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Parkinson’s Disease Research Must Include Diverse Populations

The Michael J. Fox Foundation is promoting representation of Black, Latino, Asian, Indigenous and LGBTQ people in Parkinson’s research.

October 29, 2021 By Jeanette L. Pinnace

Although Parkinson’s disease (PD) affects almost 1 million people in the United States, Black, Latino, Asian, Indigenous and LGBTQ people are underrepresented in Parkinson’s research. This lack of diversity contributes to disparities in PD diagnosis and treatment and prompted the Michael J. Fox Foundation (MJFF) to issue a paper, published in the Journal of Parkinson’s Disease, about its plan to help address these health inequities, reports a press release from IOS Press in Amsterdam.

Authored by MJFF staffers Bernadette Siddiqi, MA, the senior associate director of research engagement, and Andrew Koemeter-Cox, PhD, the senior associate director of research programs, the paper outlined the following four strategies to combat health disparities in PD research:

- Recognize the obstacles preventing participation in PD research;
- Provide funds for research that includes more diverse participants;
- Assemble a staff of clinicians and researchers dedicated to health equity;
- Reinforce a more holistic understanding of Parkinson’s.

In February 2021, MJFF, the world’s largest nonprofit funder of PD research, launched Promoting Diversity, Equity, and Inclusion in Parkinson’s Research. The initiative invites collaborative teams and researchers from underrepresented groups in science to submit proposals for comprehensive studies targeting PD incidence, cause and effects, diagnostic challenges, clinical presentation, health care behavior and outcomes, and disease burden in marginalized populations. Thus far, 98 proposals from 25 countries on six continents are under consideration for funding to be allocated in November.

“Poor representation in research gives us an incomplete picture of the true diversity of the disease,” observed the authors. “In the minority of PD clinical trials reporting race and ethnicity data, only 8% of participants were nonwhite. An accurate reflection of the PD population in research is a critical challenge as genetic variation and other factors endemic to specific populations can greatly impact disease risk as well as effectiveness and metabolism of drugs.”

Additionally, MJFF launched the Therapeutic Pipeline Program to help make diversity in clinical trial participation standard practice. Another venture is the five-year Global Parkinson’s Genetic Program (GP2), which plans to identify the genotype of 150,000 volunteers worldwide, with a focus on underrepresented groups.

“Our understanding of the etiology, clinical presentation and treatment of PD is growing but remains far from complete,” stressed the authors. “If preclinical and clinical PD research continues in its failure to represent all who have the disease, we will never develop a comprehensive understanding of the biological underpinnings of the disease, nor be ensured treatments will work for all people with PD.”

To learn more about Parkinson’s disease, read “Parkinsonism Worse for Minorities, Poor and Not Well-Educated.”
