WESTERN NEUROPATHY ASSOCIATION

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

June 2020
Issue 06
Volume 18

Awarded by GuideStar November 13, 2018

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

REPORT ON THE PAIN MEDICATION CLINICAL TRIALS

The first trial is not yet finished but so far everything looks quite good. The first one had to pause with the requirements for Covid19 shelter in place arrangements. It will now be completed and the reports be compiled. The full results should be ready by the end of June.

The next clinical trial will come after additional material is submitted and the site chosen. It could be the same or could be in one or more other locations. It is a second phase of giving it to healthy patients. The first entailed one dose at a time. The results could not be more optimistic, 5 of 6 planned doses are finished with no adverse outcomes reported. The next is several doses once a day for a week. These approaches tell if there are side effects for healthy people before it is tried on people who are not well. This trial will start in October or November. It is hoped that one dealing with people in pain could be done somewhere soon after this trial. However, it is a major goal for 2021 to get that portion completed. It does take a while but we definitely want it to be a safe medication when it is ready to be prescribed by doctors. Pain medication without major side effects. What a dream to look forward to!

Due in large part to a new MD member of the team, Irene Cortes, Eicosis was granted a fast track waiver by the FDA. This allows the company to move a little faster through the clinical trials and to make the drug available on a compassionate basis after phase IIa trials start.

Another thing we are looking forward to is an effective vaccine for Covid19. Keep a good thought and prayers, if you wish, for the team Dr. Hammock works with. Until that vaccine is available, they are working to find a cure for the cytokine storm that is so devastating to older people who get the virus. There are a number of candidates getting to clinical trials rapidly worldwide. Let's be trusting that some team gets a very effective one ready very soon. Many are getting little sleep as it is such a human need.

ERYTHROMELALGIA

Recently patients have asked about their feet or hands being bright red. This article is being repeated from a much earlier newsletter to help all of us understand Erythromelalgia better.

Background

Erythromelalgia is a rare disorder that is characterized by burning pain and warmth and redness of the extremities. There is some confusion in the literature regarding nomenclature and classification; however, in general, a distinction is made between primary (idiopathic) and secondary erythromelalgia (most commonly associated with myeloproliferative disorders), as well as between early- and late-onset disease.

The name is derived from three Greek words: erythros ("red"), melos ("limb"), and algos ("pain"). Mitchell first described erythromelalgia in the 1870s, and Smith and Allen further categorized it in 1938, proposing the term erythermalgia to emphasize the characteristic warmth. They also proposed a distinction between primary (idiopathic) erythromelalgia and secondary erythromelalgia (due to underlying neurologic, hematologic, or vascular problems).

Drenth and Michiels made a distinction between erythromelalgia and erythermalgia on the basis of responsiveness to aspirin. They established three categories: erythromelalgia (platelet-mediated and aspirin-sensitive), primary erythermalgia, and secondary erythermalgia.

Investigation into the pathophysiology of primary erythromelalgia indicates that this disorder may serve as a model for understanding common chronic pain conditions.

– Continued on page 6

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
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
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.

2020 WNA Board of Directors

Bev Anderson
President

Karen C. Polastri, IOM
Vice President

Anne Bentz
Secretary

Darrell O'Sullivan
Treasurer

Pam Hart
Director

Sonya Wells, PharmD, MPH
Director

Emeritus Council

Michael Green
Emeritus

Johnathan Istilart
Emeritus

Brad Livingood
Emeritus

Sandra Vinson
Emeritus

Dick Ward
Emeritus

Lindsay Campoy
WNA Administration
(888) 556-3356
admin@pnhelp.org

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

See page 8 for Support Group Teleconferences.

President's Message By Bev Anderson

Wherever we live, we have had some form of staying in place these past months. In areas where people stayed at home and used social physical distancing when they were out, there seems to be less spread of COVID-19. Now that areas are opening back up, there is fear of a new wave of illness. Those of us of advanced age or with health concerns must be careful beyond that of younger, healthier people who, if they get the virus, have a better chance of fighting it off. But even youth does not provide immunity. As for me, I count my blessings if I go out where there are other people. I feel concerned until the incubation period passes of when I was out and about. I try to be careful, but one never knows.

A sizable number of you sent in a donation for the Big Day of Giving. We received more than we have in any year. Thank you very much. Of course, the door is always open for more as it is always needed. We rejoice that Thrifty Bargain started using their trucks to pick up donated items left out on the curb for them. If you get a card in the mail saying they are coming around for a pick up to benefit WNA, please respond with any useable items that you would like to find a new home for.

It was pointed out to me that I didn't mention the Annual Conference we had planned for May 7 in the column last month. I also did not emphasize that that week in May was the nationally designated Neuropathy Awareness Week. We usually declare the whole month as Neuropathy Awareness Month so each group can talk about it when they meet. You are receiving this newsletter before the end of May so try to talk to at least one person about neuropathy before the end of the month so you can know you helped in one way.

One thing I do is when I talk to someone on the phone for some item of business and they say, "Is there anything else I can do for you?" and there isn't anything more I need, I say, "Do you know what neuropathy is?" If they say they do, I ask them to tell me and help them if they are hesitant. If they don't, I use the basic description: "Your brain and spinal cord are your central nervous system." You have a lot of other nerves that connect in some way to the brain or spinal cord. These are your peripheral nervous system. Any disease or disorder in the peripheral nervous system can be a form of neuropathy. It can cause tingling, numbness, pain, and odd feelings of various types." I assure them that with one of 10 of us having symptoms of neuropathy from over 200 causes, they likely know someone with neuropathy. Many times, the person I'm talking to has it. I give them our information phone number 877-622-6298 and suggest they call it to request our packet of information. It doesn't matter where in the world they live; we respond and they can join and receive the newsletter if they wish. We have members in many states. I urge you to be ready to help people know about neuropathy. Each one helps one.

We have not yet set up the webinars for the Annual Conference speakers. We hope to do this soon. We will send out information by email and the newsletter if the timing works. It is possible to call into a Zoom meeting and listen if you don't have a computer or choose to attend that way. Seats are limited though.

I encourage you to call into the telephone meetings listed on the back of this newsletter. On the first Monday evening of May, we hosted 14 callers. We had a very busy and informative time. My advice is that no matter what someone says works for them, it may not be best for you. You have the right to not choose to try their approach. The best thing is to have a balanced diet and a balanced life.

Bev

THE HOARDER By Julia Helen Tracy

Moving like a habitual hoarder
along a narrow space;
bounded by stacks and stacks of
old thoughts, old ideas, old plans,
old ways of coping.
One false move and
it will all tumble, bury me in rubble.
Why do I save this old debris?
Call in the dump truck!
Haul it all out!

Make room for the new!

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".

THE BOOK OF PERIPHERAL NEUROPATHY INFORMATION – AND MORE By Shirley Gast Lynn

The following is a small portion of a book by Shirley Gast Lynn who for some years was the Neuropathy Support Group Leader in Kansas City, Kansas. She retired several years ago. When the following was written she had had one leg amputated and later part of the other. She continued leading the group as long as she had transportation to get there and the strength to prepare and lead the meeting. In her book, if she is making a comment, she initials it SGL. When her sister does, it is JGA (Joanne Gast Anderton.) Carol and Bud are included here without initials.

I discovered a long time ago that anger creates stress, and stress increases pain, so I have to resist the feeling of anger, knowing how it will affect me. A better word to explain my feelings is frustration! Frustration is easier to deal with, and does not create as much stress as anger does.

Acceptance of the changes in your life as the result of neuropathy, or any other health problem that has come your way, is a must! Without acceptance on the first step, there is no way you can take the next step, which is today. You will need acceptance to meet tomorrow for a fresh start! – SGL

Acupuncture

Acupuncture is a complementary medical practice that entails stimulating certain points on the body, most often with a needle penetrating the skin, to alleviate pain or to help treat various health conditions. Be certain that the acupuncturist is certified.

FROM BUD

Bud reports he took acupuncture treatments hoping to find relief from PN, but was disappointed in that he obtained no relief.

(As in many different therapies, some people receive help from the therapy of acupuncture, and some don't. There is no explanation as to the answer. Other neuropathy patients, whose stories are included in this Book, have had help from acupuncture and others, like Bud, were disappointed. The secret to trying different therapies is to know when to stop the therapy if you are not getting good results from it. – SGL)

Advice

Sometimes, we have to monitor ourselves to make certain we are taking good care of ourselves! Keep moving your feet and ankles and/or your hands and arms, so they don't freeze up, making your balance go down-hill faster. Use a cane or walker if your balance is really bad. If you have a cell phone, keep it in your pocket in case you fall and need to make a call for help. Keep busy so you can focus off of your neuropathy. Put on confidence each morning as you begin your day! Drop all negatives in the waste basket! Think positive and keep your mind on happy things! Do not allow neuropathy to control your life! Remember, smile and the whole world smiles with you! (I have a friend who lives alone on about 25 acres of land. He finally listened to me about carrying his cell phone when he goes out of his house. He lit a fire, the wind blew it all over him, and he was able to call 9-1-1. It took months for him to heal. He was thankful he had his cell phone in his pocket! – SGL)

Advocate – Being Your Own Advocate

Being your own advocate means standing up for yourself in all situations. Learning how to do this in the correct way might need some thought. We have neuropathy, which means we could have some very difficult stresses to endure. Pain of all kinds, numbness, balance problems, difficulty doing things we have always done, but struggle with now – are just a few of our stresses.

Deciding when you need help from another person is an important part of being your own advocate. I personally have suffered from someone helping me, when I really didn't need help. One of the most difficult things I learned to do, after neuropathy came to live with me, was to have the courage to tell people not to help me. That may sound strange, but I learned along the way that I can get hurt easier by people helping me in their idea of help, than if I struggle to help myself.

Another time you need to be your own advocate is during an appointment with your doctor. If he/she suggests some treatment or medication you know won't help you, or that has caused adverse effects in the past, it is your right to speak up to refuse the treatment. Be prepared to be told to get another doctor if you won't follow the doctor's advice, as I was once told. You need a doctor who will listen to what you have to say, or have experienced.

Keeping a journal of what neuropathy does to you is important. It is easy to forget that day when you had excruciating pain after doing something that took a bit more energy than you evidently had at the time. Keeping a journal takes the mystery out of what ails you. Include your reactions to medications in your journal. Record the days when depression is your companion. If depression turns out to be your companion too often, talk to your doctor about it, or give yourself a pep talk to try to work it out of your life.

Remember, you are the only one who knows how you feel, and the only one who can reach out to receive the help you need, when you need it. - SGL

Advocate – Being Your Own Medical Advocate

Shirley and I both had surgery during this past month. In fact, our sister Carol in Florida led the parade on March 16th! We all had experiences we feel are worth sharing to once again remind our members of the importance of always acting as your own medical advocate. Read on! – JGA

FROM CAROL

I am currently undergoing radiation treatment for ductile carcinoma with some very good doctors at an outstanding cancer center here in Orlando. However, I began having

– Continued on page 5

problems with the medical staff during my recent surgery when my heel was re-injured while transferring me from the bed to the operating table. My Achilles tendon injury had taken six months to heal; I had been without pain for four months when this re-injury occurred, awakening the severe pain I'd previously experienced with the Achilles injury. Now I am back to square one on the heel injury.

Like many people, I have many medical problems, some of which require specialists. I have been to great doctors and to some not-so-great doctors and I have walked out on several. The problems I have found with some doctors and their staff members is that, although I am there for one thing, they fail to take into consideration any of my other medical problems when they are treating me.

I also have osteoarthritis, neck and back pain from an old injury, leg pain, knee replacement pain, shoulder pain from a recent fall, and a trauma injury to my brain. I always bring these matters to the attention of any doctor or medical staff I am involved with. I also tell them I need to move around on my own, but one of them always reaches out to try to "help" me to move. Because I am watchful, with the exception of the heel re-injury, I haven't experienced severe pain when being handled.

Consequently, I see there is a great need for all medical personnel to study each patient's chart to obtain an over-all picture of the patient's condition. And most of all, listen to what the patient is saying.

FROM SHIRLEY

Hip surgery was not something I looked forward to experiencing. Eventually, I will be pleased that I agreed to it. I had no idea, however, that my hip replacement surgery would send me into immediate, severe neuropathy pain. I am praying my leg and foot will go back to my so-called normal neuropathy pain status. That condition was bearable.

I discovered that most of the medical field is not knowledgeable about neuropathy. The therapists at the rehab hospital had their plan of treating a hip replacement. There was no consideration given for the fact that I have neuropathy and an amputation. Their attitude was "Do it this way. You can't leave until you accomplish this therapy."

I was diagnosed with PN in 1996 and had to learn by trial and error what I could do and what was no longer possible in my life. Some days were better than others. Learning to have a positive attitude helped. Sometimes that positive attitude amounted to proclaiming that PN hurts something awful.

Over the years the burning, stabbing pain, the electrical bolts of pain, and the feeling that my feet and legs were being smashed in a vise have just been something I had to accept. I was thankful that all of these feelings didn't always hit me at the same time. I experienced seven months of severe side effects, including suicidal thoughts, while taking Neurontin at the beginning of my journey. Since then I've tried other medications for pain which also caused severe side effects and was unable to tolerate them. After the hip surgery I finally had to agree to take Tylenol. Now the Tylenol has been discontinued.

"Please do not wiggle the heel of my shoe onto my foot!" I exclaimed one night in the rehabilitation hospital. The young woman backed up and said, "I'll get your nurse. I don't want to fight you." I told her I didn't want to fight her either and asked her to listen to me. She was almost to the door but came back. I told her that I have neuropathy and that wiggling my shoe onto my foot hurts tremendously. I also said I didn't know how long she'd had her job, but I hoped she would learn one thing from this situation – to listen to her patients, that they know what they need and how things need to be done. I told her I needed her help. She relaxed and helped me.

My therapist couldn't or wouldn't understand that I could not do the exercises the way she directed because of neuropathy and my amputation. She left me sitting on the exercise table for two days of therapy. On the third day at the rehab hospital, I informed my doctors that I would have to go home if I was ever going to heal. I agreed to home health care and my physical therapist is great. He understands my limitations due to neuropathy and my amputation, and finds ways to work around both.

I was accused of being uncooperative in rehab. When I tried to be cooperative, I caused myself additional pain. As a result, I realized I must be my own medical advocate even if I appear to be an uncooperative patient. I learned it is better to appear uncooperative rather than add additional and unnecessary PN pain to my foot and leg.

During my therapy I was always holding onto the walker. When I came home, I realized I couldn't walk without it. I was shocked; I felt I was regressing. Then I remembered I'd been told I'd need the walker for several months while my hip healed. It made me realize how important all of this exercise therapy is to get me back on my feet.

FROM JOANNE

Twenty-six days after Carol went to surgery, twelve days after Shirley, it was my turn. I was to have left shoulder repair, including shortening of the left clavicle. It was almost time to go in and the anesthesiologist dropped by to make final plans. After the usual Q&A about problems, meds, allergies, etc., he snapped shut his clipboard, and got ready to stand.

"There's one thing that concerns me," I said. He sat down again. "I understand the patient has to be in a certain position for shoulder surgery," I continued. "I think you need to know that I cannot sleep on my left side because I can't breathe that way. Sometimes I turn in my sleep and wake up unable to breathe. It has something to do with some long-ago surgery I had where the right diaphragm was compromised." He looked at me briefly and put his elbows on his knees, head in his hands, and started mumbling. I couldn't tell if he was praying or cussing. The look on his face when he raised his head shocked me.

"For this type of surgery," he said, "we do a nerve block that paralyzes the left side of the diaphragm. If I had given you that nerve block, we'd have been in deep doo-doo." In other words, both sides of my diaphragm would have been non-functional. Suddenly I understand the look of consternation on his face. I felt as though I might have saved my own life.

– Continued on page 7

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.

– Continued on page 7

Erythromelalgia *– Continued from page 1*

Erythromelalgia in a 77-year-old woman with longstanding polycythemia vera.

Erythromelalgia, also known as Mitchell's disease (after Silas Weir Mitchell), acromelalgia, red neuralgia, or erythermalgia,[1] is a rare neurovascular peripheral pain disorder in which blood vessels, usually in the lower extremities (or hands), are episodically blocked (frequently on and off daily), then become hyperemic and inflamed. There is severe burning pain (in the small fiber sensory nerves) and skin redness. The attacks are periodic and are commonly triggered by heat, pressure, mild activity, exertion, insomnia or stress. Erythromelalgia can occur either as a primary or secondary disorder (i.e. a disorder in and of itself or a symptom of another condition). Secondary erythromelalgia can result from small fiber peripheral neuropathy of any cause, essential thrombocytosis, hypercholesterolemia, mushroom or mercury poisoning, and some autoimmune disorders. Primary erythromelalgia is caused by mutation of the voltage-gated sodium channel α-subunit gene SCN9A.

In 2004 Erythromelalgia became the first human disorder in which it has been possible to associate an ion channel mutation with chronic neuropathic pain;[2] this became possible when a Yale neurologist spotted a Beijing geneticists team paper in the Journal of Medical Genetics titled "Mutations in SCN9A, Encoding a Sodium Channel Alpha Subunit, in Patients With Primary Erythromelalgia"; a connection was made that this sodium channel mutation was expressed primarily in peripheral pain sensing neurons.[3] Conversely, in December 2006 a University of Cambridge team reported an SCN9A mutation that created a complete "lack of" pain sensation in the family of a Pakistan street performer. He felt no pain, walked on hot coals and stabbed himself to entertain crowds.

Classification

Primary erythromelalgia may be classified as either familial or sporadic, with the familial form inherited in an autosomal dominant manner. Both of these may be further classified as either juvenile or adult onset. Juvenile onset occurs prior to age 20 and frequently prior to age 10. While the genetic cause of the juvenile and sporadic adult onset forms is often known, this is not the case for the adult onset familial form.[4]

Incidence

Recent research in the U.S. found the incidence of EM (the number of people a year diagnosed with EM) to be 1.3 per 100,000. The rate for women was higher — 2.0 per 100,000 per year — than men, which was just 0.6. The median age at diagnosis was 61. These rates were five times higher than those estimated by an earlier Norwegian study — the only other known research describing EM incidence. Approximately five percent of those with EM have the autosomal dominant (Primary-Inherited) form of the disease.[5]

Symptoms and signs

The most prominent symptoms of erythromelalgia are episodes of erythema, swelling, a painful deep-aching of the soft tissue (usually either radiating or shooting) and tenderness, along with a painful burning sensation primarily in the extremities. These symptoms are often symmetric and affect the lower extremities more frequently than the upper extremities. Symptoms may also affect the ears and face. For secondary erythromelalgia, attacks typically precede and are precipitated by the underlying primary condition. For primary erythromelalgia, attacks can last from an hour to months at a time and occur infrequently to frequently with multiple times daily. Common triggers for these episodes are exertion, heating of the affected extremities, and alcohol or caffeine consumption, and any pressure applied to the limbs. In some patients sugar and even melon consumption have also been known to provoke attacks. Many of those with primary erythromelalgia avoid wearing shoes or socks as the heat this generates is known to produce erythromelalgia attacks.[4] Raynaud's often coexists in patients with Erythromelalgia[6].

Cause

In general, erythromelalgia seems to consist of neuropathological and microvascular alterations. How this occurs in secondary erythromelalgia is poorly understood and may be specific to the underlying primary condition. Primary conditions that have been shown to elicit erythromelalgia are listed in diagnosis, below.[4]

– Continued on page 7

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:

- 30826229 This Chinese review of 13 studies of 1040 patients on either conventional rehabilitation therapy or electroacupuncture with follow-up at 2 and 6 weeks. Significant improvement was seen with the electroacupuncture group in terms of analgesia and increased function (p<0.001).
- 30898269 This article from Albany Medical College discusses spinal cord stimulation with surgically implanted electrodes following a rigorous trial period. Randomized clinical trials have shown significant alleviation of pain from a variety of causes.

Erythromelalgia

– Continued from page 6

Primary erythromelalgia is a better understood autosomal dominant disorder. The neuropathological symptoms of primary erythromelalgia arise from hyperexcitability of C-fibers in the dorsal root ganglion. Specifically, nociceptors (neurons responsible for the sensation and conduction of painful stimuli) appear to be the primarily affect neurons in these fibers. This hyperexcitability results in the severe burning pain experienced by patients. While the neuropathological symptoms are a result of hyperexcitability, microvascular alterations in erythromelalgia are due to hypoexcitability. The sympathetic nervous system controls cutaneous vascular tone and altered response of this system to stimuli such as heat likely results in the observed microvascular symptoms. In both cases, these changes in excitability are typically due to mutation of the sodium channel NaV1.7. These differences in excitability alterations between the sympathetic nervous system and nociceptors is due to different expression of sodium channels other than NaV1.7 in them.

Side effect of medication

Several medications including ergot derivatives like bromocriptine and pergolide, verapamil, and nifedipine have been associated with medication-induced erythromelalgia.

Mushroom poisoning

The consumption of two species of related fungi, Clitocybe acromelalga from Japan, and Clitocybe amoenolens from France, has led to several cases of mushroom-induced erythromelalgia which lasted from 8 days to 5 months.

Footnote references and more can be found at https://en.wikipedia.org/wiki/Erythromelalgia

The Book Of Peripheral Neuropathy Information – And More

– Continued from page 5

I had not known a nerve block was involved; the only thing I knew was that something kept nagging at me about the procedure. If they were going to turn me on my side, I wouldn't be able to breathe. I had been cleared for surgery by a pulmonologist only days earlier with the admonition that there was to be no nerve block used, but had forgotten to add that to my Life Chart which goes with me to every doctor appointment or hospital admission. (All my doctors have told me they wish every patient would make one of these.) My question is: Where was my brain? Why hadn't I remembered that very important point? Where was that pulmonologist's report? Why wasn't it in my chart there in surgery? Or was it and no one had noticed it? I don't know.

When I returned home, I took out my medical diary and went back to the pulmonologist appointment. I could hardly believe my eyes. There, on the page, in capital letters, I had written her instructions: NO SCALENE NERVE BLOCK!

Now I am on my sixth life. I'm like a cat. I may not have nine lives, but I can certainly qualify for the six-lives category! I believe God has more jobs for me to finish before I leave town!

Used by permission.

DISCOUNTS FOR WNA MEMBERS

Continued from page 6

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 JUNE

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

Monday, June 1, 6:30 PM Call for anyone who wishes to call in *

Wednesday, June 10, 1:00 PM – Placerville – anyone can call in *

Tuesday, June 16, 1:30 PM – Sacramento – anyone can call in – Sonya Wells, Pharmacist, leading

Wednesday, June 17, 12:30 PM – Folsom – anyone can call in *

Saturday, June 20, 10:30 AM – San Jose – anyone can call in *

* Bev Anderson, President, leads the undesignated four.

www.facebook.com/WNeuro

Join the Conversation!

@neuropathy_WNA

Western Neuropathy Association (WNA)
A California public benefit, nonprofit,
tax-exempt corporation.

Bev Anderson, Editor

P.O. Box 276567
Sacramento, CA 95827-6567
(877) 622-6298 ■ (888) 556-3356
info@WNAinfo.org ■ www.WNAinfo.org
WNA Headquarters: admin@WNAinfo.org

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

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

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

This newsletter is designed for educational and informational purposes only. The information contained herein is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. Western Neuropathy Association (WNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.