

PN News

Yolo County

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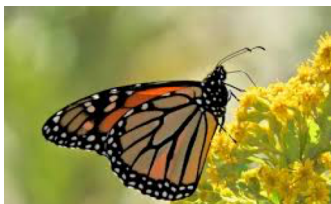
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WNA



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.** The Western Neuropathy Association (WNA) and the Yolo Neuropathy Groups (*PN News*) do not endorse any treatments, medications, articles, abstracts or products discussed herein.

Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no help at all.

Dale Carnegie



DAVIS

TUESDAY, MAY 14, 3:30-5:00 p.m.

Program: Former speaker **Dottie Pendleton** returns to share relaxation techniques and guided imagery visualization, both very helpful in reducing stress and controlling pain. She taught yoga and guided meditation at both Davis Parks and Recreation and the Davis Art Center and maintains a private studio in Davis. Her 2017 program was very well received!

Davis Senior Center
646 A Street, Davis, 95616
Contact: Mary Sprifke (530) 756-5102

SACRAMENTO

No Meeting

Leader Charles Moore has retired.

Please contact Bev Anderson, WNA President, to explore possibilities for the future.

**Bev Anderson
877-622-6298**



MEETING RECAPS



DAVIS APRIL NOTES

By Mary Sprifke

I made a cardinal mistake in choosing a video for this meeting. I didn't prescreen it. Unfortunately the quality was poor, volume bad and it was difficult to understand. She is not an experienced speaker. Aside from that, Mrs. Lincoln, "How did you like the play?"

I truly love Mims Cushings' book, titled "**You Can Cope with Peripheral Neuropathy -- 365 Tips for living a full life.**" And when Mims spoke at one of our annual conferences, she was recorded. Hers is just a small part of a larger CD and I thought that it would dovetail well with past articles about her book. I was wrong.

So my apologies to those who were disappointed by the CD. Here are my notes of her talk.

Out of 365 Tips, here are the 10 that Mims shared:

1. Be excited. A sea change is occurring in American publishing. More and more books and resources are becoming available about PN. Groups and organizations are forming. Topicals are being made for all, not just those with diabetes.
2. Practice gratitude and appreciation. This is key to reducing stress. Keep a journal.
3. Don't rely on prescriptive drugs alone. Seek activity that feeds your needs and delights, such as drumming, massage, etc. Keep seeking help.
4. Banish toxic people. Take action if you need to. Too much negativity affects our brain and our health.
5. Volunteer. Find the right thing to do that energizes you. Involve yourself in something greater than yourself. Wonderful words, "You talk and I will listen."
6. Love cabbage and caviar equally. Life and enjoyment is in the experience.
7. Exercise. No jumping jacks? Perhaps water aerobics is an option. Be creative within your limits.
8. Let good things grow. Keep worry at bay. "UFO is Unformed Freakish Observations."
9. Nourish your friendships. It's okay to treat yourself to joy.
10. Embrace something that will embrace you back. "Do dogs, not drugs."

Sacramento is losing its leader, Charles Moore, to retirement.

By Mary Sprifke



Kudos to you Charles!

You led the Sacramento group for many years, preparing programs, obtaining speakers, reviewing PN books and sharing your findings. Your secretary's excellent notes from the meetings were shared widely through your own email list and also this newsletter; they live on under 'Resources' on the WNA site. You involved yourself with PCNA, *aka* WNA, found help for yourself and others and persevered over the long haul. Your group had a core of loyal followers.

'Thanks' is just too small a word.

In a recent conversation with me, Charles said, ***"I just hope I've made a difference. I'm hoping folks will come to our last meeting and tell me if our group has been helpful."***

Such quiet words, almost sad.

Do we leaders provide what PN'ers want and need? With only the WNA newsletter, *NEUROPATHY HOPE* and the *Yolo PN News* to announce their monthly meetings, the Sacramento group depended upon word-of-mouth to encourage new attendees. Over time, without many new people involved, the group dwindled.

When attendance drops, it can be both a challenge and an opportunity. The image of the bird Phoenix, rising from his ashes, comes to mind. This is the time of ashes, of sadness, of rest.

But sometimes downtime is needed. If a group is meant to exist, new leaders will be found. There will be new venues, new resources to share. Funding will arrive to buy ads in the media. Members will recall outstanding meetings and ask for repeats or updates. Other groups can share their ideas and experiences. But it may be a long wait.

The Sacramento experience differs from Davis. We are blessed with a local newspaper, *The Davis Enterprise*, which focuses primarily on local news. Its Calendar column reliably runs our PN group meeting information and it's a rare meeting where no new person attends. Thanks to WNA support, we share a packet of

information for newcomers.

It's comprehensive! It contains back issues of PN News, and I always point to page 8, our resources page. The Davis Senior Center provides free meeting space and technical assistance.

But my challenge is to engage newcomers without neglecting 'old-timers.' And I know from my own experience that after my first meeting 16 years ago, I departed, unable to acknowledge my need for information and support. It was 2 years before I returned. This is 'normal' and understood. But by sharing their contact information, each attendee gets this newsletter and its meeting summaries until they choose to stop. They can stay in touch from a distance. And over time, our contact list numbers about 300 PN'ers. That number bolsters and encourages me to continue.

Davis monthly attendance ebbs and flows. CD's that are core information are very familiar to members who may not 'come again' to see them. A few years back I compiled a list of all program topics and asked readers to let me know their favorites. Sadly, I received no feedback. So I also wonder how our group has been effective.

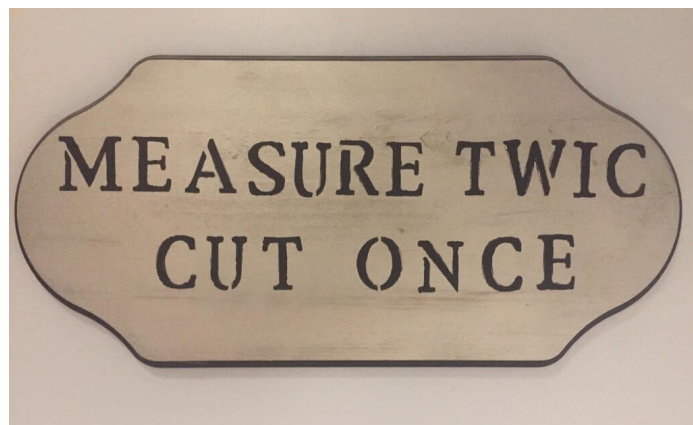
And like Charles, I need leadership partners.

??? DID YOU KNOW ??? - - The TOOL KIT

As helpful ideas or PN-related information become available we will try to include space for them.

- Apples contain pectin, which is thought to restrict cells from absorbing fat. Pectin also encourages water absorption from food, which helps break up fat deposits. A 2008 animal study featured in the *Journal of Agricultural and Food Chemistry* found that apple pectin not only reduced weight, it also lowered blood sugar levels.
- Eat your greens. Research shows that veggies are broken down slowly in the body, causing less rise in blood sugar levels, less insulin secretion and, ultimately, less fat storage.
- All you need is a couple of handfuls of nuts a day to get weight loss benefits.
- Alpha Lipoic Acid, 600mg per day, is a cornerstone supplement for PN.
- Daily cinnamon supplements reduce blood sugar.

It's To Laugh . . .





Peripheral Neuropathy Information Resources

Because “every cell of our body has a nerve component,” peripheral neuropathy can affect many parts of our bodies, literally from head to toe. For that reason, this listing includes many types of neuropathies you may never have heard of, but may in fact, actually be experiencing. The more you know about neuropathy, the better will your chances be for improving your diagnosis and care.

As one-third of us are diabetic, there are more articles about DPN than other PN types. However, many of the treatments specified for DPN are effective with other neuropathies. Pain is problematic for most of us so there are numerous articles about pain management products and strategies.

As you begin to assume more and more responsibility for your own treatment plans, in partnership with your medical providers, you will learn about more resources and we hope you’ll share them with the leadership of the Western Neuropathy Association so they can be passed on to others in future publications of this resource.

BOOKS

All of these books can be obtained through local stores by order, Barnes and Noble, Amazon, and other online bookstores. These are books people have found helpful. They are for educational and information 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. The 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.

PERIPHERAL NEUROPATHY: WHEN THE NUMBNESS, WEAKNESS AND PAIN WON’T STOP

by Norman Latov, MD, PhD. (2007)
A guide for patients and families that defines neuropathy, the function and organization of the nerves, understanding the symptoms, evaluation and diagnosis, causes of neuropathy, management of neuropathy and sharing stories and experiences. This book will help you to speak the same medical language as your physician. (If you can afford it, buy one for your primary care doctors or any other doctors you visit.)

YOU CAN COPE WITH PERIPHERAL NEUROPATHY: 365 TIPS FOR LIVING A FULL LIFE (2009)

This volume was written as a “coping book” by author Mims Cushing, a “PN’er”, with supplementary chapters by Norman Latov, M.D., a recognized expert on the subject. The author shares numerous “tips” on how to live a full life, understand the illness, develop healthy attitudes about it, and engage in activities that lessen the impact of neuropathy on one’s life. A number of case histories are shared

which serve as models for healthy adaptation.
<http://www.youcancopewithneuropathy.com>.

NUMB TOES AND ACHING SOLES: COPING WITH PERIPHERAL NEUROPATHY

by John Senneff. (1999)
This first volume of the author’s, published in 1999, covers the

entire subject of peripheral neuropathy in 300 pages: causes, pain medication, other medical therapies, alternative treatments, nutrients, unapproved drugs, diabetes and HIV, and coping. The facts are well referenced, but unselected, including studies with weak evidence for effectiveness. The author deliberately intended to be all-inclusive, realizing that a treatment may help one person and not help many others. As with any textbook, new information soon outdates the material



presented, forcing the informed reader to keep up with the current literature.

NUMB TOES AND OTHER WOES: MORE ON PERIPHERAL NEUROPATHY by John Senneff. (2001) Written as his second volume on the subject, this exhaustive, well-referenced summary of research on the multiple possible treatments of neuropathy is the product of John Senneff an attorney who suffers with the disease. It would take a lifetime to try all the treatments reviewed.

NUTRIENTS FOR NEUROPATHY by John A Senneff (2002). There is an excellent forward by neurology professor, Laurence J. Kinsella, M.D., listing supplements, which enhance and those that harm nerve function. The author's introduction discusses the need for double blind, randomized, placebo-controlled studies of supplements used for peripheral neuropathy, despite the economic barriers to pharmaceutical companies scientifically investigating these agents, which cannot be patent-protected. The author attempts to review the many vitamin and mineral substances that have been tried with PN. There is a section describing the ALADIN study of alpha lipoic acid with PN.

THE NUMB FOOT BOOK: HOW TO TREAT AND PREVENT PERIPHERAL NEUROPATHY (2008) Naturopath Alexander McLellan, Bs.C, ND and Podiatrist Marc Spitz, DPM, continuing the legacy of the Numb Toes Book series by John Senneff, while offering even more practical solutions than ever before. This text synthesizes much of Senneff's work. Of particular note is a

chapter called "Nutrients for Neuropathy," which looks at the value of supplements. The title of the chapter is borrowed from Senneff's book Nutrients for Neuropathy.

COPING WITH PERIPHERAL NEUROPATHY, HOW TO HANDLE STRESS, DISABILITY, ANXIETY, FATIGUE, DEPRESSION, PAIN, AND RELATIONSHIPS by Scott I. Berman MD, CIDP (2007) He is a physician, specializing in psychiatry, who suffers from chronic inflammatory demyelinating polyneuropathy (CIDP), a severe form of peripheral neuropathy). Dr. Berman tells the story of his illness from the perspective of a doctor, in his case, facing a particularly grim prognosis. Detailed medical information is provided. The author shares helpful advice with anyone coping with the many challenges of this chronic illness.

THE ALPHA LIPOIC ACID BREAKTHROUGH (1998) by Burt Berkson, M.D., Ph.D. Evidence is referenced regarding the benefits of ALA as a powerful antioxidant, which neutralizes free radicals and can protect against cell damage from toxins, chemotherapy, ageing, diabetes, and atherosclerosis. Specific references involve ALA's role in the treatment of cataracts, diabetic retinopathy, peripheral neuropathy, nerve degeneration and mushroom poisoning. The book was written in 1998 before the publication of more pessimistic studies of many of the vitamins he covers. Subsequently, however, the ALADIN and SIDNEY studies have been completed reaffirming the role of ALA in preventing the progression of nerve degeneration in peripheral neuropathy.

NEUROPATHY AND PAIN MANAGEMENT ORGANIZATION WEBSITES



[www. pnhelp.org](http://www.pnhelp.org) Website of the **of the Western Neuropathy Association (WNA)** for regional information about the growing network of support groups, profiles of the WNA Board of Directors, news about **WNA** regional activities, general news about neuropathy issues and developments. On the site are some archived copies of the WNA's **Neuropathy Hope** monthly newsletter and **PN News**, the monthly newsletter of the Yolo Neuropathy Groups. Monthly newsletter of the **Yolo Neuropathy Groups**.

(See www.pnhelp.org , check Resources tab and click Medical Literature Review).

www.foundationforpn.org Website of The Foundation for Peripheral Neuropathy. They have an emphasis on research but also have a wealth of information for individuals and support groups. Membership costs \$30 per year.

www.neuropathyaction.org This is the web site of the **Neuropathy Action Foundation (NAF)**, a California-based non-profit organization committed to insuring that neuropathy patients have access to individualized medications, IVIG (Intravenous Immunoglobulin, a highly purified blood product preparation that is derived from large pools of plasma donors) and other treatments through patient empowerment and advocacy. NAF increases awareness among physicians, appropriate institutions, the general public and public policy officials that neuropathy can potentially be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is available. NAF holds a yearly one-day conference in California.

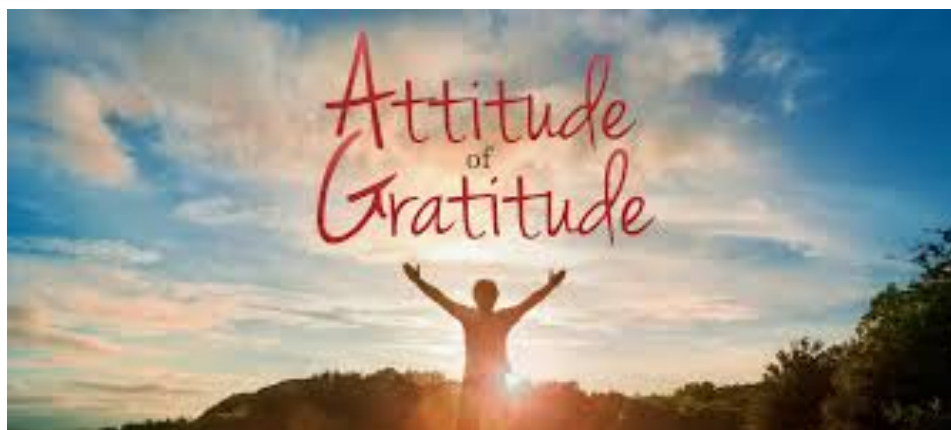
www.NeuropathySupportNetwork.org The **Neuropathy Support Network** is the organization that Gene Richardson has developed in support of and as an outgrowth of his popular DVD, *COPING WITH CHRONIC NEUROPATHY, Tips and Techniques on Living with Neuropathy*. There is a great deal of helpful information on this website with a special emphasis on the needs of veterans, and gamma globulin or antibodies, which are a highly purified blood product preparation that is derived from large pools of plasma donors. Plasma from approximately 1,000 to 10,000 persons is present in each unit or "lot" of IVIG.

www.diabetes.org The website of the **American Diabetes Association**. Provides a wide variety of information about both Type 1 and Type 2 diabetes. Click on the tab "Get Local" and type in your ZIP to find out what is going on near you. Call the toll free number 800-342-2383, 8:30 am till 8:00 pm for information.

www.theacpa.org website of the **American Chronic Pain Association**, which grew out of a support group for patients with chronic pain, and now serves these groups around the country. Extensive information is provided on various painful conditions, analgesic medications, pain management techniques, and excellent videos, including a relaxation exercise guide.

www.ncbi.nlm.nih.gov/sites/entrez As William B. Donovan, MD, outlines in his column in *NEUROPATHY HOPE*, this link accesses **The National Library of Medicine (NLM)** where information on peripheral neuropathy (PN) can be found. There are over a hundred medical articles a month written on PN. Click on this link to open PubMed. Then choose Search. You can enter article numbers (PMIDs) listed in the newsletter that he has previously checked- out, or you may search on your own. The vast world medical literature can be accessed here.

www.neuropathyjournal.org *The Neuropathy Journal* is written for patients suffering from neuropathy and their caretakers; also by neuropathy patients who share their first-hand experiences in living with this often misunderstood affliction. The journal's purpose is to advance the understanding of neuropathy in layman's terms. The information provided is intended to be educational and informative and not medically prescriptive or diagnostic. All patients are encouraged to consult with their own medical doctor when considering any of the information contained within.



UPCOMING MEETINGS



2nd Tuesday, June 11, 3:30 p.m.

Davis Senior Center, 246 A Street
(Mary Sprifke 530-756-5102)

SACRAMENTO

**No Meeting Scheduled
Seeking New Leader**

The mission of the Yolo Neuropathy Groups is to ensure through information, empowerment and mutual support, that all may have hope and that no one will face their peripheral neuropathy alone.

RESOURCES:

1. Norman Latov M.D., Ph.D. – ***Peripheral Neuropathy: When the Numbness, Weakness and Pain Won't Stop***
2. Harry J. Gould, III, M.D., and Ph.D. – ***Understanding Pain: What It Is, Why it Happens and How It's Managed***
3. Alexander McLellan N.D. and Marc Spitz D.P.M. – ***The Numb Foot Book – check Amazon.com -- Out of Print***
4. Mims Cushing & Norman Latov, MD – ***You CAN Cope With Peripheral Neuropathy 365 Days a Year***
5. John Senneff – ***Numb Toes and Aching Soles: Coping with Peripheral Neuropathy***
6. John Senneff – ***Numb Toes and Other Woes: More of Peripheral Neuropathy***
7. John Senneff – ***Nutrients for Neuropathy: How to use natural supplements to treat the severe pain of PN***
8. Dr. Valerie Monteiro & Dr. John Coppola: ***Defeat Neuropathy Now ... In Spite of Your Doctor***
9. Todd Levine, M.D., ***Neuropathy Hope? Small Nerves, Big Problems***
10. **The Foundation for Peripheral Neuropathy- www.foundationforpn.org (a national organization)**
11. **Western Neuropathy Association (WNA) – www.pnhelp.org or toll-free (877) 662-6298**
12. **www.diabetes.org**
13. **www.neuropathyjournal.org**
14. **www.neuropathysupportnetwork.org**
15. Eugene B. Richardson MDiv, MSM, EdM, MS, Patient Educator: DVD “Coping with Chronic Neuropathy”
16. DVD's: “Forks Over Knives” and “What the Health?”

To send *PN News* to others or if you no longer wish to receive this newsletter, please contact (530) 756-5102.

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