



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)

■ UNDERSTANDING NEUROPATHIC PAIN IS KEY TO MANAGING IT

By Sudhir Diwan, MD, MS

The International Association for the Study of Pain (IASP) defines neuropathic pain as “pain initiated or caused by a primary lesion or dysfunction in the nervous system.” Depending on the location of the lesion or dysfunction within the nervous system, neuropathic pain can be classified as peripheral or central in origin.

Neuropathic pain results from many diverse etiologies, including infections, inflammation, trauma, metabolic abnormalities, chemotherapy, surgery, radiation, neurotoxins, nerve compression, and tumor infiltration. The presentation of neuropathic pain varies from patient to patient. “Allodynia” is pain resulting from a normally non-painful stimulus (e.g., pain resulting from the touch of clothing or bedding). An exaggerated pain response to a painful stimulus (e.g., a pinprick) is termed “hyperalgesia.” Patients may also complain of “hypoesthesia” or diminished sensations, “paresthesia” or an abnormal sensation (e.g., crawling insects, walking on broken glass or fire), constant burning, sharp, shooting or lancinating electrical currents. It can be symmetrical affecting the area of distribution of the nerves, or it can be asymmetrical and diffused. It may or may not be associated with neurological symptoms such as numbness and weakness.

Currently, there is no single “gold standard” objective test that confirms the presence or absence of neuropathic pain. Diagnostic studies, including imaging and nerve conduction studies, do not correlate well to the severity of pain. Hence, a carefully elicited

description of neuropathic pain symptoms from the patient and a detailed clinical assessment is critical to making a diagnosis, understanding the underlying mechanism, and determining the most appropriate and effective approach for managing neuropathic pain.

In general, management of neuropathic pain requires an interdisciplinary approach, centered around pharmacological treatment. This will help patients control the pain symptoms and minimize and/or prevent the vicious cycle of comorbid conditions (such as sleep disturbances, physical inactivity, depression, and anxiety) that can result from failure to appropriately and aggressively manage chronic neuropathic pain early in the disease process. The following therapeutic strategies for chronic pain can help enhance the quality of life and the ability to function for people living with neuropathic pain:

- Pharmacological therapies—e.g., nonsteroidal anti-inflammatory drugs (NSAIDs), analgesics, tricyclic antidepressants, selective serotonin and norepinephrine reuptake inhibitors (SSNRI), anticonvulsants, opioids.
- Topical therapies—e.g., lidocaine patch, capsaicin patch.
- Interventional therapies—e.g., nerve blocks, trigger point injections.
- Advanced pain therapies—e.g., neurolytic procedures (e.g., destruction of the offending nerve), neuroaugmentation techniques (e.g., spinal cord stimulators), intrathecal drug delivery systems.

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■ CREAM BY COMPOUNDING PHARMACISTS PUT ON HOLD

The cream formula that Dr. Hammock mentioned at the WNA conference in April and was being developed for doctors to prescribe by Sierra Compounding Pharmacy has been put on hold. One ingredient is used in many products but is not currently approved by FDA for this kind of use. It is commonly found in soaps we all use so it is definitely used topically and is considered safe. It just doesn't appear on the FDA list for topicals.

It may be approved in time, but for now it won't go forward as compounding pharmacists don't compound anything that is not FDA approved. That is for your safety and for theirs. This is another challenge for researchers. If they find that a certain compounded substance works wonders, they have to get approval for all of the components of the compound individually as well as for the compound.

Roster of Our WNA Information and Support Groups

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

Bev Anderson
Editor

Newsletter Design by

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Designs

CALIFORNIA

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

Antioch-Brentwood

3rd Wednesday, 2 PM-odd numbered months
Next meeting Sept. 21
Antioch-Kaiser
AMC-1H2 (from hospital lobby)
Sandra (925) 443-6655

Auburn

1st Monday, 11 AM
Next meeting, Oct. 3
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)
Joy Rotz (510) 842-8440

Clearlake

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

Concord

3rd Thursday, 1:30 PM
Next meeting, Sept 15
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
Next meeting Sept. 13
Davis Senior Center
646 A Street
Mary Sprifke (530) 756-5102

Elk Grove

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

Eureka

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

Folsom

1st Thursday, 12:30 PM
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

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
Next meeting, Sept. 12
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 Knocti 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
Next meeting, Sept. 8
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
Next meeting, Sept. 19
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 (415) 297-1815

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
Next meeting, Aug. 16
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 (415) 297-1815

San Rafael

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

Santa Barbara

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

President's Message

By Bev Anderson



This newsletter is called NEUROPATHY HOPE. Many times I hear people bemoaning the fact that they don't see any hope. Both hope and lack of progress is all around us but there is a great deal of hope that there will be change for the better.

- In April at our Annual Conference, we heard from two researchers. Dr. Bruce Hammock, UC Davis, has a treatment in the queue to go through human testing hopefully in 2017 that has already proved its effectiveness in human trials in India.

Dr. Leonard Chuck, Diablo Research, Walnut Creek, is in continuous testing of medications for peripheral neuropathy from various pharmaceutical companies. He has an ongoing need for people to participate. They usually only need people with neuropathy who are diabetic.

- At the Neuropathy Action Foundation Conference in Los Angeles on June 23, there was information on the use of older medications that is being updated and combined with other medications to be effective. John A. Senneff's first book ***Numb Toes and Aching Soles*** is still one of the best references for medications available. Some of the newest medications may not be listed. On page 6 in this newsletter, I'm providing medication information from this book. It is out of print but you can still buy it on Amazon. They sell books from secondhand bookstores and some of them list copies available. Currently the cost is one cent to \$3.85. This is a great bargain for a wonderful resource.

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WNA Information and Support Groups – continued from page 2

Santa Cruz

3rd 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

1st Thursday, 10:30 AM
Next meeting, Sept. 1
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
Next meeting, Sept. 27
North Coast Opportunities (NCO)
413 N. State St.
Carole Hester (707) 972-2795

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse
Vista Room
Karen Hewitt (925) 932-2248

West Sacramento

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

Woodland

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

Yreka

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

Yuba City-Marysville

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

NEVADA

Reno-Sparks

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

OREGON

Brookings

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

Grants Pass

3rd Wednesday, 2:00 PM
No meeting in August
Club Northwest
2160 N.W. Vine St.
Carol Smith (541) 955-4995
www.grantspass.neuropathysupportgroup.org

Medford

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

Portland

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

Salem

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

Help With Health Care Challenges

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

Medicare

www.Medicare.gov

...

The Affordable Health Care Act

For current information go to
www.HealthCare.gov

...

HICAP

Health Insurance Counseling

for seniors and people with disabilities.
www.cahealthadvocates.org/HICAP/
Call (800) 434-0222 to ask a question or to make an appointment.

...

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.
Tollfree (888) 354-4474
or TDD (916) 551-2180.
In Sacramento, (916) 551-2100.
www.hrh.org.

...

HMO Help Center

Assistance
24 hours a day, seven days a week.
(888) HMO-2219
or (877) 688-9891 TDD

...

DRA's Health

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

Start a support group in your area:

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

DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA 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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NON-LENGTH-DEPENDENT SMALL-FIBER SENSORY NEUROPATHY (NLD-SFSN)*

By William B. Donovan, MD

This study was done at the Cleveland Clinic comparing length-dependent and non-length dependent sensory neuropathy patients. We are most familiar with neuropathy that is worse the farther peripherally (distally) it goes—it affects the toes and fingers, then works its way up the extremities.

When the presentation is not so classical, and is in a patchy, diffused distribution affecting the face, trunk, or proximal extremities, we fail to recognize the problem as neuropathy, and are likely to think it may be psychogenic.

NLD-SFSN, with its absence of the more common distal to proximal gradient, is found more frequently in women, occurs at a younger age, and is more often associated with

autoimmune disorders. As would be expected, skin biopsies show decreased intraepidermal fiber density proximally.

The diagnosis of peripheral neuropathy is not simple as we come to realize—it is many diseases!

*Khan S, Zhou L Muscle Nerve. 2012 Jan; 45(1): 86-91 PMID: 22190313

Note: Sometimes a person has symptoms of neuropathy but the electrical tests of the neurologist don't find neuropathy. It is because it is small fiber neuropathy that can be found with the skin punch test. The electric tests are chiefly effective on myelin covered nerves. Small fibers do not have a myelin coating.

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**

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:

- 25118789 This study tested a portable thermal-metered-dose marijuana inhaler (MDI) on a cohort of 8 patients with chronic neuropathic pain. A 45% reduction in pain intensity was noted 20 minutes post inhalation, returning to baseline in 90 minutes. The only adverse event was

tolerable lightheadedness.

- 25345609 This paper reviews experimental data that reveals that neuropathic pain not only results from injury to the nerves, but from the reaction of the immune system to the cytokines and chemokines released by the injured nerves. Neuropathy is an inflammatory autoimmune condition. Solutions addressing this system can hopefully reduce chronic neuropathic pain.
- 25234478 In a review of 16 randomized controlled trials the authors found evidence for the effectiveness of vasodilators, NMDA analogs and bisphosphonates (increase calcium) in the early treatment of complex regional pain syndrome.
- 25392197 It is well known that high blood sugar levels, even in those not diagnosed with diabetes, are associated with peripheral neuropathy. This study demonstrates a strong correlation (R=0.84) between the magnitude of decrease in blood sugar (HbA1c) and neuropathic pain; so, those diabetics who are rapidly controlled, can paradoxically experience the onset of peripheral neuropathy.
- 25438482 This Indian randomized placebo-controlled study of NitroSense Derm Protect patch for painful diabetic neuropathy demonstrated a significant (p<0.05) decrease in the Pain Lickert Scale, and significant (p<0.09) decrease in vibration perception threshold. The patch, however, appears to be only available in India

NEW PROFESSION - PATIENT ADVOCATES

An article by Leslie Levine encourages patients to look for a patient advocate. This is a professional that may become more well-known as time goes by as it is a growing career. Currently they are difficult to find as ones with the experience and skills needed are scarce. They charge a fee but it can be worth the cost even if it's only for the confidence you will have about getting the best care.

One website, AdvoConnection.com, provides a searchable directory of advocates who offer a variety of kinds of help to patients and caregivers, such as medical, hospital bedside assistance, insurance denials or claims, billing reviews and more. Search for an advocate by the location of the patient and the service you need. There is not a charge to use the site.

Another website offers a list of advocates who belong to an organization called NAHAC, the National Association of Health Advocacy Consultants. Use of this site is also free.

If you cannot find the name and contact information of an advocate on either list, do a web search using "patient advocate" and your location.

When you interview a potential candidate to work with you ask:

- Have you handled other cases similar to mine before?
- What are your credentials? Do you have the background or training in the services I need?

You'll want to determine what advocacy services you need the advocate to help you with. Some advocates specialize in helping you understand your diagnosis or treatment recommendations, while others can help you get permission from your

insurer for special tests or treatments, or even get your hospital billing straightened out. You'll want to find an advocate who has experience performing those services you need.

You should be aware that there is no nationally recognized credential for patient advocates. There are a handful of certificate programs advocates may take, but even those graduates are not "certified" in the classic, nationally recognized sense. If you find a patient advocate who claims he/she is certified, ask about their certification. If he/she claims it is a national certification, then think twice about hiring him/her.

- What do you charge for your services?

Charges for services will vary according to the types of services needed, the location of the patient (pricing varies across the country, just like it does for anything else) and how much time the advocate will spend doing the work that needs to be done.

Advocates may charge for doing health assessments, time spent on research, review of bills, handling insurance claims or even getting tests or treatments approved (overcoming denials) and more.

- How long will it take to perform the services I need?
- Do you have time to handle the work I need to have done?
- Do you have references?

If you or someone you know thinks this sounds like a career path they would like to explore. Google 'Patient Advocate' and check out information on the websites mentioned above. Look for training for Patient Advocates.

DISCOUNTS FOR WNA MEMBERS

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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.

CANCER-RELATED NEUROPATHY MAY RESPOND TO GENE THERAPY

by Megan Garlapow, PhD, ONCOLOGY NURSE ADVISOR, May 19, 2016

Recent research using rats indicates that gene therapy might treat the neuropathic pain that affects 90% of patients with cancer. This pain arises from nerve damage caused by tumors, surgery, chemotherapy, and/or radiation.¹

In this study, researchers transferred the KCC2 gene into the spinal canal of rats, restoring the chloride levels that had become abnormal after nerve injury. In addition to holding promise for treating neuropathic pain from the development and treatment of cancer, this gene therapy holds potential for addressing pain from diabetic neuropathy and spinal cord injury as well. Neuropathic pain is associated with lowered activity levels of KCC2.

"We found that delivery of KCC2 produced a complete and long-lasting reversal of nerve injury-

induced pain hypersensitivity by restoring chloride homeostasis," said Hui-Lin Pan, MD, PhD, professor of anesthesiology and perioperative medicine, University of Texas MD Anderson Cancer Center, Houston, and study leader.

"This information significantly advances our understanding of these processes and provides a promising gene therapy strategy for treating unmanageable neuropathic pain."

Proper chloride levels are essential for the function of nerve cells. Nerve damage, such as that accrued during surgery or as a toxic side effect of chemotherapy, disrupts the balance of chloride levels, causing inhibitory neurotransmitters GABA and glycine to be less effective. When GABA

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HOW DO WE HELP NEUROLOGISTS KNOW ABOUT NEUROPATHY?

Your WNA Board of Directors has discussed ways to help neurologists know more about neuropathy. We are choosing to give a copy of Dr. Gerard Said's new book *Peripheral Neuropathy & Neuropathic Pain, Into the Light* to every doctor in a program training to be a neurologist that we can raise the funds to provide. Some doctors choose a specialty for which they need to be in training and instruction for several additional years. Some do this immediately out of medical school and some after they have been in a general practice for a year or more.

We think that getting a book that is not huge but covers a wide range of current information about neuropathy would give them a taste of what neuropathy is about – that diabetes is not the only cause as there are over 150 other causes for example. Dr.

Said practices in Paris, France, and is considered one of if not the world authority on neuropathy. It means we are not featuring any U.S. based clinician that others would feel in competition or comparison with. It is tightly written so not lengthy. We would hope that at least some schools would incorporate it into at least their reading list so credit for reading it would encourage the residents to read it.

We are working with the publisher in England to get a bulk rate for the book. We will be able to pay for shipping, handling, and paperwork for less than the price for one copy from the publisher or from Amazon or other book dealers. We are estimating \$30 a book delivered. If it costs less, we can place more books. We will be contacting a variety of companies asking for funding help. We will also open the opportunity for individuals and groups to sponsor a book or books. We'll keep you posted.

NUMB TOES AND ACHING SOLES, Coping with Peripheral Neuropathy (c. 1999)

p. 24ff "Here then are the non-opioid drugs most commonly being used to deal with pain:"

1. for burning pain

- (a) All of the so-called tricyclic antidepressants including Elavil (amitriptyline) (this one particularly where sleep disorders are a problem); Norpramin (desipramine); Pamelor (nortriptyline), and Tofranil (imipramine)
- (b) Mexilit (mexiletine hydrochloride)
- (c) Neurontin (gabapentin)
- (d) Ultram (tramadol)

2. for shooting, stabbing, "electric shock" pains

- (a) Dilantin (phenytoin)
- (b) Klonopin (clonazepam)
- (c) Neurontin (gabapentin)
- (d) Tegretol (carbamazepine)

3. for arching, persistent pains

- (a) Catapres (clonidine)
- (b) Klonopin (clonazepam)
- (c) Lioresal (baclofen) (particularly when accompanied by spasms and cramping)

(d) Neurontin (gabapentin)

None of these drugs is likely to eliminate our neuropathic pains totally nor restore us to our Pre-peripheral neuropathy condition completely. What we should be seeing with our doctors is the single medication or combination which will give us the most relief and fewer adverse side effects.

This book describes each of these drugs and more. It gives testimonies of people as to their experience with the drug as well as their recommendations. You get a wide view of medications.

All medications are to be discussed with your doctor that prescribes medications for you. Be sure to evaluate any new medication as to whether it gives relief and does not have adverse side effects. All drugs have side effects of some kind. Each person must evaluate whether the benefit outweighs the side effects.

SHORT NOTES

A study has found that certain yoga poses may boost the risk of developing glaucoma. Down facing poses like Downward Facing Dog, Legs Up the Wall, and the Plow raise eye pressure dramatically and make developing glaucoma more possible. If you take yoga, ask your instructor not to ask you to do downward facing poses or ones that put your legs over your head. Gentle yoga probably is not a problem but do check with your doctor before starting a yoga class.

Be careful with measuring liquid meds. Use a syringe, dropper, or cup for measuring small amounts of liquid. Using a teaspoon may give you a dosage that is not correct.

Keys to a safer stay at a hospital include insisting on people washing their hands before they deal with you. Hand sanitizer is not enough. Have a friend or family member with you regularly especially weekends, holidays and shift changes as possible. Keep a record of doctors' visits and questions you

have for when they come. You can take a photo of pills that don't seem normal. Explain that it is for your memory for later so you will be able to describe what you want to remember. It is a good idea to get acquainted or have a friend or family member that gets acquainted with key personnel, like the head nurse, engages others in conversation, and lets them know you are a real person with some family photos.

On June 9, 2016, California became the fifth state in the nation to allow physicians to prescribe terminally ill patients medication to end their lives. California's new "End of Life Act" permits terminally ill adult patients with the capability to make medical decisions to be prescribed an aid-in-dying medication if certain conditions are met. (California Medical Association) Oregon has had this law for 19 years. It has been found that not all that go through the process to obtain the medication choose to use it. Sometimes being able to get it is enough relief.

Understanding Neuropathic Pain Is Key To Managing It – Continued from page 1

- Rehabilitative therapies—e.g., physical therapy, occupational therapy.
- Psychological therapy.
- Complementary and alternative therapies—e.g. exercise, dietary supplements, biofeedback, acupuncture.

Neuropathic pain management is a balance between the benefits of therapy (and often the use of a combination of therapies) and the side effects/complications, the goal being reduction of pain and suffering and improvement of functional status and psychological wellbeing.

Optimizing neuropathic pain relief requires that the patient and the health care provider(s) partner together to develop an individualized

treatment plan and keep an open—and ongoing—line of communication. Education is important for patients and their families to understand the complex and heterogeneous nature of neuropathic pain and ensure successful and realistic treatment outcomes. (Used by permission)



Sudhir Diwan, MD, MS is executive director of the Spine and Pain Institute of New York. Dr. Diwan was formerly the medical director of Weill Cornell's Division of Pain Medicine in the Dept. of Anesthesiology. His main interests include advanced interventional techniques, including minimally invasive spinal.

President's Message – Continued from page 3

• A man in a support group I led recently said he had found 5% lidocaine cream you can buy over the counter. He hadn't tried it yet but thought it might well be helpful. If you find a cream that helps you, please let us know. Personally, I've found that *Neuragen* helps and also *Sore No More*.

• Help from each other's discoveries gives hope. Share and listen at support group meetings.

Hopeless. There is a type of hope that is hopeless. That 'hopeless' is believing the ads in the papers that treatments will cure your neuropathy or make the pain go away permanently. There have been promises made with various types of equipment, with certain types of injections, and lasers of less than powerful abilities. Now, there are stem cell injections that are supposed to cure your neuropathy, even though stem cells are still in the experimental stage of treatment development. Can you really believe that chiropractors have the expertise and the access to quality, specifically formulated stem cells that will cure whatever ails you if they just inject them into you? Why is it that medical researchers have yet to report this? (Please notice the article in this issue relating to such research.) I'm getting spam e-mail currently telling me that they can stop neurological pain fast and permanently via "this unusual herbal formula." The amount of

money vacuumed from the wallets of people desperate for help by scam artists across the country is monstrous. Sometimes initial treatments by some of these 'cures' seem to give relief but when the treatments stop, the relief soon does too.

Thanks to Danielle LaFlash, leader of the Redwood City and San Jose Support Groups, for hosting a viewing party to watch the livestreaming from the L.A. Conference on June 23.

Thanks, too, to all of you who have sent your dues and donations. Every help we get, we appreciate. We received our check from The Big Day of Giving and we did receive some matching funds thanks to you who figured out a way to connect with the official website.

Hurrah, for Mito in Lakeport. She has gotten the group there restarted and growing. In addition, she recently had a baby boy that is keeping her busy. She also is a Bowen Therapist. They were featured in the local paper so expect a good attendance at their next meeting. They had 29 at their last one.

Have a wonderful August,

Bess

Cancer-Related Neuropathy May Respond To Gene Therapy – Continued from page 5

and glycine are less effective, the activity of excitatory nerve receptors, called NMDA receptors, increases.

Related Articles

- Research Identifies Underlying Mechanism of Chemotherapy-Induced Peripheral Neuropathy
- Peripheral Neuropathy Severity Linked With Lower Vitamin D Levels

"Diminished synaptic inhibition by GABA and glycine and increased NMDA receptor activity are two key mechanisms

underlying neuropathic pain," said Pan.

"However the reciprocal relationship between the two is unclear. By using KCC2 gene transfer, we were able to restore chloride balance, which also unexpectedly normalized NMDA receptor activity increased by nerve injury." (Open to general use.)

Note: You will notice that this experimentation was on rats, but gives indication that this may be possible in humans. The specific gene involved is designated as is the specific treatment for a specific purpose.



WESTERN NEUROPATHY ASSOCIATION

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2016 CHANGES

American Diabetes Association (ADA) announces 2016 changes:

- Diabetic is replaced with diabetes mellitus
- Cardiovascular disease (CVD) is now atherosclerotic cardiovascular disease (ASCVD)
- Nephropathy is now diabetic kidney disease
- Test all adults starting at age 45 years old no matter the weight
- Anyone of any age who is obese or overweight with one other factor are tested
- All tests for diabetes mellitus are acceptable
- Apps and test messaging are to be deployed to help people make lifestyle choices
- Patients over 65 are to have continuous glucose monitoring and insulin pumps as necessary
- Aspirin therapy should be considered for women starting at 50 years old



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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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