



WESTERN NEUROPATHY ASSOCIATION

September 2018

Issue 09

Volume 16

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WESTERN NEUROPATHY ASSOCIATION

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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

Celebrating 20 Years!

THREE LUNCHEONS PLANNED.

BEV ANDERSON SCHEDULED TO BE AT EACH.

Sacramento Area – Saturday, October 13 – Noon, Cattlemen's, 12409 Folsom Blvd., Rancho Cordova

Concord – Thursday, October 18 – 1:00 PM, The Old Spaghetti Factory, 1955 Mt. Diablo St., Concord

Auburn – Monday, November 5 – 10:30 AM, Black Bear Diner, 13365 Lincoln Way, Auburn

This organization started in Auburn on the first Monday of November 1998, in this very room.

ANTI-MAG PERIPHERAL NEUROPATHY RARE BUT KNOWN REGULARLY

Anti-MAG peripheral neuropathy is a rare autoimmune variety of peripheral neuropathy (PN). In this type of PN, a person's own immune system attacks cells that are specific in maintaining a healthy peripheral nervous system. As these cells are destroyed by antibodies, they lose function and create problems in both sensory and motor function.

Anti-MAG neuropathy is often associated with "monoclonal gammopathy of undetermined significance (MGUS)," a potentially cancerous (but usually benign) condition characterized by a similar over production of serum immunoglobulins.

Symptoms & Signs

(Not all symptoms and signs may be present.)

The disorder is predominantly characterized by the following symptoms:

- Sensory loss starting in toes and/or fingers
- Loss of vibration senses
- Unsteady gait
- Tremors in hands and legs
- Poor balance
- Muscle weakness

Diagnosis proceeds with a neurological examination. If the examination indicates that the

patient has a peripheral neuropathy, then testing for a monoclonal gammopathy and electrodiagnostic testing is done among many other tests. If the blood work and/or the EMG are appropriately abnormal, then blood testing for anti-MAG antibody is done. Other blood work may be done to exclude another cause for the patient's condition. Some patients will have an elevated protein in their cerebral-spinal fluid, which can be obtained through a spinal tap.

Treatment & Therapy

(Not all treatments and therapies may be indicated.)

The progression of anti-MAG may be slower and less severe than CIDP (Chronic Inflammatory Demyelinating Polyneuropathy), and many patients continue living relatively normal lives while managing their symptoms with simple exercises or drug therapies. Only 10 percent of patients become severely disabled and wheelchair-bound. The majority of patients are male, and most of them are in their 50s or 60s.

There are many therapeutic treatments that have been tried for anti-MAG neuropathy, with varying results.

- Rituximab – an antibody that binds to B-cells (cells that make antibodies) and removes them

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Roster of Our WNA Information and Support Groups

Some groups continue meeting all summer months but some don't. If the meeting you attend does not have any changes in its listing, it likely meets through the summer. If you want to be sure, call the leader at the number given.

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

Newsletter Design by

 **Diane Blakley**
Designs

CALIFORNIA

Antioch-Brentwood

Next meeting, Sept. 19
3rd Wednesday, 2 PM (odd numbered months)
Antioch-Kaiser, Deer Valley Rooms 1 & 2
Marty Price (925) 626-7988

Auburn

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

Berkeley-Oakland

Next meeting Sept. 19
3rd Wed., 3-4 PM
North Berkeley Senior Center
1901 Hearst Ave.
Kathleen Nagel (510) 653-8625

Carmichael - Atria

Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
For information, call:
Ryan Harris 916-342-8440

Castro Valley

2nd Wednesday, 1:30 PM
First Presbyterian Church
2490 Grove Way (next to Trader Joe)
Joy Rotz (510) 842-8440

Concord

Next meeting, Sept. 20
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

Next meeting, Sept. 10
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

4th Wednesday, 12:30 PM (odd numbered months)
Burger Rehabilitation
1301 E. Bidwell St.
Bev Anderson (877) 622-6298

Fresno

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

Grass Valley

Next meeting, Sept. 10
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

Next meeting, Sept. 13
2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(Hoffmeister Center across from the church)
Larry Frice (209) 358-2045

Modesto

Next meeting, Sept. 17
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

Next meeting, Sept. 11
2nd Wednesday, 1 PM
El Dorado Senior Center
937 Spring Street
John McCoy (530) 642-8511

Redwood City

Next meeting, Sept. 25
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

2nd Monday, 11 AM - 12:30 PM
Kaiser French Campus
4141 Geary Blvd. between 6th & 7th Ave.
Rm. 411A - Watch for signs.
Suzanne (415) 830-1348

San Jose

Next meeting, Sept. 15
3rd Saturday, 10:30 AM
O'Conner Hospital, 2105 Forest Avenue
SJ DePaul Conf. Rm.
Danielle LaFlash (415) 297-1815

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, 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
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
Special Speaker: Lindsay Fosler
Hereditary ATTR Amyloidosis PN

NEVADA

Las Vegas

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

OREGON

Grants Pass

Next meeting, Sept. 19
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, 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 Message By Bev Anderson



It is my hope that all fires are out by the time this newsletter reaches you. So many of us have been breathing the smoke of the fires while worrying about those of our friends and members who are experiencing the horror and terror of fleeing and possibly not having anything to return to. I talked to Roberta in Lakeport just after she returned from seven days of evacuation with the orders to keep packed as it could happen again at a moment's notice. At 91, this is not something this delightful lady needs to deal with, but she was of good cheer even with saying she had been in four different places in seven days. We have had prospects of a group restarting in Redding and in Lakeport. I trust they take the Santa Rosa Strong spirit and step forward anyway. It is a time when people need to come together.

A new San Francisco Neuropathy Support Group started on Monday, August 13. If you would like to know about their next meeting, call Suzanne at (415) 830-1348. They are meeting at Kaiser Medical, 4141 Geary Blvd. (between 5th and 6th) on the second Monday, 11:00 AM – 12:30 PM.

My toe (fourth on right foot that had the partial amputation) wants to report it is all healed and graduated from the wound care center today. It is shorter but about the size of the toe next to it that had its metatarsal bone removed some years ago. Both feet have been behaving rather well and their socks have stayed on all night. It is amazing that after they were reported, they seemed to have changed behavior for the better.

Please remember that we are willing to send NEUROPATHY HOPE to any doctor you have who is interested in receiving it. Ask them if they would like to receive it. If yes, get their email or standard mail address at whichever one they wish us to receive the newsletter and send it to Lindsay Campoy at our office WNA, P.O. Box 276567, Sacramento, CA 95827-6567 or lindsayc@pnhelp.org.

Please celebrate our 20th Anniversary by telling someone about neuropathy. You can ask, "I have neuropathy, do you know what that is?" If they don't or are confused, tell them, "My brain and spinal cord are my Central Nervous System. All the other nerves are part of the Peripheral Nervous System. Any disease or disorder in the Peripheral Nervous System can be called neuropathy. Sometimes it is called peripheral neuropathy. It causes tingling, numbness, pain, and other odd feelings." You can tell them more as it works for you and them.

I hope you will be able to come to one of our celebration luncheons!

Celebrating 20 Years!

Bev

DOES A PUFFERFISH HAVE A NEUROPATHY TREATMENT IN WAITING?

The October 10, 2017, newsletter from Ivanhoe Newswire mentions that researchers are developing a drug inspired by the toxin found in Japanese pufferfish. It is projected to help stop neuropathic pain. To read the whole article go to <http://www.ksat.com/about-us>.

COMPASSIONATE LISTENER by Dee Mahannah

Find a person who has the gift of compassionate listening. When your symptoms are making life difficult and you are needing support, call this person and share honestly how you are feeling. Allow your compassionate friend to listen and accept you just as you are without trying to "fix you" or your pain. The healing happens on an emotional level when you are listened to without judgement, correction, or interruption.

This quiet validation of who you are at this moment may open your mind and heart to a peace that you need at that very moment.

CORPORATE DONATION MATCHES

If you have a job and are working regularly or are retired from a job in a corporation or company that matches charitable donations of their employees, please find out how you can report the donations to WNA that you have or will give before the end of the year. If you think they might, please ask. No idea? Ask. You might be surprised. Examples of companies that we understand match are Raley's/Bel Air/Nob Hill, PG&E, and Johnson & Johnson. If you know of others, please let us know.

Help With Health Care Challenges

If the number is not in your area, call the one listed and ask for the right number.

Medicare

www.Medicare.gov

...

The Affordable Health Care Act

For current information go to www.HealthCare.gov

...

HICAP

Health Insurance Counseling

for seniors and people with disabilities.

www.cahealthadvocates.org/HICAP/

Call (800) 434-0222 to ask a question or to make an appointment.

...

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.

Tollfree (888) 354-4474 or TDD (916) 551-2180.

In Sacramento, (916) 551-2100.

www.hrh.org.

...

HMO Help Center

Assistance

24 hours a day, seven days a week.

(888) HMO-2219

or (877) 688-9891 TDD

...

DRA's Health

Access Project Free publications about the health care, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA a discount to WNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your WNA Membership Card and claim the discount.

Anodyne Therapy

Infrared Light Therapy equipment - **\$50 off Model Freedom 300 (single leg at a time) and \$50 discount on Model 120 that does both legs at the same time.** Contact: 800-521-6664 or www.anodynetherapy.com

HealthLight Infrared Light Therapy equipment - **10% off Single Boot System and Dual boot system.**

Contact: 888-395-3040 or www.healthlight.us

Auburn

The Footpath

825 Lincoln Way
(530) 885-2091
www.footpathshoes.com
WNA Discount: 10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
(916) 686-1050

WNA Discount: 20% off the regular price shoes.

Fortuna

Strehl's Family Shoes & Repair

Corner of 12th & Main
1155 Main Street
(707) 725-2610
Marilyn Strehl, C.PED
is a Certified Pedorthic
WNA Discount: 10% off the regular price shoes.

West Sacramento

Beverly's Never Just Haircuts and Lilly's Nails
2007 W. Capitol Ave
Hair - (916) 372-5606
Nails - (916) 346-8342
WNA discount: 10% off the regular price.

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COST OF MEDICATIONS MAY BE LESS THAN CO-PAY

At the pharmacy where I get my medications, sometimes the cost is less than my co-pay. It is because the cost of the drug is less so they charge me the cost of the drug instead of the price they might otherwise charge. NBC Nightly News with Lester Holt aired a story called "Prescriptions May Be Cheaper Without Insurance," which can be watched at <https://www.nbcnews.com/nightlynews/video/nbc-news-investigation-prescriptions-may-be-cheaper-without-insurance-1074629699698>

The pharmacy is not supposed to tell you the cost of the drug. Most of the time you are asked to pay the co-pay no matter the actual cost of the drug, but the overage doesn't go to the pharmacy, it goes to the Pharmacy Benefit Manager (PBM). The pharmacy is paid the actual

drug price and the rest is sent to the PBM. The Neuropathy Action Foundation wants to know your experience on this. Are you always asked to pay the co-pay even if you know the drug is rather inexpensive? If your co-pay is over \$5, it is more likely you have medications that don't actually cost \$10 or more. If your co-pay is higher, it is fairly certain. If you have experience with this send the information to info@neuropathyaction.org. (Neuropathy Action Foundation is the organization that sponsors the Neuropathy Action Awareness Conference in Los Angeles that several attend each year. We continue to recruit members from the Los Angeles area and hope that they will make it a must to go to this Conference.)

LYME DISEASE

Most information on Lyme Disease has indicated it is found chiefly in the Northeast, mid-Atlantic, and upper Midwest regions. Research is showing that there are other areas with a number of cases. The specific kind of ticks known to be carrying it are being taken inadvertently to other parts of the country and thriving. It is known in Placer County by a number of diagnosed cases no matter what anyone may say about the distribution of ticks. It is likely that if there are deer roaming, it may

well spread to other areas. Scientists now say that one-half of United States counties have the ticks that carry Lyme. It must be remembered that ticks carry other serious diseases besides Lyme so tick control is quite critical. If you have a pet that likes to wander in the woods, be sure to have a flea and tick collar on it and watch carefully when you pet it upon its return.

ACETYL-L CARNITINE BENEFITS AND WARNINGS

Recently information is out that Acetyl-L Carnitine has been found measuring low in people with depression. Raising it has proven quite helpful. However, in the article I did not find the warnings that are vital for people to have before taking it. It could be you will be encouraged to give it a try - this is what might be good to know first.

Acetyl-L-carnitine is **LIKELY SAFE** for most adults. It can cause some side effects including stomach upset, nausea, vomiting, and restlessness. It can cause a "fishy" odor of the urine, breath, and sweat.

Special Precautions & Warnings:

Pregnancy and breast-feeding: Not enough is known about the use of acetyl-L-carnitine during

pregnancy and breast-feeding. Stay on the safe side and avoid use.

Under-active thyroid (hypothyroidism): There is some concern that acetyl-L-carnitine might interfere with thyroid hormone. Don't use acetyl-L-carnitine if you have an under-active thyroid.

Seizures: An increase in the number or seriousness of seizures has been reported in people with a history of seizures who have used L-carnitine by mouth or by IV (intravenously). Since L-carnitine is related to acetyl-L-carnitine, there is a concern that this might also occur with acetyl-L-carnitine. If you have ever had a seizure, don't take acetyl-L-carnitine.

CAUSES OF PERIPHERAL NEUROPATHY

People are, many times, not told what caused their neuropathy as the doctor does not have the time to work through their history to pinpoint something that might be the cause. Even if they do they likely would not be able to test for it so they say idiopathic even if they have a good idea of what the cause actually is. We know there are over 150 known causes. Some even say over 200. These are the over 50 mentioned by Norman Latov, MD, PhD in his book PERIPHERAL NEUROPATHY When the Numbness, Weakness, and Pain Won't Stop.

Others have been mentioned in NEUROPATHY HOPE, the newsletter you are now reading. Even this month, the lead article tells about another one we may not know about. There are very rare ones that you may have because of ancestors coming from a specific location in the world. Most of us may not think of telling our doctors of a grandmother who came from a certain area of Russia, but it may be a key to why you have neuropathy if it is the one from which a rare neuropathy comes, for example.

For some, glossary information is given as the terms are not likely commonly known. Do remember that sometimes there needs to be a priority given. Keeping one's heart beating should be given priority, for example. A person can live with neuropathy but not with their heart stopped. If the medication aids the heart but may give neuropathy, it is likely it is best to take it anyway.

#1 in the world – leprosy

#1 in USA – diabetes and glucose intolerance

Deficiencies in vitamins B1, B6, B12, E

Bariatric Surgery for weight loss – 1-5% of patients

Malabsorption

Celiac Neuropathy

Alcoholic Neuropathy

Ciguatera Poisoning – from fish

B6 too much no more than 50 mg per day preferably less

Autoimmune neuropathies

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Multifocal Motor Neuropathy and Multifocal Demyelinating Sensorimotor Neuropathy (Lewy Sumner Syndrome)

Neuropathy with IgM monoclonal gammopathy and Anti-MAG or Ganglioside Antibodies

Autoimmune Sensory Neuronitis (Ganglioneuritis)

Autoimmune Autonomic Neuropathy

Vasculitic Neuropathy

Guillain Barre Syndrome and Variants

Neuropathies Caused by Infections

Virus Infections

Hepatitis C Infection

HIV-1 Infection

Peripheral Neuropathy in Lyme Disease

Neuropathy Caused by Bacterial Infection: Diphtheric Neuropathy

Sarcoid Neuropathy

Neuropathies caused by Parasitic Infection: Chagas' Disease

Neuropathy in Cancer and Lymphoproliferative Disorders

Neurotoxicity caused by Chemotherapy and Radiation Sensitizing Agents: CIPN

Thalidomide – multiple myeloma

Bortezomib – multiple myeloma

Misonidazole – used to sensitize cells before radiation

Paraneoplastic Neuropathy – caused by tumors

Neuropathy in Myeloma and POEMS Syndrome

Neuropathy with Primary Amyloidosis

Neuropathy with Waldenstrom's Macroglobulinemia or B-cell Leukemia or Lymphoma

Neuropathy Caused by Tumor Infiltration

Neuropathy associated with Renal Failure

Neuropathy Associated with Thyroid Disease

Hereditary Neuropathies: CMT, HSN, Amyloidosis, etc.

Drug Induced Neuropathies

Nitrous Oxide (Laughing Gas)

Nucleoside Analogs and others used in the treatment of HIV

Procainamide - <https://www.webmd.com/drugs/2/drug-8698/procainamide-oral/details>
This medication is used to treat a certain serious, life-threatening irregular heartbeat (ventricular

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DISCOUNTS FOR WNA MEMBERS

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Neuropathy Support Formula

(1-888-840-7142) is a supplement that a sizable number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back.

Additional Discounts

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

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

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:

- 16848381 This Cochrane database review confirms that intravenous lidocaine (or oral mexitilene) provides modest short-term relief of neuropathic pain.
- 16930283 This Chinese rat study of sciatic nerve injury found faster increase of evoked action potentials and increased numbers of larger diameter regenerating axons in those animals treated with fasudil, a rho A-rho kinase inhibitor.

- 25058164 This Cochrane database review of randomized double-blind studies found no evidence to support the use of topical lidocaine to treat neuropathic pain, though a few patients do experience relief from it.
- 26000320 This double-blind placebo-controlled study of a plasmid (VM202) containing two growth factor isoforms given intramuscularly to patients with painful diabetic neuropathy. The lower dose achieved more than 50% reduction in pain—48.4% compared to 17.6% in controls—at 3 months but not at 6 or 9 months.
- 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.
- 28678039 This review describes familial amyloid polyneuropathy, the most disabling hereditary neuropathy of adult onset. Recent advances in gene sequencing have enabled the identification of the transthyretin (TTR) mutation which results in the production of amyloid, which infiltrates the nerves. The only treatment available for this fatal condition has been liver transplantation; however, there is currently (2018) a TTR gene silencing agent in phase 3 clinical trials.

Please note this one as it is the medical review of what we are currently hearing about in our groups when Lindsay Fosler speaks. People who fit the description of this type of neuropathy are urged to get the genetic testing offered for no charge by the company developing the medication. It is thought to be rare but people are being diagnosed as having it more than might be expected.

NOTES FROM THE NEUROPATHY ACTION FOUNDATION CONFERENCE

By Barbara Montgomery, Leader, Las Vegas Neuropathy Support Group

These doctors came together to answer questions from the audience. Although this article doesn't attribute points made by which doctor, they all agreed the comments -- or they would have spoken up against or to clarify. All of these doctors are known to be excellent neurologists for people with neuropathy. Pacific Medical Center is a Sutter facility. It has a department of the hospital that works with patients that other facilities have given up on. They have done some amazing innovative patient approaches.

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); and Jonathan Katz, MD, Chief of Neuromuscular Services at California Pacific Medical Center

- **Chemotherapy.** Can neuropathy be prevented for people taking chemo for cancer? No medications advised to be used for chemotherapy. There is hope to reduce it. Exercise can help reduce probability of this issue. Highly encouraged: swimming, walking, jogging, and strolling in the park.
- **Stem cell.** Peripheral Neuropathy (PN) potential help with

stem cell transplants. Still used for more serious diseases. Not evolved in neuropathy. Not yet clinically available for general neuropathy. But some progress is being made in genetic neuropathy and proteins that are toxic to the nerves.

- **Lifestyle.** Suggestion in terms of lifestyle – are there medications that can slow PN in the feet? Need to identify cause of neuropathy. Exercise definitely. Supplements are weak, but Alpha Lipoic Acid (ALA) is recommended. Evidence isn't strong for many supplements. Nutrition, metabolic, toxins, chemo, hereditary are components in neuropathy. Some supplements can possibly slow heredity neuropathy. Must know cause to best treat.
- **Muscle loss.** Multifocal Motor Neuropathy (MMN) and muscle loss with Intravenous Immunoglobulin (IVIg). Can I regain muscle mass? It can be delayed if not treated. Myelin

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Anti-Mag Peripherl Neuropathy Rare But Known Regularly - Continued from page 1

from the blood, cutting off the production of anti-MAG antibodies at the source. While helpful to some patients, studies have been inconclusive.

- Cyclophosphamide – a drug that is often used in the treatment of lymphomas, works by rapidly killing dividing cells, such as antibody-producing B-cells, which in turn decreases antibody levels. This may improve quality of life and sensory loss; however, a long-term risk of cancer with chronic use of this treatment is possible.
- IVIg (Intravenous Immunoglobulin) – infusions help small segments of patients in the initial phase of the disease, though is not necessarily effective in treating anti-MAG neuropathies.
- Steroids and plasma exchange treatments are not recommended for anti-MAG.

- Current immune therapies – while temporarily effective in some patients – are mostly reserved for patients impaired in their daily activities, or for patients in a progressive phase of the disease.

Current Research

Current research is limited and has focused mostly on determining treatment options. This has been studied through clinical trials with drugs listed previously or through new therapy techniques that delay loss in function. Most drugs being studied are immunosuppressants that can attack the antibodies or other aspects in the hope of preventing damage to the Schwann cells. This will, ideally, prevent the loss of myelination on peripheral nerve fibers.

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Causes Of Peripheral Neuropathy - Continued from page 5

tachycardia). It is used to restore normal heart rhythm and to keep a regular, steady heartbeat. Procainamide is known as an anti-arrhythmic drug.

Phenytoin - <https://reference.medscape.com/drug/dilantin-phenytek-phenytoin-343019> Medscape - Seizure-specific dosing for Dilantin, Phenytek (phenytoin), frequency-based adverse effects, comprehensive interactions, contraindications, ... (If you were on Dilantin for a period of time, this could be the cause of your neuropathy.)

Statins

Tacrolimus Immunosuppressive drug - It can prevent organ rejection after transplant in its oral form. When applied topically it can treat a skin rash and type of eczema called atopic dermatitis.

Neuropathies Caused by Toxins

Heavy Metals – Lead, Mercury, Thallium
Drug Abuse

Plexopathies - Plexopathy is a disorder affecting a network of nerves, blood vessels, or lymph vessels. The region of nerves it affects are at the brachial or lumbosacral plexus. Symptoms include pain, loss of motor control, and sensory deficits.

Entrapment Syndromes

Cervical and Lumbosacral Radiculopathies

Carpel Tunnel Syndrome, Ulnar nerve entrapment at the elbow
Peroneal Nerve Entrapment at the Knee -Tarsal Tunnel Syndrome in the foot

Lateral Femoral Cutaneous Nerve Syndrome

And yet Idiopathic Neuropathies

Notes From The Neuropathy Action Foundation Conference - Continued from page 6

is lost. Axon lost thus lose muscle. Treatment will not bring back muscles. Early diagnosis to prevent progression of disease is recommended. Even if muscles are gone, IVIG prevents different axons from being lost and degeneration of muscles.

- **Bariatric surgery.** Told to take supplements to prevent PN. Sometimes don't take vitamins. Thiamin is important, but multi-vitamin is very important, as is B12.
- **Non-diabetics.** Have had PN for 20 years, not diabetic. Tried everything; beside myself and I need a cane all the time. I'm scared to stop gabapentin. What are symptoms: mainly sensory pain/numbness. Treatment in pain is important. Need to look for cause. Certain genetic testing. Right now, we don't have treatments that's why we have educational events. Lots still needs to be done. Doctor and patient work together; large or small fiber. Is it really PN or is it spinal, or a combination of things, Cognitive therapy, creams, shoes,

socks, mattress comfortable, blanket comfortable. Target the problem.

- **Types of PN.** There are over 100 types. Nothing to cure but can control pain. Can't treat numbness, sensory function; same with balance, weakness or brain. But other neuropathy treatments: ultra-new IVIG, Chronic inflammatory demyelinating polyneuropathy (CIPD) or MMN can work. or MMN can work. Diabetes most common type of diabetes. So, treat diabetes – control your glucose.
- **CIPD and MMN differences:** Autoimmune disease CIPD motor and sensory (foot slapping ground, numbness tingling/ balance). MMD Motor issue, upper arms. Overlapping treatments IVIG for both. Electrogenic testing will show difference so respondent. will know difference.



WESTERN NEUROPATHY ASSOCIATION

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■ PN Information/Advice ■ Support Group Inquiries

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PLAN TO ATTEND A 20th ANNIVERSARY LUNCHEON IN YOUR AREA, BUY A TICKET NOW

We are holding three 20th Anniversary luncheons, including one involved in the first year of our history. Auburn started in November 1998 and Sacramento in December 1998. Concord was one of the first in the Bay Area as was Walnut Creek. We hope the pioneers who may not be currently attending support group meetings will attend this 'reunion.' We'll celebrate with everyone at our 2019 Annual Conference on May 10 in Modesto.

There will be a special program at each of the luncheons reviewing the past and planning for the future. Bev Anderson, founder and president, will attend all three luncheons. We also plan to have a surprise guest at each.

The cost for the luncheon ticket will cover the cost of the lunch plus a small amount to defray other costs we may have to make these lunches possible. The tickets are \$25 each.

You may pay by check sent to WNA, P.O. Box 276567, Sacramento, CA 95827-6567 or online at www.pnhelp.org. You may also call Lindsay Campoy at (916) 932-2218 or (888) 556-3356 and she can take your credit card number over the phone. Please indicate on the check which luncheon you plan to attend: Sacramento (Saturday, Oct. 13), Concord (Thursday, Oct. 18), or Auburn (Monday, Nov. 5). There is a limited number of seats at each location so if you plan to attend, do get your ticket purchased. We will send a receipt that can be used as a ticket; we will check you in by name at the door. We hope the seats at each will be filled. It is a big milestone.



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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.

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