

**MARYLAND PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE**  
**MINUTES**  
**AUGUST 2, 2022**  
**1:00 - 3:00 PM**

The Maryland Parkinson's Disease Registry Advisory Committee held a public meeting on 8/2/2022, called to order at 1:06 P.M.

**MEMBERS PRESENT**

Ian Edwards  
Josh Gottesman  
Fei Han  
Dawn Lewis  
Xiaobo Mao  
Sohail Qarni  
F. Rainer von Coelln  
Larry Zarzecki

**MEMBERS NOT PRESENT**

Asima Cheema

**MDH STAFF PRESENT**

Kristi Pier, CCDPC  
Jessica Rose-Malm, CCDPC  
Katyayani (Katy) Bhide, Office of Enterprise Technology  
Donna Gugel, Prevention and Health Promotion Administration  
Jody Sheely, Office of Support Services  
Kimberly Stern, Cancer Registry

**MEMBERS OF THE PUBLIC PRESENT**

Mark Damesyn, California Department of Public Health  
Bill Pitcher, attorney  
Laura Mandel, CRISP  
Elizabeth Platz, Johns Hopkins University  
Marc Rabner, CRISP  
Julia Worcester, Michael J. Fox Foundation

**I. Welcome and Introductions**

Kristi Pier, Director of the Center for Chronic Disease Prevention and Control (CCDPC) at the Maryland Department of Health (MDH), called the meeting to order at 1:06pm. Ms. Pier reviewed the meeting agenda and took roll call, asking Committee members and members of the public to introduce themselves.

**II. Maryland Parkinson's Disease Registry Advisory Committee- Structure, Charge, and Member Responsibilities**

Ms. Pier provided an introductory presentation outlining the legislation establishing the Parkinson's Disease Registry Advisory Committee, [Chapter 340, 2022 Laws of Maryland \(SB 740\)](#), the Committee's membership, structure, and responsibilities. The Committee is responsible for 1) assisting in the development and implementation of a Parkinson's disease registry; 2) determining what data shall be collected and stored in a registry and methods to ensure privacy and confidentiality; and 3) advising the Maryland Department of Health on Parkinson's disease and maintaining a Parkinson's disease registry. The Committee must deliver a report with recommendations regarding a registry to the legislature by January 1, 2023.

**III. Background and Context of SB 740**

Julia Worcester, Director of U.S. State Government Relations at the Michael J. Fox Foundation presented on the background of Maryland's 2022 Parkinson's Disease Registry legislation and the national context for enhanced state data collection in Parkinson's disease. The Centers for

Disease Control and Prevention (CDC) is developing the [National Neurological Conditions Surveillance System \(NNCSS\)](#) with an initial focus on Parkinson's disease and multiple sclerosis. The CDC and Michael J. Fox Foundation are interested in promoting consistent state data collection systems to feed into the national surveillance system for the purpose of advancing research into causes and therapies for neurological conditions. Four states (California, Nebraska, Utah, and Washington) currently have state Parkinson's disease registries. In 2022, two states (South Carolina and West Virginia) established registries through legislation, two states (Massachusetts and Maryland) established advisory committees to inform registry development, and one state (Ohio) is pending a vote on a Parkinson's disease registry bill. In response to Committee members' questions, Ms. Worcester clarified the dual role of state registries in feeding into a national surveillance system and allowing for surveillance and research on Parkinson's disease at the local level.

#### **IV. Parkinson's Disease Registry Example: California**

Mark Damesyn, DrPH, Director of the California Parkinson's Disease Registry for the California Department of Public Health, presented on the history, reporting requirements, IT structure, and lessons learned from California's Parkinson's Disease Registry. California's registry was established in 2017 for the purpose of enabling research to better prevent and treat Parkinson's disease. The registry was reauthorized in 2021 and is in the process of expanding to include other neurological diseases. Healthcare providers are required to report Parkinson's disease cases, based on ICD-10 codes, either through an automated report from their electronic medical records or manual report through the state's infectious disease case reporting system. Dr. Damesyn described the registry's quality control procedures, ability to link to external data systems (e.g., vital statistics), and requirements for data use by researchers.

Committee members asked several questions regarding the reporting burden for healthcare providers. Dr. Damesyn emphasized the value of building buy-in from the beginning by involving health systems and healthcare providers in developing the registry's implementation guide and reporting requirements. California estimates 75% of the state's Parkinson's disease cases are currently captured in the registry and is working to understand missed cases and improve capture methodology.

#### **V. Discussion of Next Steps**

Ms. Pier asked Committee members to share their initial thoughts about the feasibility and utility of a Parkinson's disease registry in Maryland. Committee members expressed interest in the potential of a registry to provide information beyond incidence and prevalence to address trends and improve health equity. They also raised concerns about balancing richer data collection with the challenges of building a more complex system and increasing the reporting burden for providers. Ms. Pier reiterated that the Committee's next meeting, scheduled on August 22nd at 1:00-4:00pm, will be a working meeting where members will discuss the purpose, benefits, drawbacks, functionality, and utility of a Maryland Parkinson's disease registry, and draft recommendations for the legislative report.

#### **VI. Public Comment**

Ms. Pier invited members of the public to share questions or comments with the Committee. Katy Bhide of the MDH Office of Enterprise Technology suggested the Committee take a "working backwards" approach, starting with what they would like to achieve with a registry and using that vision to guide recommendations about data collection and system functionality.

#### **VII. Closing**

Ms. Pier thanked Committee members and members of the public for their participation. Ms. Pier closed the meeting at 2:59pm.

**Next Committee Meeting: August 22, 2022 in person at 1223 W. Pratt Street, Baltimore MD**