

Parkinson's Update

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Big Flats Parkinson's Group- June 2018

Valencia Shore's Parkinson's Group -July 2018

Goals for today's talk

Auntie J's rant

Brainstorming Ideas

Moving Day

In Our Community

Discussion Topic for today:

Me, Parkinson's and My Family

What to do when the Meds don't work

Brainstorming Ideas

Does one die from Parkinson's?

Estate planning - practical pointers on wills, trusts, etc.

What if something happens and the non-PD spouse can't take care of the PWP

When is it time to have a caretaker - what types of help are available?

PD 101 Newly diagnosed - what to expect

PD 101 Common PD meds and what they do

PD 201 Parkinson's mid-disease - using the new literature as a guide

PD 201 Non-motor symptoms - how to cope, etc.

PD 201 Keeping your marriage healthy with a degenerative disease

Auntie J's "rant"

FROM AUNTIE J, a regular contributor on [Patients Like Me](#)
"My WEBSTERS DICTIONARY defines

DISEASE as: 1. [n] any departure from health: illness in general.
2. a particular destructive process in an organ or organism with a *specific cause and characteristic symptoms*.
3. *any harmful or destructive condition*, as of society .
[v] 1. to cause disease in; infect or derange.

DISORDER as: [n] 1. a lack of order; confusion; jumble.
2. a breach of public peace, a riot.
3. *a disregard of system; irregularity*. 4. *an upset of normal function; ailment*.
[v] 1. *to throw into disorder; disarrange*.
2 *to upset the normal functions of health.*"

Auntie J's "rant"

I don't like the word 'disease.'

In what's left of my brain, disease conjures up something yukky and ugly.
.....maybe like leprosy [although I have never seen anyone afflicted.]
and according to Webster, as a noun in the highlighted #2 definition doesn't really fit.

On the other hand

the dictionary definition of 'disorder' in noun 3 & 4 and verb 1 & 2 seem to fit Parkinson's.

Since the 'preferred' physician for us is a neurologist with a MDS specialty
[MOVEMENT DISORDER SPECIALIST] I will in the future refer to this monster as a 'DISORDER!!!'
I think it has a much 'softer' sound and disorder sounds like it 'could be easier' to find the cause.
anyone care to join me in changing the monster's name to PARKINSON DISORDER???

Auntie J's "rant"

A vey silly rant, I know
But its meant to show
Even if Parkinson's Disease has me tightly by my toe[s]
He'll never have 100% control, by joe!!!

Moving Day

Gloria's Goal - 60 donors for my 60th birthday.



Results:
\$4350 between
Rochester
and Boca events

42 donors

Congratulations to
Team Lorainne
\$13,686 raised

Get Involved - Valencia Shores Support Group

Boca Raton - Nov 4, 2018

Their goal \$125,000

Supports national and local programming

Sunday November 4, 2018

- Sign up and affiliate with Valencia Shores Movers
- Donate to our team



TEAM WEBSITE

<https://www.movingdaywalk.org/moving-day-boca-raton/team/45873>

Future Treatment Updates

Ultrasound surgery -- healing without cuts

- December 2011, a TED talk
- 16:30
- <https://www.youtube.com/watch?v=x4IA-M3zbdU>

Parkinson's Disease and Cannabis Oil

- November 2014
- 6:19
- <https://www.youtube.com/watch?v=XP5yxaVksbY>

Future Treatment Updates

Noninvasive Brain Surgery

- November 2013
- 2:39
- <https://www.youtube.com/watch?v=D2FzB2FAS>

Focused Ultrasound

- November 2015
- 2:38
- <https://www.youtube.com/watch?v=Y73tVVmOjGg>

South Palm Beach Parkinson's Foundation

<http://parkinson.org/southpalmbeachcounty>

- Dues \$75 per person \$100 per couple
- Most exercise classes and daytime lectures are free
 - Only charge for boxing at Florida Movement Therapy. Boxing at their offices is free.
- Bigger fund raising events too.

Get Involved Rochester National Parkinsons Foundation

Rochester - September 30

Their goal \$125,000

Montour Movers have been in the top 5 teams for the past 5 years (data not verified)

We are currently in 2nd place

Individuals - Robin and I are in 2nd and 3rd place at the moment

Sunday September 30

Donate to our team



TEAM WEBSITE

<https://www.movingdaywalk.org/moving-day-rochester-ny/team/45122>

Current Treatment Updates

Generic Azilect - Rasagiline

- Often prescribed as a first treatment, alone or with Sinemet, Mirapax or Requip
- This drug is supposed to help the body use whatever dopamine is there more efficiently
- Is theorized to be “neuroprotective” (slow progression)
- Original from Teva. Generics from Teva and Alvogen
- Still more costly than other meds

Current Treatment Updates

Medical Marijuana

- Too many variables
- See article from Parkinson Disease Foundation (pages 69+)
- http://www.pdf.org/pdf/slides_pde_xpertbriefing_paininPD_010617.pdf

Educational Programs Available

Michael J Fox Foundation

LATEST FROM THE BLOG

MORE NEWS [▶](#)



June 21, 2018

New Study Examines Impulse Control Disorders and Parkinson's Drugs

READ MORE [▶](#)



June 20, 2018

Summit Outlines Needs to Advance Parkinson's Cures

READ MORE [▶](#)



June 19, 2018

In Case You Missed It: Jimmy Choi's Return to 'American Ninja Warrior'

READ MORE [▶](#)

MJFF LIVE



The Lancet Neurology calls the AMP PD program the "most ambitious initiative so far to find a cure for Parkinson's." Learn more about how it is speeding progress for a #Parkinsons #cure: <https://bit.ly/218E4NP>

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When managing care for someone with Parkinson's disease, it can be easy to skip taking care of yourself, too: <https://bit.ly/2GhOCcC>

LIKE US ON FACEBOOK [▶](#)



"What Is Parkinson's Disease?" whiteboard video

WATCH [▶](#)

Educational Programs Available

Michael J Fox Foundation

- Ask The Doctor Series
 - Pain and Parkinsons
 - <https://www.michaeljfox.org/foundation/news-detail.php?ask-the-md-pain-and-parkinson-disease>
 - March 7, 2017 at 1:00

Educational Programs Available

Michael J Fox Foundation

- Third Thursday Series
 - Complementary Medicine for Parkinson's
 - <https://www.michaeljfox.org/page.html?hot-topics-webinar-series&navid=webinar-series>
 - March 16 at noon

Get Involved - Clinical Trials

Michael J Fox Foundation

- THE PARKINSON'S PROGRESSION MARKERS INITIATIVE (PPMI) is a landmark study launched in 2010 to find biomarkers -- disease indicators that are critical missing links in the search for better Parkinson's disease (PD) treatments.
 - [Link for more information](#)
 - Particularly looking for people with or without PD who may be at risk for genetic mutations related to PD (Ashkenazi Jewish, Basque, North African descent)

Rochester NPF

Events in Your Area

Explore Your Medicare Options

Saturday, September 15, 2018
Rochester, NY 14620

Moving Day Rochester

Sunday, September 30, 2018
Rochester, NY 14623

Parkinson Disease Basics- Part One

Saturday, October 20, 2018
Rochester, NY 14620

Events in Your Area - Rochester Educational

Events in Your Area

Get Involved

Annual Parkinson's Symposium

Programs & Support

QUESTIONS / DISCUSSION

<http://www.Parkinson.org>



Understanding Parkinson's

Living with Parkinson's

Expert Care

Research

Get Involved

Ways to Give