COLUMBIA | NEUROLOGY

LIVING WELL WITH PARKINSON'S DISEASE

Fall 2024

Proposed New York Registry Eyed to Improve Research

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With Parkinson's disease diagnoses on the rise, researchers fighting to cure the neurodegenerative disorder say a New York registry focused on the disease could help with future studies, accuracy of treatment and a path to eradicate it.

A bill that cleared the Legislature this session would create a Parkinson's disease registry in New York, which already exists in other U.S. states like Connecticut, Maryland, Washington and California. If signed into law, the state Health Department would require hospitals, medical centers and physicians to report all cases of Parkinson's within 180 days. About 90,000 Americans are diagnosed with the progressive neurological disorder each year, costing at least $52 billion, according to the Parkinson's Foundation.

Dr. Sarah O'Shea, an assistant professor of neurology at Columbia University, said state level Parkinson's data would help understand the overall prevalence of the disease. "We could really figure out... if a certain population within a radius of some exposure, for example, we could propose policies to help change things and perhaps make it a bit of a safer environment," she said. New Yorkers diagnosed with Parkinson's would be notified of the data collection, and could opt out of participating.

Parkinson's disease is the second-fastest growing neurological disorder in the world, with at least 1 million Americans diagnosed to date — an undercount without a national database. The uptick in Parkinson's diagnoses, O'Shea said, can be linked to industrialization and an increased exposure to neurotoxins, including people in rural areas because of a higher prevalence of chemical-laden pesticides. Smoking cigarettes reduces a person's risk of developing Parkinson's disease, and the 50-year decline of U.S. adults who smoke could also contribute to its prevalence. O'Shea added better Parkinson's recordkeeping would improve related research and scientific advancements. "If we had genetic data, for example, we could help figure out associations, potentially even cures, for a subset of individuals," she said Thursday.

The bill to create the Parkinson's registry unanimously passed the state Legislature this spring. Senate sponsor Brad Hoylman-Sigal said the registry will lead to more accurate outcomes and earlier detection — similar to the state's cancer registry." It goes back to the old addage: An ounce of prevention is worth a pound of cure," the senator said. "We can save important public health dollars in the long run if we invest now in establishing this registry."The state would spend about $1 million to create the registry, but the cost will decrease over time, he said.

"With a registry... we can support patients to give them access to studies where researchers can reach out to them directly, and potentially discover existing disparities and treatment among underrepresented communities," Hoylman-Sigal said. "And also figure out some of the unknowns, which is explore potential links between environmental factors, military service and other features of many individuals with Parkinson's." The data could also help New York patients get better support, and to pool resources as they manage the degenerative disease.

"There's no cure for this disease, so it's something that people are going to have to take a lot of compensatory strategies with," said Sen. Jake Ashby, a Republican who co-sponsored the measure."People fighting this disease need help," he added. "It's certainly not an easy thing to manage, so the more resources we can gather to help find more successful outcomes, the better."

O'Shea said more data about the disease from New York's diverse population will likely target better treatment and research to discover new therapies for Parkinson's, but ultimately, O'Shea said the registry could be the next step to reach the goal of finding a cure."It's one step at a time," she said. "It's just small steps at a time."

Lawmakers worked closely with the Michael J. Fox Foundation for Parkinson's Research to draft the legislation. The foundation has worked with over a dozen state legislatures on similar legislation, and intends to fight to create a registry in every U.S. state.

PD Patient Support Group

Meets the third Tuesday of every month from 2:00PM-3:30PM.

Caregivers Support Group

Meets the first Wednesday of every month from 2:00PM-3:30PM.

Deep Brain Stimulation (DBS) Information Sessions

Meets the first Friday of every month from 3:00PM-4:00PM.

To register for our support groups, and/or our DBS information sessions, please contact Erika Adelman, LCSW, SIFI at 929-695-0282.

Music and Movement Virtual Concert Series

Meets the first and third Wednesday of every month from 5:00PM-5:45PM. To register, please contact Hannah Lee at 212-305-9718.

Speech for PD

Meets every Tuesday and Thursday from 11:15AM-12:30PM. For more information and to register please contact Gemma Moya-Gale, Ph.D., CCC-SLP at gm2446@tc.columbia.edu.

Getting involved in support groups and programs such as the ones listed above as well as on the back, are opportunities to be a part of a community where you can get support, learn from others, be yourself, feel better understood, and you will be able to feel a sense of belonging. These programs can also help you cultivate self-esteem, personal growth, inspiration, and hope for the future!

ColumbiaDoctors Neurology

Parkinson's Foundation CENTER OF EXCELLENCE

NewYork-Presbyterian The University Hospital of Columbia and Cornell

Center Spotlight: Ambiguous Loss in Parkinson's Disease

What is this study about?

We are conducting a study to explore a concept called "Ambiguous loss" and how it affects people with Parkinson's.

What is "Ambiguous Loss" and how does it relate to Parkinson's?

Ambiguous loss is any loss that "remains unclear and thus without resolution." It has been used to describe situations in which there is a powerful sense of loss accompanied by deep uncertainty. Parkinson's is a condition that is marked by progressive functional decline, but every individual's experience with the disease is different. As a result, the loss that people with Parkinson's experience has a great deal of uncertainty, and can arguably be defined as ambiguous.

Who can participate and is there a cost?

Anyone with a diagnosis of Parkinson's can participate. There is no cost to participate in this study.

What is involved?

Should you choose to participate, you will engage in a one time hour-long interview with a member of our team.

For more information, please contact:
Benjamin Shapiro, Study Coordinator
Ph: 646-267-3016
Email: BLS2194@columbia.edu

Division of Movement Disorders

Columbia University
Irving Medical Center
710 West 168th Street
New York, NY 10032
212-305-1303
www.columbianeurology.org/patient-care/movement-disorders

Parkinson's Foundation National Hotline:

1-800-473-4636

Make a Gift--Make a Difference

Wish to Donate?...

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

UPCOMING EVENTS

From September 10th-October 29th, NewYork-Presbyterian Brooklyn Methodist Hospital (NYP-BMH) will be hosting APDA's Parkinson's Roadmap for Education and Support Services (PRESS) program. This is an 8-week support group group that is open to any adult who has been diagnosed with PD within the past 5 years, their care partners, and adult family members. It will be held at NYP-BMH from 2-3pm. For more information or to register, please contact Rose Brown, APDA Information & Referral Coordinator at eqa9001@nyp.org or 646-704-1792.

On Wednesday, September 11th, NewYork-Presbyterian Brooklyn Methodist Hospital (NYP-BMH) will be hosting a "Connecting Through Art Program, which is a creative arts program that offers people with PD the space and ability to express feelings, emotions,and concerns through art. It is open to any adult who has been diagnosed with PD and their care partners. It will be held at NYP-BMH at 515 6th St. BK, NY 11215. For additional information or to register, please contact Rose Brown, APDA Information & Referral Coordinator at eqa9001@nyp.org or 646-704-1792.

On Wednesday, September 11th, Columbia University Irving Medical Center's Neurological Social Work team will be hosting an Access To Care Orientation, which is held on the 2nd Wednesday of every month from 1-2PM via ZOOM. In this workshop, you'll learn more about applying for Medicaid, disability, accessing transportation, learn what your health insurance covers and does not cover, and other resources for families affected by neurological conditions. To log-in, please use meeting ID: 969 2820 4317 and passcode: caregiver.

On Wednesday, September 18th, the Parkinson's Foundation will be hosting a "Living with Parkinson's Social and Emotional Wellness" event from 11AM-3PM at Sirico's Caterers at 8023 13th Ave. BK, NY 11228. For more information or to register, please call Nancy at 585-743-1266.

Donation Corner

Looking for a motorized wheelchair? A friend of one of our participants would like to donate a motorized wheelchair to someone in the PD community. It's in excellent condition, and adapted for "attendant controls" so either the rider or an attendant can drive it. It's made by Quantum and is an Edge 3. It also has an adjustable headrest and a rechargeable battery said to hold enough power for 12 hours. They have the manual and delivery can be arranged. For more information, please contact Erika Adelman, LCSW, SIFI via email at era2142@cumc.columbia.edu.

If you have a question regarding Parkinson's and there's a treatment that you would like featured in the next newsletter, please email your questions and/or inquiries to Erika Adelman, LCSW, SIFI at era2142@cumc.columbia.edu.

> *"Don't count the days, make the days count."*
>
> ***-Muhammad Ali, diagnosed with PD in 1984***