California Neurodegenerative Disease Registry (CNDR)
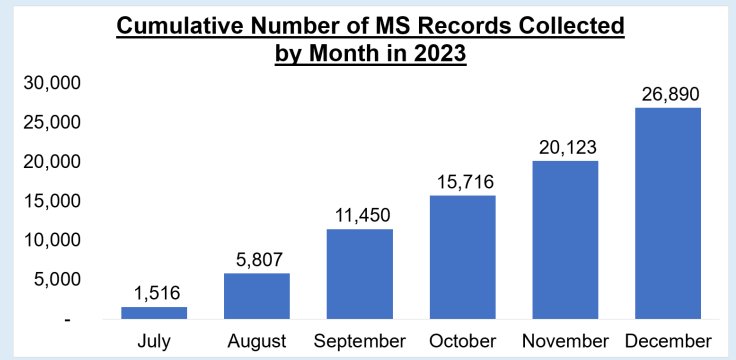
Program Summary, March 2024

> **California Neurodegenerative Disease Registry (CNDR) is California's statewide population-based neurodegenerative disease surveillance system. On July 1, 2023, CNDR started collecting multiple sclerosis (MS) information. Over 99 percent of records are collected automatically from electronic medical record systems, which do not require additional reporting effort from providers.**

CNDR Program Timeline

July 2021
Assembly Bill 133 enacted Health and Safety Code (HSC) 103871 to establish the CNDR.

January 2023
CNDR hosted two virtual listening sessions with stakeholders, data providers, and researchers about HSC 103871.

June 2023
The Neurodegenerative Disease Guide to Reporting was updated to include MS.

July 2023
CNDR started collecting MS data.

October 2023
The Governor signed Assembly Bill 424 to amend subsections of HSC 103871.

March 31, 2024
The first CNDR submission deadline for reporting MS.

Cumulative Number of MS Records Collected by Month in 2023

Month	Records
July	1,516
August	5,807
September	11,450
October	15,716
November	20,123
December	26,890

In 2023, CNDR collected a total of 26,890 MS disease encounters.

Number of Facilities Reporting MS Cases in 2023

25 (12%)

* The California Parkinson's Disease Registry (CPDR) and CNDR are sister registries. CNDR uses CPDR's 2022 facility count of 208 as baseline for MS information collection.

208*
Baseline number of facilities CNDR will strive to collect MS information from.

25
Facilities reported MS to CNDR from July to December 2023.

CNDR continues to onboard facilities to collect MS information in California.

Highlights

- A total of 26,890 MS records were reported to CNDR as of December 31, 2023. The first reporting deadline, covering July 1 – September 31, 2023, is March 31, 2024.
- CNDR data presented has not been deduplicated and does not account for misdiagnosed or unreported cases to the registry.
- CNDR is hosting Technical Advice Group (TAG) meetings with stakeholders/subject matter experts that focus on four broad areas 1) data use, 2) data collection, 3) disease case definitions, and 4) value of the registry. Specified TAG meetings will occur at least once a year beginning in summer 2024.
- One of the amendments to HSC 103871 made by Assembly Bill 424 (2023) was adding the following words, "…include, but not be limited to, amyotrophic lateral sclerosis also known as Lou Gehrig's disease" in section (b).

Source: California Neurodegenerative Disease Registry (December 31, 2023)