

MARYLAND PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE
MINUTES
SEPTEMBER 7, 2022
9:00 AM - 11:00 AM

The Maryland Parkinson's Disease Registry Advisory Committee held a public meeting on 8/22/2022, called to order at 9:03 A.M.

MEMBERS PRESENT

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

MEMBERS NOT PRESENT

Asima Cheema
Sohail Qarni

MDH STAFF PRESENT

Kristi Pier, CCDPC
Jessica Rose-Malm, CCDPC
Katyayani (Katy) Bhide, Office of Enterprise Technology

MEMBERS OF THE PUBLIC PRESENT

Zachary Hardy, Michael J. Fox Foundation
Laura Mandel, CRISP
Marc Rabner, CRISP
Julia Worcester, Michael J. Fox Foundation

I. Welcome, Roll Call, and Review of Agenda and Objectives

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 9:03am. Ms. Pier took roll call, reviewed the meeting agenda, and objectives. A quorum was present. The objectives of this meeting were to 1) vote on whether to recommend developing a Parkinson's disease registry in Maryland, and 2) finalize recommendations to include in the Committee's report.

II. Discussion: Should Maryland develop a Parkinson's disease registry?

Ms. Pier presented a summary of the potential benefits and challenges associated with developing a Parkinson's disease registry, based on the Committee's previous conversations. Members discussed the benefits of a registry for people living with Parkinson's disease and their caregivers, as well as the importance of effectively messaging the indirect or long-term benefits. Messaging about a registry will need to make clear what a population-level tool can and cannot do. Examples of actionable uses for registry data may be helpful in conveying this information. The Committee feels it is necessary to keep the benefit to people living with Parkinson's disease at the forefront of the registry's purpose and the Committee's recommendations. Larry Zarzecki shared his experience collecting case count data by county and the potential value for targeting community education and outreach.

Committee members also felt a registry would benefit healthcare providers by providing a more thorough picture of Parkinson's disease across the state's population. If a registry pulls from

CRISP data, there would be no additional reporting burden for providers who currently participate in CRISP and it could be an incentive for additional providers to participate in CRISP.

III. Vote: Does the Committee recommend developing a Parkinson's disease registry in Maryland?

Ms. Pier confirmed a quorum was present and asked for a motion to vote on whether the Parkinson's Disease Registry Advisory Committee recommends developing a Parkinson's disease registry in Maryland. Dawn Lewis moved to hold the vote and Dr. Rainer von Coelln seconded the motion. All seven members present voted in favor of recommending development of a registry in Maryland.

IV. Discussion: Additional recommendations

Ms. Pier reviewed the charge and deliverables required by [SB 740](#). Per the legislation, MDH was required to convene a Parkinson's Disease Registry Advisory Committee and produce a report with recommendations, including legislative recommendations, by January 1, 2023. The report will outline steps taken to convene the Committee, provide a summary of the Committee's activities to date, and outline the Committee's legislative recommendations pertaining to development of a Parkinson's disease registry. The Committee discussed two components of potential legislation: mandatory reporting and opt-out provisions.

Committee members agreed mandatory reporting of Parkinson's disease and parkinsonism cases by diagnosing providers should be included in legislation. Committee members discussed the degree to which required data elements should be spelled out in legislation and concluded that legislation should address broad categories of data (i.e., demographics, geography, diagnosis) instead of specific data elements. Regarding opt-out provisions, Committee members agreed all patients should have the ability to opt out of participating in the registry, and would be the least burdensome option for providers and patients. Members also discussed the possibility of allowing patients to opt-in to be reidentified and/or participate in further research, although this additional provision may not need to be included in legislation. Members expressed interest in reviewing and drawing from model legislative language used in other states. MDH will provide model language for the Committee to review.

Committee members discussed several additional provisions that may need to be addressed by legislation. Specifically, legislation should name CRISP and the Vital Statistics Administration as data sources for the registry to help overcome governance barriers to data sharing from those entities. Members recommended including a provision to conduct a close appraisal of the registry's functionality and utilization approximately 5 years post-implementation to determine whether the registry should continue, change, or be discontinued.

V. Discussion of Next Steps

The Committee was unable to address all potential legislative recommendations in this meeting and will schedule two additional meetings for late September/early October to finalize recommendations and vote to approve the report. MDH will send out potential dates for those meetings.

VI. Closing

Ms. Pier thanked Committee members and members of the public for their participation. Ms. Pier closed the meeting at 11:01am.

Next Committee Meeting: TBD