

Dear Parkinson's Mentor Candidate,

Thank you so much for volunteering your time and experience to be a mentor for a newly-diagnosed Person with Parkinson's. As a mentor, you will be expected to provide guidance/help/support to (1) a newly-diagnosed person, or (2) an individual who has had PD for a while and simply needs someone to talk with occasionally.

We are looking for People with Parkinson's who are willing and able to become generally familiar with various PD programs, websites, brochures, and other sources of information including:

--HMH JFKUMC's PD program:

Go to the JFK website, www.jfkmc.org/services/parkinsons-disease. Peruse the website with your mentee to learn what's there and how to access information.

- Check out kiosks located around the JFK Neuroscience Institute, JFK Johnson Rehab Institute and JFK's Physical Medicine lobby
- Need help? Simply ask Donna Mastropolo, Daniel Grynberg or John Kolaya (see the end of this letter for contact information)

--PARKINSON'S FOUNDATION:

Go to the Parkinson's Foundation's website, www.parkinson.org. Encourage your mentee (or learner) to take plenty of time to peruse the PF website, if only to become familiar with what's there and how to access the information.

- Review the Parkinson's Foundation's Newly Diagnosed kit with your mentee
- Visit the PF's website at www.Parkinson.org/NewlyDiagnosed and order the free book, *Living Your Best Life with Parkinson's*
- Check out HMH JFK's Parkinson's Mobile Kiosk located in one of the three lobbies
- Want copies of flyers and handouts? You may order any PF information that you need **free of charge** using the PF order blank located in our Mobile Kiosk

- If you are unable to reach any of us, you may also access the PF's Helpline (800) 4PD-INFO or (800) 473-4636 (both operational 24/7); or helpline@parkinson.org
- For any issues with the Helpline or resource orders, contact Nahid Wardeh nwardeh@parkinson.org
- Note: Donna, Daniel, or John may have spare copies of much of the above information

Other Organizations: It's okay to encourage and discuss information and resources from other organizations. They are all good, and we all work together and often collaborate on research, seminars and other events. We choose to work directly with the Parkinson's Foundation, because it is a large, national organization that offers, in our experience, the best outreach and assistance to our Parkinson's Community in managing the disease while advancing research.

Your role as a Mentor: Listen to a new patient's concerns and provide empathy, encouragement, resources and information

- Be aware that sometimes, that's all you can do
- It's okay to suggest that your mentee eat a proper diet (see pamphlet on diet from PF); get plenty of sleep at night; exercise daily (including taking a walk); engage in activities that exercise the brain (puzzles, reading, word games); and exercise the voice (Speak Out, LOUD CROWD, ParkinSINGS)
- Encourage your mentee to take meds on time and get a free Aware in Care kit in the event they need to go to the hospital
- Encourage your mentee to get regular checkups from their PCP, cardiologist and MDS
- Review instructions on how to prepare for a doctor's visit (see Parkinson's Foundation website)
- **Remember – You are not a doctor, a therapist, or a psychologist. It is illegal to offer any advice about medications, procedures or**

therapy. If your conversation comes around to a request for advice, ask the mentee to consult with their doctor

Sharing Experiences: Discussing your own personal experiences with PD can provide encouragement as a mentee begins their journey with Parkinson's Disease

You have the credentials to do this

- We all went through the troubling diagnosis and the periods of angst while we experienced denial, fear, confusion, and some form of acceptance with our Parkinson's disease. We may have had the good fortune of having someone to guide us through the morass of feelings and to help us make decisions about how to deal with our new life with Parkinson's. This may have been a doctor, clinician, friend or family member. BUT, as well-meaning as they were, they never lived in our shoes with our diagnosis. This program is intended to pair a newly-diagnosed PwP with someone who has gone through the initial stages of the disease and who is hopefully learning to live the fullest life possible. Someone who has the credentials to say, "Yes, I know what that feels like. Yes, I went through that, too."

Parkinson's is a complex disease

- Be mindful as you "relate" your situation to that of your mentee. By now, you are well aware that Parkinson's is a complex disease. Understand that your symptoms and journey are NOT on a parallel with your mentee's. The timelines may not be in sync and the degree and nature of the symptoms may vary. So while you cannot warn them or console them that their life will be the same as yours, you can prepare them--with some degree of certainty--that they will have the help to deal with whatever comes their way.

Promote positive behavior by setting a good example

- Your attitude toward PD is going to influence your own outcome and that of your mentee. *Guaranteed.* So be willing to laugh, look on the bright side, and remember to be grateful for everything that's good in

life, including new treatments and medications on the horizon. A positive attitude will grow between you and your mentee, just as the camaraderie swells in a group such as LOUD CROWD, ParkinSINGS, or a Parkinson's Support Group.

- Encourage your mentee to socialize with other PwPs while benefitting from the many programs offered at JFK's campus. Invite him or her to join you at Rock Steady Boxing, ParkinSINGS or one of the two monthly Parkinson's support groups. Share the calendar of PD group event with your mentee.

Just Business

- The Program Coordinator will meet with mentors and mentees and help set up the first meeting
- Following the group meetings, future meetings will be arranged between the mentor and the mentee
- The mentor and mentee are encouraged to communicate with each other on a bi-weekly basis by phone, Zoom, or in person when Covid-19 restrictions permit
- All communications between the mentor and mentee will remain "confidential"
- If mentor and/or mentee wish to discuss meeting protocols or situations that change the positive dynamic of the mentoring relationship, they are encouraged to contact the Program Coordinator for advice and direction

Stay Safe and Keep Moving,

John Kolaya, JFK Parkinson's Patient Advocate

Program Coordinator – Donna Mastropolo, (732) 668-2050, dmastropolo@yahoo.com

Asst. Program Coordinator – Daniel Greenberg, (609) 977-4700, grynberg.daniel@gmail.com

Parkinson's Patient Advisory Council – John Kolaya, Chairperson (914) 837-6910, jkolaya@aol.com

Clinical Advisor – Roger Rossi, D.O., (732) 321-7070, roger.rossi@hmhn.org