



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.



Emergency Room Preparedness for People with Parkinson's

Kristina Hart, DO, UC Davis Health, Department of Neurology

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While it is always the goal to keep people with Parkinson's functioning as well as possible at home for as long as possible, there may be instances when this is not possible. In fact, people with Parkinson's (PwP) have higher rates of emergency room and hospital visits than those the same age that do not have Parkinson's. Common reasons for emergency room visits for PwP include: infections (pneumonia or UTI), falls (either with or without injury), gastrointestinal issues (such as trouble swallowing or severe constipation), worsening of Parkinson's motor symptoms, sudden changes in thinking (may include confusion, hallucinations, or severe anxiety), as well as other non-PD related conditions (such as heart disease, lung disease, or other medical problems). Many acute issues, such as those mentioned above, may result in sudden worsening of Parkinson's motor symptoms (such as rigidity and bradykinesia), can cause delirium or confusion, and can increase risk of falling. It is important to be prepared for the possibility of an emergency room visit or hospitalization.



There are some things that PwP can do to be prepared for an unanticipated ER visit. First, be sure to have a designated family member or friend who knows you well to be the point of contact in case you are not able to communicate for yourself. Keep your information, along with the contact information for your Parkinson's disease doctor, easily accessible, such as on a card in your wallet or purse. If you do have to spend time in the emergency room or be admitted to the hospital, it is very important not to miss your Parkinson's medications. In order to help make sure you get all of your medications, tell your doctors

and nurses that you are taking medications for Parkinson's and that you need doses on time, every time. Keep a detailed and updated list of your medications in your wallet or purse. Include the name of your medication(s), the dosage amount, and the time(s) of day you take each dose. Be aware that not all Parkinson's medications are available in every hospital. For this reason, we recommend that you have

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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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THE PARKINSON PATH

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PANC

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PANC Annual Conference

Saturday, October 23, 2021

Keynote Speaker: Jimmy Choi

Learn more about Jimmy at:

https://www.facebook.com/watch/?ref=search&v=201705208141667&external_log_id=3029ae43-b79d-43dd-a11f-8ae41493f07d&q=jimmy+choi+-+fox+ninja

A Guiding Light - Parkinson's Disease Within Physiatry

by Eric Jones, PANC Board Member.

Excerpt from *Physiatry Forward*, Winter 2021

I'll always remember the way his hand shook in mine. It was all I knew, that was just my grandfather, "Opa". Growing up, Opa, had Parkinson's Disease (PD). Receiving his diagnosis when I was just a toddler, I supposed every grandfather must have had shaky hands. However, as his disease progressed, so did my understanding of the intricacies of this multi-faceted condition. While Opa's motor, cognitive, and behavioral symptoms slowly advanced, one thing remained constant: his enduring spirit. As I traverse my way through medical school, his journey remains a steadfast pillar of my devotion to serving my community and the field of physiatry. Physiatry is a lesser known specialty that focuses on quality of life and improving function, mainly in regards to neurological and musculoskeletal conditions. It is sometimes called Physical Medicine & Rehabilitation (PM&R).



Perhaps my most stark memory came on a routine high school afternoon as I ran on the treadmill at the local gym. Opa's balance had become increasingly concerning at this point, to the point that he needed a specialized walker. As I neared the end of my run, I looked up to see Opa and my grandmother at the front desk purchasing a membership. Naïve to the impact of rehabilitation in PD, I was perplexed by the idea of Opa at the gym. Upon the recommendation of his PM&R physician, he began strength training at the gym in addition to physical therapy. Months later, he even began neuro-boxing, a proven form of neurorehabilitation to increase balance, mobility, gait, and quality of life. In this short time, a spark was created as I was introduced to the novel role of rehabilitation in PD.

As I gathered information throughout my medical education and within the physiatry community, I developed a greater understanding of the physiatrist's role in PD and have become excited about the first PM&R PD fellowship beginning in 2021. While my aim is not to educate on this topic, I grew inspired by the unique value of rehabilitation in PD. Inclined to contribute to this growing field, I had an idea. Last year, I proposed a local 5K run to my university, with hopes of bringing the school, surrounding community, and local Parkinson's community together. Spring was the best time of year for a run, and April just so happened to be Parkinson's Awareness Month. Thus, as a tribute to Opa's dignified fight, the California Northstate University (CNU) Students 5K for Parkinson's was put in motion, with all proceeds being donated to The Michael J. Fox Foundation for Parkinson's Research.

It turns out planning a 5K wasn't as easy as it seems. After months of sorting out city road closures, local sponsors, registration, race timing, etc, the logistical roadblocks made it seem near impossible at times. But seeing classmates' excitement, I couldn't let it go. Our team regrouped and found new ways of fundraising including Pancakes for Parkinson's, and the opportunity to send a runner to the Chicago Marathon as a charity sponsor for The Michael J. Fox Foundation. The 5K was finally coming together: t-shirts ordered, sponsors confirmed, and course approved!

However, COVID-19 struck just weeks prior to the 5K. Although runners could not come together on race day, the community effort was felt as \$750 was raised for Parkinson's. Further, I am honored to have been given the opportunity to join the Board of Directors for the Parkinson Association of Northern California (PANC), serving over 3,000 people affected with Parkinson's through support groups, exercise classes, conferences, and establishment of a medical student volunteer program. I remain grateful to CNU, PANC, and The Michael J. Fox Foundation for their unwavering support in making this vision possible.

Above all, I hope this narrative serves as a reminder to continue pursuing that spark, regardless of the obstacle ahead. While the memory of Opa's hand shaking in mine resides, his unwavering grasp and prevailing light remain rooted within me as I continue my journey in physiatry.

Stay tuned, as I will be representing The Michael J. Fox Foundation at the next running of the Chicago Marathon. New this year, you can join me for the 5K run at the COP Walk on September 18, 2021.

Parkinson's Awareness Month

By Dr. Fredrick Lowe, PANC Board Member

The month of April is designated as Parkinson's Awareness Month. You are invited to become more informed and advocate for research to eradicate Parkinson's disease.

One million cases - and growing. One million families impacted - and growing. 60,000 people and their families added each year. Those are the stark numbers for the fastest growing brain disorder in America - Parkinson's disease. It is time for the public to take notice, to stand with the Parkinson's community, and to join your voice with our call to deal with this mushrooming problem.

This is an invitation to learn and understand the effects of this disease, which is the world's fastest growing brain disorder. And do something about it. Join in the **PACT**:

1. **Prevent the disease.** Several environmental factors, including air pollution, heavy metals, certain pesticides, and industrial chemicals like trichloroethylene are linked to Parkinson's. One herbicide called paraquat more than doubles the risk of developing Parkinson's disease. It is used to kill weeds that RoundUp cannot. Paraquat has been banned by 32 countries, including China while its use in the U.S. has doubled in the past decade. Despite a petition signed by more than 100,000 members of the Parkinson's community, the U.S. Environmental Protection Agency has failed to act. We need your help to ban this herbicide to minimize the risk of Parkinson's disease to farm workers and remove it from our foods, our water, and our air. The pesticides Rotenone and DDT have been banned for good reason. We need to do more.
2. **Advocate for better policies and resources.** Ending Parkinson's disease will require additional resources. The National Institute of Health (NIH) funds \$3 billion per year to enhance our understanding of HIV. This research has likely prevented millions from ever developing the disease and led to numerous treatments that now make HIV a chronic, rather than a rapidly fatal condition. By contrast the NIH funds less than \$200 million per year for Parkinson's disease. We must change that.
3. **Care for all affected.** Expert care models, like ParkinsonNet developed by Bas Bloem, MD, and his colleagues, telemedicine and Centers of Excellence can provide better care to almost anyone anywhere. We need to embrace such models and ensure that Medicare, supported by taxpayers like you, does the same.
4. **Treat the disease with novel therapies.** The most effective medication for Parkinson's remains a 50-year-old drug, levodopa. While effective, it does not address the underlying disease and has its own complications. We need to develop a new generation of therapies aimed at the underlying pathology of the disease, not just to reduce symptoms. We need better, objective measures of the disease to find it earlier, so intervention can begin before there is disability. We need to support efforts to develop novel treatments, such as gene-targeted therapies. That is why massively increased research is needed.

Your slower, shakier neighbors appreciate your patience and occasional helping hand. Now we are also calling you to join us in action.

Thank you to our Community Partner | Archival Gallery

3223 Folsom Blvd, East Sacramento, 95816



"The gallery, now in their 37th year, is family owned and operated by Tom and D. Oldham Neath. Tom has an advanced brain disease which has steadily progressed over the past several years.

Finding ways to exercise his motor skills has been important and over the holiday season he was gifted with two beanie hat makers which have provided hours of productive stimulation."

Tom loves making hats and D. loves giving back to their community. In January we received a call offering a free "Beanie" (actually a very nice knitted hat), to anyone who could show or send a receipt for a \$10 donation to PANC. They did all the work; promotion, supplies, knitting, mailing etc. and PANC received donations of \$1360. Thank You D. and Tom for this warm, loving way to call attention to the importance of providing support for those with Parkinson's and associated diseases. Watch for more of Tom's Beanies later this year!

Parkinson's Cards to Heroes

This article is sponsored content that was developed by Neurocrine Biosciences.

Whether you're a caregiver or someone living with Parkinson's disease, you can always use more time, more patience and more resources. We want to share information about a new program from Neurocrine Biosciences that honors everyday heroes through handwritten letters from people living with Parkinson's disease.

Parkinson's Cards to Heroes is a free program that addresses one of the challenges of living with PD: losing the ability to hold a favorite pen to write a note or a letter or to sign a check. The program was designed to help motivate people with Parkinson's disease to keep up their handwriting exercises by writing messages of gratitude to heroes around the nation, including those at the frontlines of the COVID-19 pandemic.



Here's how it works:

- People with Parkinson's, or their loved ones or caregivers, can visit PDCardstoheroes.com and sign up to request a free kit of custom greeting cards.
- Neurocrine will mail you a kit with custom cards, exercise grids, instructions, and a pre-paid envelope to Operation Gratitude, which distributes the completed cards to heroes, our frontline medical workers.
- Once the heartfelt messages are finished, simply pack up and send all your handwritten cards in the envelope provided.

So, as our frontline heroes keep fighting, we can all keep fighting, too. Thank you for supporting people with Parkinson's.

SAVE THE DATE AND START THINKING ABOUT HOW YOU CAN SUPPORT THE 2021 COP WALK!

September 18, 2021 @ Maidu Park, Roseville

The 5th Annual 'COP Walk' (Robert G. Smith Walk to Cancel Out Parkinson's) is scheduled for September 18, 2021. This year we hope to have the biggest year ever and we need your help. The walk, organized and coordinated by the Embarcadero Lions Club and supported by regional Lions Clubs and the State Lions Organization is held in honor of 'Bob' Smith, with all proceeds donated to support the efforts of the Parkinson Association of Northern California (PANC).

This event has raised over \$100,000 for PANC in the past four years. In essence... every dime we help the Lions raise means funding comes back for PANC local programs and services.



How can you help?

- ▶ **Make a donation and attend the event:** Cheer our supporters on, participate in the health fair, visit our wonderful sponsors, enjoy the entertainment, eat a free lunch, all in a beautiful park setting with easy parking!
- ▶ **Gather a walk team:** Encourage your support group to join together, gather their friends/families to generate a group of supporters to walk as a team. And then enjoy the festivities.
- ▶ **NEW this year ... Join the 5K run.**

Go online for registration and pledge forms: www.rgsmith.org

Any questions call the PANC Office: 916-357-6641



Join in Sacramento's annual 24-hour fundraising event in support of local non-profit organizations. Donate: on Thursday, May 6, you can donate to the Parkinson Association of Northern California (PANC) by visiting www.bigdayofgiving.org and make a gift with a credit or debit card. Your donations will make a big difference. If you bank with Golden 1 Credit Union, use your bank card for your donation – they offer a match. Invite your friends and family to also support our PANC organization.

Emergency Room Preparedness for People with Parkinson's *continued from front page*

some extra doses of all of your medications set aside in an “emergency pack” in case you need to make a trip to the hospital.

It is also important to know that some medications commonly used in the ER may not be safe for PwP. These include a class of medications called dopamine blockers. Medications that block dopamine are often used to treat conditions such as confusion or nausea, but should be avoided in PwP. Safer medications for nausea in PwP include Ondansetron, Granisetron, or Trimethobenzamide. Medications that can be used safely for management of confusion or delirium in PwP include Quetiapine (low dose), Clozapine, or Pimavanserin. There may be instances in which patients are unable to safely swallow medications. In the event that this occurs, a temporary tube that is passed through the nostril and into the stomach may be necessary in order to administer medications. Furthermore, there may be some alternative forms of medications, like a dissolving form of carbidopa/levodopa, dopamine patches, and (in the event that you are already using these at home), dopamine injections that go under your skin.

If you have a surgically implanted device to treat your Parkinson's disease such as a Deep Brain Stimulator (DBS) or a Duopa pump, you should also prepare for how to handle these in the event of an emergency visit. If you have DBS, talk to your Parkinson's doctor ahead of time and ask them to teach you or a family member how to check if your DBS is on and how to turn it off if you need to. Be sure to bring your Patient Programmer with you to the hospital. There may be some instances (i.e, to obtain an EKG or surgery), in which you may need to turn your DBS off using your patient programmer. If you have DBS, you should not have an unplanned MRI without talking to your Parkinson's doctor or device representative first. Other types of imaging such as CT scans or X-rays are generally safe and can be performed in the emergency setting if needed. If you have a rechargeable DBS, you should also bring your charging system with you to the hospital. Keep the information for your device company available and give this to your doctors or nurses so they may contact the company if they need assistance. If you have a Duopa pump you should bring your pump and extra medication cartridges with you to the hospital. Some symptoms that suggest you are having a problem with your Duopa pump include abdominal pain, new nausea or vomiting, severe constipation, or signs of infection around your stoma. If you are experiencing these symptoms, be sure to tell the physicians in charge of your care. If assistance is needed managing your Duopa pump at any time, you or your providers may call Duo Connect at 1-844-386-4968.

Another special circumstance that PwP may encounter is the need to have surgery. It is important to know that some medications used to treat Parkinson's can interact with anesthesia and pain medications. One such class of medications is called MAOI-B's, including Selegiline (Eldepryl, Emsam, Zelapar), Rasagiline (Azilect), or Safinamide (Xadago), or medications used to treat depression and anxiety. Be sure to tell your surgeon and anesthesiologist the names of all the medications that you are taking. If surgery can be planned ahead of time, ask your Parkinson's specialist whether any of your medications should be held prior to surgery. Following surgery, restart your Parkinson's medications as soon as possible. It's also important that you get out of bed and work with a physical therapist as soon as possible. Another issue that can be particularly troublesome for PwP following surgery is slowed bowel motility resulting in severe constipation. We recommend you ask for medications to help you have regular bowel movements while you are in the hospital, especially if you are using any opioid medications to treat pain.

If you or your emergency room doctor or surgeon have any questions or concerns regarding the management of your Parkinson's while you are in the emergency room or admitted to the hospital, we encourage you to talk to your Parkinson's disease specialist or consult with a neurologist available at the facility.



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
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*

see listing under Sacramento County

Placerville

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

Napa County

Napa

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
Shelly Butler 916-837-3307
sbutler7221@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
kmfujino@outlook.com

Sacramento County

Carmichael/Eskaton

Colette Coleman
Colemanhior@gmail.com

El Dorado Hills/Folsom Caregiver Luncheon*

In person 1st & 3rd Fridays 11:30-1pm
John Kemp Comm Park
Larry Alver 916-933-2465 lalver@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

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

San Mateo County

Foster City Atria

Will Corkern 650-534-7799
wcorkern@aol.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
fergj45@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
Marc Alexander 707-431-8767
malexander109@comcast.net

Stanislaus County

Modesto

Zoom 3rd Wed. from 1:30-3:30 p.m.
Beth Bollinger 209-668-9434
sdboyandcagirl@hotmail.com

Sutter Yuba Colusa Counties

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



PARKINSON ASSOCIATION OF NORTHERN CALIFORNIA
 1024 Iron Point Road #1046
 Folsom, CA 95630



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The Parkinson Association of Northern California (PANC) exists because of your contributions. We rely on donations to provide programs and services for people with Parkinson's disease, their families and care-partners throughout the Northern California region. Your donation is a great investment and helps us remain a vibrant partner in the Parkinson's support community.

Donations or memorial gifts of any size are most welcome.

Please accept my tax-deductible donation of \$ _____

Name: _____

Address: _____

Telephone number: _____

This gift is _____ in honor of _____ in memory of _____

Name: _____

Send acknowledgement to: _____

▶ Please make checks payable to Parkinson Association of Northern California and send to 1024 Iron Point Rd, Ste. 1046, Folsom, CA 95630

We also accept donations with a credit card online or by phone. Visit www.panctoday.org to complete your secure transaction. For information or assistance please call 916-357-6641.

