



PDU-182X (07.26.2021)



PDUpdate No. 18 Extra Extra

JFK's Parkinson's Newsletter

DBS Support Group TODAY Monday, July 26th at 4:05 pm

Dr. Anton Svetlanov will present another session about DBS Surgery. He will answer all of your questions about DBS, including qualifications, safety, efficacy, unintended consequences, the actual surgery, and the many success stories associated with this procedure. You will also have an opportunity to hear from some people who have had the surgery.

You may join all of our Zoom meetings at <https://us02web.zoom.us/j/2128260907>

Dr. Svetlanov's last lecture

We had 30 PwPs attend Dr. Svetlanov's lecture on meds last Monday. Unfortunately, we ran out of time leaving a number of unanswered questions. Dr. Svetlanov will return in the near future to answer all of your questions. In order to make best use of his time, please send your questions to **Ed Rodrigo** (edrodrigo926@gmail.com), who will assemble and send them to Dr. Svetlanov. Watch for the new date in future newsletters.

Support Group Dates for 2021 - Mark your calendars!

Parkinson's Support Groups (3rd Monday of every month)

August 16, September 20, October 18, November 15 & December 20

Care Partner Support Groups (4th Monday of Even months)

August 23, October 25, December 27

DBS Support Groups (4th Monday of Odd months)

July 26, September 27, November 22

Newly-Diagnosed Lecture Series

To Be Announced

A Call for Mentors and Mentees

Our Newly-Diagnosed Program has been a successful addition to our Comprehensive Parkinson's Program. With 18 mentors/mentees (that's right...we're **still** growing!) in the program as of now, we see a tremendous benefit to our Newly-Diagnosed colleagues who are in the process of learning the ropes of their new life with PD.

The mentor/mentee program is essentially for newly-diagnosed PWDs, although anyone who is having difficulty coping may become a mentee. The mentors will act as "big brothers" or "big sisters" and will serve as sounding boards, sharing experiences, offering hope to the mentees and providing them with lots of helpful resources.

The program starts with six introductory lectures to provide mentees with the necessary tools to function in the Parkinson's world. The topics selected will bring the Newly-Diagnosed person up to speed on the basics of treatment rather than have them learn a little at a time over a long period of time. Once these foundation blocks have been laid, and with the help of their mentors, the Newly-Diagnosed will have the knowledge that will help them to get through their day.

Newly-Diagnosed Lecture Series (July 2021):

1. Nahid Wardeh - The Parkinson's Foundation (PowerPoint is available)
2. Speech, Swallowing & Singing (Aly Chananie needs ParkinSINGS volunteers)
3. Jennifer Lazaro - The importance of Exercise (Lecture is available)
4. Dr. Rossi -The Role of the Physiatrist and JFK's Comprehensive PD Program (Lecture available)
5. Dr. Svetlanov - The right Medications for you, dosages and timing (Lecture available)
6. D. Hanna - How to prepare for your next MDS visit and what to expect (Lecture available)
7. Dr. Svetlanov – Meds Part 2 (To be Announced)

Note: Copies of all lectures will be distributed following the series

Do you have the desire to volunteer as a mentor or, as a newly-diagnosed PwP or someone who is having difficulty dealing with their diagnosis, would you like to join our mentee group? Please contact John Kolaya (914) 837-6910, jkolaya@aol.com or Donna Mastropolo, Program Director, dmastropolo@yahoo.com to become a part of this rewarding new program!

Moving Day New Jersey is on Saturday, October 2, 2021

Summer is here and Moving Day is right around the corner! Let's begin some serious fundraising for our first in-person post-COVID event! Everyone has the ability to form a team with friends, teams, clubs, and organizations. This will result in wider coverage and will increase our fundraising efforts.

Go to: <https://movingdaywalk.org/event/moving-day-new-jersey/#news-and-updates> and let's get to work!

Rock Steady Boxing (RSB) – An optimal exercise that delays symptoms.

Contact **Lauren Karpinski** at Lauren.Karpinski@hmhn.org at JFK or call 732-632-1610 to sign up for Rock Steady Boxing, a non-contact exercise program. For those in the Garwood area, Rock Steady Boxing is offered at 340 North Avenue. Contact **Dayel Giammarino** at RSBoxingCJ@gmail.com or call 908-922-7280.

ParkinSINGS meet for virtual practice every Wednesday a 3:00 pm. If you want to join in the fun, contact Aly Chananie, Senior Speech Pathologist at (732) 321-7063 or Alyson.chananie@hmhn.org. No experience necessary!

IWNQ – Our slogan reflects our attitude about Parkinson's disease. A good friend of mine, **Scott Rider**, and fellow PwP, has coined the phrase **I WILL NEVER QUIT!** He offered to let me use it for our support groups and has donated 50 IWNQ bracelets to get us started. We now have 150 bracelets and 100 key chains which I will hand out to fellow PwPs when the in-person opportunity arises. Wear them proudly!

The Aware in Care Kit

If you have Parkinson's disease, are you fully prepared for an unexpected trip to the hospital? Most people with Parkinson's do not receive their medications on time when staying in the hospital – leading to unnecessary complications. Save yourself a big headache and order an AWARE IN CARE KIT from the Parkinson's Foundation by clicking on: <https://www.parkinson.org/Living-with-Parkinsons/Resources-andSupport/Patient-Safety-Kit/Kit-Contents>. The kit contains forms, fact sheets, meds lists, alerts, and a Hospital Action Plan to keep you safe during your stay.

Parkinson's Foundation HelpLine and Website

The Parkinson's Foundation's HelpLine at 1-800-473-4636 is always a great resource for all PD-related questions and resources. The Parkinson's Foundation Website is at <https://www.parkinson.org>

We're now on Facebook!

For topics, details, photos, and updates, go to **Facebook:** Public Groups, Parkinson's Support Group at HMH JFK University Medical Center

Get the Latest Parkinson's News from JFK University Medical Center

PDUpdates will be e-mailed directly to you. All you need to do is send me your name and your e-mail address indicating you would like to receive your own copy when it is published. As noted below, your information will remain confidential.

Stay Safe and *Keep Moving!*

John Kolaya,

JFK Parkinson's Patient Advocate

(914) 837-6910; jkolaya@aol.com

I WILL NEVER QUIT!

PDUpdates are distributed as needed to keep HMH JFK clients informed of important information about Parkinson's Disease and HMH JFK's Comprehensive Parkinson's Program. For your privacy, your name will not appear on any of the email documents. You may opt out of this free service by replying to this email with your desired intentions.