

# PN News

Yolo County

VOL. 12, No. 9

November 2016

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Neuropathy Journal.org  
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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 Pacific Chapter of The Neuropathy Association (PCNA) 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, NOVEMBER 8, 3:30 – 5:00 p.m.

**Program: Round-table Discussion:  
Focus on Nutrition for Neuropathy**

Davis Senior Center  
646 A Street, Davis, 95616  
Call: Mary Sprifke (530) 756-5102 or  
Retta Gilbert at (530) 747-0186

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**WOODLAND – NO MEETING, NO LEADER(S)**

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## SACRAMENTO

TUESDAY, NOVEMBER 15, 1:30 – 3:30

**Program: John Richards, Dr. of Pharmacy, is  
owner of the Professional Village Pharmacy.  
He will be discussing medications used for  
neuropathy pain.**

Northminster Presbyterian Church  
3235 Pope Avenue, Sacramento, CA 95825

Call: Charles Moore (916) 485-7723

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## MEETING RECAPS



### DAVIS OCTOBER NOTES

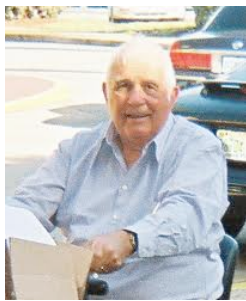
Originally published in May, 2015

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, "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. To see this DVD, contact one of our Yolo support groups or WNA at (877) 662-6298.

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 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.

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?"

Summing up, he said, "Our approach influences our feelings and actions. "When we feel loss of

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.



#### **"CLIFF NOTES" from Mary, taken during the October 2016 screening:**

- 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
  - "Coping With Peripheral Neuropathy: How to handle stress, disability," is highly recommended
  - Plan 'to do' lists
  - Increase life's meaning: help others
  - Help your doctor by using the 5 "W"s": who, what, where, when, why. Your past may be more important than now
  - Have a secret place of peace
- The Davis Group has this DVD available for checkout.

## SACRAMENTO OCTOBER NOTES

By Charles Moore

Because our presenter had to cancel, we decided to hold a round table discussion. To facilitate the discussion, I solicited a series of topics and rounded up some interesting expert observations on each. I provided alternative therapy handouts that might apply to neuropathy treatment.

### The alternative therapies that we discussed:

- 1) Stem cell treatment
- 2) Gene therapy
- 3) Earthing or Grounding

#### 1) Stem Cell Therapy

##### **WARNING ON THE MARKETING OF UNPROVEN STEM CELL-BASED INTERVENTIONS**

*The ISSCR* (International Society for Stem Cell Research) condemns the administration of unproven stem cell-based interventions outside of the context of clinical research or medical innovation compliant with the guidelines in this document and relevant laws, particularly when it is performed as a business activity.

Scientists and clinicians should not participate in such activities as a matter of professional ethics. For the vast majority of medical conditions for which putative "stem cell therapies" are currently being marketed, there is insufficient evidence of safety and efficacy to justify routine or commercial use. Serious adverse events subsequent to such procedures have been reported and the long-term safety of most stem cell-based interventions remains undetermined.

The premature commercialization of unproven stem cell treatments, and other cell-based interventions inaccurately marketed as containing or acting on stem cells, not only puts patients at risk but also represents one of the



most serious threats to the stem cell research community, as it may jeopardize the reputation of the field and cause confusion about the actual state of scientific and clinical development.

Government authorities and professional organizations are strongly encouraged to establish and strictly enforce regulations governing the introduction of stem cell-based medical interventions into commercial use."

Over several months, I have been in communication with Professor Paul Knoepfler, Prof. of Cell Biology at UC Davis Med Center. His book, *Stem Cells: An Insider's Guide*, lays out a clear case against taking part in such

therapy since stem cell use is still in the research stage. He warns that there are some

clear dangers that numerous stem cell clinics do not mention.

## 2) Gene Therapy

### What is gene therapy? (From the National Institutes of Health)

Gene therapy is an experimental technique that uses genes to treat or prevent disease. In the future, this technique may allow doctors to treat a disorder by inserting a gene into a patient's cells instead of using drugs or surgery. Researchers are testing several approaches to gene therapy, including:

- Replacing a mutated gene that causes disease with a healthy copy of the gene.
- Inactivating, or "knocking out," a mutated gene that is functioning improperly.
- Introducing a new gene into the body to help fight a disease.



Although gene therapy is a promising treatment option for a number of diseases (including inherited disorders, some types of cancer, and certain viral infections), the technique remains risky and is still under study to make sure that it will be safe and effective. Gene therapy is currently only being tested for the treatment of diseases that have no other cures.

### What are the ethical issues surrounding gene therapy?

Because gene therapy involves making changes to the body's set of basic instructions, it raises many unique ethical concerns. The ethical questions surrounding gene therapy include: How can "good" and "bad" uses of gene therapy be distinguished?

Who decides which traits are normal and which constitute a disability or disorder?

Will the high costs of gene therapy make it available only to the wealthy?

Could the widespread use of gene therapy make society less accepting of people who are different?

Should people be allowed to use gene therapy to enhance basic human traits such as height, intelligence, or athletic ability?

Current gene therapy research has focused on treating individuals by targeting the therapy to body cells such as bone marrow or blood cells.

This type of gene therapy cannot be passed on to a person's children. Gene therapy could be targeted to egg and sperm cells (germ cells), however, which would allow the inserted gene to be passed on to future generations. This approach is known as germline gene therapy.

The idea of germline gene therapy is controversial. While it could spare future generations in a family from having a particular genetic disorder, it might affect the development of a fetus in unexpected ways or have long-term side effects that are not yet known. Because people who would be affected by germline gene therapy are not yet born, they can't choose whether to have the treatment. Because of these ethical concerns, the U.S. Government does not allow federal funds to be used for research on germline gene therapy in people.

## 3) Earthing or Grounding: Statement by Dr. Andrew Weil, MD



... also called "grounding" stems from the idea that in modern city life we no longer have direct physical contact with the Earth, and therefore are losing out on purported health benefits of exchanging electrons with the surface of our planet. A handful of small studies have found that grounding appears to provide some general health benefits, such as better sleep, less pain, reduced stress and tension, and better immune function compared to study participants who weren't grounded. One study suggested that earthing



eliminates the potentially harmful effects of the electromagnetic given off by all the electronic devices that surround us.

According to earthing proponents, you can ground yourself by walking outside barefoot, sitting on the ground or being connected to the Earth via grounding devices that transfer electrons from the earth to your body. There are even special shoes that feature copper contacts the soles, linking the body to the earth.

Supposedly, electrons drawn into the body from the earth neutralize damaging free radicals and by extension reduce disease-related chronic or acute inflammation. In one investigation, participants slept on a special mat that had a connection to a grounding device outside the house. When compared to the ungrounded participants in the same study, the grounded ones showed significant changes in key biomarkers including serum sodium, potassium, magnesium, iron, total protein and others.

Earthing enthusiasts claim that throughout history, our ancestors walked barefoot or wore shoes made from animal skins, which gave them direct contact with the Earth. Of course, for the most part those ancestors, grounded or not, lived short, hard lives for a variety of reasons, so it is difficult to draw conclusions about the effect of grounding, if any, on their overall health.

We'll need additional studies of better design and with more participants before we can know

if it is really possible to derive health benefits from earthing.

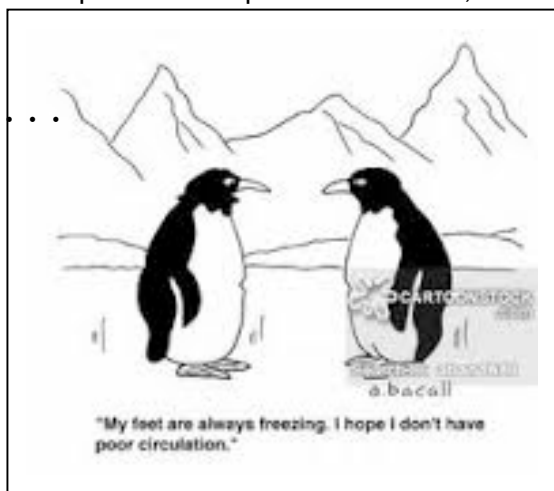
While the studies done so far are intriguing, some of the hype for earthing is over-the-top. I don't buy the extravagant claim by one proponent that, "You can literally feel the pain draining from your body as soon as you touch the earth." Is that something you've noticed whenever you've stood barefoot in your backyard or kicked off your sandals at the beach?

Be aware that there's a substantial commercial aspect to earthing. One website that I visited sells a range of equipment, including earthing beds said to do what "no other mattress on the planet can...(reconnect) you to the Earth's gentle, natural healing energy while you sleep." I'm all for going barefoot whenever possible, outdoors or in. It simulates the feet and can be very relaxing.

Those who practice [reflexology](#) often recommend walking barefoot on round stones to help stimulate pressure points on the feet, and I've written on this site about the relatively new enthusiasm for [barefoot running](#), which (when you get used to it) is supposed to be less jarring and less likely to lead to injuries. As for earthing, let's wait see if future research confirms and expands on the very little we know now

The room discussion following these topics seemed to agree that stem cell treatment and gene therapy are as yet not sufficiently studied to agree to submit to treatment. Frequently, stem cell clinics charge a great deal (often cited is \$5,000 for the treatment) without assurance that the process is truly safe. However, earthing is an attractive possibility, but again: further study is needed before we accept it without question. All in all, the discussion proved to be interesting and informative!

It's To Laugh . . .



## PLEASE USE CAUTION WITH “NEUROPAHTY CLINICS”

By Bev Anderson, President, Western Neuropathy Association  
Reprinted from the October 2016 edition of WNA's *Neuropathy Hope*

Clinics promising cures or at least much relief from neuropathy are popping up everywhere. A clinic in one part of the country that has had success will open a facility in another part of the country. They actively tell you they are concerned about helping people and they are there for the good of those they serve. They may appear to be caring people with clean, up to date offices and equipment.

The names sound appropriate, too. They offer free initial exams and consults. “We never pressure people,” I’m told when contacted. However, a person who contacts the same clinic may be told they must take these treatments or they will lose a foot or leg or at least be in a wheelchair.

Some of them approach our group leaders and want to speak to the group or invite them to a dinner or some such overture. Please don’t open the doors of your group to these clinics or whatever they call themselves. The usual rate is now \$5,000-410,000 up front without a guarantee or money back if it doesn’t help. For that sum, a patient could buy the same equipment to use at home on an ongoing basis and other treatments with the first \$1,000 or so and save the rest. They will help you with a long-term loan that you may not live long enough to pay off which they

call “easy payment loans.” There are treatments like massage, acupuncture, and exercise that can be helpful, but they, too, must be continued, but for much longer with the amount of money charged by the clinics. Also a person can quit these other alternative treatments if they weren’t helping.

If we had members who reported great improvement that lasted beyond a few months, we might be more supportive. A few notice some residual relief that takes longer to recede. We got excited about one clinic for a while as it seemed like things were changing drastically for people, but when the treatments ended, the help faded as well.

This has happened in major clinical trials with some of the equipment as well. For example, we know that infrared light treatments with Anodyne, Health Light or Big Foot do wonders for some people. However, you have to be able to keep up the treatments for the rest of your life and the best way is with a home unit available from either of the first two listed here. Some of the “clinics” call them Low Level Lasers, but they are not lasers. You can find these at [AnodyneTherapy.com](http://AnodyneTherapy.com) (800-521-6664) or at [www.HealthLight.us](http://www.HealthLight.us) (888-395-3040).





## UPCOMING MEETINGS

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

### Davis

**2<sup>nd</sup> Tuesday, December 6, 3:30-5:00**

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

### Sacramento

**3<sup>rd</sup> Tuesday, December 13, 1:30-3:00**

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

### Woodland

Cancelled, pending new leadership

A special thank you to everyone who receives this newsletter via e-mail. It helps save a lot of postage!

Call the editor if you would like to change to electronic mail:  
530-756-5102

### 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](http://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*
  - The Foundation for Peripheral Neuropathy- [www.foundationforpn.org](http://www.foundationforpn.org) (a national organization)
  - Western Neuropathy Association (WNA) (formerly PCNA) – [www.pnhelp.org](http://www.pnhelp.org) or toll-free (877) 662-6298
  - [www.diabetes.org](http://www.diabetes.org)
  - [www.neuropathysupportnetwork.org](http://www.neuropathysupportnetwork.org)
  - Neuropathy Journal at [www.neuropathyjournal.org](http://www.neuropathyjournal.org)
  - Eugene B Richardson MDiv, MSM, EdM, MS, Patient Educator in the DVD “Coping with Chronic Neuropathy”

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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