



WESTERN NEUROPATHY ASSOCIATION

September 2019

Issue 09

Volume 17

- FDA Approves Lyrica Generics
- Can You Guess What's Causing This Woman's Neuropathy?
- WNA Support Groups
- President's Message
- Bev Anderson Reports On Alpha Lipoid Acid
- Esketamine Approved For Treatment-Resistant Depression
- Neuropathy Medical Literature Review
- Medical Notes
- International Pain Summit 2019



Awarded by GuideStar November 13, 2018

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)

FDA APPROVES LYRICA GENERICS Ten Copycats Start To Roll Out

By Judy George, Senior Staff Writer, MedPage Today July 22, 2019

SILVER SPRING, Md. -- The FDA announced today it had approved multiple applications for the first generics of pregabalin (Lyrica) for fibromyalgia, diabetic and spinal cord injury nerve pain, pain after shingles, and partial onset seizures in patients 17 years and older.

"Today's approval of the first generics for pregabalin, a widely-used medication, is another example of the FDA's longstanding commitment to advance patient access to lower cost, high-quality generic medicines," Janet Woodcock, MD, director of the FDA's Center for Drug Evaluation and Research, said in a statement.

Alembic Pharmaceuticals, Alkem Laboratories, Amneal Pharmaceuticals, Dr. Reddy's Laboratories, InvaGen Pharmaceuticals, MSN Laboratories Ltd., Rising Pharmaceuticals, Sciegen Pharmaceuticals, and Teva Pharmaceuticals all won approval to sell generic versions of the drug. Several companies announced the launch and commercial shipment of pregabalin generics in the

U.S. soon after the FDA decision was made last Friday.

Lyrica has been a blockbuster drug for Pfizer, generating U.S. sales of nearly \$3.6 billion in 2018. The drug's patent shield was set to expire at the end of last year, but that protection was extended until June 30 based on the drug's most recent approval as adjunctive therapy to treat pediatric partial onset seizures.

Pregabalin must be dispensed with a patient Medication Guide, the FDA said. The Lyrica label carries warnings for angioedema, hypersensitivity reactions including hives, dyspnea, and wheezing, suicidal ideation, and peripheral edema. Increased seizure frequency or other adverse reactions may occur if the drug is discontinued rapidly. The most common side effects reported by adults in Lyrica clinical trials were dizziness, somnolence, dry mouth, swelling, blurred vision, weight gain, and difficulty with concentration and attention. Used by permission of MedPage Today

CAN YOU GUESS WHAT'S CAUSING THIS WOMAN'S NEUROPATHY?

By Kate Kneisel, Contributing Writer, MedPage Today June 10, 2019

(This is a case presented to doctors. I was fascinated. Some of you may well enjoy reading it – good to find something mind stretching from time to time. It also gives us an idea of what it takes to understand some cases of neuropathy and the lengths to which doctors go to find out. Editor)

A 56-year-old woman presents to the hospital complaining of generalized weakness that has been progressing for the past month. Her initial symptoms involved numbness and weakness in her legs and lower body. She explains that over the course of the next few days, the loss of strength and sensation progressed to involve her hands and neck.

The patient's medical history includes type 2 diabetes, mellitus and high blood pressure. Regarding her past medical history, she notes that about a year ago, she had gallstones that provoked an episode of necrotizing pancreatitis. At that time, she says, she was also suffering from severe protein calorie malnutrition. This was treated with total parenteral nutrition (TPN) until about 6 months ago, she notes, when she was able to return to a normal diet.

The patient is admitted to the hospital,

where a lumbar puncture identifies albumin cytologic dissociation in the cerebrospinal fluid (CSF), consistent with a presumptive diagnosis of Guillain-Barré syndrome (GBS), or acute inflammatory demyelinating polyradiculoneuropathy (AIDP). Clinicians also perform a brain magnetic resonance imaging scan that shows small vessel ischemic changes. She is empirically treated for five days with intravenous immunoglobulin, but has no clinical response. Shortly thereafter, the patient develops worsening pancytopenia and encephalopathy, and is transferred to a specialist center.

At The Specialist Center

The patient arrives in a hypotensive state (blood pressure 64/48 mm Hg). She does not respond to verbal questioning, and has a minimal

– Continued on page 6

Roster of Our WNA Information and Support Groups

2019 WNA Board of Directors

Bev Anderson
President

Karen C. Polastri, IOM
Vice President

Anne Bentz
Secretary

Darrell O'Sullivan
Treasurer

Pam Hart
Director

Sonya Wells, PharmD, MPH
Director

Emeritus Council

Michael Green
Emeritus

Johnathan Istilart
Emeritus

Brad Livingood
Emeritus

Sandra Vinson
Emeritus

Dick Ward
Emeritus

Lindsay Campoy
WNA Administration
(888) 556-3356
admin@pnhelp.org

**Please contact
your group leader or
check your group
page on the
WNA website –
www.WNAinfo.org
to find out about the
topic/speaker for the
upcoming meeting.**

Bev Anderson
Editor

Newsletter Design by



CALIFORNIA

Auburn

Next meeting Oct. 7
1st Monday, 11 AM
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

Castro Valley

2nd Wednesday, 1:30 PM
First Presbyterian Church
2490 Grove Way (next to Trader Joe)
Joy Rotz (510) 842-8440

Concord

Next meeting Sept. 19
3rd Thursday, 1:30 PM
First Christian Church
3039 Willow Pass Road
Wayne Korsinen (925) 685-0953

Davis

Next meeting Sept. 10
2nd Tuesday, 3:30-5:00 PM
Davis Senior Center, 646 A Street
Mary Sprifke (530) 756-5102

Elk Grove

Next meeting, Oct. 8
2nd Tuesday, 1 PM
New Senior Center of Elk Grove
8230 Civic Center Drive
Roger White (916) 686-4719

Folsom

Next meeting Sept. 18
3rd Wednesday, 12:30 PM
Association Resource Center
950 Glenn Dr., Suite 150
Bev Anderson (877) 622-6298

Fresno

Next meeting Sept. 17
3rd Tuesday, 11:00 AM
United Community Church of Christ
5550 N. Fresno St.
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

Next meeting Sept. 24
4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
Lee Parlett (925) 292-9280

Merced

Next meeting Sept. 12
2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(Hoffmeister Center across from the church)
Larry Frice (209) 358-2045

Modesto

Next meeting Sept. 16
3rd Monday, 10:30 AM
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Ray (209) 634-4373

Monterey

Next meeting Sept. 18
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

Next meeting Sept. 11
2nd Wednesday, 1 PM
El Dorado Senior Center
937 Spring Street
Bev Anderson (877) 622-6298

Redwood City

Next meeting Sept. 24
4th Tuesday, 1 PM
Sequoia 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
Bev Anderson 877-622-6298

San Diego

3rd Monday, 1:30 PM
Ed Brown Center for Active Adults
18402 W. Bernardo Dr.
Chhattar Kucheria (858) 774-1408

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.
Kathy Romero (407) 319-2557

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

Next meeting Sept. 4
1st Wednesday, 10:30 AM
Steele Lane Community Center
415 Steele Lane
Judy Leandro (707) 480-3740

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse
Vista Room
Karen Hewitt (925) 932-2248

Westlake Village - Thousand Oaks

2nd Monday, 4:30-5:30 PM
United Methodist Church
Youth Classroom 1 (faces parking lot)
1049 S. Westlake Blvd.
Angie Becerra (805) 390-2999

NEVADA

Las Vegas

Next meeting Sept. 19
3rd Thursday, 1 PM
Mountain View Presbyterian Church
8601 Del Webb Blvd.
Barbara Montgomery
lvneuropathygroup@gmail.com

OREGON

Grants Pass

Next meeting Sept. 18
3rd Wednesday 2:00 PM
Club Northwest
2160 N.W. Vine St.
David Tally 541-218-4418

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.

New Leadership needed. No meetings for now. Contact for information: Bev Anderson 877-622-6298. **California:** Alturas, Antioch-Brentwood, Bakersfield, Berkeley - Oakland, Carmichael, Clearlake, Costa Mesa, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, 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.



September is around the corner and it will soon be here along with the first day of Autumn, which I was thinking was September 21. But I happened to check my calendar and, surprise, Autumn falls on September 23. September also means that support groups that were off for part of the summer are meeting again, except for Auburn that starts again in October. Many groups don't meet in December but watch the Support Group information on page 2 for updates.

The Lyrica article outlines that soon the generic version of Lyrica will be less expensive so many who are on Lyrica now will get a price drop if they change to the generic. Those that haven't felt they could afford it, can give it a try if their doctor agrees. Some medical groups that didn't have it on the formulary may now offer it.

In another article, I'm giving you an opportunity to look at a very serious case of neuropathy the way a doctor would and discover a cause for neuropathy that you may not have known about.

Many people with neuropathy have depression so I'm including this new information about a medication for depression.

We do not have a specific date for the start of the first clinical trial of the medication that Distinguished Professor Bruce Hammock Ph.D. and staff on the campus of U.C. Davis have developed. We do know that it will be in Austin, Texas. This has delighted us and The Neuropathy Alliance of Texas, which is headquartered there with two support groups in the city. Nancy Herlin, their leader, is excited and ready to have her group help them in any way they can. The National Institutes of Health (NIH) may not realize it but they put the trials in one of the most knowledgeable cities about neuropathy in the nation.

NIH has to wait until the Federal budget is signed, which is slated for September so they know they are funded for their fiscal year. The closing of the Federal government earlier this year delayed the clinical trials as the NIH is a major part of these trials and in charge of orchestrating them. The NIH is a Federal agency so it was also closed. Let's hope that the budget will go through quickly and immediately signed as soon as Congress reconvenes in September.

A few weeks ago, your summer fundraising letter was sent asking those that are not members of WNA to join and for all to give a donation of some kind to help move the organization forward. If you have not responded and you are able to, please contribute now.

Happy September,

Bev

PRESIDENT BEV ANDERSON REPORTS ON ALPHA LIPOIC ACID

The neuropathy I have is Hereditary Sensory Autonomic Neuropathy (HSAN).

Autonomic symptoms are not easily described. The autonomic nerves operate all of our internal organs in a sort of automatic way. I was having symptoms all the way to the top of my legs and they were moving into the lower abdomen causing me to think I had a urinary tract infection when I didn't. About that time, I happened to start taking Alpha Lipoic Acid. It was recommended as it is widely prescribed in Europe. Many times, it is the first thing prescribed and the person may not need anything else. I'd taken it for several months and saw the miracle of my symptoms receding to below my knees. I was delighted, to say the least, and so was my doctor.

Then suddenly, the symptoms started returning and I was faced with an uncertain future. I put my morning pills out for several weeks ahead in three of the divided into seven sections containers. The evening pills, at that time, I just took from the two bottles. I saw that I'd left the Alpha Lipoic Acid bottle with the evening pills and had forgotten to put them in with the morning pills. I'd gone this way for a couple of weeks.

I immediately started taking it again in the morning as well as the evening and the symptoms again receded below my knees. For me, it is a well-tested major help. 300 mg. in the morning and 300 mg. at night. I had noticed symptoms starting in my hands and this receded as well.

– Continued on page 5

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

...

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.

- Continued on page 5

ESKETAMINE APPROVED FOR TREATMENT-RESISTANT DEPRESSION

Fast-acting drug called a "groundbreaking advance" in depression treatment

By Judy George, Contributing Writer, MedPage Today March 06, 2019

WASHINGTON -- The FDA approved esketamine (Spravato) nasal spray, to be used with an oral antidepressant, for treatment-resistant depression late Tuesday.

Esketamine is the S-enantiomer of ketamine, an FDA-approved anesthetic and a street drug called Special K which is known for its dissociative and hallucinogenic effects. Agency approval came with a Risk Evaluation and Mitigation Strategy (REMS) to restrict esketamine to certified treatment centers where patients are monitored for 2 hours, prohibit it from being dispensed directly to patients, and enroll patients in a registry.

Esketamine has the potential to be a game-changer in treating depression, said Walter Dunn, MD, PhD, of the University of California Los Angeles, and a member of the FDA's Psychopharmacologic Drugs Advisory Committee.

"The approval of esketamine is a groundbreaking advance in the treatment of depression, given its novel mechanism of action and time frame at which it produces clinically meaningful improvements," he told MedPage Today.

The drug "is different than traditional antidepressants that modulate monoamine activity," he added. "This has implications for treatment-resistant patients who have not responded to standard antidepressants, as esketamine potentially offers a better chance at achieving remission than traditional medications."

Esketamine works on the N-methyl-D-aspartate (NMDA) receptor, an ionotropic glutamate receptor in the brain. Its onset of action can be extremely rapid, improving depression symptoms in hours or days, as opposed to weeks for standard antidepressants.

The drug's approval came after only one positive short-term phase III trial. Drugmaker Janssen Pharmaceuticals brought five phase III studies to the FDA's advisory committee meeting in February: two of three short-term studies did not meet their primary endpoint, but a flexible dose trial in adults younger than 65 and a withdrawal

maintenance-of-effect study were positive. Despite this, advisory committee members voted overwhelmingly to support the drug.

"There has been a long-standing need for additional effective treatments for treatment-resistant depression, a serious and life-threatening condition," Tiffany Farchione, MD, acting director of the Division of Psychiatry Products in the FDA's Center for Drug Evaluation and Research, said in a statement. To date, the agency has approved only one other medication for treatment-resistant depression, a fixed-dose combination of fluoxetine and olanzapine (Symbyax).

Esketamine is designed to be administered intranasally twice a week for an initial 4 weeks, in conjunction with a newly initiated oral antidepressant. The proposed initial adult esketamine dose is 28-56 mg at each administration which can be titrated to 84 mg by week 2, with patients continuing treatment weekly for 4 more weeks, then weekly or every other week.

The drug will carry a boxed warning that patients taking the drug are at risk for sedation and problems with attention, judgment, thinking, abuse, misuse, and suicidal thoughts and behaviors -- the major concerns underlying the REMS.

Also, patients with poorly controlled hypertension or pre-existing aneurysmal vascular disorders may be at increased risk for adverse cardiovascular or cerebrovascular effects. The most common adverse effects seen in the trials were disassociation, dizziness, nausea, sedation, vertigo, hypoesthesia, anxiety, lethargy, increased blood pressure, and vomiting.

Janssen said it plans to offer information about insurance coverage, out-of-pocket costs, and treatment support through its CarePath program. It did not, however, reveal the drug's list price. The company did not respond immediately to a request for comment.

Used by permission of MedPage Today. LAST UPDATED 03.06.2019

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:

- 30278221 This article discusses the use of poly ADP-ribose polymerase (PARP) inhibitors to improve the progression-free survival of cancer patients taking platinum-based chemotherapy.
- 30403270 This study provided "lifestyle" instruction to a group with diabetic peripheral neuropathy patients on a weekly basis for 12 weeks. The areas of instruction covered lowering blood sugar, exercise, prudent diet, weight loss and foot care. Compared to the control group, there was a highly significant ($p < 0.001$) improvement in the Toronto Clinical Neuropathy score.
- 30477853 Four trials involving 383 participants with herpetic neuropathy receiving vitamin B12 or placebo were reviewed. There was significant improvement in pain and quality of life in the B12 group.
- 30521680 This Korean paper on acupuncture treatment of carpal tunnel syndrome reviewed 12 studies with 869 participants. The article concluded that there was little evidence of adverse events, but also little evidence of improvement

DISCOUNTS FOR WNA MEMBERS

Continued from page 4

Neuropathy Support Formula/Nerve Renew

(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 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.

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. 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 (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.

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

President Bev Anderson Reports On Alpha Lipoic Acid – *Continued from page 3*

Places that you can obtain Alpha Lipoic Acid as contained in our suggestions from support groups. *(This is the S or standard form. Supplements like Nerve Renew and people independently chose to buy the R form which is the natural form. The S form is uniform in each dose. The R form may or may not have the same strength in each capsule but it seems to work well for those that choose to use it. If doesn't seem to help everyone but it helps many with different causes of neuropathy.)*

Alpha Lipoic Acid (ALA) is a universal anti-oxidant.

It works in all types of cells to put down free radicals. It also helps to refresh other antioxidants like Vitamin E and C, CoQ10, and glutathione. ALA has been used in Europe for many years to treat diabetes by reducing blood sugar levels and diabetic neuropathy reducing DPN symptoms. *(It has also been effective with other types of neuropathy.)* One caution is that it can affect the strength of thyroid medication so dosage may need to change with long term use. Recommended dosage: 600 mg. - 300 in the morning and 300 at night. It can be obtained in pharmacies and health food stores but possibly at a lower cost at Vitacost: 1-800-793-2601 or www.Vitacost.com.

Two bottles of 120 (240 total) \$12.69 each plus \$4.95 for shipping no matter the size of your order is \$30.33. The recommended choice when asked is NSI Alpha Lipoic Acid, 300 mg. - 120 caps. Or Swanson: 1-800-437-4148 Item #D4SWU136. This is for bottles of 60 of the 300 mg. capsules. Each bottle is \$9.89. You save on shipping and handling by ordering more. So it is $\$9.89 \times 3 = \$29.67 + \$4.95 (S/H) = \34.64 is the total. Prices subject to change. The Vitacost product is reported to be a smaller, easier to swallow capsule. It is important to take the capsules with food and best to not lie down immediately after taking it. Like other vitamins or supplements, you want to let it begin digesting before changing its environment. COSTCO is always a good place to check on the price of medicine and over the counter items due to their drug pricing policies. It is a much lower markup than most pharmacies.

As always, make sure you talk with your doctor before starting any supplements.

Can You Guess What's Causing This Woman's Neuropathy? – Continued from page 1

response to painful stimuli; her Glasgow Coma Scale score is 6. Examination reveals pronounced generalized edema and flaccid paralysis of all four extremities.

Lab tests show that the patient is malnourished and in a septic state.

Findings include:

- Calcium: 6.7 mg/dL
- Hemoglobin: 9.4 g/dL
- White cell count: 2.1 X 10⁹/L
- Phosphorus: 1.1 mg/dL
- Creatinine: <0.2 mg/dL
- Albumin: <1.5 gm/dL
- Lactate: 4 mmol/L

Another Provisional Diagnosis

She is noted to be suffering from malnutrition, based on a nutritional risk screening (NRS-2002) score of 5 points and a malnutrition universal screening score of 5. She is intubated to protect her airway and resuscitated with intravenous fluids, and several hours later, requires an intravenous infusion of norepinephrine. To prevent sepsis, she is also started on meropenem, vancomycin, and anidulafungin.

The patient is provisionally diagnosed with AIDP complicated by septic shock, and is started on empirical treatment with high-dose intravenous thiamine (500 mg every 8 hours).

There is no evidence of seizure activity on the electroencephalogram, but it does show diffuse slow waves consistent with severe metabolic encephalopathy.

Day 3

The patient has received four doses of high-dose thiamine therapy which has restored her serum thiamine level to normal (104 nmol/L; reference range, 70-180 nmol/L).

A magnetic resonance imaging scan of the brain finds hyperintensity of the bilateral medial thalamus on T2-weighted and fluid-attenuated inversion recovery axial images. Clinicians consider that the findings suggest Wernicke's encephalopathy.

Day 4

The patient's mental status is significantly improved and she can respond correctly to simple commands. Based on her restored hemodynamic stability and negative blood and urine cultures, clinicians discontinue norepinephrine and antimicrobial treatment.

Days 5-7

The patient is successfully extubated.

Electromyography (EMG) shows severe sensorimotor polyneuropathy, and her cognition and weakness are gradually improving.

Day 14

The patient is transferred out of the intensive care unit.

Thiamine supplementation is continued throughout her hospital stay.

Discussion

Clinicians reporting this case of thiamine deficiency resulting in beriberi¹ note that the patient's initial symptoms of encephalopathy, ascending lower extremity weakness, and cerebrospinal fluid (CSF) findings led to an initial provisional diagnosis of Guillain-Barré syndrome (GBS).

This resulted in the patient's receiving initial treatment with intravenous immunoglobulin rather than thiamine supplementation, which ultimately resolved the symptoms rapidly, authors noted. This rapid clinical improvement following thiamine supplementation in thiamine deficiency-associated neuropathy^{2,3} is an important contrast to IVIG therapy in the treatment of GBS, which may take 2-4 weeks to show an effect.

Thiamine (vitamin B1) is a water-soluble vitamin that has a vital role in cell metabolism, specifically in the tricarboxylic acid cycle (Krebs's cycle),⁴ case authors write. While recommended daily thiamine intake for an average adult is 1-1.5 mg⁵, the human body can only store an average amount of 25-30 mg at any one time.⁶ This means that thiamine depletion can occur within 14 days of inadequate thiamine intake or malabsorption.⁷

In addition to the four causes of thiamine deficiency listed in Case Challenge 2, other contributing factors⁸ include:

- Anorexia nervosa
- Dieting
- Bariatric surgery-related malabsorption
- Diarrhea
- Celiac disease
- Dysentery
- Pregnancy
- Dialysis

Case authors suggest that the peripheral and ascending neuropathy seen in both GBS and thiamine deficiency can make clinical differentiation quite difficult.⁹ In addition to causing sensorimotor polyneuropathy, they write, both GBS and dry beriberi can lead to albumin cytologic dissociation -- an increase in CSF protein (>0.55 g/L) without an increase in white blood cells -- within the CSF. They explain that axonal injury in severe dry beriberi is what causes symptoms mimicking the ascending motor paralysis usually seen in GBS.^{10,11}

Thiamine deficiency leads to beriberi, which has both dry and wet manifestations. Dry beriberi is characterized by varying degrees of neuropathy; it can be associated with Wernicke's encephalopathy (which can also result from chronic alcohol abuse¹² and Korsakoff syndrome).

– Continued on page 7

MEDICAL NEWS NOTES

UC Berkeley scientists used a breakthrough gene therapy to help blind mice gain sight. Some on the team think the same therapy could eventually be used to help cure blindness in humans.

UC Davis is thrilled to announce the opening of a joint cancer care center in Chico on April 9, as a continuation of our partnership with Adventist Health. The new center will fill a hole in care left by the Camp Fire and provide access to critical care for the community. The care center at Adventist Health in Paradise is one of several buildings on the hospital campus that burned in the fire. https://lnkd.in/g_HmvX7

UC Davis is also excited to say that we are the first health system in California, and the second on the West Coast, to welcome the arrival of a new robotic surgery system that allows surgeons to complete procedures, such as prostate or tonsil removal, through just one small incision! Not only will having this single-incision robotic-surgery technology reduce scarring, hospital stays, blood loss, infection rates, pain medication use and recovery time for patients, but it also makes our robotic surgery program the most advanced in the region. <https://lnkd.in/gwQqFj>

Can You Guess What's Causing This Woman's Neuropathy? – Continued from page 6

While not seen in this patient's case, classic presentation of Wernicke's encephalopathy involves a triad of altered mental status (confusion and mild memory impairment), ataxia, and ocular symptoms (ophthalmoplegia or nystagmus). Without treatment, Wernicke's encephalopathy can lead to irreversible cognitive impairment and can be fatal.

Although Wernicke's encephalopathy is a clinical diagnosis, magnetic resonance imaging and serum thiamine levels (not assessed on presentation in this case) may assist with confirmation of diagnosis in some cases, clinicians note.

Wet beriberi is marked by cardiomyopathy and cardiomegaly, with presenting symptoms of heart failure, such as dyspnea and peripheral edema. In a fulminant form of wet beriberi known as Shoshin beriberi, patients develop cardiogenic shock, lactic acidosis, and if left untreated, multi-organ failure.

Chronic inflammatory demyelinating polyneuropathy:

- Includes a spectrum of acquired inflammatory sensory and motor polyneuropathies with relapsing and remitting clinical features 13,14
- Typically involves more motor than sensory deficits
- Can involve cranial and bulbar nerves in 10–20% of cases
- Usually includes evidence of a viral or bacterial pathogen to explain an inflammatory response [as with AIDP]

Due to the underlying severe protein-calorie malnutrition and duration of critical illness in this patient, clinicians also considered critical illness myopathy and critical illness polyneuropathy in the differential diagnosis. Both disorders share the risk factor of sepsis, and can be complicated by encephalopathy and delirium¹⁵, although their EMG findings differ.^{16,17}

Citing the many factors that can lead to thiamine deficiency, case authors opine that prevalence of beriberi is likely to

be greater than previously reported. It is important that physicians consider the possibility of thiamine deficiency in patients with a history of alcohol abuse, severe protein-calorie malnutrition, bariatric surgery, dependence on total parenteral nutrition, or any disease state complicated by malabsorption and increased caloric requirements.¹⁸⁻²⁰

They conclude that thiamine deficiency²¹ resulting in beriberi should be considered in the differential diagnosis for any patient presenting with neuropathy, weakness, cardiomyopathy, or autonomic instability when in the appropriate clinical context.

Authors had no disclosures to report.

Primary Source

Am J Case Reports

Source Reference: Shible AA, et al "Dry Beriberi Due to Thiamine Deficiency Associated with Peripheral Neuropathy and Wernicke's Encephalopathy Mimicking Guillain-Barré syndrome: A Case Report and Review of the Literature" Am J Case Rep 2019; 20: 330-334.

Used by permission of MedPage Today

By the way, thiamine is B1. A doctor I had years ago, recommended that I take it. I take a 100 MG tablet daily. It is the standard form and is water soluble. It is hard to find on a vitamin counter in a pharmacy but can be special ordered from the pharmacy from which you get your prescriptions. It is usually rather inexpensive. There is a fat-based type called Benfotiamine which builds up in your system. It is sold on line and through Amazon. It is also in formulas of supplements like Nerve Renew. Most pharmacists are not familiar with it. Editor)



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

■ PN Information/Advice ■ Support Group Inquiries

(888) 556-3356 ■ Email: admin@WNAinfo.org

■ Membership Information/Inquiries ■ Sponsorships

■ General Organizational Inquiries ■ www.WNAinfo.org

INTERNATIONAL PAIN SUMMIT 2019

You are invited to attend the **International Pain Summit 2019 by the International Pain Foundation**. It will be held November 14-16, 2019 at the UCLA Lustin Conference Center.

If you are a chronic pain patient or caregiver and interested in participating in the conference, you may apply for a scholarship to attend. All individuals who receive an event scholarship will have their registration fee for the conference waived. Parking fees will be your responsibility.

Want to apply for a Patient/Caregiver Scholarship to attend the International Pain Summit 2019? Please fill out this application and be sure to list The Western Neuropathy Association for prompt approval. We have 10 scholarships assigned to WNA so the first 10 applicants will receive the scholarship. We do have a discount code and hotel info can be found on our website at this link for discounted rates. <https://internationalpain.org/ipain-summit-hotel-venue/>



Western Neuropathy Association (WNA)

A California public benefit, nonprofit,
tax-exempt corporation.

Bev Anderson, Editor

P.O. Box 276567

Sacramento, CA 95827-6567

(877) 622-6298 ■ (888) 556-3356

info@WNAinfo.org ■ www.WNAinfo.org

WNA Headquarters: admin@WNAinfo.org

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.

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. Western Neuropathy Association (WNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.



www.facebook.com/Neuro

Join Us!

@Neuropathy_WNA

