

Attachment 1: ALS Registry Act

ALS Registry Act - (Sec. 2) Amends the Public Health Service Act to authorize the Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention (CDC), if scientifically advisable, to: (1) develop a system to collect data on amyotrophic lateral sclerosis (ALS) and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, or progress to ALS; and (2) establish a national registry for the collection and storage of such data to develop a population-based registry of cases.

Authorizes the Secretary, acting through the Director, to establish the Advisory Committee on the National ALS Registry, which may review information and make recommendations to the Secretary concerning: (1) the development and maintenance of the registry; (2) the type of information to be included; (3) the manner in which data is to be collected; (4) the use and availability of such data; and (5) the collection of information about diseases and disorders that primarily affect motor neurons that are considered essential to furthering the study and cure of ALS.

Allows the Secretary, acting through the Director, to award grants to, and enter into contracts and cooperative agreements with, public or private nonprofit entities for the collection, analysis, and reporting of data on ALS and other motor neuron disorders.

Authorizes the Secretary, acting through the Director, to: (1) identify, build upon, expand, and coordinate among existing data and surveillance systems, surveys, registries, and other federal public health and environmental infrastructure wherever possible; and (2) provide for research access to ALS data as recommended by the Advisory Committee in a manner that protects personal privacy.

Allows the Secretary to ensure that epidemiological and other types of information is made available to the National Institutes of Health (NIH) and the Department of Veterans Affairs (VA).

(Sec. 3) Authorizes the Secretary to report to the appropriate congressional committees on ALS registries, including: (1) the registries currently under way and future planned registries; (2) the criteria involved in determining what registries to conduct, defer, or suspend; (3) the scope of those registries; and (4) the activities the Secretary undertakes to establish partnerships with research and patient advocacy communities to expand registries.