

Promoting diversity, equity and inclusion in Parkinson's research and care

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Current knowledge about Parkinson's disease (PD) does not reflect the diversity of people with the disease, according to The Michael J. Fox Foundation for Parkinson's Research (MJFF). In a position paper

published in the *Journal of Parkinson's Disease*, MJFF research staff define four major areas of action to reduce health disparities and advance treatments for everyone with PD. It highlights steps the Foundation is taking in these areas, including a new program launched earlier this year.

PD affects nearly one million people in the United States and over six million worldwide, and those numbers are expected to rise considerably over the coming decades. However, there is a real lack of definitive evidence on if and how the incidence, morbidity, or mortality from PD varies between socioeconomic or [ethnic groups](#).

"The current picture of PD has been assembled from a relatively homogenous population, and data remain sparse or are non-existent on many traditionally underrepresented groups: Black, Latino, Asian, Indigenous groups, LGBTQ+, and individuals of lower socioeconomic status," explained Bernadette Siddiqi, MA, Senior Associate Director, Research Engagement, and Andrew Koemeter-Cox, Ph.D., Senior Associate Director, Research Programs of The Michael J. Fox Foundation, New York, NY, U.S.. "Without these data, it is impossible to fully comprehend the breadth and depth of PD across the entire population."

"Poor representation in research gives us an incomplete picture of the true diversity of the disease," added the authors. "In the minority of PD [clinical trials](#) reporting race and ethnicity data, only 8% of participants were non-white. 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 drug."

The Michael J. Fox Foundation has defined four major areas of action:

- Identifying barriers and solutions to research participation
- Funding inclusive research with greater participant diversity
- Building a clinician/researcher workforce committed to health equity
- Supporting a more holistic understanding of PD

In February 2021, MJFF launched a new funding opportunity: Promoting Diversity, Equity, and Inclusion in Parkinson's Research. Applicants were invited to submit proposals that focused on the study of incidence, etiology, and underlying pathology; diagnostic challenges; clinical presentation; healthcare behavior; health outcomes; and/or disease burden in underrepresented populations. Interdisciplinary teams were encouraged to apply, along with researchers from groups underrepresented in the scientific workforce. The Foundation is currently reviewing 98 proposals from 25 countries in six continents and plans to make funding decisions in November 2021.

MJFF is also piloting an effort within one of its core funding programs, the Therapeutic Pipeline Program, for interventional trials to integrate inclusive practices toward normalizing greater diversity in trial participation. It is also supporting a clinician-researcher workforce committed to inclusive research and health equity by establishing fellowships that train the next generation of specialists in those practices. Another initiative is the Global Parkinson's Genetic Program (GP2), an ambitious five-year program led by Andrew Singleton, Ph.D., at the National Institutes of Health, to genotype more than 150,000 volunteers worldwide with emphasis on underrepresented populations. GP2 is an initiative of the Aligning Science Across Parkinson's (ASAP) program, a coordinated research program to address key knowledge gaps in the basic mechanisms that contribute to Parkinson's development and progression.

"Our understanding of the etiology, clinical presentation, and treatment

of PD is growing, but remains far from complete. 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," commented the authors.

"While factors driving these disparities, including broader societal challenges, are complex, it is imperative that the PD research, care, and patient communities move in a decisive and coordinated fashion to identify and implement strategies that can support the process of creating health equity in PD," they concluded.

This position paper is the first in a series of perspective pieces that will be published in the *Journal of Parkinson's Disease* to increase awareness of the current state of Parkinson's research along with available resources and infrastructure for investigators.

More information: Bernadette Siddiqi et al, A Call to Action: Promoting Diversity, Equity, and Inclusion in Parkinson's Research and Care, *Journal of Parkinson's Disease* (2021). [DOI: 10.3233/JPD-212593](https://doi.org/10.3233/JPD-212593)

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