory, Autonomic Neuropathy). It is one of the 10 or more types of hereditary peripheral neuropathy. Charcot-Marie-Tooth Disease is the most commonly known and is basically HSMN (Hereditary, Sensory, Motor Neuropathy). It is one of the ways you can help yourself understand the type of neuropathy you have. There are three types of peripheral nerves:

- **Sensory** – feeling of heat, cold, touch, pain, numbness, etc. The numbness can give a person a feeling of loss of balance at times but not to the intensity that the motor nerves do.
- **Motor** – the connection of nerves with muscles dealing with movement, balance, etc.
- **Autonomic** – nerves that control all organs of the body - heart, lungs, bowel function, urinary tract function, sexual function, and a variety of other interactions that keep us being alive.

Some neuropathy affects only one of these nerve types; some include all three.

For me alpha lipoic acid helps some with numbness and pain, but its chief benefit is dealing with the autonomic problems.

NOTE TO WNA FROM A READER

I enjoy your newsletter. I wanted to tell you that foot massages every 10 days has helped my neuropathy. I am able to sleep up to six hours per night, which is very good for this 87-year-old.

– James Hall

Grant Whitney Co-Founder Of The Western Neuropathy Association Died - Continued from page 1

themselves and learned a lot so they said, "We're meeting again next month aren't we?" I checked and found we could use the room on the first Monday night ongoing. We met there, then at the hospital, and now Woodside Village Mobilehome Park. The group meets at 11:00 AM on the first Monday. I think Sharlene McCord, the current leader, may have been there that night. If not, she started shortly afterward. There are several other veteran members, but many new people come as well. It is still a popular group. The Sacramento area had received the publicity and a couple of men decided they should have a group and started another in December 1998. Other groups have started from that beginning – today, we have groups still forming.



active in construction and as a Registered Architect in Nebraska and California. From 1981 to 1995, Grant and Barbara owned and managed a wood/alternative energy heating distribution company in Auburn.

Grant was active in many organizations including the Western Neuropathy Association. He and Barbara were avid skiers making 30 to 40 trips to the summit per season. Grant is survived by his brother George and his children Julie and Tim, as well as one granddaughter Elle, two grandsons Mason and Parker, and a great granddaughter Lilly. He was preceded in death by his daughter Gayle Suzanne, his son Gregg Quinton, and wife Barbara.

In Memoriam – Grant Q. Whitney

From The Auburn Journal - *I'm delighted they used a photo of both Grant and Barbara. When Grant was asked how he was on any given day, he would say, "I woke up." He resigned from the Board some years ago and has not been active recently, but we are using our current name herein.*

Grant Q. Whitney, a resident of Meadow Vista, Clipper Gap, and Auburn, California, since 1981, no longer "wakes up." Grant was born in Omaha, Nebraska, and raised in the western United States until 1950, when his family moved back to Nebraska. He married Barbara Louise Young in 1953, and graduated from the University of Nebraska as an architectural engineer. Grant was

The family held a Celebration of Life gathering for Grant. Any memorial donations should be sent to the Western Neuropathy Association, P.O. Box 276567 Sacramento, CA 95827-6567 or by visiting: www.wnainfo.org

Published in Gold Country Media Newspapers on June 28, 2017
The Celebration of Life was held on Saturday, July 22, 2017, First Congregational Church, 710 Auburn Ravine Road. from 1:00 to 3:00 PM in the Fellowship Hall. It was open house style – people could come and go as they pleased. Grant was an AA member and the group of which he was a member is helping the family with this event. Grant actively told people that it was alcohol that gave him neuropathy.

WNA SHIRTS NOW AVAILABLE

We have polo and t-shirts available for purchase. Polo shirts are stone color and t-shirts are either white or black. Sizes are men adult sizes small, medium, large, extra-large, additional price for 2x-5xs. (\$2 extra per shirt). Shipping is \$2 per shirt. Price includes tax. Allow approximately 3 weeks order time. To order: fill out the form below and return with your check:

Name _____
 Phone (_____) _____
 Address _____
 Email: _____

Polo shirt (stone) \$28.00 ea. Qty: _____ Size: _____ \$ _____
 add \$2. per shirt for 2x, 3x, 4x, or 5x \$ _____
 Nerve T-shirt (white) \$18.00 ea. Qty: _____ Size: _____ \$ _____
 add \$2. per shirt for 2x, 3x, 4x, or 5x \$ _____
 Nerve T-shirt (black) \$18.00 ea. Qty: _____ Size: _____ \$ _____
 add \$2. per shirt for 2x, 3x, 4x, or 5x \$ _____

Shipping: \$2 per shirt # of Shirts ordered: _____ X \$2. \$ _____

Order total: \$ _____

Mail your check to WNA, P.O. Box 276567, Sacramento, CA 95827-6567





WESTERN NEUROPATHY ASSOCIATION

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P.O. Box 276567, Sacramento, CA 95827-6567

Call WNA using our toll free phone numbers:

(877) 622-6298 ■ Email: info@WNAinfo.org

■ PN Information/Advice ■ Support Group Inquiries

(888) 556-3356 ■ Email: admin@WNAinfo.org

■ Membership Information/Inquiries ■ Sponsorships

■ General Organizational Inquiries ■ www.WNAinfo.org

NEW MEMBER OF THE WNA BOARD OF DIRECTORS

On Monday, July 10, 2017 Antonio Benevento was elected as a member of the Western Neuropathy Association Board of Directors. Antonio is a financial planner with LPL Financial with his office in Folsom. He also serves as chairman of the Board of The Wish List Project, which helps youth meet their goals for education and enrichment when families are unable to help them make the progress they could in order to be successful adults. He has been married five years and lives in El Dorado Hills. He loves classic cars and enjoys cooking Italian food. His parents have a restaurant in Folsom.



Antonio found the WNA through Volunteer Match noting that we listed the need for a financial person and he has a degree in finance. He likes to help people to plan their estate including a donation to a nonprofit organization as a legacy that continues to live and help people. He will be helping us with our corporate financial planning including a variety of approaches to fundraising. He is discovering neuropathy and realizing he knows people that likely have it.



Western Neuropathy Association (WNA)

A California public benefit, nonprofit,
tax-exempt corporation.

Bev Anderson, Editor

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(877) 622-6298 ■ (888) 556-3356

info@WNAinfo.org ■ www.WNAinfo.org

WNA Headquarters: admin@WNAinfo.org

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.

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. Western Neuropathy Association (WNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.



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