

What to do when the medicines don't work..

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Valencia Shores Parkinson's Group

March 2018



Goals for today's talk

Opening discussion

Rock Steady and Pound It Out

April and May programs

Moving Day

What to do when the meds don't work



Upcoming Events in Our Area

Parkinson's on the Horizon and Champagne Celebration

- Tuesday, March 13, 2018
- Boca Raton, FL 33433

Sequins & Sparkle

- Saturday, April 14, 2018
- Boca Raton, FL 33496

(Online) Expert Briefing: Marijuana & PD: What Do We Really Know?

- Tuesday, April 17, 2018

(Online) Expert Briefing: Living Alone: Home Safety & Management in PD

The Annual Leo Geller Golf Tournament

- Monday, March 26, 2018
- Boca Raton, FL 33433

Signature Gala: Honoring Gail and Robert Milhous

- Saturday, April 14, 2018
- Boca Raton, FL 33496

Why Can't I Sleep?

- Wednesday, April 18, 2018
- Boca Raton, FL 33433

South Palm Beach Parkinson's Foundation

<http://www.parkinson.org/southpalmbeachcounty>

January 2018

Classes & Events At The PD Center (21301 Powerline Road, Suite 303, Boca Raton)



Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1 HAPPY NEW YEAR! NO CLASSES	2 NO CLASSES	3 Rock Steady Boxing Advanced: 2:00 – 3:00 p.m. Rock Steady Boxing Beginner: 3:00 – 4:00 p.m.	4 Balance Workshop Beginning 2:00 – 2:45 p.m. Balance Workshop Advanced 3:00 – 3:45 p.m.	5 Yoga 11:00 – 11:30 a.m. Tai Chi 11:30 – 12:00 p.m.	6
7	8 NO CLASSES	9 Lunch 'n Learn 12:00 p.m. Pound Fit For Parkinson 11:00 a.m.–12:00 p.m.	10 Rock Steady Boxing Advanced: 2:00 – 3:00 p.m. Rock Steady Boxing Beginner: 3:00 – 4:00 p.m.	11 Balance Workshop Beginning 2:00 – 2:45 p.m. Balance Workshop Advanced 3:00 – 3:45 p.m.	12 Yoga 11:00 – 11:30 a.m. Tai Chi 11:30 – 12:00 p.m.	13
14	15 MARTIN LUTHER KING, JR. DAY NO CLASSES	16 Pound Fit For Parkinson 11:00 a.m.–12:00 p.m.	17 NO CLASS Young Onset Support Group* 6:00 – 7:00 p.m.	18 NO CLASS	19 NO CLASSES "Rock The Runway" FASHION SHOW at the Boca Rio Golf Club	20
21	22 Speech Workshop 2:00 – 3:00 p.m.	23 Pound Fit For Parkinson 11:00 a.m.–12:00 p.m.	24 Rock Steady Boxing Advanced: 2:00 – 3:00 p.m. Rock Steady Boxing Beginner: 3:00 – 4:00 p.m.	25 Balance Workshop Beginning 2:00 – 2:45 p.m. Balance Workshop Advanced 3:00 – 3:45 p.m.	26 Yoga 11:00 – 11:30 a.m. Tai Chi 11:30 – 12:00 p.m.	27
28	29 Speech Workshop 2:00 – 3:00 p.m.	30 Pound Fit For Parkinson 11:00 a.m.–12:00 p.m.	31 Rock Steady Boxing Advanced: 2:00 – 3:00 p.m. Rock Steady Boxing Beginner: 3:00 – 4:00 p.m.	<p>Don't miss our Lunch 'n Learn Program "How To Have A Successful New Year" Tuesday, January 9 12:00 p.m.</p>		

*Please Note That Young Onset Support Group Will Meet At Florida Movement Therapy Center 6:00 - 7:00 p.m. – 3rd Wednesday of the month.

New Publications



Resources Order Form

To place your order, return this form to the address at the bottom of the page, call 1-800-4PD-INFO (473-4636), or email: helpline@parkinson.org

English

Books

- What You and Your Family Should Know
- Medications
- Caring and Coping
- Mood (NEW!)
- Cognition (NEW!)
- Managing parkinson's Mid-Stride (NEW!)
- Fitness Counts
- Nutrition Matters
- Speech and Swallowing
- Guide to Deep Brain Stimulation
- Psychosis

- Helpline Postcard 1-800-4PD-INFO
- Parkinson Report (newsletter)
- About NPF (brochure)
- Medical Alert Card
- 10 Early Warning Signs of PD (brochure)
- Aware in Care Hospitalization Kit

Español

Libros

- Lo que usted y su familia deben saber
- Medicamentos
- Estar en forma cuenta
- El cuidado y la adaptación necesaria
- Mente, estado de ánimo y memoria
- Enfermedad de Parkinson en su etapa avanzada

- 1-800-4PD-INFO Línea de Ayuda (postal)
- 1-800-4PD-INFO Línea de Ayuda (postal)
- la enfermedad de Parkinson (folleto)
- Aware in Care kit para hospitalización

For support group leaders, health care centers, etc.;

- Aware in Care poster
- Aware in Care postcard (pack of 25)
- CareMAP postcard (pack of 25)

Name: _____ Phone Number: _____

Organization: _____ Email: _____

Address: _____ City: _____ State: _____ Zip: _____

Check here if you do not wish to receive information and mailing from NPF.

If you don't have an Aware in Care kit, I highly recommend you order one

Valencia Shores Upcoming Meetings

Sunday April 8 11:30-12:30

- General Discussion - suggested topics
 - Taking care of the Caregiver
 - Learning when additional help is needed with caring for the Person with Parkinson's

Sunday May 6 11:30-12:30

- Sherry from Paradise Home Care
 - "ask the socialworker"

What to do when the medicines don't work

Sinemet is known to be less effective "after many years"

Wears off and can have sudden slowness or freezing

Can cause Dyskinesia or involuntary movements

- This can be too much or too little medication

Medicine schedules are less "forgiving"

Treatments when the medicines don't work

"Rescue" medicines - some tested but not yet on market

- Apokyn (injection), a sublingual, a nasal spray

Change/add other medicines

- COMT inhibitors, dopamine agonists, MAO-B inhibitors

DBS - Deep Brain Stimulation

Intestinal Gel (DUPOA - stomach pump)

Survey My Friends

What symptom was the deciding factor for deciding to have the DBS procedure.

Any tips for dealing with Hospital and this procedure. What would you have done differently

Are you awake for the procedure

Post surgical complications? Post surgical discomfort?

In what ways are you better post procedure

What else did you consider?

A personal friend, not yet 60

(Robin's answers were a lot longer, these are a summary)

Dyskinesias - and I don't think mine were that severe. Mine were bothersome, but I was used to them. I wanted to cut down on meds and I'm no longer taking Amantadine. I am very glad that I had the procedure. It wasn't the cure of my PD, but it has helped me.

I had talked to Dr. Burack a lot about the surgery. She held off saying it was right for me until my risk factors for getting hurt from falling and having repercussions was greater than the risk factors for having the surgery

I was not awake to have the crown that stabilized my head attached and removed. I was "out" for a short period of time. I was awake throughout the procedure and it was fascinating.

A personal friend, not yet 60

(Robin's answers were a lot longer, these are a summary)

The surgery did not fix everything all at once. I have had follow-up visits to tweak the stimulator settings and find a good mix for meds and stim.

No dyskinesias. I know that I don't necessarily have to live with something with no control. I know that I have the ability to make some changes if necessary.

My insurance paid for everything. I have copays for office visits.

We all know there may something better coming along, but my advice is to look into having DBS now, especially if you are in crisis.

Steve - PLM

Deciding factor

- Tremors

Tips

- Check different brands if possible

Procedure

- Yes;. Don't know if it was necessary.; I was actually looking forward to it as an adventure and hoping that my being awake would help the doctors make better decisions, which is what you should think. "My surgery had some things go wrong with it, more than I've ever heard of, but still it wasn't that bad.

Better post procedure

- Tremors: GONE. 100%. They will come back but for now they are gone.
- Highs and lows are no longer this huge precipice; more like small hills and valleys.
- Sleep: Initially was great, though you can see by my timestamp, I've had some problems return at the 3 year mark. Not nearly as bad as before - realistic dreams, hallucinations, etc.
- tremor and dyskinesia eliminated

Worse post procedure?

- I picked up a little tinnitus which can always happen during brain surgery.
- I also have to do voice exercises now to keep my voice

Bill - PLM - age 56

Deciding factor

- Dyskinesia

Tips

- Be trained on sterile wound care. Consider hiring RN to change bandage.

Procedure

- Asleep-drill holes, insert leads
- Woken up - ad just leads to stop tremors and dyskinesia
- Put back to sleep

Post surgical

- needed morphine for pain for about 48 hours

Better post procedure

- tremor and dyskinesia eliminated

What else did you consider?

- Going on disability

A member from PLM

I had been waiting for almost ten years for a better option. I didn't have severe dyskinesias, and had no tremor even when off (once I was properly medicated). My main problem was walking. So I wasn't in a crisis, but was concerned that DBS (my MDS had told me I was an excellent candidate) might become out of reach.

I was concerned that I might develop something that would prevent my having DBS in the future (I was 66 when I had the DBS. Rytary was essentially the last straw, and I didn't have much success with it.

So I went ahead with dbS, and have been very happy with the results. I don't have any special insights, but I think the better options are probably five to ten years away

Daddytom - PLM

Deciding factor

- Tremors and Shuffling

Tips

- Research your neurosurgeon thoroughly. And ask lots of questions. Especially the questions that you might think are dumb questions

Procedure

- No and yes. Asleep for the placement of the halo, Asleep for drilling the burr holes. Was wakened for lead placement and to answer questions. Asleep for placement of the generator

Post surgical

- Very mild, minor discomfort at incision site where the generator was placed. Gone in 2 days.

Better post procedure

- No tremors 5 years post DBS, My gait is still improved 5 years post DBS

QUESTIONS / DISCUSSION

