

Draft Maryland Parkinson's Disease Registry Advisory Committee

Meeting Minutes

July 3, 2024 2:00 PM – 3:00 PM

Meeting Objective: Meet the SB383 mandate to submit the 2024 Parkinson's Disease Registry Advisory Committee report for submission to the General Assembly.

The meeting was called to order at 2:02pm. Ms. Pier reviewed the meeting objective and the agenda, then took roll, and it was determined there was a quorum.

Members Present: Friedrich Rainer von Coelln, MD, Fei Han, Dawn Lewis, Xiaobo Mao, Sohail Qarni, Larry Zarzecki

Members Not Present: Ian Edwards, Josh Gottesman, Saba Sheikh

Public: Laura Mandel (CRISP) and Kristi Pier (MDH)

Review of SB584 (2023) report and content discussion

Ms. Pier reviewed the requirements in the SB584 2023. The completed tasks, the launch of a Parkinson's disease webpage and the data report were reviewed. The focus then shifted to the mandatory report, which is stated in the bill: submit a report "on recommendations for a path forward toward the establishment of a fully functional State Parkinson's Disease Registry."

The committee then reviewed a draft report, which contained the recommendations from the SB740 (2022) report, which was submitted to the General Assembly on May 30, 2024. The committee reviewed each of the six prior recommendations, and made modifications (see attached). Discussion of changes were as follows:

Overarching: The members revisited the use of "parkinsonism(s)" in the recommendations, as this was not in the bill and also may be difficult to determine; use of this term was removed from the recommendations.

Recommendation #2: How would "sufficient information" be determined and was this broad and could this be determined when establishing the reporting requirements; this statement was removed. Also, use of "case reports" for CRISP data was not accurate, and the term was removed from the recommendations.

Recommendation #3: The last sentence concerning other state registries was determined to be educational and not needed.

Recommendation #6: The committee chose to remove the last sentence, and focus on providing a review at the 5 year mark for an implemented registry.

Vote to submit 2024 report

A quorum was present. The members voted to submit the report with the above changes (6 Approve votes and no abstain or do not approve votes)

Public Comment: There were no additional comments.

The meeting was closed at 3:04pm.