

November 2018 Issue 11 Volume 16

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WESTERN NEUROPATHY ASSOCIATION

P.O. Box 276567 Sacramento, CA 95827-6567 877-622-6298 888-556-3356 info@WNAinfo.org www.WNAinfo.org

Neuropathy Hope

Hope through caring, support, research, education, and empowerment
A newsletter for members of Western Neuropathy Association (WNA)

UNDERSTANDING A NEUROLOGIST'S APPROACH TO THE DIAGNOSIS AND TREATMENT OF PERIPHERAL NEUROPATHY

RICHARD LEWIS, MD. FAAN, Director EMG Laboratory and Co-Director Neuromuscular Clinic, Cedars-Sinai Notes by Barbara Montgomery

There is a

need for a good

communicator

as what the doctor

means by what they

say may not be what

you think it means.

What We'll Talk About:

The first information that the doctor will talk about is the history and the results of the initial examination. There is a need for a good

communicator as what the doctor means by what they say may not be what you think it means. Pain is different from numbness. Some symptoms may indicate Plantar Fasciitis, for instance, not neuropathy. Both feet burning at night likely not from your back.

Treatable Neuropathies - We will explore which you have.

- What are treatable neuropathies?
- Why do all the tests we do?
- How the tests determine if you have a disorder that is amenable to treatment.

What Factors go into the decision as to how to treat?

Why your Dr. Asks All Those Questions

- When did your symptoms start?
- Chronic vs acute
- Not just when it became severe...when did it start!! Critical to know when it started. As a teen, its inherited, later in life, more acquired disorder.
- How has it changed over time?
- Progressive, Monophasic or Relapsing
- If it moves up...it's progressing
- Some with chemo timed when you got chemo.
 Chemo was toxic, it can get worse or better.
- Guillain Barre: Fast 2-3 weeks, takes months/ years. Monophasic IVIG is of no benefit.

- CIDP: Long term treatment and IVIG treatment, if necessary
- Starts in toes, length dependent. The further it spreads; the more likely damage occurs.

Tap into our own fears. About 90% of the time patients ask the doctor if you are going to walk the rest of your life. Tell the doctor your concerns so they can be dealt with. Most people do continue to walk.

Where were the first symptoms and how has that changed: Dr. needs to know how it evolved. There is no quick fix.

- Symmetry
- Distal (length dependent) or generalized

(90% of diagnosis is based on history) What are your symptoms?

- Numbness
- Weakness
- Pain
- Autonomic
 - Perspiration
 - Bowel
 - Bladder
 - Sexual Function
 - Fainting when standing up

Dr. and patients don't always speak the same language. If you don't understand, ask.

Numbness=Tingling=Pins and needles

Numbness/Weakness

Pain, Discomfort, annoyance - "Want it to go Away."

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2018 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

Diane Blakley Designs

Roster of Our WNA Information and Support Groups

CALIFORNIA

Auburn

November 5, 10:30AM

20th Anniversary Luncheon

Black Bear Diner

RSVP necessary, \$25pp

Call 888-556-3356

Berkeley-Oakland

3rd Wed., 3-4 PM

North Berkeley Senior Center

1901 Hearst Ave.

Kathleen Nagel (510) 653-8625

Carmichael - Atria

Atria - Carmichael Oaks

8350 Fair Oaks Boulevard

For information, call:

Bev Anderson 877-622-6298

Castro Valley

2nd Wednesday, 1:30 PM

First Presbyterian Church

2490 Grove Way (next to Trader Joe)

Joy Rotz (510) 842-8440

Concord

3rd Thursday, 1:30 PM

First Christian Church

3039 Willow Pass Road

Wayne Korsinen (925)685-0953

Costa Mesa

3rd Wednesday, 10:00 AM

Call Martha Woodside

949-573-0056 for the location

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

Folsom

4th Wednesday, 12:30 PM (odd numbered months)

Burger Rehabilitation

1301 E. Bidwell St.

Bev Anderson (877) 622-6298

Fresno

3rd Tuesday, 11:00 AM

Denny's Restaurant

1110 East Shaw

Bonnie Zimmerman (559) 313-6140

Grass Valley

2nd Monday, 1:30 PM

GV United Methodist Church

236 S. Church Street

Bev Anderson 877-622-6298

Livermore

4th Tuesday, 10 AM

Heritage Estates, 900 E. Stanley Blvd.

Lee Parlett (925) 292-9280

Merced

2nd Thursday, 1 PM

Central Presbyterian Church

1920 Canal Street

(Hoffmeiser Center across 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 St.

Ron Patrick (707) 257-2343 bonjournapa@hotmail.com

Placerville

2nd Wednesday, 1 PM El Dorado Senior Center

937 Spring Street

Bev Anderson (877) 622-6298

Redwood City

4th Tuesday, 1 PM

Seguoia Hospital Health and Wellness Center

749 Brewster Avenue

Danielle LaFlash (415) 297-1815

Roseville

2nd Wednesday, 1PM (odd numbered months) Sierra Point Sr. Res., 5161 Foothills Blvd.

Stan Pashote (916) 409-5747

Sacramento

3rd Tuesday, 1:30 PM

Northminster Presby. Church

3235 Pope Street

Charles Moore (916) 485-7723

San Francisco

2nd Monday, 11 AM – 12:30 PM

Kaiser French Campus

4141 Geary Blvd. between 6th & 7th Ave.

Rm. 411A - Watch for signs.

Merle (415) 346-9781

San Jose

3rd Saturday, 10:30 AM

O'Conner Hospital, 2105 Forest Avenue

SJ DePaul Conf. Rm.

Danielle LaFlash (415) 297-1815

Santa Barbara

4th Saturday, 10AM (Sept., Oct., Jan., March,

May) St. Raphael Catholic Church

5444 Hollister Ave., Conference Room

Shirley Hopper (805) 689-5939

Santa Cruz

3rd Wednesday, 12:30 PM (odd numbered months)

Trinity Presbyterian Church

420 Melrose Avenue

Mary Ann Leer (831) 477-1239

Santa Rosa

1st Wednesday, 10:30 AM

Steele Lane Community Center

415 Steele Lane

Judy Leandro (707) 480-3740

Thousand Oaks - Westlake Village

2nd Monday, 2:30 – 4 PM

United Methodist Church of Westlake Village

1049 S. Westlake Blvd.

Angie Becerra (805) 390-2999

Walnut Creek

4th Friday, 10 AM Rossmoor, Hillside Clubhouse

Vista Room

Karen Hewitt (925) 932-2248 NEVADA

Las Vegas

3rd Thursday, 1 PM

Mountain View Presbyterian Church 8601 Del Webb Blvd.

Barbara Montgomery (818) 400-0296

OREGON

Grants Pass 3rd Wednesday 2:00 PM

Club Northwest

2160 N.W. Vine St. Carol Smith 541-955-4995

David Tally 541-218-4418

Editor

Newsletter Design by

For information on groups in the following areas or any other place you are interested in finding out about a support group, call Bev Anderson at (877) 622-6298. She is actively trying to open new groups and re-open closed groups. Check with her about a group in your area especially if you would volunteer to be the leader. California: Alturas, Antioch-Brentwood, Bakersfield, Clearlake, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, Salinas, San Francisco, Santa Maria, San Rafael, Sonoma, Sonora, Stockton, Susanville, Truckee, Tulare-Visalia, Turlock, West Sacramento, Weed, Ukiah, Woodland, Yreka, Yuba City-Marysville. Nevada: Reno-Sparks. Oregon: Brookings, Medford, Portland, Salem.

President's Message By Bev Anderson

The joys of the first rain of the season gathered together this first week of October. The question comes – When will we see the next as the dangerous north winds threaten. My habit is not to lay the first fire in the fireplace until after the second rain. The temptation was great tonight but it isn't time yet.

In this issue, we are featuring notes taken of Dr. Richard Lewis at the Neuropathy Action Foundation Conference in Los Angeles in June. Barbara Montgomery took the notes as she watched the Live Streaming from her home in Las Vegas. I greatly appreciate her doing this. There will be more from different speakers.

In reading the article about Biotin affecting blood tests (page 4), I wondered how many other supplements do this and research on them is not readily available as they basically are outside of regulation. Be very careful of any supplement you take to be sure it is from a reputable source. Some are medications from other countries, including Russia, that were not accepted for trial in the United States. Since there is little to no testing or oversight required of supplements, there is an open door for them. So be very, very wary of supplements.

I notice that November 27 is listed on my calendar as Giving Tuesday. We are going to send a letter to everyone pointing this out and suggesting that a gift be given to WNA on that day or a day of your choice. It is a nationwide special emphasis that we want to encourage. It is a period of time when a lot of financial outlays come due, but it is also a good time to encourage your neuropathy organization that helps you during the year. We greatly appreciate the contributions many of you have made in 2018.

We continue to celebrate our 20th anniversary, which is actually November 5, with the anniversary luncheon in Auburn where it all started. Thank you to all of you who have helped for the years, months, or even days you have been part of this organization which changed its name four times.

Some of you may be like me in that I usually have my birthday candles in a pumpkin pie as it is near Thanksgiving. At the Sacramento Area Anniversary Luncheon, Charles Moore, leader of our Sacramento Neuropathy Support Group, pointed out to all that we are almost twins but I am much older than he by about 24 hours. My birthday is the 24th and his the 25th.

Happy Thanksgiving,

Bev

BIOTIN SUPPLEMENTS MAY INTERFERE WITH BLOOD TESTS

Biotin supplements taken at common over-the-counter does can interfere with the results of certain hormone assays, giving falsely high or low results that could lead to a misdiagnosis, researchers reported.

In six healthy adults taking 10 mg/day of biotin for 1 week, biotin-associated interference was found in nine of 23 biotinylated assays (39%), compare with zero of 14 non-biotinylated assays (P=0.007 for comparison) according to Danni Li, PhD, of the University of Minnesota in Minneapolis, and colleagues.

The results of five of eight biotinylated competitive immunoassays (63%) tested falsely high and the results of four of the 15 biotinylated sandwich immunoassays (27) tested falsely low, the authors wrote in the Journal of the American Medical Association (JAMA).

Note: You would be wise to not take a biotin supplement for a few days before a blood test if you are taking any at all. To read the entire article go to Li D, et al "Association of biotin ingestion with performance of hormone and non-hormone assays in healthy adults" JAMA 2017; 318:1150-1160. (https://www.medpagetoday.com/endocrinology/generalendocrinology/68137) Used by permission of MedPage Today.



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

Affords

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 WNA Membership Card and claim the discount.

Anodyne Therapy
Infrared Light Therapy
equipment - 12%
off all home units.
Contact: 800-521-6664 or
www.anodynetherapy.com

HealthLight Infrared Light Therapy equipment - 5% 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 WNA Discount: 10% off the regular price shoes.

Elk Grove Shoes That Fit 8649 Elk Grove Blvd.

(916) 686-1050 WNA 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 WNA Discount: 10% off the regular price shoes.

West Sacramento
Beverly's Never Just
Haircuts and Lilly's Nails
2007 W. Capitol Ave
Hair – (916) 372-5606
Nails – (916) 346-8342
WNA discount: 10% off
the regular price.

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RUSSIAN DRUGS PASS AS SUPPLEMENTS IN U.S.

Two pharmaceutical-grade drugs are being marketed as brain-boosting supplements. By Kristina Flore, Staff Writer, MedPage Today, October 01, 2015

Two pharmaceutical-grade drugs are being marketed as brain-boosting botanical supplements, researchers found.

Both vinpocetine and picamilon are prescribed as cerebrovascular drugs in several other countries, but are sold as nutritional supplements in the U.S. and marketed to improve focus and memory. Neither is a simple botanical extract: vinpocetine is the product of heavy refinement of the alkaloid vincamine (found in the lesser periwinkle function – for health patients to prevent disease as well as for patients with neurological or muscle diseases, including Alzheimer's, dementia, and multiple sclerosis (MS), but in some instances these compounds may cause more harm than good.

Vinpocetine, for instance, has been observed to obstruct myelin repair which could be seen especially problematic for MS patients.

In an analysis of the brands of these supplements sold at GNC and the Vitamin Shoppe, many delivered the same daily doses as when the drug is prescribed pharmacologically, Pieter Cohen, MD, of Harvard Medical School and the Cambridge Health Alliance, and colleagues reported in Drug Testing and Analysis.

"The FDA has permitted an unapproved new drug with unproven efficacy and known adverse effects to be sold directly to consumers," Cohen wrote in an accompanying commentary in May Clinic Proceedings about vinpocetine. "The FDA should not permit unapproved drugs, even semisynthetic derivatives of natural compounds, to be sold as dietary supplements."

Vinpocetine is prescribed in Russia, China, Germany, and other countries for acute stroke and cognitive impairment, but it has never been approved by the FDA as a prescription drug.

Data on its neuroprotective effects are conflicting, while its known ide effects include flushing, headaches, and decreased blood pressure.

Om 1997, a manufacturer submitted a new dietary ingredient notification to FDA, and since then it has been permitted as a supplement.

Cohen said the agency "may have assumed that vinpocetine was a botanical extract,

but it is not." It can be synthesized from vincamine, which is found in the leaves of the lesser periwinkle, but it is the result of heavy processing and has never been identified by itself in any plant.

Unlike vinpocetine, picamilon has never been submitted to the FDA. Cohen said.

For their study, Cohen and colleagues analyzed 23 brands of vinpocetine and 31 brands of picamilon supplements to determine the accuracy of their labels. They used the ultrahigh-performance liquid chromatography photodiode-array method to quantify these ingredients.

They found that 23 of the vinpocetine brands contained quantities ranging from 0.3 mg to 32 mg per recommended daily serving – with many of these falling in the pharmaceutical dose range of the drug, which is 5 mg to 40 mg. There was no vinpocetine in six samples.

They also compared two samples of Vinca minor and found the alkaloid vincamine, but there was no vinpocetine at all, they reported.

Of the 31 brands of picamilon supplements, 30 had quantities ranging from 2.7 mg to 721.5 mg per recommended daily serving. Prescription doses range from 50 mg to 200 mg.

"New drugs can bypass the rigorous drug approval process and be sold directly to consumers without FDA approval," Cohen said.

The study was limited because the researchers only sampled one of each supplement, but Cohen said this kind of practice wouldn't be unusual in a system that doesn't require companies to report how much active ingredient is in the product or what its side effects might be.

He and his team concluded that the findings show that drugs prescribed as pharmaceuticals in other countries are being sold openly in dietary supplements in the U.S. "Remarkably," he added, "the FDA has done nothing to intervene in the sale of these brain enhancing supplements containing unapproved drugs."

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Understanding A Neurologist's Approach To The Diagnosis And Treatment Of Peripheral Neuropathy – Continued from page 1

PATIENT:

Wants to impress about how terrible pain is.

Wants relief now

Afraid of wheelchairs/paralysis

Feelings about walking with aids

Wants cure

Wants pain to stop

Want worst defects to go away

Fatigue=weakness

DOCTOR:

Needs to understand the evaluation of the problem

Can't help without understanding

Unaware of patients fear. Knows paralysis is rare.

Most people walk. (maybe braces or walkers)

Knows cure is unlikely

Try to CONTROL pain

Knows worst defects are hardest to get rid of

Define long and short-term goal treatments

Fatigue and no weakness

WILL THE QUESTIONS NEVER END?

- · Other Disorders
 - Do they relate to the neuropathic symptoms?
- Family History
 - A common cause of neuropathy
- Medication/Diet
- · Sexual function, bladder control, bowels
- All relevant and provide clues as to the cause and severity

The Examination:

Focuses on specific issues and feet are key. If it moves up...it is progressing.

- · Tuning forks and vibration
 - Why do so many patients guess?
- Large Fiber sensations
 - Vibration and Position
- Small Fiber Sensations
 - Pain and temperature
- Reflexes
 - Reduced or absent
 - Brisk may be too brisk
 - When reduced need to hit hard with heavy hammers
- Babinski Sign
 - When present means the disorder may not be neuropathy
 - Scratching the bottom of the feet and seeing a big toe bending forward.

Testing Motor System:

Tone

- · Reduced is consistent with neuropathy
- Atrophy
 - Suggest there has been significant loss of muscle tissue which may not be reversible
- Strength
 - Looking for persistent effort
 - Max strength measures how the nervemuscle connection is working

Why do I need an EMG?

- · Safe and discomfort can be limited
- Is essential to understand the nature of the disease
- Unfortunately, not all EMG's are created Equal
- The exam must be tailored to the individual's specific problems
- What nerves and muscles to test? Can change depending on the findings of the nerves already tested
- · No one recipe works

What the Nerve Conduction Studies tell

- Symmetry
- Localization
 - Distal
 - Generalized
 - Multifocal
- Sensory, motor or both
- Severity
- Axonal vs Demyelination

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DISCOUNTS FOR WNA MEMBERS

Continued from page 4

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 30day supply is \$40 (normally \$49.97). It can be autoshipped 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.

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.

Understanding A Neurologist's Approach To The Diagnosis And Treatment Of Peripheral Neuropathy

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Axonal vs. Demyelinating Neuropathies:

Axonal

Most common Less Treatable Less Severe

Primary finding in diabetes Most nutritional and toxic The major of idiopathic

Improvement is often incomplete and slow

Demyelinating

Inflammatory=CIDP

Immune

Most common form of CMT More likely to be treatable Can be very severe

Can improve relatively quickly

Why do they stick needles in my Muscles?

- Needle EMG gives a direct measurement of how many nerve fibers are connected to the muscle.
- Can give an idea of chronicity and severity.
- Can localize a problem in ways that nerve conduction studies can't.
- Can look at more proximal regions.

When should I have a Nerve Biopsy?

- Most of the time biopsy is unnecessary
- Rarely diagnose a disorder unless
 - Vasculitis
 - Infiltrating disorders: amyloid, cancer
 - Unique signature: Tomacula suggests HNPP
- Can occasionally tell axonal vs demyelinating when EMG unclear
- Minor surgery but will leave numb region (sometimes painful)
- Best done at centers that have expertise

TREATMENT: A Contract Between Patient and Physician

- Patient expectations and physician goals need to be in synch.
 - Short term vs long term
- You need to know what would signify treatment effect
 - Subtility (stopping progression) or improvement
 - Strength or sensation or pain?
 - What muscles are likely to get stronger. Which aren't.
 - Change in exam or improved function
- Some with chemo, timed when you get chemo. Chemo was toxic, can get worse, better with time.

How long till meds take effect? Is it even beginning to work?

With meds know what to expect.

CIDP: Inflammation, can't get out of braces, but is the med working at all. Markers: Muscles getting stronger, doing things not doing before, good sign.

Meds control, but don't cure.

Lumbar Spinal Stenosis may develop and cause trouble.

**B6 can be problematic. B6 is important for nerves, but too much can be harmful to the nerves. Anything taken in the mouth is medication

Large or small fibers involved.

Sometimes not coming from peripheral nerves but from Central Nervous System.

Axon wires have myelin sheaf-like insulation, demyelinating insulation or the sheaf breaking down indicates major damage and increasing neuropathy.

Meds: Benefit MUST be better than the risk.

 Side effects are not risks: Risk is perhaps death. Not everyone gets the same side effects. Even natural substances can be meds. Prescriptions have at least tests. Whatever you put in your body is a medication.

Improving sleep is critical. Have to deal with sleep. Mindfulness/relaxation will reduce pain.

Treatment Considerations:

- Risky treatments should be used for risky diseases
- Risk varies by age, comorbid conditions
- Patients want to get better but do you take the risk of medication toxicities to improve in a disease that is not dangerous but troubling

Side Effects and Toxicity

- Most side effects go away when you stop taking the meds.
 Why not give it a try?
- Risk is different. A life-threatening infection may not go away if you stop the treatment

I won't take medication: Aren't there natural treatments?

- Anything you take to change your body chemistry is a medication doesn't matter if its natural or organic' or developed by a pharmaceutical company.
- Prescribed meds are neither inherently better or worse or less risky.
- With prescribed meds because they have had to pass FDA standards (so have Opioids) we know most (but not all) risks, side effects and benefits.

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NEUROPATHY MEDICAL 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 connect 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.

The reader can also go to the WNA website www.pnhelp.org , click on the RESOURCES tab and select MEDICAL LITERATURE REVIEW from the menu to review the archive of summaries that have appeared in this column over recent years.

This month's PMIDs:

- 26599185 This is a review of distal symmetric polyneuropathy, the most common form of neuropathy, affecting 2%-7% of the population. If the cause is not known, the diagnostic evaluation should include the following: complete blood count, comprehensive metabolic panel, B 12 level, serum protein electrophoresis with immunofixation, and glucose tolerance test. If onset is acute or subacute; or, if motor, asymmetric, non-length-dependent, or autonomic, a neurologic consultation should be sought.
- 27350330 This Johns Hopkins paper reports on the testing (rodents) of a compound, ethoxyquin, that prevents neuropathy caused by the cancer chemotherapy agent, paclitaxel. Ethoxyquin is an antioxidant widely available as a food additive.
- 27813425 This paper by Papanas and Ziegler emphasizes the fact that there is no monotherapy for the pain of diabetic neuropathy effective in more than 50% of patients—a substantial unmet need.
- 28067783 This paper explores stem cell transplantation to effect peripheral nerve regeneration. The problem of harvesting the stem cells is the donor site morbidity. The stem cells become Schwannlike cells that secrete neurotropic factors that promote axonal growth and remyelination.

NOT ANTISCIENCE By William Donovan, M.D.

Why do I write my column, Neuropathy Medical Literature Review?

There has been a troublesome trend to devalue science, including its warnings on pollution, global warming, vaccinations and pesticides. I assume that Neuropathy Hope readers will want the best scientific information they can get on their neuropathic illness. I believe you want to know what well-trained, serious scientists are finding out the causes and cures of what ails us.

I search all neuropathy articles in the world literature published in "peer-reviewed" medical journals. Peer-reviewed means that all articles that have been accepted for publication have been reviewed by prominent researchers, recognized experts and teachers in the authors' field.

You may see such terms as "randomized" and "placebocontrolled." They mean that the patients have been selected by chance as to whether they get the active medication being tested (treatment group), or placebo (control group).

Other methods of avoiding bias and assuring objectivity include the following. "Double blinded" means that neither

the doctor administering the drug (or placebo) and evaluating its effects nor the patient taking the drug (or placebo) and reporting its effects know which one they are giving or receiving. Please read this sentence again. It is difficult to get but important.

Statistical tests are applied to the data, resulting in a "p" value, a number representing the probability that the difference between groups could have happened by chance even though there might not have been any effect. Read this sentence twice! The lower the number the better. For example, p=0.001 would mean that such a big difference could have happened one in a thousand by chance alone. The lower the probability of a chance result, the more confident we are about the result.

High quality scientific articles may be the most reliable source of information, but that does not mean that we are not excited when we hear that something helped a fellow sufferer. At least we know that help is possible. What I try to do in my column is to share good scientific information that might help us—hopefully in a most understandable form!

Any Questions? Email me at neuropathy@sbcglobal.net .

Understanding A Neurologist's Approach To The Diagnosis And Treatment Of Peripheral Neuropathy – Continued from page 6

 Natural Treatments are less well studied and so the benefits are unknown. The risks tend to be small but not zero.

Treatable Neuropathies:

What is meant by treatable?

 All neuropathies can be helped but few can be treated to reverse, control or cure the disease.

Helping:

- Controlling symptoms=pain meds, therapy
- Improving function-adaptive aids/therapy
- Slowing progression by impacting risk factors
 - Better control of diabetes
 - Better nutrition
 - Better sleep



WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit, tax exempt corporation

P.O. Box 276567, Sacramento, CA 95827-6567

Call WNA using our toll free phone numbers: (877) 622-6298 Email: info@WNAinfo.org

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- General Organizational Inquiries www.WNAinfo.org

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Western Neuropathy Association (WNA)

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Bev Anderson, Editor

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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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