



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)

## ■ EXPERTS GIVE HOUSE PANEL DIFFERING VIEWS OF OPIOID Tx MARKET

**Generic competition is being stifled some witnesses say.**

By Joyce Frieden, News Editor, MedPage Today 9-23-2016

WASHINGTON -- Is the market for medications to treat or deter opioid abuse working well? Witnesses at a House hearing Thursday gave conflicting answers to that question.

"We think there is robust competition in this space," said Anne McDonald Pritchett, PhD, vice president for policy and research at the Pharmaceutical Research and Manufacturers of America (PhRMA), a trade group for the pharmaceutical industry, at a hearing held by the House Judiciary Subcommittee on Regulatory Reform, Commercial and Antitrust Law. "When you look at the pipeline, we have 31 abuse-deterrent formulations in development for the treatment of pain ... There are 35 addiction medicines in development, and 49 opioid pain medications in development potentially providing important treatment alternatives to what's currently on the market."

But Robin Feldman, JD, director of the Institute for Innovation Law at the University of California

Hastings College of the Law, begged to differ. "Open competition is the backbone for U.S. markets, but we're not seeing that in the market for addiction medicine," she said. "Rather, drug companies are engaging in regulatory games, stringing these out one after another while competition languishes on the sidelines.

"These games come in two baskets: one involves manipulating Hatch-Waxman -- the system for quick approval of generic drugs when the patent on the main drug expires," she continued. "The other basket relates to the system for non-patent exclusivity ... We've seen petitions asking the FDA to deny approval of any generic version. One addiction medicine company asked the FDA to require things for generic Suboxone [buprenorphine and naloxone] that it didn't have the authority to do. The agency denies 80% of these petitions -- as it denied this one -- but the

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## ■ NOVEL TREATMENT MAY PREVENT DIABETIC NEUROPATHY

Originally Published on [www.specialtypharmacytimes.com](http://www.specialtypharmacytimes.com)

Lauren Santye, Assistant Editor

Publish Date: Thursday, September 22, 2016 googletag.cmd.push(function() { googletag.display('482'); });

Depleting the chemical GM3 was found to prevent the development of neuropathy in obese mice with diabetes in a recent study. It's estimated that about 25% of patients with type 2 diabetes suffer from numbness and extreme nerve pain in their feet. With few treatment options available for patients suffering from neuropathy, new findings from a study published in Molecular Pain could potentially prevent, or reverse diabetic neuropathy. "We have such terrible treatments right now for the neuropathy of diabetes," said corresponding study author Amy Paller. "We're basically only treating the pain. This is a novel pathogenesis-based approach that looks at what's causing the neuropathy and reverses that instead of just treating the pain." During the study, researchers applied a gene therapy ointment to

the footpad of diabetic mice to deplete GM3 and GM3 synthase, the enzyme that makes GM3. The authors noted that this type of neuropathy goes beyond the typical numbness that some patients with this condition experience. "It's not that you just don't have sensation in your feet," said first study author Daniela Menichella. "You have shooting pain, which is the unbearable part. Pain is a debilitating affliction and one of the worst complications of diabetes." Prior to this treatment, researchers discovered that routine diabetic mice had significantly more GM3 and GM3 synthase in their nerves compared with normal mice. These same findings were seen in the skin of both humans and mice with diabetes.

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## Roster of Our WNA Information and Support Groups

### 2016 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

#### Alturas

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

#### Antioch-Brentwood

3<sup>rd</sup> Wednesday, 2 PM- odd numbered months  
Antioch-Kaiser  
AMC-1H2 (from hospital lobby)  
Sandra (925) 443-6655

#### Auburn

1<sup>st</sup> 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

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

#### Carmichael - Eskaton

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 - Atria

3<sup>rd</sup> Tuesday, 3:30 PM  
Atria - Carmichael Oaks  
8350 Fair Oaks Boulevard  
Tanysha (916) 944-2323  
Community members welcome

#### Castro Valley

2<sup>nd</sup> 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

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

#### Costa Mesa

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

#### 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

1<sup>st</sup> Thursday, 12:30 PM  
Berger 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

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  
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

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  
Ray (209) 634-4373

#### Monterey

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

#### Napa

1<sup>st</sup> Thursday, 2 PM  
Napa Senior Center  
1500 Jefferson Street  
Ron Patrick (707) 257-2343  
[bonjournapa@hotmail.com](mailto: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  
Danielle LaFlash (415) 297-1815

#### Roseville

2<sup>nd</sup> Wednesday, 1PM - odd numbered months  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Bev Anderson (877) 622-6298

#### Sacramento

3<sup>rd</sup> 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

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](mailto: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.  
Danielle LaFlash (415) 297-1815

#### San Rafael

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

# President's Message

By Bev Anderson



Here we are in the month of Thanksgiving. My thankfulness overflows for the people who joined and contributed in our last request. Every person willing to be on a Leadership Team brings me joy and much thanks. The only thing that holds us back from having support groups in every community is the lack of people willing to take time to lead a group. Also needed are the people who will support those leaders by showing up for the meeting so they are encouraged that they are making a difference for someone.

I'm thankful for our Board of Directors. What a wonderful group of creative and supportive people who really care about each of our members and leaders. Some may have noticed that Johnathan Istilart has moved from director to emeritus council. He received training to teach English as a second language and just started a year in South Korea teaching elementary children who come to a camp for a three-day stint of learning English. They receive some instruction in school but this is working with an American English speaker to gain more ability in pronunciation and usage in certain situations.

We had a surprise this month. Sandra Grafrath a member of the Board of Directors and also the leader of the Livermore Peripheral Neuropathy Support Group celebrated her birthday where she was born and raised with her relatives in the San Diego area. She decided it was time to move back, but also that there is a great need for a support group in the area north of San Diego (Escondido) where she plans to live. Her house sold quickly and she has already purchased a house in her new area. By the time you receive this newsletter, she will be settling into her home there. How thankful I am for Sandra's desire

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

### **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  
For information call  
Bev Anderson (877) 622-6298

### **Santa Maria**

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

### **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**

3<sup>rd</sup> 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**

4<sup>th</sup> 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**

3<sup>rd</sup> 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) 622-6298

#### **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](mailto:info@pnhelp.org)



## BEV'S NOTES FROM LIFE LIVED LATELY

### 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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**Medicine manufacturers.** If you are taking thyroid medication, know what manufacturer your pharmacy is using for the one prescribed to you. Be sure to have them keep using that same manufacturer. I changed pharmacies and received a different manufacturer. My blood test came out high so I was changed to a lower dosage which doesn't work as well. In talking to several pharmacists, I found out that makers of generics have a standard to meet in regard to the medication they are copying but there is a very small variation allowed. In most medications, it is not a problem. Thyroid medication is so exacting; it can make a difference. Most pharmacies have contracts with several manufacturers so they should be able to keep you on the same manufacturer's product. I plan to keep track of what manufacturer is used with all my generics and be sure to have the same manufacturer each time it is filled. My thyroid level affects my heart and thus the heart medications so I don't want variations so as to keep the balance intact.

**Computers.** If you use Microsoft Office 2016 and need to use the repair option, use the non-internet one first. When you use the internet option be prepared for the software to be deleted and reinstalled. Don't panic. Stay calm and know that it will be reinstalled automatically but may take a while depending on your computer speed. Also know that none of your e-mail settings will be disturbed. This was my experience this past month. There are listings on the Web of people screaming and upset. It would help a lot if there were

instructions as to what was about to happen so panic didn't have to set in. I was fortunate as I didn't turn it off while going into shock. When I looked back, I saw the reinstalling had started and was amazed. Even more, I have a unique server due to my rural locality which requires someone to come to reinstall the connections. Even these were still there when the reinstalling was completed.

**Supplements I Take.** If you have evidence of autonomic neuropathy which means internal problems not explained by usual medical tests or responding as usual like UTIs and other digestive tract disturbances, first be sure you are taking an effective dose of alpha lipoic acid (300 mg. am and 300 mg pm). Then, possibly add CoQ10 100 mg and cranberry capsules. You can take more capsules according to the bottle but I take two thinking I can increase them if I need to. I may have started with more and cut back. It is more convenient, less calories, less sugar, and less cost than drinking that much straight cranberry juice. If you take an antibiotic for a UTI, be sure the infection is totally gone before stopping the antibiotic even if you need to take it twice as long. If it keeps coming back, it is likely it wasn't totally gone from the last time. Be sure to consult your doctor and keep in touch with your doctor as this can develop kidney problems if it continues.

*(If you learn something that might be helpful to others and want to send a note about it, please do so. I will reserve the right to edit it. Thanks to those that sent a response to wanting life stories outlining your neuropathy experience. Please keep them coming.)*

## NEUROPATHY ACTION FOUNDATION ANNOUNCES RESULTS FROM MULTIFOCAL MOTOR NEUROPATHY (MMN) SURVEY

**International quality of life survey for Multifocal Motor Neuropathy (MMN) patients gives insight into diagnosis and treatment**

Santa Ana, CA, September 29, 2016 - The Neuropathy Action Foundation (NAF) announced the results from the first ever international Multifocal Motor Neuropathy (MMN) Quality of Life (QOL) Patient Survey. The survey focused on three primary areas: timely and accurate diagnosis, efficacy of treatment, and the impact of the disease on patient's quality of life.

"Early and accurate diagnosis can mean the difference between MMN patients being successfully managed or becoming permanently disabled," said NAF President Dominick Spatafora. "Timely intervention can make a difference in patients' lives." The NAF believes these survey results will increase awareness and action among researchers, providers, the general

public and public policy officials.

The majority of the 214 patients completing the survey were from the United States (71.15%) and the United Kingdom (6.73%) with respondents from 22 other countries also contributing to the results. While the majority of patients reported that they were diagnosed between the ages of 41 and 65 years (56.52%), more than 67% of those completing the survey reported that it took more than one year to be diagnosed. Of these individuals, more than 44% reported that it took two to three years or longer to be accurately diagnosed. The majority of the misdiagnoses were reported by neurologists (54.60%) and family care providers (20.69%). The data also showed that

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## PERIPHERAL NEUROPATHY LITERATURE REVIEW By William B. Donovan, MD

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:

- 26245776 This Mayo Clinic study performed a pilot test of Scrambler®, an electroneurostimulation device, on 37 patients suffering from chemotherapy-induced peripheral neuropathy pain (CIDP). In this uncontrolled trial there was a 53% reduction in pain score, 44% reduction in tingling, and 37% reduction in numbness.

- This Columbia University chart review of 373 patients referred with the diagnosis of idiopathic neuropathy. The following were the final diagnoses at completion of their evaluations: 32.7% remained idiopathic; 25.3% were diabetic or prediabetic; 20% chronic inflammatory demyelinating polyneuropathy; 7% monoclonal gammopathy. The remaining 15% included the following etiologies: toxic, Sjogren's, celiac disease, other immune-mediated diseases, B1, B12 and B6 deficiencies, vasculitis, hypothyroidism, hereditary neuropathy, Lyme Disease and anti-sulfatide antibody.
- 26245776 This Mayo Clinic study performed a pilot test of Scrambler®, an electroneurostimulation device, on 37 patients suffering from chemotherapy-induced peripheral neuropathy pain (CIDP). In this uncontrolled trial there was a 53% reduction in pain score, 44% reduction in tingling, and 37% reduction in numbness.
- 26581442 This study found, among patients with peripheral neuropathy pain, greater satisfaction from a single application of an 8% capsaicin patch compared to an optimized dose of pregabalin (Lyrica®): 52.1% vs. 44.8%.
- 26599185 This is a review of distal symmetric polyneuropathy, the most common form of neuropathy, the latter 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.

### Neuropathy Action Foundation Announces Results From MMN Survey – Continued From Page 4

51.96% of the respondents had conduction block, a characteristic finding of the condition.

"It is very clear that we need to do a better job at accurately diagnosing these patients. The sooner we can identify MMN, the sooner we can start individuals on the proper therapy, alleviate their symptoms and improve their lives," said Jonathan Katz, chief of neuromuscular services at California Pacific Medical Center.

When asked about treatment options, 91.43% reported receiving intravenous immunoglobulin (IVIg) and 8.57% reported receiving subcutaneous immunoglobulin (SCIg) therapy. A reduction in symptoms was reported within one week of their first IG treatment by 36.30% of respondents. Only 6.67% reported that IG did not help them manage their symptoms. If recommended by their neurologist, 81.05% would consider SCIg treatment.

Half of all participants in the survey stated that MMN

often or always interferes with their employment and 56% said it impacts their overall quality of life. Basic tasks such as turning a key in a lock are either difficult or impossible for 53.24% of the MMN patients participating in this assessment. The data showed that 61.19% were either unable or had difficulty buttoning a shirt, though 61.62% are able to shop and run errands by themselves. While 58.38% of survey participants said that they had difficulty falling asleep at night due to MMN, 77.66% reported daytime sleepiness.

"The survey results illustrate the complexity of MMN and the impact it can have on people's lives," said Spatafora. "The good news is that the data also shows that treatment clearly helps these individuals."

A more detailed analysis of the survey findings is available on the NAF website at [http://www.neuropathyaction.org/downloads/MMN\\_article%209-26-2016.pdf](http://www.neuropathyaction.org/downloads/MMN_article%209-26-2016.pdf) Used with permission.

### 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.

# SACRAMENTO NEUROPATHY GROUP LEARNED ABOUT BALANCE IN SEPTEMBER

By Charles Moore, Sacramento Leader

Debbie Eernisse, fitness trainer, yoga instructor and balance specialist of the Davis Senior Center, presented an instructional workshop to the Sacramento PN Support Group on September 20, 2016. Debbie had chosen "Building Balance," a particularly appropriate title for her presentation. Debbie provided an excellent handout with illustrated exercises, in each case providing exercises that do indeed build toward improving balance, so important to PN sufferers who often experience numbness in the feet and legs, creating problems of balance and the danger of falling.

Before turning to the "7 Components of Balance," she had us perform an interesting exercise: we stood on one foot on "the face of a clock on the floor." Standing on the left foot we moved the right foot to different times on the clock face. With each move, we shifted our weight so that both legs bore the weight equally. Debbie said we should feel the weight equally in both buttocks. Clearly, some points on the clock were easier to manage (e.g., 3), while some were more difficult (e.g., 6), which requires reaching in back. We repeated the exercise standing on the right foot and moving the left around the clock face.

## The 7 Components of Balance

1. Proprioception
2. Vestibular System
3. Vision
4. Strength
5. Flexibility
6. Reactions
7. Confidence

A little vocabulary check is in order.

"Proprioception" is the sense of the relative position of neighboring parts of the body and strength of effort

employed in movement. If one suffers loss of feeling, especially in the feet or legs, one may suffer impaired proprioception.

The "Vestibular System" is the sensory apparatus of the inner ear that helps the body maintain its postural equilibrium. Loss can lead to vertigo.

As we moved through the 7 Components of Balance, Debbie provided some typical movements or exercises that helped to develop each component. For example, under Proprioception, she urged walking, walking backwards, and walking as if on a balance beam.

Activating the vestibular system would involve using a rocking chair, dancing, and imitating a maypole by swinging the upper body around so that the arms were raised a bit.

Vision required standing on one leg, marching in place, and tracking one's thumb as far to the right and as far to the left as possible.

Strength is best developed by moving from sitting to standing and moving from standing to sitting, rising quickly and lowering slowly. Modified push-ups against a wall or kitchen cabinet were also useful.

Flexibility involved exercises including calf stretching with a strap, seated rotation of the upper body for thoracic spine mobility, and leg swings forward and back.

Reaction made use of heel drop, stomping, hopping and jumping.

Confidence involved all the 7 Components of balance and the "Super Hero Stance" (with a Superman-like illustration).

Feedback from the support group members indicated that this was a most successful workshop. I observed that all 20 workshop members participated in the various exercises, realizing the value of fall prevention in our PN lives.

Now it is up to us to make use of Debbie's valuable approach toward building balance.

*(Thanks, Charles)*

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## Novel Treatment May Prevent Diabetic Neuropathy – Continued from page 1

Next, researchers compared the function and appearance of the nerves in mice, which had GM3 depleted by genetic manipulation. In routine diabetic mouse skin, the nerves were found to have virtually disappeared from degeneration, but were still normal in appearance in the GM3-depleted mice, despite the mice being as obese and diabetic as routine diabetic mice. Researchers tested the response to pain through filaments of increasing force that touched the paws of the mice, and then timed how long it took for the mice to withdraw their paw from the pain stimulation. "The routine diabetic mice had nerve changes that intensified their pain sensation, and they experienced a lot of pain with just a light touch," Paller said. "When we rescued them by depleting their GM3, they didn't withdraw their feet (suggesting pain)

any more quickly than the mice without diabetes." From these findings, researchers advanced their approach to regionally depleting GM3 in the feet with the novel ointment, according to the study. "If the studies look promising in mice, our long-term goal would be to further test safety and advance to human clinical trials to prevent and/or reverse the development of diabetic neuropathy," Paller said. See more at: <http://www.specialtypharmacytimes.com/news/novel-treatment-may-prevenovel-treatment-may-prevent-diabetic-neuropathy-nt-diabetic-neuropathy>

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## Experts Give House Panel Differing Views Of Opioid Tx Market – Continued from page 1

process takes time, even for silly petitions.”

There definitely is a problem when it comes to the pricing of both buprenorphine, to treat opioid addiction, and naloxone, to treat opioid overdoses, according to Eric Ketcham, MD, immediate past president of the New Mexico chapter of the American College of Emergency Physicians. “One would think that life-saving and life-transforming medications such as buprenorphine ... would be accessible to hundreds of thousands more opioid-dependent patients; unfortunately, that’s not the case,” he testified.

“For example, based on surveys I’ve conducted with local pharmacies ... the cost for a 30-day supply [of buprenorphine] is \$334, compared with just \$142 just 6 months ago ... and a month of Suboxone combination filmstrips was \$532. Shockingly, the generic version of the combination tablets is even more than the brand-name filmstrips ... and costs \$625 for a 30-day supply.”

The price of naloxone also has been steadily climbing, despite various efforts to increase access to it, Ketcham continued. “In my community, the cost of a 1-ml syringe of 0.4 mg of naloxone went from about \$12 in 2012 to \$30 in 2016 ... The consequence of these rising prices may force naloxone out of the budget for the rural fire or EMS service that doesn’t have the buying power of a hospital or a larger municipal agency.”

This is a balancing act, said Rep. Bob Goodlatte (R-Va.). “Competition in the addiction medicine markets, like the pharmaceutical market as a whole, involves a delicate balance. On the one hand, we want to encourage pharmaceutical companies to invest in expensive research and development ... On the other hand, we also want to encourage sufficient competition to insure an appropriate check on consumer prices.”

Brand-name companies’ efforts to prevent generic competitors are definitely a problem in the market for treatments for opioid abuse, said David Gaugh, RPh, senior vice president for sciences and regulatory affairs at the Generic Pharmaceutical Association. Generic drugmakers “often face significant delay tactics from brand manufacturers,” including use of the Risk Evaluation and Mitigation Strategies (REMS) that are required for certain drugs. Under REMS, companies face tighter restrictions on how the drug can be distributed to doctors and patients.

“While current law forbids brand-name companies from using REMS to delay competition, they are nonetheless denying

generic manufacturers access to samples of their products,” Gaugh said. “These samples are required to conduct the bioequivalence studies necessary for FDA approval of the generic application ... [Some companies have] even begun applying restricted access programs to drugs for which FDA has not required a REMS program, in order to delay generic entry.”

Subcommittee members also heard from Mark Merritt, president and CEO of the Pharmaceutical Care Management Association, a trade group for pharmacy benefit management (PBM) companies. Merritt argued for requiring clinicians to e-prescribe controlled substances, and for having state governments make their prescription drug management program databases “more easily accessible, more user-friendly, and more integrated across the country.”

He also urged Congress to “accelerate FDA approval of drugs with little or no competition, unlock more innovative, value-based pricing arrangements by removing existing barriers such as the Medicaid ‘Best Price’ requirements, and ... eliminate any and all Medicare Part D ‘protected [drug] classes,’ which significantly weakens the power of PBMs to negotiate rebates and lower prices.”

But he was challenged on another issue by subcommittee member Rep. Doug Collins (R-Ga.). “Isn’t it an inherent conflict of interest when a PBM mandates or heavily incentivizes patients to use its own pharmacy or mail-order pharmacy?”

“The FTC [Federal Trade Commission] has looked into this and found there is not a conflict,” Merritt replied. As for using their own mail-order pharmacies, “think about it [as being] like Amazon.com,” he said. “They have Prime, [in which] Amazon is its own deliverer. Would it be better to force them to use Federal Express or UPS or some other higher-cost carrier to deliver their goods? No, I think it would cost more; it wouldn’t add any value for consumers.”

Subcommittee members seemed to agree that competition in this market was a thorny problem. “We have to pay particular attention to this and react, because it’s only going to get worse,” said subcommittee chair Tom Marino (R-Pa.).

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## President’s Message – Continued from page 3

to keep in touch and to start a group there. She plans to remain on the Board. We offer meeting by teleconference for Board members who are not able to attend meetings in person.

Let’s be thankful for our pharmacists and be sure to pass any supplement or new product you want to try for pain, etc. by your pharmacist to see if what it has in it works for you. Some supplements are OK for most people but some can lead to kidney damage for some or add or subtract from the efficiency of other drugs you take especially if they are blood thinners. Be sure every prescription and every supplement or vitamin you take is listed on the chart you get at your doctor’s office.

If you would be interested in learning or meeting people by telephone or computer, you might like to check out Senior Center Without Walls – [www.seniorcenterwithoutwalls.org](http://www.seniorcenterwithoutwalls.org) or call (877) 797-7299 to get a catalog. They have telephone groups and computer groups that learn and discuss all kinds of topics and courses of study. It is free.

Please take care of yourself and stay warm and dry as much as possible as winter shows itself,

*Bev*



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

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