The California Parkinson’s Disease Registry
Accomplishments and Updates, October 2019

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Presentation Overview

1. CA Senate Bill (SB) 97
   • Objectives of the California Parkinson’s Disease Registry (CPDR)

2. Operational Highlights
   • What CDPH has accomplished to date

3. Data Submitted
   • Data deadlines and facility reporting

4. Next Steps and Future Aims
   • Estimating incidence & prevalence of PD in CA
   • Provide data to qualified researchers
CPDR History & Progress

- **July 2017**: SB 97 Signed into Law, July 1, 2017
- **July 2018**: Created Helpdesk for Reporting Entities, Reporting Mandate Begins
- **July 2019**: First Deadline for Submission, March 31, 2019, Over 170,000 Records Received
- **July 2020**: Second Deadline for Submission, June 30, 2019, Program Report
- **July 2021**: Sunset Date of SB 97, January 1, 2021
CA Senate Bill 97

Objectives of the CPDR
CA Senate Bill 97
Richard Paul Hemann Parkinson’s Disease Program

Beginning on July 1, 2018:

1. All physicians, hospitals, clinics, and other entities providing diagnosis or treatment to PD patients are required to report to CPDR within 90 days

2. CDPH must establish a system for the statewide collection of information to determine the incidence and prevalence of PD

3. CDPH must develop a data disclosure protocol to provide confidential information to qualified researchers with a valid scientific interest
Operational Highlights

• What CDPH has accomplished to date

- SB 97 Signed into Law
  July 1, 2017
- Created Helpdesk for Reporting Entities
- Reporting Mandate Begins
- First Deadline for Submission
  March 31, 2019
- Second Deadline for Submission
  June 30, 2019
- Over 170,000 Records Received
- Program Report
- Sunset Date of SB 97
  January 1, 2021

- Designed Program Model
  July 2017
- Initiated Partnerships
- Implementation Guide Published
  July 2018
- Second Deadline for Submission
  June 30, 2019

California Department of Public Health
California Parkinson's Disease Registry
CPDR Development and Data Collection

1. Established and implemented IT system for data capture
2. Developed program model
3. Created help desk and technical support for reporting entities
4. Formed partnerships with external entities
5. Assured patient confidentiality protections
## CPDR Development and Data Collection

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Data Submitted

• Data deadlines and facility reporting
1. 175,669 records collected through the first five quarters of mandated reporting (July 1, 2018-September 30, 2019)

*The information presented reflects the total records received and not the consolidated, deduplicated dataset used to calculate incidence or prevalence.
As of October 1, 2019, CPDR has received about 175,000 records* from approximately 500 reporting entities. CPDR is identifying and onboarding facilities and providers that are not reporting to CPDR.

*The information presented reflects the total records received and not the consolidated, deduplicated dataset used to calculate incidence or prevalence.
Next Steps and Future Aims

1. Continue working with facilities and providers

2. Determine incidence and prevalence of PD in California

3. Use of CPDR data
   - Research (qualified applicants)
   - Surveillance
   - With data security and patient protections
CPDR Impact

1. Data collected about PD patients is invaluable for CA and beyond

2. Research will accelerate our understanding about the causes of PD

3. Reporting will raise awareness and contribute to earlier diagnosis of PD
Acknowledgements

• Patients

• Facilities, providers, and health system administrators

• Academic institutions

• PD organizations
  • Michael J. Fox Foundation
  • Parkinson’s Association of Northern California