

APPLICATION FOR DISCLOSURE OF CALIFORNIA NEURODEGENERATIVE DISEASE REGISTRY CONFIDENTIAL DATA

For Other States' Neurodegenerative Disease Registries, Federal Neurodegenerative Disease Control Agencies, or Local Health Officers – Surveillance Use Only

Requester's Name:	Request Date:
Requester's Title:	Organization Name:
Work Street Address:	City:
State:	Zip Code:
Contact Number:	Disease Name:
Email:	
Title of Project:	

Statement of Intended Use
<p>Attach a signed statement of intended use from the head of a state neurodegenerative disease registry, federal neurodegenerative disease control agency, or local health officers describing:</p> <ul style="list-style-type: none"> Major research question and/or aims of the project How you propose to use the requested patient-level data, including the years needed The method of the study and the site location

Data Delivery				
<p>Custom data files will be created based on the data variables selected from the California Neurodegenerative Disease Guide to Reporting and tailored to the request. Attach a list of variables to include on the custom data file and provide a reason for including each variable in the data file and indicate the year(s) requested.</p> <p>Data files can be retrieved in either SAS file or CSV flat file format. Please indicate which type of file you would like to receive.</p>				
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <th colspan="2" style="background-color: #d3d3d3; padding: 5px; text-align: center;">Type of File Requested (check one):</th> </tr> <tr> <td style="width: 50%; padding: 5px;">SAS file <input type="checkbox"/></td> <td style="width: 50%; padding: 5px;">CSV flat file <input type="checkbox"/></td> </tr> </table>	Type of File Requested (check one):		SAS file <input type="checkbox"/>	CSV flat file <input type="checkbox"/>
Type of File Requested (check one):				
SAS file <input type="checkbox"/>	CSV flat file <input type="checkbox"/>			

Data Access

List the names of all persons who will have access to the requested data files and explain their affiliation to the requesting department. Please include a separate attachment if additional space is needed.

Full Name and Title	Affiliation	Address (if different than the requestor's)

Disclaimer

Data files may not be accurate or complete due to a variety of circumstances, including amendments to the legal records that may have been filed after the production of the data files. Data files are not legal records and should not be used as substitutes for the legal records from which they were derived.

Notes:

1. This application is designed solely for other states' neurodegenerative disease registries, federal neurodegenerative disease control agencies, and local health officers to request confidential patient level data for surveillance purposes. For research data requests, please refer to the policy document which is available on the [California Neurodegenerative Disease Registry webpage](https://go.cdph.ca.gov/cndr) (<https://go.cdph.ca.gov/cndr>). To obtain tabulated or aggregated data, please use the [Instructions for Requesting Tabulated Data](#) which is available on the [California Neurodegenerative Disease Registry webpage](#).