California Parkinson’s Disease Registry
Accomplishments & Updates, September 2019

Operational Highlights

- The California Department of Public Health (CDPH) has designed and implemented the California Parkinson’s Disease Registry (CPDR), including an implementation guide informing providers how and when to report as well as an information technology system for both automatic and manual submission of Parkinson’s disease cases
  - Automatic via Electronic Health Record (EHR): sent electronically from the health system EHR
  - Manual Entry via Web Portal: entered manually by the provider via the web portal of the California Reportable Disease Information Exchange (CalREDIE)
- CPDR has implemented and maintains a Help Desk to provide technical support to reporting entities
- CPDR has onboarded and is receiving reports from some of the largest health systems in California including Sutter Health, Scripps Health, and UC San Diego
- CPDR is working with large health systems to increase data capture
  - Kaiser Permanente (North) has recently begun automatic reporting to CPDR
  - Dignity Health has registered to report automatically to CPDR

Total Records = 175,669
- Automatic: 86%
- Manual Entry: 14%

Number of Unique Reporting Entities
= 497

Top Reporting Entities
1) Sutter Health    Automatic
2) Scripps Health   Automatic
3) UC San Diego     Automatic
4) Stanford Health  Automatic
5) Kaiser Permanente (South) Manual Entry
Data Highlights

- As of September 30, 2019, CPDR has received 175,669 total records* from 497 reporting entities
  - Data has been successfully collected in the first five quarters of mandated reporting (July 1, 2018 – September 30, 2019)
  - The top five reporting entities constitute about 46 percent of the total records
- Records submitted automatically outnumber those submitted manually by a ratio of about 9:1, minimizing the burden to providers
  - Cases submitted manually require about five minutes per case to complete
  - Cases submitted automatically are triggered and sent through the health system EHR and do not require direct action by the provider
- The next deadline for reporting is December 31, 2019
- Many providers are complying with the mandated reporting
- CPDR continues to outreach to additional providers and health systems across California to increase the number of entities reporting

**Total CPDR Records Received Over Time**
Based on total, non-deduplicated records

Source: California Parkinson’s Disease Registry, California Department of Public Health
Prepared by the California Department of Public Health, California Parkinson’s Disease Registry

*The information presented in this report reflects the total records received and not the consolidated, deduplicated dataset used to calculate incidence or prevalence.

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