



WESTERN NEUROPATHY ASSOCIATION

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Issue 02  
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# Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

## ■ GROUND-BREAKING DISCOVERY: UC DAVIS RESEARCHERS FIND KEY MECHANISM THAT CAUSES NEUROPATHIC PAIN

Author: Kathy Keatley Garvey, Published on: July 6, 2015

DAVIS--In ground-breaking research estimated to affect millions of patients globally, scientists at the University of California, Davis have pinpointed a key mechanism that causes neuropathic pain--a complex, chronic and difficult-to-treat pain caused by nerve injuries from trauma or from such diseases as diabetes, shingles, multiple sclerosis and stroke.

A biological process, termed endoplasmic reticulum stress or ER stress, is the significant driver of neuropathic pain, said lead researchers Bora Inceoglu of the Bruce Hammock lab, UC Davis Department of Entomology and Nematology/UC Davis Comprehensive Cancer Center, and Ahmed Bettaieb of the Fawaz Haj lab, Department of Nutrition.

The ground-breaking discovery, published July 6, 2015, in the Proceedings of the National Academy of Sciences, "should ignite the discovery of a new generation of therapeutics," paving the way for more efficient and effective ways to alleviate neuropathic pain, the researchers said.

"This is a fundamental discovery that opens new ways to control chronic pain," said corresponding author and senior researcher Hammock, a distinguished professor of entomology who holds a joint appointment with the UC Davis Department of Entomology and Nematology, and the UC Davis Comprehensive Cancer Center.

"We can now specifically search for agents to control ER stress and its downstream pathways," said Hammock. "This search is already underway in a number of laboratories working on cancer and other diseases."

In the study, "Ahmed demonstrated key molecular signatures associated with diabetes and diabetic pain indicative of ER stress," said Fawaz Haj, a senior author and corresponding author. The Haj laboratory studies the molecular basis of metabolic diseases, mainly obesity and type 2 diabetes.

"Diabetic neuropathy is a common consequence of both type 1 and type 2 diabetes which affects 60

to 70 percent of the diabetic patients," said Ahmed Bettaieb, who has just accepted a position as assistant professor in the Department of Nutrition, University of Tennessee-Knoxville. "Knowledge on the specific contribution of individual cellular signaling pathways in the pathobiology of diabetic neuropathy is required to identify optimal drug targets. Identifying ER stress as a potential molecular mechanism that underlies

diabetic neuropathic pain will open novel routes for the search of new therapeutic strategies therapies and optimizing currently available pain control medications."

Inceoglu showed that neuropathic pain could be initiated by diverse compounds that cause ER stress and reversed by agents that block it.

"We were trying to understand how a class of natural bioactive lipids in our body can have such powerful analgesic effects," said Inceoglu. "Our previous collaboration with Drs. Haj and Bettaieb had already established that blocking the degradation of these natural molecules is strongly analgesic (reduces pain) in diabetic animals without

any of the side effects of known drugs. Expanding on these observations, in diabetic rodents, we looked at nerves and in particular those that are away from the skin, deeply embedded in the body. ER stress was obvious in these areas such as the sciatic nerve trunk and the spinal cord. Once we realized that ER stress had taken over the nervous system, we asked if it had any immediate consequences that can be measured."

Said Inceoglu: "It was an exciting moment when we could block pain in diabetic rodents using known inhibitors of ER stress. Later inducing ER stress in healthy rodents resulted in neuropathic pain-like behaviors which could be eliminated with ER stress blockers, but not so well with known drugs that are prescribed to patients suffering from neuropathic pain, with or without diabetes."

"Unfortunately, neuropathic pain remains an unmet medical need and available drugs are either not so effective or have serious side effects that limit their



Bora Inceoglu of the Bruce Hammock lab. (Photo by Kathy Keatley Garvey)

# Roster of Our WNA Information and Support Groups

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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**

### **Alturas**

For information, call:  
Bev Anderson (877) 622-6298

### **Antioch-Brentwood**

3<sup>rd</sup> Wednesday, 2 PM- odd numbered months  
Antioch-Kaiser  
AMC-1H2 (from hospital lobby)  
Marty Price (925) 626-7988

### **Auburn**

1<sup>st</sup> Monday, 11 AM  
Woodside Village MH Park  
12155 Luther Road  
Sharlene McCord (530) 878-8392

### **Bakersfield**

For information, call  
Bev Anderson 877-622-6298

### **Berkeley-Oakland**

3<sup>rd</sup> Wed., 3-4 PM  
North Berkeley Senior Center  
1901 Hearst Ave.  
Kathleen Nagel (510) 653-8625

### **Carmichael - Eskaton**

2<sup>nd</sup> Tuesday, 1:30 PM  
Eskaton, 3939 Walnut Ave.  
Karen Robison (916) 972-1632  
*Call Karen before coming as it is a gated  
community and sometimes the day/time  
changes. She welcomes newcomers!*

### **Carmichael - Atria**

3<sup>rd</sup> Tuesday, 3:30 PM  
Atria - Carmichael Oaks  
8350 Fair Oaks Boulevard  
Tanysha (916) 944-2323  
Community members welcome

### **Castro Valley**

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

### **Clearlake**

For information, call  
Bev Anderson (877) 622-6298

### **Concord**

3<sup>rd</sup> Thursday, 1:30 PM  
First Christian Church  
3039 Willow Pass Road  
Wayne Korsinen (925)685-0953

### **Costa Mesa**

3<sup>rd</sup> Wednesday, 10:00 AM  
Call Martha Woodside  
949-573-0056 for the location

### **Crescent City**

For information, call:  
Bev Anderson (877) 622-6298

### **Davis**

2<sup>nd</sup> Tuesday, 3:30-5:00 PM  
Davis Senior Center  
646 A Street  
Mary Sprifke (530) 756-5102

### **Elk Grove**

2<sup>nd</sup> Tuesday, 1 PM  
Elk Grove Senior Center  
8830 Sharkey Avenue  
Roger White (916) 686-4719

### **Eureka**

For information, call:  
Earlene (707) 496-3625

### **Folsom**

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

### **Fort Bragg**

For information, call:  
Bev Anderson ((707) 964-3327

### **Fresno**

3<sup>rd</sup> Tuesday, 11:00 AM  
Denny's Restaurant  
1110 East Shaw  
Bonnie Zimmerman (559) 313-6140

### **Garberville**

For information, call:  
Bev Anderson (877) 622-6298

### **Grass Valley**

2<sup>nd</sup> Monday, 1:30 PM  
GV United Methodist Church  
236 S. Church Street  
Bev Anderson 877-622-6298

### **Jackson**

For information, call  
Bev Anderson (877) 622-6298

### **Lakeport**

Meeting day and time, call Mito.  
Lakeport Senior Center  
507 Konocti Ave.  
Mito Shiraki (707) 245-7605

### **Lincoln**

For information, call:  
Bev Anderson (877) 622-6298

### **Livermore**

4<sup>th</sup> Tuesday, 10 AM  
Heritage Estates  
900 E. Stanley Blvd.  
Lee Parlett (925) 292-9280

### **Madera**

For information, call  
Bev Anderson (877) 622-6298

### **Merced**

2<sup>nd</sup> Thursday, 1 PM  
Central Presbyterian Church  
1920 Canal Street  
(The Hoffmeister Center across the  
street from the church)  
Larry Frice (209) 358-2045

### **Modesto**

3<sup>rd</sup> Monday, 10:30 AM  
Trinity United Presbyterian Church  
1600 Carver Rd., Rm. 503  
Ray (209) 634-4373

### **Monterey**

3<sup>rd</sup> Wed., 10:30 AM-odd numbered months  
First Presbyterian Church  
501 El Dorado Street  
Dr. William Donovan (831) 625-3407

### **Napa**

1<sup>st</sup> Thursday, 2 PM  
Napa Senior Center  
1500 Jefferson Street  
Ron Patrick (707) 257-2343  
[bonjournapa@hotmail.com](mailto:bonjournapa@hotmail.com)

### **Oxnard**

For information, call:  
Bev Anderson (877) 622-6298

### **Placerville**

For information, call  
Bev Anderson (877) 622-6298

### **Quincy**

1<sup>st</sup> Thursday, 1 PM  
Our Savior Lutheran Church  
298 High St.  
Stacey Harrison (530) 283-3702

### **Redding**

For information, call:  
Tiger Michiels (530) 246-4933

### **Redwood City**

4<sup>th</sup> Tuesday, 1 PM  
Sequoia Hospital Health and  
Wellness Center  
749 Brewster Avenue  
Danielle LaFlash (415) 297-1815

### **Roseville**

2<sup>nd</sup> Wednesday, 1PM - odd numbered months  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Stan Pashote (916) 409-5747

### **Sacramento**

3<sup>rd</sup> Tuesday, 1:30 PM  
Northminster Presby. Church  
3235 Pope Street  
Charles Moore (916) 485-7723  
<http://sacramento.neuropathysupportgroup.org/>

### **Salinas**

Contact Bill Donovan (831) 625-3407

### **San Francisco**

4<sup>th</sup> Thursday, 10 AM  
UC-San Francisco Med Ctr.  
400 Parnassus Avenue  
Amb. Care Ctr. 8th Fl., Rm A888  
Y-Nhy (e nee) Duong  
[Nhy-y.duong@ucsf.edu](mailto:Nhy-y.duong@ucsf.edu)

### **San Jose**

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

### **San Rafael**

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

### **Santa Barbara**

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

### **Santa Cruz**

3<sup>rd</sup> Wednesday, 1PM- odd numbered months  
Trinity Presbyterian Church  
420 Melrose Avenue  
For information call  
Mary Ann Leer (831) 477-1239

# President's Message

By Bev Anderson



This issue is a bit different than others in that it is basically two articles. The one on the research at U C Davis offers an overview of the research we are to be updated on at the Annual Conference on April 18. Bruce Hammock, PhD will tell us when human trials start and what has happened so far. Those present at last year's conference will remember the remarkable videos of the cat and the horse.

The second article is critical for us now as we have one of these stem cell clinics in Sacramento that people from other parts of California are being drawn to. There may be some in other areas or will be. We want our members and people in our groups to be aware of problems that can happen from an excellent source – The American Academy of Neurology. Their magazine, NEUROLOGY NOW, covers all areas of neurology so neuropathy is not in every issue. When it is, it is excellent information. They offer it as a free subscription to people with a neurological disease, a caregiver of one, or a professional interested in the disease. To receive a copy, you can sign up on line at NeurologyNow.com or send a note with your name, address, and e-mail (if you have such) to NEUROLOGY NOW, PO BOX 1908, LOWELL, MA 01853-9967. Include a signed note that you have neuropathy, are a caregiver of someone with neuropathy, or a professional interested in the disease and how long a duration you or they have had the disease. We continue to warn our members and others to be wary of the groups offering treatments of various kinds for which they charge thousands of dollars up front without guarantee or opportunity to stop and receive part of their money back if they realize it is not working. However, it is still each person's choice. We urge you to consult with your own doctor about it if you are tempted to try it and check the information with the facts your doctor likely has.

Happy Valentine's Day to all of you valentines. Thank you for being the wonderful people you are,

*Bev*

## WNA Information and Support Groups – continued from page 2

### **Santa Maria**

For information, call  
Bev Anderson (877) 622- 6298  
or Mary (805) 344-6845

### **Santa Rosa**

1<sup>st</sup> Wednesday, 10:30 AM  
Meeting on Dec. 7  
Santa Rosa Senior Center  
704 Bennett Valley Road  
Larry Metzger (707) 541-6776

### **Sonoma**

For information, call  
Bev Anderson (877) 622-6298

### **Sonora**

For information, call  
Bev Anderson (877) 622-6298

### **Stockton**

For information, call  
Bev Anderson (877) 622-6298

### **Susanville**

For information, call:  
Bev Anderson (877) 622-6298

### **Thousand Oaks Region**

For information, call  
Bev Anderson (877) 622-62988

### **Truckee**

For information, call:  
Bev Anderson (877) 622-6298

### **Tulare-Visalia**

For information, call  
Bev Anderson (877) 622-6298

### **Turlock**

3<sup>rd</sup> Monday, 1 PM- odd numbered months  
Covenant Village Adm. Bldg. Classroom  
2125 N. Olive St.  
Joanne Waters (209) 634-0683

### **Ukiah**

Last Tuesday, 5:30 PM  
Next meeting, Sept. 27  
North Coast Opportunities (NCO)  
413 N. State St.  
Carole Hester (707) 972-2795

### **Walnut Creek**

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

### **West Sacramento**

No meeting until new leader is found  
Sandra Vinson (916) 372-6093  
slvins11@gmail.com

### **Woodland**

For information, call  
Bev Anderson (877) 622-6298

### **Yreka**

For information, call  
Bev Anderson (877) 622-6298

### **Yuba City-Marysville**

For information, call  
Bev Anderson (877) 622-6298

### **NEVADA**

#### **Reno-Sparks**

For information, call  
Bev Anderson (877) 622-6298

### **OREGON**

#### **Brookings**

For information, call  
Robert Levine (541) 469-4075

#### **Grants Pass**

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

#### **Medford**

For information, call  
Bev Anderson (877) 622-62988

#### **Portland**

For information, call  
Bev Anderson (877) 622-6298

#### **Salem**

For information, call  
Bev Anderson (877) 622-6298

### **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".

Start a support group in your area:  
Contact Bev Anderson at  
(877) 622-6298  
or [info@WNAinfo.org](mailto:info@WNAinfo.org)

## 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](http://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](http://www.healthlight.us)

### Auburn

#### The Footpath

825 Lincoln Way  
(530) 885-2091  
[www.footpathshoes.com](http://www.footpathshoes.com)  
**WNA Discount: 10% off the regular price shoes.**

### Elk Grove

#### Shoes That Fit

8649 Elk Grove Blvd.  
(916) 686-1050  
**WNA Discount: 20% off the regular price shoes.**

### Fortuna

#### Strehl's Family Shoes & Repair

Corner of 12th & Main  
1155 Main Street  
(707) 725-2610  
Marilyn Strehl, C.PED  
is a Certified Pedorthic  
**WNA Discount: 10% off the regular price shoes.**

### West Sacramento

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

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## STEM CELL REALITY

**FREE ACCESS.** Desperate patients are vulnerable to the promise of stem cell therapy—most of it unproven. Protect your health—and your wallet—with these facts.

By Gina Shaw

A stroke in 2009 left Jim Gass, now 66, with a paralyzed left arm and a weakened left leg. He could still live independently in his home in Wilmington, MA, half an hour north of Boston, but he needed a leg brace and a cane to walk—a depressing setback from his previously vigorous life. Seeking improvement, he scoured the internet, finding hopeful anecdotes touting the promise of stem cell therapy to treat everything from multiple sclerosis (MS) and Parkinson's disease to traumatic brain injury and stroke.

Over the next several years, Mr. Gass told *The New York Times*, he spent nearly \$300,000 on treatments at unregulated clinics in Mexico, China, and Argentina—places with glowing testimonials from former patients who claimed miraculous cures. His doctors and family members strongly discouraged him, but Mr. Gass couldn't be dissuaded. He was willing to spend whatever it took to get back what he'd lost. The worst that could happen, he figured, was that he wouldn't get any better. He was wrong.

### MYSTERIOUS GROWTH

Gass had first sought stem cell treatments in China and Argentina in 2011. They didn't seem to help much, but they didn't hurt, either, so he tried again. In 2014, he went to Mexico, where fetal stem cells from Russia were injected into his spinal cord. At first, Gass thought his walking had improved—but then he started to notice pain when he was lying down. He began to fall frequently. He underwent an MRI scan of his spine at Brigham and Women's Hospital, where doctors discovered an enormous mass pressing against the lower portion of his spinal column.

It turned out that the mysterious mass wasn't quite a cancer, but it wasn't benign, either. In an article in the *New England Journal of Medicine*, doctors wrote, "It could not be assigned to any category of previously described human neoplasm [an abnormal growth] on the basis of the data we gathered." But one thing was certain: the mass was partly made up of cells from another human being and had originated with the stem cells.

Radiation treatments initially shrank the mass and gave Gass back some of the mobility he'd lost, but in the spring of 2016 another scan showed that the mass had begun to grow again. The former lawyer is now paralyzed from the neck down, except for his right arm. He has relocated to California, where he is working with a paralysis recovery center in San Diego County. Doctors are stumped and have no idea how to stop the tumor from growing.

### THE ORIGINS OF STEM CELL THERAPY

Stem cell therapy has been around since at least the mid-1960s, when researchers first started transplanting

bone marrow (or hematopoietic cells) to treat cancer, blood diseases, and disorders of the immune system. More recently, stem cells have also been used in tissue grafts to repair injuries or for diseases of the skin, eyes (specifically the corneas), and certain musculoskeletal tissues, including bone and cartilage. These are the only conditions for which stem cell therapy has been approved by the US Food and Drug Administration (FDA). All other uses of stem cells in medical treatment, including in neurologic diseases, are unproven and experimental at this point.

### WHAT ARE STEM CELLS?

Every organ and tissue in the human body has its origins in stem cells, which have two special characteristics. First, they can make copies of themselves. Second, when they divide, instead of just replicating themselves, they can turn into another type of cell in the body.

Different types of stem cells have distinct abilities. Human embryonic stem cells are derived from the inner cell mass of the blastocyst, a group of cells that form a few days after a sperm fertilizes an egg. They can develop into every cell type in the body, which defines them as being pluripotent. Adult stem cells are tissue-specific, meaning that they can only develop into cells for the tissue or organ from which they were extracted, such as skin, muscle, or bone marrow.

The blood-forming hematopoietic stem cells are the most understood. They can turn into red or white blood cells, or platelets, and have been particularly effective in treating blood-borne cancers such as leukemia, Hodgkin's lymphoma, and multiple myeloma.

Another type, induced pluripotent stem cells, or iPSC cells, are created in a laboratory. Scientists have found ways to genetically reprogram adult stem cells into cells that act more like embryonic stem cells. They are useful for studying diseases and testing new therapies.

### THE PROMISE OF STEM CELLS

Researchers are particularly focused on investigating cell-based therapies, using stem cells to replace or repair damaged organs and tissues. In the future, it may be possible to regenerate damaged heart muscle, repair an injured spinal cord, or replace missing or injured neurons in the brains of people with Parkinson's disease or Alzheimer's disease. Scientists are even working on ways to grow entirely new organs from stem cells. Still, despite the potential of these experimental approaches, therapies are years away from being proven safe and effective.

Unfortunately, that hasn't stopped the proliferation of clinics in the United States and abroad offering stem cell therapy for all kinds of neurologic diseases.

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Nor has it stopped people like Gass from shelling out thousands of dollars for these so-called treatments, says Gary Gronseth, MD, FAAN, professor and vice chair of neurology at the University of Kansas.

People with neurologic conditions are particularly vulnerable to unscrupulous claims because so many neurologic disorders are progressive and existing treatments can't alter the course of the disease. "Consider people with amyotrophic lateral sclerosis (ALS), a disease that's relentlessly progressive and fatal," says Dr. Gronseth. "These patients and their families are desperate to try new therapies, even ones that are unproven, just in the hope that maybe this one will turn out to be legitimate."

### DESPERATE FOR HELP

The journey to stem cell treatment often starts with an anecdote from someone who claims to have been cured by the procedure, either heard in person or found on the internet, or both. That's what happened to Gass—he had read accounts online—and to Joe and Nettie Aufenkamp.

The Aufenkamps first heard about stem cell therapy from a flight attendant on a trip to Las Vegas. "She had been paralyzed after a car accident and told us that she had gone to Germany for a stem cell transplant, with excellent results," recalls Nettie. Like the flight attendant, Joe had been in a car accident: An out-of-control semi-tractor trailer had spun into his car and sent it flying into a ditch. Joe, who was 48 at the time, sustained head trauma and spent weeks in a coma. After emerging from the coma, he had balance and coordination problems, extreme weakness, and short-term memory loss.

For more than a decade, he and Nettie had looked for any possible treatment that could improve his condition. He underwent extensive physical therapy but was still unable to walk without a walker. And his speech, which had been compromised since childhood by cerebral palsy, worsened after the accident, and no amount of speech therapy made a difference.

After hearing about the flight attendant's experience, the Aufenkamps searched the internet for information about stem cell therapy for traumatic brain injury. They eventually found a clinic in Arizona. The clinic's website states that none of its treatments are approved by the FDA, but it also says that "many reputable international medical clinics" use stem cell therapy to treat chronic degenerative conditions, including neurologic diseases. The website also explained that it harvests stem cells by removing a small sample of fat tissue from a patient's lower back or abdomen. Then those cells are injected back into the patient, either into the skin or muscle near the affected area, or are administered through a nasal spray.

### UNVERIFIABLE TREATMENT

"They sent us references, and we decided to go for it," says Nettie, even though her husband's doctors opposed the treatment. Joe and Nettie plunked down \$7,000 in cash and signed consent forms saying they wouldn't file with insurance or sue if anything went wrong.

The Aufenkamps were told the only risk of the procedure was possible infection in the area where the cells were extracted. Infection is usually the greatest concern with most injections of stem cells, but it's not the only hazard, says Nicholas Maragakis, MD, director of the Michael S. and Karen G. Ansari ALS Center for Cell Therapy and Regeneration Research at Johns Hopkins University in Baltimore. "There is also potential for bleeding, and any time you deliver stem cells to any region, there is potential for them to malignantly transform into a tumor. No one should undergo a procedure like this outside of a well-controlled clinical trial at a reputable research institution."

Joe received a nasal spray, which was purportedly administered to open up the sinus cavity. Then he had to sniff deeply for a count of three to bring the cells in deeper. "It was explained that the cells would attach throughout the sinuses and brain and cascade downward," Nettie says.

For the first 48 hours after the nasal spray, Joe's speech was clear and fluent, says Nettie, but it didn't last. Once they returned home, they noticed another improvement: Joe seemed to be able to stand more independently. "We have a power chair with a lift that comes out of the back of our van, and he was able to stand there without hanging onto anything and loosen the straps," Nettie says. That improvement also faded, and today Joe copes with all the same day-to-day impairments he had before getting the stem cell treatment.

Misunderstanding of the placebo effect or of the natural history of recovery or progression of certain illnesses or injuries makes it easier for unscrupulous stem cell clinics to sell their 'snake oil', explains Clive Svendsen, PhD, the Kerry and Simone Vickar Family Foundation Distinguished Chair in Regenerative Medicine at Cedars-Sinai Medical Center in Los Angeles. "There would need to be a double-blind, placebo-controlled trial to demonstrate the ability of a spray like this to provide temporary relief of symptoms. So far, no such trials have been conducted. I think this family's experience is typical of what many people who seek unproven stem cell treatments report: mild placebo effect followed by no lasting change. They feel better for having tried, but they are also \$7,000 worse off, and the clinic has sold them a scam treatment."

### INEFFECTIVE, EXPENSIVE, AND UNSAFE

And as Jim Gass' story illustrates, the outcomes for people who seek these treatments can be much worse.

Although stem cell therapy holds great promise, many unknowns remain. That is why the treatment must be administered and monitored closely in clinical trials. "When cells are taken from fetal tissue and the tissue hasn't been processed correctly, that can be very dangerous," says Dr. Svendsen. "Because these cells can renew themselves infinitely, they have the potential to replicate out of control and cause tumor growth."

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

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

## Stem Cell Reality – Continued from page 5

Dr. Maragakis says almost every one of his patients asks about stem cell therapies. “I’ve talked with people who had their bone marrow cells isolated and injected back into their bodies, with the claims of magical stabilization of disease after one day, only for the patients to return to their previous condition after a few days,” he says. “In China, people were getting cell transplants right into the brain itself.”

With such clinics springing up around the world and defying regulatory efforts to close them, more and more people will likely be ensnared—and risk disastrous outcomes like what Jim Gass experienced.

### PIPELINE PROJECTS

In the meantime, legitimate research continues. Various types of stem cells are being studied for many neurologic conditions in test tubes or on animals. A few approved clinical trials are underway to test stem cell treatments for conditions such as ALS, spinal cord injury, and stroke, with more on the horizon.

FDA-approved clinical trials in a number of stroke centers are now researching the effectiveness of mesenchymal stem cells—a specific type of adult stem cell usually found in bone marrow or connective tissue—in reducing inflammation and helping the brain repair itself after stroke. These cells do not survive more than two weeks in the body and would probably be used more like a drug that would have to be given at regular intervals, Dr. Svendsen explains.

A few human clinical trials are testing various methods for spurring stem cells to take root and grow within the brain and central nervous system. As of press time, three companies are approved by the FDA to conduct clinical studies using direct injections of neural stem cells. [See “3 Neural Stem Cell Studies” below.]

Dr. Svendsen’s group at Cedars-Sinai is awaiting FDA approval for clinical trials using a combination of stem cells and gene therapy in another ALS trial. They have developed fetal tissue cells engineered to make a substance called glial cell line-derived neurotrophic factor (GDNF), which has been found to protect motor neurons from damage in animal models of ALS, but not yet in human trials.

“We modify human neural stem cells to produce GDNF and then inject them directly into the spinal cord. There they act as Trojan horses, arriving at sick motor neurons and delivering the growth factor exactly where it is needed,” he explains. The researchers are testing the safety of this approach in a phase 1 trial.

### SIGN UP FOR LEGITIMATE TRIALS

To participate in an approved clinical trial of stem cell therapy, search <http://clinicaltrials.gov> to find studies that might be right for you. No legitimate clinical trial should ever require that you pay for the treatment you receive. If you choose to enroll in a trial, you might benefit from a new therapy if you receive it, says Dr. Gronseth. “You’re also contributing to medical science by helping to figure out whether a new therapy actually works.”

### IRRESISTIBLE PULL

With just a few legitimate trials currently available, Dr. Maragakis understands that patients who have no other options for stopping or reversing the course of their disease can be tempted by the unproven promises of stem cell clinics. “I discuss the risks and the costs of these places with my patients. I tell them how rigorous the science has been to get legitimate research to the point it is now,” he says. “But I also tell

them I will support whatever decision they might make. The reality is, though, that none of my patients who have tried these treatments have come back thinking that it helped them. Most often they tell me, ‘For the first week or two, I felt like it was helping, but now things are just the same as they were before.’”

### PROTECT YOURSELF FROM STEM CELL SCAMS

Despite a government crackdown, the number of clinics offering unproven treatments continues to rise. In September, the US Food and Drug Administration held a two-day public meeting focused on regulation of human cells, tissues, and cellular- and tissue-based products.

Until federal and state regulations are enforced more aggressively, you can avoid enrolling in bogus trials by asking these questions:

Is this treatment based on a randomized, controlled trial in which patients given the stem cell therapy were compared to similar patients not treated with stem cell therapy? Individual patient testimonials may be impressive, but they’re not scientific evidence.

How many people were in the trial? In smaller trials, it’s harder to distinguish between a true treatment effect and random variation.

Were the results assessed by “blinding”, meaning the researchers determining whether or not a patient improved did not know which patient received stem cell therapy and which did not? Blinding prevents the findings from being manipulated, intentionally or unintentionally.

How many patients with my condition experienced permanent improvement after the therapy? Be wary of dramatic claims that the treatment has cured or brought major improvements to most patients.

What diseases can be treated with this therapy? If the response is a long list of varying conditions, be skeptical.

How does this treatment actually work? Consider whether the answer seems to make sense. For example, how would cells taken from your own fatty tissue migrate, take root in the brain, and form new brain cells?

Where are the cells coming from? “Push them on that, and get it in writing,” says Clive Svendsen, PhD, the Kerry and Simone Vickar Family Foundation Distinguished Chair in Regenerative Medicine at Cedars-Sinai Medical Center in Los Angeles. He strongly advises avoiding any centers that claim to administer fetal tissue-derived stem cells outside of a clinical trial.

For example, he points to one stem cell clinic, Stem Cell of America in California, that claims to have used fetal-derived cells to “successfully treat” everything from Alzheimer’s disease to stroke in more than 3,000 patients, with no known negative side effects. “That’s pretty much every red flag there is, and every claim you would expect from people who are making money from this,” he says.

### 3 NEURAL STEM CELL STUDIES

Three companies have received FDA approval to start trials using neural stem cells for neurologic conditions

**Neuralstem, Inc.** This biotech company in Rockville, MD, has completed a phase 2 trial (which tests for efficacy) in amyotrophic lateral sclerosis (ALS) in which human spinal cord-derived stem cells were injected directly into the spinal cord to protect the motor neurons that are destroyed by the disease. Results from the trial have not yet been published. The company announced in mid-2015 that the treatment appeared to be safe and well tolerated, and early findings showed that 47 percent of patients had some

## Ground-Breaking Discovery: UC Davis Researchers Find Key Mechanism That Causes Neuropathic Pain – Continued from page 1

use in many patients,” Inceoglu said. “The bottom line is that we do not fully understand neuropathic pain and our work sheds new light onto one out of many diverse biological processes that mediate neuropathic pain. With this knowledge, one can test if ER stress blocking drugs can control pain in the clinic, and in parallel, ask fundamental questions in the lab, such as how multiple types of pain grouped under the name ‘neuropathic’ differ from each other and respond to new ER stress blockers.”

John Imig, professor of pharmacology and toxicology at the Medical College of Wisconsin, Milwaukee, who was not involved in the study, said: “This scientific study provides convincing evidence for a novel concept as to what causes neuropathic pain. Cellular endoplasmic reticulum stress, ER stress, has been implicated in diabetes and findings in this scientific study now implicate ER stress in neuropathic pain.”

“This group of investigators previously found that drugs that target ER stress reduce symptoms of diabetes,” Imig pointed out. “Interestingly, this scientific study provides exciting data clearly demonstrating that molecular chaperones and soluble epoxide hydrolase inhibitors reduce ER stress and neuropathic pain in a synergistic manner. This provides a new opportunity for developing innovative single molecule or combination therapeutics for neuropathic pain.”

In earlier work, the UC Davis team showed that by stabilizing analgesic and anti-inflammatory natural molecules in the body, they could block ER stress and improve a variety of disease states. In this report, the researchers blocked ER stress using a powerful transition state inhibitor of the soluble epoxide hydrolase enzyme made by co-author/researcher Kin Sing Stephen Lee of the UC Davis Department of Entomology and Nematology/UC Davis Comprehensive Cancer Center.

“The compound reduces dramatically the pain associated with diabetic neuropathy and illustrates that one can reduce neuropathic pain by increasing natural chemical mediators already in the body,” said Hammock. He and his laboratory discovered and study potent enzyme inhibitors that dramatically reduce inflammation, inflammatory pain and neuropathic pain.

The research “Endoplasmic Reticulum Stress in the Peripheral Nervous System Is a Significant Driver of Neuropathic Pain,” is the work of a six-member research team: Inceoglu, Bettaieb, Lee, Haj,

Hammock and Carlos Trindade da Silva of the Department of Entomology and Nematology/UC Davis Comprehensive Cancer Center.

“Despite intensive effort and resulting gains in understanding the mechanisms underlying neuropathic pain, limited success in therapeutic approaches have been attained,” the authors wrote in their abstract. “A recently identified, non-channel, nonneurotransmitter therapeutic target for pain is the enzyme soluble epoxide hydrolase (sEH).”

“The sEH degrades natural analgesic lipid mediators, epoxy fatty acids (EpFAs), therefore its inhibition stabilizes these bioactive mediators,” they explained. “Here we demonstrate the effects of EpFAs on diabetes-induced neuropathic pain and define a previously unknown mechanism of pain, regulated by endoplasmic reticulum (ER) stress. The activation of ER stress is first quantified in the peripheral nervous system of type 1 diabetic rats. We demonstrate that both pain and markers of ER stress are reversed by a chemical chaperone.”

“Next we identify the EpFAs as upstream modulation of ER stress pathways. Chemical inducers of ER stress invariably lead to pain behavior that is reversed by a chemical chaperone and an inhibitor of sEH. The rapid occurrence of pain behavior with inducers, equally rapid reversed by blockers and natural incidence of ER stress in diabetic peripheral nervous system (PNS) argue for a major role of the ER stress pathways in regulating the excitability of the nociceptive system. Understanding the role of ER stress in generation and maintenance of pain opens routes to exploit this system for therapeutic purposes.

The research was supported in part by a National Institute of Environmental Health Sciences (NIEHS) grant and a NIEHS Superfund Basic Research Program grant, awarded to principal investigator Bruce Hammock; and National Institutes of Health (NIH) grants awarded to Fawaz Haj. In addition, Hammock, Inceoglu and Bettaieb received grants from NIH and/or the National Institute of Arthritis and Musculoskeletal and Skin Disease.

Used with permission of Bruce Hammock, Ph.D.

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## Stem Cell Reality – Continued from page 6

response to the therapy, either improving or showing almost no decline on functional status tests.

**ReNeuron.** This UK-based company has phase 1 trials (which test the safety of a procedure) and phase 2 trials (which test for efficacy) underway in stroke. Neural stem cells are injected directly into the brain, where it’s thought that they may reduce inflammation and release growth factors that help rebuild damaged areas.

**Q Therapeutics, Inc.** Based in Salt Lake City, UT, this company received approval last year to begin a trial of its patented glial progenitor cells into the spinal cords of people with ALS. The company hopes the cells will combat the disease by successfully developing into two different types

of specialized cells that protect neurons and improve transmission of nerve signals in the brain and spinal cord. The trial is still in the planning stages.

To find out more about these and any future trials of stem cell therapies, search <http://clinicaltrials.gov> for “stem cell” and the condition you’re interested in.

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# WESTERN NEUROPATHY ASSOCIATION

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## The 2017 Annual Neuropathy Conference April 18, 2017

The Mind Institute • U.C. Davis Medical Center Campus, Sacramento, CA

Speakers: Yuen So, MD, Neurologist, Stanford University Medical Center

Bruce Hammock, PhD, Researcher, U.C. Davis

**MARK YOUR CALENDARS NOW!**

### NEW PRESCRIBING INFORMATION RELEASED FOR HUNDREDS OF FDA-APPROVED OPIOIDS

Sharon Hertz, MD, Director, Division of Anesthesia, Analgesia, and Addiction Products (DAAAP) Office of New Drugs, Center for Drug Evaluation and Research, U.S. Food and Drug Administration. Warnings and dosing information provide clearer instructions to promote safety.

The updated labels are an important part of the FDA's continuing effort to educate patients and prescribers about the risks related to prescription opioids, including the importance of balancing the benefits and risks for each individual patient and emphasizing information important for appropriate patient selection.

### FDA APPROVES MORPHINE WITH ABUSE-DETERRENT PROPERTIES

The FDA has approved morphine sulfate (Arymo ER, Egalet) extended release (ER) tablets for the management of pain severe enough to require daily, around-the-clock, long-term opioid treatment and for which alternative treatment options are inadequate.

An interactive Multimedia News Release can be found here:

(<http://www.multivu.com/players/English/7999051-egalet-corp-arymo-er-fda-approval/>)



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