

**Parkinson’s Disease Registry Advisory Committee**

**First Meeting January 26, 2022**

* Welcome and Introductions
* Overview of Committee’s Charge and Deliverables
* Open Meeting Law and Conflict of Interest Policy
* Member Discussion of Committee Expectations
* Election of Chair(s)
* Next Steps

– Meeting Schedule

SECTION 45. Chapter 111 is hereby further amended by adding the following Section 243.

1. The department shall establish a Parkinson’s disease registry for the collection of information necessary to determine the incidence and prevalence of Parkinson’s disease in the commonwealth
2. There shall be within the department, a Parkinson’s disease registry advisory committee to advise and assist in the development, implementation and progress of the Parkinson’s disease registry established in subsection (a).

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The committee shall review and submit recommendations on:

1. what data shall be collected, including, but not limited to, demographic information and data by areas and regions of the commonwealth, with specific data from urban, low and median income communities and minority communities of the commonwealth
2. the means of collecting and disseminating such data
3. how to ensure privacy and confidentiality of such data
4. the purpose, design and functionality of the registry
5. the implementation of the registry

The committee shall recommend to the department any information deemed necessary and appropriate for the statistical identification and planning for treatment and education of health care providers and persons diagnosed with Parkinson’s disease.

“The committee shall consist of the commissioner, or a designee, and 10 members to be appointed by the commissioner as follows: 3 physicians, 1 of whom shall be a general neurologist, 1 of whom shall be a movement disorder specialist and 1 of whom shall be a primary care physician; 1 health informaticist; 2 population health researchers familiar with registries; 2 Parkinson’s disease researchers; and 2 persons diagnosed with Parkinson’s disease.

The committee shall meet at least bi-annually to assess registry progress and recommend changes.”

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| **Role as Legislatively mandated** | **Member Name** |
| **Commissioner’s Designee** | Lauren Fogarty |
| **Neurologist (General)** | Dr. Samuel Frank |
| **Neurologist (Movement Disorder Specialist)** | Dr. Anindita Deb |
| **Neurologist (Primary Care Provider)** | Dr. Terrell Johnson |
| **Informaticist** | Dr. Glenn Tucker |
| **Population Health Researcher** | TBD |
| **Population Health Researcher** | TBD |
| **Parkinson’s Disease Researcher** | Brett Miller |
| **Parkinson’s Disease Researcher** | Cathi Thomas |
| **Person Diagnosed with Parkinson’s Disease** | James Cornell |
| **Person Diagnosed with Parkinson’s Disease** | Matt Keswick |

* + Share your name and affiliation
  + Why are you interested in participating on this Committee?
  + What do you think is your biggest strength to contribute to this Committee’s discussions?
    - The purpose of OML is transparency in government.
    - All meetings of a public body must be open to the public.
    - A public body includes any multi-member board, commission, committee, or subcommittee if established to serve a public purpose.
* A meeting is “a deliberation by a public body with respect to any matter within the body’s jurisdiction.”
* **Deliberation** is defined as “an oral or written communication through any medium, including electronic mail, between or among a quorum of a public body on any public business within its jurisdiction.”
* Deliberation does not include scheduling or procedural information.
* If a quorum of a public body wants to discuss public business within that body’s jurisdiction, they must do so during a properly posted meeting.
  + ***NOTE: If a public body member sends an email to a quorum of the public body expressing an opinion on any matter that could come before that body, the communication violates the OML, even if no recipient responds.***
* A public body must post notice of its meetings on its website at least 48 hours before the meeting, excluding Saturdays, Sundays, and legal holidays.
* The notice must include the following:
  + Date;
  + Time and place; and
  + List of topics the chair reasonably anticipates will be discussed at the meeting.
* The list of topics should provide sufficient information to inform the public of the issues to be discussed at the meeting.
* A Quorum is defined as:
* A **simple majority** of the members of a public body, unless otherwise provided in a general or special law, executive order, or other authorizing provision. G.L. c. 30A, § 18.
* As applied to the Advisory Committee for Parkinson’s Disease Registry, the quorum equals 6 members (½ of 11 members + 1)

**Avoiding OML Violation-Best Practice Recommendations**

* + Public body members must not engage in “serial deliberations”—a series of separate, independent conversations outside of a meeting among a quorum of the members regarding a topic within its jurisdiction.
  + In order to avoid even the appearance of a potential OML violation, the AGO advises public body members to refrain from communications over email except for distributing meeting agenda, scheduling meetings and distributing documents created by nonmembers.

Chapter 20 of the Acts of 2021, *An Act Extending Certain COVID-19 Measures Adopted During the State of Emergency* (June 16, 2021), authorizes remote participation of public bodies through April 1, 2022:

* + - Public bodies are permitted to have live “adequate, alternative means” of public access, including video conference;
    - Remote participation is allowed by all members of the public body; and
    - All votes taken during a meeting in which a member participates remotely

**must be by roll call vote.**

* + A member of the public may not address the public body without permission of the chair.
  + A member of the public may not disrupt the meeting.
  + The public body must create and maintain minutes of all meetings.
  + Records reviewed by the public body during the meeting are public records.
  + The Attorney General’s Office enforces OML.
  + A member of the public may file a complaint alleging an OML violation, first with the public body, and subsequently with the Attorney General’s Office if necessary.
* The Conflict of Interest (COI) law, M.G.L. c. 268A, is meant to prevent conflicts (and appearances of conflict) between a state employee’s private interests and his or her public duties.
* As statutory public body members, you are considered to be “special state employees” subject to the COI law.
* The COI law is complex; State Ethics Commission attorneys are available, through the “Attorney of the Day” program, to provide confidential advice/guidance on how the COI law applies to you in a particular situation.

o ***Contact Attorney of the Day @ (617) 371-9500***

* Asking for and taking bribes is prohibited.
* Asking for or accepting a gift because of your official position is prohibited.
* Using your official position to get something you are not entitled to, or to get someone else something they are not entitled to, is prohibited.
* Participating as a state employee in a matter in which you, your immediate family, your business organization, or your future employer has a financial interest is prohibited.
* Acting in a manner that would make a reasonable person think you can be improperly influenced is prohibited.

# Conflict of Interest Law-Training Requirements

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* All state employees subject to the COI law are required to:
  + Certify they received and reviewed the annual Summary of Conflict of Interest Law, and
  + Complete the biannual online training program

**Training Requirements**

**Required Conflict of Interest Law Online Trainings Conflict of Interest Law Online Training Program Conflict of Interest Law Summary**

Summary of COI law:

https://[www.mass.gov/service-details/summary-of-the-conflict-of-interest-law-for-](http://www.mass.gov/service-details/summary-of-the-conflict-of-interest-law-for-) state-employees

COI training:

https://[www.mass.gov/how-to/complete-the-online-training-program-for-state-and-](http://www.mass.gov/how-to/complete-the-online-training-program-for-state-and-) county-employees

**State Ethics Commission**

For information regarding the Education & Training requirements, refer to the State Ethics Commission website: <http://www.mass.gov/ethics/revised-implementation-> procedures.html

Phone: (617) 371-9500

* You must complete the training within 30 days.

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Conflict of Interest Law:

* https://[www.mass.gov/laws-regulations-rulings-opinions-and-advisories](http://www.mass.gov/laws-regulations-rulings-opinions-and-advisories)
* https://[www.mass.gov/learn-more-about-conflicts-of-interest](http://www.mass.gov/learn-more-about-conflicts-of-interest) Office of Attorney General, Open Meeting Law Website and Guide:
* https://[www.mass.gov/files/documents/2017/09/25/2017%20Guide%20only.pdf](http://www.mass.gov/files/documents/2017/09/25/2017%20Guide%20only.pdf)
* <http://www.mass.gov/ago/government-resources/open-meeting-law/>

Proposed schedule of future meetings; four meetings on the 4th Wednesday of each month:

* + January 26, 2022
  + February 23, 2022
  + March 23, 2022
  + April 27, 2022
  + May date : optional and TBD

Thank You

Mary Lou Woodford, RN, BSN, MBA, CCM Parkinson’s Disease Registry Advisory Committee Project Manager

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