



WESTERN NEUROPATHY ASSOCIATION

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Issue 9
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Neuropathy Hope

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

A newsletter for members of Western Neuropathy Association (WNA)

■ STEM CELLS – IS THIS AN OPPORTUNITY FOR HELP OR AN UNREGULATED HEALTH RISK?

Over the years, we have seen a parade of “clinics” open up claiming that for so many thousands of dollars up front we might get effective treatments for one ailment or another. Some sufferers have been convinced and paid for treatments. Some have even borrowed money on a long term loan they paid on long after the treatments were over. Some people have received some short term positive results. Some are worse off and are suffering more than they did before the treatment and the large outlay of funds.

Now we have a new generation of clinics springing up offering stem cell therapy. Below are excerpts from a recent article, **Growing Industry or Unregulated Risk? UC Davis Looks at Booking Stem Cell Clinics**, in the Sacramento Bee by Adam Ashton about a clinic opening in Sacramento. (Used with permission.)

In Beverly Hills, a clinic says it can help athletes heal from sports injuries and avoid invasive surgeries by employing regenerative stem cells.

In Miami, another clinic says it can reuse stem cells from patients' bodies to erase wrinkles.

And in Sacramento, a clinic's website has NFL wide receiver Marlon Moore touting the relief he felt after

undergoing stem cell treatment from local doctors.

All of those clinics are part of a growing industry that promotes what its advocates describe as low-risk alternative treatments for conditions that range from nerve damage to cosmetic surgery.

Yet they're also operating outside of the normal realm of medical oversight from the Food and Drug

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■ MEDICAL MARIJUANA OVERVIEW

Kristian Meyer from Abatin Wellness Center, a medical marijuana dispensary, in Sacramento spoke at the August 16 meeting of the Sacramento Neuropathy Support Group. A member of the leadership team obtains product from this dispensary and made the arrangements for this presentation. Charles Moore and his leadership team are to be congratulated on the open door given to others from the general area to attend. I saw people from Auburn, Grass Valley, Folsom, Roseville, San Jose, Redwood City, and, of course, Sacramento. There may have been others.

Meyer shared that the human body has an Endocannabinoid System, which is a lipid signaling system essential to health, healing, and homeostasis, which is the system by which the body's response to cannabinoids is experienced. These are any of a group of closely related compounds that include cannabidiol and the active constituents of cannabis.

Medical properties are basically achieved through two types: CBD – Cannabidiol is one of at least 113 active cannabinoids identified in cannabis. It is a major phytocannabinoid. Inactive THC/CBD is a biosynthetic precursor of tetrahydrocannabinol (THC), the active component of cannabis. The inactive form is used in medical marijuana preparations. Active THC is used

in recreational marijuana. Its medical components are retained when it is inactive, but the psychological impact is removed.

These preparations can be made in many forms besides being smoked – tinctures which can be consumed usually in a dropper form or a spray; edibles such as brownies, cookies, chocolate candy bars; creams that can be rubbed on the skin, etc.

THC and CBD help by activating the two main cannabinoid receptors (CBD1 and CBD2) of the Endocannabinoid System within the body. These receptors regulate the release of neurotransmitter and central nervous system immune cells to reduce pain levels.

If a person wants to try medical marijuana, they talk to their primary care doctor about it or another doctor they are dealing with that knows about their pain concerns. The doctor can write a prescription. If the doctor does not choose to do so, the patient may make an appointment with the doctor at the Abatin Wellness Center or other dispensaries. No one may enter into the dispensary without a doctor's prescription. The doctor does not specify what product to use. The person

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Roster of Our WNA Information and Support Groups

2016 WNA Board of Directors

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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

Alturas

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

Antioch-Brentwood

3rd Wednesday, 2 PM-odd numbered months
Next meeting Sept. 21
Antioch-Kaiser
AMC-1H2 (from hospital lobby)
Sandra (925) 443-6655

Auburn

1st Monday, 11 AM
Next meeting, Oct. 3
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

Bakersfield

For information, call
Bev Anderson 877-622-6298

Berkeley-Oakland

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

Carmichael - Eskaton

2nd 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

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

Castro Valley

2nd 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

3rd Thursday, 1:30 PM
Next meeting, Sept 15
First Christian Church
3039 Willow Pass Road
Wayne Korsinen (925)685-0953

Crescent City

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

Davis

2nd Tuesday, 3:30-5:00 PM
Next meeting Sept. 13
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

Eureka

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

Folsom

1st Thursday, 12:30 PM
Berger 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

3rd Tuesday, 11:00 AM
Denny's Restaurant
1110 East Shaw
Marvin Arnold (559) 226-9466

Garberville

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

Grass Valley

2nd Monday, 1:30 PM
Next meeting, Sept. 12
GV United Methodist Church
236 S. Church Street
Bev Anderson 877-622-6298

Jackson

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

Lakeport

March meeting day and time, call Mito.
Lakeport Senior Center
507 Knocti Ave.
Mito Shiraki (707) 245-7605

Lincoln

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

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
Sandra Grafrath (925) 443-6655

Madera

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

Merced

2nd Thursday, 1 PM
Next meeting, Sept. 8
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
Next meeting, Sept. 19
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 Street
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Oxnard

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

Placerville

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

Quincy

1st 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

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.
Bev Anderson (877) 622-6298

Sacramento

3rd 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

4th Thursday, 10 AM
UC-San Francisco Med Ctr.
400 Parnassus Avenue
Amb. Care Ctr. 8th Flr., Rm A888
Y-Nhy (e nee) Duong
Nhy-y.duong@ucsf.edu

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

President's Message

By Bev Anderson



This is a full issue on alternative treatments that are timely for many. Throughout our area a variety of clinics have opened with various approaches to treating neuropathy. We've seen gadgets, light therapies, lasers of different descriptions, injections of substances such as a type of Novocain and a unique formula and other descriptions. Now we are seeing non-FDA approved stem cell therapies. Many of these take a syringe of stem cells from your body, separates them out, and reinjects those retained back into your body. To me, this is rather scary as if you have had some corrective surgery or treatment to take care of some problem, you might well get it back. Some across the country are finding conditions develop that are not curable. As one of the articles in this newsletter says, they are live cells. There will be a response from your body and they aren't all positive.

We waited a couple of days to get this newsletter to the printer so we could include an article from the Sacramento Neuropathy Support Group meeting with a medical marijuana dispensary in Sacramento. It sounded like information many would want to have.

Shortly, if not already, you will receive our summer letter to everyone in our data base providing information about our activities, specifically we are asking for a donation to help us expand our reach by training people to do what I've done in planting and servicing support groups and other activities necessary to continue this organization. WNA is unique among neuropathy organizations and it is vital to many people with neuropathy that it continue beyond my ability to do so. I trust that many will give a donation and that at least some, as they are able, will be especially generous.

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WNA Information and Support Groups – continued from page 2

Santa Cruz

3rd Wednesday, 1PM– odd numbered months
Trinity Presbyterian Church
420 Melrose Avenue
For information call
Bev Anderson (877) 622-6298

Santa Maria

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

Santa Rosa

1st Thursday, 10:30 AM
Next meeting, Sept. 1
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

3rd 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

4th 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

3rd 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@pnhelp.org

PATIENTS' GUIDE TO TREATMENTS: 2016

Paul Knoepfler, M.D., UC Davis Medical Center

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 PCNA/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
PCNA Discount: 10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
(916) 686-1050
PCNA 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
PCNA Discount: 10% off the regular price shoes.

Sacramento

Midtown Comfort

Shoes

3400 Folsom Blvd.
(916) 731-4400
PCNA discount: 15% on the regular price.

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Top 10 list of important, easy to understand facts for patients about stem cell treatments

I know there are thousands of people out there looking for more practical information about stem cell therapies and treatments. These folks understandably are using the Internet to look for some clear, good information on stem cell treatments either for themselves or their loved ones. Too often the information that is out there is either wrong, partially misleading, biased, or overly complex.

So in this post I want to address this need for trustworthy factual information and no-nonsense perspectives. I am speaking as a scientist, patient advocate, and cancer survivor in the form of 10 key realities list below to help you guide your way through the jungle of stuff out there about stem cells. I have now updated this post for 2016 as some things have changed in big ways in just the past few years. Keep in mind this is not medical advice and you should absolutely talk to your personal doctor with whom you should make your own decisions.

1) Stem cells are often essentially a type of drug and possibly permanent in your body after a transplant. Yeah, stem cells can be extremely unusual drugs, but they are often drugs even if some argue they aren't. The FDA considers them drugs in many cases. Unlike other drugs, once a patient receives a stem cell drug, it will not necessarily simply go away like other drugs because a stem cell drug consists of living cells that often behave in unpredictable ways. What this means is if the stem cells are doing bad things your doctor has no way to stop it. You have no way to stop it. Also because stem cells are alive they can grow inside your body, move around, and change. This can be helpful or harmful, but the big point is that it is not something that is controllable or reversible.

2) Side effects. Like any medical product, even aspirin, stem cell treatments will have side effects. Not maybe. Definitely. Our hope is the side effects will be relatively mild. Different kinds of stem cells have variable risk profiles, but if someone tells you that the stem cell treatment they are selling has no risks then that is a big red flag and I would walk away. They are either woefully lacking in knowledge or aren't being honest with you. Sometimes clinics will either on their websites or in person acknowledge risks almost as sort of a disclaimer, but then they'll tell more casually that there aren't really any risks. A common statement is "The only risk is that it won't work." That's false.

3) The only stem cell treatment explicitly

approved by the FDA for use in the U.S. consists of versions of bone marrow/hematopoietic stem cell transplantation. What this means is that any other stem cell treatment you see advertised on Facebook or Google or elsewhere that indicates it will be given to you inside the U.S. is not FDA approved. The exceptions to this are if it is part of an FDA-approved clinical trial or it is using stem cells in a procedure that meets other criteria (e.g. being both homologous use and minimally manipulated—yeah I know these are jargon terms).

4) If you venture outside the U.S. for a stem cell treatment, use extra caution, but in 2016 also be very careful inside the U.S. Whether you travel abroad or closer to home, have a knowledgeable physician inside the U.S. guiding you, preferably your primary care doctor who most often are not going to buy into hype. We have to avoid the trap of thinking that only the U.S. can offer advanced medical treatments and these days many American patients get their stem cell transplants here in the U.S. from dubious clinics.

5) Stem cells are not a cure-all. I am as excited as anybody about the potential of stem cells to treat a whole bunch of diseases and injuries, but they are not some kind of miracle cure for everything. When a doctor offers to inject some kind of stem cells into a patient either into the bloodstream or into a specific place that is injured such as a shoulder, we just do not know at this point if it will do any good with the exception of bone marrow transplant. You should start getting worried if the clinic tells you that one kind of stem cell such as fat, bone marrow, or amniotic stem cells can treat many different conditions. There's no science behind that kind of claim. Stem cells are not a panacea.

Patients often mention to me that the doctors offering stem cell treatments told them that the treatments are proven safe....or that your own stem cells cannot harm you...or that adult stem cells are harmless. I often tell people to think about how much research and how many questions they ask when looking to get a new car. You should bring at least that level of intensity (ideally much more) to getting information about stem cell transplants too as the stakes are even higher. Be skeptical. Ask many questions and if you aren't convinced, then don't do it.

6) Don't let celebrities be your guide to medical care. The number of famous people getting stem cell treatments is increasing including sports stars and politicians. Don't let what these folks do influence what you decide to do about your health. Just because they are famous do not believe for one minute that they are any more informed than

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PERIPHERAL NEUROPATHY LITERATURE REVIEW By William B. Donovan, MD

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over 100 medical articles a month written on PN.

I review these references and select articles that would appear to be most interesting to us neuropathy sufferers. This is the link to **PubMed** that will take us to the **NLM: www.ncbi.nlm.nih.gov/sites/entrez**

If you are reading this article on the computer, just click on the above link to go there. If you are reading the print edition of the newsletter, type this link into the address bar of the browser on a computer. If you don't know how, get a librarian or friend to help you.

After you get to **PubMed**, you will see a line that says "**Search PubMed**" followed by "**for**" and a space. Every article in the **NLM** is given a **PMID**, an eight digit identification number. I will give you **PMID** numbers of the selected articles. Type the **PMID** into the space after the "**for**" and click on "**Go**" at the end of the space, or press the ENTER key on your keyboard. You will then see a one paragraph abstract of the article appear, as well as links to related articles.

This month's PMIDs:

- 25751285 This is a meta-analysis of randomized

controlled trials of acetyl-L Carnitine (ALC) in the treatment of peripheral neuropathic pain. It significantly reduced pain in diabetics ($p=0.00001$), but less so in diabetics ($p=0.05$).

- 25614498 This is a detailed discussion of the multitude of possible treatments available for painful diabetic neuropathy.
- 25655006 This demonstrates the effectiveness of sublingual fentanyl for the treatment of breakthrough neuropathic pain. The average pain reduction was 3.30 points from baseline ($p < 0.0001$).
- 25685786 This detailed Italian review of the mechanism underlying chronic inflammatory, neuropathic and cancer pain implicates rapamycin (mTOR) kinase activity in the primary sensory axons, dorsal root ganglia and dorsal horn neurons. Inhibition of kinase activity may prove to be an important target in the management of chronic pain.
- 25751285 This Chinese 20 year review of literature comparing acetyl-L carnitine (ALC) with placebo treatment of peripheral neuropathic pain found four randomized controlled trials (523 patients) showing moderate, statistically significant reduction of pain on the Visual Analog Scale.

Medical Marijuana Overview - *Continued from page 1*

works with one of the counselors at the dispensary to decide what to try in a limited amount. "Low and slow" is Albatin's motto as is ours in the case of medication. The response is usually not immediate but over some weeks the person's body will respond or not to the substance chosen to try.

Some medical groups will not write medical marijuana prescriptions but the patient has the right to make a decision on their own. The chief concern is to have a doctor who will track the progress of a person who is using medical marijuana. It can mean changing one's doctor or medical group. It was mentioned that there are Sutter doctors who will work with a person who chooses to use medical marijuana, but not all. More interest in medical marijuana has developed since doctors are withdrawing opioid medications even though the person has used the prescription successfully for years for a chronic condition. Our state law indicates that people with chronic, lifetime disease responses are not to lose their medication, but the pressure is great on doctors to roll back all opioid prescriptions. One person present said that he was with a medical group that will not write a prescription for medical marijuana. They chose to cut his opioid prescription and leave him in major pain. He told them he wanted a medical marijuana prescription and would get one outside if that was his only option. They gave him back his opioid prescription.

Meyer said that Abatin Wellness Center has four locations throughout the state with most in Northern California. They have their own lab to test and confirm

their products. She said that not all dispensaries do this. Meyer also said that each dispensary has its own product inventory so you may not be able to get the same product at another dispensary. Medical marijuana doesn't usually have interaction with other medications; but the counselors at the dispensary either know or can check on that question and are constantly in study and training to be more informed about the ramifications of the product.

It was an informative presentation that let those present know what medical marijuana is and does and how one goes about getting access to it. Meyer emphasized that it is legal in California but it is still illegal federally. This would also be true if recreational marijuana is approved in November in California. Approval for recreational use would not change the medical marijuana dispensaries as they operate for patients with product that can be used to help with pain and other disease symptoms.

The Western Neuropathy Association makes no recommendation for use of medications or supplements, but urges anyone considering medical marijuana or any other treatments to consult with their primary care doctor and any other doctor they see on a regular basis before making a decision. Any doctor writing a prescription should interview and know the conditions from which the patient suffers and their specific reason for wanting to try medical marijuana or other treatment options before any decision by the patient is made. (Bev Anderson, Editor)

DISCOUNTS FOR WNA MEMBERS

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

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.

WAYS TO AVOID A SCAM

1. Talk to someone who will listen to what you have been told with an evaluative ear and tell you what they think about the claims made.
2. Look at any of the paperwork given you or written claims with a person you trust to point out misrepresentations or questionable evidence.
3. Don't do business over the telephone with an unknown individual who has called you or anyone you are not fully confident.
4. Talk to your bank about what has been told you. Ask if anyone else to their knowledge has paid what they are asking for what they proposed to do and what the bank's attitude is toward what you are being told.
5. Talk with family members and friends that might have some knowledge. Don't let someone tell you that others wouldn't understand and not to talk about it as it was between you and the one trying to sell it to you. Cornering you and trying to isolate you from others you might discuss it with is a sure indication that it is questionable.
6. Do not be afraid to say NO. It is your money and your life. Don't let them make you feel you will let them down or make it hard for them if you don't agree to do what they say. This is actually a reason to turn them down. Also don't let them make you think you will die or be sicker if you don't do what they say. Only your doctor should be advising you on that kind of matter. Be sure to consult one or more of your doctors before committing to anything dealing with your health. They may not wish to continue being your doctor if you bring in a new team with which they don't have a working relationship.
7. Don't sign anything for payments before treatments for which there is no money back guarantee that they will work for you. Don't sign to borrow money to pay for treatments or benefits promised without a written money back guarantee that they will work for you. Testimonials that it worked for someone else are no guarantee that it will work for you or scientific proof that it works at all.

(Bev Anderson, Editor)

Patients' Guide To Treatments: 2016– *Continued from page 4*

you or your personal doctor about medical treatments or stem cells. If anything I think sometimes famous people are more reckless with their health than average people like you and me.

7) Reach out to scientists as a source of information. As a scientist I am always happy to hear from people outside the scientific community with questions about stem cells and other research. I can't speak for all stem cell scientists but you might be surprised at how likely it is that if you send them a very short, clear email with one or two questions that they will respond and be helpful. We can't or shouldn't offer medical advice, but we can give our perspectives on stem cell research and its clinical potential, etc. Just do not cold call scientists as you are unlikely to find them that way and even if you do, they may be cranky. Email. If they don't reply try someone else and don't be offended that we didn't answer. Often times we may not answer because we are super busy. For instance, I often get more than 100 emails a day.

8) The people selling you non-FDA approved stem cell treatments want your money. As such they will do their best to convince you that their treatment is safe and effective. The more convincing they are then the more money they make. They may offer patient testimonials either from patients who truly believe they were helped or from people who are paid to say the treatment helped them. The bottom line is that the sellers of dubious stem cell treatments are generally in it for the big bucks. Admittedly I do think that some of these providers truly believe stem cells are helpful, but you'll never see even them offering to give patients the cells at cost. These are instead very much for-profit operations.

9) NEW—Just because something is called a stem cell “clinical trial” doesn't mean it really is and being listed on www.clinicaltrials.gov means a lot less than it used to. I am contacted weekly or even daily at times by patients or their families and they are rightly focused on getting information that they can trust. Many stem cell clinics call the treatments that they offer by the name “clinical trial” and that's often misleading. In the standard meaning of “clinical trial” the

experimental therapy being tested has the FDA's approval to be used in the study, there are data supporting the study, and those doing the trial do not charge patients to be in it. You shouldn't have to pay to be a guinea pig. I think that's almost always going to be unethical on the part of those giving it. I often suggest that people turn to the federal website clinicaltrials.gov for information. It is still a great resource, but be aware that many pseudo-clinical trials are popping up on there that are really mostly about making money. They do not have FDA approval in many cases and there are other issues of concern. So even on that website use caution.

10) The most important thing is information/data and you have a right to see it before treatment. Before you or a loved one get a stem cell treatment, ask two key questions. First, is the treatment FDA approved and if not, why not? Second, can you please show me the data that proves your treatment is safe and effective? See what kind of answer you get. If they criticize the FDA or invoke a plot by “big pharma” to block stem cells then that is a warning flag. If they refuse to show you data, then that is a big red warning flag. They may say it is confidential or that it is not published yet, but as a patient you have a right to see the data, assuming they have any data at all.

These facts will likely change over the coming years, but right now I think they represent reality. I know as patients we need hope, but these unapproved stem cell treatments will at best take your money for nothing, and at worst will endanger you or your loved ones.

The post above is for information only and is not medical advice. All medical decisions should be made by patients in consultation with their personal physicians.

Dr. Knoepfler's blog:

<http://www.ipsell.com/patients-guide-to-stem-cell-treatments/>

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Stem Cells – Is This An Opportunity For Help Or An Unregulated Health Risk? – Continued from page 1

Administration (FDA) by carrying out procedures that have not been tested and sanctioned by the agency.

A new study published Thursday in the journal *Cell Stem Cell* by UC Davis professor Paul Knoepfler and a partner from the University of Minnesota is drawing attention to the increasing number of clinics in the U.S. that offer stem cell therapies not approved by the FDA.

Using extensive internet searches, Knoepfler and bioethics professor Leigh Turner found 351 businesses promoting those services at 570 different clinics. California is home to 113 of them.

It's a striking number that illustrates the reach of what Knoepfler and his partner describe as a largely unregulated industry that has not yet collected enough clinical data to prove whether its methods are safe and effective.

"Most of these businesses kind of took the shortcut route," Knoepfler said. "They decided we're not going to do any trials and we're going to take the stem cells directly to the people."

He and his partner are wading into a national debate about how the government should regulate new procedures five years after famous athletes such as retired Broncos quarterback Peyton Manning and Mets pitcher Bartolo Colon turned to stem cell treatments for their injuries. Most of the clinics operating in the U.S. have opened since then.

In 2004, California voters approved an initiative funding stem cell research in the state. Since then, the California Institute for Regenerative Medicine has allocated about \$2 billion for research.

Paul Knoepfler and Turner want the FDA to rein in the industry so patients have a better understanding that they're seeking

procedures that have not undergone extensive scientific tests to determine whether they work. They also argue that compelling stem cell procedures to undergo the full FDA approval process could protect the industry by ensuring its practices are safe.

"The problem is that so much of the information that's provided by the industry, so many of the marketing claims being made, they're not particularly accurate," Turner said. "They're not trustworthy, and they don't have any meaningful science behind them."

So far, the FDA has taken a fairly light touch regulating clinics that provide stem cell therapies. It issued draft guidelines to regulate the industry in 2014 and in September it's holding a public hearing at the National Institutes of Health in Maryland to gather opinions on how it should regulate stem cell treatments. The federal agency also issued a warning letter in 2012 urging people to be critical of clinics that promote stem cell treatments.

"At this time, the value of stem cells as a treatment for most conditions is largely unproven, and more information is needed about their potential benefits," FDA spokeswoman Andrea Fischer wrote in a statement to *The Sacramento Bee* summarizing the agency's stance.

Most stem cell procedures involve taking cells from a patient's body and reintroducing them to the same patient, which means they're not considered a drug that would be regulated by the FDA. The agency, however, could choose to regulate them as a practice.

Clinics popping up around the country have some influential backers encouraging the FDA to refrain from compelling all stem cell procedures to undergo the expensive and lengthy approval process the agency uses when it considers new medications or medical devices.

There is a wide ranging discussion between medical researchers and doctors and those that want to apply these therapies. It is a similar discussion that is related to supplements versus prescription drugs. Supplement manufacturers convinced Congress to give them a free rein with little oversight. Now we are finding that a number of medical conditions are thought to be caused by supplements. Taking them off the market is difficult as they are considered medical. (More on this in next month's issue)

The Western Neuropathy Association urges anyone considering any of these clinics, stem cell or otherwise, to consult with their primary care doctor and any other doctor they are seeing before making any decision to go forward with any therapy, alternative or not. There are stem cell research clinical trials in medical centers with specific stem cells for specific concerns and medical supervision of the procedures. We are offering here in the newsletter information about what is happening in these clinics and guidance to use in checking on these. Please include <http://www.closerlookatstemcells.org> in your research especially Stem Cell Treatments: What to Ask?. This is a fascinating overview of what is available and questions to ask if considering such treatments. (Bev Anderson, Editor)

President's Message – Continued from page 3

Special Announcement: The Board of Directors is already working on the 2017 Annual Conference. There is a good chance it will be on the U.C. Davis Medical Center Campus in Sacramento in late April. Speakers are likely to be neurologists who specialize in treating neuropathy. Details will be coming when finalized.

If you live in the Greater Sacramento Area and northward you may receive a postcard saying a truck will be picking up clothing and household items for a good cause and listing The Western Neuropathy Association (WNA) as that cause. It is not a mistake. We hope you and your neighbors clean out your closets of anything you'd rather pass on to someone else. It is a project of a long time member of our Association. He has a thrift shop much like Salvation

Army in the Chico area where the goods are sold. WNA will receive a rebate for each container filled with collected items. The contributor chooses the amount they consider their contribution worth, based on IRS guidelines, to put on the receipt they receive. Use this as an income tax deduction as we are a 501 (c) 3 tax exempt organization. People who come to the Thrift Shop get good items at a price they can afford. We also get a large amount of door to door publicity.

Happy season of colorful leaves,

Bev



WESTERN NEUROPATHY ASSOCIATION

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tax exempt corporation

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■ PN Information/Advice ■ Support Group Inquiries

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STEPS TO BETTER BALANCE

1. Stand on one foot. Support yourself by holding onto a sturdy chair or wall. As you feel steady try standing without support, and then with eyes closed. Alternate feet.
2. Walk Heel-to-Toe. Walk like on a tightrope. Initially have support handy.
3. Lift your arms out to the sides. Focus on a spot on the wall to help stay steady as you walk.
4. Move your head. Turn your head from one side to another while you are walking straight.
5. Backward leg lift. Hold onto a chair or stand near a wall and put your hand on it for support. Lift one leg and then the other and backward without bending the leg or pointing toe.
6. Lift to the side. Make the same movement with your legs alternately to the side. Try to get to 15 times in each #5 and #6. (Please see Neurology Now, June/July 2016 for the full article on Balance. If you don't receive it, call 1-800-422-2681 Monday through Friday (8:30 am – 5:00 pm EST). It is free to those with a neurological condition, family members, and caregivers.

Planning on doing some online shopping? We recommend AmazonSmile.

AmazonSmile is an easy and automatic way for you to support WNA every time you shop, at no cost to you. 

When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that AmazonSmile will donate a portion of the purchase price to the Western Neuropathy Association!!! Make sure you type in our organization.



Western Neuropathy Association (WNA)

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Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year

All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

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