



WESTERN NEUROPATHY ASSOCIATION

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Issue 03
Volume 15

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WESTERN
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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ SMALL FIBER NEUROPATHY CAN BE PAINFUL By Teresa Davenport

The pain of small fiber neuropathy drove the author to consider the unthinkable, but a letter from her daughter helped save her.

When I found the note on my bed, I could barely read it. But there it was: scribbled in my daughter's wobbly lines with hearts drawn in the corners, words stabbing me almost as much as the physical pain. She was sorry I was sick and she wanted me to be okay.

My 8-year-old's sentiments struck a deep chord, her words reflecting my own struggle with questions I would ask over and over. Why do my kids have to see me like this? Why can't I be normal, like everyone else?

These are questions I've asked ever since being diagnosed with small fiber neuropathy, a condition affecting small fiber nerves in the skin and autonomic nervous system that cause tingling, shooting pains, itching, numbness, and other strange sensations that migrate all over my body. I also get migraines. That day, four years ago, when my daughter left the note, was one of my worst. I'd pushed it aside to grab a trash can to my chest, rocking back and

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■ LIVING WITH AUTONOMIC NEUROPATHY

As a result of a progressive polyneuropathy known as Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), I have lived with autonomic neuropathy symptoms for over five decades. There are a number of unavoidable issues when dealing with the symptoms of autonomic neuropathy many of which are covered in Dr. Norman Latov's book "Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop."

Autonomic neuropathy is a result of damage to the autonomic nerves which control your involuntary body functions that keep you alive. These functions include the cardiac cycle (heart beat), pulmonary systems (breathing), bladder function, and digestion. It also affects the body's ability to regulate temperature, tearing, sexual functions, blood pressure, saliva production, and swallowing among other body systems that function automatically.

In the process of dealing with autonomic neuropathy symptoms for more than half my life, I have developed the most effective ways for me, personally to deal with some of the symptoms of autonomic neuropathy.

Autonomic Neuropathy Symptoms and How to Treat Them

It is important when considering the following suggestions that you discuss them first with your own primary care doctor. That said, and having dealt with each of the symptoms below, here are some practical ideas which have worked best for me in dealing with my autonomic neuropathy symptoms:

Rule #1: From Dr. Latov's book, "Do not OVER treat your autonomic neuropathy symptoms." This is great advice when dealing with alternating diarrhea and constipation while trying to find a balance. (Books on Peripheral Neuropathy)

Diarrhea – Simple advice – eat smaller and more frequent meals with lower fat and carbohydrates helps. Of course, doing what your mother taught you, drink lots of fluid, eat bananas, while increasing intake of salads are all natural approaches that work. There are some medications that your doctor may prescribe, but from my experience in using these medications you may end up with the opposite of diarrhea, so it is often best to try the natural ideas first. Note: A natural approach to resolving diarrhea due to autonomic neuropathy will work for most patients but in all things, it is best to speak to your treating doctor.

Constipation – Simple advice – drink lots of fluids, especially coffee with caffeine, eat prunes in moderation, while increasing your intake of salads are all practical ideas that work. Dr. Latov adds that taking stimulating laxatives are usually ineffective and cause increased cramping and diarrhea, but for some patients, doctors may prescribe stool softeners. Note: A natural approach to resolving constipation due to autonomic neuropathy will work for most patients but in all things, it is best to speak to your treating doctor.

Bladder Dysfunction – According to neurologists I have spoken, bladder dysfunction can involve overflow incontinence or difficulty in urinating at all, decreased sensation, reduced urine flow, incomplete bladder emptying with retention of urine, over distention because what is damaged is the nerve that controls the motor and sensory muscle that allows the bladder to function normally.

Overflow Incontinence – I have found that frequent voiding is important to reduce accidents. The use of Depends/pads works to avoid the embarrassing accidents that do occur. For males, you will find that doctors will always want to

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Roster of Our WNA Information and Support Groups

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Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.

Bev Anderson
Editor

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CALIFORNIA

Alturas

For information, call:
Bev Anderson (877) 622-6298

Antioch-Brentwood

3rd Wednesday, 2 PM- odd numbered months
Antioch-Kaiser
AMC-1H2 (from hospital lobby)
Marty Price (925) 626-7988

Auburn

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

Bakersfield

For information, call
Bev Anderson 877-622-6298

Berkeley-Oakland

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

Carmichael - Eskaton

2nd Tuesday, 1:30 PM
Eskaton, 3939 Walnut Ave.
Karen Robison (916) 972-1632
*Call Karen before coming as it is a gated
community and sometimes the day/time
changes. She welcomes newcomers!*

Carmichael - Atria

Atria - Carmichael Oaks
8350 Fair Oaks Boulevard
For information, call:
Bev Anderson (877) 622-6298

Castro Valley

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

Clearlake

For information, call
Bev Anderson (877) 622-6298

Concord

3rd Thursday, 1:30 PM
First Christian Church
3039 Willow Pass Road
Wayne Korsinen (925)685-0953

Costa Mesa

3rd Wednesday, 10:00 AM
Call Martha Woodside
949-573-0056 for the location

Crescent City

For information, call:
Bev Anderson (877) 622-6298

Davis

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

Elk Grove

2nd Tuesday, 1 PM
Elk Grove Senior Center
8830 Sharkey Avenue
Roger White (916) 686-4719

Eureka

For information, call:
Earlene (707) 496-3625

Folsom

1st Thursday, 12:30 PM
Burger Rehabilitation
1301 E. Bidwell St., Folsom
Bev Anderson (877) 622-6298
<http://folsom.neuropathysupportgroup.org/>

Fort Bragg

For information, call:
Bev Anderson ((707) 964-3327

Fresno

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

Garberville

For information, call:
Bev Anderson (877) 622-6298

Grass Valley

2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church Street
Bev Anderson 877-622-6298

Jackson

For information, call
Bev Anderson (877) 622-6298

Lakeport

Meeting day and time, call Mito.
Lakeport Senior Center
507 Konocti Ave.
Mito Shiraki (707) 245-7605

Lincoln

For information, call:
Bev Anderson (877) 622-6298

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
Lee Parlett (925) 292-9280

Madera

For information, call
Bev Anderson (877) 622-6298

Merced

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

Modesto

3rd Monday, 10:30 AM
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Ray (209) 634-4373

Monterey

3rd Wed., 10:30 AM-odd numbered months
First Presbyterian Church
501 El Dorado Street
Dr. William Donovan (831) 625-3407

Napa

1st Thursday, 2 PM
Napa Senior Center
1500 Jefferson Street
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Oxnard

For information, call:
Bev Anderson (877) 622-6298

Placerville

For information, call
Bev Anderson (877) 622-6298

Quincy

For information, call:
Bev Anderson (877) 622-6298

Redding

For information, call:
Tiger Michiels (530) 246-4933

Redwood City

4th Tuesday, 1 PM
Sequoia Hospital Health and
Wellness Center
749 Brewster Avenue
Danielle LaFlash (415) 297-1815

Roseville

2nd Wednesday, 1PM - odd numbered months
Sierra Point Sr. Res.
5161 Foothills Blvd.
Stan Pashote (916) 409-5747

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Charles Moore (916) 485-7723
<http://sacramento.neuropathysupportgroup.org/>

Salinas

Contact Bill Donovan (831) 625-3407

San Francisco

For information, call:
Bev Anderson (877) 622-6298

San Jose

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

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Avenue
Scott Stokes (415) 246-9156

Santa Barbara

4th Saturday, 10AM - odd numbered months
The First Methodist Church
Garden & Anapamu
Shirley Hopper (805) 689-5939

Santa Cruz

3rd Wednesday, 1PM- odd numbered months
Trinity Presbyterian Church
420 Melrose Avenue
For information call
Mary Ann Leer (831) 477-1239

Santa Maria

For information, call
Bev Anderson (877) 622- 6298
or Mary (805) 344-6845

Santa Rosa

1st Wednesday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Larry Metzger (707) 541-6776

Sonoma

President's Message By Bev Anderson



Our Annual Conference is April 18 which is just 2 months away. We got started early but suddenly we are running to catch up. We have a tremendous program. Do check page 7 and get your registration in as soon as possible if you plan to come. Space is limited. We are limited to 120 which is the same as last year. We have some special guests that we hope can attend that will take up some spaces as well. Do not come if you are not registered. We don't want to have to turn anyone away at the door.

We are privileged to meet at The Mind Institute on the UC Davis Medical Center campus. This is a world recognized center for study of the mind especially autism and Fragile x as it was founded by parents of autistic children who wanted a family oriented treatment and research institution. If you have family or friends who have children on the autism spectrum or have an interest in this, plan to come early or stay a bit after the conference to check out the Visitors Center just inside the front door with all the information it has. Pick up a brochure that tells you how to connect with resources they offer no matter where you live. I have a step-great-great-grandson who is dealing with this and got some information for his mother who is working with their school district to give him the help he needs. We are delighted that he is doing well in kindergarten this year.

You will notice that Dr. William Donovan's column is not included in this issue. He combs through current neuropathy oriented research and provides a summary as well as reference so you can read the whole article, if you wish. He would like some feedback if you have found it helpful and any suggestions as to how it could better serve our readers. Please send a note to him at WNA, P.O. Box 276567, Sacramento, CA 95827-6567 or an e-mail to info@WNAinfo.org and we will get them to him. Some of you remember hearing him at a conference or seeing the video of his talk at a support group meeting. It is an excellent overview of neuropathy.

I'd really appreciate it if those of you who are familiar with his column and used it would send feedback or if you received help from the video. It is a hard time for him right now. His wife of many years passed

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WNA Information and Support Groups – *Continued from page 2*

For information, call
Bev Anderson (877) 622-6298

Sonora

For information, call
Bev Anderson (877) 622-6298

Stockton

For information, call
Bev Anderson (877) 622-6298

Susanville

For information, call:
Bev Anderson (877) 622-6298

Thousand Oaks Region

For information, call
Bev Anderson (877) 622-62988

Truckee

For information, call:
Bev Anderson (877) 622-6298

Tulare-Visalia

For information, call
Bev Anderson (877) 622-6298

Turlock

3rd Monday, 1 PM- odd numbered months
Covenant Village Adm. Bldg. Classroom
2125 N. Olive St.
Joanne Waters (209) 634-0683

Ukiah

Last Tuesday, 5:30 PM
Next meeting, Sept. 27
North Coast Opportunities (NCO)
413 N. State St.

Carole Hester (707) 972-2795

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse
Vista Room

Karen Hewitt (925) 932-2248

West Sacramento

No meeting until new leader is found
Sandra Vinson (916) 372-6093
slvins11@gmail.com

Woodland

For information, call
Bev Anderson (877) 622-6298

Yreka

For information, call
Bev Anderson (877) 622-6298

Yuba City-Marysville

For information, call
Bev Anderson (877) 622-6298

NEVADA

Reno-Sparks

For information, call
Bev Anderson (877) 622-6298

OREGON

Brookings

For information, call
Robert Levine (541) 469-4075

Grants Pass

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

Medford

For information, call
Bev Anderson (877) 622-62988

Portland

For information, call
Bev Anderson (877) 622-6298

Salem

For information, call
Bev Anderson (877) 622-6298

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".

**Start a support group in your area:
Contact Bev Anderson at (877) 622-6298 or info@pnhelp.org**

DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA members 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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GROUND-BREAKING DISCOVERY: UC DAVIS RESEARCHERS FIND KEY MECHANISM THAT CAUSES NEUROPATHIC PAIN

(This is the title of the lead article in the February issue of Neuropathy Hope that some of you asked about. I promised I would tell the information in a way that the basic information and its importance to us might be better understood. Overview by Bev Anderson)

At last year's WNA Annual Conference, we heard from Bruce Hammock, PhD, who is the lead researcher on this project that came from a study of insects. He is an outstanding and awarded professor of entomology (study of insects). While studying a moth, they found an enzyme that seemed to coordinate all the functions of the moth. By dealing with this enzyme, they could impact systems of the body that related especially to a nervous system. They wondered if other organisms had this enzyme and if so if it did something similar in that organism. They worked their way up to more and more intricate structures in more complicated living creatures. They found that each creature has this enzyme.

They had worked with mammals extensively by the time we found out about this research. We saw a video of a cat and a horse where the treatment they had discovered at the moth level and had tested as they went progressed was applied. The cat was having trouble walking and was not able to get into its litter box. After a shot of the treatment they developed, it was able not only to get into the litter box easily, but could move quickly and lively; basically jumping in.

The horse was a racehorse in a breeding program in Kentucky. It was on the ground with the malady some horses suffer from wherein they can't move well enough to get up. Even though this horse was a granddaughter of Seattle Slough, a famous Triple-Crown Winner, they were going to put her down as horses don't survive this. The veterinarian ready to do this stood outside the gate when Dr. Hammock and an assistant entered the stall. They gave the horse one shot of the treatment and she was on her feet immediately. They

gave her a second shot and she was moving normally. They only had one more shot with them so they gave it to her. With no further treatment, she has had no further illness for over seven years.

Funds have to be raised for human treatments to begin. We hope it will happen in 2017. Dr. Hammock is scheduled to be our closing speaker for the WNA Annual Conference on April 18 in Sacramento. He will be able to tell us where they are in the process and when human trials begin. He expects it to handle pain well and to facilitate better function. We are excited to see what it does with human neurological problems. It could be amazing. We are hopeful.

The article appearing in last month's newsletter provided some history of the study and used some terminology that was difficult for many. This, I hope, gives you an overview of the concepts being covered and how they were developed. It takes years for some of these projects to get to human trial stage. One thing about this research that is especially interesting is that it is being done at a lab on the University of California - Davis campus. It is registered to a company through which funding may come to support it. Any profit from sales or licensing of any product goes through this company back to U.C. Davis for further research projects. They received a four-million-dollar grant from the National Institutes of Health and other grants, which are a good start but more funding is needed. To get a new treatment approved takes years of research plus critical human trials as well as lots of funding.

MANY QUESTIONS, FEW ANSWERS RELATING TO HORMONES

National Institute on Aging (NIA)

The National Institute on Aging (NIA) sponsors many research projects that will reveal more about the risks and benefits of hormone supplements. One goal is to determine whether DHEA, melatonin, and other hormonal supplements improve the health of older people, have no effect, or are actually harmful.

It is important to remember that these studies may not give immediate or final answers, especially in the cases of DHEA, melatonin, and Hgh, since research on these supplements is fairly new. For example, some of the

studies may simply give researchers more information about what kinds of questions they should ask in their next studies. Research is a step-by-step process, and larger studies may be needed to give more definite answers.

Until more is known about DHEA, melatonin, and Hgh, consumers should view them with a good deal of caution and doubt. Despite what advertisements or stories in the media may claim, hormone supplements have not been proven to prevent aging. Some harmful side effects already have been discovered, and further research may uncover others.

STANFORD RESEARCHERS IDENTIFY SOURCE OF OPIOIDS' SIDE EFFECTS

The chief concerning side effects of opioids that doctors are concerned about are a growing tolerance to the opioid and a paradoxical increased sensitivity to pain. In prescribing opioids for pain, a balance is needed. If a person is tolerant of the drug so they think more would be better and there is an increased sensitivity to pain, the doctor has a challenge to know how much can be given

before breathing ability is affected.

Stanford researchers found that if a patient takes the compound methylnaltrexone bromide which is currently used to combat constipation which is also caused by the opioid, these side effects basically disappear. They combined it with morphine making it a safer drug.

NSAIDs AND OTHER OVER THE COUNTER (OTC) DRUGS CAN BE DANGEROUS

NSAIDs (nonsteroidal anti-inflammatory drugs) and Over the Counter (OTC) drugs should be used at the lowest dose possible to be effective and not be used for long periods of time. "NSAIDs are commonly used in my daily practice," said David Lazar, MD, MPH, a rheumatologist at the University of Florida's College of Medicine in Gainesville. "There is a risk of kidney disease, gastrointestinal bleeding and cardiovascular

disease. Many patients are unaware of the interactions of these medications with other prescriptions. During a new consultation, I may discover a patient taking two different NSAIDs daily such as meloxicam and ibuprofen. I explain to the patient the dangers of combining NSAIDs and the risks involved. I am concerned that there is a lack of patient education with regards to NSAIDs."

Small Fiber Neuropathy Can Be Painful – Continued from page 1

forth with waves of nausea.

The pain was so intense, I thought life wasn't worth living. I'd never had thoughts like that before: sincere feelings that I wanted to give up on life. The pain was very strong, intense. And my will wasn't strong enough. Even as I opened my eyes and saw the note – a blurry scrap of paper on top of crumpled sheets – the feeling was still there.

But then I read her words and something clicked. For too long I'd tried to deal with everything on my own. In the beginning, I'd gone from doctor to doctor but eventually stopped, no diagnosis in hand, no advice or relief in sight. Now I realized I'd given up too soon. My life was consumed by fear. I feared the pain, the attacks that would come and cause me to have the horrific thoughts, ones a loving wife and mother should never have. This had to stop. I realized my life wasn't over. I had too much to live for. I knew I had to go back and pound the pavement again and not stop until I found answers and relief. I feared side effects from drugs, but at that point I feared continuing my life in that state even more.

Today, two years after my daughter scribbled that note, I no longer experience that level of pain. With a diagnosis in hand, I now have medication with minimal side effects. I use alternative therapies along with the drugs to bring much-needed relief. I have a diet and exercise plan that helps immensely. But most of all, I have a life free of those terrible thoughts, a life that still isn't easy but is definitely worth living.

I don't know what the future holds, but I do know I will never return to that state of mind. I'll do whatever it takes to live in balance with small fiber neuropathy, and I will treasure and

appreciate many blessings in this life, including sweet words scribbled on a piece of paper from my precious young daughter. I've kept that note as a reminder of a place I will never go to again.

Thanks to her words, I recognize that life is worth living. I begin each day thankful for being strong and persistent enough to ask for help. Each morning I look at my reflection with pride. I feel triumphant that, for now, I've won.



Teresa Davenport has a background in journalism and lives with her husband and children in Marietta, GA. She writes about small fiber neuropathy to raise awareness of the condition. Used with her permission.

Small Fiber Neuropathy affects the unmyelinated fibers at the end of the nerve axon that come out to the skin. A person can have neuropathy in just this area and have some difficulty with diagnosis as the electrical tests may not reach these well. There is a skin punch biopsy that is specifically for this type. It is something you can ask your primary care doctor or neurologist about. It is quick, easy, and not much more painful than a blood test. It just goes through all the layers of the skin. At the lab that processes it, nerve endings it finds are counted and a judgment made as to whether you have the normal amount or not. (Bev Anderson, Editor)

alone it was nearly five inches. This is 3,000 ft. elevation in the Sierras 50 miles east of Sacramento. Please stay warm and dry,

Bev

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.

Free DVD on "Coping with Chronic Neuropathy"

introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at www.neuropathysupportnetwork.org/order-neuropathy-dvd.html

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.

President's Message – Continued from page 3

away just before Christmas from a sudden illness. Notes of encouragement would be gratefully received.

My hope is that all of you escaped flooding and other impacts of the tremendous amount of rain we have had this winter so far. In my neighborhood, we have topped 80 inches. The week before the sun came out for a few days we got 11 inches of rain in three days. In one day



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Living With Autonomic Neuropathy – Continued from page 1

check the prostate as the symptoms of your condition mimic problems with the prostate. You will find that some doctors will want to attribute the symptoms to aging if you are over 60 except some of us have had these symptoms when we were 32, myself after exposure to Agent Orange in 1968. I even had pain on urination which finally went away as damage to the nerves increased and I was now 'numb' from the waist down.

Then the bad news that was good news. The pain returned temporarily after months on gamma-globulin infusions, indicating according to my neurologist that the damaged nerves were attempting to work again. This experience coincided with the severity of overflow incontinence decreasing significantly on IVIg! Note: There are aids (depends, exercises, and medication) to help with overflow incontinence due to autonomic neuropathy and gamma globulin has reduced overflow incontinence significantly by protecting the damaged sensory and motor nerves. But in all things, it is best to speak to your treating doctor.

Retention Problems – It is important that all attempts to empty the bladder be tried, like exerting local pressure, but some patients must use self-catheterization to prevent infections from this retention. In all these issues, it is important to work closely with your medical doctor. Dr. Latov has other information and medication that can be used in his book on page 81. Note: Working with a knowledgeable doctor who is familiar with treating autonomic neuropathy is important in resolving retention problems and to prevent dangerous infections. But in all things, it is best to speak to your treating doctor.

Loss of Sexual Sensations (and normal responses of the sexual systems in both males and females) – Emotionally and physically, this is perhaps one of the most devastating results of damage to the autonomic nervous system. I do not have to explain to anyone how this impacts your life and the life of your partner. It takes away life and living at the deepest physical and emotional levels. The most important aspect is for you to understand that this is NOT your fault and there is nothing you or your partner have done to cause this to happen. This may not help with the ability to enjoy a major function of the human body, but knowing this provides understanding and stops the guilt or blame and perhaps one can stop beating on each other or themselves as if they or their partner is to blame. No, it is damage caused by the herbicides. Creativity in finding ways to express sexual needs with your partner is important once you get beyond the damaging blame game. It is what it is until it is not, is a good attitude as you find creative loving ways to bring sexual joy to the one you love.

Arrhythmia or Silent Tachycardia – Over the years, I have been sent me to the cardiologist so many times I lost count. Numerous times I was told that I was having a heart attack, which was checked out, rushed to the hospital tested, retested, had heart catheterization, was put on and off medications, then told my heart was fine. The doctors even implied that I was the cause of all this testing when the doctors were the ones sending me for the testing! The strange thing about this symptom was that it was silent or I never felt the tachycardia. Doctors would ask “Do you feel what your heart is doing?” The answer was “No.” For me these episodes came and went and did not kill me and with IVIg they stopped completely. Note: It is not the heart, but the damaged nerves supplying the heart and muscles surrounding the chest in an autonomic polyneuropathy. But in all things, it is best to speak to your treating doctor.

Chest Pains – Then there were the chest pains in the top left center of my chest that resolved with gamma globulin and whether they were related to muscle spasms or heart I have no idea. Without gamma globulin, the chest pains and tachycardia return along with severe muscle spasms in the

chest and upper back with pain so severe (level 8) that it would bring me to my knees (doubled over on the ground) and squeeze my chest making breathing difficult. In 1978, I believe it was, I was rushed from Weirhof, Germany to the military hospital and the diagnosis was ‘hyperventilation’ when there were no signs pointing to such a diagnosis. Knowledge of the symptoms of autonomic neuropathy just did not exist and even today it is underdiagnosed according to an expert, Dr. Brannagan of Columbia University. Note: All indications are gamma globulin resolved chest pains, muscle spasms and tachycardia associated with autonomic neuropathy. But in all things, it is best to speak to your treating doctor.

Breathing – After years of this experience, I was finally told that with my breathing problems, it was important we make sure that the right side of the heart is not damaged, especially by the sleep apnea which had been present for years. This condition after a sleep study confirmed is treated with a BIPAP machine which is a life saver as I will stop breathing at night in deep sleep. It does not matter if the doctors understand that this may be a part of your experience with autonomic neuropathy. Either way, it is treated the same, with a BIPAP. The other issue I learned is that my lungs are smaller than normal and that does not help. If you are overweight to any degree, lose the weight as this pressure on your lungs does not help your situation. Note: If you have autonomic neuropathy be tested for sleep apnea and especially so if you are awakening with severe headaches. But in all things, it is best to speak to your treating doctor.

Orthostatic Hypertension (or for me a generalized spinning sensation) – For decades I have had the on and off sensation of spinning. This symptom over the years increased to the point by 2004, of a 24/7 experience of the worse seasickness one could experience. Nothing helped as this symptom continued day and night, standing or sitting or lying down. Doctors stared at me and prescribed nothing. Today I carry medication from my current doctor to help if this happens. In 2004 a neurologist explained that there are peripheral nerves in the inner ear and if one side is affected by my illness or the infusion of gamma that this would cause and then tend to modulate this symptom. After eight years with gamma globulin, this symptom is reduced from a level 9 to a level 1 to 3 with only occasional severe bouts. Today, the doctors gave me a script for Meclizine which is a blessing. Without gamma globulin, the violent 24/7 symptom returns to a level 9 and living becomes impossible. Note: Gamma globulin reduces the generalized spinning sensation of autonomic neuropathy. But in all things, it is best to speak to your treating doctor if this symptom continues.

References:

One of the best patient and doctor articles on the scope of dealing with autonomic neuropathy symptoms was published in 2000. To read this article, request a copy from gene@neuropathysupportnetwork.org. This newsletter has three articles by patients or doctors: “A Twenty-Five Year Medical Nightmare”; “Diagnosis and Treatment”; and “Living with Autonomic Neuropathy”.

One of the best resources to find patient information and doctors on autonomic neuropathy is at the American Autonomic Society.

Also see Autonomic Nervous System Merck Manual.

Note: This article on autonomic neuropathy symptoms, updated Nov 13th 2016, was originally published in Nov 2012. Used with permission.

About the Author

Lt. Col. Eugene-Richardson, USA-Retired. Lt. Col. Richardson has suffered with severe neuropathy for over 45 years. A 27-year military veteran and veteran of the Vietnam War, he was diagnosed with a progressive chronic peripheral neuropathy resulting in severe disability. This diagnosis has been confirmed as due to exposure to Agent Orange. It was not until 2010, 42 years after his exposure to Agent Orange, that his diagnosis was recognized by Veterans Affairs as service connected.



WESTERN NEUROPATHY ASSOCIATION
 Hope through caring, support, research, education, and empowerment
 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.

Western Neuropathy Association 2017 Annual Conference

Date: Tuesday, April 18, 2017

Time: 9:30 AM to 3:30 PM

**Pre-register By:
 Tuesday, April 4, 2017
 Seating is limited.
 Must register in advance.**

Registration Fee: \$25.00

**Location: UC Davis Mind Institute
 UC Davis Medical Center
 2825 50th Street
 Sacramento, CA**

**Questions?
 Toll-free: (888) 556-3356
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Neuropathy Today & Tomorrow

- 9:30 am Registration check-in (must register in advance; limited seating)
Morning snacks and coffee included.
- 10:00 Announcements and Introductions
- 10:30 **Yuen So, M.D., Ph.D.**—Professor, Neurology & Neurological Sciences; Associate Chair, Clinical Services; Chief, Neurology Clinic; Stanford University Medical Center; oversees clinical trials. “What is a neuro-muscular neurologist?” “Why is this type of neurologist often recommended for treating people with neuropathy?”
- Noon Catered Lunch**
- 1:00 pm **Stem Cell Researcher**—Invited
“What is a stem cell?” “What does the research consist of?” “What does the future possibly hold for the impact of stem cells in the treatment of neuropathy?”
- 2:00 pm **Bruce D. Hammock, Ph.D.**— Distinguished Professor Department of Entomology & UCD Comprehensive Cancer Center, Director, NIEHS-UCD Superfund Research Program PI, NIH Biotechnology Training Program
“Report on the progress of his current neuropathy treatment research and how soon human clinical trials begin.”
- 3:00 pm Closing activities:
 - Evaluations
 - Door Prizes and Silent Auction
 - Closing Announcements
- 3:30 pm Adjournment



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If you need a special diet, please indicate: Vegetarian Gluten Free Other

I am enclosing my check for the \$25 registration fee (includes lunch and morning snacks).



WESTERN NEUROPATHY ASSOCIATION

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The 2017 Annual Neuropathy Conference April 18, 2017

The Mind Institute • U.C. Davis Medical Center Campus, Sacramento, CA

Speakers: Yuen So, MD, Neurologist, Stanford University Medical Center

Bruce Hammock, PhD, Researcher, U.C. Davis

SEE PAGE 7 FOR MORE INFORMATION!

FRAUDS TO AVOID

(Source: Consumer Reports, January, 2017 Full description available there.)

It is hard to avoid frauds and scams but if we are alerted, we can try to avoid as many as possible.

- Medicare Open Enrollment Ploy – People approaching 65 are called saying the caller is from Medicare and they need to sign up for a card or some such to be ready to get on Medicare. Medicare does not call, e-mail, or visit anyone to get personal information for this purpose. If you get such a call – just hang up the phone.
- Veteran’s Pension Scam – Do not deal with people who tell you they can help you qualify for a veteran’s benefit. Go to the Veterans Administration (VA) directly to ask about these and their recommended help if needed. Scams will get you to spend money on something needlessly. If you are contacted to alert you to a benefit the VA has that you might not know about, contact the VA directly. Don’t respond to opportunists.
- Pump and Dump Investment Schemes – Telemarketing stockbrokers will call people, especially seniors promoting a stock investment. They get people investing because the stock goes up as they are heavily promoting it. When they get it up and get their portion, they go on to something else, the stock drops and all investors lose their investment. Research carefully any stock you buy and don’t buy any out of the country as the money sent is hard to trace. www.Morningstar.com or www.finance.yahoo.com are two research sites.



Western Neuropathy Association (WNA)

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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

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