



WESTERN NEUROPATHY ASSOCIATION

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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)

GENETIC TESTING MAY PREVENT NERVE DAMAGE FROM CHEMOTHERAPY IN ASYMPTOMATIC CMT *By Alice Melao In News*

A thorough physical examination and genetic testing to rule out Charcot-Marie-Tooth (CMT) disease prior to chemotherapy is an important step to prevent further damage to nerve cells, Kern Medical Center researchers suggest.

This conclusion was supported by a case report of a 56-year-old patient with a family history of genetic disorders whose diagnosis of asymptomatic CMT subtype 1A was only revealed after she experienced neurotoxic effects from vincristine therapy. "Prior to starting chemotherapeutic agents notorious for causing neuropathy, we recommend examination of patient's feet for deformities such as pes cavus and hammertoes," the researchers said.

The case was reported in the study, "Unmasking a Case of Asymptomatic Charcot-Marie-Tooth Disease (CMT1A) with Vincristine," published in the Journal of Investigative Medicine High Impact Case Reports. CMT is caused by mutations in the genes involved in myelin production, the main component of peripheral nerve cells' protective sheath. In the absence of myelin, nerve cells cannot communicate properly and are more prone to damage. Depending on the affected genes and pattern of inheritance, the disease can have different manifestations and progression rates.

It has been known that chemotherapeutic agents widely used to treat cancers can cause peripheral nerve damage. Their use is not recommended for patients with CMT or other similar neuropathies.

In this recent report, the research team presented the case of a 56-year-old woman of Hispanic origin, who was diagnosed with diffuse large B-cell lymphoma. To treat the cancer, she underwent an R-CHOP chemotherapy regimen, which combines cyclophosphamide, doxorubicin, vincristine, prednisone, and the immunotherapy Rituxan (rituximab).

Four days after the first cycle of treatment, the patient began experiencing mild weakness and numbness in the tips of her fingers and toes. These symptoms extended to all four limbs 10 days after the second cycle. Then, her symptoms worsened and she



became unable to perform daily life activities.

The fast, progressive symptoms led her clinical team to perform a more detailed physical evaluation, focusing on her motor weakness and loss of sensitivity. This revealed that she had high arched feet, a condition her siblings and father also had.

"Everyone in the family were asymptomatic and did not suffer any disability as a result of the feet deformities," the researchers reported.

Further evaluation of peripheral nerve cell activity and muscle response confirmed an acute loss of myelin with chronic polyneuropathy. Genetic testing revealed the presence of a disease-associated mutation and duplication of the PMP22 gene, which are consistent with the diagnosis of CMT subtype 1A.

Supported by the new diagnosis, vincristine therapy was discontinued and Rituxan was continued as the main anti-cancer treatment. This change in treatment strategy led to significant motor symptom improvements with some residual sensory loss.

"The genetic testing for CMT or any neurological disorders are currently not a standard of care before administration of vincristine chemotherapy," the team said. However, researchers believe that for patients with a preexisting family background of inherited diseases, genetic testing "before starting vincristine therapy can potentially prevent a disability.

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May 6-12 is Peripheral Neuropathy Awareness Week

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

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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

1st Monday, 11 AM
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

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

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

Folsom

Last Tuesday, 12:30 PM (odd numbered months)
Burger Rehabilitation
1301 E. Bidwell St., Folsom
Bev Anderson (877) 622-6298

Fresno

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

Grass Valley

2nd Monday, 1:30 PM
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

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 St.
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Placerville

2nd Wednesday, 1 PM
El Dorado Senior Center
937 Spring Street
John McCoy (530) 642-8511

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

San Francisco

New leadership needed.
No meetings for now.
Contact for information
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

New leadership needed.
No meetings for now.
Contact for information
Bev Anderson (877) 622-6298

Santa Barbara

4th Saturday, 10AM (odd numbered months)
St. Raphael Catholic Church
5444 Hollister Ave., Conference Room
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

1st Wednesday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Judy Leandro (707) 480-3740

Thousand Oaks - Westlake Village

2nd Monday, 2:30 - 4 PM
United Methodist Church of Westlake Village
1049 S. Westlake Blvd.
Angie Becerra (805) 390-2999

Walnut Creek

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

NEVADA

Las Vegas

3rd Thursday, 1 PM
Mountain View Presbyterian Church
8601 Del Webb Blvd.
Barbara Montgomery (818) 400 0296

OREGON

Grants Pass

3rd Wednesday, 2:00 PM
Club Northwest
2160 N.W. Vine St.
Carol Smith (541) 955-4995

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, Quincy, Redding, Salinas, San Francisco, Santa Maria, Sonoma, Sonora, Stockton, Susanville, Truckee, Tulare-Visalia, Turlock, West Sacramento, Weed, Ukiah, Woodland, Yreka, Yuba City-Marysville. **Nevada:** Reno-Sparks. **Oregon:** Brookings, Medford, Portland, Salem.



Did you receive an invitation from me? For some months I have been saying to people in areas where there are no current support groups that I'd try starting a teleconference group in their area. In mid-March I decided to give it a try in a big way. I sent out about 300 invitations to 11 areas. Not many responded. I am not sure if it was because of fear of trying something new, disinterest, or not the right time. The experiment was great for those that called in. I was able to talk and share information for an hour. In some of the scheduled teleconferences, no one called in. I did some while traveling to speak at a support group, which made it so I had to use my cell phone. I wondered if some tried to call in and it didn't work for them.

If you received an invitation and didn't call in or would have responded if you had gotten an invitation, or if you tried to call in but couldn't connect, please send an e-mail to me at info@WNAinfo.org or a letter to WNA, P.O. Box 276567, Sacramento, CA 95827-6567. Teleconferences are a way to share information and stories from the comfort of your own home.

The Big Day of Giving or Big DOG is coming on Thursday, May 3. This year's Big Day of giving is a way for us to receive some matching funds to magnify your gift.

- Big Day of Giving is Thursday, May 3, from midnight to midnight.
- Donors can give at www.bigdayofgiving.org.
- Any funds received in this time period designated to **Western Neuropathy Association** will be in the group that will be partially matched by funds given by large corporations in the Sacramento area. The more received, the greater the percentage of match.

Donations received through the mail or through our website (www.WNAinfo.org) are very welcome in this time of springing forward in anticipation of summer. Thank you for your dues and donations. If you are required to make a minimum distribution from your IRA, think about a contribution to WNA.

Warning, Please Don't Fall Victim. People/companies that ask for large sums of money up front for treatments with no guarantee of getting your money back if it doesn't work are not trustworthy – no matter how convincing they may sound – no matter how desperate you may be. I receive calls regularly from people who are or want to be pulled in by these people. Don't be fooled by their large ads in the newspaper. If they have found a cure for neuropathy, it would be known to many. I recommend you not go to their free dinners. Besides their ability to talk persuasively, psychologically you are pre-disposed to think kindly of them due to the free meal. That's why they provide something free. In addition to neuropathy treatments, we also have warned you about stem cell treatments. We have reported in this newsletter on the dangers of stem cell treatment. You can locate past newsletters on our website.

Neuropathy Awareness Week is May 6-12, 2018, although we like to identify the entire month of May as 'neuropathy month.' We encourage you to honor neuropathy month by telling someone new about neuropathy each day. I'm going to make an effort to say, "Do you know this is Neuropathy Awareness Week? Do you know what neuropathy is?" If they don't know, I say, "Your brain and your spinal cord are your Central Nervous System. All your other nerves are connected to these and form the Peripheral Nervous System. All diseases and disorders in the Peripheral Nervous System can be a form of neuropathy." I usually also mention that some of the first symptoms are tingling, numbness, and pain in the feet and or hands. Count how many you tell that week and send an e-mail or note to me telling how many you told. We might even have a prize for the one who informs the most people.

Happy spring. Let people know about neuropathy.

Bev

FOOT EXERCISE THAT HELPS

With one foot and then the other, draw in the air or on the ground each of the letters of the alphabet. Do it printing (manuscript) or flowing (cursive). You can try it both ways to see which gives the better exercise.

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

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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 members a discount to give 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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FDA AND OPIOIDS: TOO MUCH REGULATION OR NOT ENOUGH?

Agency's Call For Public Input On The Health Emergency Yields Conflicting View

By Shannon Firth, Washington Correspondent, MedPage Today, January 31, 2018

SILVER SPRING, Md. -- If the FDA (Federal Drug Administration) is looking for a streamlined approach to respond to the opioid crisis, it didn't come from a public meeting of the agency's Opioid Policy Steering Committee.

At a recent meeting, academics, physicians, patients, advocates, and industry officials shared sometimes conflicting recommendations on how the FDA can best handle the problem.

Advocates generally fell into two camps: pain patients and their supporters, concerned that opioids are being over-regulated and becoming harder to access, and people who have lost loved ones to addiction and overdoses, and would like to see stronger restrictions on such products.

Meanwhile, healthcare experts stressed addiction and overdose prevention, better provider education and awareness efforts, and the elimination of "doctor-shopping."

In September 2017, the FDA issued a request for comment, which said the national crisis is one that requires "action by federal agencies that may in some instances be unprecedented." The notice solicited public input to help the agency determine what it should leverage to respond to the crisis.

President Trump declared the opioid epidemic a public health emergency a month later. Approximately 64,000 people died from opioid overdoses in 2016.

The FDA notice included a handful of direct questions for stakeholders, such as:

- How can the agency use the available public health data to influence opioid related regulatory decisions?
- What changes can the agency make with regard to "dispensing and packaging" to encourage proper prescribing practices?
- Should mandatory education be required for clinicians who prescribe opioids?

At the recent meeting, agency officials also discussed whether to specify dose limits, the creation of a nationwide prescription history database, and how to assess the impact of prescription drug monitoring programs (PDMP).

With regard to provider education, "there is no evidence, in the published literature, that mandatory education increases knowledge or changes behavior and practice," pointed out Norman Kahn, MD, of the Conjoint Committee on Continuing Education. "If the goal is to count the number of people who complete the education, then of course we should make it mandatory."

"If ... the goal is to make people learn and change the behavior and practice, that doesn't happen with mandatory education. That happens with voluntary education," he stressed.

Kahn said he has discussed the idea of an "adaptive

learning" approach with the Centers for Medicare and Medicaid Services. He said he has hopes that such an approach might count as an improvement program under the Merit-Based Incentive Payment System (MIPS).

Another concern is the language used to describe opioids, stated Diana Zuckerman, PhD, of the National Center for Health Research. She said "abuse deterrent" may mean different things to doctors, patients, and family members.

She urged the FDA to include education on the meaning of "abuse deterrent" within its Risk Evaluation and Mitigation Strategies (REMS) because "too often it's misinterpreted to mean it's not as addictive."

But Zuckerman also questioned the value of REMS itself, claiming that the "vast majority" of physicians don't even know REMS exists. Following the implementation of REMS, one prescriber-based survey found 48% of respondents said they did not change their prescribing habits, she noted. Also, while 49% said they made use of the patient counseling documents, that means roughly half did not, she added.

On the advocates' side, Richard Lawhern, PhD, co-founder of the Alliance for the Treatment of Intractable Pain, urged the FDA to "stand down" from additional regulations on opioids.

He said that the agency is chasing the wrong crisis, as more regulation "is going to make the real crisis worse," by driving patients into the realm of heroin and/or other illegal street drugs. He also urged the FDA to "remove and rewrite" its practice standards regarding opioids, and he dismissed the Centers for Disease Control and Prevention's revised guidelines as "nonsense."

Emily Walden, of Louisville, Kentucky, called on the FDA to remove the highest dose opioids from the market and "immediately delay any new approvals." Her 22-year-old son died because of an opioid addiction, she said.

She also pressed the agency to end its use of enriched enrollment in clinical trial design. The FDA describes the method as a way to "increase the likelihood that data collected during a clinical trial will demonstrate that an effective drug is effective."

Other topics discussed at the meeting included the need to increase e-prescribing, improve PDMP, and integrate both into electronic health records (EHR) systems.

Robert Heary, MD, of the American Association of Neurological Surgeons, suggested providers complete a short (less than 5 minutes), standardized form, with each opioid prescription, to explain why the prescription is medically justified. If a national PDMP were established, data from those forms could feed into it and be cross-checked at the pharmacy.

He noted that having a connected PDMP would prevent doctor-shopping across state lines.

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HACKING NEUROPATHY - AN INTRODUCTION TO ONE WOMAN'S STORY

New Writer: *Julia Helen Tracy, MS, is a retired research scientist. She wants to write about the experience of having neuropathy and what she has learned in the years she has had this disease. It will likely be a blog. This is her first one that we are using to encourage her and get feedback from all of you who read it. Please send any comment you wish to make to info@pnhelp.org about her topic or presentation. It will help her to understand what might be the most helpful to readers.*

Walking has been a dear friend throughout my life. When broken-hearted, I walked for miles, composing songs and poems in my head, healing as I wandered. When depressed, I walked up steep hills, breathing deeply, pumping fresh blood through my heart, fresh ideas into my brain. When angry, I walked at a brisk pace, flushing toxic emotions out of my liver, calming my spirit. While traveling, I walked to get lost in strange places, then walked to find my way back. It was simply a joy to walk.

Then, slowly, almost imperceptibly, things changed. There was the first time I had to consciously push myself up onto my toes while reaching for something on a high shelf and the occasional, strange off-balance feeling. At 60 years old, perhaps more exercise was needed? I began a strength-training program. After 11 weeks my arms were clearly stronger but it was even more difficult to raise up on my toes or lift them easily. I couldn't skip or take off at a good run.

My fear was MS, as I felt my nerves were being demyelinated. A neurologist confirmed this suspicion, but also determined it was not MS. A lumbar puncture and blood tests revealed immunoglobulin proteins (IgM) in my body, so he referred me to an oncologist. More testing revealed a clonal population of B-cells in my bone marrow. These abnormal cells led my body to produce auto-antibodies which were demyelinating the nerves. The diagnosis was "Monoclonal Gammopathy of Unknown Significance (MGUS) with Peripheral Polyneuropathy" (though to me, it's simply NGC Nerves Gone Crazy).

Reading extensively about the condition and potential treatments led us to try an immunotherapeutic drug, rituximab, that tags B-cells for removal. Healthy B-cells would presumably re-populate more quickly than abnormal cells. Unfortunately, while the drug lowered the level of IgM in my body, it also sent my neuropathy into overdrive. Three treatments left me more dysfunctional than ever.

I learned that nerves do remyelinate, at the staggering pace of 1-2mm per day! Eight months later, blood work indicated IgM proteins were still present, though at a lower

concentration, presumably as a result of the treatments. Auto-antibodies were also still present, in large numbers. As I was feeling stronger we decided to try another course of the immunotherapy. However, after only two treatments I was again so shaky and exhausted that we stopped. It was a huge step backward, and took two months to regain some of my strength.

Four years post-diagnosis, it's never entirely clear if I'm getting better or worse. Stabbing nerve pains (mostly in my feet) sometimes keep me awake or wake me out of a deep sleep. No matter how much I force myself to walk my legs and feet don't seem to improve. But it also seems the less I move the worse the neuropathy gets. Small injuries, such as minor strains, can set me back for weeks.

For now, the medical community has done all I will let them do in terms of treatments. To avoid unpleasant side-effects I don't use anti-depressants or heavy-duty pain drugs, and am not in favor of more toxic chemotherapeutic treatments, which might lead to problems further down the line. Aside from the presence of the IgM spike and the auto-antibodies, my blood always looks healthy. I am determined to do all I can to improve the neuropathy — or at the very least, learn new strategies to help me live with it.

Full-time work was exhausting. I retired on September 21, 2017, about five years earlier than I'd always planned. Keeping my mind out of the pit of fear and despair is a full-time job in itself! I have learned that neuropathy, particularly the pain of neuropathy, is strongly affected by my emotions. And it's an interesting challenge to find new, useful activities that my compromised body can handle.

A great blessing in all this is the love, help, and support of a core group of dear friends. I have learned that it is OK, and necessary, to ask for help. They help me with shopping and laundry, listen to me weep, wail, and rage. They share their lives, stories, time, and food with me. Beloved friends...what an unexpected silver lining of this miserable condition.

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.

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.

FDA and Opioids: Too Much Regulation or Not Enough? - Continued from page 4

Janet Woodcock, MD, director of the FDA's Center for Drug Evaluation and Research called it a "bold proposal," but questioned how much of a burden these additional measures would be for providers.

Patrice Harris, MD, an American Medical Association trustee and chair of the AMA's Opioid Task Force expressed skepticism about the capacity of today's EHRs. Recommendations on e-prescribing "overstate and overestimate the current capabilities of today's

electronic systems," she said, adding that e-prescribing "in its current state" may not be suited to "explain medical necessity."

While physicians may prefer e-prescribing, the pin numbers, passwords, and authentication processes can be "onerous" and may take time away from direct patient care, she added.

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PROGRAM AND AGENDA

9:00–9:30 Registration and Exhibits
9:30–9:40 Welcome
 Kathleen Creason, NAF Board Member

9:40–10:15 The Whole Body Experience: Neuropathy from Head to Toe
 Todd Levine, MD, Co-Director GBS/CIDP Center of Excellence at Phoenix Neurological Associates and Clinical Associate Professor of Neurology, University of Arizona School of Medicine

10:15–10:50 Understanding a Neurologist's Approach to the Diagnosis and Treatment of Peripheral Neuropathy
 Richard Lewis, MD, FAAN, Director EMG Laboratory and Co-Director Neuromuscular Clinic, Cedars-Sinai

10:50–11:20 Non-Opioid Treatments for Neuropathy
 Steven Richeimer, MD, Professor of Anesthesiology and Psychiatry, Chief, Division of Pain Medicine, University of Southern California (USC)

11:20–11:45 Ask The Experts - Your Chance to Ask Questions of Top Neurologists
 Said R. Beydoun, MD, FAAN, Professor of Neurology, Keck Medical Center of USC University of Southern California;
 Jeffrey W. Ralph, MD, Clinical Professor, Director, Neuromuscular Medicine Fellowship Program Department

of Neurology, School of Medicine, University of California, San Francisco (UCSF);
 Jonathan Katz, MD, Chief of Neuromuscular Services at California Pacific Medical Center

11:45–12:15 Break and Exhibits
12:15–1:15 Lunch Program
 NAF Update and Recognition of Sponsors and Exhibitors
 Dominick Spatafora, Founder and President, Neuropathy Action Foundation (NAF)
 Food As Medicine: Improve Health, Increase Vitality & Live Longer!
 Melina Jampolis, MD, Celebrity Internist and Board Certified MD Nutrition Specialist

1:15–1:45 Putting YOU into the Caregiving Equation
 Sherri Snelling, CEO, Caregiving Club and author of A Cast of Caregivers

1:45–2:15 Refreshments and Exhibits Break
2:15–3:00 Understanding and Championing Healthcare Rights for Yourself and Others
 Aileen Harper, Executive Director, Center for Health Care Rights;
 Krystin Herr Larkin, Principal, KL Government Affairs and Board Member of the California Chronic Care Coalition (CCCC)

To access the entire brochure, go to www.WNAinfo.org

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

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 connect to the

NLM: 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.

The reader can also go to the WNA website www.pnhelp.org, click on the RESOURCES tab and select MEDICAL LITERATURE REVIEW from the menu to review the archive of summaries that have appeared in this column over recent years.

This month's PMIDs:

- 9153445 In an NIH randomized placebo controlled double blind crossover study of 13 patients with painful diabetic neuropathy, a decrease of 24% was obtained with a mean daily dose 381 mg dextromethorphan (DM commonly found in cough medicine).

- 10741812 This is an uncontrolled open label study of 22 patients with neuropathic pain who decreased their pain scores from 6.7 to 5.3 after 8 weeks on bupropion SR (Wellbutrin SR®) 150mg twice a day.
- 11706096 This is a double blind, randomized, placebo controlled, crossover study of 41 patients with neuropathic pain. They received bupropion SR (Wellbutrin SR) 150mg daily for a week, followed by twice a day for another 5 weeks during which their pain score decreased from 5.7 to 4.0 (p<0.001).
- 20447305 This Israeli study assessed the effectiveness of agmatine sulfate (decarboxylated arginine) with lumbar disc related sciatic pain. Compared to baseline agmatine improved pain from 26.7% to 70.8%, whereas the placebo group improved from 6% to 20%.
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Please note that the conference is being held in California and Live Streaming will take place during Pacific Standard Time (PST).

12TH ANNUAL
**NEUROPATHY ACTION
AWARENESS DAY**

- 3 EASY WAYS TO REGISTER**
- 1** CHECK VIA MAIL
 - 2** CREDIT CARD VIA MAIL
 - 3** CREDIT CARD ONLINE

JUNE 22, 2018

**INTERCONTINENTAL/CENTURY CITY HOTEL
2151 AVENUE OF THE STARS
LOS ANGELES, CA 90067**

REGISTRATION FORM

ATTENDEE

Name _____

Company / organization (if applicable) _____

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QUESTIONS CONTACT (877) 512-7262

- Please check off which events you will attend*
- I am a neuropathy patient or caretaker and will attend the Event and Luncheon: **\$25 per person**
 - I am NOT a neuropathy patient or caretaker and will attend the Event and Luncheon: **\$125 per person**
Total number of people attending event in person: _____
 - I cannot attend but would like to make a contribution in the amount of \$ _____
 - I cannot attend in person but will watch on the Internet via Live Stream: **FREE**

Payment

Pay online at www.neuropathyaction.org

- My check or money order, payable to **Neuropathy Action Foundation (NAF)**, is enclosed.
- Please charge my credit card for \$ _____ MasterCard Visa AMEX

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Name as it appears on card _____ CVV _____

Signature _____ Date _____

**RETURN BY JUNE 11TH
TO AVOID A \$50 CHARGE**

**PLEASE MAIL YOUR
COMPLETED FORM (AND
CHECK, IF APPLICABLE) TO:**

**Neuropathy Action Foundation
1950 Old Tustin Avenue
Santa Ana, CA 92705**



WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit,
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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

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12th Annual

“Neuropathy Action Awareness Day”

Friday, June 22, 2018

Intercontinental Hotel
Los Angeles/Century City Hotel
2151 Avenue of the Stars
Los Angeles, CA 90067

Registration Information and Application on pages 6 & 7

Big Day of Giving

May 3, 2018

Go to www.bigdayofgiving.org

Also, donations made to WNA and received by check or online to www.WNAinfo.org
by May 3 will be entered that day and will count for matching funds.



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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.

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