

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.



Young Onset Parkinson's Disease (YOPD): "What makes me different?"

by Dr. Nicklesh Thakur, D.O.
Sutter Medical Group Neurology

Typically Parkinson's disease (PD) is described as a neurologic condition that affects an elderly person with prominent symptoms of tremors, shuffling gait, and falling. Michael J. Fox and Muhammad Ali have changed this perception after being diagnosed with YOPD at the ages of 29 and 42, respectively. YOPD will start before the age of 50 and occurs in 2-10% of PD patients in the United States. The symptoms of YOPD are similar to classic PD with a higher risk of developing dystonia (muscle contractions with abnormal postures) and a lower risk of developing falling and freezing of gait.

The cause of PD is believed to be a combination of genetic predisposition and environmental exposures. In YOPD, genetics play a larger role and multiple genes have been found to increase the risk of developing Parkinson's at a young age.

Testing positive for a genetic mutation helps determine the risk of PD in family members and it is recommended to have genetic counseling before and after testing. Genetic forms of YOPD are treated with the same medications and currently there are no available preventive therapies for at-risk family members.

The motor symptoms of YOPD respond well to medications with a slower progression than classic PD. YOPD usually has an earlier onset of motor complications to Levodopa with dyskinesias (abnormal dance like movements) and wearing off (return of symptoms as a dose of Levodopa loses effectiveness). Motor complications are treated with Deep Brain Stimulation (DBS) surgery or intestinal gel infusion of Levodopa (duopa). YOPD patients are typically considered excellent candidates for DBS since they are less likely to have other medical conditions and their symptoms are very responsive to Levodopa.

Developing PD at a young age leads to unique challenges of financial planning, career adjustments, parenting responsibilities, etc. A multi-disciplinary team of specialists (movement disorder neurologist, counselor, social worker, physical and speech therapist, etc) is vital for managing these challenges of YOPD. It is important to work towards a balanced lifestyle with a focus on exercise, nutrition, emotional well-being, family, and personal relationships.



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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News From The Board

Hooray for FOUR new Support Groups!

Parkinson Support Group of Paradise Valley Estates

Parkinson Support Group of Natomas

Vacaville Parkinson Support Group

Parkinson Support Group of Carmichael Eskaton

For the latest information on these newly formed Support Groups see our website, www.panctoday.org

Welcome to TWO new Board Directors

Kate Rodrigues

Suketu Khandhar M.D.

A Hair-raising Discovery

by Dorothy Ross, Davis Support Group

When I turned sixty, I stopped coloring my hair. Imagine my dismay when the new growth came in bright white and curly tight, like the artificial straw in a child's Easter basket. On a windy day, my stand-on-end hair makes me look like Phyllis Diller in a fright wig.

I've only come to appreciate my Einstein look-alike hairdo since Michelle, my hairdresser, noted that my crop was thinning on top. She held a mirror behind my head so I could see how much of my scalp was showing.

"Don't worry," Michelle said. "We'll just cut it short and perky and no one will notice."

"I've seen older women with very thin hair and high foreheads," I said. "I've always wondered what caused it."



"Aging seems to be the single biggest factor, but I guess some of the Parkinson's drugs could be involved." Michelle secured a pink drape around my neck and started clipping my split ends. While she worked, I watched another stylist using a curling iron to tame the long shiny locks of teen-age prom goers. Beautiful. I remember when.

Until that day at the salon, I thought I was familiar with all the symptoms of Parkinson's—from insomnia to drooling—but I had never come across baldness (alopecia) in the literature. Sure enough, when I checked the fine print, hair loss was listed as a possible side effect of all my medications.

I appealed to my doctor, hoping for a different prescription that might halt the free fall. Her response was, "Those drugs have kept you mobile for more than ten years. Which would you prefer, a full head of hair or freedom of movement?" Not much of a choice. Is it?

The next time you see me I'll be wearing a hat.

Amazing Annual Conference

Over 850 people attended the Parkinson Association's Annual Conference 2018! Thanks to outstanding speakers and informative presentations, we all were treated to an extraordinary day of inspiration and enlightenment. Tremendous thanks go to ALL who volunteered their time to be a part of this special program. We are especially grateful to our sponsors.

Respite Support Available

Those that dedicate their heart and energy to caring for a loved one with Parkinson's disease know their work is a 'labor of love'. However, they often don't recognize (or admit) that they could use a break from the constant responsibility of caregiving to tend to their own needs. It's important. Thanks to the generous attendees of the Annual Conference September 22nd, the Parkinson Association was gifted with almost \$7,000.00 to Fund the Program for giving carepartners a break in their duties.

YOU CAN DO IT! *by Loy Baxter*

In May I went on an adventure to Togo in West Africa. I was concerned with the challenge of such a trip, since I have known for two years that I have Parkinson's. I kept telling myself though, "You can do it." It was not my first trip to Togo, since I had gone there a few years earlier to teach missionary children after retiring from teaching elementary school here in Sacramento.

With the help of friends, I had started a non-profit organization (www.bmotogo.org) to help and encourage some pastors and small churches that I came to know in the Kara area of Togo. So, along with a friend, I set off to visit these churches and villages. We wanted to see how they were doing and how the funds that we had raised for some special projects were being used.

We were greatly encouraged by the growth of the churches, the new building in one of the villages, the well with clean water in another place and the malaria program that was treating many sick children. Our fundraising efforts were paying off.

I was also encouraged because I was able to keep up with the many activities everyday, such as the nine hour bus ride up country, traveling out to remote villages and attending church services there, visiting the pastors and their families in their homes, checking out the building projects and the new well.

I think I was able to make the trip successfully because participating in the work there is a passion of mine. If I am involved in something so important to me, I seem to be able to rise to the occasion. Having a traveling companion was also very helpful; it gave me confidence in case something unforeseen came up. Also we planned the trip carefully and had people in Togo who could meet us at the airport and provide transportation for us. I have found as well that my faith in God helps me in difficult situations.

Go ahead and try that challenging task. You can do it too!



Finding Joy

by Nancy Kretz

On a recent visit with dear girlfriends, we sipped wine and waxed nostalgic of things past. "Remember when we actually had to 'sprinkle' and iron our clothes?", I laughed. Jayne countered that she STILL presses her mother's pillowcases and sheets, as her 93 year old mother insists on it. Period.

Just mentioning ironed sheets brought me back to my days in childhood, where indeed, I learned how to iron by pressing my dad's handkerchiefs and the family's pillowcases. And I remembered the crisp feel and smell of sunshine on those linens. Aaaaaw.

Surely you can guess that the next time I changed my bed, I dried the pillowcases outside and ironed them. I dried the sheets in the dryer, but did press out the upper hem of the top sheet. And when I got into bed that night, it was heaven. Talk about recreating a memory. **Joy!**



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Thank
You



Regional Support Groups

For additional information, visit www.panctoday.org

Auburn

Caregivers Luncheon

2nd Tuesday, 12 p.m.
(No meeting June/Dec)
Awful Annie's Cafe
13460 Lincoln Way, Auburn, CA 95603
Karen Hancock 530-885-0950
karen@hancockonline.net

Benicia

2nd Saturday, 10:30 a.m.–12 p.m.
201 Raymond Dr., Benicia, CA 94510
Brad Miller 707-515-9216
bradfordmiller807@gmail.com

Carmichael

Sacramento Area Young Onset Support Group

1st Wednesday, 6:30 p.m.
Carmichael Presbyterian Church
5645 Marconi Ave., Carmichael, CA 95608
Mary Beth Arjil 530-409-4118
marjil@sbcglobal.net
Tony Wong 916-730-6303
acwong60@gmail.com

Chico

1st Wednesday, 1:30 p.m.
Sycamore Glen Ret. Community
1199 Diablo Ave., Chico, CA 95973
Bill Bragdon 530-342-7272
tinmanb@sbcglobal.net

Davis

3rd Thursday, 1:30 p.m.
Davis Senior Center
646 A Street, Davis, CA 95616
Sue Curry 530-304-9927
smcurry@sbcglobal.net

Davis Care Partners Group

2nd Wednesday, 1:30 p.m.
Davis Senior Center
646 A Street, Davis, CA 95616
Sue Curry 530-304-9927
smcurry@sbcglobal.net

El Dorado Hills

2nd Tuesday, 12 p.m.
Rolling Hills Church Multipurpose Bldg,
West End of Complex-Rm 8
800 White Rock Rd.
El Dorado Hills, CA, 95762
Donna Rixmann 916-712-9642
donna@yogapeace.net
Larry Alver 916-933-2465
ldalver@sbcglobal.net

El Dorado Hills/Folsom Caregiver Luncheon
3rd Thursday, 11 a.m.–1 p.m.
Round Table Pizza,
2793 East Bidwell St., Folsom, CA 95630
Larry Alver 916-933-2465
ldalver@sbcglobal.net

Elk Grove

3rd Wednesday, 10 a.m.
Senior Center of Elk Grove,
8830 Sharkey Ave., Elk Grove, CA 95624
Myron Jantzen 916-686-4555
mpjantzen@aol.com

Fairfield

4th Tuesday, 11 a.m.
Paradise Valley Estates
Social Services Coordinator AL/IL
2600 Estates Drive
Fairfield, CA 94533
Robin Murray 707-207-7831
RobinM@pvestates.com

Folsom

4th Monday, 10 a.m.
Folsom Senior & Arts Center
48 Natoma Street, Folsom, CA 95630
Mary & Gene Cabaluna 916-987-1684
cabalunaem@comcast.net

Grass Valley

2nd Friday, 1:30 p.m.
Atria Grass Valley
150 Sutton Way, Grass Valley, CA 95945
Nancy Lockwood 530-272-7950
nmlockwood@aol.com

Lake County

2nd Monday, 2–3:30 p.m.
United Christian Parish
745 N. Brush St., Lakeport, CA 95453
Phil Myers 707-263-4624
phillip.e.myers@att.net
Lin Pifer 707-263-5728

Lincoln

3rd Tuesday, 10 a.m.
Granite Springs Church
1170 E. Joiner Pkwy., Lincoln, CA 95648
Brenda Cathey 916-253-7537
bjcathey@gmail.com

Lodi

1st Monday, 10 a.m.
Temple Baptist Church
801 S. Lower Sacramento Rd.
Lodi, CA 95242
Ron & Maureen Olsen 209-745-1011
molsen@softcom.net
Robbin & Pat Bray 209-269-1080
braywaves@gmail.com

Caregivers Group

3rd Monday, 10 a.m.–12 p.m.
Temple Baptist Church
801 S. Lower Sacramento Rd.
Lodi, CA 95242
Call for directions/information
Jean Whitted 209-368-2809
bjwhitted@hotmail.com

Loyalton

1st Friday, 1:30 p.m.
Golden West Restaurant
Main Street, Hwy 49, Loyalton, CA 96118
Betty Ferguson 530-993-4002
fergi45@gmail.com

Modesto

3rd Wed., 1:30–3:30 p.m. Jan.–Nov.
Trinity United Presbyterian Church
1600 Carver Rd., Modesto, CA 95350
Paul Vantress 209-526-6184
modestoparkinsons@gmail.com

Napa

Young Onset Group

4th Sunday, 3 p.m.
Covenant Presbyterian Church
1226 Salvador Ave., Napa, CA 94558
Joe Burger 707-266-6156
jeburger99@gmail.com

Oroville

1st Thursday, 1:30–3 p.m.
Trinity Presbyterian Church
2350 Foothill Blvd., Oroville, CA 95966
Carol Rawlins 530-282-8769

Don't see a support group in your area? Let us help you start one!

Contact us at 916-357-6641 or panc@panctoday.org

Placerville

1st Tuesday, 1:30–3 p.m.
Senior Center Dining Room
937 Spring Street, Placerville, CA 95667
Peggy Kline 408-309-1125
pegkline103@gmail.com

Redding

2nd Friday, 1:00 p.m. Social Time;
1:30–3 p.m. Meeting.
3–3:30 p.m., Shasta Shout – speech therapy
First United Methodist Church
1825 East Street, Redding, CA 95350
Kim Hawkins 530-945-7628
kim.reddingpsg@yahoo.com

Roseville

1st Tuesday, 1:30–3 p.m.
Maidu Community Center
1550 Maidu Dr., Roseville, CA 95661
Harry Butler 916-837-3366
hapbutler@comcast.net
Website: rosevillepsg.weebly.com

West Roseville

4th Tuesdays, 2:30–3:30 p.m.
Sierra Pointe Senior Living
5161 Foothills Blvd., Roseville, CA 95747
Jim Morris 916-359-4859
jimor1940@gmail.com

Sacramento

Arden/Arcade

3rd Thursday, 10 a.m.
Arden Christian Church
4300 Las Cruces Way, Carmichael, CA 95864
Keith Tronson 916-395-2771
keithtronson@sbcglobal.net
Jim Morris 916-359-4859
jimor1940@gmail.com

Sacramento Caregivers Lunch Bunch

3rd Tuesday, 11 a.m.
Ettore's
2376 Fair Oaks Blvd., Sacramento, CA 95825
Anne Spaller 916-728-9333
aspaller@deloro.org

Gold River Lewy Body Dementia (Collaboration Group)

2nd Thursday, 10 a.m.
Eskaton Lodge Gold River
11390 Coloma Rd., Gold River, CA 95670
Denise Davis 800-272-3900
denise.davis@alz.org

Sacramento Men's Group

1st Thursday, 10 a.m.
Crown Plaza, Theater Room
1071 Fulton Ave., Sacramento, CA 95825
Arnold Loveridge 916-485-0150
arnoldvl@surewest.net
Jim Morris 916-359-4859
jimor1940@gmail.com

Natomas Area

2019–2nd Thursday, 10 a.m.–Noon
Adventure Christian Church
1500 N Market Blvd., Sacramento, CA 95834
Irene Duggan 916-710-6912
parkinsons1018@gmail.com

Northeast Area

4th Thursday, 1 p.m.
St. Marks Unified Methodist Church,
Room E-24
2391 St. Marks Way, Sacramento, CA 95864
Sean Tracy 916-482-7014
ssffam@winfirst.com

Post DBS Patients

See class schedule, location and contact information at www.panctoday.org

South Area

2nd Thursday, 1 p.m.
Asian Community Center
7334 Park City Dr., Sacramento, CA 95831
David Teraoku 916-685-4162

Sonoma County

1st Saturday, 1 p.m., Feb/Mar/Apr/May/
June/Oct/Nov
2nd Saturday, 1 p.m., Aug/Dec
NO meetings in Jan/Jul/Sept.
Christ Church United Methodist
1717 Yulupa Ave., Santa Rosa, CA 95405
Kathy Osbun 707-480-7230
osbun@aol.com
Marc Alexander 707-431-8767
malexander109@comcast.net

Stockton

2nd Thursday, 1:30 p.m.
O'Connor Woods, West Hall
3400 Wagner Heights Rd.
Stockton, CA 95209
Mary Ann Behrens 209-477-6496
mbehrens64@gmail.com

Tracy

Parkinson Support Group of Tracy

2nd & 4th Mondays, 10 a.m. –12 p.m.
St. Paul's Lutheran Church
1635 Chester Ave., Tracy, CA 95376
Kathy Clark 209-879-3108
classieladyat63@yahoo.com

Vacaville

Parkinson's Support Group

4th Wednesday, 1:30–3 p.m.
The McBride Senior Center
91 Town Square Place, Vacaville, CA 95688
Brenda DeMartini 707-330-1551
brendaldemartini@gmail.com

Woodland

4th Tuesday, 1 p.m.
No meeting Jul/Aug
Woodland Comm. & Senior Center
2001 East Street, Woodland, CA 95776
Bernadette Murray 530-661-1950
bemurray2008@gmail.com

Yuba City

2nd Monday, 1 p.m.
Sutter Medical Foundation
969 Plumas St., Suite 208
Yuba City, CA 95991
Janice Herbert 530-673-3064
tricityparkinsons@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.



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