



2022 Legislative Report of the Parkinson's Disease Registry

Report Required by Chapter 340 of the Acts of 2022 (SB 740)

Convening the Parkinson’s Disease Registry Advisory Committee

Following Governor Hogan’s signing of the establishing legislation, staff at the Maryland Department of Health’s Center for Chronic Disease Prevention and Control started the process to identify, recruit, and process nominees for seats on the Parkinson’s Disease Registry Advisory Committee. In addition to the eight seats specified in legislation, the Secretary chose to include the following additional seats on the Committee:

- A representative from the Maryland Department of Aging;
- A representative from the Michael J. Fox Foundation;
- A representative from the Parkinson’s Foundation (Mid-Atlantic Chapter);
- A caregiver of an individual diagnosed with Parkinson’s disease; and
- A physical therapist or occupational therapist with experience working with individuals who have Parkinson's disease.

The Department seated nine Committee members; seats for a neurologist, a physician informaticist, a caregiver, and a physical therapist or occupational therapist were not filled due to time constraints and lack of applicants. Several seated members have professional credentials covering multiple fields, broadening the expertise of the Committee as a whole. Dr. Friedrich Rainer von Coelln is both a movement disorder specialist and a neurologist. Dr. Sohail Qarni is both a public health professional and a primary care provider. Ian Edwards is both a representative of the Department of Aging and a practicing physical therapist.

Parkinson’s Disease Registry Advisory Committee Members - 2022

Movement Disorder Specialist
Friedrich Rainer von Coelln, MD

Primary Care Provider
Asima Cheema, MD

Patient with Parkinson’s Disease
Larry Zarzecki

Public Health Professional
Sohail Qarni, MD, MPH

Population Health Researcher
Fei Han, Ph.D.

Parkinson’s Disease Researcher
Xiaobo Mao, Ph.D.

Maryland Department of Aging
Ian Edwards, DPT

Michael J. Fox Foundation
Josh Gottesman

Parkinson’s Foundation, Mid-Atlantic Chapter
Dawn Lewis

Committee Meetings

The Parkinson's Disease Registry Advisory Committee met five times in 2022 to learn about Parkinson's disease registries in other states, determine the purpose of a registry in Maryland, discuss the benefits and challenges of creating a registry, and develop recommendations to share with the Senate Finance Committee and the House Health and Government Operations Committee in this report. All meetings were held in accordance with Open Meetings Act requirements and included a public comment period. Pertinent accomplishments from the Committee's 2022 meetings include:

- August 1, 2022
 - Introduced Committee members to one another and reviewed the charge, responsibilities, and deliverables of the Committee.
 - Presentation by Julia Worcester of the Michael J. Fox Foundation which described the national context underlying Parkinson's disease registry legislation.
 - Presentation by Mark Damesyn of the California Department of Public Health which provided an overview of California's Parkinson's disease registry as a state registry example.
- August 22, 2022
 - Defined the purpose of a Parkinson's disease registry.
 - Presentation by Laura Mandel of Maryland's Health Information Exchange, Chesapeake Regional Information System for our Patients (CRISP), which described CRISP's function, reach, current Parkinson's disease data collection, and capacity to collect data on behalf of the Maryland Department of Health.
 - Prioritized critical data elements to include in a registry.
 - Discussed the technical infrastructure, staffing, and regulatory steps necessary to develop, implement, and maintain a registry.
- September 7, 2022
 - A quorum of members was present to vote on the recommendation to develop a Parkinson's disease registry in Maryland; all members present voted to recommend a Parkinson's disease registry in Maryland.
 - Discussed legislative recommendations regarding mandatory reporting and opt-out provisions.
- September 20, 2022
 - Discussed legislative recommendations regarding funding, data use, and additional recommendations.

- October 11, 2022
 - Achieved consensus on the recommendations and draft report for the Department to move forward into final review and submit to the Maryland General Assembly.

Committee Progress to Date

The Center for Chronic Disease Prevention and Control engaged the Committee through virtual meetings, surveys, and an online collaborative platform to address the three core areas of responsibility laid out in its establishing legislation: 1) Assist in the development and implementation of a Parkinson's disease registry; 2) Determine the data to be collected and stored in a registry and methods to ensure the privacy and confidentiality of data collected and stored in a registry; and 3) Advise the Department on Parkinson's disease and maintaining a Parkinson's disease registry. If future legislation establishes a Parkinson's disease registry, the Committee will reconvene in an advisory capacity to continue discussing these issues and providing strategic and technical guidance to the Department regarding the development and maintenance of a Parkinson's disease registry.

1. Assist in development and implementation of a Parkinson's disease registry.

The Committee developed the following statement to define the purpose of a Parkinson's disease registry in Maryland:

To provide actionable data on the frequency and distribution of Parkinson's disease and parkinsonism across Maryland's population, and to serve as a tool to enable diverse stakeholders to make data-driven decisions pertaining to public health, research, and the lives of those impacted by Parkinson's disease.

The Committee identified California's Parkinson's disease registry as a successful state-based instructive model for the technical structure of a Parkinson's disease registry, with three main components:

- A reporting interface allowing healthcare providers to submit data reports for cases of Parkinson's disease and related parkinsonism;
- A backend database to store patient data; and
- A user interface providing information about the Parkinson's disease registry and how to request access to registry data.

Additionally, the Committee discussed the value of developing registry infrastructure that is adaptable, flexible, and has the capability to expand to reflect the changing knowledge and needs regarding Parkinson's disease and other neurological conditions in the future. California's Parkinson's disease registry followed a similar progression, gathering data about Parkinson's

disease and parkinsonism for several years before recently expanding to include other neurological conditions.

2. *Determine what data shall be collected and stored in a registry and the methods to ensure the privacy and confidentiality of data collected and stored in a registry.*

Committee members deemed it premature to determine specific data elements at this juncture and instead identified four core categories of data to include in a registry: 1) Patient demographics; 2) geography; 3) diagnosis; and 4) sufficient information to allow for de-duplication of patient records in the registry. Committee members noted the importance of balancing meaningful data collection with minimal additional reporting burden on the part of providers and healthcare systems. Should a Parkinson's disease registry be established in Maryland, the Committee will reconvene and engage in a more vigorous process to determine specific data elements to be collected and stored in a registry. The Committee recommends the Department, in consultation with the Committee, review and revise any list of data elements periodically to ensure data and data collection procedures adapt to new knowledge and technology. The Committee also recommends careful review of registry data for quality and completeness prior to the initial registry launch and any substantive changes to data collection or reporting requirements.

The Committee reviewed legislative language from other states to inform its discussion of how to address privacy and confidentiality in a Parkinson's disease registry. Committee members agreed the Department must develop policies and procedures to assure privacy, confidentiality, and security of registry data, however they determined it was premature to make specific recommendations at this time. Should the development of a registry be approved, the Committee will reconvene to provide guidance on privacy and confidentiality provisions.

3. *Advise the Department on Parkinson's disease and maintaining a Parkinson's disease registry.*

The Committee also discussed the components of a Parkinson's disease registry program necessary to develop and maintain a registry capable of achieving its stated purpose. Financial and personnel resources would be necessary to build and maintain the data storage system and reporting interface; perform ongoing system maintenance; review data sharing requests; as well as perform data extraction, analysis, and reporting. Additional resources would be necessary to oversee the registry; develop rules, procedures, and regulations pertaining to mandatory clinician reporting; and communicate key findings about prevalence and incidence of Parkinson's disease and parkinsonism.

Legislative Recommendations

The Parkinson's Disease Registry Advisory Committee respectfully submits the following six recommendations for the Maryland General Assembly to consider pertaining to the establishment of a Parkinson's disease registry in Maryland.

1. Establish a Parkinson's disease registry at the Maryland Department of Health (the Department) to provide actionable data on the frequency and distribution of Parkinson's disease and parkinsonism across Maryland's population, to serve as a tool to enable diverse stakeholders to make data-driven decisions pertaining to public health, research, and the lives of those impacted by Parkinson's disease.
2. Require diagnosing providers, such as physicians, nurse practitioners, and physician assistants, to report all diagnosed cases of Parkinson's disease and related parkinsonism, in accordance with reporting requirements established by the Department, in consultation with the Parkinson's Disease Registry Advisory Committee. Reported data should include: 1) Patient demographics; 2) geography; 3) diagnosis; and 4) sufficient information to allow for de-duplication of patient records in the registry.
 - Consider authorizing CRISP, in its capacity as the state-designated Health Data Utility, to collect mandatory case reports on Parkinson's disease and related parkinsonism and share the reports with the Department. Working with CRISP as a designated data collector could minimize the reporting burden for providers and health systems already participating in CRISP. The Department would be responsible for developing a minimally-burdensome reporting process for providers and health systems not currently participating in CRISP.
3. All patients must be notified about the registry and have the ability to opt out of participating. Committee members felt informing patients about the registry and reporting requirements was important for transparency, and an opt out provision would allow those who do not wish to have identifying information collected to decline participation. Some Parkinson's disease registry states allow patients to opt out of having personally identifiable information submitted to the registry, with only a minimal case report collected in those instances.
4. Authorize the Department to establish clear guidelines and procedures for reviewing and approving requests to use registry data for valid scientific research. Registry data should remain private and confidential. The Maryland Cancer Registry, which has detailed procedures for reviewing data requests and releasing data for approved uses, may serve as a model for developing similar guidelines and procedures pertaining to a Parkinson's disease registry.

5. Dedicate ongoing funding in an amount sufficient to ensure the proper development, maintenance, and staffing of a Parkinson's disease registry for at least 5 years. Committee members agreed a Parkinson's disease registry could not achieve its purpose without adequate funding to design, build, maintain, and staff a registry program.
6. No later than 5 years after implementation, the Department and the Committee should conduct a thorough review of the registry, including how it is being used and whether it is fulfilling the intended purpose, and recommend any necessary changes to update the registry. Committee members determined 5 years was an appropriate timeframe within which to build and implement a Parkinson's disease registry and gather sufficient information to assess the registry's effectiveness in achieving its purpose.