



PDU-18X (07.17.2021)



PDUpdate No. 18 Extra

JFK's Parkinson's Newsletter

Barry Blaustein to speak on Monday, July 19th at 4:05 pm

Join us as we host comedy writer, **Barry Blaustein**, on ZOOM at our July Support Group meeting. Many of us know Barry for his writing on **The Nutty Professor**, **Saturday Night Live** and recently, for his screen writing on **Coming 2 America** starring **Eddie Murphy**. But did you know that Barry has Parkinson's disease?

In the words of **Victoria Miller**, PwP and author of ***The Right attitude***, "Barry is a Parkinson's Hero because of his involvement with the greater Parkinson's community. Barry, who has had a long career as a film writer and director, now teaches screen writing at a local university. His background has prepared him well to be an official spokesperson for the **Parkinson's Foundation**. He now travels to speak at PD conferences around the country. His inspirational speeches help many with PD learn about the good things about having Parkinson's. "It's still awful having it, but if God gives you lemons, you got to make lemonade!"

You may join the meeting simply by clicking on:

<https://us02web.zoom.us/j/2128260907>

Newly-Diagnosed Lecture on Thursday, July 22nd at 4:05 pm

On Thursday, **Dr. Philp Hanna** will be presenting a lecture about your next visit to your Movement Disorder Specialist. Dr. Hanna will discuss the Unified Parkinson's disease examination used to assess the progression of the disease, or in some cases, how your medications and exercise have stalled the progression...which may lead to a decrease in the frequency of your meds. He will also explain how you can help his assessment by monitoring your "ON and OFF" periods and other symptoms between visits.

This lecture will be principally for our Mentor/Mentee Program in conjunction with our Newly-Diagnosed Lecture Series. However, I guarantee that this information will be useful for our more experienced PwPs.

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

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

Dr. Anton Svetlanov will team with surgeon Dr. Steven Bloomfield to present another session about DBS Surgery. They 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. We may also have a representative from one of the manufacturers of the devices. 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)

July 19, 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

July 22

A Call for Mentors and Mentees

Our Newly-Diagnosed Program has been a successful addition to our Comprehensive Parkinson's Program. With 15 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 PWPs, 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. The Parkinson's Foundation (PowerPoint is available)
2. Speech, Swallowing & Singing (Aly Chananie needs ParkinSINGS volunteers)
3. The importance of Exercise (Lecture is available)
4. The Role of the Psychiatrist and JFK's Comprehensive PD Program (Lecture available)
5. The right Medications for you, dosages and timing (Dr. Svetlanov) – July 12th
6. How to prepare for your next MDS visit and what to expect (Dr. Hanna) – July 22nd

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@hmn.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@hmn.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

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I WILL NEVER QUIT!

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