



WESTERN NEUROPATHY ASSOCIATION

April 2017
Issue 04
Volume 15

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WESTERN NEUROPATHY ASSOCIATION
 P.O. Box 276567
 Sacramento, CA 95827-6567
 877-622-6298
 888-556-3356
 info@WNAinfo.org
 www.WNAinfo.org

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ WESTERN NEUROPATHY ASSOCIATION ANNUAL REPORT FOR 2016

2016 was a busy year for the Western Neuropathy Association with some major advances and persistent challenges.

A new Strategic Three-Year Plan was adopted late in 2015. Much Board time in 2016 was spent in bringing our infrastructure up to date as well. All policies were reviewed, updated, and a standard approach to structure them adopted. A few are being completed in 2017 and a few new ones needed are being developed.

The biggest change was to restructure the way we manage support group funds. From every \$30 dues, we set aside \$6 for specific use to support our groups. We were allocating each support group's funds separately as individual accounts according to the amount of dues received. Some groups never used any of the funds and some needed a bit more some years. When we conducted an activity that involved and/or benefited all groups that should come from that fund, it sometimes was not readily available. This skewed our financial perception on the IRS 990 EZ. So, we combined the funds into one fund making it easier and more efficient to track and having it more readily available for the support groups. One benefit of the new policy is related to the distribution of information packets for those in support groups, including new members. This helps us to maintain consistent information. These will continue to be available to group leaders as needed. Leaders are free to include additional resources if they choose to do so. Group leaders may still send in Requests for Reimbursement of Funds for items such as copies, name tags, and other items specifically needed for the group to help fulfill our mission goals. As support groups are a main function of WNA, some of the general fund is also used to support groups.

Support Group Leaders of the Year for 2015 were Ron Patrick, Napa; Marvin Arnold, Fresno; and Monte Schrader, Modesto.

The Annual Conference on April 20 was located at the Jelly Belly Factory and featured a research theme. We were introduced to Bruce Hammock, PhD, and continue to follow the progress of his treatment that we saw in action on videos of animal testing. Leonard Chuck, MD, spoke about the research done at Diablo Research in Walnut Creek. A few people are currently participating in one of the research projects. Discussions were held at

each table after lunch responding to questions that would help the FDA learn more about neuropathy patients. All the notes were compiled and sent to the FDA in time for their special day of listening to patients and doctors talk about neuropathy. Vanessa Kettler closed the day with a grand set of exercises to help with balance. Our first silent auction was held during this conference which also included a raffle.

Lindsay Campoy was hired as administrative associate to replace our previously assigned staff and is our part-time clerical support. She is employed by Association Resource Center (ARC) where our office is located. About 25 small to large nonprofit organizations are located in this office. More than 25 staff in a variety of specialties are also employed at ARC; and several of them help provide support to us as well.

The Big Day of Giving was a bit confusing due to the technology difficulties of the contractor, but we did collect more funds than we initially anticipated given the problems connecting on that day. We received a larger portion of the matching funds designated for that day.

Director Anne Trim of our Board of Directors organized a group for a health fair in Woodland including Director Sonya Wells and Anne's mother and another at Denio's Auction in Roseville which included Anne, her fiancé, Sonya and Sonya's daughter, Elena. Anne also put together a group that organized a gift wrapping booth at the outlets in Folsom.

In May, there was the major meeting on neuropathy at the FDA (Food and Drug Administration). We had two representatives there and some watched the five-hour live streaming from Bethesda, Maryland. It dealt with getting acquainted with neuropathy, talking to patients, and looking at various treatments. It was hopeful that those in this agency will have more knowledge of neuropathy as a result of this day and the notes we sent them.

We have been researching to identify a project that could help with the woeful lack of knowledge by doctors as to what neuropathy is and how to treat it. In 2016, we

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ANNUAL CONFERENCE, APRIL 18, 2017

More Information and Registration Form on Page 7

Roster of Our WNA Information and Support Groups

2017 WNA Board of Directors

Bev Anderson
President

Karen C. Polastri, IOM
Vice President

Anne Trim
Secretary

Darrell O'Sullivan
Treasurer

Sandra Grafrath
Director

Pam Hart
Director

Brad Livingood
Director

Sonya Wells, PharmD, MPH
Director

Emeritus Council

Michael Green
Emeritus

Johnathan Istilart
Emeritus

Arvin Magusara
Emeritus

Casimir Sammanasu
Emeritus


Sandra Vinson
Emeritus

Dick Ward
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

3rd Wednesday, 2 PM- odd numbered months
Antioch-Kaiser
AMC-1H2 (from hospital lobby)
Marty Price (925) 626-7988

Auburn

1st Monday, 11 AM
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

Bakersfield

For information, call
Bev Anderson 877-622-6298

Berkeley-Oakland

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

Carmichael - Eskaton

2nd 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

Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
For information, call:
Bev Anderson (877) 622-6298

Castro Valley

2nd 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

3rd Thursday, 1:30 PM
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

Crescent City

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

Davis

2nd Tuesday, 3:30-5:00 PM
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

Eureka

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

Folsom

1st Thursday, 12:30 PM
Burger 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

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

Garberville

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

Grass Valley

2nd 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

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

Madera

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

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeiser Center across the
street from the church)
Larry Frice (209) 358-2045

Modesto

3rd Monday, 10:30 AM
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 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

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

Redding

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

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

3rd 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

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

San Jose

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

San Rafael

3rd Wednesday, 1 PM
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
For information call
Mary Ann Leer (831) 477-1239

Santa Maria

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

Santa Rosa

1st Wednesday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Larry Metzger (707) 541-6776

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President's Message By Bev Anderson



It is hard to believe, but at the time you receive this newsletter we are nearing the final boarding time for the 2017 Annual Conference – Neuropathy Today and Tomorrow. You can view the complete schedule on Page 7 of this newsletter. The Registration Information is also there. If you plan to attend, please get your registration in as soon as possible. The form is also available on the home page of our website, or you may call in to the office to register with a credit card if you don't want to mail in the form. We will establish a waiting list if we get past the room capacity.

We plan to have a raffle and a silent auction as well as have books, videos, and T-shirts for sale. One of the books is mentioned in an article elsewhere in this newsletter. It is not about neuropathy, but I'm excited that because of it, we may get publicity in places we otherwise wouldn't as well as the fundraising opportunity mentioned in the other article.

Parking is tighter than at previous conferences. If you have a handicap placard or license plate, parking is free wherever you park. If not, it is \$2 an hour with some exceptions. A detailed description will come with confirmation of your registration. If we have your e-mail address, it will likely come that way. If you carpool, I suggest a person with a placard be included as long as they bring it along.

Elsewhere in this newsletter is an article on the Big Day of Giving. Please put it on your calendar for Thursday, May 4. Much more information will be coming to you before that. Some of the way it is done has changed to make it easier to participate.

There is much in the news about the current U.S. administration's approach to health care. It is drastically different from the previous administration's approach. It will likely include a change in the way medical care is provided and may include a reworking of Medicare as well. How much change is instituted may be impacted by the attitude of those affected. Try to keep up with what is actually happening and let your legislators know what you think. Be sure to get your information from more than one source.

I need personal notes from you on two subjects:

- What WNA has done for me – experience, something that helped you.
- Have you ever tried putting a bar of soap between the sheets at the end of the bed beyond your feet – did it help? Describe the help. What did it help?

Thanks,

Bev

WNA Information and Support Groups – Continued from page 2

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) 622-62988

Truckee

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

Tulare-Visalia

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

Turlock

3rd 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

4th 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

3rd 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) 622-62988

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".

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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EXERCISE CAN TREAT TINGLY HANDS AND FEET AFTER CHEMOTHERAPY

February 17, 2017

Researchers have discovered a simple and inexpensive way to reduce neuropathy in hands and feet due to chemotherapy—exercise.

Scientists for the study, which included more than 300 cancer patients, directly compared the neuropathic symptoms in non-exercisers to the pain among patients who took part in a specialized six-week walking routine with gentle, resistance-band training at home.

The exercisers reported significantly fewer symptoms of neuropathy—which includes shooting or burning pain, tingling, numbness, and sensitivity to cold—and the effects of exercise seemed to be most beneficial for older patients.

The lead author, Ian Kleckner, is a biophysicist and research assistant professor in the University of Rochester Wilmot Cancer Institute's Cancer Control and Survivorship program.

Not all chemotherapy drugs cause neuropathy, but 60 percent of people with breast cancer and other solid tumors who receive taxanes, vinca alkaloids, and platinum-based chemotherapies will likely suffer this type of side effect, Kleckner says.

Neuropathy is more commonly associated with diabetes or

nerve damage. No Food and Drug Administration approved drugs are available to prevent or treat chemotherapy-induced neuropathy, he adds.

A previous randomized, controlled study of 619 patients showed that Wilmot's EXCAP (exercise for Cancer Patients) program reduced chronic inflammation and cognitive impairment among people receiving chemotherapy.

Kleckner's study involved a subset of patients from that trial, which is the largest phase 3 confirmatory exercise study ever conducted among cancer patients during chemotherapy.

"Exercise is like a sledgehammer because it affects so many biological and psycho-social pathways at the same time—brain circuitry, inflammation, our social interactions—whereas drugs usually have a specific target," says Kleckner.

"Our next study is being designed to find out how exercise works, how the body reacts to exercise during cancer treatment, and how exercise affects the brain."

The National Cancer Institute and coauthor Karen Mustian's PEAK lab supported the work. It will be presented at the American Society of Clinical Oncology (ASCO) annual meeting in Chicago, Illinois.

CALMARE THERAPY ARRIVES IN BERKELEY, CA

After a long wait and many inquiries on our part, Calmare Therapy is now in Northern California. I've been getting information about it for at least five years. I have to keep telling the ones that contact me about it, "We don't have one near any one of us that is available to us." One lady went to Salt Lake City to try it as it was the closest available. A person in San Diego got one but it was not widely available. An oncologist in Los Gatos was trying one and he limited the use to chemo induced neuropathy (CIPN) patients only as it is advertised to especially help them and he was having plenty of his patients that were using it. Now, we have a neurologist in Northern California who knows about neuropathy who is letting us know there is a unit there. They are pronouncing it "Cal mary."

Calmare Therapy, also called "The Scrambler," is now being used in the practice of neurologist Selena Ellis, MD, in Berkeley, California, to help reduce nerve pain in patients suffering from trigeminal neuralgia, peripheral neuropathy, Complex Regional Pain Syndrome (CRPS), headache, and migraines. It is expected that people with chemo induced neuropathy (CIPN) may be helped greatly by this therapy. She offers the first treatment free to see if it helps. If it does, the patient is invited to take 10 additional treatments. Dr. Ellis says that your insurance may cover at least part of the cost. Both the Mayo Clinic and Johns Hopkins Medical Center have used this equipment successfully. To inquire or make an appointment call 510-644-2282.

This is a report and a celebration that this rather expensive machine is now available in an area where many might like to give it a try. If a treatment we know has been proven to help is available, we will want to let you know. However, a lot of treatments are touted but are not long lasting. This is what I want to know from this one. If it does help. Does it last. If you or someone you know tries it, please let us know what your experience is. Please remember that we know there is nothing yet that helps everyone, even in medications. So this might not help either, but she offers a free trial. We'd also want to know that if it didn't help you, was pressure put on you to take the additional 9 or 10 treatments? This is a highly tested treatment, but we also want to be aware of how it affects those in our area who try it. You would want to consult with your primary care doctor and/or others before choosing to try even equipment that seems like it might be safe.

This newsletter for Western Neuropathy Association (WNA) 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.

BEV ANDERSON PENS STORY SELECTED FOR "Chicken Soup for the Soul: Inspiration for Teachers" *By Bev Anderson*

I'm excited to tell you that I have the great honor to have a true story I wrote and submitted chosen for the *Chicken Soup for the Soul: Inspiration for Teachers*. They tell me over 7,000 stories were submitted, 101 were chosen. Almost as amazing as this is, they announced the "publication date" or the day it goes on sale is April 18, the day of our Annual Conference. We will have copies for sale at the Conference and afterward. They give us a special price if it is for a fundraiser so any purchased from us will benefit the Western

Neuropathy Association (WNA). The purchase price is \$15. So please think of gift opportunities wherein you might be able to use the book. You might know teachers in your family or community you'd like to gift with one. Maybe you have a child or grandchild that would like one for their teacher. No matter who reads it, however, they will likely be inspired in some way. We've all been teachers at some point in our life whether in a schoolroom or not. My story is called "Soaked Alive."

Western Neuropathy Association Annual Report For 2016 – *Continued from page 1*

decided distributing the new book, *Peripheral Neuropathy & Neuropathic Pain – Into the Light*, by Gerard Said, MD, FRCP, would be a helpful endeavor. Dr. Said practices in Paris, France, and is considered a world authority on neuropathy. The book is sponsored by The Neuropathy Trust in the United Kingdom. We are working with the publisher there that also works with a publisher in the United States that is giving us a lower cost for our distribution. We hope in 2017 to distribute several hundred books to the Neurology Residents (doctors training to be neurologists) in California, Nevada, and Oregon. The first set was recently presented to the Neurology Department, U.C. Davis Medical Center, Sacramento, California. We were waiting for this to happen to move to involve other training hospitals.

We have been warning people about not spending their money with the groups with big ads in the newspapers promising results for a sizable amount of money that don't last. This year we started seeing stem cell clinics popping up saying they will use your own stem cells that they take out, spin out the fat, and put them back into you. Then there was talk about other sources of stem cells being used. We learned that this is a dangerous practice and people are experiencing severe health consequences. The cells from our body are not likely to help us. Cells from another body, especially, are rogue elements that our bodies don't know how to deal with. Doctors can't treat someone else growing inside of us as there is no system involved. We published information in *Neuropathy Hope* and informed people in support groups to be extra cautious, remain informed, and speak with your own medical physician.

We were approached by Ted Mock, a long-time member and retired CPA, with a proposal to partner with his thrift shop in Chico, Thrifty Bargain. In essence, his company collects donated items and provides WNA with a monthly donation in recognition of our and our members' support. The program has gone well and we continue to receive an amount each month. It has been

an appreciated and helpful source of additional funds for us. In our winter membership/fundraising letter one member pledged \$1,000 if we raised that much and at least one other person gave \$1,000, so we received the pledged funds. Offering a matching gift gives encouragement to those who can give. We receive the benefit and you may receive a write-off on your taxes. We so much appreciate each person who joins with the membership amount, but thanks and more thanks to those who go the extra mile and give more than their dues; and thanks as well to those who give throughout the year.

We had 12 issues of *Neuropathy Hope* that were well received and a Board of Directors that met 12 times plus 33 support groups that met from three to 11 times. A new group started in Costa Mesa, California. We have a group that meets in Laguna Woods, California, which is not listed as it is limited to people who live in this retirement community in Southern California.

Goals for 2017 include:

- Continued effort to raise the funds for books to present to Neurology Residents and to present them to the Neurology Department in each medical center that trains new neurologists.
- Continued effort to support current groups, find leaders when leaders can't continue, and to start new groups.
- Develop teleconference groups where we don't have support groups to build momentum that will eventually produce a Leadership Team to support a group in the area. One each will soon start for Northern Oregon, Reno, and in California -- Indio to Redlands including Palm Springs.
- Work with Volunteer Match to find Group Leaders.
- Continue with a variety of fundraising possibilities to develop a better financial base for future strength.

DISCOUNTS FOR WNA MEMBERS

Continued from page 4

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"

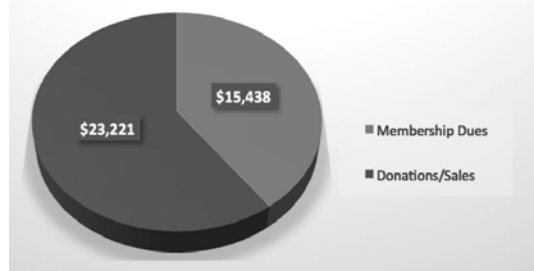
introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at www.neuropathysupportnetwork.org/order-neuropathy-dvd.html

Additional Discounts

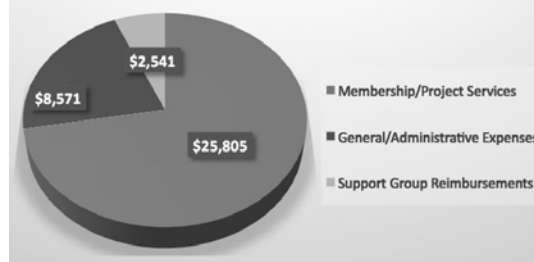
Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail info@pnhelp.org.

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

WNA 2016 Income



WNA 2016 Expenses



MAY 4TH, 2017, OUR REGION COMES TOGETHER FOR THE 4TH ANNUAL BIG DAY OF GIVING

A program of the Sacramento Region Community Foundation's initiative to grow local philanthropy, Big Day of Giving is a 24-hour online giving challenge that brings together the region's nonprofit community to help raise much needed unrestricted funds and shine a spotlight on the work nonprofits do to make the Sacramento region the place we call home. For the past few years, the giving day has united our community, raising more than \$16 million for local nonprofits from over 36,000 donors from all over the region, the state, the country, and the world.

WNA is excited to participate again this year. There are a lot of changes – such as the date – which is on a Thursday this year, the processing company (due to all the issues last year) and the manner in which you can donate. After April 14th, you will be able to access our donation page and schedule a donation. (<https://www.bigdayofgiving.org/wna>). (This can be a one-time donation, or, you can make it recurring. The minimum donation this year is \$15.00. There are also categories that you can consider when donating, such as:

1) Book Sponsor (\$50.00) – this will purchase two of Dr. Said's books to be given to Neurology Residents – your name will be added to an honor roll on our website. It can be given in honor of a person or as a memorial as well.



- 2) New Support Group Meeting Sponsor (\$100.00) – this will cover the start-up materials for new groups forming.
- 3) Annual Meeting Sponsor (\$500.00) – this will help us to bring quality speakers to inform and educate us.
- 4) Major Donor (\$1,000 and above) – this lets us know that you appreciate the work that we do and would like to see it continue.

We look forward to this event and hope you will join us in making a difference for Neuropathy in this region.

NEUROPATHY ACTION FOUNDATION (NAF) ANNOUNCES 11TH ANNUAL “NEUROPATHY ACTION AWARENESS DAY,” LARGEST NEUROPATHY-RELATED PATIENT EVENT IN THE UNITED STATES

LOS ANGELES, March 14, 2017 / PRNewswire-USNewswire/ The Neuropathy Action Foundation (NAF) announced that registration is now open for its 11th Annual “Neuropathy Action Awareness Day,” an all-day educational event on June 23 in Los Angeles. “Neuropathy Action Awareness Day” will be the largest neuropathy gathering in the United States this year and will bring together patients and caregivers from across the country to learn about neuropathy, strategies for managing the condition, patient advocacy, and tools that empower patients to become advocates for their own health care.

The event consists of educational presentations, luncheon, exhibit area, and silent auction. Cancer survivor, artist, author, Darryle Pollack, will speak during the luncheon and Carolyn Johnson, award winning journalist and co-anchor, NBC Channel 4 Southern California News will be the master of ceremonies during the luncheon. Other speakers include:

- Perry Shieh, MD, PhD, Associate Clinical Professor, University of California, Los Angeles (UCLA), will discuss the signs, symptoms, and causes of peripheral neuropathy;
- Richard Lewis, MD, FAAN, Director EMG Laboratory and Co-Director Neuromuscular Clinic, Cedars-Sinai, will discuss understanding a neurologist's approach to the diagnosis and treatment of peripheral neuropathy;
- Jeffrey Ralph, MD, Associate Clinical Professor, University of California, San Francisco (UCSF), will discuss current treatment options for peripheral neuropathy;
- Manny Hernandez, Co-Founder, Diabetes Hands Foundation and Senior Vice President of Livongo Health, will discuss Diabetes and

“Why You Are Not Alone;”

- Jim Romano, Director of Government Relations and Advocacy, Patient Services, Inc. (PSI).

“Neuropathy Action Awareness Day provides patients with a critical forum to help empower themselves to be the most effective advocates for their own care,” said NAF President Dominick Spatafora. “As insurance benefit restrictions make it more difficult to access IVIG and other medications, it is more important than ever that the neuropathy advocacy community has a strong voice to protect access to care and ensure that the health care cost debate does not focus on short-term savings at the expense of patient health and long-term costs.”

The event is from 9:30 AM to 3:30 PM on Friday, June 23 at the Intercontinental Hotel Los Angeles located at 2151 Avenue of the Stars. The event is FREE of charge; however, NAF requests a \$25 donation from patients and caregivers and \$125 from others who attend the luncheon. Register today at (877) 512-7262 or www.neuropathyaction.org

Interested individuals who are unable to attend in person can register for free to stream the event online and submit questions digitally to be answered in real-time by event speakers.

About the Neuropathy Action Foundation

The Neuropathy Action Foundation (NAF), a 501(c)(3) non-profit, is dedicated to ensuring neuropathy patients obtain the necessary resources to access individualized treatment to improve their quality of life. The NAF increases awareness among physicians, the general public and public policy officials that neuropathy can potentially be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is provided.



WESTERN NEUROPATHY ASSOCIATION
 Hope through caring, support, research, education, and empowerment
 Our mission is to provide support, information and referral to people with neuropathy and to those who care about them to inform and connect with the health care community, and to support research.

**Western Neuropathy Association
 2017 Annual Conference**

Date: Tuesday, April 18, 2017

Time: 9:30 AM to 3:30 PM

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

**Registration Fee: \$25.00
 Includes morning snacks, coffee, lunch
 Does not include parking**

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

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

Sponsor



Neuropathy Today & Tomorrow

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

10:00 Announcements and Introductions

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

Noon Catered Lunch

1:00 pm **Kyle Fink, PhD**— Assistant Adjunct Professor, Neurology and Institute for Regenerative Cures, UC Davis School of Medicine—Stem Cell Program.
 “What is a stem cell?” “What does the research consist of?”
 “What does the future possibly hold for the impact of stem cells in the treatment of neuropathy?”

2:00 pm **Bruce D. Hammock, PhD**— Distinguished Professor Department of Entomology & UCD Comprehensive Cancer Center, Director, NIEHS-UCD Superfund Research Program PI, NIH Biotechnology Training Program
 “Report on the progress of his current neuropathy treatment research and how soon human clinical trials begin.”

3:00 pm Closing activities:
 • Evaluations
 • Door Prizes and Silent Auction
 • Closing Announcements

3:30 pm Adjourment



Mail registration fee and form to:

**WNA
 PO Box 276567
 Sacramento, CA 95827**

Name _____

Address _____

City / State / Zip _____

E-mail _____

Support Group _____ At Large Member

If you need a special diet, please indicate: Vegetarian Gluten Free Other

I am enclosing my check for the \$25 registration fee (includes lunch and morning snacks).



WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit,
tax exempt corporation

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

The 2017 Annual Neuropathy Conference April 18, 2017

The Mind Institute • U.C. Davis Medical Center Campus, Sacramento, CA

Speakers: Yuen So, MD, Neurologist, Stanford University Medical Center

Bruce Hammock, PhD, Researcher, U.C. Davis

SEE PAGE 7 FOR MORE INFORMATION!

HOW TO TALK SO YOUR DOCTOR WILL LISTEN

(To access the full article, go to the January-February of the AARP Bulletin) Doctors have busy workloads and a short time to devote to each patient. Getting and keeping the doctor's attention is vital to your health. You can be more easily misdiagnosed if the time isn't spent well.

- **Make a human connection** – Greet the doctor and ask how their day is going. I ask about my doctor's daughter and how she is today.
- **Stay on message** – After the greeting, get to the point. Over sharing any unrelated information takes time away from why you are there.
- **Tell the whole truth** – Tell it specifically without unnecessary side information – fear of falling, substance abuse, sexual dysfunction, change in sleep patterns, etc.
- **Rehearse before you go** - Write out a script and rehearse it in front of the mirror if you are at all nervous about it and use specific words as much as possible.
- **Don't accept "It's just aging"** – Be specific about changes you've noticed. Aging may have nothing to do with it. Ask about tests to check on things like forgetting appointments or other new things you have noticed. Young people get these too and sometimes they are indicative of something that needs attention. (If your doctor attributes more than something casual to aging, think about finding a doctor who respects older people better.)
- **Don't save questions for the end** – Come with your list of questions. Ask them in the first minutes of the visit so they have time to be addressed. That is why you came. Do the important things first.
- **Explain what you can afford** – Doctors don't keep up with the costs of medicines and tests and what your insurance covers. If you can't afford something tell the doctor and asked for a less expensive alternative. Prioritize your medicines and ask which ones you can skip and which you can't.
- **Have that end-of-life discussion** – Talk to your family and also your doctor about what you want when you are near death. Be sure to have an up-to-date Power or Attorney for Health Care which is considered an advance directive. The doctor may not read it or have it handy so telling them so it is your records is a good idea.



Western Neuropathy Association (WNA)

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

Bev Anderson, Editor

P.O. Box 276567

Sacramento, CA 95827-6567

(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.