

Victor Post

Telemedicine program will extend Parkinson's care across New York

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A new program launched by neurologists at UR Medicine will expand access to care and serve as a national model for the management of Parkinson's disease and other chronic illnesses. The Parkinson's Disease Care, New York program will be a largely virtual network providing free care to as many as 500 underserved patients across New York state.

"Providing coordinated, ongoing care to Parkinson's patients in the traditional settings of a doctor's office requires these individuals and their caregivers and families to travel, often long distances, and is expensive for payers and patients alike," said URM neurologist Kevin Biglan, the director of the PDCNY program. "The PDCNY program will break down the barriers of geography and deliver care directly to patients who have never seen a specialist and in the comfort of their own homes."

Participants in the PDCNY program will interact via a secure web-based teleconferencing system with Parkinson's disease specialist at URM. There will be no charge for these virtual house calls. Physicians and nurses at URM will develop and regularly reevaluate coordinated care plans for each patient, including referrals to speech, occupational and physical therapists, mental health providers, social workers and home health providers, if warranted. The program is supported with grants from the Greater Rochester Health Foundation and the Edmond J. Safra Foundation.

"For the first time for anyone in a defined geographic area with defined conditions can receive care in their home virtually, regardless of their ability to pay," said URM neurologist Ray Dorsey. "This brings us one step closer to fulfilling our vision to deliver Parkinson's care to anyone, anywhere."

"My husband Edmond and I were very lucky to have had access to leading Parkinson's experts when he became sick, yet this should not be a privilege available only to those with resources to travel," said Lily Safra, chairwoman of the Edmond J. Safra Foundation. "Telemedicine can make this kind of care available to anyone, anywhere, and I am very proud to be supporting projects like this one, aimed at making the dream a reality."

Participants with iPhones will be able to use the mPower app developed by URM and Sage Bionetworks to track and share information about their symptoms with their physicians. The app, initially designed as a research study using Apple's ResearchKit, uses sensors in the iPhone to measure dexterity, voice fluctuations, balance and gait, and memory. Now using CareKit, the latest software framework designed by Apple, is able to better inform patients and providers about their symptoms and care.

Parkinson's disease lends itself to telemedicine because many aspects of the treatment of the disease are visual and only require the physician to observe the patient performing certain tasks such as repeatedly tapping their fingers together, walking and describing their symptoms. These exchanges can be conducted just as effectively via

telemedicine as they can in a doctor's office and allow physicians to monitor the progression of the disease, manage and adjust medications accordingly, and refer the patient to other specialists, therapists and support services.

There is a tremendous need to make specialists more accessible to Parkinson's patients. It is estimated that more than 40 percent of people with the disease do not see a neurologist, placing these individuals at greater risk for poor health outcomes. For example, people with the disease who do not see a specialist are more likely to fall and fracture a hip, end up in a skilled nursing facility or hospital, and die. Geography is often a determining factor in whether a person with Parkinson's sees a specialist.

Neurologists with training in movement disorders like Parkinson's disease tend to be concentrated in major academic medical centers in large urban areas. Additionally, the nature of the disease — particularly the impact on movement, balance and coordination — can make frequent long trips to the doctor's office unfeasible.

The PDCNY program will provide care to 500 patients, approximately 400 of whom will reside in the nine-county Greater Rochester area. An estimated 7,000 individuals with Parkinson's in the Rochester area have not seen a specialist in the last five years.

“By providing care directly into the homes of individuals with Parkinson's, this program will address barriers to access of care, improve the quality of care these individuals receive, and improve their function and quality of life,” said Biglan.

Biglan and Dorsey have been pioneers in demonstrating the feasibility of providing quality and cost-effective care for Parkinson's patients via telemedicine. The two have authored several studies on the subject and are in the midst of a large federally-funded study that entails providing remote care to Parkinson's patients across the country.

The program is part of a growing movement to extend specialized neurological care to underserved populations. URMC neurologists already provide Parkinson's care via telemedicine directly to patients in New York State nursing homes located in New Hartford, Johnson City, Watertown and Otsego. The team will also be providing care for Huntington's disease patients at a new neurodegenerative nursing home that will open in Utica, New York, in June.

For information: pdcareny.org.