WESTERN NEUROPATHY ASSOCIATION

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

September 2020
Issue 09
Volume 18

WESTERN NEUROPATHY ASSOCIATION
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NEUROPATHY OR SOMETHING ELSE? UNDERSTANDING HEREDITARY ATTR AMYLOIDOSIS

Symptoms of neuropathy, such as numbness and tingling in the hands and feet, pain, the inability to walk or stay balanced, and constantly feeling tired or weak, are well known among doctors and the patients who experience them, but these common symptoms could be caused by an underlying rare, genetic condition called hereditary ATTR (hATTR) amyloidosis.

Estimated to affect approximately 50,000 people worldwide, hATTR amyloidosis is caused by a gene variant (mutation) that affects the function of a protein called transthyretin (TTR). In hATTR amyloidosis, the TTR gene variant causes the protein to take on an abnormal shape and misfold, which causes the protein to build up in various parts of the body, including the nervous (nerve), cardiac (heart), and gastrointestinal (digestive) systems. This build-up of proteins, also called amyloid deposits, can cause a range of symptoms from polyneuropathy – numbness, tingling, and burning pain – to cardiomyopathy – dizziness, shortness of breath, and leg swelling, as well as gastrointestinal manifestations, such as diarrhea, nausea, and vomiting.

As a hereditary disease, hATTR amyloidosis is passed down through family members. If one parent has hATTR amyloidosis, each child will have a 50% chance of inheriting the variant from the parent. However, inheriting the variant does not necessarily mean that they will develop the condition. Despite this family connection, hATTR amyloidosis is often misdiagnosed because its symptoms resemble those of other conditions and can vary widely among people with the same variant.

Educating yourself and your loved ones about the symptoms of this condition can help you identify them if they occur. Symptoms may worsen over time, so it's important to talk to your doctor to determine the right plan of action. This may include referring you to a specialist knowledgeable about hATTR amyloidosis who can perform further diagnostic tests, which may include genetic testing. Genetic counseling services may also

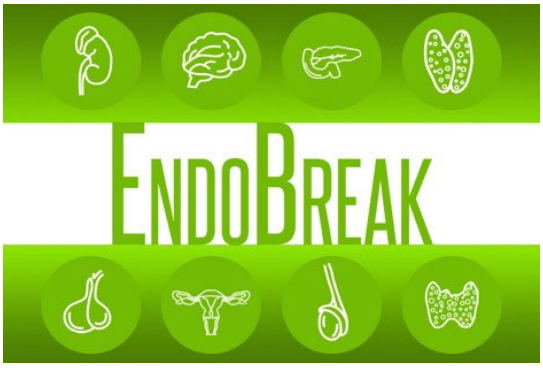
– Continued on page 7

FDA OK's Diabetic Neuropathy Capsaicin Patch; EDCs Still a Threat — News and commentary from the endocrinology world

By Kristen Monaco, Staff Writer, MedPage Today July 24, 2020

The FDA approved an 8% capsaicin patch (Qutenza) for the treatment of neuropathic pain associated with diabetic peripheral neuropathy of the feet in adults, Grünenthal and Averitas Pharma announced.

During the pandemic, kids and teens with newly diagnosed type 1 diabetes saw an uptick in diabetic ketoacidosis and severe ketoacidosis, a German study found. "Underlying causes may be multifactorial and reflect reduced medical services, fear of approaching the health care system, and more complex psychosocial factors," the group wrote in JAMA.



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Please contact your group leader or check your group page on the WNA website – www.WNAinfo.org to find out about the topic/speaker for the upcoming meeting.

Bev Anderson
Editor

Newsletter Design by
Diane Blakley Designs

Roster of Our WNA Information and Support Groups

Support groups are not meeting unless a leader notifies the group they are. If in doubt, call your Leader.

CALIFORNIA

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

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

Davis
2nd Tuesday, 3:30-5:00 PM
Davis Senior Center, 646 A Street
Mary Sprifke (530) 756-5102

Elk Grove
2nd Tues., 1 pm
New Senior Center
8230 Civic Center Dr.
Roger White (916) 686-4719

Folsom
3rd Wednesday, 12:30 PM
Association Resource Center
950 Glenn Dr., Suite 150
Bev Anderson (877) 622-6298

Fresno
3rd Tuesday, 11:00 AM
United Community Church of Christ
5550 N. Fresno St.
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

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

Modesto
3rd Monday, 10:30 AM
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Harkaman Ghag (209) 541-5404

Monterey
Next meeting September 16
3rd Wed.,10:30 AM
Online Zoom Meeting
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
Bev Anderson (877) 622-6298

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
Sonya Wells (916) 627-0228

San Diego
3rd Monday, 1:30 PM
The Remington Club
16925 Hierba Dr.
Chhattar Kucheria (858) 774-1408

San Francisco
2nd Monday, 11 AM – 12:30 PM
Kaiser French Campus
4141 Geary Blvd. between 6th & 7th Ave.
Rm. 411A - Watch for signs.
Merle (415) 346-9781

San Jose
3rd Saturday, 10:30 AM
O'Conner Hospital, 2105 Forest Avenue
SJ DePaul Conf. Rm.
Kathy Romero (407) 319-2557

Santa Barbara
4th Saturday, 10AM (Sept., Oct., Jan., March, May)
St. Raphael Catholic Church
5444 Hollister Ave., Conference Room
Nancy Kriech (805) 967-8886

Santa Cruz
3rd Wednesday, 12:30 PM (odd numbered months)
Trinity Presbyterian Church
420 Melrose Avenue
Mary Ann Leer (831) 477-1239

Santa Rosa
1st Wednesday, 10:30 AM
Steele Lane Community Center
415 Steele Lane
Judy Leandro (707) 480-3740

South San Diego
4th Thursday, 2 PM
Garden Room
3541 Park Blvd.
Jacklyn (858) 228-7480

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

Westlake Village - Thousand Oaks
2nd Monday, 4:30-5:30 PM
United Methodist Church
Youth Classroom 1 (faces parking lot)
1049 S. Westlake Blvd.
Angie Becerra (805) 390-2999

NEVADA

Las Vegas
3rd Thursday, 1 PM
Mountain View Presbyterian Church
8601 Del Webb Blvd.
Barbara Montgomery
lvneuropathygroup@gmail.com

OREGON

Grants Pass
3rd Wed., 4:30 – 6:30 PM
(except July, Aug., and Dec.)
Club Northwest
2160 NW Vine Street
David Tally 541-218-4418

TEXAS

Austin
2nd Wednesday, 9:30-11:00 AM
Education Room
Conley-Guerrero Activity Center
808 Nile Street
Marty Meraviglia RN, ACNS-BC
(512) 970-5454 • mgmeraviglia@gmail.com

Houston
3rd Saturday, 1-2:30 PM
Memorial Drive United Methodist Church
12955 Memorial Drive
South Parking Lot, Southeast Entrance
Room D100 (Ground Floor)
klstenzel@hotmail.com

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.

New Leadership needed. No meetings for now. Contact for information: Bev Anderson 877-622-6298. California: Alturas, Antioch-Brentwood, Bakersfield, Berkeley – Oakland, Carmichael, Clearlake, Costa Mesa, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Livermore, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, Redwood City, Salinas, Santa Maria, San Rafael, 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 Report By Bev Anderson

A special welcome to our members in Texas. This month, the newsletter will be going to all people for whom we have an address or an email address in Texas. Support groups exist in the Austin and Houston areas. They, like the rest of our support groups, are not meeting currently. We do not have a date when they will start again.

This issue starts with an article that gives the basic information given by Rita Lazenby in the webinar we had on July 28 relating to Hereditary ATTR Amyloidosis. If your neuropathy is hereditary and it is not Charcot Marie Tooth Disease which involves the sensory and motor aspects of neuropathy chiefly, you should look at what Hereditary ATTR Amyloidosis is and see if it matches with any concern you have. It is more sensory and autonomic aspects of neuropathy. All our internal organs are operated and regulated by the autonomic nervous system in the Peripheral Nervous System. There are 10 or more hereditary neuropathies. It is also possible to be the first one to have a type of hereditary neuropathy if those genes happened to be impacted when your parent's genes were matched to make you.

We are expecting to have another webinar on September 23 and October 28. You will notice this is the 4th Wednesday. I hope to have the announcement of the speaker before this newsletter goes to the printer. It will be announced several times by an informative email. If you don't have an email address and want to participate, please call Lindsay at (888) 556-3356 and leave a message with your phone number and you will receive a phone call. The webinar can be accessed by video or by telephone.

Many of you have heard me mention Dr. Jeffrey Ralph at U.C. San Francisco Medical Center and have heard him speak at one of our Conferences. We also have DVDs on his presentations. This month I happened to see a listing of rankings of neurology departments. Johns Hopkins University is no. 1 as would be expected. U.C. San Francisco is no. 2 in the nation. This is a huge honor for them and a great encouragement especially to those in Northern California. Of course, people come there from all over the world, too.

You will see a Lyme Disease article on page 5 in this issue. Lyme Disease is a cause of neuropathy. There are many more cases than are diagnosed. This one has a surprise as it is about a type of Lyme Disease for which there are now two tests (see page 7). There is Lyme Disease in California, Nevada, Oregon, and Texas as well as most other states but the attention is most often in the New England states and along the East Coast. Basically, wherever there are deer on which ticks ride, there will likely be Lyme Disease. It is a reason that it is so important for dogs and cats in those areas to have flea and tick protection. Either can run through areas where these ticks live and bring them home to you. Ticks carry many more diseases than Lyme Disease. If you are bitten by a tick, you want to be sure to follow it up with your doctor if any symptoms of something arise. Looking at the symptoms, you can see how someone with Lyme Disease could think they have Covid19 and so might medical people if there is no test for this type.

We are still having Teleconferences. The schedule is on page 8 in this newsletter. Some of you have called in once and some many times, but many of you have not called at all. Please give it a try. It is good to talk with other people that know about neuropathy. If you are living alone in this stay at home time or even if you're not, give yourself some company. Call to see who is talking together and join the conversation. You can call into any of the meetings listed. Some just remind people that their regular meeting was at that time so there might be more of people you know calling in then. Sonya and I hope to hear your voice.

September brings the first day of Fall/Autumn and possibly cooler weather.

Happy Autumn,

Bev

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".

NEW GENETIC CAUSE OF A FORM OF INHERITED NEUROPATHY

Discovery in siblings may hold answers to new gene therapies for Charcot-Marie-Tooth disease.

August 3, 2020 • Source: University of Pennsylvania School of Medicine

Summary: Inherited mutations in a gene that keeps nerve cells intact was shown, for the first time, to be a driver of a neuropathy known as Charcot-Marie-Tooth disease. This finding presents a clearer picture of the disease's genetic underpinnings that could inform the development of gene therapies to correct it.

Inherited mutations in a gene that keeps nerve cells intact was shown, for the first time, to be a driver of a neuropathy known as Charcot-Marie-Tooth (CMT) disease. This finding is detailed in a study led by researchers in the Perelman School of Medicine at the University of Pennsylvania, which published in Neurology® Genetics, an official journal of the American Academy of Neurology.

The findings, thanks to siblings treated at Penn since the late 1980s, present a clearer picture of the disease's genetic underpinnings that could inform the development of gene therapies to correct it.

The mutations in the gene known as dystonin (DST) add to a growing list of malfunctions found to cause their type of CMT, known as CMT2, which is defined by the loss of the nerve fibers, or axons, in the peripheral nerve cells. The researchers also showed that these mutations affect two key protein isoforms, BPAG1-a2 and BPAG1-b2, that are involved in nerve fiber function. Mutations in other isoforms of the same protein were previously tied to a blistering skin disease.

Neuropathies are common, occurring in nearly half of all diabetic patients, while hereditary neuropathies affect nearly one of out of 2,000 people. CMT is a debilitating neurodegenerative disorder that usually strikes in the second or third decade of life, and leaves patients with numbness and weakness in the hands and feet, among other neurological-related conditions.

There are more than 100 mutations found to be associated with CMT, with likely many more out there. Past studies from Penn researchers have identified some of these mutations by studying patients treated at Penn Medicine.

"We are determined to fill in the blanks of this giant jigsaw puzzle," said senior author Steven S. Scherer, MD, PhD, a professor of Neurology. "This latest paper is but one of many examples of where breakthroughs have happened between patients and the doctors at Penn and the support of different organizations and institutions to bring it all together."

The researchers applied whole exome sequencing to analyze the more than 30 million base pairs of DNA that encode the 20,000 proteins in humans. By examining three siblings -- two affected and one unaffected -- the researchers were able to deduce the genetic basis of mutations that caused the two siblings to be affected.

Backed by a mouse model from past studies showing a role of dystonin in neuropathies, the researchers identified two recessive mutations on the DST gene, each received from a biological parent, as the culprit. Together, the two mutations in the affected siblings disrupt the BPAG1-a2 and BPAG1-b2 isoforms, the researchers found, which weakened their axonal health. The DST gene gives rise to proteins that regulate the organization and stability of the microtubule network of sensory neurons to allow for transport of different cellular material along the nerve fibers.

"We have collaborated with this family for 30 years, and now we finally have an answer," Scherer said, "and the answer was a new genetic cause of neuropathy."

The findings put the field steps closer to developing new targeted therapeutics as well as CMT gene therapies designed to replace missing genes or correct mutations driving the disease. Clinical trials to investigate these latest mutations and others are not far off in the future, the researchers believe, particularly at an institution like Penn, which is home to the second largest clinic for CMT patients in the country and well-known for its gene therapy program.

"We are in the era where treatments for genetic diseases are possible," Scherer said. "This brother and sister stand to benefit from that approach because we know the gene that is missing, and if we could replace it, that should at least prevent their progression."

Story Source:

Materials provided by University of Pennsylvania School of Medicine. Note: Content may be edited for style and length.

Journal Reference:

1.William W. Motley, Stephan Züchner, Steven S. Scherer. Isoform-specific loss of dystonin causes hereditary motor and sensory neuropathy. Neurology Genetics, 2020; 6 (5): e496 DOI: 10.1212/NXG.0000000000000496

WHAT IS BORRELIA MIYAMOTOI?

Do you have all the symptoms of Lyme disease but test negative? Besides the fact the standard test for Lyme misses half the cases, there may be another reason—Borrelia miyamotoi.

A new study out of San Francisco State University (SFSU) has found more Borrelia miyamotoi than Borrelia burgdorferi (Lyme disease) in Ixodes pacificus ticks in some areas of Northern California.

Borrelia miyamotoi disease poses a difficult problem for patients and doctors who are unfamiliar with it. Its symptoms may present as viral-like or Lyme-like and there is currently no FDA-approved test.

The family of tick-borne Borrelia is divided into two broad groups that correspond to the disease manifestations they cause in humans: Lyme disease or relapsing fever. Borrelia miyamotoi is in the tick-borne relapsing fever group (TBRF).

Unlike B. miyamotoi, most North American TBRF species (B. hermsii, B. turicatae, B. parkeri), are transmitted by soft-bodied ticks.

B. miyamotoi is different. It's transmitted by the same blacklegged tick that carries Lyme disease and several other pathogens.

Furthermore, B. miyamotoi can be transmitted from the adult female tick to her eggs. This is called transovarial transmission. It means that baby ticks can be infected with B. miyamotoi from the get-go.

In contrast, blacklegged ticks don't start out being infected with Lyme. They must acquire the infection by feeding on an animal that carries it—such as a mouse or squirrel.

The research and findings

For the SFSU study, researchers collected 1,358 Ixodes pacificus ticks and 370 rodents from eight different sites in Northern California from April to May 2018. The ticks included 894 larvae, 281 nymphs and 183 adults.

On average, 0.11% of the larvae, 4.98% of nymphs, and 8.74% of the adult ticks tested positive for B. miyamotoi.

With the prevalence of infection increasing at each life stage of the tick, and each stage including one blood meal, the researchers estimate that horizontal transmission (from mammal to tick) accounts for 97% of B. miyamotoi infection in nymphal ticks and 43% of infection in adult ticks.

Interestingly, the researchers detected B. burgdorferi in 9.86% of nymph and 2.33% of the adult I. pacificus ticks—a decrease in prevalence of 76% from one life stage to the next. In addition, an average of 5.21% of the mice had blood that tested positive for B. miyamotoi.

During the same time, researchers also took skin biopsies from the ears of the rodents they had collected, and examined them for the presence of miyamotoi infection and Lyme. They found more B. miyamotoi in the blood samples and more B. burgdorferi in the skin.

This matches with other types of TBRF, which are more easily detected in human blood samples, especially when the person is symptomatic. In contrast, Lyme disease is harder to detect in blood samples after it disseminates throughout the body.

The SFSU authors conclude, "the human risk of B. miyamotoi in the western USA may be even greater than B. burgdorferi in certain disease hot spots."

How this study compares

The SFSU study only included counties around the San Francisco Bay Area. However, a prior California Department of Public Health 12-year study found B. miyamotoi in I. pacificus ticks in 24 out of 48 California counties.

Another study published in 2018 by Professor Robert Lane, along with researchers at UC Berkeley and Yale, examined a biobank of frozen blood samples. The results showed that 26 out of 101 samples[1] collected from residents of Mendocino County, California, in the 1980s were reactive for relapsing fever borreliosis, including B. miyamotoi.

Similarly, another study published in 2018 looked at blood samples drawn from patients in 25 California counties. The results showed positive testing for TBRF in 16 of those counties[2],

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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 - **12% off all home units.**
Contact: 800-521-6664 or www.anodynetherapy.com

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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NEUROPATHY MEDICAL 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:

- 17461700 This Korean study of 29 patients with piriformis syndrome (mimics sciatica) were injected with 150 units of botulinum type A under CT guidance into the piriformis muscle. Pain intensity scores decreased significantly ($p<0.0001$) at 4, 8, and 12 weeks. Controls receiving dexamethasone 5 mg and lidocaine 1% failed to improve.
- 23432384 This University of Leiden paper reviews three studies involving the use of prolonged infusion (4-14 days) of ketamine for chronic pain with a neuropathic component resulting in up to three months' analgesia.
- 25245776 The Mayo Clinic Department of Oncology performed a pilot study of 37 patients with cancer induced peripheral neuropathy using a cutaneous neurostimulation device, Scrambler. The patients had been symptomatic for over a month and had a score of 4/10 or more for a week prior to treatment. They were treated with up to ten daily 30-minute sessions. There was a 50% reduction of pain, 44% reduction of tingling and a 37% reduction of numbness lasting throughout the 10-week study.

UPDATE ON PAIN MEDICATION FROM UC DAVIS

Bruce Hammock, PhD, distinguished professor on the campus at UC Davis, reports that Clinical Trial 1a was completed successfully with no issues. In this test, each person had to not have any medical concerns and be deemed healthy. Each person was given a daily pill. No one reported any adverse response to the pill. So it was deemed very positive.

The next clinical trial, which is 1b, will again be administered to healthy people but this time they will take a dose that an ill patient might receive to see if there are any side effects. None are expected. This test will start in October, hopefully. The trial is supposed to be on a fast track.

Karen Wagner, from the research team who spoke at our 2019 Annual Conference, is projected to be the speaker at our October 28 webinar. She has received a grant to do a clinical trial with cancer patients to see how the medication works with cancer pain. This will likely be early in 2021. Other trials are likely in 2021 as well. She will speak with us about what the future of this medication looks like and when it may be available for doctors to prescribe. All clinical trials are with people chosen by the clinic in the area where the trial is based. 1a was in Austin, Texas. The site of any of the others is not yet announced.

The research team that Dr. Hammock leads has been very busy with work on COVID-19 projects. They are working internationally on a vaccine. Dr. Hammock has a treatment for a stage of COVID-19 that he is hoping to put into a clinical trial. Dr. Hammock is also involved in the UCD Comprehensive Cancer Center and is the Director, NIEHS-UCD Superfund Research Program.

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Join the Conversation!

@neuropathy_WNA

Neuropathy Or Something Else? Understanding Hereditary ATTR Amyloidosis

– Continued from page 1

be recommended to help individuals and families understand their chances of inheriting a gene mutation associated with hATTR amyloidosis and to help make sense of genetic testing results once they are obtained.

If you think you or someone you know may be at risk for hATTR amyloidosis, it's important to learn more. You can access educational resources and information at Alnylam Pharmaceuticals' website www.hattrbridge.com. In addition, you can request to speak with an Alnylam Patient Education Liaison who can answer any additional questions you may have about hATTR amyloidosis at www.hattrpel.com.

Content sponsored and provided by Alnylam Pharmaceuticals.

Hawkins PN, et al. Annals of Medicine. 2015; 47(8):625-638.

Adams D, Coelho T, Obici L, et al. Neurology. 2015;85(8):675-682.

Conceicao, et al. Journal of the Peripheral Nervous System. 2016;21:5-9.

Shin, et al. Mt Sinai J Med. 2012;79(6):733-748.

Dungu et al. Heart. 2012;98(21):1546-1554

National Institutes of Health: Department of Health and Human Services. Genetics Home Reference. Transthyretin amyloidosis.

https://ghr.nlm.nih.gov/condition/transthyretin-amyloidosis#inheritance. Accessed July 16, 2020.

What is Borrelia Miyamotoi? – Continued from page 5

with the highest rates of positivity coming from Santa Clara, Alameda, Marin and San Francisco.

That study used a novel laboratory technique that can detect multiple species of TBRF[3]. Co-author Jyotsna Shaw, of IGeneX, Inc., says "we hope that these techniques can be used to develop accurate FDA-approved tests for the future."

A hidden epidemic?

B. miyamotoi was discovered in ticks more than 20 years ago in Japan. But it wasn't proven to cause illness in humans until 2011, when the first human cases were reported in Russia.

It is now known to be widespread in North America, wherever Ixodes scapularis ticks and Ixodes pacificus ticks are found

Unfortunately, Borrelia miyamotoi disease (BMD) is not reportable to the CDC, and the standard test for Lyme disease will not detect it. Because of this, many patients are likely going undiagnosed, and therefore we really have no idea how widespread the illness is.

As of 2020, there are two sources of a test for Borrelia Miyamotoi disease: https://www.mayocliniclabs.com/test-catalog/Overview/64970

http://www.imugen.com/test-menu/borrelia-miyamotoi-antibody/)

The symptoms of Borrelia Miyamotoi Disease (BMD)(according to the CDC

Symptoms

1. Fever
2. Chills
3. Fatigue
4. Severe headache
5. Muscle or joint pain
6. Dizziness, confusion, vertigo (uncommon)
7. Rash (uncommon)
8. Shortness of breath (uncommon)
9. Nausea, abdominal pain, diarrhea, and anorexia (uncommon)

A recent feature in the New York Times discusses a difficult case where a patient tested negative for Lyme and many other conditions. Medical detective work by Dr. Brian Fallon of the Columbia Lyme and Tick-Borne Disease Center eventually determined that she suffered from B. miyamotoi. (She tested negative for Lyme disease. So what was wrong?)

LymeSci is written by Lonnie Marcum, a Licensed Physical Therapist and mother of a daughter with Lyme. [1] https://www.lymedisease.org/lyme-sci-study-finds-lots-b-miyamotoi-california-ticks/

[2] https://www.lymedisease.org/relapsing-fever-calif/

[3] https://www.lymedisease.org/better-lyme-diagnostic-tests/

Used by permission of LymeDisease.org.

DISCOUNTS FOR WNA MEMBERS

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Neuropathy Support Formula/Nerve Renew (1-888-840-7142) is a supplement that a 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. They now have Nerve Renew Fast Acting Cream at $20 for WNA members. It reportedly takes the edge off numbness.

Building Better Balance DVD, Developing Spine Health – The DVDs are $30 each. The price of a full set (4 DVDs) is $100 (that's a 20% discount). You can order the DVDs by going to the website www.building-better-balance.com. Shipping is free. You can also order the DVDs over the phone using a credit card. Call (707) 318-4476 and leave a message" Vanessa Kettler, Balance and Fall Prevention www.building-better-balance.com (707) 318-4476

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.

WESTERN NEUROPATHY ASSOCIATION
A California public benefit, nonprofit,
tax exempt corporation

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

TELECONFERENCES IN SEPTEMBER

Call 1-877-366-0711 • Passcode 36199447#

Monday, September 7, 6:30 PM PDT – All areas
Wednesday, September 9, 1:00 PM PDT – All areas
Tuesday, September 15, 1:30 PM PDT - Sacramento
Wednesday, September 16, 12:30 PM PDT – All areas
Thursday, September 17, 1:00 PM PDT – Nevada/Las Vegas
Saturday, September 19, 10:30 AM PDT – San Jose

Monterey Neuropathy Support Group: Wednesday, Sept. 16, 10:30–11:30am by online Zoom. Sign-in opens at 10:00 AM. For Zoom link – email Bill Donovan MD at seabreezex09@gmail.com, giving name, address, telephone number and email address.

DOING SOME ONLINE SHOPPING?

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

amazonsmile
You shop. Amazon gives.

You can also support WNA by shopping at one of the 1700+ stores at **iGive.com** and selecting the Western Neuropathy Association as your charity of choice - they will donate a rebate of your purchase at no extra cost to you!

iGive.com
You Shop. Your Charity Gets Money. For Free.

Western Neuropathy Association (WNA)
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Bev Anderson, Editor

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

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

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.