

UPDATES FROM THE FIELD



Parkinson's Outcomes Project

Improving the lives of people living with Parkinson's through research



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James Beck, PhD

Letter from Chief Scientific Officer

The Parkinson's Foundation strives to make life better for people with Parkinson's disease (PD) by improving care and advancing research toward a cure. In everything we do, we seek to build on the energy, experience and passion of our global Parkinson's community. To improve the lives of those living with Parkinson's, it is critical for clinicians and researchers to comprehensively understand the individual symptoms and unique trajectory of PD over time.

Through its two flagship research studies, the Parkinson's Foundation aims to improve the lives of people with Parkinson's and care partners. With the **Parkinson's Outcomes Project** we followed more than 13,000 people with Parkinson's for more than a decade, establishing the largest clinical registry tracking the experiences of Parkinson's patients. Now, we are building on this legacy with **PD GENEration: Mapping the Future of Parkinson's Disease**, a comprehensive study to better understand the genetic basis of the disease while accelerating the development of the next generation of PD therapies.

Together, these initiatives will help researchers understand why and how PD develops. These initiatives may also answer questions that researchers may never have asked, providing hope and a vision towards a cure for PD.

We thank all the individuals within the PD community who contributed to these clinical research studies. Our goal is to give back to people with PD by providing meaningful insights from the data that they have contributed over the years. I am pleased to share some key insights from this work along with how it currently informs research and care.

A handwritten signature in black ink, appearing to read "James Beck".

James Beck, PhD
Parkinson's Foundation
Chief Scientific Officer

Overview of the Parkinson's Outcomes Project

Launched in 2009, the Parkinson's Outcomes Project is a seminal Parkinson's disease study that captures the experiences of people with Parkinson's and care partners over time on topics such as medications, treatment, exercise and lifestyle measurements. By collecting these individual experiences and looking at them together, we can identify new and better ways to provide care and manage Parkinson's. Our goal is to improve health outcomes and quality of life for people with Parkinson's and care partners.

The Foundation works in partnership with our global Centers of Excellence network and the centers' teams of clinicians and researchers to collect and analyze information of more than 13,000 people with Parkinson's who volunteered to share their experiences.

How the Parkinson's Outcomes Project Has Driven Parkinson's Foundation Priorities

By asking people with Parkinson's and care partners about their experiences through the Parkinson's Outcomes Project, the Parkinson's Foundation identified the following five key clinical practices that can improve the quality of life for people with Parkinson's and care partners:

- Early referral to **physical therapy**
- Integrating **exercise** into treatment plans
- Psycho-social therapy and increased focus on **mental health**
- Greater communication with patients **during hospital stays** and between **doctors visits**
- Understanding **care partner** strain to improve daily care



A typical patient registry is a snapshot for each patient, but a community can only be represented by adding the dimension of time. The Parkinson's Outcomes Project is our three-dimensional image recorded in specified ways during clinical care over many years, that this study offers to researchers. The project, nurtured by a multidisciplinary steering committee and shared globally, both values and provides value to each community member by multiplying the data available to shape treatment plans.

Marilyn Neault, PhD

Parkinson's Outcomes Project Steering Committee member and Research Advocate living with Parkinson's

Based on Parkinson's Outcomes Project findings, the Parkinson's Foundation launched targeted initiatives to address gaps in care and support.

- **Rehabilitation:** Rehabilitation medicine, including physical therapy, exercise and other therapies, can slow progression, address motor symptoms, optimize daily functioning and improve quality of life for people living with Parkinson's disease. Yet only a small percentage of these individuals receive rehabilitative care. With learnings from the Parkinson's Outcomes Project, the **Rehabilitation Medicine Initiative** was developed by the Foundation to address life-changing gaps regarding rehabilitation in PD to better serve the Parkinson's community through increasing early and more frequent referrals for rehabilitation therapies, increasing access and utilization of rehabilitation services, and educating and empowering the Parkinson's community.
- **Exercise:** The Parkinson's Foundation has served as a leader in bringing together professionals in the fields of exercise and education to establish **exercise**





recommendations in partnership with the American College of Sports Medicine (ACSM) and a **competency framework for exercise professionals** working with people with Parkinson's. This groundbreaking work built upon key findings from the Parkinson's Outcomes Project and will result in universal standards for exercise education programming, leading to greater access to consistent exercise programs as well as improved care and greater well-being for people living with Parkinson's.

- **Mental Health:** Based upon the analysis of the Parkinson's Outcomes Project data showing very low (2%) referral rates to mental health professionals and potential underdiagnosis and undertreatment of anxiety and depression, in 2020, the Parkinson's Foundation launched a study focused on improving mental health by implementing depression screening as part

of standard of care. The data collected from this study will help inform clinicians about best practices to screen and treat depression among people with Parkinson's, leading to greater understanding and awareness of the intersection of PD with mental health and well-being.



Connie Marras, MD, PhD

Principal Investigator of the Parkinson's Outcomes Project, University of Toronto/Toronto Western Hospital Movement Disorders Centre



- **Hospital Care:** In 2020, data from the Parkinson's Outcomes Project reported that up to one-third of people with Parkinson's had a hospital encounter each year. Of these, three out of four do not receive medications on time, leading to unnecessary complications when hospitalized and hospital stays that are up to 14 days longer than their peers without Parkinson's. These and other findings led to the creation of the Parkinson's Foundation **Hospital Initiative**. In coalition with clinicians, researchers, advocates and hospital administrators, the Foundation is leading culture and policy change to improve health outcomes during and following hospital visits.

Care Partner Summit 2018



The **Aware in Care** kit was developed to ensure that every person with Parkinson's is well-prepared for planned and unplanned hospital visits. Learn more at Parkinson.org/AwareInCare.

- **Care Partners:** Every year, the Foundation hosts the **Care Partner Summit** — a series that focuses on providing support, tools and advice for care partners. In the wake of the COVID-19 pandemic, the Foundation has established the **Parkinson's Foundation Care Partner Program**. Released in June 2021, this series of self-paced online courses offers videos, journal prompts and opportunities to connect with care partners around shared topics and concerns focused on managing

a loved one's care. This work grew from the early findings from the Parkinson's Outcomes Project around the impacts on care partners. Learn more at Parkinson.org/Caregiving.

- **PD Health @ Home:** These virtual programs provide education from leading experts in PD to address the key needs of the community. Key topics cover the landmark findings reported by the Parkinson's Outcomes Project including:
 - Exercise and Physical Therapy
 - Mental Health
 - Caregiving
 - Hospital Care

Learn more at Parkinson.org/PDHealth.

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Nabila Dahodwala, MD
University of Pennsylvania

Understanding the strain of care partners and addressing their needs is critical to ensure a strong care team that ultimately leads to better outcomes and quality of life.

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The Next Generation of Parkinson's Research

The impact of the Parkinson's Outcomes Project has been significant in directing the work of the Parkinson's Foundation and our Centers of Excellence globally. The Parkinson's Outcomes Project will next focus on:

Greater understanding of underrepresented people with PD:

A focus for the Parkinson's Outcomes Project will be to engage and recruit people with Parkinson's who have been traditionally underrepresented in clinical research, with an emphasis on Young Onset Parkinson's (younger than age 50), newly diagnosed, early and late-stage disease progression and broader ethnic and racial diversity. This focus will enrich data across these diverse groups, helping researchers better understand the cause of PD and develop more effective treatments.

PD GENEration

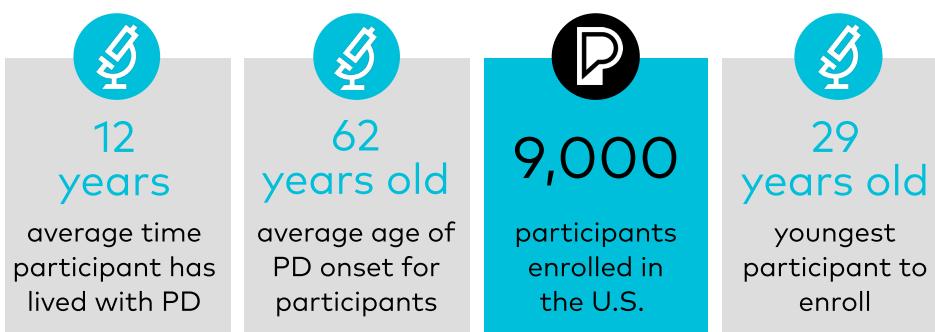
MAPPING THE FUTURE OF PARKINSON'S DISEASE

Linking genetics with clinical characteristics through PD GENEration: Genetic testing is offered through *PD GENEration: Mapping the Future of Parkinson's Disease* to all Parkinson's

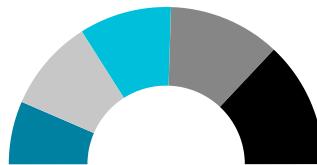
Parkinson's Outcomes Project



13,130 participants enrolled worldwide



Participant Level of Education



Hosted across **27** Parkinson's Foundation Centers of Excellence

4,871 Women
8,289 Men

Learn more at Parkinson.org/Outcomes.

Outcomes Project participants. Genetic testing is a powerful tool that can help people learn more about their own disease, uncover biological pathways that cause Parkinson's and can accelerate the development of improved treatments and care for all people with Parkinson's.

Open data sharing: 2021 marks a new era of the Parkinson's Outcomes Project as the Foundation makes this study data publicly available to the entire scientific community. Through this large-scale sharing of the experiences of people with PD, more clinicians and researchers will be better equipped and informed to further advancements in Parkinson's research and care globally.



Celebrating Landmark Findings



Exercise and Physical Therapy

Increasing physical activity to at least 2.5 hours a week can slow the decline in quality of life and help people with Parkinson's live fuller lives. At the same time, referrals to physical therapy during the early stage of disease can help prevent hospitalization and falls. These findings led to the establishment of the Exercise Initiative, partnering with physical therapists and exercise professionals nationally.



Mental Health

Depression and anxiety are the top factors impacting the overall health of people with Parkinson's. This understanding has led to greater supports across Parkinson's Foundation Centers of Excellence as well as a dedicated sub-study looking at mental health.



Hospital Care

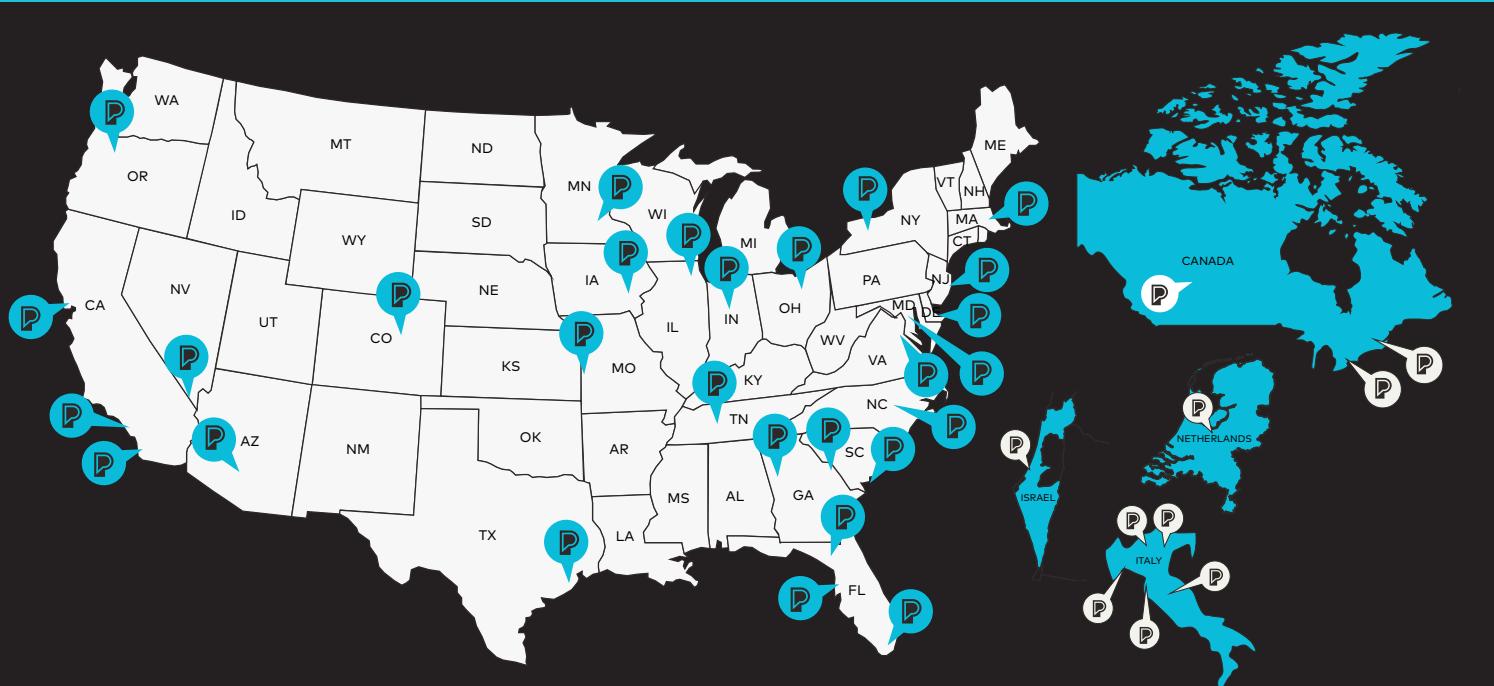
People with Parkinson's are hospitalized 1.5 times more often than their peers without Parkinson's, and these visits bring with them a host of complications. These findings resulted in the Foundation's Hospitalization Initiative to drive culture and policy change at the hospital administration level.



Caregiving

The cost of caregiving increases 180% from early to advanced stages of Parkinson's, with female care partners predominantly (72%) carrying the weight of care. Acknowledging these factors and how to best provide day-to-day care will help improve the quality of life for those with Parkinson's and their care partners.

Parkinson's Outcomes Project Site Locations



U.S. LOCATIONS

- Baylor College of Medicine, TX
- Beth Israel Deaconess Medical Center, MA
- Georgetown University Hospital, DC
- Johns Hopkins University, MD
- Medical College of Georgia, GA
- Mount Sinai Medical Center, NY
- Muhammad Ali Parkinson's Disease Center, AZ
- New York University, NY
- Northwestern University, IL
- Oregon Health Sciences University, OR
- Struthers Parkinson's Center, MN
- The Parkinson's Institute, CA
- University California San Diego, CA
- University of Florida, FL
- University of Kansas Medical Center, KS
- University of Miami, FL
- University of Pennsylvania, PA
- University of South Florida, FL
- Vanderbilt University Medical Center, TN

CANADA

- McGill University, Montreal
- Toronto Western Hospital
- University of Alberta

ISRAEL

- Tel Aviv Sourasky Medical Center

NETHERLANDS

- Radboud University Nijmegen Medical Center

ITALY

- IRCCS Ca' Granda Policlinic Hospital, Milan
- IRCCS Policlinico Hospital San Martino
- University Hospital of Perugia
- Santa Chiara University Hospital of Pisa
- Villa Margherita, Arcugnano

The Parkinson's Foundation shares our deepest gratitude to the 13,000 individuals who contributed their experiences to this long-term study, as well as the 27 Parkinson's Foundation Centers of Excellence and other partners around the globe who contributed to this critical Parkinson's research.

Find out how the Parkinson's Outcomes Project furthers research and changes lives at Parkinson.org/Outcomes.
1.800.4PD.INFO