



WESTERN NEUROPATHY ASSOCIATION

March 2016
Issue 3
Volume 14

Professor/Researcher
To Speak On
Neuropathic Pain
Research At Our
Conference

Central Nervous
System May
Contribute To Diabetic
Peripheral Neuropathy

WNA Support Groups

President's Message

Did FDR Actually
Suffer From Peripheral
Neuropathy?

PN Literature Review

WNA 2016 Annual
Conference
Registration Form

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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)

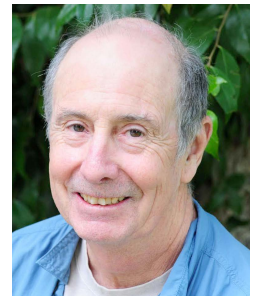
WNA 2016 Annual Conference: Exploring Neuropathy Research Options

9:30am	Registration and Morning Snacks
10:00am	Announcements and Introductions
10:10am	Keynote - Bruce Hammock, Ph.D, Distinguished Professor, Department of Entomology & UCD Comprehensive Cancer Center; Director, NIEHS-UCD Superfund Research Program; Principal Investigator, NIH Biotechnology Training Program, UCD, "Research on Neuropathic and Inflammatory Pain"
11:00am	Break
11:10am	Leonard Chuck, M.D., Medical Director of Diablo Research, Walnut Creek: "How is Research Conducted?"
Noon	LUNCH
1:00pm	Small Group Development of Research Ideas
1:30pm	Compiling a List of What Groups Propose
2:00pm	Vanessa Kettler: "Balance Techniques that Help"
2:45pm	Door Prizes; Closing Announcements
3:00pm	Adjournment

**Wednesday
April 20, 2016**
Registration Form
on page 7

PROFESSOR/RESEARCHER TO SPEAK ON NEUROPATHIC PAIN RESEARCH AT OUR CONFERENCE

A Davis-based startup, EicOsis LLC, has received a \$4 million federal grant to target diabetic nerve pain. This startup, founded by Bruce Hammock, Ph.D., a professor at UC Davis, will use this grant from the Blueprint for Neuroscience Research in the National Institutes of Health to advance an oral analgesic through the first phase of clinical trials. The trials, scheduled to begin in 2017, will target diabetic nerve pain, occurring in an estimated half of the world's 347 million diabetics, and 29 million Americans. We look forward to hearing from Dr. Hammock on this new and promising nonopioid, neuropathic pain relieving medication.



CENTRAL NERVOUS SYSTEM MAY CONTRIBUTE TO DIABETIC PERIPHERAL NEUROPATHY

Central nervous system (CNS) factors might explain the development of diabetic peripheral neuropathy.

One of the key contributors to peripheral nerve disease in patients with diabetes is the central nervous system (CNS), a new report suggests.

Published in the journal *Pain*, the study, conducted by Dr. Solomon Tesfaye of Sheffield (UK) Teaching Hospitals NHS Foundation Trust and colleagues, outlines additional insights that examine the role of the CNS in the development of diabetic peripheral neuropathy.

"Although [diabetic peripheral neuropathy] has been considered a disease of the peripheral nerve, from numerous studies it is becoming apparent that there

are indeed changes within the CNS that ... appear to be concomitant with the evolution of painful and painless [diabetic peripheral neuropathy]," the researchers wrote.



Reviewing evidence resulting from the use of advanced imaging techniques in several studies, Dr. Tesfaye and colleagues determined that CNS factors might explain the development of diabetic peripheral neuropathy.

Key findings from the report include the following:

- Differences in the cross-sectional area (width) of the spinal cord, particularly before symptoms of diabetic peripheral neuropathy have appeared.

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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

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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)
Sandra (925) 443-6655

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

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

Castro Valley

2nd 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

3rd 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

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 Tuesday, 12:30 PM- odd numbered months
Journey Church
450 Blue Ravine Rd.
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
Marvin Arnold (559) 226-9466

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

March 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.
Sandra Grafrath (925) 443-6655

Madera

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

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeister 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

1st 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

4th Tuesday, 1 PM
Sequoia Hospital Health and
Wellness Center
749 Brewster Avenue
Danielle LaFlash (650) 593-6758

Roseville

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

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

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

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital
2105 Forest Avenue
SJ DePaul Conf. Rm.
Danielle LaFlash (650) 593-6758

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
Bev Anderson (877) 622-6298

President's Message

By Bev Anderson



This month I had one of the best demonstrations of the value of support group meetings I've ever experienced.

One of the volunteers who makes calls to people without e-mail mentioned talking to a long time group member who had experienced great illness, but now her husband, her caregiver, was quite ill. Those that knew her were quite concerned. A few minutes later, this lady who had not been able to come to a meeting for months arrived. She was welcomed like an old friend. She explained what was happening which was even more serious than first thought. On her way home, she needed to stop at the police station to report a lost item. One of the members of the group offered to go with her. The group member took the lady in her own car and brought her back to the meeting place to pick up the car she had driven to the meeting. Two members gave her their phone number so that she could call if she needed to talk or get help.

Another example is about a new attendee who had moved into the area not long before. She needed recommendations for doctors and other local resources from long-time residents in addition to knowledge about her neuropathy. She was delighted with the resources mentioned and exchanged phone numbers with a lady who lives a couple of blocks from her.

If people are willing to take time to be with others periodically and discuss their neuropathy and pain, they build friendship skills and grow to truly care about the others. To not return after one or a few meetings robs you of a resource you might wish you had.

Please remember that at every meeting everyone there should at least be able to say their name and ask anything they need to know about their neuropathy. Always give time for people to talk to the others that came even when you have a speaker. This builds on the concept of support groups, helps develop a sense

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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".

WNA Information and Support Groups – continued from page 2

Santa Maria

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

Santa Rosa

1st 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

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
North Coast Opportunities (NCO)
413 N. State St.
Carole Hester (707) 972-2795

Walnut Creek

4th 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

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

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

Start a support group in your area:

Contact Bev Anderson at (877) 622-6298 or info@pnhelp.org

■ DID FDR ACTUALLY SUFFER FROM PERIPHERAL NEUROPATHY?

By LtCol Eugene B. Richardson, USA (Retired) BA, MDiv, EdM, MS

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

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
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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The question remains, did former President Roosevelt have polio or a peripheral neuropathy known as GBS and why should we care?

In August 1921, at the age of 39, while vacationing at Campobello Island in Canada, soon to be President Franklin D. Roosevelt (FDR) contracted an illness characterized by the acute onset of symptoms over a period of days, characterized by fever, protracted symmetric, ascending paralysis of the upper and lower extremities; facial paralysis; bladder and bowel dysfunction; numbness; and dysesthesias (abnormal sensation often painful). Given the clues of sudden acute onset of symptoms and a fever, these symptoms however left an unanswered question. Was it polio or GBS a peripheral neuropathy?

A peer-reviewed study published in 2003, found that six of eight posterior probabilities favored a diagnosis of a peripheral neuropathy known as Guillain-Barré Syndrome (GBS) over poliomyelitis. The diagnostic importance of the spinal tap will be shared later, but first, what is GBS?

Guillain-Barré Syndrome is an acute form of peripheral neuropathy attacking the peripheral nerves in a short period of time. As sometimes happens, but not always in GBS, the President's symptoms gradually resolved except for paralysis of the lower extremities.

First, one might ask, "Why is this important?"

FDR is a bigger than life person and his contributions are beyond measure during a critical period in U.S. history. However, given former President Roosevelt's medical diagnosis in 1921, neuropathy patients are led to ask, are we putting more patients at risk because medicine too often fails to completely diagnose and treat the peripheral neuropathies in this century?

It is common knowledge that there are estimated to be over 20 million neuropathy patients and too many are still not getting the help they need. While we have made significant progress in raising awareness and developing tools for diagnosis and some possible treatments, many of these patients are at risk for the development of severe disabilities if left undiagnosed and untreated. They too often suffer untold nightmares within their own bodies, because of the remaining lack

of awareness, poor attitudes which fail to take the neuropathies seriously, coupled with limited clinical training and resources to adequately diagnose, interpret the tests, and treat the neuropathies. Too many long held assumptions about neuropathy stand in the way of the doctor's ability to let loose critical thinking when working with a neuropathy patient.

This leaves millions of neuropathy patients without a diagnosis, without treatment, and with little hope for a disease that can be anywhere from a painful or non-painful nuisance or a mind numbing challenge to daily living, to a potentially life-altering disease with severe disabilities. Some of the immune mediated neuropathies may even turn deadly.



President Franklin D. Roosevelt presenting Lieutenant Colonel Jimmy Doolittle with the Medal of Honor.

In 1921 knowledge of Guillain Barré Syndrome (GBS), a peripheral neuropathy, was not widely known among medical professionals. GBS was seldom diagnosed or treated let alone the many other forms of chronic neuropathy or the immune mediated neuropathies during these years. (Immune mediated neuropathies involve the malfunction of the body's immune system which attacks the peripheral nerves throughout the human body).

So this brings us to the question, how could FDR have been properly diagnosed?

Today, scientists note that without a spinal tap which may have been diagnostic of GBS for the former President, the question must remain open without a definitive answer, as a spinal tap is now impossible.

The analysis of the cerebral spinal fluid (CSF) via what is called a lumbar puncture or spinal tap is important as a diagnostic tool for it reveals the levels of protein and other helpful information from the analysis of the spinal fluid, which is very important as a component of diagnosis in the immune mediated neuropathies. (Textbook of Peripheral Neuropathy by Peter D. Donahue MD FAAN Editor, DEMOS Medical Press, 2012, Drs. Ulane and Brannagan, chapter 13, page 191 and Drs. Menze and Burns, chapter 12, page 168.)

However, here is the point. If in 1921 the physicians did not do a spinal tap which by many current neurological experts may have been diagnostic of Guillain Barré Syndrome or Chronic Inflammatory

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Demyelinating Polyneuropathy (CIDP) or one of the many immune mediated neuropathies or variants, why do too many practitioners continue to fail to mention or use this diagnostic tool today?

The value of the spinal tap is not mentioned as a diagnostic tool in an article titled, "How to Diagnose Peripheral Neuropathy? No Simple Answers: Experts Offer Some Guiding Principles" by Mark Moran (Neurology Today, 15 March 2012, Vol. 12(6); pp 30, 32-33). Why?

Granted diagnosis of the neuropathies, as the article notes, is often a mind numbing challenge due to all the many causes and types of neuropathy. Yet this question is very important to patients who have peripheral neuropathy and who are far too often unable to get an accurate diagnosis.

Mr. Moran's article includes comments from leading scholars who are committed to finding answers. But why is the spinal tap or analysis of the CSF not mentioned? Throughout current medical literature the value of the spinal tap, more than the diagnostic value of a nerve/muscle biopsy, is diagnostically important when infection or inflammation are present or an immune mediated neuropathy is suspected.

Norman Latov, MD, of Columbia University, in his book for patients, *Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop*, he notes that two of the clues for doing a spinal tap are infection or inflammation. For President Roosevelt these would have been clues to a possible immune mediated neuropathy along with many other symptoms that are not common with a diagnosis of polio.

Today this is even more important, for as we learn more about these neuropathies, we find we know less and often the only clue is the patients' medical history especially when all previous tests for other causes are negative. This is especially true if the neuropathy is a progressive polyneuropathy involving the autonomic nervous system and does not follow known patterns or clinically present in 'expected' ways. It is these expected ways, while helpful on one level to the clinician, stand in the way of the important 'whys' and 'I wonder' of a critical thinker.

Colonel Richardson was asked "Why did they not do a spinal tap?" to help diagnose his situation. This did not happen until after he was put on a trial of IVIg and responded to this treatment in 2004. But a spinal tap was not even considered until after he was administered IVIg and not until he had developed severe disabilities following 34 years without diagnosis and treatment. Treatment with a trial of IVIg was suggested by a group of neurologists which included Dr. Brannagan in which was stated that a trial of IVIg should be

considered under certain criteria.

Dr. Walter Bradley DM, FCRP, Professor of Neurology, Chairman Emeritus of the Department of Neurology, University of Miami, commented with great kindness and support to the Colonel upon mentioning this helpful article to which Dr. Bradley had contributed, that unfortunately, "The article was considered only medical opinion at the time."

Medical opinion had failed the Colonel for decades, so why is it not valid in something that worked? One of the reasons is that the Colonel's symptoms did not follow the 'standard' expected patterns of his immune mediated neuropathy. Yet this is exactly why the spinal tap should have been performed.

While we have made some progress, too many physicians continue to run the standard tests for the neuropathies; stating that all tests are normal and either dismisses the patient or provides a rather unhelpful diagnosis of "idiopathic" neuropathy or of unknown cause.

We wonder how many men, women, and even children; we will help from the debilitating effects of this too often under-diagnosed and under-treated condition by having a united physician and patient effort. We wonder how many lives will be saved from going 'south' from the scourge of this horrible condition which affects the lives of over 20 million at a great cost to society. Together we have the answers in our hands while physicians and patients can make FDR proud by providing increased hope through better tools for diagnosis and options for treatment for those who suffer with any peripheral neuropathy.

Final observation: In the strange world of medicine and discovery, the possible misdiagnosis of FDR, who in founding on January 3, 1938 of the March of Dimes, resulted in discoveries that stop the plague of polio and its deadly effect on so many children. What better legacy could there be than this, for a great American, even with a possible misdiagnosis.



About the Author

Colonel Richardson has suffered from 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.

Reference:

<https://neuropathyjournal.org/fdr-peripheral-neuropathy/>

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

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.

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

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:

- 24261316 This is a small, uncontrolled, Scandinavian study that demonstrated synergistic improvement in 3 of 6 patients on a maximum tolerable dose of gabapentin (Neurontin®) to which was added donepezil (Aricept®) 5 mg daily. The pain scale reduction was increased by the combination ($p < 0.001$).
- 24297951 This study of 353 colon cancer patients does not support using calcium/ magnesium to protect against oxaliplatin-induced neurotoxicity.
- 24350851 Neuritin (candidate plasticity gene 15) functions to protect, promote the growth, maturation and regeneration of spinal axons and peripheral nerves. This article suggests neuritin as a potential therapeutic target in peripheral neuropathy.
- 24524594 This article suggests tapentadol (Nucynta®) as a unique opiate for the supplementary treatment of painful diabetic neuropathy as the drug blocks both the mu opioid receptor and the reuptake of norepinephrine (as do many of the antidepressants used to control neuropathic pain).

Central Nervous System May Contribute To Diabetic Peripheral Neuropathy – Continued from page 1

- Loss of volume (atrophy) in the primary sensory cortex – the main brain area involved in sense of touch.
- Differences in blood supply in a part of the brain called the thalamus – oversupply (hyperperfusion) in painful diabetic peripheral neuropathy, compared with undersupply (hypoperfusion) in painless diabetic peripheral neuropathy.
- Changes in higher brain areas, specifically the "pain processing matrix" – thought to be involved not only in detecting the location and intensity of pain but also the emotional responses.
- Reductions in the brain gray matter, particularly in areas where "somatosensory perceptions" are processed.

"Imaging may help us to unravel one of the fundamental unanswered

questions – where can the primary pathophysiology of the painful symptomatology of [diabetic peripheral neuropathy] be found?" the researchers wrote. "They hope that further detailed MRI studies "may lead to development of more rational therapies to help reduce the burden of [diabetic peripheral neuropathy]."

Reference

1. Tesfaye S, Selvarajah D, Gandhi R, et al. Diabetic peripheral neuropathy may not be as its name suggests: evidence from magnetic resonance imaging. *Pain*. 2016;157:S72-S80. doi:10.1097/j.pain.0000000000000465.

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President's Message – Continued from page 3

of community, and eliminates feelings of isolation. So, don't miss a meeting—it's good for you and others. If your group is too large to have everyone introduce themselves and share their stories, break into small groups for a time. A group of three to five can greet each other and check in with an answer to a question or share a helpful remedy. Often asked questions are about pain, or something you discovered that helps your neuropathy, or just sharing what career work you're doing or did do before retirement. Anything that couldn't be addressed in the small group can be brought to the attention of the whole group for answers and/or support.

The first article in this newsletter on the central nervous system is fascinating and a major breakthrough. This discovery could open the door for more research on the nature of neuropathy, which needs to be more certain than it is now before a cure or cures can likely be found. Since most attention and funding for neurological research is targeted to the central nervous system diseases, to have the peripheral nervous system tied into the central nervous system may motivate doctors to look at it more closely. Remember

that what is found for diabetic peripheral neuropathy may well be true of other neuropathies as well.

Gene Richardson's article on Franklin Delanor Roosevelt is a historical piece of some note. When you read it, you can see that his symptoms were more like Guillian Barre Syndrome than polio, but polio was more familiar to those treating him.

If you plan to come to our annual conference, please register on-line or send in the form in this newsletter with your check. We now have additional t-shirts and summer is coming. You might like to order one or more and be well-dressed for the conference. They will be on sale there, too.

Please encourage your group leader by attending support group meetings. If you don't have a group, please consider volunteering to lead one – two or three or more working together works well and helps spread the work around. The Grants Pass, Oregon's leadership team has seven individuals collaborating and sharing responsibilities.

Happy Spring,

Ben

Date: Wednesday, April 20, 2016

Time: 9:30am to 3:00pm

Preregister by April 14, 2016

Registration Fee: \$25.00

Jelly Belly Factory Conference Center
1 Jelly Belly Lane
Fairfield, CA

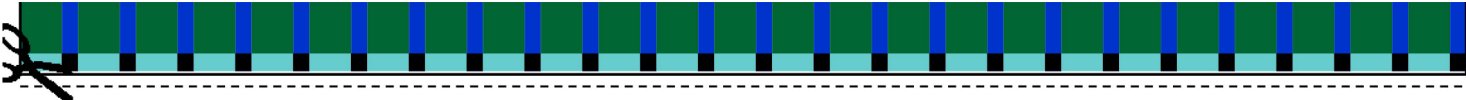
Questions:
Toll Free: (888) 556-3356
Email: admin@WNAinfo.org



2016 Annual Conference Exploring Neuropathy Research Options



AGENDA
See page 1 of this newsletter



Mail registration fee and form to:

WNA Conference

P.O. Box 276567
Sacramento, CA 95827-6567

Name _____

Address _____

City / State / Zip _____

E-mail _____

Support Group _____ At Large Member

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

I am enclosing my check for the \$25 registration fee.

I am interested in taking a tour of the Jelly Belly Factory after the Conference.

WNA SHIRTS NOW AVAILABLE

We have polo and t-shirts available for purchase. Polo shirts are stone color and t-shirts are either white or black. Sizes are men adult sizes small, medium, large, extra-large, additional price for 2x-5xs. (\$2 extra per shirt). Shipping is \$2 per shirt. Price includes tax. Allow approximately 3 weeks order time. To order: fill out the form below and return with your check:

Name _____

Phone (_____) _____

Address _____

Email: _____

Polo shirt (stone) \$28.00 ea. Qty: _____ Size: _____ \$ _____
add \$2. per shirt for 2x, 3x, 4x, or 5x \$ _____

Nerve T-shirt (white) \$18.00 ea. Qty: _____ Size: _____ \$ _____
add \$2. per shirt for 2x, 3x, 4x, or 5x \$ _____

Nerve T-shirt (black) \$18.00 ea. Qty: _____ Size: _____ \$ _____
add \$2. per shirt for 2x, 3x, 4x, or 5x \$ _____

Shipping: \$2 per shirt # of Shirts ordered: _____ X \$2. \$ _____

Order total: \$ _____

Mail your check to WNA, P.O. Box 276567, Sacramento, CA 95827-6567



Shirt color may be slightly different.



(Note: T-shirt sizes 4x and 5x limited to supply on hand. No more will be ordered.)



WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit,
tax exempt corporation

P.O. Box 276567, Sacramento, CA 95827-6567

Call WNA using our toll free phone numbers:

(877) 622-6298 ■ Email: info@WNAinfo.org

■ PN Information/Advice ■ Support Group Inquiries

(888) 556-3356 ■ Email: admin@WNAinfo.org

■ Membership Information/Inquiries ■ Sponsorships

■ General Organizational Inquiries ■ www.WNAinfo.org

PLAN ON ATTENDING!

THE 2016 ANNUAL CONFERENCE

Wednesday, April 20, 2016

Jelly Belly Factory Conference Center in Fairfield, CA

• See page 7 for Registration Form •



WNA board members attended the **California Coalition for Chronic Care Stars of Advocacy** awards program to help honor Dominick Spatafora of the Neuropathy Action Foundation (left to right: Bev Anderson, Dominick Spatafora, Pamela Hart, Brad Livingood, not pictured Karen Polastri)



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[@Neuropathy_WNA](https://twitter.com/Neuropathy_WNA)



Western Neuropathy Association (WNA)

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tax-exempt corporation.

Bev Anderson, Editor

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WNA Headquarters: admin@WNAinfo.org

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

Dues - \$30 a year

All contributions and dues are tax-deductible.

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

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