



WESTERN NEUROPATHY ASSOCIATION

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Issue 06  
Volume 19

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Celebrating our 23rd Year!

# Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

## IS IT NEUROPATHY? MAYBE NOT.

By Bev Anderson, WNA President and editor of NEUROPATHY HOPE

A sizable number of you have called me at some time over the nearly 23 years I've been available by phone. Each of you have contributed to what I know about neuropathy. I've either told you something I'd learned or because of your questions and research, I've learned more so I could tell you and others. Recently a gentleman called and much has been learned that I want to share with you.

It started with hearing about descriptions of pain in areas that are not that commonly mentioned by a person initially talking about neuropathy. Then he said he had been diagnosed as having polyneuropathy. This is a common diagnosis meaning more than one nerve is involved. He had seen several neurologists who confirmed this diagnosis. The first one had prescribed a higher amount of gabapentin than might be considered an initial dosage. The subsequent physicians he went to asking for more relief of pain said to keep taking what he was currently taking which he was telling them wasn't working after several months. I checked their credentials. One physician was said to be a neuromuscular neurologist but his profile didn't list the specialty for his fellowship. Three other physicians listed neuropathy, general neuropathy and finally another specialized in epilepsy.

I've mentioned this last year and a year or so before that anyone with symptoms of neuropathy should see a neuromuscular neurologist. In the United States most neurologists are doctors who graduated from medical school as internists or other general practice doctors first. They may or may not have practiced as primary care physicians for a few or many years before choosing to begin a residency in neurology and ultimately to become a neurologist. This is a three-year course. In this residency, they will chiefly study the central nervous system and the diseases involved in the brain and spinal cord which are crucial for them to know. These diseases can be fatal sooner or later where few neuropathies do this.

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## BANNED STIMULANTS AGAIN FOUND IN SUPPLEMENTS

— Researchers question FDA's commitment to enforcement

By Ryan Basen, Enterprise & Investigative Writer, MedPage Today March 23, 2021

Weight loss and sports supplements were found to contain cocktails of banned and unapproved stimulants, including one dangerous stimulant FDA ordered manufacturers to stop using years ago. That's according to a study published Tuesday in Clinical Toxicology, with its lead author saying the FDA's oversight of the supplement industry continues to lag.

Pieter Cohen, MD, of Harvard Medical School and Cambridge Health Alliance in Massachusetts, and co-authors examined the makeup of 17 brands of over-the-counter supplements in the U.S., purchased online, that were labeled to include deterenol, a beta-agonist that has never been approved for use in the U.S., and which FDA banned from supplements in 2004.

Across those brands, the researchers found nine stimulant compounds that are not allowed in supplements, and eight different combinations of stimulants. Fewer than half contained only deterenol (47%). Four brands included two stimulants, two brands combined three stimulants, and two other brands combined four stimulants.

These stimulants included phenpromethamine (Vonedrine), BMPEA, oxilofrine, octodrine, higenamine, 1,3-DMAA, 1,3-DMBA, and 1,4-DMAA. Deterenol has been found in several supplements sold in the U.S. in

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## 2021 WNA Board of Directors

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Please contact  
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page on the  
WNA website –  
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to find out about the  
topic/speaker for the  
upcoming meeting.

**Bev Anderson**  
Editor

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## WNA MAY TELECONFERENCES AND ONLINE ZOOM SCHEDULE

Everyone is welcome to join any of the following calls. We encourage you to join in this opportunity to be on a call with other people that know about or experience neuropathy.

- **June 9** (Wednesday) 1:00 pm PDT 3:00 pm CDT
- **June 14** (Monday) 6:30pm PDT 8:30 pm CDT
- **June 15** (Tuesday) 1:30 pm PDT 3.30 pm CDT
- **June 19** (Saturday) 10:30 am PDT 12:30 pm CDT

### HOW TO CALL IN TO TELECONFERENCES

At the meeting time, call this number: 1-877-366-0711. You will hear an automated voice ask for the pass code to join the conference call. Using your telephone keypad, dial 36199447# A notification sound will chime in the "conference room" so we know someone has joined the call, and we will welcome you.

**ZOOM MEETINGS** - Everyone is invited to join in on any of the online meetings. Contact the leader for the link to join the meeting.

- **Saturday, June 12 and 26**, 11:00am-12:30pm PDT / 1:00-2:30pm CDT: Houston, TX Neuropathy Support Group. For Zoom link – email Katherine Stenzel at klstenzel@hotmail.com, giving name, address, telephone number and email address.
- **Wednesday, June 16**, 10:30am-11:30am PDT / 12:30pm-1:30pm CDT: Monterey, CA Neuropathy Support Group. Sign-in opens at 10:00 AM. For Zoom link – email Bill Donovan MD at wbdpad@gmail.com (new email address), giving name, address, telephone number and email address. Do this even if you have done it before. He may have a new link to give you.
- **Thursday, June 17**, 1:00pm PDT / 3:00pm CDT: Nevada Neuropathy Support Group. For Zoom link – email Bev Anderson at faith95@colfaxnet.com, giving name, address, telephone number and email address. You will also receive a telephone number you may call if you want to participate by voice only.

**Support groups are not meeting in person unless a leader notifies the group that they are. If in doubt, call your leader.**

### CALIFORNIA

#### Auburn

Sharlene McCord (530) 878-8392  
Kathy Clemens (916) 580-9449

#### Castro Valley

Joy Rotz (510) 842-8440

#### Concord

Wayne Korsinen (925) 685-0953

#### Davis

Mary Sprifke (530) 756-5102

#### Elk Grove\*\*

Bev Anderson (877) 622-6298  
faith95@colfaxnet.com

#### Folsom\*\*

Bev Anderson (877) 622-6298  
faith95@colfaxnet.com

#### Fresno

Bonnie Zimmerman (559) 313-6140

#### Grass Valley\*\*

Bev Anderson (877) 622-6298  
faith95@colfaxnet.com

#### Merced

Larry Frice (209) 358-2045

#### Modesto

Harkaman Ghag (209) 541-5404

#### Monterey\*

Dr. William Donovan (831) 625-3407  
wbdpad@gmail.com

#### Napa

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

#### Placerville

Bev Anderson (877) 622-6298  
faith95@colfaxnet.com

#### Roseville

Stan Pashote (916) 409-5747

#### Sacramento #

Sonya Wells (916) 627-0228

#### San Diego

Chhattar Kucheria (858) 774-1408

#### San Francisco

Merle (415) 346-9781

#### San Jose\*\*

Bev Anderson (877) 622-6298  
faith95@colfaxnet.com

#### Santa Barbara

Nancy Kriech (805) 967-8886

#### Santa Cruz

Mary Ann Leer (831) 477-1239

#### Santa Rosa

Judy Leandro (707) 480-3740

#### South San Diego

Jacklyn (858) 228-7480

#### Walnut Creek\*\*

Bev Anderson (877) 622-6298  
faith95@colfaxnet.com

#### Westlake Village - Thousand Oaks

Angie Becerra (805) 390-2999

### NEVADA

#### Las Vegas

Barbara Montgomery  
lvneuropathygroup@gmail.com

### OREGON

#### Grants Pass

David Tally 541-218-4418

### TEXAS

#### Austin

Marty Meraviglia RN, ACNS-BC  
(512) 970-5454 • mgmeraviglia@gmail.com

#### Houston\*

Katherine Stenzel  
klstenzel@hotmail.com

\* Leader of online Zoom Meeting(s)

# Leader of Teleconference(s)

For information on new groups or other online teleconferences or Zoom meetings, call Bev Anderson at (877) 622-6298. Once we are safe for in-person meetings, new leadership will be needed in the following areas and others: California: Alturas, Antioch-Brentwood, Bakersfield, Berkeley – Oakland, Carmichael, Clearlake, Costa Mesa, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Livermore, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, Redwood City, Salinas, 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 Report By Bev Anderson

**Already this season people are drowning in waterways due to carelessness or misjudgment.** Please be careful if you are boating or swimming in lakes, rivers, oceans, etc. and urge family members to do the same. Each person is precious and having a life cut short is tragic.

**June is a milestone month.** When it ends, half the year has passed. June 21, the day after Father's Day this year, is the first day of summer – the longest day and shortest night. After this date, we start sneaking towards the first day of winter in December, which is the longest night and shortest day of the year. Enjoy our longer days. If you have someone, child or adult, in your family that is interested in science, they might like to track nature -- how many hours and minutes there are of light and darkness each day.

**Our Annual Conference went very well, I thought.** All our speakers were excellent and we learned a lot. The videos of the speakers will be on our website soon for any who missed the conference or want to listen again. There will be articles in upcoming newsletters as well. All videos are now on WNA's YouTube Channel - <https://www.youtube.com/channel/UC5bNYVSu-SlppJ0ZVGs1o5A> .

**Thank you for your response to the Big Day of Giving.** During the period of time that counted for that \$2001.65 was received. We needed \$2,500 to match the amount put forward for matching for \$5,000 to help the research being done in the lab of Bruce Hammock, Ph.D. at UC Davis. More has come in. Hurrah, the goal is reached! Any more will be used by WNA. Good news!! A review of Clinical Trial 1a is being conducted in Austin, TX where it was conducted earlier. They are testing whether the tablet form will be accepted as well as the capsule was accepted. The long awaited Clinical Trial 1b will be conducted in Southern California starting before the end of June (this month!) according to the current schedule. If these Clinical Trials come through well without any problems, it will be going forward more quickly. This pain medication is urgently needed.

**In person support groups may be possible by September** if the progress of vaccinations keeps going and the opening up of areas doesn't start a spike of new COVID-19 cases. We should know by August when we will be ready to start and which groups will need new leaders. We will continue to have one or two telephone groups and several Zoom groups. Some of you have not joined any calls during the COVID-19 period. We hope you may be interested and will try to attend a meeting. We have people calling in and zooming in who do not live near any support group meeting. They are finding it fun and helpful.

I wish you a happy summer of doing warm weather activities that are fun and uplifting for you and others.

*Bev*

## ATTENTION NEVADA RESIDENTS

**Please notice that there is a Zoom meeting for you on the 3rd Thursday of each month.** The next one is June 17 at 1 PM PDT. If you didn't receive a notice in April or May, we don't have your email address. If you would like to attend, please email Bev Anderson at [faith95@colfaxnet.com](mailto:faith95@colfaxnet.com) and the link will be sent to you.

### TELECONFERENCE AND ZOOM MEETINGS OPEN TO ALL

Please remember that you can attend any of the meetings listed on the schedule. It also can mean you attend more than one in a month. Some people attend more than one and say they do this as each is different and they are looking for ideas of what can be done to help themselves with their neuropathy. We have a variety of people attending with different information so it is quite possible to learn something new in each discussion at the meeting. Personally, I learn something new regularly so I'm sure others do too.



### 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](http://www.Medicare.gov)

...

#### The Affordable Health Care Act

For current information go to [www.HealthCare.gov](http://www.HealthCare.gov)

...

#### HICAP

#### Health Insurance Counseling

for seniors and people with disabilities.

[www.cahealthadvocates.org](http://www.cahealthadvocates.org) /HICAP/

Call (800) 434-0222 to ask a question or to make an appointment.

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#### 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](http://www.hrh.org).

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#### 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](http://www.anodynetherapy.com)

### Auburn

#### The Footpath

825 Lincoln Way  
(530) 885-2091  
[www.footpathshoes.com](http://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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## RESEARCH SITES TO EXPLORE

Prepared by Dr. Donovan

After Jan Nolta, Ph.D.'s presentation at the Annual Conference, Dr. Donovan prepared this list of research sites to explore.

Items 1-8 of 8 (Display the 8 citations in PubMed)

### 1. Stem cell therapy for neurological disorders.

Alessandrini M, Preynat-Seauve O, De Bruin K, Pepper MS.

S Afr Med J. 2019 Sep 10;109(8b):70-77. doi: 10.7196/SAMJ.2019.v109i8b.14009.

PMID: 31662153 Review.

<https://pubmed.ncbi.nlm.nih.gov/31662153/>

### 2. Peripheral Nerve Injury: Stem Cell Therapy and Peripheral Nerve Transfer.

Sullivan R, Dailey T, Duncan K, Abel N, Borlongan CV.

Int J Mol Sci. 2016 Dec 14;17(12):2101. doi: 10.3390/ijms17122101.

PMID: 27983642 Free PMC article. Review.

<https://pubmed.ncbi.nlm.nih.gov/27983642/>

### 3. Stem-cell-based therapies to enhance peripheral nerve regeneration.

Kubiak CA, Grochmal J, Kung TA, Cederna PS, Midha R, Kemp SWP.

Muscle Nerve. 2020 Apr;61(4):449-459. doi: 10.1002/mus.26760. Epub 2019 Dec 3.

PMID: 31725911 Review.

<https://pubmed.ncbi.nlm.nih.gov/31725911/>

### 4. Stem Cell Therapy for Chronic Pain Management: Review of Uses, Advances, and Adverse Effects.

Chakravarthy K, Chen Y, He C, Christo PJ.

Pain Physician. 2017 May;20(4):293-305.

PMID: 28535552 Review.

<https://pubmed.ncbi.nlm.nih.gov/28535552/>

### 5. Mesenchymal stem cell exosomes as a cell-free therapy for nerve injury-induced pain in rats.

Shiue SJ, Rau RH, Shiue HS, Hung YW, Li ZX, Yang KD, Cheng JK.

Pain. 2019 Jan;160(1):210-223. doi: 10.1097/j.pain.0000000000001395.

PMID: 30188455

<https://pubmed.ncbi.nlm.nih.gov/30188455/>

### 6. Chronic Inflammatory Demyelinating Polyradiculoneuropathy.

Shije J, Brannagan TH 3rd.

Semin Neurol. 2019 Oct;39(5):596-607. doi: 10.1055/s-0039-1693008. Epub 2019 Oct 22.

PMID: 31639843 Review.

<https://pubmed.ncbi.nlm.nih.gov/31639843/>

### 7. A Review on Stem Cell Therapy for Neuropathic Pain.

Asgharzade S, Talaei A, Farkhondeh T, Forouzanfar F.

Curr Stem Cell Res Ther. 2020;15(4):349-361. doi: 10.2174/1574888X15666200214112908.

PMID: 32056531

<https://pubmed.ncbi.nlm.nih.gov/32056531/>

### 8. Stem-cell plasticity and therapy for injuries of the peripheral nervous system.

Tohill M, Terenghi G.

Biotechnol Appl Biochem. 2004 Aug;40(Pt 1):17-24. doi: 10.1042/BA20030173.

PMID: 15270703 Review.

<https://pubmed.ncbi.nlm.nih.gov/15270703/>

## BROCCOLI AND BRUSSELS SPROUTS MAY PROMOTE HEART HEALTH

Good news if you regularly pile your plate high with broccoli and brussels sprouts: cruciferous vegetables may bring special heart benefits. A study published on line July 17 by the British Journal of Nutrition found that people who ate more cruciferous veggies (which also included cauliflower and cabbage, in the study) had less calcium buildup in their aortas (the body's largest blood vessel) than people who ate less of these veggies. Fatty deposits in arteries attract calcium and the buildup is known as calcification. Research shows that people with calcified aortas are more likely to have a heart attack or stroke.

The study's authors looked at data from 684 women ages 70 and older, measuring both their intake of cruciferous vegetables and their level of aortic calcification. They found that women who regularly ate more than 44.6 grams (equivalent to about 1/8 cup of cooked chopped broccoli) each day were 46% less likely to have high amounts of calcified fatty deposits in their aortas compared with women who rarely or never ate cruciferous vegetables.

To access the entire article - Harvard Women's Health Watch, November 2020.

## RECIPES FROM THE ANNUAL CONFERENCE

By Barbara Montgomery, Nutrition Speaker

### BAKED OATMEAL CUPS

#### Ingredients:

Rolled oats (3 cups)  
Oat flour (1/2 cup)  
Flax meal (3 tbsp)  
Cinnamon (1 tbsp)  
Sea salt (1/8 tsp. rounded)  
Banana, overripe (2 cups)  
Brown rice syrup (1/3 cup)  
Raisins (1/3 cup)  
Nondairy chocolate chips (2 tbsp) optional

#### Directions:

- Preheat oven to 350. Bake 20 minutes.
- Line a muffin tin with 15 parchment cupcake liners.
- In a large mixing bowl combine oats, oat flour, flax meal, cinnamon, and salt. Stir to combine. Next, mash or puree the banana.
- Add banana, brown rice syrup, raisins, and chocolate chips. Stir until thoroughly combined.
- Place 1/4 to 1/2 cup of the batter in each muffin cup. Use a spatula or your fingers to lightly pack in the mixture.
- Place in oven.
- Remove after 20 minutes and let cool in the pan for about 5 minutes and transfer to a cooling rack.
- Enjoy warm or cooled. Store in an airtight container in the fridge.

### HERB CRUSTED ASPARAGUS SPEARS

#### Ingredients:

1 bunch of asparagus (about 12 spears)  
1 tbsp. hemp seeds or substitute ground flax seeds, chia seeds, sunflower seeds  
1/4 cup nutritional yeast  
1 tsp. garlic powder or 3 garlic cloves minced  
1/8 tsp. ground pepper  
Pinch of paprika  
1/4 cup whole wheat bread crumbs  
Juice of 1/2 lemon

#### Directions:

- Preheat the oven to 350 degrees.
- Wash the asparagus. To remove the white

bottom end, hold each asparagus spear with both hands and bend it near the white end. The white end will snap off.

- Transfer hemp seeds or substitute to a small bowl and mix in the nutritional yeast, garlic, pepper, paprika, and bread crumbs. Stir and set aside.
- Arrange the asparagus spears side by side in a baking dish and sprinkle with mixture.
- Bake for 20-25 minutes or until asparagus spears are crispy. Sprinkle with some lemon juice.

### SMASHED BRUSSEL SPROUTS

#### Ingredients:

2 pounds whole Brussel sprouts ends trimmed  
2 tbsp. extra virgin olive oil  
2 1/2 tsp. kosher salt divided  
1/4 tsp. ground pepper  
Pinch red pepper flakes (optional)  
3 tbsp. finely grated parmesan cheese  
Juice of one small lemon (optional)

#### Directions:

- Preheat oven to 425 degrees.
- Boil sprouts for 10 minutes in water salted with 2 tsp. of the salt.
- Drain sprouts and add to an ice bath for one minute.
- Place sprouts to the center of a baking sheet. Drizzle with oil.
- Sprinkle with the remaining 1/2 tsp. salt, black pepper, and red pepper flakes (if used).
- Toss to coat, lay out in even layer. Use base of a drinking glass, gently press on each to flatten it to 1/2 inch or so thick.
- Bake Brussel sprouts for 15 minutes, then remove from the oven and carefully flip.
- Sprinkle the parmesan over the top, then return the sprouts to the oven and continue baking until they are crisp on the outside and the cheese is golden, about 5 to 10 minutes more.
- If you would like the top crisper, transfer the pan to the upper rack and turn the oven to broil. Let broil for 2 to 3 minutes.
- Remove from the oven and squeeze the lemon juice over the top (if you choose to use it).
- Enjoy hot.

### DISCOUNTS FOR WNA MEMBERS

*Continued from page 4*

#### Neuropathy Support Formula/Nerve Renew

(1-888-840-7142) is a supplement that a number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back. They now have Nerve Renew Fast Acting Cream at \$20 for WNA members. It reportedly takes the edge off numbness.

#### Building Better Balance DVD, Developing Spine Health

– The DVDs are \$30 each. The price of a full set (4 DVDs) is \$100 (that's a 20% discount). You can order the DVDs by going to the website [www.building-better-balance.com](http://www.building-better-balance.com). Shipping is free. You can also order the DVDs over the phone using a credit card. Call (707) 318-4476 and leave a message. Vanessa Kettler, Balance and Fall Prevention [www.building-better-balance.com](http://www.building-better-balance.com) (707) 318-4476

#### 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](mailto:info@pnhelp.org).

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

## DIABETES IS NOT INEVITABLE

If you do have prediabetes, developing diabetes is not a foregone conclusion. You can prevent it. The best way to do so is by adopting a healthier lifestyle. The National Diabetes Prevention Program showed that people with prediabetes, who adopted intensive lifestyle changes, reduced their likelihood of developing diabetes over the next three years by 58%, Dr. Hamdy notes. The most effective approach, he says, is a weight management program that combines nutrition counseling, at least 150 minutes of exercise per week, and a

variety of cognitive behavioral modifications, such as learning stress reduction strategies and adopting healthier eating habits than you can sustain over the long term.

You don't need to lose a lot of weight to make a difference in your diabetes risk. High-risk adults who lost just 5% to 7% of their starting body weight – that's approximately 8 to 11 pounds for a 160-pound-woman – lowered their risk of diabetes by 58%.

## PROTECT YOUR MEMORY AS YOU AGE

1. **Get plenty of exercise.** Get exercise that fits the condition you are in or the medical challenges you face.
2. **Stay social.** Research shows that being among other people and doing things together can lower the risk of dementia.
3. **Include brain exercise.** Keep your brain active by using

a computer, doing craft activities, participating in social activities, and playing games.

4. **Eat a healthy diet.**

Those that participated in these activities were most apt to stay sharp with good memory.

Info from FOCUS ON HEALTHY AGING.

## Is It Neuropathy? Maybe Not. – Continued from page 1

The peripheral nervous system is not emphasized in many of these residencies. Depending on the medical school, the person graduating from their residency may or may not know much about neuropathy. Many or most graduates apply and receive a fellowship for a specialty in neurology. Many or most of these again are in the central nervous system like multiple sclerosis, Parkinson's Disease, or epilepsy. However, a sizable number of physicians choose neuromuscular neuropathy for their fellowship and study the peripheral nervous system. Sometimes the fellowship includes the means of diagnosing neuropathy as the main topic. I'm finding that neuromuscular neurologists are found often at university medical centers and other large hospital based medical centers. However, I've examined the neurologists profiles in some medical centers and found none. There is one exception I've found. If a person had their medical school training in India, they are more likely to have knowledge of the peripheral nervous system. Some other countries may train more widely as well.

Given that this gentleman was still in pain and he could not get help where he had been seen, I asked if he would be willing to go to The Neuropathy Center at UC-San Francisco to see Dr. Jeffrey Ralph, the director who is a neuromuscular neurologist and trains neurologists in this field. The Johns Hopkins University Medical Center in Baltimore, Maryland, is designated to have the top neurology department in the nation. U.C. San Francisco is a close second. He agreed to go to UC San Francisco and had a friend willing to drive him there. Dr. Ralph saw him for a lengthy time discussing his case and ordered a couple additional tests that he wanted before making a diagnosis. These he could do in his home area and the results were sent to UC San Francisco. He was also referred to the UC San Francisco Pain Management Clinic.

He received a call very soon and his medications changed to ones that have started to help calm the pain.

If you said there was neck pain, numbness, tingling or weakness in your hand, arm, leg, or foot, difficulty walking, balance problems, and possibly bowel or bladder disfunction, you might think it is neuropathy but you could also be very wrong. It could be spinal stenosis. Spinal stenosis is in the spine itself. It is a compression response like carpal tunnel. The sides of the tube in which the spinal cord lays in contracts and compresses the spinal cord. The more this happens, the more pain that is produced. This can happen in the cervical spine (neck), thoracic spine (chest), and lumbar spine (lower back).

Cervical stenosis can cause the pain mentioned above. If it is in the neck, it affects the body from head to feet. Thoracic stenosis causes pain, spasms, and weakness in the legs and buttocks typically after walking or standing. It can affect bladder, bowel, or sexual function. Lumbar stenosis problems usually affect the lower part of the body most. In addition to symptoms mentioned above the person may complain of lower back pain.

Some causes of spinal stenosis include bone overgrowth, herniated discs, tumors, ligaments that are thickened, and spinal injuries. Neuropathy and spinal stenosis may occur together.

To investigate whether some or all of the symptoms you have could be resulting from spinal stenosis, talk to your neurologist about having one or more MRIs of your spine. If you don't have a neurologist, talk to your primary care doctor about referring you to a neuromuscular neurologist.

previous studies, with its presence confirmed by FDA chemists -- even though the agency has prohibited it. Yet, the researchers noted, the agency “has not advised manufacturers to remove deterenol from products nor warned consumers to avoid supplements labeled as containing deterenol.”

Cohen told MedPage Today that is why the new study was needed: “It’s really unfortunate it would require any new information like publishing our study to get the FDA to act,” Cohen said, “and they haven’t.”

He said he was especially surprised to find that phenpromethamine was the second most commonly detected stimulant. It was used briefly as a nasal inhaler in the 1940s, but has never been approved for oral administration.

FDA also noticed phenpromethamine’s presence in supplements while Cohen’s team was working on this study, he said, yet, as with deterenol, the agency has declined to ask manufacturers to remove it or to alert the public.

“The FDA is not removing the lowest-hanging fruit, not even warning consumers about their finding,” Cohen said.

FDA declined to answer specific questions from MedPage Today, instead emailing a statement: “The FDA is reviewing the findings of this paper,” a spokesperson wrote. “We appreciate studies like this for raising awareness and bringing needed attention to these matters. However, in general, the FDA does not comment on specific studies, but evaluates them as part of the body of evidence to further our understanding about a particular issue.”

Cohen’s group pointed out that theirs is not the first study to report such findings, some going back at least 7 years.

“It seems like the FDA is not active within this space so companies can do what they wish,” Cohen said. “Even when the FDA tries to do something ... they clearly don’t follow up in a way that ensures that stimulants are removed.”

Banning ephedra in 2004 has led to the “explosion” of other questionable stimulants in supplements, Cohen said. Manufacturers have slipped lesser-known, untested stimulants into supplements, often listing them on the bottle. Sometimes “it’s a matter of FDA reading the label and doing its job,” Cohen said.

Cohen called for Congress to reform supplement laws and for FDA to enact “robust” enforcement.

Steve Tave, JD, who directed FDA’s Office of Dietary Supplement Programs for 5 years until this month, favored mandating that manufacturers be listed in a national database, he said at a conference in September. (A copy of his prepared remarks was shared with MedPage Today by Cohen.)

“The question of ‘are dietary supplements regulated’ is a red herring. Of course, they are, and it’s silly to suggest otherwise,” Tave said. “I think we can comfortably say, at a minimum, that the dietary supplement market isn’t perfectly regulated.... While we

might know about more than 10,000 registered facilities around the world, we do not know what they are producing, and we don’t have a systematic way to know when new products are introduced to the market or what ingredients they contain.”

FDA inspected less than 5% of registered supplement facilities annually pre-pandemic, he said, adding: “The rate of non-compliance when we do inspect is very high -- probably the highest it is for any FDA-regulated commodity, with frequent deficiencies in fundamental requirements.”

“Why is there so much non-compliance?” he asked rhetorically. He went on to assert a “regulatory gap” that prevents the FDA from taking enforcement action in many cases, because of the need to establish proof, resource availability, and what he called “quirks in the law” that stay the agency’s hand.

And he denied that the agency turns a blind eye to illegal supplements, pointing out the agency had issued “at least 57 warning letters” and filed one injunction and two seizures in fiscal 2019.

In the study by Cohen’s group, 35 samples of 17 supplements were analyzed at NSF International and the Netherlands’ National Institute for Public Health and the Environment, yielding matching results. Most were marketed for either weight loss (eight) or sports/energy enhancement (six).

Study limitations included a small sample size, and the focus on products with deterenol clearly listed as an ingredient.

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• Ryan Basen reports for MedPage’s enterprise & investigative team. He has worked as a journalist for more than a decade, earning national and state honors for his investigative work. He often writes about issues concerning the practice and business of medicine.

### Disclosures

Cohen reported relationships with Consumers Union and Pew Charitable Trusts, and having been a defendant in a lawsuit brought by a supplements company. One co-author is an employee of NSF International, which has supplement manufacturers among its clients.

### Primary Source

### Clinical Toxicology

**Source Reference:** Cohen P, et al “Nine prohibited stimulants found in sports and weight loss supplements: deterenol, phenpromethamine (Vonedrine), oxilofrine, octodrine, beta-methylphenylethylamine (BMPEA), 1,3-dimethylamylamine (1,3-DMAA), 1,4-dimethylamylamine (1,4-DMAA), 1,3-dimethylbutylamine (1,3-DMBA) and higenamine” Clin Toxicol 2021; DOI: 10.1080/15563650.2021.1894333.

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# WESTERN NEUROPATHY ASSOCIATION

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## HELP FOR NEUROPATHY WEBINAR

THURSDAY, JUNE 24, 2021 1PM PDT / 3 PM CDT

Presentations from three providers with help for people with neuropathy. Nano Bubble Technologies is one. Other presentations will be announced soon. Some of the presentations were talked about at the Annual Conference. An email announcement will be sent out to all email addresses we have.

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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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