



WESTERN NEUROPATHY ASSOCIATION

August 2017

Issue 08

Volume 15

- A Teenager's Story: Born With Lyme Disease - Finally On The Road To Recovery
- Diabetic Nerve Pain - Research Volunteers Needed And Will Get Paid
- WNA Support Groups
- President's Message
- Questions And Answers – Dysautonomia
- Toxic Concerns In Agricultural Chemicals
- A Food And Drug Administration Panel Opened A New Era In Medicine

Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ A TEENAGER'S STORY: BORN WITH LYME DISEASE – FINALLY ON THE ROAD TO RECOVERY

By Elizabeth Hancock, July 2017

My Lyme disease story begins before I was even born. It starts with a nymphal tick, no bigger than the tip of a Sharpie, that infected my mother and changed the course of my family's life.



A few years later my mom, still undiagnosed, had my brother, Tommy, and then two years later, she had me. From birth on, my brother and I were continually sick.

My mom persistently worked with the gastroenterologist, allergist, ENT, ophthalmologist, dermatologist, occupational therapist, physical therapist, speech therapist, and pediatrician to help us.

When I was a baby, my depleted immune system triggered several autoimmune disorders. I looked malnourished with a bloated stomach. By the time I was two, I was diagnosed with celiac disease.

A year later, still unaware of my Lyme disease, I was re-infected by a tick. Following the bite, my eyes crossed and I experienced headaches, back pain, night sweats, and even a small seizure. By the time I was four years old, we all had developed late-stage Lyme.

I used bifocals, my brother experienced multiple emergency visits for central nervous system issues, and my mom's symptoms worsened considerably. She felt as though she was detached from the world physically and mentally. She experienced horrific tremors and pain from head to toe, and made many

emergency room visits for shortness of breath. She couldn't lift her head, get out of bed, or raise her children.

What pains me most is that this lifelong suffering could have been avoided had doctors listened to her and diagnosed us earlier. Even though we lived in a Lyme-endemic area on the east coast, finding a doctor that was knowledgeable and willing to treat us was like looking for a needle in a hay stack.

For years, although my mom consulted many orthopedic, rheumatology, infectious disease, and primary doctors with her classic Lyme symptoms, they always diagnosed her with something else.

Top specialists in New York City for neurology and rheumatology failed to recognize what was really

– Continued on page 6

■ DIABETIC NERVE PAIN – RESEARCH VOLUNTEERS NEEDED AND WILL GET PAID

Are you a diabetic that suffers from diabetic neuropathy? Do you have pain in the lower limbs, legs, feet, and may feel a burning sensation, tingling, itching, a feeling of pins and needles? Northern California Research is looking for volunteers 18 years and older with diabetes. The diabetic neuropathy study will last 12 weeks. There is no cost to participate and you will receive a physical exam, lab testing, neuro exams, and study medication. Compensation up to \$525 for completed clinic visits. Call today for more information and to see if you qualify.

Northern California Research, 3840 Watt Avenue, Bldg. E, Sacramento, CA 95821, 916.484.0500, Northerncaliforniaresearch.com.

If you are interested in being in a clinical trial, call them. They have ongoing studies of several types and not all require the person to have diabetes. Some are not for neuropathy. Diablo Research in Walnut Creek is another research facility looking for volunteers. There is likely such a group somewhere near you live if Sacramento and the Bay Area are not near you.

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

Roster of Our WNA Information and Support Groups

2017 WNA Board of Directors

Bev Anderson
President

Karen C. Polastri, IOM
Vice President

Anne Trim
Secretary

Darrell O'Sullivan
Treasurer

Antonio Benevento
Director

Pam Hart
Director

Brad Livingood
Director

Sonya Wells, PharmD, MPH
Director

Emeritus Council

Michael Green
Emeritus

Johnathan Istilart
Emeritus


Sandra Vinson
Emeritus

Dick Ward
Emeritus

**Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.**

Bev Anderson
Editor

Newsletter Design by

 **Diane Blakley
Designs**

CALIFORNIA

Antioch-Brentwood

3rd Wednesday, 2 PM (odd numbered months)
Antioch-Kaiser, Deer Valley Rooms 1 & 2
Marty Price (925) 626-7988

Auburn

Next meeting Oct. 2, 2017
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

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:
Ryan Harris 916-342-8440

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

1st Thursday, 12:30 PM (odd numbered months)
Burger Rehabilitation
1301 E. Bidwell St., Folsom
Bev Anderson (877) 622-6298
<http://folsom.neuropathysupportgroup.org>

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
(The Hoffmeiser Center across the street 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
Lolly Jones (505) 228-3233

Redwood City

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
Charles Moore (916) 485-7723
<http://sacramento.neuropathysupportgroup.org/>

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital, 2105 Forest Avenue
SJ DePaul Conf. Rm.
Danielle LaFlash (415) 297-1815

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Avenue
Scott Stokes (415) 246-9156

Santa Barbara

4th Saturday, 10AM (odd numbered months)
The First Methodist Church
Garden & Anapamu
Shirley Hopper (805) 689-5939

Santa Cruz

3rd Wednesday, 1PM (odd numbered months)
Trinity Presbyterian Church
420 Melrose Avenue
Mary Ann Leer (831) 477-1239

Santa Rosa

1st Wednesday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Larry Metzger (707) 541-6776

Thousand Oaks Region

To be announced
Daytime meeting
Angie Becerra 805-390-2999

Ukiah

Oct. 3 meeting
1st Tuesday, 1:30 PM
Ukiah Senior Center
499 Leslie St.
Carole Hester (707) 972-2795

Walnut Creek

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

Woodland

3rd Tuesday, 1:00 PM
Woodland Senior Center
2001 East Street
Sue (530) 405-6304

OREGON

Grants Pass

3rd Wednesday, 2:00 PM
Club Northwest
2160 N.W. Vine St.
Carol Smith (541) 955-4995
<http://grantspass.neuropathysupportgroup.org>

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, Bakersfield, Clearlake, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Lodi, Madera, Mt. Shasta, Oxnard, Placerville, Quincy, Redding, Salinas, San Francisco, Santa Maria, Sonoma, Sonora, Stockton, Susanville, Truckee, Tulare-Visalia, Turlock, West Sacramento, Weed, Yreka, Yuba City-Marysville. **Nevada:** Reno-Sparks. **Oregon:** Brookings, Medford, Portland, Salem.



Dear members and friends,

You may have wondered about the strong emphasis in the newsletters on Lyme Disease this summer. I think the lead article in this issue sums it up. Ticks carry more than Lyme. One researcher termed them "a cesspool of disease." It does not have to look like a tick to be a tick if it is a young one. If you don't know the cause of your neuropathy, please ask your primary care doctor to order the best test for Lyme Disease available today be given you or to refer you to a neurologist who can. There are many symptoms listed in this article. You may have had some that haven't gotten a definite source diagnosed. If so, it is another reason to be tested.

Several years ago, I had an odd circling around a small bruise-like mark. It compared almost perfectly with the picture of a tick bite containing Lyme Disease on the computer screen of the doctor I consulted. She ordered a blood test immediately. It turned out clean. We were both glad.

I'm reading through the archive of articles I've received to find information that will fill the next couple of newsletters. One topic that I will be including uses the strongest language I can muster – BE EXTREMELY WARY OF SUPPLEMENTS. Before starting a supplement, check with your doctor first, but understand that they may not be aware of all the ingredients. Manufacturers of supplements do not have to submit to the FDA for approval – not testing or confirming what the manufacturers claim to be the ingredients, if they are the ingredients or not. It is the greatest scam on the consumer that Congress has ever specifically allowed to my knowledge. If the FDA knows a supplement manufacturer is injuring or even killing people, their hands are tied. One manufacturer I talked with the FDA about years ago that I questioned was finally stopped due to water pollution regulations when they were advertising it was coming out of pristine waters.

IT IS NOW KNOWN THAT SOME SUPPLEMENTS ARE ACTUALLY CLINICAL DRUGS COMING OUT OF RUSSIA AND OTHER COUNTRIES. THE FDA WON'T CONSIDER THEM FOR THE U.S. PHARMACEUTICAL MARKET AS THEY HAVE KNOWN PROBLEMS BUT THEY HAVE FOUND A LUCRATIVE WAY TO MARKET THEM AS SUPPLEMENTS AND GET A FREE PASS TO THE U.S. OVER THE COUNTER MARKET. Some years ago, the supplement marketers got their free pass through Congress. Currently, measures to keep water and air clean are being withdrawn. As citizens, we need to let our law makers know what we think about such matters and how they affect us and others we value.

You have likely received a letter from me – reminding some that their dues are up for renewal or asking people who are not members to join or inviting members and others to give a donation to help the Western Neuropathy Association meet goals like starting new neuropathy groups. I have the joy of announcing that the Placerville Neuropathy Support Group came back to life with all new people in August and other groups are looking hopeful. Donations for expenses of starting groups and meeting other goals are very welcome.

Happy Autumn ('Fall' just didn't seem like the term to use as it is a bad word in my neuropathy experience.),

Bev

QUESTIONS AND ANSWERS – DYSAUTONOMIA Bev Anderson, Editor

From time to time, I ask questions to clarify something I read. Here is one that I received and I'm including it in the newsletter so you get the information too.

Question: Do you consider dysautonomia a form of neuropathy? Is it all in the Peripheral Nervous System or are you also thinking it has a presence in the Central Nervous System? I have been questioned about this and don't find a definitive statement in the information I read.

Answer: Dysautonomia is not a specific diagnosis. It simply means any malfunction

of the autonomic nervous system. This can include central or peripheral malfunction. This can include a structural loss of brain tissue, as in Multiple Sclerosis or Parkinson's, a structural loss of peripheral nerve fibers, as in diabetic autonomic neuropathy, or intact nerve fibers that aren't working properly due to antibodies, receptor mutations, abnormal neurotransmitter levels, etc.

We would only use the term autonomic neuropathy when there is structural damage to or loss of the peripheral autonomic nerve fibers.

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 - **\$50 off Model Freedom 300 (single leg at a time) and \$50 discount on Model 120 that does both legs at the same time.** Contact: 800-521-6664 or www.anodynetherapy.com

HealthLight Infrared Light Therapy equipment - **10% 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

I corresponded with the California Department of Pesticide Regulation, Pesticide Registration Branch by referral from the first person I contacted and was referred to Susan McCarthy.

Question: I had a call from a young man in Alabama suffering from neuropathy. When I talked with him, I found he was a farmer who was the chemical man of the team. He mentioned Storcide as one chemical he used. He is also a veteran and goes to the VA in Pensacola, FL for medical help. They are going to send him to a neurologist. Many neurologists have little training in neuropathy. I'm wondering if his close contact with this and other agricultural chemicals may be the cause of his neuropathy as toxins are one of the over 150 causes of neuropathy. What indications do you have for Storcide? Is it sold in California?

Susan's answer: Ms. Anderson, By this email, I am forwarding your questions to Dr. Shelley DuTeaux, Chief of the Human Health Hazard Assessment Branch and Ms. Jolynn P. Mahmoudi-Haeri of the Pesticide Registration Branch - both part of the Department of Pesticide Regulation. Dr. DuTeaux may be able to address your toxicity questions and Ms. Mahmoudi-Haeri will know whether or not the product is registered in California. Best regards, Susan.

Hello Bev, Thank you for your inquiry regarding the product, Storcide II Grain, Bin and Warehouse Insecticide, EPA Reg. No. 264-992, which contains the actives: Chlorpyrifos-methyl and Deltamethrin.

This product is not registered in California and therefore should not be sold/distributed into California. Also, DPR would not have any toxicology studies for this particular product but may have toxicological studies on the same active ingredients of similar products.

You may submit a public records request for the information by email to publicrecords@cdpr.ca.gov. I have also attached information on how to make a records request. However, the product is registered with U.S. Environmental Protection Agency (EPA), I have attached the product label registered with EPA. You may want to contact U.S. EPA to inquire about this product: U.S. EPA Health Effects Division, Immediate Office # 703-305-5147 Chemistry and Exposure Branch David J. Miller, Branch Chief # 703-305-5352 Other U.S. EPA contacts

can be found at <https://www.epa.gov/pesticide-contacts>.

Regards, Jolynn Mahmoudi-Haeri, Senior Environmental Scientist (Specialist), CA Dept. of Pesticide Regulation, Pesticide Registration Branch, (916) 324-3545.

I sent a note of thanks and received the following:

Hello Bev, There are toxicological summaries available online at DPR's website for the active ingredients, Chlorpyrifos and Deltamethrin. However, not for Chlorpyrifos-methyl. This may be helpful for your research. The summaries can be found at <http://cdpr.ca.gov/docs/risk/toxsums/toxsumlist.htm>. Also, staff have also suggested that since the material is almost 40% Naphtha and has additional aromatic solvents involved, you may want to look at the patient's potential exposure to the solvents. The solvents can have neurologic effects in addition to the irritation. There is also a reference for Hayes "Pesticides Studied in Man", now in its 3rd (2010) edition which should be accessible at any college library. Attached is the MSDS for the subject product.

Regards, Jolynn Mahmoudi-Haeri, Senior Environmental Scientist (Specialist), CA Dept. of Pesticide Regulation Pesticide Registration Branch (916) 324-3545

From Bev Anderson:

Thank you Jolynn, From what I gathered from the man I spoke with, I have the understanding that they don't know the danger in the products they are using. I don't think they take the precautions they should. I'm going to ask him if he has a hazmat suit to wear when he uses it. I very much appreciate you indicating the neurological impact portion. It is not something we have dealt with enough as people call me from across the country with concerns. California doesn't allow a number of damaging chemicals that other states do. This one, for example, is not listed in California. It doesn't mean, however, that a farmer won't smuggle it in and have people under their auspices use it and be irreversibly damaged.

I grew up in my elementary grade years on a large dairy ranch freely using DDT. Even as a child, I wondered if it was so deadly related to its proposed use, wouldn't there be some damage to larger mammals and people? Being

- Continued on page 6

A FOOD AND DRUG ADMINISTRATION PANEL OPENED A NEW ERA IN MEDICINE

According to The New York Times reporting on July 13, on July 12, 2017, A Food and Drug Administration (FDA) panel opened a new era in medicine unanimously recommending that the agency approve the first-ever treatment that genetically alters a patient's own cells to fight cancer, transforming them into what scientists call "a living drug" that powerfully bolsters the immune system to shut down the disease.

If the FDA accepts the recommendation, which is likely, the treatment will be the first gene therapy ever to reach the market in the United States. Others are expected. Researchers and drug companies have been engaged in intense competition for decades to reach this milestone. Novartis is now poised to be the first. Its treatment is for a type of leukemia, and it is working on similar types of treatments in hundreds of patients for another form of the disease, as well as multiple myeloma and an aggressive brain tumor.

To use the technique, a separate treatment must be created for each patient — their cells removed at an approved medical center, frozen, shipped to a Novartis plant for thawing and processing, frozen again, and shipped back to the treatment center.

A single dose of the resulting product has brought long remissions, and possibly cures, to scores of patients in studies who were facing death because every other treatment had failed. The panel recommended approving the treatment for B-cell acute lymphoblastic leukemia that has resisted treatment, or relapsed, in children and young adults aged three to 25.

One of those patients, Emily Whitehead, now 12 and the first child ever given the altered cells, was at the meeting of the panel with her parents to advocate for approval of the drug that saved her life. In 2012, as a six-year-old, she was treated in a study at the Children's Hospital of Philadelphia. Severe side effects — raging fever, crashing blood pressure, lung congestion — nearly killed her. But she emerged cancer free, and has remained so.

"We believe that when this treatment is approved it will save thousands of children's lives around the world," Emily's father, Tom Whitehead, told the panel. "I hope that someday all of you on the advisory committee can tell your families for generations that you were part of the process

that ended the use of toxic treatments like chemotherapy and radiation as standard treatment, and turned blood cancers into a treatable disease that even after relapse most people survive."

The main evidence that Novartis presented to the FDA came from a study of 63 patients who received the treatment from April 2015 to August 2016. Fifty-two of them, or 82.5 percent, went into remission — a high rate for such a severe disease. Eleven others died.

"It's a new world, an exciting therapy," said Dr. Gwen Nichols, the chief medical officer of the Leukemia and Lymphoma Society, which paid for some of the research that led to the treatment.

The next step, she said, will be to determine "what we can combine it with and is there a way to use it in the future to treat patients with less disease, so that the immune system is in better shape and really able to fight." She added, "This is the beginning of something big."

At the meeting, the panel of experts did not question the lifesaving potential of the treatment in hopeless cases. But they raised concerns about potentially life-threatening side effects — short-term worries about acute reactions like those Emily experienced, and longer-term worries about whether the infused cells could, years later, cause secondary cancers or other problems.

Oncologists have learned how to treat the acute reactions, and so far, no long-term problems have been detected, but not enough time has passed to rule them out.

Patients who receive the treatment will be entered in a registry and tracked for 15 years.

Treatments involving live cells, known as "biologics" are generally far more difficult to manufacture than standard drugs, and the panelists also expressed concerns about whether Novartis would be able to produce consistent treatments and maintain quality control as it scaled up its operation.

Another parent at the meeting, Don McMahon, described his son Connor's grueling 12 years with severe and relapsing leukemia, which started when he was three. Mr. McMahon displayed painful photographs of Connor,

– Continued on page 7

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 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.

Free DVD on "Coping with Chronic Neuropathy"

introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at www.neuropathysupportnetwork.org/order-neuropathy-dvd.html

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.

A Teenager's Story: Born With Lyme Disease – Finally On The Road To Recovery – *Continued from page 1*

wrong with her. My mom even specifically requested to be tested for Lyme multiple times, and the few doctors that agreed ran inappropriate tests that provided inaccurate results.

She had MRIs, CAT scans, spinal tap, bone density, nerve conduction tests, and many other labs and procedures, in an effort to determine what was the cause of all of her health problems. Unsure of the root cause, doctors began treating her as if she had ALS, MS, or fibromyalgia, with very strong narcotics.

My mom kept searching for answers and finally found a rheumatologist who was highly regarded in the Lyme community. Her appointment with this doctor lasted several hours and was a very in-depth exploration of her issues. They evaluated all of her records and completed the appropriate labs and brain scans for tick-borne diseases. She was positive for Lyme, Babesia, Bartonella, and Ehrlichia.

Having been diagnosed so late, my mom was completely debilitated and had severe brain inflammation. Soon after her diagnosis, my brother and I were appropriately tested and found positive for Lyme, Babesia, and Bartonella.

Finally, after a 10-year journey, we were all diagnosed and put on a rigorous treatment plan that included weekly visits and three years of PICC lines.

Fortunately, we had wonderful family support like our cousins, Brenda and Carol, who dropped everything to come live with us. My grandparents helped us with our homework, bathed us, and drove us to school and appointments. My dad supported the family, took care of my mom, and did everything he could to ensure that my brother and I had a normal childhood despite the obvious tribulations.

I am lucky to have this kind of family support (especially my mom's persistence), and I know without them I would not be on a positive road to recovery.

Elizabeth Hancock is entering her senior year in high school in Columbus, Ohio. She hopes to continue her education in college and work in Washington D.C. someday.

Lymedisease.org July 19, 2017 Focus - Opinions and Features
www.LymeDisease.org

Toxic Concerns In Agricultural Chemicals – *Continued from page 4*

a regularly inspected Grade A dairy, it was a basic requirement to use it at that time. I've surveyed a sizable number of people with neuropathy and found the only seemingly common connection was with the fluoroscope machines in shoe stores to see where the bones of the foot fit in the shoes. They were specifically used for checking children's feet. My brother and his friends went regularly to the shoe store in our little town to "check their feet." No one thought it was a problem. Then suddenly, those machines were gone. I've never done any research to find out why they were removed to see if there was a problem found that could account for some of what I see today.

Thank you, Bev Anderson, President, The Western Neuropathy Association, P.O. Box 276567, Sacramento, CA 95827-6567, 877-622-6298, www.WNAinfo.org

Hello Bev, You bring up a good point. I have also attached the product label that has been accepted by the U.S. EPA, since you mentioned precautions and hazmat suit.

According to the label, under the Precautionary Statements and Personal Protective Equipment (PPE), there are specific wear

required when applicators are using this product.

This label and all pesticide labels registered in the U.S. can be found at [https://iaspub.epa.gov/apex/pesticides/f?p=PPLS:1::: .](https://iaspub.epa.gov/apex/pesticides/f?p=PPLS:1:::) You can search by product name, company name, and EPA Registration Number.

I hope this will be useful information.

Regards, Jolynn Mahmoudi-Haeri Senior Environmental Scientist (Specialist) CA Dept. of Pesticide Regulation, Pesticide Registration Branch, (916) 324-3545

In the attachments which would take pages to show, the listing of what precautions must be taken and the results of not following them are listed solemnly. You might wonder what use it has. It is used on grain that is stored to kill a dozen or so insects that attack stored grain. How it is removed from the grain when it used for cattle feed or human consumption is not mentioned but the grain is chiefly used as seed so there may be no treatment prior to planting it. Agricultural workers face different working conditions than they did a few years ago.

Join In The Discussion!



www.facebook.com/Neuro

@Neuropathy_WNA



A Food And Drug Administration Panel Opened A New Era In Medicine – Continued from page 5

bald and intubated during treatment. And he added that chemotherapy had left his son infertile.

A year ago, the family was preparing for a bone marrow transplant when they learned about the cell treatment, which Connor then underwent at Duke University. He has since returned to playing hockey. Compared with standard treatment, which required dozens of spinal taps and painful bone marrow tests, the T-cell treatment was far easier to tolerate, Mr. McMahon said, and he urged the panel to vote for approval.

A third parent, Amy Kappen, also recommended approval, even though her daughter, Sophia, five, had died despite receiving the cell treatment. But it did relieve her symptoms and give her a few extra months. Sophia's disease was far advanced, and Ms. Kappen thought that if the treatment could have been given sooner, Sophia might have survived.

"We hope that more families have a longer time with their children fighting this evil disease, and our children deserve this chance," she said.

The treatment was developed by researchers at the University of Pennsylvania and licensed to Novartis.

Use will not be widespread at first because the disease is not common. It affects only 5,000 people a year, about 60 percent of them children and young adults. Most children are cured with standard treatments, but in 15 percent of cases — like Emily's and Connor's — the disease does not respond, or it relapses anytime. Analysts predict that these individualized treatments could cost more than \$300,000, but a spokeswoman for Novartis, Julie Masow, declined to specify a price.

Although the figure may seem high, people with cancer often endure years of expensive treatment and repeat hospital stays that can ultimately cost even more.

Because the treatment is complex and patients need expert care to manage the side effects, Novartis will initially limit its use to 30 or 35 medical centers where employees will be trained and approved to administer it, the company said.

As to whether the treatment, known as CTL019 or tisagenlecleucel (pronounced tis-a-gen-LEK-loo-sell), will be available in other countries, Ms. Masow said by email: "Should CTL019 receive approval in the U.S., it will be the decision of the centers whether to receive international patients. We are working on bringing CTL019 to other countries around the world." She added that the company would file for approvals in the European Union later this year.

By late November 2016, 11 of the 52 patients in the study who went into remission relapsed. Twenty-nine were still in remission. Eleven others had further treatments, like bone marrow transplants. One patient was not available for assessment. Three who had relapses died, and one who did not

relapse died from a new treatment given during remission. The median duration of remission is not known because it has not been reached: Some patients were still well when last checked.

Researchers are still debating about which patients can safely forgo further treatment, and which might need a bone marrow treatment to give the best chance of a cure.

The treatment requires removing millions of a patient's T-cells — a type of white blood cell often called soldiers of the immune system — and genetically engineering them to kill cancer cells. The technique employs a disabled form of H.I.V., the virus that causes AIDS, to carry new genetic material into the T-cells to reprogram them. The process turbocharges the T-cells to attack B-cells, a normal part of the immune system that turn malignant in leukemia. The T-cells home in on a protein called CD-19 that is found on the surface of most B-cells. The altered T-cells are then dripped back into the patient's veins, where they multiply and start fighting the cancer.

Dr. Carl H. June, a leader of the University of Pennsylvania team that developed the treatment, calls the turbocharged cells "serial killers." A single one can destroy up to 100,000 cancer cells. Because the treatment destroys not only leukemic B-cells but also healthy ones, which help fight germs, patients need treatment to protect them from infection. So, every few months they receive infusions of immune globulins.

In studies, the process of re-engineering T-cells for treatment sometimes took four months, and some patients were so sick that they died before their cells came back. At the meeting, Novartis said the turnaround time was now down to 22 days. The company also described bar-coding and other procedures used to keep from mixing up samples once the treatment is conducted on a bigger scale.

Michael Werner, a lawyer and expert on gene and cell technologies and regulation, and a partner at Holland and Knight in Washington, said that results so far proved that T-cell treatment works.

"The fact that it can be done means more people will go into the field and more companies will start developing these products." He added, "I think we're in for really exciting times."

Correction: July 20, 2017 An article last Thursday about a gene-altering leukemia treatment referred incorrectly to the availability of gene therapy. If the Food and Drug Administration approves the leukemia treatment, it will be the first gene therapy approved in the United States, but not the first anywhere; other forms of gene therapy have already been approved and marketed in Europe and China.

Katie Thomas contributed reporting.

A version of this article appears in print on July 13, 2017, on Page A1 of the New York edition with the headline: FDA Panel Urges New 'Living Drug' To Fight Cancer.



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

SAVE THE DATE: 2018 WNA NEUROPATHY CONFERENCE

April 17, 2018 is the confirmed date for the 2018 WNA Neuropathy Conference. It will again be at The Mind Institute on the campus of the U.C. Davis Medical Center in Sacramento.

Check In starts at 9:30 AM and the conference begins promptly a 10 AM.

Registration is for a limited number of participants and is determined by the facility capacity. Pre-registration will start in January 2018.

The WNA Neuropathy Conference will be a basically medical conference with at least one neurologist speaking.

We hope that Bruce Hammock, Ph.D. will be present to give us an update on how his project is progressing.

We trust that the program will be ready to be announced in the January newsletter.



www.facebook.com/Neuro

Join Us!

[@neuropathy_WNA](https://twitter.com/neuropathy_WNA)



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.