



WESTERN NEUROPATHY ASSOCIATION

June 2015  
Issue 6  
Volume 13

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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)

## ■ WHAT IS DYSAUTONOMIA?

Dysautonomia is an umbrella term used to describe several different medical conditions that cause a malfunction of the Autonomic Nervous System. The Autonomic Nervous System controls the “automatic” functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion, dilation and constriction of the pupils of the eye, kidney function, and temperature control. People living with various forms of dysautonomia have trouble regulating these systems, which can result in lightheadedness, fainting, unstable blood pressure, abnormal heart rates, malnutrition, and in severe cases, death.

Over 70 million people worldwide live with various forms of dysautonomia. People of any age, gender or race can be impacted. There is no cure for any form of dysautonomia at this time, but Dysautonomia International is funding research to develop better treatments, and hopefully someday a cure for each form of dysautonomia. Despite the high prevalence of dysautonomia, most patients take years to get diagnosed due to a lack of awareness amongst the public and within the medical profession.

Some of the different forms of dysautonomia include:

**Postural Orthostatic Tachycardia Syndrome (POTS)** - estimated to impact 1 out of 100 teenagers and a total of 500,000 to 3,000,000 Americans. POTS can cause lightheadness, fainting, tachycardia, chest pains, shortness of breath, GI upset, shaking, exercise intolerance, temperature sensitivity and more. While POTS

predominantly impacts young women who look healthy on the outside, researchers compare the disability seen in POTS to the disability seen in conditions like COPD and congestive heart failure.

**Neurocardiogenic Syncope (NCS)** - NCS is the most common form of dysautonomia, NCS impacts tens of millions of individuals worldwide. Many individuals with NCS have a mild case, with fainting spells once or twice in their lifetime. However, some individuals have severe NCS which results in fainting several times per day, which can lead to falls, broken bones and sometimes traumatic brain injury. Individuals with moderate to severe NCS have difficulty engaging in work, school and social activities due to the frequent fainting attacks.

**Multiple System Atrophy (MSA)** - MSA is a fatal form of dysautonomia that occurs in adult ages 40 and up. It is a neurodegenerative disorder with some similarities to Parkinson's disease, but unlike Parkinson's patients, MSA patients usually become fully bedridden within a 2 year of diagnosis and die within 5-10 years. MSA is considered a rare disease, with an estimated 350,000 patients worldwide.

Dysautonomia can also occur secondary to other medical conditions, such as diabetes, multiple sclerosis, rheumatoid arthritis, celiac, Sjogren's syndrome, lupus, and Parkinson's. 1,3

There is currently no cure for dysautonomia, but secondary forms may improve with treatment of the underlying disease. 4

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## ■ WELCOME DARRELL O'SULLIVAN

Darrell recently joined the WNA Board of Directors. He is a clinical laboratory scientist, State of California, and served in the US Air Force as the manager of the pathology and clinical laboratory for oversight of base wide drug testing of Air Force officers and enlisted. Afterward, he worked in this field at several Central California hospitals. He retired in 2012 as chief administrative officer,

Department of Pathology and Laboratory Medicine, University of California Davis Medical Center, Sacramento, CA and UC Davis School of Medicine, Davis, CA. Darrell is a graduate of California State University, Fresno, CA. President Bev Anderson's joy was evident as she welcomed a fellow Bulldog (Fresno State grad) to the Board.

## Roster of Our WNA Information and Support Groups

### 2015 WNA Board of Directors

**Bev Anderson**  
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**Karen C. Polastri, IOM**  
Vice President

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**Darrell O'Sullivan**  
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Emeritus

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Emeritus

**Casimir Sammanasu**  
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**Sandra Vinson**  
Emeritus

**Dick Ward**  
Emeritus

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

#### Alturas

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

#### Antioch-Brentwood

3<sup>rd</sup> Wednesday, 2 PM  
Antioch-Kaiser  
Sand Creek 1C  
Bev Anderson 877-622-6298

#### Auburn

1<sup>st</sup> Monday, 11 AM  
Woodside Village MH Park  
12155 Luther Road  
Bev Anderson (877) 622-6298

#### Bakersfield

3<sup>rd</sup> Wednesday, 1:30 PM  
Stockdale Moose Lodge  
905 S. Stine Rd..  
David Wollard (661) 663-9406

#### Berkeley-Oakland

No meeting  
Go to the Annual Conference  
See info in this edition.  
Kathleen Nagel (510) 653-8625

#### Carmichael

2<sup>nd</sup> 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

3<sup>rd</sup> Thursday, 6 PM  
Atria El Camino Gardens  
2426 Garfield, Ave.  
Tanysha Kaye (916) 488-5722

#### Castro Valley

2<sup>nd</sup> Wednesday, 1:30 PM  
First Presbyterian Church  
2490 Grove Way (next to Trader Joe)  
Judson Leong (510) 581-6697

#### Clearlake

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

#### Concord

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

#### Crescent City

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

#### Davis

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

#### Elk Grove

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

#### Eureka

For information call:  
Earlene (707) 496-3625

### Folsom

3<sup>rd</sup> Monday, 1:00 PM- odd numbered months  
Journey Church  
450 Blue Ravine Rd.  
Bev Anderson (877) 622-6298

### Fort Bragg

For information call:  
Betty Adams (707) 964-3327

### Fresno

3<sup>rd</sup> Tuesday, 11:00 AM  
Denny's Restaurant  
1110 East Shaw  
Marvin Arnold (559) 226-9466

### Garberville

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

### Grass Valley

2<sup>nd</sup> Monday, 1:30 PM  
GV United Methodist Church  
236 S. Church Street  
Salli Hearn (530) 268-1017

### Jackson

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

### Lakeport

May 4, 10 AM  
Lakeport Senior Center  
507 Konocti Ave.  
Mito Shiraki (707) 245-7605

### Lincoln

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

### Livermore

4<sup>th</sup> Tuesday, 10 AM  
Heritage Estates  
900 E. Stanley Blvd.  
Sandra Grafrath (925) 443-6655

### Madera

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

### Merced

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

### Modesto

3<sup>rd</sup> Monday, 10:30 AM  
Trinity United Presbyterian Church  
1600 Carver Rd., Rm. 503  
Monte Schrader (209) 531-3838

### Monterey

3<sup>rd</sup> Wed., 10:30 AM-odd numbered months  
First Presbyterian Church  
501 El Dorado Street  
Don & Ann Trout (831) 372-6959

### Napa

1<sup>st</sup> 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

1<sup>st</sup> Thursday, 1 PM  
Our Savior Lutheran Church  
298 High St.  
Stacey Harrison (530) 283-3702

### Redding

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

### Redwood City

4<sup>th</sup> Tuesday, 1 PM  
Sequoia Hospital Health and  
Wellness Center  
749 Brewster Avenue  
Stan Pashote (510) 490-4456

### Roseville

2<sup>nd</sup> Wednesday, 1PM- odd numbered months  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Carol Brosk (916) 531-2752

### Sacramento

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

### Salinas

Contact Bill Donovan  
(831) 625-3407

### San Francisco

4<sup>th</sup> Thursday, 10 AM  
UC-San Francisco Med Ctr.  
400 Parnassus Avenue  
Amb. Care Ctr. 8th Fl., Rm A888  
Y-Nhy (e nee) Duong  
Nhy-y.duong@ucsf.edu

### San Jose

3<sup>rd</sup> Saturday, 10:30 AM  
O'Conner Hospital  
2105 Forest Avenue  
SJ DePaul Conf. Rm.  
Stan Pashote (510) 490-4456

### San Rafael

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

### Santa Barbara

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

### Santa Cruz

3<sup>rd</sup> Wednesday, 1PM- odd numbered months  
Trinity Presbyterian Church  
420 Melrose Avenue  
Mary Ann Leer (831) 477-1239  
maleer@comcast.net

# President's Message

By Bev Anderson



Thanks to all of you who attended the Annual Conference at the Jelly Belly Factory in Fairfield on April 22. From the evaluations turned in, it was a quite successful conference. The speakers were excellent and the food was well received. Dr. Sawchuk's presentation was an overview of neuropathy from his perspective as a neurologist, which may have been new to many. Dr. Ralph's description of nerves, their function, regrowth and repair presented information that was new to most. Some of Dr. Sawchuk's morning presentation laid good groundwork for Dr. Ralph's presentation in the afternoon.

At the Annual Conference we try to offer a range of information so that those that are just learning about neuropathy get what they can use and those that have a deeper knowledge hear something new to them. I remember a general meeting we had years ago in Loomis. A top neurologist was flown in from Las Vegas by a medical group as a gift to us. He gave us a talk that he had given to medical students. Afterward, we could have had an interesting survey as to how far into the presentation we had gotten before we were lost – we really didn't fully understand what he was saying. I was delighted to know that I'd understood almost as much as the nurse sitting beside me, but some were struggling after the first few paragraphs. It is challenging to cover all the bases at any one conference.

It is important for all to know that the speakers came at no charge to us -- as speakers to support groups do. If they expect to be paid, you usually don't have them come. There is a benefit to most speakers and/or their organization for them to meet with patient groups as there are likely people who will make an appointment to see a doctor they met at the conference. We definitely hope that at least some of those who attended will give blood or platelets and will ask people they know to do the same. Vanessa did a grand service to all with her exercises .

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## WNA Information and Support Groups – continued from page 2

### **Santa Maria**

2<sup>nd</sup> Tuesday, 12:00 Noon  
Elwin Mussel Senior Center  
510 Park Street  
Wanda (805) 938-1086  
Mary (805) 344-6845

### **Santa Rosa**

1<sup>st</sup> Thursday, 10:30 AM  
Santa Rosa Senior Center  
704 Bennett Valley Road  
Larry Metzger (707) 541-6776

### **Sonoma**

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

### **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**

3<sup>rd</sup> Monday, 1 PM  
Covenant Village Adm. Bldg. Classroom  
2125 N. Olive St.  
Joanne Waters (209) 634-0683

### **Ukiah**

Last Tuesday, 5:30 PM  
North Coast Opportunities (NCO)  
413 N. State St.  
Shirley Blattner (707) 621-0208  
Carole Hester (707) 972-2795

### **Walnut Creek**

4<sup>th</sup> Friday, 10 AM  
Rossmoor, Hillside Clubhouse  
Las Trampas Room  
David Woods (925) 287-8100

### **West Sacramento**

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

### **Woodland**

1<sup>st</sup> Tuesday, 1:00 PM  
Woodland Comm & Senior Center  
2001 East Street  
Elizabeth Chaudhry (530) 661-3859

### **Yreka**

For information call  
Bev Anderson (877) 622-6298

### **Yuba City-Marysville**

2<sup>nd</sup> Tuesday, 10:30 AM  
St. Andrew Presbyterian Church  
1390 Franklin Rd.  
(next to Winco Shopping Center)  
Ken Lux (530) 673-3479

### **NEVADA**

#### **Reno-Sparks**

For information call  
Bev Anderson (877) 622-6298

### **OREGON**

#### **Brookings**

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

#### **Grant's Pass**

3<sup>rd</sup> Wednesday, 10:30 AM  
Three Rivers Medical Center  
500 S.W. Ramsey Ave.  
Carol Smith (541) 955-4995

#### **Medford**

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

#### **Portland**

For information call  
Joe Mozena (503) 505-0692 or  
Bev Anderson (877) 622-6298

#### **Salem**

3<sup>rd</sup> Monday, 6:30 PM  
Community Health Education Center  
Salem Hospital Campus, Bldg. D  
890 Oak Street SE  
Michael (503) 857-3508  
newssofsalem@gmail.com

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

### **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".



## PERIPHERAL NEUROPATHY LITERATURE REVIEW By William B. Donovan, M.D.

### 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 PCNA/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](http://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](http://www.healthlight.us)

#### Auburn

##### The Footpath

825 Lincoln Way  
(530) 885-2091  
[www.footpathshoes.com](http://www.footpathshoes.com)  
**PCNA Discount: 10% off the regular price shoes.**

#### Elk Grove

##### Shoes That Fit

8649 Elk Grove Blvd.  
(916) 686-1050  
**PCNA 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  
**PCNA Discount: 10% off the regular price shoes.**

#### Sacramento

##### Midtown Comfort

##### Shoes

3400 Folsom Blvd.  
(916) 731-4400  
**PCNA discount: 15% on the regular price.**

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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 take us to the **NLM: [www.ncbi.nlm.nih.gov/sites/entrez](http://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.

This month's PMIDs:

- 23691937 This meta-analysis of seventeen studies comprised of 5,975 subjects with chronic peripheral neuropathic pain revealed the most pain reduction with duloxetine (Cymbalta®) 120mg. and pregabalin (Lyrica®) 600mg.
- 23703408 Sixty-two patients with refractory unilateral lumbar radiculopathy were randomly assigned to either transforaminal steroid injection with or without a Fogarty balloon catheter. During 52 weeks follow-up the balloon group experienced significant improvement in pain and distance walked before claudication pain commenced.
- A study of eight patients with chronic intractable neuropathic pain who were treated with a neurosurgical procedure – stereotactic central lateral thalamotomy (CLT). They experienced significant improvement in both pain and depression.
- 23794648 This article describes the "pathway" for care of neuropathic pain developed by the British Pain Society for non-specialists. It includes initial assessment; topical treatment as indicated with lidocaine (Xylocaine®) patch and capsaicin 0.075% cream; initial prescription of gabapentin (Neurontin®) or pregabalin (Lyrica®) -- carbamazepam (Tegretol®) in trigeminal neuralgia; possible use of tricyclic antidepressants -- duloxetine (Cymbalta®) are also mentioned; tramadol (Ultram®) for pain; followed, if necessary, by the judicious use of strong opioids to prevent the development of chronic pain. Multi-disciplinary referral is employed in refractory cases.
- 23959683 A Cochrane Database review of 32 randomized controlled trials involving 2762 patients with acute low back pain, with or without sciatica, concluded that either manual or machine traction, either alone or in combination with other therapy, had little or no impact on pain intensity, functional status, global improvement or return to work.
- 23917673 This double blind placebo controlled study of refractory post-herpetic (shingles) pain, comparing methadone 5mg twice a day with placebo, found 50% reduction of pain with methadone versus zero% with placebo. Side effects were similar under both conditions.
- 24096743 This update of a Cochrane database review in 2011 looked at 49 randomized controlled trials including 3639 patients receiving 38 different Chinese herbal medicines for peripheral neuropathy. None of the studies were considered to be of good enough quality to support conclusions as to effectiveness or safety of the agents evaluated.

## There's Still Time to SIGN UP!

9th Annual

## Neuropathy Action Awareness Day Conference

June 18, 2015

Intercontinental Los Angeles/Century City Hotel, 2151 Avenue of the Stars, Los Angeles, CA 90067

To get the brochure with all the information and registration form,  
go to **[www.naf.org](http://www.naf.org)**, download and print it.

**Pre-registration by June 11 • \$20 per person**

After June 11 • \$50 per person

## EFFICACY OF ALPHA LIPOIC ACID IN DIABETIC NEUROPATHY

Papanas N1, Ziegler D.

Expert Opin Pharmacother. 2014 Dec;15(18):2721-31. doi: 10.1517/14656566.2014.972935. Epub 2014 Nov 10.

Author information

• 1Democritus University of Thrace, Second Department of Internal Medicine , Alexandroupolis , Greece.

### INTRODUCTION:

Neuropathy is a serious complication of diabetes. Its management focuses on glycaemic control, multifactorial cardiovascular risk intervention, pathogenesis-oriented therapy, and analgesics where needed.

### AREAS COVERED:

The objective of this review is assessment of efficacy and safety of  $\alpha$  lipoic acid (ALA, also thioctic acid) in pathogenesis-oriented treatment of diabetic neuropathy. The mechanisms of action of ALA in experimental diabetic neuropathy include reduction of oxidative stress along with improvement in nerve blood flow, nerve conduction velocity, and several other measures of nerve function. There is ample evidence from randomised, double-blind, placebo-controlled clinical trials and meta-analyses, suggesting that ALA is efficacious and safe for the diabetic neuropathy, accomplishing clinically

meaningful improvements.

### EXPERT OPINION:

ALA is a valuable therapeutic option for diabetic neuropathy. When compared with currently licensed analgesic drugs, it is better tolerated, has a more rapid onset of action, and improves paraesthesiae, numbness, sensory deficits, and muscle strength in addition to neuropathic pain. In clinical practice, ALA may be chosen in patients with early neuropathic deficits and symptoms, in whom clinical improvement is more likely. ALA should also be considered when comorbidities render other analgesics less appropriate or in the presence of cardiovascular autonomic neuropathy.

### KEYWORDS:

diabetes mellitus; diabetic neuropathy; efficacy; oxidative stress; thioctic acid; treatment

PMID:25381809 [PubMed - indexed for MEDLINE]

## DISCOUNTS FOR WNA MEMBERS

*Continued from page 4*

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

### 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](http://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](mailto:info@pnhelp.org).

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

## GBS-CIDP FOUNDATION INTERNATIONAL - SAM RICHMOND

This story is told about Renee Richmond and her son, Sam. Renee is an ambassador for the GBS-CIDP Foundation International. This means she helps the organization by being a person in the community actively supporting its work.

"Your child has a chronic disease.. ' ..wait a minute, what?" Renee remembers the moment when the severity of her then 10-year-old son's diagnosis set in.

"Sam expressed concerns of increasing weakness, fatigue and sharp pains in his shoulders and hands that began in early November. By New Year's, on a family ski trip, he was unable to stand up after falling on the slopes. In mid-January, he was crawling up the stairs. And so our journey began," Renee remembers. Sam was diagnosed with CIDP via EMG and Nerve Conduction Studies by a pediatric neurologist who told the family on the spot, "This is out of my scope."

Renee made an appointment with Dr. Susan Iannconne, a member of the Foundation's Medical Advisory Board, and within a week Sam was admitted to Children's Medical Center Dallas for his first round of IVIg. Sam started outpatient physical and occupational therapy three times a week, and continued therapy at home.

Slowly, Sam started gaining strength. Within a couple of months, he was walking up the stairs again. Although just one step at a time, he was walking and not crawling! He attended school for

half days for the remainder of that school year. The school system made accommodations so Sam could attend school and not be homebound.

After six months of successful treatment, Sam had a reaction to a dose of IVIg that sent him to the ER. "Our doctor made the decision to hold IVIg, continuing with only PT and OT. He continued to gain strength. We'd made the right decision," Renee recalls.

Although it was the right decision at the time, Sam began to relapse after a few months, which placed him back on IVIg. He currently is admitted as an inpatient each month for five days of infusions to manage his CIDP.

Having CIDP is not much fun for anyone, let alone a 12 year old. Sam misses at least a week of school each month between the infusions and IVIg side effects. He insists on staying in school full days, not wanting to miss out on middle school, band, or hanging out with his friends. He loves school, and really thrives there. This year, Sam was inducted into the National Junior Honor Society. He was a

*- Continued on page 7*

# THE ROLE OF THE PHARMACIST IN PAIN MANAGEMENT

By Sonya Wells, Pharm.D., MPH

Pharmacists are the most frequently encountered member of the healthcare team for ambulatory patients. This fact, coupled with the recent developments in Medicare Part D and the opportunity for pharmacists to provide Medication Therapy Management (MTM) services, makes your pharmacist an ideal professional to address chronic pain problems.

MTM services are not new to pharmacists who have been working with patients for years to identify and resolve drug-related problems. However, MTM services are now a required component of the Medicare prescription drug benefit.

“MTM services are independent of, but can occur in conjunction with, dispensing a medication,” Dr. Kathryn Hahn, PharmD, said in a session where pharmacists learned about pain management and MTM services. “MTM services encompass a broad range of professional activities or responsibilities that are within the licensed pharmacist’s scope of practice.”

The American Pharmacists Association has worked with the National Association of Chain Drug Stores Foundation to develop 5 “core elements” of MTM services. These include:

- Medication Therapy Review: The pharmacist conducts this review with the patient and/or caregiver, usually in a face-to-face encounter.
- Personal Medication Record: After reviewing the patient’s medication regimen, the pharmacist provides the patient with a personal medication record. The patient is encouraged to share this with all healthcare providers and to bring it on future pharmacist visits.
- Medication Action Plan: At the end of the MTM visit, the pharmacist will provide the patient with a medication action plan that contains information for the patient to

use in optimizing medication self-management. This plan may include non-drug action items, such as lifestyle modification (eg, diet and exercise).

- Intervention and/or Referral: The pharmacist may need to intervene with the prescriber or refer the patient to additional healthcare providers for further care.
- Documentation and Follow-Up: The pharmacist will document his or her services in a format that allows patient follow-up. A summary of the patient encounter is also documented and shared with the patient’s primary care provider.

MTM services will be reimbursed for eligible patients. Eligibility will be defined by the number of chronic medications the patient is receiving, the number of comorbid conditions, and/or the total annual drug expenditure. These criteria will likely yield a large number of patients from a community pharmacy practice.

Given the high prevalence of pain in our society, patients who meet MTM services criteria likely have pain as a complaint. Pain may not be the patient’s primary complaint, but it often is associated with common disease states such as osteoarthritis, diabetes, insomnia, or a variety of conditions for which patients seek nonprescription medications.

Your pharmacist should be asking these patients, “Do you have any pain or discomfort that you have not previously mentioned?” Building on this, the pharmacist should determine whether analgesics have been prescribed for the patient in the past and whether the patient is using these medications correctly.

MTM services are a tremendous opportunity for pharmacists and their patients where the ability to intervene on behalf of patients with chronic pain is significant.

Reference: Hahn K, McPherson ML. Neuropathic pain. Program and abstracts of the American Pharmacists Association 2006 Annual Meeting; March 17-21, 2006; San Francisco, California.

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## President’s Message – Continued from page 3

We did have one concern I’d like to share with you. We were excited with the registration numbers. The day we had to provide confirmation of attendees to the caterer, we said 117. Towards the end of the registration period, we approved some to pay at the door as the mail would not reach us in time. By the time of the conference we had 124 registrations with just four more seats available. We heard from several that they were ill and couldn’t come, which with most having neuropathy is understandable. We had some that came without registering, which if all had come that we expected would have created a problem. You can imagine our surprise when the lunch count at the time lunch was served was 107, which means we had to pay for 10 more lunches than were actually served. The \$20 registration fee does not cover the full cost of lunch, so paying for lunches that we did not serve is painful to our budget. Putting on a conference has many challenges

– food management is just one of them. A small amount came from our one sponsor again this year, the Occupational Therapy Association of California. They funded and prepared the snack bags and covered the cost of some of the materials. The rest is taken from the WNA account. This pays for the facility, the food, publicity, printing, etc.

I think the lead article in this newsletter is one of the most important articles we have published. It is an excellent presentation of what is involved in the autonomic component of the Peripheral Nervous System. Sensory and motor we can understand somewhat, but the mystery of the “automatic” functions in our body that are effected by neuropathy are harder to comprehend.

*Bev*



## What Is Dysautonomia?

– Continued from page 1

There are some treatments available to improve quality of life, both with medications and lifestyle changes/adaptations, but even using all treatments available, many dysautonomia patients experience disabling symptoms that significantly reduce their quality of life. 1, 2, 3, 4, 5

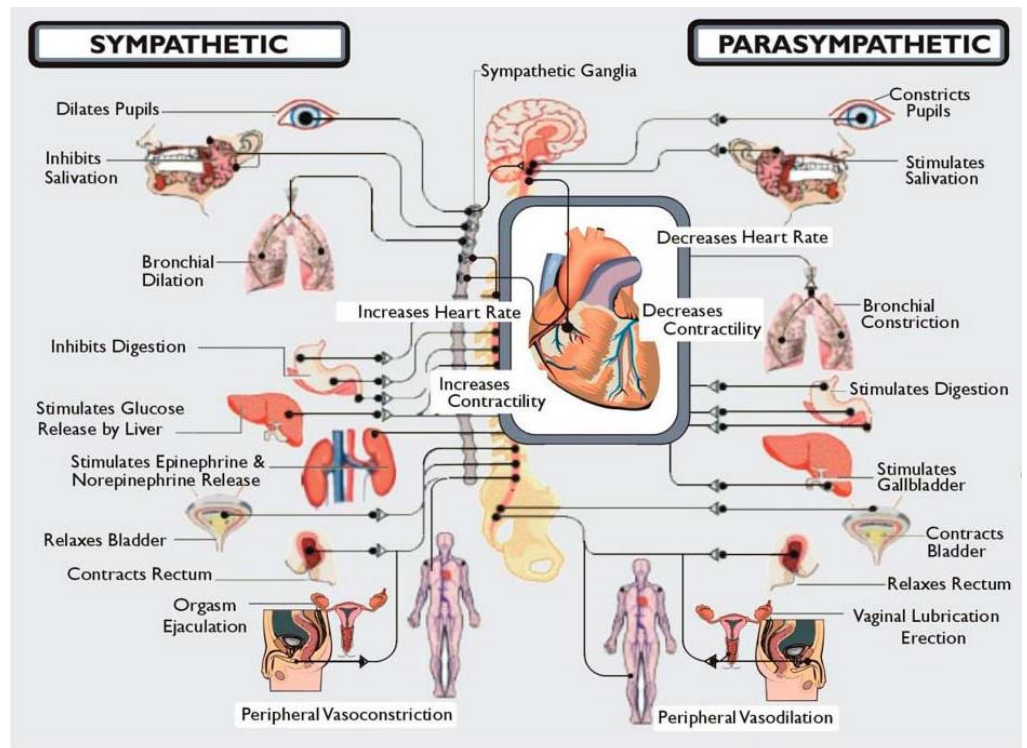
Dysautonomia International encourages you to Learn More. You can make a difference in the lives of people living with dysautonomia by donating today!

### Sources

1. National Institutes of Health Rare Disease Network's Autonomic Disorders Consortium
2. Dysautonomias: Clinical Disorders of the Autonomic Nervous System. Moderator: David S. Goldstein, MD, PhD; Discussants: David Robertson, MD; Murray Esler, MD; Stephen E. Straus, MD; and Graeme Eisenhofer, PhD
3. Dysautonomia, A family of misunderstood disorders. Richard N. Fogoros, M.D., About.com Guide Updated November 13, 2011.
4. National Institute of Neurological Disorders and Stroke Information Page
5. Clinical Disorders of the Autonomic Nervous System Associated With Orthostatic Intolerance: An Overview of Classification, Clinical Evaluation and Management. Blair P. Grubb, M.D. Associate Professor of Medicine and Pediatrics, Divisions of Cardiology and Neurology, Barry Karas, M.D. Assistant Professor of Medicine, Division of Cardiology, The Medical College of Ohio.

<http://www.dysautonomiainternational.org/page.php?ID=34>  
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1/15/2015



## GBS-CIDP Foundation International - Sam Richmond - Continued from page 5

finalist in his school district for the Regional Science Fair. He plays in the symphonic band and practices even when he would rather be resting. His attitude and strength are indestructible.

Sam has an amazing support system around him. He and his family have been surrounded by amazing friends helping through this journey. His friends visit him in the hospital, sit with him during infusions, and drop by to say hello when he's feeling not well enough to attend school. Sam has even met two boys close to his age who also have CIDP. They continue to be in touch and support one another through this journey. Renee has met both boys' mothers and formed a bond with them.

As a pediatric nurse at Children's Medical Center of Dallas for 17 years, Renee spends time every day reading about medical treatments, alternative treatments, therapies and psychosocial affects related to CIDP.

"We are so fortunate that we are surrounded by love and support and that we have discovered a wonderful extended network through the Foundation," Renee acclaims. "We attended the GBS|CIDP Symposium in Orlando last October and had a

wonderful time!" The Symposium led to new friends from all over the country and the world and exposure to the latest research from top physicians in the field of these diseases. "We felt a part of this community, our new community."

When Sam first was diagnosed, Renee wanted to get more involved, do more to bring awareness, and to search for a cure. She volunteered to be the chair for the Dallas Walk and Roll and accepted the role with privilege and pride. On May 3, Team Sam joined 350 other GBS and CIDP friends, family, and community to walk together to bring awareness and raise much needed funds in our biggest walk in history. "My husband and I feel some days as if we're drowning," Renee tells us, "other days like we've got it all under control, and always that we are so lucky to have these amazing children."

"This has not been easy," Renee expresses. "Through it, we've gotten stronger. We've done things we never thought we could do".

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# WESTERN NEUROPATHY ASSOCIATION

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## Mark Your Calendar:

**June 18, 2015**

The 9th Annual Neuropathy Action Awareness Day Conference  
Intercontinental Hotel in the Century City area of Los Angeles.

Pre-Registration by June 11 • [www.naf.org](http://www.naf.org)

## 9TH ANNUAL NEUROPATHY ACTION AWARENESS DAY CONFERENCE, JUNE 18, 2015

Please remember the 9th Annual Neuropathy Action Awareness Day Conference is Thursday, June 18, 2015, at the Intercontinental Los Angeles/Century City Hotel, 2151 Avenue of the Stars, Los Angeles, CA 90067. The cost to patients and those that come with them is \$20 per person. To get the brochure with all the information, go to [www.naf.org](http://www.naf.org), download and print it. The Registration Form is in the brochure as is the program and instructions. The deadline for receipt of the Form and check is June 11. After that date the charges is \$50. We hope some of you will be able to attend. Pam Hart of our Board and Bev plan to be there. Stan Pashote and his wife are planning to be there. Stan is to receive an award we will say more about in our next newsletter.

LIVE STREAMING is available again this year. This means you can watch it on your computer if it has internet access during the day at the same time it is happening at the conference. You must register, but this is free. You will be sent the link. After the conference, it will be on the NAF website to view anytime.



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### 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

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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