



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.



PD Related Psychosis

*Suketu M Khandhar, MD & Michel Medina, MD
Kaiser Permanente Sacramento*

“Creativity and Psychosis often go hand in hand.” This line can be heard as you watch the trailer for the Netflix show, *The Queen's Gambit* (great show by the way). What is psychosis? As taken from the dictionary, psychosis is a severe mental disorder in which thought and emotions are so impaired that contact is lost with external reality. Sounds scary and to be honest, it can be, for both the individual and their loved ones.

Marie Curie once said, “Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we fear less.” So, let's dissect this condition.

Psychosis in Parkinson's disease is not uncommon. It is more likely to occur in the later stages of the disease and can be associated with Parkinson medications, as well as the natural progression of the condition itself. The underlying pathology of psychosis is less understood. Epidemiological research puts the prevalence of significant PD related psychosis at 10%, however we feel it's more common than that. We also feel there is a range to the symptoms. Not everyone with PD related psychosis fits the definition above.



About 50% of all patients with Parkinson's disease will experience hallucinations and/or delusions over the course of their disease. It is more likely to occur in those who are older, who have had a longer duration of disease, who are on large pulse doses of dopaminergic medication and who have ongoing REM Sleep Behavior Disorder (this is when you unknowingly act out your dreams during sleep and at times shout out). Some may experience visual hallucinations, which is an experience involving the altered visual perception of something that is not actually present. Some may experience illusions, which is the experience of wrongly mistaking something for something else. And some may experience delusions which are the experience of firmly thinking things that are not anchored in reality. Not everyone experiences all these and there is a spectrum to these symptoms.

From our experience, the range of psychotic experiences seen in PD can be quite variable. For some, it

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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@pantoday.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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Welcome to the Board

The Parkinson Association of Northern California (PANC) is delighted to introduce two new members of the Board of Directors. Joining us on the board are Kim Hawkins, R.N., from Redding, CA and Dr. Matt Brown, Assistant Professor at Sacramento State University in the Department of Kinesiology.

Kim Hawkins is a registered nurse retired from Dignity Health. She has facilitated the Redding Parkinson Support Group since 2012 where they

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PANC Rural Outreach is Looking to Northern California Stars!

*by Sean Tracy, Board President,
 Parkinson Association of Northern California (PANC)*

Rural Stars Outreach will create new support groups, provide English and Spanish language resources, and mental health information for seven "star" communities in Northern California



Sean Tracy

If you know people with Parkinson's (PwP), their care partners, medical or service professionals working with PwP in the communities of Crescent City, Eureka, Lakeport, Susanville, Red Bluff, Ukiah, and Willows, PANC wants to meet them!

PANC is reaching out for community stars in rural northern California and will provide information about Parkinson disease (PD) for English and Spanish speaking communities – with an emphasis on mental health support. This program is supported by a community grant from the Parkinson's Foundation (PF).

With the support of the PF technical assistance experts, a team from the PANC Board of Directors and community volunteers are creating outreach strategies and materials to help build new PD support groups in these communities. These

sustainable support groups will help deliver assistance to PwP and the broader community based on locally identified priorities and service delivery gaps, including some mental health support.

It is important that PANC and PF partner effectively to serve rural Northern California, as the needs and service gaps may be quite different than in urban or suburban centers. This grant will advance PANC's goal of supporting locally identified needs in these seven regions. Support will be provided to both English and Spanish speaking people who are seeking education, information and connections to help people with Parkinson's disease. This is especially important after a year of COVID and the mental health impacts we know exist.

To become involved and for information about the PANC and PF Rural Stars community outreach grant program, please contact the PANC Office at panc@panctoday.org or call (916) 357-6641.

Thank you to our Community Partner **events!**

PANC contracted with **events!*** to coordinate both the 2019 and 2020 Annual Educational Conferences. We thank them for two very successful conferences and for giving a lot more than the contract called for....more time, more support and incredible caring!

***events!** is a full service strategic event coordination company specializing in meetings, conferences and virtual events.



Bruce Norton and his 'Barrels to Art'

What do you do when you sell your Vineyard and retire? Well if you are Bruce Norton you take some of your extra time and decide to "Give Back" for the good life you enjoy. Bruce makes beautifully crafted pieces of art out of used wine barrels and other repurposed materials. Until March 31, 2021, Bruce has made PANC the beneficiary of his creative talents. 'Barrels to Art' items include candle holders, serving trays, lazy Susan turntables, end tables, custom made items and more:



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Interested? Send Bruce an email at brucevnr@ranchomurieta.org. He will contact you to discuss your order and set the price (which becomes your donation amount to PANC*). You make your donation to PANC, and then your donation receipt allows you to make arrangements with Bruce for pick up or delivery of your items. Because of distribution challenges, this offer is limited to the first 50 people in greater Sacramento area.

*Make your donation by sending a check payable to PANC and send it directly to the office at 1024 Iron Point Road #1046, Folsom, CA 95630. Or donate online with www.panctoday.org. Your receipt will verify your donation.

Thank you, Bruce, for this wonderful offer of support for our local Parkinson's community.

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— Dorothy Ross —

I've had the pleasure of writing for this publication for more than five years. My thanks to Carolyn Loveridge and Nancy Kretz, the editors of the Parkinson Path for encouraging my efforts. These days, dealing with my husband's sudden death and all the attendant decisions, I can't seem to find the words or even new subjects to write about. So I leave you with this thought— fight back against PD by doing whatever gives you joy, be it dancing, boxing or yoga. Just keep moving!

Editor's note: We express our profound gratitude to Dorothy Ross. She has been our most consistent and dedicated contributor, submitting an article for every Parkinson Path newsletter for more than five years. We thank her for her insightful and uplifting articles as a person with Parkinson disease. Below is her final article. We love you Dorothy and wish you the very best. Please keep in touch.

Even if the Shoe Fits...

by Dorothy Ross, Davis Support Group

I used to have a colorful collection of strappy shoes for California's long sandal season. But as a person with Parkinson's, I now have to choose my shoes with safety in mind.



My favorite slide-on Birkenstock sandals were implicated in the only auto accident I've ever caused. To avoid hitting a dog, I slammed on the brakes of my VW Beetle. My sandal fell off, got wedged between two of the foot pedals, and I lost control of the vehicle. In that single car, non-injury accident, I jumped the curb, bent the axle, and incurred an expensive repair. Thankfully the dog wasn't hurt. That was the last time I drove a stick shift car, and I've also given up my well-loved black patent Birks.

I still wear sandals, but I make sure they have enough straps and

buckles to stay on my feet and keep me safe. I don't have stock in the Keen brand, but I do wear their shoes all year round—hiking shoes in the winter and sandals in the summer. They have enough tread and straps to keep me feeling secure, and the front bumper cushions my little piggies when I stub my toes.

I got to a point in my PD journey where I was having trouble tying my shoelaces. Just bending that low to the ground was a challenge. Having succeeded in folding my body over my knees, my fingers were not capable of managing a trim bow—no pretty bunny ears. My solution is stretchy laces that allow me to pull a shoe on without loosening the laces.

Bottom line: Even if the shoe fits, don't wear it if it isn't safe. Pride is one luxury we can't afford.

PD Related Psychosis *continued from front page*

could be mild and not troublesome: for example, visual perceptual changes (e.g. brief sensation of a presence or a shadow) or complex, formed, brightly detailed visual hallucinations (small animals or children playing in the yard) and may carry a Lilliputian quality to them (Lilliputian hallucinations are taken from the book 'Alice In Wonderland' – remember how characters became smaller in the story). But for other people with PD and psychosis, the experience can be much more severe and include 'Phantom Boarder Syndrome' whereby the visual hallucinations are seen as intruders in the house, and the individual no longer recognizes the “intruders” as hallucinations, but as reality. Care-partners have told us how their loved ones have set the table for 8 when only 2 of them live in the house. To make things worse, the troublesome delusions and hallucinations can be very paranoid in nature. As you can imagine, this can be scary, anxiety provoking, and concerning to everyone.

So, what can we do about it? First, please bring this to the attention of your physician and neurology team. Social embarrassment and lack of understanding that this could be related to PD is the main reason this is often not brought to the attention of providers. In 2010, the American Academy of Neurology put out guidelines on quality measures in Parkinson's disease. They recommended annual evaluations for everyone with Parkinson's disease which included assessing for psychiatric disorders and disturbances such as psychosis, depression, anxiety, apathy and impulse control disorders. A proper assessment for psychosis includes:

1. Assessing for any triggers such as dehydration or underlying urinary & pulmonary infections
2. Review of sleep habits and patterns as poor sleep can provoke psychosis
3. Reviewing ALL prescribed medications that may contribute to psychosis
4. Reassuring and educating the individual and family
5. Reviewing the need for blood work or imaging looking for reversible causes of dementia
6. Reviewing the need for a full battery of neurocognitive testing
7. Considering REDUCING or ADJUSTING dopaminergic medications
8. Considering adding dopamine blocking medications, especially at night, such as Quetiapine
9. Considering adding medications such as Pimavanserin

For patients with troublesome hallucinations or delusions that continue despite some of the above interventions, pharmacologic treatment directed at the psychotic symptoms may be necessary. If antipsychotic medications are deemed necessary, preferred agents in patients with PD include Quetiapine, Pimavanserin, and Clozapine. All antipsychotic drugs carry significant risks and a thoughtful conversation with your physician is necessary in order to make an informed decision before starting one of these medications. Among the antipsychotics, Quetiapine is the most commonly used, and Clozapine may be the most effective but is rarely used due to its need for frequent laboratory monitoring (necessary as it carries a risk of lowered white blood cell counts).

A newer medication, Pimavanserin, was approved by the U.S. Food and Drug Administration in 2016 for the treatment of Parkinson's Disease Psychosis. Pimavanserin is unique in that it does not act via dopamine blockade (like other antipsychotics) and therefore carries less risk of worsening PD motoric symptoms. One drawback is that it takes about 4-6 weeks to begin working whereas the other antipsychotics have a more rapid onset.

As you can see, there are options if you are plagued by these symptoms. It all starts with honest conversation. I am reminded of a line from a song from the band Coldplay called Clocks. “Am I part of the cure? Or am I part of the disease?”

Welcome to the Board *continued from page 2*

regularly have 20 to 40 people at their monthly meetings. The group also sponsors an annual conference each spring in Redding. Kim has been a volunteer on a variety of PANC committees.

Matt Brown's teaching and research focuses on how people learn and control movement (particularly from a neurological perspective). This includes people with Parkinson's disease (PwP). His research

with PwP started over a decade ago while volunteering in an exercise rehabilitation program as a student. He continues to aspire to help improve the life of PwP through teaching, research and his service with PANC.

With the addition of Matt and Kim we now have 15 members on our Board of Directors, a full complement.



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

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Robbin and Pat Bray 209-269-1080
braywaves@gmail.com

Lodi Caregivers Group*

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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 nilwilson.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



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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.

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