



# PARKINSON NEWSLETTER

Summer 2020

## Perspective Piece: My Experience With COVID-19 as a Person with Parkinson's disease

In an effort to better understand the individual experiences of people within the Parkinson's community during these unprecedented, we asked two people with Parkinson's disease (PD) who have conquered COVID-19 to share their stories. We thank these individuals for their willingness to share with us their narratives.

"I first noticed flu like symptoms and suspected COVID because my father and aide had it, and I had spent an hour with both of them on March 10. A few days later I had some few like symptoms (achy shoulders, shortness of breath) and went to my doctor who gave me medicine for what he diagnosed as bronchitis. The antibiotic was not working and my symptoms kept getting worse. My wife and children were concerned about my difficulty breathing, so they called a voluntary ambulance service. We also contacted a neighbor who was an ER doctor. He said I belong in the hospital but let me know that I was better off staying at home as going to hospital could make things worse. I was provided an oxygen tank at my bedside.

The only connection I had with PD was that my movement neurologist was in touch with my wife and myself 24/7 as my primary doctor was very curt in his responses. My PD doctor was essentially our guiding light. In my mind I did not see a physical connection between COVID-19 and my PD. In order to deal with SOB, I tried using my breathing exercise that I learned in my PD kickboxing classes. I filled my lungs with as much air as possible and relaxed. As a result, I was more relaxed and therefore my PD symptoms, specifically tremors, were not as frequent as they usually are. The best control I had was controlling my ability to relax. This helped me to remain calm in the face of COVID."

**-54 year old man with PD**

"I was experiencing fatigue, coughing, and a temperature of 103. I called the COVID hotline and they advised to go to the hospital. I was tested positive for the virus and spent 12 days in the hospital on oxygen. I also had temperatures of 103 that persisted. I developed pneumonia in one lung after about a week. I could have no visitors, and was confused a great deal of the time, which I was told is common with the virus. I did have my cell phone, but had a lot of trouble using the phone because of the confusion and being so sick. I fell early in my stay while trying to get up and thereafter was confined to my bed. The nurses and doctors were excellent and did provide good care. However, due to the large numbers of patients with the virus this was not a normal hospital stay. It was very difficult for my family to get information and they spent many hours calling and often hanging on the line for long periods of time until someone was available to answer. My family continually asked the doctor if my Parkinson's would cause a problem for my recovery. They were assured it would not impact my getting better. Before going to the hospital, I was going to PT twice a week and was moving about very well. However, while in the hospital I lost all my strength and the ability to walk and any progress I had previously attained. The hospital did not feel I could go home until I could move around. I did receive some PT and was able to move slowly with a walker. Fortunately, I did recover enough and was able to return home. I was very weak, could not move around very well. I also lost 20 pounds and was tired all the time. The virus took its toll. My neurologist got in touch with the Center social worker who set up PT to come into my home which was wonderful. After a month I was doing very well. I do not need a walker and can move around as I did before my hospitalization. I am still receiving PT at home. Of course PT is ongoing with Parkinson's! My experience with the COVID-19 was a nightmare for myself and my family. However, I was blessed to recover and return home when so many did not!"

**-73 year old man with PD**



## Support Groups!

The Department of Neurology currently hosts 3 support groups:

**PD Patient Support Group.** Meets the last Tuesday of every month. **NOW VIRTUAL!!**

**Care Partner Support Group** Meets the first Wednesday of every month. **NOW VIRTUAL!!**

**Deep Brain Stimulation (DBS) support group.**

For more information and to register please contact Elizabeth Delaney, LMSW at 212-305-5779.

## Center Spotlight! : Center Re-Opening Updates

The Neurological Institute at CUIMC is continuing to see both new and follow up patients via telehealth. We do everything possible to schedule patients very promptly, in understanding of the challenges of social distancing in the times of COVID-19 pandemic. In addition, CUIMC is allowing case by case in person visits at the Neurological Institute in the NYC and Tarrytown offices. Specifically, in person urgent visits will be considered for those with Deep Brain Stimulators and those who have been receiving Botox treatment.

We are taking the necessary precautions to protect both CUIMC staff and patients. In person patient appointments are being spaced out to avoid crowding in the waiting rooms. Those patients coming in person for appointments will be screened over the phone for COVID-19 symptoms. Any red flags would prompt referral to primary care or fever clinics. Upon arrival to the Neurological Institute, patients and caregivers will be screened once more. Any concerns would prompt isolation and their provider will come speak with them to give further instructions. Patients are required to wear masks, and staff and physicians will also be wearing the proper personal protective equipment.

CUIMC wants to ensure your safety while providing quality care. We are proceeding with caution, and will continue to provide updates as we re-open.



### Columbia Neurology: Ready for You!

We are open, patient care & safety remain our top priority.

[TeleNeurology / Telehealth – Virtual Visits](#) and essential in-person appointments are available across all specialties.

Call 646-426-3876

Schedule Online 

To schedule a virtual visit with a movement disorders specialist at CUIMC call [212-305-1303](tel:212-305-1303)

### Division of Movement Disorders

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[www.columbianeurology.org/patient-care/movement-disorders](http://www.columbianeurology.org/patient-care/movement-disorders)

#### Wish to Donate?...

Should you be interested in discussing how you can help support our clinical, research, and patient care activities, please contact Matt Reals, Senior Director of Development, at 212-304-7203 or [mr3134@columbia.edu](mailto:mr3134@columbia.edu)

## The Doctor Is In

Introducing new CUIMC Faculty member Kimberly Kwei, MD, PhD

**Q: What drew you to neurology and Parkinson's disease? Tell us about yourself!**

**A:** I became interested in movement disorders because I enjoy working with the elderly and I have been fascinated with how the brain works since I was in college. I am interested in how gait and balance are affected in patients with Parkinson's disease and atypical parkinsonisms. Specifically, I am hoping to explore different avenues of treatment for freezing of gait, a phenomena of gait arrest that is most frequently seen in later stages of PD but also in atypical parkinsonisms. I am also interested in better understanding the pathophysiology of gait and in so doing, perhaps also gaining a better understanding of the underlying disease mechanisms that differentiate Parkinson's disease from other neurodegenerative illnesses, including multiple system atrophy, progressive supranuclear palsy and normal pressure hydrocephalus.

I am about to finish my fellowship in movement disorders at Columbia University, during which time I was the Edmond J. Safra Fellow in Movement Disorders. Before that, I was a resident in neurology at the Mount Sinai Hospital, where I also completed my MD and PhD in neuroscience as a graduate of their NIH-funded medical scientist training program. I completed my undergraduate degree at Amherst College, where I majored in chemistry and neuroscience. In my spare time, I like to spend time with my husband and our sons Arthur and Benjamin, who in turn like to terrorize our dog Albie.



If you have a question regarding Parkinson's and its treatment that you would like featured in the next newsletter, please e-mail your question to Elizabeth Delaney, LMSW at [movementdisorders@columbia.edu](mailto:movementdisorders@columbia.edu)

The information published in this newsletter is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Please refer to your own professional for all advice concerning legal, medical, or other matters published in connection with this article.

*"Don't count the days, make the days count."*

**-Muhammad Ali, diagnosed with PD in 1984**