



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



Dystonia

By Dr. Suketu Khandhar, Medical Director, KP Northern Comprehensive Movement Disorders Program

We all know that the cardinal motor symptoms of PD are resting tremor, rigidity and bradykinesia (slowed movements). But did you know they are not the only motor symptoms patients may experience? What about Dystonia?

Dystonia is a sustained muscle contraction causing abnormal postures and positions. It is more than simple muscle cramping. There is a pattern to these movements and they occur in specific areas of the body. For example a common form of dystonia is Cervical Dystonia, previously called Spasmodic Torticollis. It occurs when neck muscles contract involuntarily causing the head to turn or twist to one side. This can happen in isolation or in specific conditions like PD. It most commonly happens when dopaminergic medications wear off. It can be painful. It can interfere with daily activities. Imagine this happening when someone is driving. They would not be able to keep their head looking straight to drive safely.

There are other common forms of dystonia in PD.

1. Toe Curling Dystonia - this commonly occurs in the early hours of the day before meds have a chance to kick in
2. Foot Inversion Dystonia - this is where the whole foot turns inward making it difficult to walk with surefootedness
3. Truncal Dystonia - this is where the torso leans or is pulled to one side
4. Writer's Cramp
5. Facial Dystonia - this includes jaw clenching
6. Blepharospasm - excessive eyelid blinking or forced eyelid closure

So how do we identify and confirm this condition?

Continued on Page 3: Dystonia



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Board Notes

From the Heart

When we hear of a celebrity having Parkinson's disease, we all pause for a moment. That's how it was for Jack Wright, professional performer and tribute singer of Neil Diamond's work. Jack and his wife were so touched by Neil Diamond's announcement of having Parkinson's disease that they decided to do what they could to bring attention and support to the Parkinson's community. Specifically, Jack has embraced the Parkinson Association of Northern California and is dedicating to PANC \$1 of every ticket sold on his upcoming concert in San Ramon on July 14, 2018. Check it out! www.jackwrightshow.com. **Hope to see you there!**

Continued on Page 3: Board Notes

Continued from Page 2: Board Notes

California launches new Parkinson’s Disease Registry

PANC has been working with the California Department of Public Health (CDPH) to understand the scope and expected outcomes of the State’s new Parkinson’s Disease Registry. Effective July 1, 2018 healthcare providers diagnosing or providing treatment to Parkinson’s disease patients are required to report each case of Parkinson’s disease to CDPH in a secure and confidential database system. CDPH has an inquiry system for questions you may have at (916) 731-2500, or by email to CPDRhelp@cdph.ca.gov.

The Department has been very cooperative including PANC questions and concerns into the program plans for this new statewide registry. A great resource for more information is the CDPH Frequently Asked Questions page at <https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDSRB/Pages/CPDR-FAQs.aspx>

We will continue to work with CDPH to address concerns, questions, and evaluate the statewide data as it is made available to the public

Continued from Page 1: Dystonia

A neurologist best identifies Dystonia. There is no blood test or imaging study to help confirm a diagnosis. It relies on taking a good history and clinical examination. Often times however, the dystonia may not be present when in the doctor’s office. I recommend video-recording symptoms in advance in order for the neurologist to review and consider treatment.

Dystonia is best treated by:

1. Reviewing one’s medications to see if any adjustment could improve symptoms

Finding JOY

By Nancy Kretz

“I Didn’t Know I Could..”

I didn’t know I could make cream puffs! Didn’t know I’d love taking an early morning water aerobics class! And surely didn’t expect I could quit smoking cigarettes (after 50 years of lighting up)! WhooHoo for all three!

The old saying, “You’ll never know unless you try” holds true for all of us. And the advice is especially applicable as we encounter different circumstances in life. Trying new –or even challenging things adds spice to life. And accomplishing the unexpected is Joy.

I wonder, by summer’s end, how you will finish the sentence - “I didn’t know I could...”

Horseback riding, anyone?



2. Considering adding or increasing PD medications
3. Considering muscle relaxants
4. Physical Therapy to relax and stretch the affected muscles
5. Injecting Botulinum Toxin into the affected muscles - this is a chemical toxin that reduces the transmission between nerve muscle, thereby weakening muscles

If you think you may have Dystonia, please discuss your symptoms and concerns with your neurologist.

It Ain't Necessarily PD

by Dorothy Ross, Davis Support Group

***Like so many other People with Parkinson's,
I tend to blame the disease whenever a new symptom strikes.
But, as the old song goes, "It Ain't Necessarily So."***

I've been dealing with increasingly debilitating pain in one leg for several years. Assuming that I was suffering from dystonia--a state of abnormal muscle tone common in Parkinson's--the movement disorder neurologists prescribed physical therapy and drugstore painkillers.

When the pain got so bad that I couldn't walk normally, even with the aid of a walker, I tried two very different treatments, beginning with Botox. Injections of that drug into my foot were successful in halting the cramping and curling of my toes--a very good thing. Unfortunately, Botox did nothing for the aches in the rest of the leg--from hip to heel.

In frustration, I've recently turned to medical marijuana for pain relief. I had never before experimented with pot in any form, but I was desperate. Now I buy tinctures in expensive little bottles with droppers to deliver the goods sublingually. I know cannabis isn't a cure for PD. I'm just grateful that it dulls the pain and helps relieve my anxiety.

I'm told the latest treatment for dystonia is Deep Brain Stimulation surgery, the same type of DBS procedure that surgeons perform to control PD tremors. I might be tempted to go under the knife if all my pain was caused by dystonia, but, as I said before, it ain't necessarily so.

A physical therapist specializing in spinal problems told me a pinched nerve in my low back could be causing sciatica or stenosis. He said there was a chance targeted exercises and stretches could alleviate the situation.

To aid in the diagnostic process, I have agreed to undergo my first ever MRI--a procedure I have dreaded and successfully avoided--until now.

Wish me luck and stay tuned. I'll keep you posted.



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Regional Support Groups

For additional information, visit www.panctoday.org

Sacramento

Arden/Arcade

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

Northeast Sacramento Area

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

Sacramento Caregivers Lunch Bunch

3rd Tuesday, 11 a.m.
Ettore's, 2376 Fair Oaks Blvd.
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.
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.
Arnold Loveridge 916-485-0150
arnoldvl@surewest.net
Jim Morris 916-359-4859
jimor1940@gmail.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.
David Teraoku 916-685-4162

Auburn

Caregivers Luncheon

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

Carmichael

Sacramento Area Young Onset Support Group

1st Wednesday, 6:30 p.m.
Carmichael Presbyterian Church
5645 Marconi Ave., Carmichael
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.
Bill Bragdon 530-342-7272
tinmanb@sbcglobal.net

Davis

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

Davis Care Partners Group

2nd Wednesday, 1:30 p.m.
Davis Senior Center
646 A Street
Karen Eagan 530-564-4323
kareneagan747@gmail.com

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

Elk Grove

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

Folsom

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

Grass Valley

2nd Friday, 1:30 p.m.
Atria Grass Valley
150 Sutton Way
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
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
Brenda Cathey 916-253-7537
bjcathey@gmail.com

Lodi

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

Lodi Caregivers Group

3rd Monday, 10 a.m. - 12 p.m.
Temple Baptist Church
801 S. Lower Sacramento Rd.
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
Betty Ferguson 530-993-4002
fergi45@gmail.com

Modesto

3rd Wed., 1:30-3:30 p.m.
Jan.-Nov.
No meeting in July
Trinity United Presbyterian
Church
1600 Carver Rd., Modesto
Paul Vantress 209-526-6184
modestoparkinsons@gmail.com

Napa-Young Onset Group

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

Oroville

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

Placerville

1st Tuesday, 1:30-3 p.m.
Senior Center Dining Room
937 Spring Street, Placerville
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
Kim Hawkins 530-945-7628
kim.reddingpsg@yahoo.com

Roseville

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

West Roseville

4th Tuesdays, 3:30-4:15 p.m.
Sierra Pointe Senior Living
5161 Foothills Blvd, Roseville
Jim Morris 916-359-4859
jimor1940@gmail.com

Sonoma County

1st Saturday, 1 p.m.,
Feb/Mar/Apr/May/June/Oct/Nov
2nd Saturday, 1p.m., Aug/Dec
NO meetings in Jan/Jul/Sept.
Christ Church United Methodist
1717 Yulupa Ave., Santa Rosa
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.
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.
Kathy Clark 209-879-3108
classieladyat63@yahoo.com

Vacaville

1st Saturday, 1:30 p.m.
Community Presbyterian Church,
425 Hemlock Street
Theresa Pate 707-642-2173
theresa3842@sbcglobal.net

Vallejo

1st Saturday, 10 a.m.
Community Presbyterian Church,
Room 2
2800 Georgia Street
Theresa Pate 707-642-2173
theresa3842@sbcglobal.net
Margarita Romo (Spanish
interpreter) 707-803-9220
meguiromo@yahoo.com

Woodland

4th Tuesday, 1 p.m.
No meeting Jul/Aug
Woodland Comm. & Senior
Center
2001 East Street
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
Janice Herbert 530-673-3064
tricountyparkinsons@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.

ANNUAL CONFERENCE

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THE PARKINSON'S JOURNEY

9am to 3pm



SATURDAY

22nd
SEP

Parkinson Association Of Northern
California's Annual Education Conference
McClellan Conference Center
5411 Luce Ave, Sacramento

Registration Fee: \$25

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Questions: panc@panctoday.org

or call 916 357 6641.