



WESTERN NEUROPATHY ASSOCIATION

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Issue 11
Volume 13

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WESTERN
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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ INFORMATION ABOUT GABAPENTIN/NEURONTIN

If you are taking Gabapentin, do not stop taking it without working with your doctor to stop gradually. According to Sonya Wells, Pharmacist, Gabapentin alters the seizure threshold. If you discontinue therapy too quickly, there is a real chance of having a seizure.

The reason you are given Gabapentin is that there is a theory that the problem with nerves in

neuropathy is that the nerves are having small seizures so it changes the threshold to stop this. We got this information from Sonya in answer to a member who wrote in asking about his wife's experience in stopping her 400 mg dosage. She was having what probably amounted to small seizures. They didn't continue, but were rather disconcerting when they occurred.

■ A VERY SPECIAL ARTICLE FROM PN NEWS

Mary Sprifke is the leader of our Davis Neuropathy Support Group. She also writes a great newsletter covering the news from Yolo County (Davis & Woodland) and Sacramento Neuropathy Support Group and a variety of articles. The newsletter is added to our website each month and is there for you to read and enjoy. This article is from last April. I thought it gives all of us a view of Gene Richardson that many of us may not have. We

have seen him on his DVD but may not know much about him. He has his DVD available to order. However, we have copies so if you want one and don't have one you can call Amy at the office (888-556-3356) and she will send you one or you can order one from Gene himself. They are free but he asks for a contribution toward research. We don't mind receiving a contribution either.

■ GETTING TO KNOW GENE RICHARDSON By Mary Sprifke

After a brief time of sharing, we viewed a DVD featuring Col. Eugene Richardson entitled *Coping With Chronic Neuropathy*. This is a personal story, from a real-world patient. He began by recommending a book called, "Vasculitis: Sick and Tired of Being Sick and Tired" by Sheri Schwar. For him, 'this book says it all.' (This title is available from Amazon.com for 19.95 or on Kindle for \$3.99.) Col. Richardson is a retired military man, whose physical problems began in Vietnam with Agent Orange.

Some notes taken while watching Col. Richardson's DVD:

Peripheral Neuropathy can affect different body systems and thus is a mystery that needs to be unraveled by competent physicians. In his case, this took 39 years. But he persevered. Finally one day a doctor (not even a G.P. or Neurologist, but rather a Urologist) diagnosed PN and prescribed IVIG treatments. This was followed by a miracle day when he was able to stand again, free of his wheel chair. He calls PN a grim disability (his case was severe, involving the autonomic system) and

he sought peace and serenity, adapting to new limits presented by his illness. He laughed a lot and told us learning to enjoy simple acts is the secret to living with chronic disease.

So, he turned his quest into a "serendipitous journey of discovery." When faced with anger, he harnessed its power to help him search for answers. When emotionally drained, he turned to help from The Neuropathy Association (TNA) and found a caring listener. He learned to listen to his body and treat it kindly. And most importantly, he found a doctor who could really LISTEN. His family, too, was very supportive. His personal toolkit contains large doses of humor, knowledge, support and prayer. All these helped him find his "secret place of peace."

First Steps: Any loss is a form of death and anger is a necessary component of our reaction. "Why me?" we ask. Self-pity is normal but is hopefully short-lived. For him, prayer for God's guidance became a focus. Self-doubt and misdiagnosis over time grind away at our reliance. Let your anger

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Roster of Our WNA Information and Support Groups

2015 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)
Bev Anderson 877-622-6298

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
Salli Hearn (530) 268-1017

Jackson

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

Lakeport

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 Hoffmeiser Center across the
street from the church)
Larry Frice (209) 358-2045

Modesto

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

Monterey

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

Napa

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

Oxnard

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

Placerville

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

Quincy

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.
Stan Pashote (510) 490-4456

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
Mary Ann Leer (831) 477-1239
maleer@comcast.net

President's Message

By Bev Anderson



I want to start this message with something I put on the introduction to the e-mail edition of the newsletter last month. People getting the e-mail edition get a few bonus paragraphs on a variety of topics.

If you are employed by or are retired from a company that matches charitable contributions from employees, please remember that when you make a contribution to WNA to send in the request for the matching amount. If you need our nonprofit corporation number it is 68-0476041. Use the address information on the back page of this newsletter for other information requested on the form.

There is exciting news in this issue. Dr. Gerald Said, considered one of the world's leading experts in neuropathy with office in Paris, France, has a new book that is just out and in English and likely other languages than French as well. He and I have corresponded by e-mail for some years now after I asked permission to use an article he wrote in NEUROPATHY HOPE. When I was contacted by an attorney in Turkey wanting a neurologist he could go to that knew about neuropathy, I consulted with Dr. Said. He said he would see him in Paris, but also suggested a neurologist in Dusseldorf, Germany. The attorney chose to go there as his law firm actually had an office in Dusseldorf. I've been in contact with a question once in a while and know him to be a good person as well as a great neurologist. He served as President of the European Neurology Society at the time I asked for the article. This book may be more medically oriented than you may be comfortable reading, but if you want to get it and give it a try like I am, by all means do so. If you are financially able to do so, buy one for your doctor

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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) 622-6298

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

2nd Tuesday, 1:00 PM
Woodland Comm & Senior Center
2001 East Street
Elizabeth Chaudhry (530) 661-3859

Yreka

For information call
Bev Anderson (877) 622-6298

Yuba City-Marysville

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, 10:30 AM
Three Rivers Medical Center
500 S.W. Ramsey Ave.
Carol Smith (541) 955-4995

Medford

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

Portland

For information call
Bev Anderson (877) 622-6298

Salem

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

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".

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.

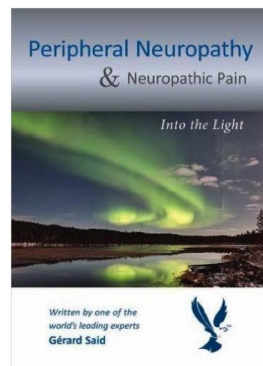
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EXCITING NEW BOOK BY EXPERT NEUROLOGIST

Written by one of the world's leading experts – Professor Gérard Said MD FRCP, Dpt de Neurologie, Hôpital de la Salpêtrière, Paris, France. Peripheral neuropathy is a common medical condition, the diagnosis of which is often protracted or delayed. It is not always easy to relate a neuropathy to a specific cause. Many people do not receive a full diagnosis, their neuropathy often being described as 'idiopathic' or 'cryptogenic'. It is said that in Europe, one of the most common causes is diabetes mellitus but there are also many other known potential causes. The difficulty of diagnosis, the limited number of treatment options, a perceived lack of knowledge of the subject – except in specialised clinics, the number of which are limited – all add to the difficulties which many neuropathy patients have to face.

Another additional problem for many patients is that once having received a full, or even a partial diagnosis, they are then often discharged back to their primary healthcare team who, in many instances, know little about this condition and how it may impact upon their patients' lives. In order to help bridge this gap in medical knowledge and to give healthcare providers a better understanding of this often distressing condition.

The Neuropathy Trust has commissioned a



EXCITING NEW BOOK
Peripheral Neuropathy &
Neuropathic Pain: Into the Light
By Gérard Said, M.D.

new book on this complex topic. Written by one of the world's leading experts on neuropathy, Professor Gérard Said, it is a 'must read' and also a handy reference book for doctors, nurses, physiotherapists, chiropodist/podiatrists and other health professionals. As well as covering the anatomy of the nervous system and the basic pathological processes that may affect the peripheral nerves, the book covers a whole range of neuropathic conditions. These include, for example, Guillain-Barré syndrome, chronic inflammatory demyelinating polyneuropathy, vasculitic neuropathies, infectious neuropathies, diabetic and other metabolic neuropathies, hereditary neuropathies and neuropathies in patients with cancer. Given the almost explosive increase in diabetes predicted over the coming years and the high incidence of HIV infections alone, not to mention all the other possible causes of peripheral neuropathy, no self-respecting medical unit should be without a copy of this new book on their shelves. The author, Professor Gérard Said, is based in the Department of Neurology at the prestigious Hôpital de la Salpêtrière in Paris. He has devoted a lifetime to the study of peripheral neuropathy and – alongside other great neurological names – added much to the world's ever-growing store of knowledge on this complex but fascinating condition which affects so many individuals.

MARTY PRICE'S EXPERIENCE

Marty is a member and active in the Antioch-Brentwood Neuropathy Support Group. He found something that helped him recently and reported on it. Here is his letter to me. (Bev)

Hi Bev,

I think I have a success story to tell... Remember when I asked you about ALA-R dosage and B1, B12?

I was going to stop using Gabapentin and try the ALA-R plus Benfotiamine. After about two days of being off Gabapentin my feet began to burn like crazy for two days straight, it was awful. So I went back to Gabapentin 1800 mg per day and started ALA-R 300 mg and Benfotiamine 150 mg per day.

Remarkably within hours my feet stopped burning completely and now no pain at all. I have my fingers crossed that they will stay that way! Three days straight so far.

I also found that using a foot cream called Magnilife cools the feet. I now apply it in the

am and the pm daily rather than only when they burned. It is probably helping too. Another benefit of it, it also keeps the skin from getting dry.

By the way the ALA-R is more than double the strength of regular ALA. The dosage for regular ALA is 600mg per day but with ALA-R 300mg works just fine.

Also, I found that by cutting one Gabapentin 600 mg pill in half plus one full pill giving me 900 mg taking it one hour before or after I take any supplement in the am then at night before bed take the other 900mg solved the side effect of Gabapentin making you so sleepy. Now I have it working to help me sleep. One thing no one seemed to be aware of is that Gabapentin also cuts absorption of any supplement like ALA-R way down, thus one hour before or after any supplement is taken to be sure to get full benefit of supplements.

Regards,
Marty Price

LEGISLATIVE ALERT FROM NEUROPATHY ACTION FOUNDATION

CA Governor Jerry Brown Signs AB 339 Reducing Out-Of-Pocket Prescription Drug Expenses for Millions of Californians

On Friday AB 339 was signed into law which will help Californians with chronic conditions like neuropathy afford their medications by capping the amount an individual pays out-of-pocket (OOP) for medications at \$250 for a single 30-day prescription. The NAF applauds Governor Brown and the bill's author Assemblyman Rich Gordon for addressing specialty tiers and high OOP costs which has been the NAF's number one policy issue for years.

Californians with neuropathy, HIV/AIDS,

hemophilia, multiple sclerosis and other serious conditions can face costs of thousands of dollars for necessary medications and can pay as much as \$6,600 OOP. AB 339 will make it easier for Californians to afford vital treatments. AB 339 does the following:

- Establishes caps on copays/co-insurance pre-deductible for patients. Most patients would see copays capped at \$250 for a 30-day supply.

- Defines tiers to prohibit plans from moving a drug

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President's Message – Continued from page 3

as a special gift. The price listed here at Amazon is \$39.95. It is in that neighborhood plus tax and shipping.

Gene Richardson and David Morrow of the Neuropathy Support Network have offered support group leaders a website to use to help promote the work of the local support group. These are individual websites so each group has its own. It takes a person who does e-mail and is comfortable checking information on various websites so there are some computer skills. This is important to be able to handle the website as there are some portions that can be changed to fit the occasion. Information about speakers or other events can be put up. If you are not the Leader, but have computer skills and would like to help, please talk to your group Leader. In some groups, the group leader has the skills and might like help. In other groups the Leader does not have those skills, but someone in the group may. You might be that person. It is not something that is required of any group but is an option. There is a link to the WNA website that will make it easy for people to access our organization's central website, too. We hope it will add people who access it by finding us through the local sites.

Besides the local information, there will be information on this site that people may find helpful. The Neuropathy Journal done by the Neuropathy Support Network with articles on many topics related to neuropathy will be easily accessed. There are articles there that a group leader can download and use as handouts as the site is fully usable. This is also true of articles on the Western Neuropathy Association website www.pnhelp.org or the new way to access the

same site www.WNAinfo.org. Videos from the Neuropathy Action Awareness Conference put on by the Neuropathy Action Foundation in Los Angeles last year are housed on it so you can watch them individually or a group leader can show them via computer – probably laptop – at a support group meeting. Support groups will be listed in a variety of ways on the site so they can easily be found by someone looking for one.

If you use a computer, I hope you are using Dr. William Donovan's column to find information not found otherwise. He found that I had somehow reused some so we are doing some catch up. That is why the column is longer this month. He has a whole year's worth in waiting so it will likely be fairly long most months. Please use it to dig out some great information.

Has anyone tried FootHuggers Comfort Socks? I got an ad that makes them sound quite good. I thought I'd ask the experts on these things. Are you one of those?

A word to the wise – if you are traveling by car or by plane and it entails a lot of sitting, be sure to get up and walk every hour or so. You will want to get to your destination so you may want to ignore this warning, but you may have to spend more time later fighting blood clots that form in the legs and lungs if lack of exercise has allowed the blood to pool. I know someone who had a wonderful time but now could have lost her life because of blood clots that formed.

Please take care of yourself. You are needed and are irreplaceable. There is no one like you. You are one of a kind.

Beverly

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.

Getting To Know Gene Richardson - Continued from page 1

morph into energy, leading to positive thinking and outcomes. Are you feeling vulnerable, powerless and fearful? This is common, but your PN can be helped by positive actions and thoughts, being 'in charge' and working with your doctor.

Second Steps: Learn to laugh – to see the irony in life. Let your inner child play (he shared sledding in the snow at his age and in his condition!) Look for simple joys and also change your expectations and let humor heal your body.

Third Steps: Knowledge is very important, so educate yourself about PN. Today, there are several recent books – a real help now compared to the old days when patients were 'flying blind.' Become your doctor's partner, not a passive patient. Any passivity may hinder your finding the help you need. Some titles he recommends are:

- Scott Berman, M.D. – Coping with Peripheral Neuropathy; How to Handle Stress, Disability
- Mims Cushing – You Can Cope With Peripheral Neuropathy; 365 Tips for Living a Better Life
- Norman Latov, M.D. – Peripheral Neuropathy; When Numbness, Pain and Weakness Won't Stop (2007)
- Sheri Schwar – Sick and Tired of Being Sick and Tired

Fourth Steps: Preventive medicine and a cure are still goals. In the meantime, stop PN damage early. Your doctor only has your subjective information, so create an adult-adult relationship with one who both cares and listens to you. Request appropriate testing. Focus on the disease, not the doctor.

Summing up, he said, "Our approach influences our feelings and actions. When we feel loss of value and importance the result is anger that can be channeled to new outcomes. He quoted the Serenity Prayer: "God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference." He found this prayer helpful when faced with needing a cane and now asks, "Why not use a cane to avoid those falls?"

He encourages attending and sharing at support groups.

Being a thinking man, Col. Richardson notes we must acknowledge that change is or will be necessary and he has ranked his own responses to this concept:

1. Things I can't do now - e.g., power walking
2. Things I can do - e.g., writing, speaking
3. Things I can do the same as before
4. Things I still do, but use aids or modified behavior - e.g., sitting down or a cane
5. Things I can do differently, but am not really ready for yet - e.g., a trip to Alaska

So, for him, "CAN'T" becomes 'What CAN I do? And then progresses to . . . "What can I do differently?"

Last steps: Focus on Today. Don't dwell on unknowns and avoid 'what if' centered fears.

- Choose realistic goals of can do stuff
- Help others with PN
- Adjust your daily schedule to your own physical limits
- Enjoy the simple things that bring you peace

Support:

- Partner with your doctors – remember, they aren't Gods. Help them help you. Discuss the real meaning of the pain scale (e.g., 10 = passed out). Remember, your medical history is critical, and should include when, where, how long, and other results.
- Often, the best questions and answers come from fellow PN'ers.
- Family can understand and become willing to listen, to truly hear you. Tell them your realistic expectations as to why you share with them.
- In the workplace, go carefully; safety first. Tell others on a 'need to know' basis, keeping information simple and short. If need be, consider contacting Human Relations staff with concerns.
- Pets often play a big role in creating comfort.

ABOUT THE AUTHOR

Col. Richardson has suffered with severe neuropathy for over 45 years. A 27-year military veteran having served in 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.

EUGENE RICHARDSON'S EIGHT TIPS ON TRAVEL (excerpt from Mims Cushing: You Can Cope With Peripheral Neuropathy, pg.111)

Richardson says take your neuropathy along and Travel, with a capital T. Keep going and don't give up.

His advice:

1. If you overly worry about your neuropathy on a trip, you could miss some of life's miracles.
2. The best humor is often found in the common, simple events of traveling, providing moments for a good laugh or two – at life, at yourself.
3. Never take your illness so seriously that it overwhelms you. You are much more than your illness or disabilities. Travel can help divert you.
4. Thinking of the worst that can happen tomorrow is a sure-fire way to throw yourself into a state of helplessness and ruin a vacation.
5. Don't be driven by the fear of what might be around the bend by saying, "Tomorrow will be worse. I just know it." That helps nothing, at home or away.
6. Travel has a way of helping us discover what we need to know.
7. Travel gives rise to surprises that we could miss if we sit at home wallowing in despair, anger, and negativity.
8. Hope is always a possibility. Besides, there is today, and if there is today, there is hope. Keep traveling!

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

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:

- 15288403 This double blind, placebo controlled study of the effectiveness of pregabalin (Lyrica®) 300mg daily for diabetic peripheral neuropathy demonstrated statistically significantly decreased pain, improved mood and quality of life.
- 15288411 This is a double blind, randomized; placebo

controlled study Of 244 adult diabetics with painful neuropathy. At higher doses of venlafaxine (Effexor®) 150mg-225mg, the Visual Analog Pain Relief Scale at week 6 was 44mm vs. 60mm for placebo (p<0.001).

- 16235318 This is a Cochrane Database review of 32 double blind randomized trials utilizing lidocaine anesthetic intravenously or analogs—tocainide, mexitilene or flecainide—orally, to relieve neuropathic pain. These agents were as effective and safe as carbamazepine, amantadine, gabapentin or morphine.
- 17157116 This University of Chicago dose escalation study of dextromethorphan (DM) 45mg/ quinidine 30mg one to four daily resulted in significant pain relief (p=0.001—probability of chance result less than 0.1%). Adverse events occurred as follows: nausea 27.8%, dizziness 25.0% and headache 25.0%. DM is the ingredient found in cough medicine and is an NMDA inhibitor. Quinidine is a cardiac drug used to control arrhythmias and incidentally increases blood levels of DM.
- 20373255 This paper discusses a novel combination drug, Nuedexta®, which contains the NMDA (N-methyl-D-Aspartate) antagonist, dextromethorphan (DM) and quinidine, a cytochrome p450 2D6 enzyme inhibitor that effectively prevents the metabolism of DM, increasing its blood level. DM (commonly used as a cough suppressant in cold medicines) is effective in reducing diabetic neuropathic pain as well as pseudo bulbar affect (uncontrolled emotionality post stroke).

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■ General Organizational Inquiries ■ www.WNAinfo.org

Legislative Alert From Neuropathy Action Foundation - continued from page 5

from a lower tier to a higher tier, but allows plans to move a drug from a higher tier to a lower tier.

- Prohibits health plans from having more than 4 tiers.
- References federal guidance which prohibits discriminating against patients who must take expensive drugs. This will allow state regulators to enforce federal provisions.

This success follows an earlier win this year on OOP costs when Covered California made history by becoming the first health benefit exchange in the nation to set caps on how much patients have to pay for specialty drugs. The vast majority of Covered California patients will see their specialty drugs capped at \$250 per month, per prescription. Overall, the caps will range from \$150 to \$500 beginning in 2016.

Special thanks to all of you that have supported the numerous bills in California on this topic over the years. This historic legislation once again proves that one should "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."



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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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