



## Advancing Research for Neurological Diseases

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**Position:** The Epilepsy Foundation supports efforts to track neurological diseases and conditions to provide additional information for researchers. **We urge Congress to support the *Advancing Research for Neurological Diseases Act (S. 849)*, bipartisan legislation that would create a system to gather data about neurological conditions and diseases.**

**About Epilepsy:** The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of nearly 3 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime.

**Background:** Millions of Americans live with epilepsy and other neurological conditions and diseases, and the numbers continue to grow. In 2000, the Pew Environmental Health Commission recommended that neurological conditions and diseases be tracked by a national data system. However, such a system still does not exist in the United States.

Without basic data concerning the size and makeup of the epilepsy population and the populations of other neurological diseases and conditions, researchers are working at a distinct disadvantage. Additional epidemiological data on populations living with epilepsy and other neurological conditions and diseases could lead to new treatment targets, better clinical understanding of these conditions and diseases, and, eventually, new treatments and cures.

The *Advancing Research for Neurological Diseases Act* grants the Secretary of the Department of Health and Human Services (HHS) the authority 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 conditions and diseases.

While the final decision as to what conditions and what data would be collected is up to the HHS Secretary, we believe that epilepsy, as the 4<sup>th</sup> most common neurological condition or disease, is a prime candidate to be included should this system be established.

**If you have any questions or concerns, please contact Angela Ostrom, COO & Vice President Public Policy at [aostrom@efa.org](mailto:aostrom@efa.org) or 301-918-3766.**