



Hackensack
Meridian Health
JFK Medical Center



Hackensack
Meridian Health
JFK Johnson
Rehabilitation Institute

PDU-17 (06.22.2021)

***PDU*Update No. 17**

JFK's Parkinson's Newsletter

Parkinson's Support Group – Thursday, June 24th at 4:00 pm

The June PD Support Group will be this THURSDAY and will feature Dr. Roger Rossi. Dr. Rossi will present his **“Top Ten Questions asked about Parkinson's Disease.”** This topic is sure to spark a lively conversation, so please come prepared to learn important aspects of the disease.

Newly Diagnosed Lecture to follow Support Group

Immediately following the Support Group on Thursday, June 24th Dr. Rossi will be presenting **The role of the psychiatrist in treating Parkinson's Disease and a review of JFK's Comprehensive Parkinson's Wellness Program.** 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, so stick around for Part 2!

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

Support Group Dates for 2021 - Mark your calendars!

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

June 24^{**}, July 19, August 16, September 20, October 18, November 15 & December 20

^{**} Thursday

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

June 28, August 23, October 25, December 27

DBS Support Groups (4th Monday of Odd months)

July 26, September 27, November 22

Care Partner Support Group, Monday, June 28th at 4:05 pm

Are you providing informed care for your loved one with Parkinson's disease? I first met **Nancy Redkey** at the Parkinson's Foundation Volunteer Summit in 2018. Her involvement as a Care Partner to her husband inspired her to continue Parkinson's advocacy for many years, including her most recent participation as moderator for the New York State Parkinson's

Education Symposium. Nancy is the chairperson of the Parkinson's Disease Support Group of the Mid-Hudson Valley and will share her experience and answer your questions.

A Call for Mentors and Mentees

Our Newly Diagnosed Program has been a successful addition to our Comprehensive Parkinson's Program. With 14 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 lectures to provide the 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 all-important knowledge that will help them to get through their day.

Newly Diagnosed Lecture Series (June & July 2019):

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 (Dr. Rossi) – June 24th
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

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 your friends, teams, clubs, and organizations. This will result in a much 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!

The following article has been reprinted from The Parkinson's Foundation

Women and Parkinson's Disease – the Facts

Parkinson's disease (PD) affects an estimated 10 million men and women worldwide. Women have been shown to have a lower risk of developing PD, and research suggests that there are differences in the way that men and women experience Parkinson's. Studies indicate that women diagnosed with PD report different symptoms, more often report side effects and changes in their symptoms throughout the day ("fluctuations") and receive lower quality healthcare than men.

What explains these differences? Based on the evidence so far, researchers can make some educated guesses. Some differences may have to do with biology—the way men's and women's bodies react to the disease or to therapies. Others may be due to lack of access to healthcare or to unintended differences in the way women are treated for PD compared to men.

Why the Lower Risk?

Studies conducted around the world, and across race, ethnic and age groups, support the finding that women overall have a lower risk of developing PD than men, but we still don't know why. Environmental factors could explain this lower risk. It may be that women are less likely than men to be exposed to pesticides or heavy metals, or to sustain a head injury—all of which may increase a person's PD risk.

Biological differences between women and men may also play a role. Estrogen, the female sex hormone, may protect the brain against PD, but little is known about its influence. If estrogen is preventative, it may only be helpful at certain levels or for a specific time.

What Are the Symptom Differences Between Men and Women?

Parkinson's symptoms vary enormously from person to person. PD symptoms include motor symptoms, like tremor and stiffness, and nonmotor symptoms, like depression and fatigue. Although women report experiencing some symptoms (including depression) more often than men, research to date has not conclusively shown whether symptoms affect women and men

differently. This may be because symptoms vary as much among women as between women and men.

Are There Differences in Parkinson's Treatment Between Men and Women?

All current treatment options (including medications, surgical options and exercise) address PD symptoms, but they do not slow down or stop the progression of PD. Levodopa, often prescribed as Sinemet, is considered the gold standard therapy for Parkinson's movement symptoms. However, many people with PD experience changes in the effectiveness of the drug as the disease progresses. And some studies suggest that women are more likely than men to report these fluctuations earlier in the disease course and more frequently overall.

In particular, it seems that women are more likely to have involuntary movements called dyskinesias that occur when levodopa levels are highest in the blood. There are several factors that could be contributing to dyskinesia, including dosage, body weight and age of onset. Lower body weight can affect how medications build up in someone's system. Lighter people sometimes need a smaller dose of medication to feel its effect. On average, women weigh less than men. If women and men are receiving similar doses, this may explain how levodopa levels are causing dyskinesias.

Physicians have also suggested that they find it harder to fine-tune Parkinson's medications for women than for men. Women more often experience large swings in symptoms from even small changes in medications or schedules.

Deep brain stimulation (DBS) is an accepted surgical therapy for both men and women whose symptom fluctuations are difficult to control. Yet, even though women are reported to have greater improvement in quality of life after DBS, studies have shown that they are less likely than men to receive this therapy.

Are There Differences in Parkinson's Care Between Men and Women?

Women with PD may face more barriers to quality healthcare and social support than men. Women are less likely than men to be cared for by a Parkinson's specialist, such as a neurologist or movement disorder specialist, and are also less likely to have a care partner. On the other hand, women with Parkinson's are more likely to do the following:

- Go to doctor's appointments alone
- Use home healthcare
- Live in a skilled nursing facility

All these factors mean that women may not have access to adequate Parkinson's care.

Conclusion

Research to date on women's experience of PD underscores the need to focus more on this important part of the Parkinson's community. Compared to men, women are diagnosed with PD less often, respond differently to current therapies, have less access to and lower use of

expert care and are less socially supported. These combine so that women with PD have poorer quality of life than men. Studies that specifically address these issues are needed to improve the lives of all people affected by Parkinson's.

Key Facts

- Women have a lower risk of developing Parkinson's.
- There may be sex differences in PD symptoms, but the data are inconsistent.
- Small changes in medications or schedule can cause women to experience big changes in their symptoms, with dyskinesias being the most frequently reported side effect.
- Despite greater reported improvements to quality of life than men, women are less likely to receive deep brain stimulation (DBS).
- Women are less likely than men to be cared for by a PD specialist, neurologist or movement disorder specialist.
- Women with PD are accessing medical care for their Parkinson's less than men.

The Bottom Line is women all over the country are diagnosed in large numbers every day and should take advantage of Movement Disorder Specialists, medical care... and would do well to sign up as **Mentors and/or Mentees!**

Stay Safe and *Keep Moving!*

John Kolaya,

JFK Parkinson's Patient Advocate

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

PDUpdates are distributed as needed to keep HMM JFK clients informed of important information about Parkinson's Disease and HMM 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.