Advancing Research for Neurological Diseases

BACKGROUND

1 in 6 Americans (approximately 50 million) is living with a neurological disease. According to the National Spinal Cord Injury Statistical Center, 282,000 individuals live with spinal cord injury in the United States with 17,000 new cases each year.[1] However, existing databases and registries collect uncoordinated data on individuals with spinal cord injury and paralysis and the 282,000 number may be low. In 2000, the Pew Environmental Health Commission recommended that neurological diseases be tracked by a national data system – such a system does not currently exist in the United States. The number of Americans living with neurological diseases continues to grow at significant rates. Consequently, the need has never been greater to track the epidemiology of these diseases and to provide researchers with better data. According to the Society for Neuroscience, disorders of the brain and nervous system result in more hospitalizations than any other disease group, including heart disease and cancer. Additionally, the United States spends about $25 million every 30 minutes treating neurological conditions, totaling a staggering $500 billion each year.

Without basic data concerning the size and makeup of people with neurological diseases, researchers are working at a distinct disadvantage. Additional epidemiological data on the neurological disease populations could lead to new treatment targets, better clinical understanding of diseases, and eventually new treatments and cures. The Advancing Research for Neurological Diseases Act will collect this essential data.

The Advancing Research for Neurological Diseases Act allows the Secretary of the Department of Health and Human Services (HHS) to establish a centralized data collection system within the Centers for Disease Control and Prevention (CDC) to collect and aggregate data on the epidemiology of neurological diseases. This data will provide a foundation for evaluating and understanding aspects of neurological diseases, (both CDC and NIH include spinal cord injury/disease SCI/D in their categorization of neurologic diseases including multiple sclerosis, Parkinson's disease) such as:

•   The natural history of neurological diseases;
•   Demographics, such as age, race, ethnicity, sex, geographic location, and family history;
•   Geographic clusters of diseases;
•   Diagnosis and progression markers;
•   Risk factors that may be associated with certain neurological diseases;
•   Disease burden;
•   Outcomes measures; and
•   Research for the prevention, detection, management, and development of therapies

The Secretary of the Department of Health and Human Services will have the ultimate discretion to decide what types of data to collect and how it will be collected. Data can be drawn from existing databases, including but not limited to: Medicare, State Medicaid Programs, the Department of Veterans Affairs, and State and local registries. This data will be made available to other agencies and researchers.

The bill requires that privacy and security protections be at least as stringent as those required by the Health Insurance Portability and Accountability (HIPAA), de-identifying personal information and eliminating the possibility of privacy breaches.

REQUEST TO POLICYMAKERS
Co-sponsor S.849, Advancing Research for Neurological Diseases Act of 2015 that would create a centralized data collection system and the Centers for Disease Control and Prevention to track and collect data on the epidemiology of neurological diseases. Lead Senate sponsors: Sen. Johnny Isakson (R-GA) and Sen. Chris Murphy (D-CT).

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[1] National Spinal Cord Injury Statistical Center, Facts and Figures at a Glance. Birmingham, AL: University of Alabama at Birmingham, 2016.