



Parkinson's Disease Registry Advisory Committee Meeting Minutes

Date: Wednesday, March 23rd, 2022 (2:00 – 4:00 pm)

Location: Zoom (<https://umass-amherst.zoom.us/j/93968180415>)

Materials Provided: Meeting agenda.

Committee Members:

Brett Miller (co-chair), Cathi Thomas (co-chair), Dr. Samuel Frank, Lauren Fogarty, Dr. Anindita Deb, Dr. Terrell Johnson, Dr. Glenn Tucker, James Cornell, Matt Keswick

Others Present:

Mary Lou Woodford, Casey Hall

Call to Order by co-chair Cathi Thomas

Roll Call:

- Cornell, present
- Deb, present
- Fogarty, present
- Frank, present
- Johnson, present
- Keswick, not present
- Miller, present
- Thomas, present
- Tucker, not present at roll call

I. Welcome

Motion to accept minutes from the 3/4/22 meeting by member Fogarty, seconded by member Frank.

Members present unanimously accepted proposed minutes.

II. Overview of California's Parkinson's Disease Registry (CPDR)

Presented by Dr. Mark Damesyn, MPH, DrPH,
Chief, California Parkinson's Disease Registry



Dr. Damesyn presented on the history, purpose, and procedures of the CPDR as well as highlights from data reporting and next steps for their registry. Committee members were invited to ask questions as the presentation progressed.

Topical focuses included data gathering difficulties, data provider relationships, legislative mandates, HIPPA boundaries, interstate and military data, ongoing data collection related to identified cases, commissioned versus existing software solutions, budget, and staffing.

IIb. Report back on ALS registry by member Lauren Fogarty

\$287,0000 budget with two staff and consultants. Data reporting is done by hospitals, clinics, and neurologists; tis includes Veterans' Affairs hospitals. Death certificates are referenced as well as a control measure. The ALS Registry took five years to develop due to the introduction of HIPPA during the process, requiring new authorizations. The ALS Registry also faced difficulties due to the lack of a centralized source of data at the time. This registry exists in Microsoft Access and is run by DPH. Paper forms are used currently, but DPH is exploring digital data submission. The ALS Registry data is available through DPH on an application basis with more strict protocols to access patient-specific information. Additional information will become available on the return of DPH staff currently on leave.

III. Committee Deliverables and Planning Discussion

- What is the purpose of the registry?
- What design would the committee like to recommend?
- What is the functionality of the registry?
- What data should be collected?
- How should the data be disseminated?

The committee discussed the new understanding and questions raised from today's meeting with the remaining time before discussion returned to scheduling and next steps.

VI. Next Steps

Mary Lou Woodford to connect with CDC regarding existing neurological disease tracking and database.

Motion to adjourn from Frank, seconded by Miller.