



WESTERN NEUROPATHY ASSOCIATION

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Issue 11

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WESTERN NEUROPATHY ASSOCIATION

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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ THE FIRE WITHIN By David Glenn

Nerve damage in neuropathy progresses quicker than previously thought, lending urgency to earlier detection and treatment.

"If we wait until these patients have large-fiber neuropathy, we've needlessly lost time and nerve function. This is one more reason to be aggressive about controlling patients' glucose levels."

William Loughran retired from his job as a bank director in northeast Maryland in 2014, when he was 68. Like many new retirees, he vowed to ramp up his exercise routine.

"I started going to the gym three or four times a week and walking every day," he says. "I felt better than I had in years."

But then, after a long day of walking with his son during a visit to California, it began: "I went to bed, and the soles of my feet felt like they were on fire," Loughran recalls. "It was jabbing pain, pins-and-needles pain, and it was pretty severe."

Within weeks, Loughran's feet had become so painful that driving his car was a struggle. "Just the slight pressure from the pedals was too much to tolerate," he says. For months, he spent almost all of his time at home, in bare feet.

Loughran had developed peripheral neuropathy, a condition shared by hundreds of thousands of Americans. Peripheral neuropathy often begins with damage to the unmyelinated small-fiber nerves, resulting in numbness, tingling and lightninglike shooting pains, most commonly in the feet and hands. The best-known causes of peripheral neuropathy are type 2 diabetes and chemotherapy, but there are several other potential culprits. Vitamin B12 deficiency, high cholesterol, smoking and HIV/AIDS have all been implicated. Roughly one-fifth of peripheral neuropathy cases have no clear cause at all.

After several false starts with physical therapists, podiatrists and other specialists, Loughran realized that he needed to see a neurologist. He searched online and learned that Johns Hopkins has a prominent research program in peripheral neuropathy.

In early 2016, Loughran found himself in the Johns Hopkins office of Mohammad Khoshnoodi, an assistant professor of neurology. Here at last he received a thorough workup. "Dr. Khoshnoodi did much more extensive blood work than anyone else had done," Loughran says. "He did nerve conduction studies to see if I had damage to the large-fiber nerves, which I didn't. And he took three skin biopsies from my leg." The idea of having skin samples extracted sounded odd at first, Loughran says. But if that was what was required, he was game.

The technique of using skin biopsies to assess peripheral neuropathy was pioneered at Johns Hopkins in the early 1990s by Justin McArthur, who now chairs the Department of Neurology, and the late John Griffin, one of the best-known neurologists in Johns Hopkins history. A major advantage of these biopsies is that they permit objective, quantifiable measurement of nerve damage. They can be taken sequentially from the same sites over a period of months or years, allowing researchers to see exactly how a patient's nerves and their supporting structures change over time, and how that neurological damage is affected by changes in the patient's underlying condition (whether that be diabetes, chemotherapy exposure or something else).

Sequential skin biopsies have become an increasingly powerful tool for uncovering the mysteries of neuropathy. Last spring, Khoshnoodi and five Johns Hopkins colleagues published a much-discussed study in JAMA Neurology that offered some provocative findings. The study considered skin biopsies that were taken sequentially from 52 patients with neuropathy at Johns Hopkins between 2002 and 2010, along with biopsies from 10 healthy volunteers for purposes of comparison.

Roster of Our WNA Information and Support Groups

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

Bev Anderson
Editor

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CALIFORNIA

Antioch-Brentwood

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

Auburn

1st Monday, 11 AM
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392
Nov. Speaker: Bev Anderson, WNA President

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

2nd Tuesday, Nov. 14, 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 Gallinas 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 - Westlake Village

First meeting - Nov. 13
2nd Monday, 2:30 - 4 PM
United Methodist Church of Westlake Village
1049 S. Westlake Blvd.
Angie Becerra (805) 390-2999

Ukiah

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

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.



As you start looking toward Christmas and gift giving, if you use Amazon, be sure to sign up for Amazon Smile so you can list Western Neuropathy Association as the recipient of the charitable amount they give from each purchase. Also, remember IGive that has a huge number of stores together that give discounts and rebates back to your charity. Go to www.WNAinfo.com, click on the IGive logo and it will take you to their home page.

If you are on Facebook, be sure to visit the WNA page and 'like' it. You can look at what Pam Hart of our Board has listed on it. Go to www.facebook.com/Neuro If you're on Twitter, be sure to check out @neuropathy_WNA to see what Anne Bentz is tweeting.

We are inviting any medical doctor of anyone associated with the members and friends of the Western Neuropathy Association to receive our monthly newsletter. It's easy. Give us their name, type of practice, address, phone, and e-mail address and we will e-mail it to them.

I included the article on Fragile X as there is an interchange in neuropathy with Fragile X so advance in that area might affect research in help for neuropathy.

This issue features basically one long article presenting neuropathy patients being treated by an outstanding medical institution and some of their neurologists who are neuropathy specialists. Johns Hopkins Medical Center is located in and around Baltimore, Maryland. It is not near most of us here on the west coast, but some of our members live on the East Coast so it would be readily available to them. It is also an option to someone who can manage a trip there. Of course, an appointment and consultation with your health care team would be vital first.

I've never been in Baltimore; but ancestors on my maternal grandmother's side came in through Pennsylvania and traveled overland to found the city of Baltimore and the state of Maryland. One of their children became the first Roman Catholic Bishop of Baltimore. Many of those that moved west became Baptists. When they married in Iowa, my grandparents brought the north and south together as he was a descendant of John and Priscilla Alden of the Plymouth Colony who helped start Massachusetts and Connecticut. Maybe you have similar ties to the early history of our country. It was our ancestors that established that all are created equal. I guess it is our responsibility to remind others of this and other truths again. Having to discriminate against a person who happens to be different from me in some way doesn't seem to me to be appropriate. All of us are the same in some ways and different in others. That is what makes the world a fascinating place.

Happy Thanksgiving,

Bev

NEUROQUELL QUESTIONABLE SUPPLEMENT

Due to questions people were asking about Neuroquell, a new supplement, it was presented to our medical advisor in pharmaceuticals and supplements.

Here is the reply: Neuroquell looks like a potentially helpful supplement. It does have a good blend of vitamins and amino acids. However, ALA, it is a low dose. It also lacks L-Carnatine which has been showing so good results. Also, there isn't much information published on the herbal ingredients. I wouldn't recommend that anyone that takes prescription medications take this product without checking with their doctor or pharmacist. It's not too expensive, but I don't like that when you order it, you're signed up for a subscription. So, although it might be helpful, there are probably better supplements available.

(Please remember that supplements interact with anything else you are taking and can be dangerous.)

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.
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www.hrh.org.

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24 hours a day, seven days a week.
(888) HMO-2219
or (877) 688-9891 TDD

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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.

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DAVIS NEUROPATHY SUPPORT GROUP MEETING NOTES FROM VIEWING WNA VIDEO

By Peter T. Skaff, M.D.

"Peripheral Neuropathy: What It Is and What Can Be Done About It" (2008) featuring Peter T Skaff, M.D.

In our group, we call this 'PN 101.' It is down to earth and full of detail about symptoms, treatments and how to best talk to our doctors. A copy is available for check out at a meeting.

First, how our bodies are 'wired.' Peripheral refers to nerves away from the center, which start in the spine and go down legs and arms. We have three types of nerves: motor, sensory and autonomic (e.g., lungs, heart, blood pressure, intestines).

Peripheral nerves are like a long wire, with insulation sheathe around it called "myelin" and axons inside. Damage to one or both can cause neuropathy.

Symptoms: Altered sensations, e.g., numb feet and/or hands, tingling, pins & needles, creepy-crawly feelings. Pain may present as burning, stinging, or electrical stabbing. Imbalance may lead to unsteady walking, less steadiness or dizziness, weakness or atrophy of muscles. Organ system dysfunction, e.g., bowel, bladder, sexual organs.

Some Causes: • Diabetes and pre-diabetes cause 50% of PN • Vitamin deficiency, e.g., B12, B6 and folate • Medications such as Amiodarone, Chemo, Nitrofurantoin • Metabolic dysfunction e.g., thyroid, kidney, and high triglycerides • Heredity • Gastrointestinal, e.g., Crohn's or Celiac disease • Heavy metal poisoning, toxins (alcohol) • Autoimmune disorders

• Carpel Tunnel or Radiculopathy pinched nerves • Infections – acute, chronic and/or post-infection e.g., HIV/AIDS, Hepatitis C, Lyme disease, GBS or Shingles. • Cancer • Vasculitis • Amyloidosis • Paraproteinemia • Toxins With permission of Mary Sprifke, Editor, PN News, Yolo-Sacramento County newsletter (This video is available for purchase for \$5 on the website (www.WNAinfo.org) or by mail to WNA, P.O. Box 276567, Sacramento, CA 95827-6567)

ALTERNATIVE MEDICINE FOR PN – FROM MAYO CLINIC WEBSITE

Some people with peripheral neuropathy try complementary treatments for relief. Although researchers haven't studied these techniques as thoroughly as they have most medications, the following therapies have shown some promise:

Acupuncture. Inserting thin needles into various points on your body might reduce peripheral neuropathy symptoms. You might need multiple sessions before you notice improvement. Acupuncture is generally considered safe when performed by a certified practitioner using sterile needles.

Alpha-lipoic acid. This has been used as a treatment for peripheral neuropathy in Europe for years. Discuss using alpha-lipoic acid with

your doctor because it can affect blood sugar levels. Other side effects can include stomach upset and skin rash. (Bev Anderson note: I found out recently that It can also minimally affect thyroid testing.)

Herbs. Certain herbs, such as evening primrose oil, might help reduce neuropathy pain in people with diabetes. Some herbs interact with medications, so discuss herbs you're considering with your doctor.

Amino acids. Amino acids, such as acetyl-L-carnitine, might benefit people who have undergone chemotherapy and people with diabetes. Side effects might include nausea and vomiting.



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The study's first striking finding was that patients with impaired glucose regulation—a condition often known as prediabetes—saw their neuropathies progress just as aggressively as patients with full-blown diabetes. The second finding was that nerve damage increased just as fast at sites on the patients' upper thighs as it did on patients' toes and feet, where they actually perceived their symptoms.

"This study reinforces the idea that early neuropathy tends to progress," says Michael Polydefkis '93, a professor of neurology and the paper's senior author. "Primary care doctors should always take it seriously, even if the patient is just talking about slight numbness."

The fact that prediabetes can cause neuropathies just as severe as full-blown diabetes is relatively well-known among neurologists and endocrinologists, Khoshnoodi says, but it isn't sufficiently appreciated by generalist primary care doctors. The sequential skin biopsy study should be a wake-up call, he says. "If we wait until these patients have large-fiber neuropathy, we've needlessly lost time and nerve function," he says. "This is one more reason to be aggressive about controlling patients' glucose levels."

Left unattended, Polydefkis says, peripheral neuropathy can advance to more severe kinds of neurological dysfunction, including problems with balance, blood pressure regulation and difficulties in walking. In this study, 14 of 52 patients with small-fiber neuropathy progressed to mild large-fiber neuropathy, meaning that their ankle reflexes were reduced and they were less sensitive to the vibrations of a tuning fork. Such problems are often a prelude to more severe deficits in motion and sensation.

Though Loughran arrived at Johns Hopkins too late to take part in that particular sequential skin biopsy study, the three specimens taken from his ankle confirmed that his skin had a significantly reduced density of small-fiber nerves—the classic sign of small-fiber peripheral neuropathy.

Loughran says he was grateful to have a definitive diagnosis after months of confusion and anxiety. While there are currently no treatments that readily reverse neuropathy in Loughran's situation, peripheral neuropathy pain can be relieved with various combinations of anti-seizure medications, antidepressants and opioid pain relievers.

Michael Polydefkis

"We've seen some dramatic improvements over time in these patients' nerves. It's an example of a severe form of peripheral neuropathy, a fatal form, that appears to be changing before our eyes."

None of those drugs can cure the condition or even slow its progression. What can slow neuropathy's progression—at least for many patients—is correction of the underlying cause. If the patient's neuropathy is caused primarily by diabetes or prediabetes, strict control of blood glucose levels through diet, exercise and medication can do the trick. If the neuropathy is caused by vitamin B12 deficiency, that is usually simple to correct. If chemotherapy is the villain, the patient and his or her oncologist may want to consider a change in treatment.

"Skin biopsies can tell us exactly how much neuropathy you have, but they don't tell us anything about the cause," says Ahmet Hoke, a professor of neurology and another of the study's authors. "The blood work becomes key. The blood work helps us establish the etiology."

In Loughran's case, the blood work strongly suggested prediabetes. He is acting accordingly. "I've cut out sodas," he says, "and I'm trying to get back to exercising."

For many patients, that last step is easier said than done. "We tell them to exercise," Polydefkis says, "but exercise can be intolerable because of the burning pain and electric shocks in their feet. That's why it's so important to find the right combination of medications to get the neuropathy symptoms under control. Those medicines won't cure the neuropathy, but they'll allow patients to be more active, which in turn helps with glucose control when diabetes is a factor." Swimming and other non-weight-bearing exercises are often the best options, Polydefkis adds.

Hoke notes that the sequential skin biopsy study also shed light on the still-unsettled question of why exactly diabetes and prediabetes tend to damage the nerves. Some theories have emphasized the fact that the longest sensory neurons, which extend all the way from the spine to the toes, have huge metabolic needs because of their extreme surface-to-volume ratios. The metabolic dysfunctions associated with diabetes, according to this theory, make it difficult for the long neurons to balance their energy requirements, and they eventually stop working properly. Other scientists have emphasized a simpler, more mechanical model. Diabetes, they say, slowly damages the blood vessels that supply nerves with oxygen and nutrients. Diabetic neuropathy, in this view, is mostly a problem of the vasculature.

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DISCOUNTS FOR WNA MEMBERS

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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.

For Mark E. Rubenstein, It's Personal

Much of the recent Johns Hopkins research on peripheral neuropathy, including this year's high-profile study of sequential skin biopsies, has been financially supported by Mark E. Rubenstein, a trustee emeritus of The Johns Hopkins University and Johns Hopkins Medicine.

This sort of gift is nothing new for Rubenstein. For decades, he has supported several lines of medical research at Johns Hopkins. This one, however, is more personal for him than others, as he himself has contended with one of the most severe types of diabetic neuropathy.

Rubenstein, who retired in 2004 as chief executive of the Rubenstein Company, a major commercial real estate firm, was diagnosed with type 2 diabetes more than 40 years ago. He has long experience with the common symptoms of diabetic neuropathy, including numbness, tingling and shooting pains in the feet. In 2011, those symptoms suddenly blossomed into something much more severe. "Over a period of two weeks, I lost 15 pounds," he says, "and the muscles in my left leg started to waste away."

Those were the hallmarks of diabetic amyotrophy, which is sometimes known as Bruns-Garland syndrome. The condition often recedes on its own but sometimes leads to full-blown paralysis in the affected limb. Rubenstein went to see Michael Polydefkis at Johns Hopkins, who prescribed new medications to manage the pain and, more importantly, referred Rubenstein to expert physical therapists for an exercise program that allowed him to rebuild the lost muscle in his leg.

"He's a fantastic doctor," Rubenstein says. "He has great empathy for patients. He really got me through this."

Polydefkis, for his part, is grateful for the research support Rubenstein has provided in the last few years. "For an ambitious program like ours," he says, "it makes an enormous difference to have this kind of open-ended support."

The Johns Hopkins studies tend to support the metabolic theory, Hoke and Polydefkis say (though both add that vascular problems probably contribute). "What's so interesting," Hoke says, "is that we see damage that is just as bad in prediabetes as in diabetes. That suggests that it isn't the overall amount of glucose that is causing the neuropathy, but instead that its rapid fluctuations in glucose levels. There's something about those fluctuations that the nerve cells can't tolerate."

What about patients who have been diagnosed with diabetes or prediabetes but don't have any symptoms of neuropathy? "If I were in that situation, I would be vigilant," Polydefkis says. "There's reason to believe that nerve damage is already occurring in such patients. I would be very careful about trying to keep my glucose levels stable."

Howell Todd's story began much like Loughran's. He retired as a university president in 2001, moving to a 55-acre farm in rural

Tennessee. He looked forward to spending his days reading and raising crops. Not long after retirement, however, he began to notice odd tingling in his feet when he exercised on his elliptical trainer.

"At first, it was just uncomfortable," he says. "Then, it began to progress. It got to the point where I would wake up at 2:30 in the morning with my feet flaming."

In 2012, he flew to Johns Hopkins for a workup. Like Loughran, Todd had skin biopsies that clearly indicated peripheral neuropathy. Unlike Loughran, however, Todd turned out to have no identifiable underlying cause—no diabetes or prediabetes, no hyperlipidemia, no B12 deficiency. His is one of the roughly 20 percent of peripheral neuropathy cases that are classified as idiopathic.

These are the cases that Polydefkis finds most frustrating. All he can do as a neurologist is suggest medications to keep the symptoms in check. (He recommended that Todd start a daily regimen of pregabalin and tramadol, a combination that Todd says has served him well for four years.)

Todd says that he is glad he made the trek to Johns Hopkins, even if there is no miracle cure at hand. "Dr. Polydefkis had an excellent bedside manner," he says. "He and everyone there took the time to talk with me. I'll be 73 this fall, and I'm still able to do maintenance work on the farm, as long as I watch my limits. I don't think I could have done that without the medications he suggested."

While there are currently no treatments that readily reverse peripheral neuropathy, Johns Hopkins researchers are looking at a number of potential molecular targets for medications and are also actively involved in planning clinical trials.

Hoke has been studying medications that might offer protection to cancer patients' nerve cells before they begin chemotherapy. In 2014, he and his colleagues screened thousands of compounds from a Johns Hopkins drug library. They discovered that ethoxyquin—an antioxidant that is sometimes used as a pet food additive—seems to protect nerves exposed to paclitaxel and cisplatin, two of the most notoriously neurotoxic chemotherapeutic drugs. In recent months, Hoke and Polydefkis have also tested ethoxyquin in animal models of diabetic neuropathy, with promising results. To bring these studies closer to human clinical trials, the team recently received one of the inaugural grants from the Louis B. Thalheimer Fund for Translational Research, a new Johns Hopkins effort to accelerate the development of university discoveries.

Ahmet Hoke

"Skin biopsies can tell us exactly how much neuropathy you have, but they don't tell us anything about the cause. The blood work becomes key."

Polydefkis is also involved in an international clinical trial of

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■ NEW DRUG SHOWS PROMISE – MENTIONED IN ARTICLE “The Fire Within”

Success Seen for Novel Drug in Nerve Disorder (STAT) Patisiran showed benefits for familial amyloid polyneuropathy in phase II by MedPage Today Staff September 20, 2017

The investigational agent patisiran has shown positive results in a phase III trial evaluating the drug for the rare disorder familial amyloid polyneuropathy (FAP), which is caused by a mutation in a gene that leads to buildup of a harmful protein in the nerves and tissues, according to a report in STAT.

Patisiran is the first drug with the novel mechanism of action referred to as RNA interference, which uses small pieces of genetic code to turn off disease-associated genes. Scientists who developed the technology received a Nobel prize in 2006.

The trial included 225 patients with FAP, and the primary endpoint of reduction in nerve damage was met, as were other secondary endpoints, reported manufacturer Alnylam Pharmaceuticals. The company hopes to seek approval for marketing by the end of 2017.

■ CANNABIS-BASED FRAGILE X DRUG SUCCEEDS IN MID-STAGE TRIAL (Reuters)

Gel treatment derived from cannabidiols, not TH by MedPage Today Staff September 28, 2017

A cannabis-based gel treatment for Fragile X syndrome succeeded in a mid-stage study, the maker Zynerba Pharmaceuticals Inc. announced today.

The drug -- ZYN002 -- achieved the primary endpoint in the 20-person, mid-stage study by reducing levels of

anxiety, depression, among other behavioral symptoms. Other benefits regarding social avoidance, hyperactivity, and temper tantrums also showed improvement with treatment, Reuters reported.

Zynerba, which is planning a larger trial, said it planned to meet with the FDA early next year.

■ FIGHTING LEG CRAMPS

Leg cramps can be very painful and may be the result of dehydration. If you take a diuretic or exercise while low on calcium, potassium, or magnesium, it makes them more likely. The most common causes are overusing the

leg muscles and being dehydrated. If you sit or stand for long periods without sipping on water, you may expect the cramps to occur. They are fairly common during pregnancy.

The Fire Within – Continued from page 6

a new medication that may be effective against a rare and devastating inherited neuropathic disorder. The condition, known as transthyretin familial amyloid polyneuropathy, affects roughly 10,000 people worldwide, usually striking in middle age.

“The transthyretin protein normally has a four-leaf clover structure,” Polydefkis says. “But in people who inherit this condition, it has a malformed structure and clumps within the nerves. When those deposits build up, peripheral nerves start to malfunction, and the patient experiences peripheral neuropathy. The disease eventually involves sensory, motor and autonomic nerves, and it is fatal.”

The ongoing clinical trial is assessing a medication known as patisiran, which inhibits the liver’s production of the malformed proteins. Polydefkis and his colleagues have a specific role: to examine skin biopsies sent every few months from trial participants around the world. “We’ve been getting biopsies from Brazil, from Norway, from all sorts of places,” Polydefkis says. “We’ve seen some dramatic improvements over time

in these patients’ nerves. It’s an example of a severe form of peripheral neuropathy, a fatal form, that appears to be changing before our eyes.”

Loughran, meanwhile, has signed up for a study that will closely monitor patients’ neuropathic status, glucose control, blood pressure and a wide variety of other variables, with an eye toward developing a deeper understanding of how these factors affect each other.

“My symptoms are gradually improving,” he says. “I’ve finally gotten to the point where I can at least do some exercise. It was initially both feet—front, back, everywhere. Now it’s regressed to just the bottom of the feet. And now that I’ve heard about this possible prediabetes, I’m going to get back to the gym.”

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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

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