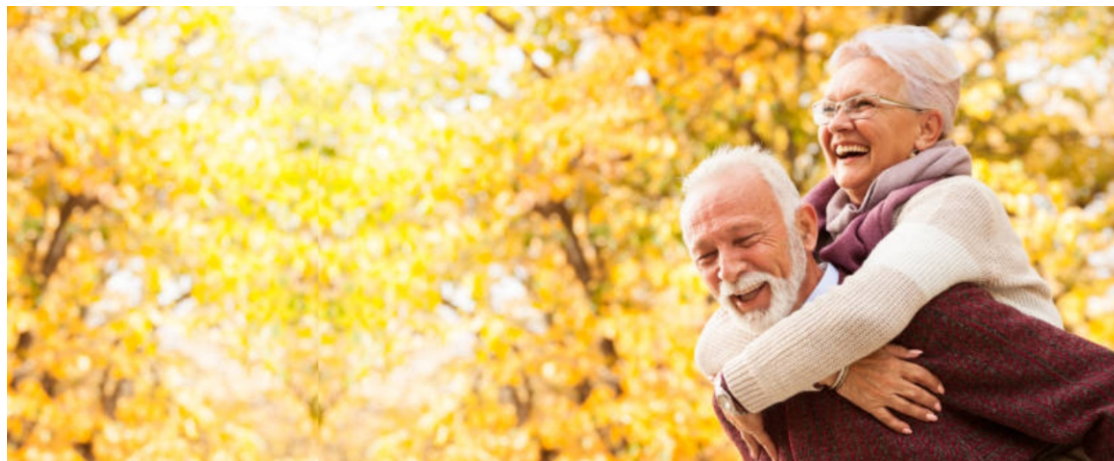




THE PARKINSON PATH

The Parkinson Association of Northern California is an organization dedicated to enhancing the lives of people with Parkinson's, their families and care partners.



Making Sense of Stem Cell Therapy for PD

Suketu M. Khandhar, MD

Medical Director, KPNC Comprehensive Mvt Disorders Program

We have long known by the time an individual is diagnosed with PD, they have lost nearly 70-80% of their dopamine producing cells. It is this significant lack of dopamine that leads to the classic motor symptoms of PD and precisely where treatment has fixated for 5 decades. At times it may seem futile to continue supplementing dopamine in a system that is degenerative.

Stem cell therapy is not a new concept. It's been around for years. The idea that we can take precursor cells and redirect them into mature dopamine producing cells is attractive. Why not, as long as it's safe. It drew the attention of Michael J. Fox to where he appealed to voters and Congress to support stem cell research in 2006.



What are stem cells? Stem cells are cells with the potential to develop into many different types of cells in the body. For our purposes there are 2 main types, embryonic stem cells and adult stem cells. These cells do not have any specific function but can be developed to address specific functions in the body.

So why hasn't this caught on? There are many reasons that stem cell therapy has not become mainstream treatment. Cell sourcing, cell line viability, cell survival, cell rejection, lack of standardization towards treatment approach and side effects (esp that of dyskinesia) with possible tumor formation. At this time stem cell therapy for Parkinson's disease is not an FDA approved treatment and not considered standard of care.

There are many for-profit organizations that conduct stem cell therapy for various neurological conditions, some abroad and some local to us in California. These can be expensive with varying results. I would be wary of any program that claims this is "a cure". Until we have medically reviewed, randomized control trials looking at safety and efficacy in human trials, it's hard to support promoting these programs.

continued on page 4

As good stewards of your financial support PANC is sending our quarterly newsletter via email. This will save paper, postage and time. If you prefer to have it mailed to you please contact the PANC office at 916-357-6641 or email your preference to panc@panctoday.org and we will update your contact information.



The Parkinson Path is published four times a year by the Parkinson Association of Northern California.

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916-357-6641



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July - September 2020

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Remembering Chris Hopson 1953 - 2020

We wish to acknowledge the passing of Christopher Hopson, a former PANC board member from 2002 - 2008 and past board president 2006 - 2008. Chris was diagnosed with Parkinson at the age of 38 and responded by riding 89 miles around Lake Tahoe on his bike. When his cycling became hazardous he started walking three miles daily with his dogs. Chris loved music and had an exciting career spanning 30 years with Tower Records. He started as a store clerk and retired as the executive Vice President and Chief Marketing Officer. In addition to raising funds for various Parkinson's organizations, he also served on the board of the Sacramento Theater Company. His was a life well lived.

Thank You to our community partner Ryan G. Jantzen. Ryan generously supports PANC by serving as our Financial Advisor, gratis, and has given his time and expertise since 2016. Ryan is passionate about our Parkinson's Community because his Mom was a PwP and she participated in many PANC activities.



Partner/Senior Financial Advisor
1130 Iron Point Road #100
Folsom, CA 95630
916 932-0153

Letter from our Executive Director



I am delighted to report that PANC's two virtual conferences were a stunning success. We are so proud to be partners with California Department of Public Health as they promote and support the California Parkinson's Disease Registry (CPDR). The 2020 Virtual Educational Conference attracted more than 700 attendees. We are grateful to our sponsors and the highly qualified speakers who gave our conference such depth and value.

I am also pleased to announce that AB 2821, which provides funding for CPDR, was extended by California Governor Newsom. This means the Richard Paul Hemann Parkinson's Disease Registry will continue to collect data through December 2021. CPDR is a statewide population-based registry that will be used to measure the incidence and prevalence of Parkinson's disease. PANC is proud to support such a great program that will help determine the incidence and

prevalence of Parkinson's disease in California, examine disparities in Parkinson's disease risk and support studies of Parkinson's disease.

If you want to learn more about this data, how it will be used by researchers and how you can participate in any studies please visit

<https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDSRB/Pages/California-Parkinson's-Disease-Registry.aspx>

On another note...this fall PANC will be developing an outreach program to rural cities in Northern California, thanks to a grant from The Parkinson's Foundation. The program will target physicians who serve Parkinson's disease patients in Crescent City, Eureka, Lakeport, Susanville, Red Bluff, Ukiah and Willows. Stay tuned to learn more about this innovative program which aims to share Parkinson's resources in English and Spanish. If you would like to get involved, please call me. Our committee will begin planning in November!

I look forward to extending the arm of PANC support throughout Northern California. Thank you for supporting us in these efforts.

Warm regards,
Barbara Fleck, Executive Director
(916) 357-6641

Tax Deductible Donation Opportunity

COVID 19 has brought a lot of hardships, unknowns and frustrations. Within this cloud, there is a silver lining for donors. Thanks to the federal coronavirus relief bill, donors can deduct up to \$300 on their 2020 taxes – without itemizing. This has been referred to as the “above the line deduction.” The standard deduction for 2020 taxes is \$12,400 for singles or \$24,800 for married-filing jointly. With a \$300 charitable donation to PANC, those deductions can become \$12,700 or \$25,400.

Your tax-deductible contributions support:

- Respite care for care partners of Persons with Parkinson's (every \$300 charitable donation to PANC translates to 10 hours of respite care for a Parkinson's care partner).
- Education, communication and support programs that connect people with PD to one another (36 support groups affiliated with PANC).
- An annual educational conference presenting internationally renowned speakers and specialists from the four Sacramento area medical organizations.

How you can donate:

- Become a monthly supporter to ensure stable funding throughout the year.
- Double your gift through corporate matching gift programs. Check with your employer to see if they will match your donation.
- Honor someone special in your life or remember loved ones who have passed on.
- Leave a legacy! By naming PANC in your will you can help assure Parkinson's patients throughout Northern California will continue to have support in the future.
- Give a onetime donation anytime, night or day. Go to PANCtoday.org – click on the donate button.
- Use the included donation form to mail your check to: PANC, 1024 Iron Point Road, #1046, Folsom, CA 95630.

Thank you!

The Silver Lining - Our Own Zooming Exercise

By Dee Samuel

Before COVID, Ken, Steve and I belonged to a group of Parkinson's folks who regularly attended PD exercise classes. Weekly we did two Rock Steady Boxing (RSB) classes, LOUD class and BIG class. When our classes closed we thought "now what?"

Ken called asking if I'd be interested in doing Zoom exercise classes with him. I was thrilled. Quickly we were up and running, Ken as technical director and me for exercises. Our original format was a 40 minute Zoom session three times a week. Soon we expanded to five times a week for 1.5 hours each class. Early on Steve researched BIG and hand exercises which were added with Steve leading. We truly feel our Zoom class is a silver lining to the COVID cloud. Regularly there are 7 to 11 of us at class and we have continued for 6 months without missing a day!

Each day there is variation to assure we hit each muscle

group and the kind of work we need, plus keeping it interesting. A typical workout is: 10:20 a.m. - Check in: Time to share news and info ranging from shopping to how meds are working. This has fostered a sense of trust, commitment, openness, and fun for us. 10:30 a.m.: Work out starts! - Short video "Dynamic Stretching" (RSB); LOUD: neck stretches, smiles & tones (Dee); 6 to 1 video (RSB) (fast weight work); classic weight & strength training (Dee); Tabata boxing - (Ken - combos); hand & BIG movements (Steve); stretching, balance, and cool down (Dee); 11:50 a.m. finish with LOUD sentences.

The benefits are amazing: great social connection, increased strength and agility, and feeling upbeat at the end of class. The benefits are due to our consistency and intensity 5 days a week, a sense of responsibility to the group to show up and work hard with each other, plus our sense of community.

— continued from front page —

Making Sense of Stem Cell Therapy for PD

So what is promising? Recently, induced pluripotent stem cells (iPSC) have gained a lot of attention. iPSC are derived from skin or blood cells that can be "reprogrammed" back into an embryologic-like pluripotent state that theoretically allows for an unlimited supply of any type of human cell, in our case dopamine producing cells. It was Professor Shinya Yamanaka, from Kyoto University, who was awarded the Nobel Prize in Medicine (2012) for their discovery. He was the keynote speaker at the recent World Parkinson Congress held in Kyoto last year.

You may have read about a recent report on a patient by the name of George Lopez (not the comedian) who self funded (\$2 million) his treatment working with Southern California researchers and neurosurgeons building on Professor Yamanaka's work. Their goal was to take undifferentiated iPSCs and turn them all into dopamine producing cells, tens of millions of them. Any left over undifferentiated cells would have to be eliminated in a safe way. The FDA, under a compassionate use protocol, approved their one-patient study. The surgeons created new experimental instruments to deliver the cells safely into the putamen (a structure that is part of the basal ganglia, close to areas targeted in DBS surgery).

It has been 2 years since the surgery and Mr. Lopez seems to continue to get benefit from surgery via improved motor function. The researchers do not believe they cured him but rather "stabilized" him. They continue to monitor him and routinely get brain scans looking for signs of tumors. When patients ask me about stem cell therapy, I usually refer back to this experiment. The researchers were thoughtful to eliminate undifferentiated iPSCs, thoughtful to use newer instruments to safely deliver the cells and thoughtful to keep Mr. Lopez's safety as a central priority. However this was a study of one. We can't generalize this to the whole Parkinson population and more experiments on a larger scale looking at long term efficacy and safety are required before this may enter mainstream treatment.

Another promising study was done by researchers at UC San Diego, looking to create a cell line that is lacking a protein called PTB, which was found to influence which genes are turned on vs off. They found in Parkinson mouse models injected with these cells lines, that they were able to increase the number of dopamine producing cells by nearly 30%. That does not sound like much but it was enough to reduce the motor symptoms of PD in mouse models, restoring dopamine levels to near normal as found in normal mice. The researchers used something called antisense oligonucleotide approach allowing an artificial piece of DNA to bind to the RNA (translators of genetic information) coding for PTB, thereby not allowing PTB to be produced. This particular approach has since been patented with the hope to conduct human trials in the future.

2020 has been a tough year to say the least but it has brought us a better understanding of the utility of stem cell therapy and its hopes for the future.

Mystery Vegetables

by Dorothy Ross, Davis PD Support Group

Like children on Christmas morning, Bill and I were up early, eagerly awaiting our first box of local produce. When it arrived, Bill carried the box in and ceremoniously set it on the kitchen table. We peered into the carton to see what the farmer had harvested for us. And what to our wondering eyes should appear but...? Weeds! I thought the weeds in the box might have been in the carrot family. They were stalky umbels, a bit like Queen Anne's Lace. It was a mystery.

We checked the packing list and, by process of elimination, determined that our mysterious wild carrots must be fennel. I was familiar with the word from my years of crossword puzzling, but I didn't know it was considered edible. A short Internet search revealed that fennel is native to the Mediterranean shores, where it was harvested by ancient Egyptians and Greeks for its medicinal and magical qualities— and prized as an aphrodisiac. I rushed back to the kitchen to share my findings with Bill, and to look more closely at the wonder-herb. But I was too late. Bill had already tossed the fennel out!

That was six months ago. Since then, only one of our weekly boxes has contained a mystery vegetable—lacinato—also known as Tuscan kale. The large fleshy leaves looked nothing like the curly kale we see in the supermarket. The network of veins puckering the lacinato leaf reminded us of the folds and valleys of the human brain—not very appetizing. We didn't eat the lacinato leaves, but neither did we throw them away. I used them to dramatic effect in an end-of-summer centerpiece.

Nutritionists advise people with Parkinson's to follow a Mediterranean diet. The farmer makes it easy for us, delivering a variety of fresh, local, organic produce in season.

To find a farmer near you who makes deliveries, do an Internet search for farm boxes. You'll savor the flavors of fresh picked produce and have fun identifying the occasional mysterious fruit or vegetable.



Conquering Apathy

Suketu M. Khandhar, MD, Medical Director, KPNC Comprehensive Mvt Disorders Program
Dr. Beverly Chang, Geriatric Psychiatry, Private Practice

Apathy is not just the lack of motivation. Apathy doesn't just occur out of hopelessness. Apathy is defined as the reduction in goal-oriented behavior as a result of lessened interest and lessened emotional response. It is often mistaken for depression but can occur independently in the context of neurologic disorders. Doctors are seeing more and more of this especially during these trying times.

Those with Parkinson's disease are more susceptible to developing apathy. Once someone has apathy, they are less likely to feel motivated in doing anything, including things that are known to help improve symptoms or delay progression like exercise or being socially engaged.

Prolonged apathy can be a harbinger of further executive dysfunction and cognitive decline. This can be terribly frustrating to a loved one or a care partner who recognizes the apathy but feels powerless to help.

Here are a few things that you can do to help overcome apathy and not derail a patient.

1. Recognize the symptoms of apathy and bring this to the attention of the neurologist or a mental health provider.
2. Understand that one does not “choose” apathy, therefore try not to become angry with the affected individual or yourself.
3. Consider trying to help motivate a patient by constructing a list of quantifiable GOALS rather than SYMPTOMS. For example, “my goal is to get back on the golf course” rather than “my goal is to reduce my tremors.”
4. Try to keep a routine schedule of activities that provide sensory stimulation.
5. Consider anti-depressant medications that elevate serotonin levels to treat any underlying mood issues that can exacerbate apathy.
6. Socially Engage, Socially Engage, Socially Engage – via video or physically distanced when in-person – reach out to your local PANC support group.



Regional Support Groups

To maintain our health during this pandemic, most Support Groups are not meeting Face to Face. Many groups are meeting via video or conference calls. Please contact your local (or any) support group leader to see if there are meetings you can join in virtually. For the latest information visit www.panctoday.org/support-groups

Butte County

Chico

Zoom 1st and 3rd Wednesdays beginning 11/20
Terry Donnelly 650-743-6871
tmdonnelly68@gmail.com
Bob Murray 530-321-6157
ordferry@yahoo.com

Oroville

Carol Rawlins 530-282-0499

El Dorado County

El Dorado Hills

Zoom, every Thursday 1:30 to 2:30 PM
Donna Rixman 916-712-9642
donna@yogapeace.net

El Dorado Hills/Folsom Caregiver Luncheon*

Larry Alver 916-933-2465
ldalver@sbcglobal.net

Placerville

Peggy Kline 408-309-1125
pegkline103@gmail.com

Napa County

Napa —

Young Onset Group
Zoom 3rd Sunday, 3 - 4 pm
Colleen Winters 209-602-1536
cfwinters@yahoo.com

Nevada County

Grass Valley

Nancy Lockwood 530-272-7950
nmlockwood@aol.com

Truckee

Ellen Roumasset 650-759-3666
dr.eroumasset@gmail.com

Placer County

Auburn

Karen Hancock 530-885-0950
Karen@hancockonline.net

Auburn Caregivers Luncheon*

Karen Hancock 530-885-0950
karen@hancockonline.net

Lincoln

Gary High 916-434-5905
Gwhigh@wavecable.com

Roseville

Zoom 4th Tuesday 1:30-3:00 pm
Harry Butler 916-837-3366
hapbutler@comcast.net
Website: rosevillepsg.weebly.com

Roseville West

Zoom 4th Tuesday 11:00 am
Ken and Arlene Fujino 916-474-4788
Cell 360-461-3489
kfujino1@msn.com

Sacramento County

Carmichael/Eskaton

Colette Coleman
Colemanhior@gmail.com

El Dorado Hills/Folsom Caregiver Luncheon*

Larry Alver 916-933-2465
ldalver@sbcglobal.net

Elk Grove

Zoom 3rd Wednesday 10:00 - 11:30 am
Myron Jantzen 916-804-6497
mpjantzen@aol.com

Folsom

Zoom every Thursday 1:00-2:30 pm
Donna Rixman 916-712-9642
donna@yogapeace.net
Cathy Johnson 916-791-2425

Sacramento Caregivers Lunch Bunch*

Zoom 3rd Tuesday 11:00 am to 1:00 pm
Gain Saetern 916-728-9333
gsaetern@deloro.org

Sacramento

Post DBS Patients-meeting via zoom
See class schedule, zoom and contact information at www.panctoday.org/support-groups.html
email: HS-DBS@ucdavis.edu

Sacramento/Arden Arcade Area

Zoom 3rd Thursday 10:00 am
Keith Tronson 916-395-2771
keithtronson@sbcglobal.net
Jim Morris 916-359-4859
jimor1940@gmail.com

Sacramento/Carmichael Area

Young Onset Support Group

Zoom 1st Wednesday 6:30 pm
Mary Beth Arjil 530-409-4118
marjil@sbcglobal.net
Tony Wong 916-730-6303 acwong60@gmail.com

Sacramento/Gold River

Lewy Body Dementia Care Partner Group*

Google Meet (like zoom)
2nd Thursday 10-11:30am
Denise Davis 800-272-3900
denise.davis@alz.org

Sacramento Natomas Area

Zoom 2nd Thursday 10 a.m.
Irene Duggan 916-710-6912
parkinsons1018@gmail.com

Sacramento Northeast Area

Zoom-coming soon

Sean Tracy 916-482-7014 sstfam@winfirst.com
Judy Tracy j-tracy@att.net

Sacramento South Area

Jerry Miyamoto 916-441-1020
jmiyamoto72@gmail.com
David Teraoku 916-685-4162

San Joaquin County

Lodi

Ron and Maureen Olsen 209-329-1185
molsen@softcom.net
Robbin and Pat Bray 209-269-1080
braywaves@gmail.com

Lodi Caregivers Group*

Jean Whitted 209-329-7075
bjwhitted@hotmail.com

Stockton

Christy Carruthers 209-478-2731
carruthers209@gmail.com

Tracy

Kathy Clark 209-879-3108
classieladyat63@yahoo.com

Shasta County

Redding

Coffee in the Park 1st and 3rd Friday,
9:30 to 11:00 am
Zoom-2nd Friday, noon - 1:30 pm.
Kim Hawkins 530-945-7628
Kim.reddingpsg@gmail.com

Sierra County

Loyalton

Betty Ferguson 530-993-4002
fergi45@gmail.com

Solano County

Benicia

Zoom 2nd Saturday 10-11:30 am
Brad Miller 707-515-9216
bradfordmiller807@gmail.com

Vacaville

Brenda DeMartini 707-330-1551
brendaldemartini@gmail.com

Sonoma County

Sonoma

Zoom 2nd Saturday 1 p.m.
see www.parkinsonsonomacounty.org
Nancy Wilson nlbwilson.41@gmail.com
Marc Alexander 707-431-8767
malexander109@comcast.net

Stanislaus County

Modesto

Paul Vantress 209-526-6184
modestoparkinsons@gmail.com

Sutter County

Yuba City

Mary Lou Chumbley 530-671-0767

Yolo County

Davis

Zoom 3rd Thursday 1:30-3 pm
Sue Curry 530-304-9927
smcurry@sbcglobal.net

Davis-Care Partners Group*

Karen Eagan 530-564-4323
kareneagan747@gmail.com

Woodland

Zoom 2nd and 4th Tuesdays, 1:00 to 2:20 pm
Bernadette Murray 530-661-1950
bemurray2008@gmail.com

PANC Advisory Support Group Facilitators and attendees should be aware that not all medications, treatments or theories about Parkinson's disease are 'right' for every person. If presentations or discussions within your Group raise issues in your mind regarding your personal condition or treatment plan, you are advised to bring those questions to your treating physician for further exploration prior to making any changes in your medications or routines.

* Caregiver / Care Partner meeting

Donations

Shirley Barbula
Lynn Beldner
Jane Burhoe
Lynda Cadman
Rosalia Camann
Rosalia Camann
Lora Cammack
John Christiansen
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Margaret Wilson
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Parkinson Support Group
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Sing for America Fundraiser
Teri and Dave Ruggiero

PANC Volunteer Program

By Eric Jones, Medical Student, CA Northstate University

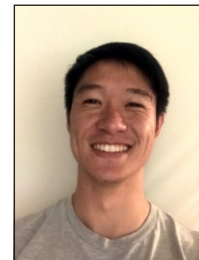
Throughout my education, I've found a common theme: the joy of connection. As a third-year medical student on the PANC Board of Directors, a significant reason that I joined was to serve as a bridge to the younger generation. While PD is traditionally perceived as an "elderly" disease, I recognized that many classmates are interested in neurology, movement disorders, and even PD specifically. And like myself, some have had loved ones with PD. On the other side of the coin, as I began to join PD support groups, I saw the renewed energy that a young face brings to those with PD. Alas, it became clear how both medical students and PANC members could greatly benefit one another – the PANC Volunteer Program.



Stella Knowlton



Nidhi Reddy



Alex Chiang

As medical students, we have a "Service Learning" requirement of 20 hours of volunteerism over our 4-year education. First-year medical students are eager to get involved in the community, and each year are presented with various local opportunities. Thus I recently spoke to students about the launch of the PANC Volunteer Program, including opportunities such as joining support groups, journal club, technology troubleshooting, and being able to intimately understand what it's like to live with PD – beyond the textbook. Three first-year medical students have now joined the PANC Volunteer Program, and are already filling a much-needed role by helping troubleshoot CPDR and PANC conference virtual onboarding. I look forward to the innumerable ways volunteers will become involved, and remain grateful for PANC's support in connecting with the next generation of health professionals.



Rebuilding Together Sacramento Offers Home Safety Modification Services

**Free or reasonably priced Repairs,
Grab Bars and Safety Aids
Available for Homeowners**

Falls in the home are a serious health issue that can often be prevented with simple lifestyle and home updates. Rebuilding Together Sacramento provides minor home safety modifications that can decrease the risk of injury and improve independence.

The organization's Safe at Home program helps residents and caregivers live safer at home, by installing safety and accessibility features, such as grab bars and shower and bath aids. The Safe at Home program is available for free to qualified low-income households located in Sacramento County and is available for a reasonable fee for those above the income guidelines.

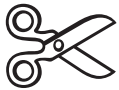
Rebuilding Together Sacramento is a non-profit organization that has improved home safety in over 7,000 homes since 1991. Call (916) 455-1880 to find out if you or your family member is eligible or visit www.rebuildingtogethersacramento.org for more information. Other counties in northern California have organizations that offer similar services.

Those who qualify for the low-income services must submit an application available on the website or by calling the number above. Due to COVID 19, there is a delay in services so apply as soon as possible to be added to the waiting list. The workers follow strict safety precautions to keep our clients healthy.



PARKINSON ASSOCIATION OF NORTHERN CALIFORNIA
1024 Iron Point Road #1046
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