

# PN News

Yolo County

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MARCH 2019

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Charlie Patton  
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Mary Sprifke



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, MARCH 12, 3:30-5:00 p.m.

**Program:** View and discuss 3 short TED talks on neurogenesis, chronic pain and understanding your brain. Part of each talk may have applications to PN.

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

## SACRAMENTO

TUESDAY, MARCH 19, 1:30-3:00 p.m.

**Program:** The presenter at this meeting will be John Richards, owner of Professional Village Pharmacy and compounding pharmacist. John is one of our all-time finest presenters, ready to discuss whatever you may ask about drugs.

Northminster Presbyterian Church  
3235 Pope Avenue, Sacramento  
Contact: Charles Moore 916-485-7723



This issue's theme is caring, self-care and learning to 'deal with it.'

## MEETING RECAPS



### DAVIS FEBRUARY NOTES

By Mary Sprifke

Tracking a robust conversation is rather like herding cats. I become engaged with the verbal

flow and neglect taking cogent notes, so bringing our round-table meeting to you resolves into a series of bullet points of some topics covered. An intrinsic part of these occasional open topic meetings is that we leave reaffirmed and possibly clutching a tip or two to pursue.

Several members have an “idiopathic” diagnosis, so there’s a lot in common as to trial and error, frustration and resolve. Finding lifestyle changes that help our symptoms can become an activity of faith over time.

One, who had chronic sleeping issues, just started to dance and jog before bed. “After all, why not?” The outcome was a good night’s sleep, so dancing before bed has become a lifestyle change.

We agree that no matter what our diagnosis is, symptoms cross over lots of causes, so if something works for diabetics or chemo PN, it may also work for us.



One shared part of a diagnosis that uncovered a Vitamin B12 deficiency and led to infusion therapy. Another keeps active with Pilates, physical therapy and biking. We heard of a visit to Dr. Eric Hassid, who outlined a protocol of Nutraceuticals (see p.3) and sought naturopathic answers to pain. We learned about Sutter’s robust heart health gym at our Davis hospital and how it also serves as a caring support group.

Some had experience with a local neurologist that seemed to lack empathy. They felt that the doctor was dismissive. (Our policy is to keep information from our meetings private.)

A question asked, “Does Cymbalta help your symptoms?” The reply was, “Don’t really know, since I’m doing ok and have no idea how I would feel if I wasn’t taking it.”

Having PN can feel like there are too many scattergun ideas for relief, but if one results in a positive change, we are willing explorers. I will put some tips I heard into the Toolkit (p.3) along with others from past meetings.

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### SACRAMENTO FEBRUARY NOTES

By Charles Moore

I hired Vicki Denman, Yoga and Tai Chi teacher to focus on fall prevention for this meeting. I was unable to attend due to my surgery, but I’m told she was well-received.





Eric I. Hassid, M.D.  
2801 K Street  
Suite 502  
(916) 887-4660  
• Offers My Health Online

**SPECIALTIES:**  
**Holistic/Integrative Medicine**

Accepting new patients

**Professional Interests**  
**HOLISTIC / INTEGRATIVE**  
**MEDICINE**

My personal recommendation: \*

In the Davis group we often discuss our varied experiences with doctors. Over the past several years one name has received consistently good reviews, so I want to share his contact information with you.

He has not sought our focus or publicity. I was referred to him over 10 years ago when he was with Sutter Davis. He then opened his own Institute for Restorative Health in Davis. Eventually he decided to practice in Vacaville. He has been a speaker at a WNA conference.

I am delighted that he and 3 other integrative doctors are practicing at the downtown Sacramento Sutter Institute for Health & Healing.

Mary Sprifke

\* [Yolo PN News and WNA do not recommend treatments or individual doctors. Check with your own doctor.]

**Dr. Hassid's expertise includes:**

Anti-inflammatory diets, Detoxification programs, Functional medicine, Integrative allergy treatment, Integrative autoimmune disorders care, Integrative cancer support, Integrative chronic pain management, Integrative digestive disorders care, Integrative nutrition services, Integrative physician assessments, Migraine relief, Nutraceuticals and dietary supplements, Nutritional supplements, Pain management, Personalized testing and assessments, Stress management, Weight management.

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

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

- Topicals that may help PN: Elmore Oil, Aspirin Cream, Tripinin cream, Neuragen, Capsaisin. Check the foot-care section of your pharmacy.
- **Avoid the antibiotic LEVAQUIN.** It can actually cause PN. (See side effects)
- Arnica + 1% cortisone applied to your feet at bedtime.
- Don't be a couch potato if you can help it. Movement keeps the body healthy and happy!
- Online meditation prompts can assist with stress reduction. You're NOT alone.
- If a primal scream in the car doesn't do it for you, try massage or acupuncture.

## FROM THE WNA VIDEO LIBRARY: *Coping With Chronic Neuropathy*.

A summary by Mary Sprifke

The Western Neuropathy Association has DVDs 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, "Sick and Tired of Being Sick and Tired" by Sheri Schwar. For him, 'this book says it all.'

Col. Richardson is a retired military man, whose physical problems began in Vietnam with Agent Orange. To receive this DVD, contact WNA at 877-622-6298 or [www.WNAinfo.org](http://www.WNAinfo.org).

If taking time to watch may not be optimal for you, here are notes from the 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 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, anxiety, fatigue, depression, pain, and relationships***
- 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, the 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:

Things I can't do now - e.g., power walking

Things I can do - e.g., writing, speaking

Things I can do the same as before

Things I still do, but use aids or modified behavior - e.g., sitting down or a cane

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 being service-connected.



### FINALLY:

- Faith is important
- It's OK to be mad at God
- Ask, "What does God want me to do here?"
- Humor is central to coping
- Humor has a healing effect on the body
- We need affirmation from our family and our doctor
- Insurance companies rule our doctor's time
- When all tests are normal and all causes known are ruled out, keep seeking
- Give your doctors complete, subjective information
- The book "Coping With Peripheral Neuropathy: How to handle stress, disability," is highly recommended
- Plan 'to do' lists
- Increase life's meaning: help others

It's To Laugh . . .

So after winning the game, I decided to throw the ball into the crowd, like they do on the T.V. Apparently, it's unacceptable in bowling.



"He's taken the health monitoring benefit to a whole other level." #94272763



## By Charlie Patton – Times Union, Jacksonville, Florida

(Posted Jul 14, 2009) **Review of book by Mims Cushing**

While this article is not necessarily current, the information is relevant. (Editor)

At first **Mims Cushing** blamed her new deck shoes, which she'd bought at a mall in Georgia in January 1996. When her feet started burning and tingling, she assumed she was allergic to the shoes and consigned them to a closet. But that didn't stop the maddening sensations. At times it felt like electrical currents were coursing through her feet. At other times they'd be numb. Then the numbness would give way to unbearable heat, as if she'd suffered a terrible sunburn.

It took a while before Cushing, who now lives in Ponte Vedra Beach, got an explanation and longer still before she found

a sympathetic neurologist who understood what was happening.

That was Norman Latov, a professor at the Cornell medical school, who in 1999 identified Cushing's condition as a form of peripheral neuropathy, a condition that affects the nerves in feet, lower legs and hands in ways that can range from annoying to completely debilitating. An estimated 20 million people in the United States suffer from the disease. Peripheral neuropathy can have many causes, including diabetes (about 33 percent of people with diabetes experience peripheral neuropathy). But Cushing's case was idiopathic, meaning the cause is unexplained.

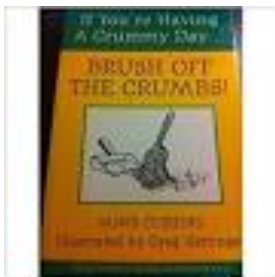
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### ***"If You're Having a Crummy Day ... Brush Off the Crumbs!"***

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Cushing, a 65-year-old divorced grandmother and freelance writer, started putting her thoughts about living with peripheral neuropathy on paper. In 2002 she self-published a collection of essays titled "If You're Having a Crummy Day ... Brush Off the Crumbs." In it she talks about the frustrations of dealing with a condition that

few people understand and that can vary wildly in symptoms from one person to the next.



"A magic pill is out there," she wrote. "I just know it. But for now, the

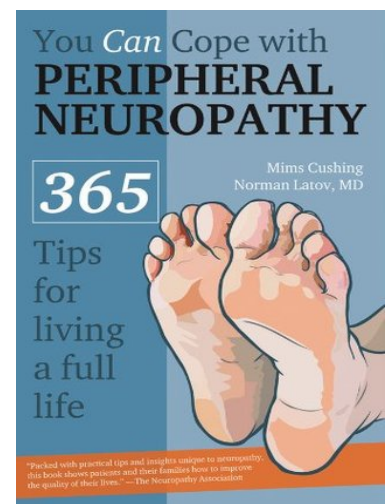
best symptom-relieving 'pills' for many people are the little support groups ... that chug along month after month ... spreading the word about peripheral neuropathy." She founded one of those groups in Jacksonville in 1999.

Latov particularly liked the book's closing essay (which had been published in 2001 in "The Neuropathy News"). With Cushing's permission, he included it in his 2007 book

"Peripheral Neuropathy: When the Numbness, Weakness and Pain Won't Stop."

The publishing company, Demos, liked Cushing's informal style and asked her to collaborate with Dr. Latov on a book about how to live with the condition.

The result is just-published ***You Can Cope with Peripheral Neuropathy: 365 Tips for Living a Full Life***. The book can be ordered through Amazon.com. Selling lots of books would be nice, Cushing said.



"But this is not about the money," she said. "It's about getting the word out about this damnable disease."

## UPCOMING MEETINGS

**2<sup>nd</sup> Tuesday, April 9, 3:30 p.m.**

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



## SACRAMENTO

**3<sup>rd</sup> Tuesday April 16, 1:30-3:00 p.m.**

Northminster Presbyterian Church  
3235 Pope Avenue, Sacramento  
(Charles Moore 916-485-7723)

*The mission of the Yolo Neuropathy Groups is to ensure that through information, empowerment and mutual support, 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](http://www.foundationforpn.org) (a national organization)**
11. **Western Neuropathy Association (WNA) – [www.pnhelp.org](http://www.pnhelp.org) or toll-free (877) 662-6298**
12. **[www.diabetes.org](http://www.diabetes.org)**
13. **[www.neuropathyjournal.org](http://www.neuropathyjournal.org)**
14. **[www.neuropathysupportnetwork.org](http://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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