

MARYLAND PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE

MINUTES

SEPTEMBER 20, 2022

4:00 PM - 5:00 PM

The Maryland Parkinson's Disease Registry Advisory Committee held a public meeting on 9/20/2022, called to order at 4:02 P.M.

MEMBERS PRESENT

Asima Cheema
Ian Edwards
Fei Han
Xiaobo Mao
Sohail Qarni
F. Rainer von Coelln
Larry Zarzecki

MEMBERS NOT PRESENT

Josh Gottesman
Dawn Lewis

MDH STAFF PRESENT

Kristi Pier, CCDPC
Jessica Rose-Malm, CCDPC
Kimberly Stern, Cancer Registry

MEMBERS OF THE PUBLIC PRESENT

Zachary Hardy, Michael J. Fox Foundation
Laura Mandel, CRISP

I. **Welcome and Business**

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 4:02 P.M. Ms. Pier took roll call and reviewed the meeting agenda and objective. A quorum was present. The objective of this meeting was to finalize recommendations to include in the Committee's report.

Dr. Qarni moved to approve the minutes for meetings 1, 2, and 3. Dr. Cheema seconded the motion and the motion passed.

II. **Discussion: Funding Recommendations**

The Committee discussed recommendations for funding a Parkinson's disease registry. Members agreed a registry cannot be built or maintained without sufficient and sustained funding for system infrastructure and staffing. As was discussed in previous meetings, the Committee recommended funding for at least five years, at which point the registry would undergo thorough assessment to determine whether and/or how it should exist in the future. As the specific structure and data elements of the registry are still to be determined, the Committee deemed it premature to recommend a specific dollar amount for funding.

III. **Discussion: Data Use, Privacy, and Confidentiality Recommendations**

The Committee reviewed sample language from other registry states, as well as the original text of SB 740 to guide discussion of how to address data use, privacy, and confidentiality of registry

data. Committee members discussed keeping the language around allowable data use broad so as not to limit the registry's potential impact in fields outside of Parkinson's disease research. The Committee recommended allowing data use for valid scientific research, based on MDH review and approval. Dr. Qarni noted MDH has a process (the Strategic Data Initiative or SDI) for developing and reviewing data use agreements and MDH-related data systems. The SDI will be involved in the development and maintenance of a registry and any associated data or data sharing agreements.

IV. Discussion: Additional recommendations

Committee members discussed two additional items raised at previous meetings regarding data sharing with the state health information exchange (CRISP) and Vital Statistics Administration. Committee members agreed that authorizing CRISP to collect mandatory reported data on behalf of MDH would be the most efficient and least burdensome approach to data collection for a registry. Laura Mandel of CRISP provided draft language as an example of how CRISP could be designated as a data collection entity in legislation. In this case, MDH would own the data. Members discussed including a recommendation for the Vital Statistics Administration to release data necessary to calculate Parkinson's disease prevalence, however they determined such a recommendation did not need to be included in legislation.

V. Draft Report and Next Steps

Jessica Rose-Malm of the CCDPC shared a timeline for the Committee to review the draft report and return suggestions/comments via the Basecamp project platform. Ms. Pier reminded the Committee of its upcoming meeting on October 11, 2022 to vote on the draft report. Once the Committee approves the draft, it will be submitted internally at MDH and will likely undergo further revision. If substantive questions or changes arise from the internal review, the Committee may reconvene to discuss the changes.

VI. Public Comment

Ms. Pier invited members of the public to provide comments. No members of the public spoke at this time.

VII. Closing

Ms. Pier thanked Committee members and members of the public for their participation. Ms. Pier closed the meeting at 5:00 P.M.

Next Committee Meeting: October 11, 2022 3:00 PM - 3:30 PM