

# MARYLAND PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE

## MINUTES

AUGUST 8, 2023

3:00 - 4:00 PM

The Maryland Parkinson's Disease Registry Advisory Committee held a public meeting on August 8, 2023, which was called to order at 3:02 PM.

### **MEMBERS PRESENT**

Ian Edwards  
Josh Gottesman  
Dawn Lewis  
Sohail Qarni  
F. Rainer von Coelln  
Larry Zarzecki

### **MEMBERS NOT PRESENT**

Fei Han  
Rachel Guilfoyle  
Xiaobo Mao

### **MDH STAFF PRESENT**

Kristi Pier, CCDPC  
Katyayani (Katy) Bhide, Office of Enterprise Technology  
Jody Sheely, PHPA OSS

### **MEMBERS OF THE PUBLIC PRESENT**

Laura Mandel, CRISP

#### **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 3:02PM. Ms. Pier reviewed the meeting agenda and asked Committee members and members of the public to introduce themselves.

#### **II. Maryland Parkinson's Disease Registry Advisory Committee- Updates**

Ms. Pier stated the webpage was not live yet, however, would be ready in time to place the data report, which is due by the end of the year, as per the 2023 legislation, [Chapter 383, 2023 Laws of Maryland \(SB 584\)](#).

#### **III. CRISP Data Reporting Plan**

SB 584 requires MDH to work with the state-designated health information exchange (CRISP) to develop a public Parkinson's disease website with accessible data on statewide Parkinson's disease incidence. Ms. Laura Mandel, Public Health Data Lead at CRISP, presented the draft data plan (see attached) for feedback from the Committee members. There were some suggestions, including changing the use of "study" to "report," There was discussion on the limitations of the data, including that only Maryland facility data is included. Also, the numerator is calculated based on anyone who the most current information in CRISP says they lived in Maryland in the past 5 years. People who may have died or moved to a state that is not connected to CRISP Shared Services (CSS) were not removed.

#### **IV. Data Plan Approval**

The data plan was approved by the members present. Ms. Pier stated the initial data report would be sent to members for review prior to posting on the webpage.

#### **V. Closing**

Ms. Pier thanked Committee members and members of the public for their participation. Ms. Pier closed the meeting at 4:02pm.