

Research Update

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Valencia Shores Parkinson's Group - March 2017

Goals for today's talk

Auntie J's rant

Treatment Updates

Educational Programs

Clinical Trials

In Our Community

Future Research

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!!!

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 theoried 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

Diagnosis PD, Now What?

- Parkinsons Disease Foundation
 - www.pdf.org
- March 7 - 1pm
- Signup at http://www.pdf.org/en/parkinson_briefing_diagnosis

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 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)

Get Involved - Valencia Shores Support Group

Boca Raton - Nov 6, 2016

Their goal \$125,000

They raised \$97,000

Valencia Shores - 14th place \$1440

Individuals

- Gloria Friedman - 11th \$1340.00

Sunday November 5, 2017

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



TEAM WEBSITE

<http://www3.parkinson.org/goto/valshores>

Get involved - Valencia shores support group

Ideas for future planning

Symposium

- Run by National Parkinsons Foundation
- [flyer](#)

Get Involved - Valencia Shores Support Group
Ideas for future planning

Open to people with other chronic diseases such as MS, Essential Tremor and Rheumatoid Arthritis

Get Involved - Valencia Shores Support Group

Ideas for future planning

Speakers

- University of Miami Clinical Neurology
- Stuart Rubin, Pain Management
- Kevin Pallone, PT - Falling and balance
- Speech therapist from Florida Movement Therapy

Note - these are totally separate ideas and are not mutually exclusive

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>

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>

QUESTIONS / DISCUSSION

Ask the Doctor: Michael S. Okun, M.D., and Daniel Martinez-Ramirez, M.D., answer medical questions regarding Parkinson's disease and related matters.

<http://www.Parkinson.org>

<http://www.parkinson.org/find-help/ask-the-doctor-forums>



Parkinson's HelpLine

- Available at **(800) 457-6676** or info@pdf.org
- Monday through Friday
- 9:00 AM – 5:00 PM ET