

June 2018

Understanding Hereditary ATTR Amyloidosis

Issue 06

Volume 16

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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)

UNDERSTANDING HEREDITARY ATTR AMYLOIDOSIS (hATTR amyloidosis) The Varying Symptoms of hATTR Amyloidosis

hATTR amyloidosis is an inherited, progressive disease caused by a genetic mutation that results in the buildup of misfolded transthyretin (TTR) protein. This results in the formation of amyloid deposits in the heart, nerves, and GI tract. hATTR amyloidosis affects approximately 50,000 people worldwide. Treatment options for people with this disease are limited and many people remain undiagnosed or misdiagnosed.

CAUSE

People with hATTR amyloidosis have a genetic mutation that prevents TTR protein, which is made in the liver, from performing its normal function. Instead, TTR misfolds and accumulates as amyloid deposits in the body-in the heart, nerves, and GI tract, as well as other organscausing symptoms:

- Progressive dementia
- Headache
- Loss of movement control
- Seizures
- Weakness
- Stroke-like episodes.

LIVER TTR TTR MISFOLDED TTR **AMYLOID DEPOSITS**

- Glaucoma
- Blurred or spotty vision
- Abnormalities of the pupil or blood vessels on the white of the eve
- Irregular heartbeat
- Heart failure
- · Leaky heart valves
- Decreased blood pressure upon standing
- Urinary tract infections
- Sexual dysfunction
- · Abnormal sweating
- Swelling (edema of the legs and feet)
- Altered sensation and/or mobility in the arms, hands, legs and feet: Numbness/tingling, Weakness, Pain
- Nausea and vomiting
- Feeling full early
- Diarrhea
- Severe constipation

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TAI CHI EASES FIBROMYALGIA PAIN

More benefit from exercise in randomized trial. (Fibromyalgia relates to neuropathy as it is thought to have central and peripheral nervous system components - this study can give clarification for the help tai chi can be for neuropathy.)

By Nancy Walsh, Senior Staff Writer, MedPage Today March 21, 2018

ACTION POINTS

- · The mind-body practice of tai chi was as effective or better than currently recommended aerobic exercise for fibromyalgia.
- At week 52, significant benefits persisted on patient's global assessment, anxiety, self-efficacy, and coping strategies, and the fibromyalgia impact questionnaire score was significantly better in the most intensive tai chi group compared with aerobic exercise.

The mind-body practice of tai chi was as effective or better than currently recommended aerobic exercise for fibromyalgia, a randomized controlled trial demonstrated.

At week 24, scores on the revised fibromyalgia impact questionnaire (FIQR) showed significantly more improvement among patients participating in 12 or 24 weeks of once or twice weekly tai chi compared with those enrolled in 24 weeks of twice weekly aerobic exercise classes, with a mean between group difference of 5.5 points (95% CI 0.6-10.4, P=0.03), according to Chenchen Wang, MD, director of the Center for Complementary and Integrative Medicine at Tufts Medical Center in Boston, and colleagues.

That difference, however, did not reach the estimated minimal clinically important difference on the FIQR of 8.1 points.

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2018 WNA Board of Directors

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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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Roster of Our WNA Information and Support Groups

CALIFORNIA

Antioch-Brentwood

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

Auburr

Tst 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: Rvan 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.

President's Message By Bev Anderson

Many thanks to all of you who responded to the Big Day of Giving. We are delighted to report that all of our Board gave that day, too. Others sent in a donation or paid dues as a response to the letter that was sent out. Every cent counts and pays for something that may aid someone with neuropathy. You will notice that in the article on Shoes, two quotes from people responding to the first e-mail are included.

e-mail are included.

We are observing Neuropathy Month by sending out helpful emails each

Wednesday to those we have on our email list. If you have email and would like to be included, please be sure we get your email address by sending your email address to info@pnhelp.org. Karen Polastri, our vice president, initiated and programmed these helpful emails. Karen is assisted by Lindsay Campoy, our administrative Associate.

This newsletter lets you know about a somewhat rare but very impactful hereditary neuropathy (ATTR Amyloidosis) for which there are medications that are possibly being developed soon. Lindsay Fosler, who is based in Thousand Oaks, will be traveling to speak to at least a few of our WNA groups about this type of neuropathy.

The article on tai chi indicates that it may show better results than the usual care given for people with Fibromyalgia in how it relates to neuropathy. Many people have both diagnoses and have found tai chi works for them.

There are many new medications and treatments coming soon. We raised funds to help move the pain medication research that we have been hearing about for three years now from the UC Davis University campus researchers led by Bruce Hammock, Ph.D.. Clinical Trial One is to start as soon as possible, which looks like early 2019. They may be able to get Phase One and Phase Two done during 2019 if Phase One starts early in the year.

Be sure to check with your primary care doctor on any vitamin or other supplement you take, especcially turmeric, for example. It interacts with other medications and if not reported to your doctor and stopped before surgery it can cause fatal bleeding. There are other side effects as well.

If you hear of or read of a new medication or treatment being developed, please feel free to send us a note. We will check it out and mention it if it is from a reputable source. Thanks for your input as we enjoy hearing from people about what they have found that works.



Copied from the wall of the Sutter Roseville Medical Center Wound Clinic:

Fact: Smoking one cigarette reduces the blood flow to your wound by 50% for 1 hour.

With this being true, it is no wonder that smoking is now listed as a cause of neuropathy because of its toxicity to the body. If your neuropathy is idiopathic and you are or have been a heavy smoker, it could be the cause. The reduction in blood flow for each cigarette smoked would be true if you had a wound or not.



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

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the regular price.

SHOES

Iris Gardner from Sonora responded to the e-mails for our recognition of our designation as Neuropathy Awareness Month, she wrote:

"Your list for using caution in parking lots is probably the most helpful thing I've ever read concerning neuropathy. Especially about keeping your eyes forward... I've found that even in the house I have to make certain my eyes are focused on the direction in which I'm going. No more quick turns for me.

I've had neuropathy for over 20 years (not diabetic) and it's increased exponentially over the. years. I take Neurontin (300 mg, 3 times a day) and it helps tremendously, to the point where if I forget to take one my body is very quick to let me know. I've fallen a couple of times because my feet don't always automatically land where I'm expecting them to and I've found that tends not to happen if I'm wearing shoes. I now make a point of wearing them ALL THE TIME, even when I have to get up at night. The type of shoe doesn't seem to matter, even house slippers work well. I haven't seen this mentioned in any of the articles I've read and thought it might be a tip worth trying to those similarly affected."

Scott Stokes sent another thought, "Avoid walking backwards at all cost! Always slowly turn to the direction you need to walk, check the ground

carefully for solid footing and then proceed. Falling backwards can be much worse than falling forwards where your arms might help break your fall."

These fit very well with an experience with shoes that I had recently. I went to a new podiatrist. She recommended I get orthotics made for me and recommended a gentleman who others had mentioned was quite good. She said it should be in an extra depth shoe. At first, we thought it would fit in my SAS shoes. However, it didn't work as well as it should so I relented and went for the extra depth shoe. In shoe stores, they measure the right foot as that is usually the largest. When the gentleman measured both feet, he laughed and said, "We were thinking of going a half size larger and your left foot is that size." So, the shoes came and took a little getting used to, but an amazing thing happened. The pain in my toes disappeared for the most part. They don't even hurt like they usually did at night. Giving them more space made a huge difference. I suggest that when you try on shoes have both your feet measured. You might be surprised like I was. Since they are tied shoes, having them looser works better than if there was no tie or buckle. I, like many others, don't shop for style any more, but rather for comfort and ability to keep them on my feet.

(Bev Anderson, Editor)

Understanding Hereditary ATTR Amyloidosis (hATTR amyloidosis) - Continued from page 1

- Alternating episodes of diarrhea and constipation
- Unintentional weight loss
- Excess protein in urine
- Kidney failure
- Carpal tunnel syndrome

SYMPTOMS

The symptoms of hATTR amyloidosis vary from person to person, depending on which organs or tissues are affected. As the disease progresses, symptoms may worsen (e.g., numbness or tingling of the feet can result in the need to walk with an aid or use a wheelchair) and can lead to significant disability, decreased quality of life, and, in many instances, a shortened lifespan.

DIAGNOSIS

People affected with hATTR amyloidosis need an early and accurate diagnosis due to the potential for rapid disease progression. Misdiagnosis of hATTR amyloidosis is common because of the number of symptoms that overlap with those of many other diseases, which may result in potentially ineffective or harmful treatment. Procedures commonly used to confirm the diagnosis of hATTR amyloidosis include

blood tests, organ biopsies, and tissue biopsies. Genetic testing can be used to confirm a mutation in the TTR gene. Once a TTR gene mutation is identified, family members of an affected individual can use this information to help determine their own risk. hATTR amyloidosis is passed down when one parent carries the mutation, giving children a 50% chance of inheriting that mutation. Some people with a hATTR gene mutation may not experience symptoms. Genetic counseling can be helpful for individuals at risk of developing hATTR amyloidosis (i.e., individuals with family members carrying the mutation).

TREATMENTS

There are no medicines approved by the FDA for hATTR amyloidosis. Affected individuals may work with an amyloidosis specialist and a coordinated health care team to determine an individualized disease management plan to manage symptoms. Liver transplants may be an option for some individuals. Therapies are in development for the treatment of hATTR amyloidosis.

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Tai Chi Eases Fibromyalgia Pain - Continued from page 1

But in the highest intensity tai chi group -- twice weekly for 24 weeks -- the difference compared with the aerobic exercise group reached 16.2 points (95% CI 8.7-23.6, P<0.001), which was considered clinically important, the researchers reported online in The BMJ.

"The prevailing causal paradigm [of fibromyalgia] views it as a disorder of pain regulation associated with neuroendocrinologic changes in the central and peripheral nervous systems," they wrote.

Medical therapies such as analgesics have had only modest effects, and many patients discontinue because of a lack of efficacy and/or toxicity. Moreover, an estimated 11% to 69% of patients with fibromyalgia reported using opioids, with the attendant risks of misuse. The current standard of care includes moderate aerobic exercise, but many patients find this approach difficult and do not adhere to treatment programs.

Tai chi derives from ancient practices in Chinese traditional medicine. "This complex, multicomponent mind-body intervention integrates physical, psychosocial, spiritual, and behavioral elements to promote health and fitness," the researchers explained.

Two previous studies demonstrated that 12 weeks of tai chi had beneficial effects on physical and mental health among fibromyalgia patients, but the optimal frequency and duration of treatment have not been determined.

Therefore, Wang and colleagues enrolled 226 adults who met the criteria of the American College of Rheumatology for fibromyalgia, randomizing them to one of four different intensity tai chi groups or supervised aerobic exercise. All sessions lasted for 60 minutes, and participants were encouraged to continue the program at home between sessions as well as after the intervention ended. They also were permitted to continue whatever regular medical regimen they had been following.

Participants' mean age was 52, more than 90% were women, and they represented a racially/ethnically diverse population. Mean body mass index was 30, and mean duration of fibromyalgia pain was 9 years. Baseline FIQR score was 56 (range 0-100).

Approximately half were using narcotic medications at baseline, and 58% were on antidepressants.

Patients who were assigned to the tai chi classes attended 62% of the sessions, while those in the exercise group attended 40%.

Secondary endpoints that differed significantly at week 24 between the combined tai chi groups and the exercise group included:

- Patient's global assessment, 0.9 points (95% CI 0.3-1.4, P=0.005)
- Anxiety measured on the hospital anxiety and depression scale, 1.2 points (95% Cl 0.3-2.1, P=0.006)
- Self-efficacy, 1 point (95% CI 0.5-1.6, P=0.0004)
- Coping strategies, 2.6 points (95% CI 0.8-4.3, P=0.005)
 Also, at week 24, FIQR scores showed significantly more

improvement in the 24-week tai chi groups than in the 12-week groups, with a difference of 9.6 points (95% CI 2.6-16.6, P=0.007). The 24-week tai chi groups also had greater improvements on depression scores and the Short Form-36 mental component.

At week 52, significant benefits persisted on patient's global assessment, anxiety, self-efficacy, and coping strategies, and the FIQR score was significantly better in the most intensive tai chi group compared with aerobic exercise (11.1 points, 95% CI 2.7-19.6, P=0.01).

Medication usage among all groups declined throughout the study, including analgesics, antidepressants, and muscle relaxants.

Ten serious adverse events occurred, seven in the tai chi groups and three in the exercise group, but none were considered related to treatment. These included cancer, pneumonia, concussion, and aseptic meningitis.

"What we found suggests that patients may be more likely to enjoy, manage, and continue to practice tai chi, perhaps because it is a gentler, low impact movement with minimal side effects," Wang said in an accompanying blog comment.

"It may be time to rethink what type of exercise is most effective for patients with fibromyalgia," she noted.

"More importantly, what types or combinations of exercise would patients embrace in the long term? The public health problem of chronic pain calls for an 'all hands-on deck' approach to give patients feasible therapeutic options for the management of fibromyalgia," she concluded.

Limitations of the study included patient awareness of their treatment assignment and substantial loss to follow-up, as is common in studies involving chronic pain.

The study was supported by the NIH's National Center for Complementary and Integrative Health, the National Center for Research Resources, and the National Center for Advancing Translational Sciences.

The authors reported financial support from the National Center for Complementary and Integrative Health, and no financial relationships with any organizations that might have an interest in the submitted work.

- Reviewed by Robert Jasmer, MD Associate Clinical Professor of Medicine, University of California, San Francisco
- · Primary Source: BMJ

Source Reference: Wang C, et al "Effect of tai chi versus aerobic exercise for fibromyalgia: comparative effectiveness randomized controlled trial" BMJ 2018; doi:10.1136/bmj. k851. Used with permission of MedPage Today.

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 30day supply is \$40 (normally \$49.97). It can be autoshipped 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.



12th Annual NEUROPATHY ACTION AWARENESS DAY

JUNE 22, 2018 · Los Angeles, California

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 Avizana Sabael of Medicine

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 Longert

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:

 26599185 This is a review of distal symmetric polyneuropathy, the most common form of neuropathy, affecting 2%-7% of the population. If the cause is not known, the diagnostic evaluation should include the following: complete blood count, comprehensive metabolic panel, B 12 level, serum protein electrophoresis with immunofixation, and glucose tolerance test. If onset is acute or subacute; or, if motor, asymmetric, non-length-dependent, or autonomic, a neurologic consultation should be sought.

- 26581442 This multicenter European study of over 277 patients with peripheral neuropathic pain compared to the effectiveness of a single application 8% capsaicin patch (Quetenza®) with an optimized dose of pregabalin (Lyrica®). The patch gave faster and better pain relief than the oral medication with fewer side effects.
- 27484434 This Japanese paper reviews the animal literature reviews the effects of exercise on various parts of the nervous system with dramatic changes in inflammatory cytokines, neurotropins, neurotransmitters, endogenous opioids and histone acetylation.
- 27180954 This randomized double blind parallel group study of 232 patients with diabetic peripheral neuropathy compared acetyl L carnitine 500mg with methylcobalamine (B12). There was significant and equal improvement in symptoms and disability in both groups.
- 276717799 This study reviews the evolution and advances of peripheral nerve stimulation using external percutaneous approaches rather than implantable methods in the treatment of chronic neuropathic pain.



ATTENDEE



12[™] ANNUAL

Please note that the conference is being held in California and Live Streaming will take place during Pacific Standard Time (PST).

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

Name			
Company / organization (if applicable)			
Address			
City	State	Zip	
Phone	Email		
 I am NOT a neuropathy pati Total number of people atternorm. I cannot attend but would limple attend in person but the person but th	r caretaker and will attend the ent or caretaker and will atterending event in person: ke to make a contribution in the will watch on the Internet watch. action.org ayable to Neuropathy Action		
Credit Card Number	E	expiration Date	
Name as it appears on card	C	w	
Signature	С	Date	

PAYME

QUESTIONS CONTACT (877) 512-7262

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, 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

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

Register by June 11, 2018

NAMING CONTEST - PRIZE POSSIBLE

Bruce Hammock, PhD, Chief Researcher on the pain medication we have been talking about, is searching for the right name for this new product. Read the last newsletter with the latest information and send any ideas for a name you have to Bev at info@ pnhelp.org or mail them to WNA, P.O. Box 276567, Sacramento, CA 95827-6567.



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Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year All contributions and dues are tax-deductible.

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