



LIVING WELL WITH PARKINSON'S

Spring 2022

Raising Awareness with Storytelling: PD Movers Narratives Project Hiral Shah, MD

In the wake of the COVID-19 pandemic, light has been shed on the many healthcare disparities that face our underserved and minority communities. The Parkinson's community does not remain untouched by these challenges. With a passion for addressing these disparities, Dr. Hiral Shah, a movement disorders specialist neurologist, and Medical Director for the Center of Excellence at Columbia Medical Center, invited a group of African American people with Parkinson's disease and their care partners to participate in a project to share their narratives. This group has been named the "PD Movers". The PD Movers have gathered and shared their stories in narrative form. Illustrations to accompany the stories have been developed. Dr. Shah answers some questions regarding the PD Movers Project below:



Illustration by Randy Pearson

Q: What made you want to do this project?

A: During my years of practice as a movement disorders specialist I have noticed that there is a lack of representation of minorities with Parkinson's disease in the media. I have found the PD Movers stories moving and uplifting, and felt they needed to be shared more widely.

Q: What do you hope patients and families take away after reading the PD Movers' Narratives?

A: I hope that those from minority communities may see themselves and their family members in these stories, and that they may find some kinship, hope and inspiration to keep moving despite this disease and its impacts on one's life. I hope that hearing about experiences from people who resemble them might help them to feel less alone.

Q: How can families and patient access the stories?

A: We hope to have them available in digital and hard copy as well as YouTube videos - stay tuned!



Support Groups!

The Department of Neurology currently hosts 3 support groups:

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

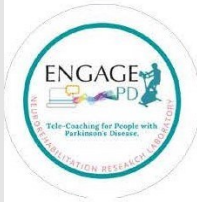
Care Partner Support Group Meets the first Wednesday of every month. **NOW VIRTUAL!!**

Deep Brain Stimulation (DBS) monthly info-session. NOW VIRTUAL!!

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

↓ NewYork-Presbyterian

Please join us for Parkinson's Awareness month as we host the "**NewYork-Presbyterian 2022 Annual Parkinson's Disease Symposium.**" This year's event is a three-day virtual symposium led by staff from across the NYP movement disorder sites! Our presenters are experts from NYP-Brooklyn Methodist Hospital, NYP-Weill Cornell Medical Center, and NYP-Columbia University Irving Medical Center who are coming together to share their knowledge on some of the newest updates in Parkinson's Disease. **See attached flyer for details.**



Study Overview: Single cohort implementation study on physical activity Tele-coaching intervention among people with early stages of PD.

Time commitment 60 min assessment + Up to 5 follow up coaching sessions 30 min each. 2 follow up assessments.



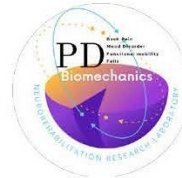
Study Overview: Randomized Clinical Trial on the feasibility, acceptability and effectiveness of behavior change occupational therapy coaching intervention among people with early-stage PD.

Time commitment 60 min assessment + Up to 5 follow up coaching sessions 30 min each + 2 follow up assessments.



Study Overview: Feasibility study of a collaborative Individualized tele-health program of multidisciplinary allied healthcare (Speech and physical therapies) to persons with neurological disorders.

Time commitment: 1 h Physical + 1 h Speech and Language assessment sessions. 30-60 min (6 Physical therapy, 6 Speech and language therapy) over 3 m. 1 h Physical therapy + 1 h Speech and language post study evaluations



Study Overview: Cross sectional biomechanics study aims to explore the effect performance of gait, balance, and functional tasks.

Time commitment
30 min online survey + One 2 hours In-person assessment

Interested in participating?

Contact NRL at:

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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

Center Spotlight! : Fox BioNet Project

What is this study about?

The aim of this study is to identify reliable markers of LRRK2 activity in human cerebrospinal fluid. Increased LRRK2 protein activity is found in LRRK2 mutation carriers (with or without Parkinson's disease) and in patients having Parkinson's disease but without LRRK2 mutation. Better methods to assess protein activity can lead to better diagnostic tests, disease tracking, and the ability to assess the effectiveness of treatments.

What is involved?

The study will include a blood draw to assess the safety of performing a lumbar puncture (spinal tap), followed by a lumbar puncture to draw a cerebrospinal fluid sample.

Who is the study sponsor?

The Michael J. Fox Foundation.

Who can participate?

An individual may take part in the study if he or she is age 30 or older, and meets one of the following criteria:

- LRRK2 mutation carrier without PD
- LRRK2 mutation carrier with PD
- Idiopathic Parkinson's disease (without a known cause)
- Healthy control

For more information, contact:

Alexander Haimovich (research coordinator)

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

-Muhammad Ali, diagnosed with PD in 1984