



**National
Multiple Sclerosis
Society**

**Advancing
Research for
Neurological
Diseases**

Why Data Collection?

- Researchers are working at a distinct disadvantage not knowing vital information about many neurological conditions.
- For example, the last MS prevalence study was done in the mid-1970s.
- In 2000, the Pew Environmental Health Commission recommended that neurological diseases be tracked by a national data system

Why Data Collection?

- Information collected will provide a foundation for better understanding and evaluating factors like:
 - Geographic clusters
 - Variability in racial and ethnic risk
 - Changes in gender ratio
- This could lead to:
 - Causes
 - Better Treatments
 - Policies for optimal care
 - Cures

Definitions

Prevalence – The total number of people diagnosed with a condition at a single point in time or during a period of time. *“All”*

Incidence – The total number of people newly diagnosed with a condition during a 12-month period. *“New”*

History of the Bill

- Started as MS & Parkinson's
- Next iteration was the National Neurological Diseases Surveillance System Act
- The House passed the surveillance system bill in 2010 by voice vote
- Lessons learned from ALS Registry & MS Prevalence Project

Key Components of the Bill

- Mandates the Centers for Disease Control to establish a data collection system to track prevalence and incidence data for neurological diseases/conditions
 - Both CDC and NIH include SCI/D in their categorization diseases and disorders
- Data can be drawn from existing databases like Medicare and the Department of Veterans Affairs; Secretary has discretion about what types and how it will be collected
- Requires privacy standards at least as stringent as HIPAA; data would be de-identified and anonymous

Coalition Supporting the Bill

ADVANCING RESEARCH FOR NEUROLOGICAL DISEASES:

THE POWER OF POPULATION DATA



Capitol Hill Briefing – September 2015

- Sponsored by the 12 supportive organizations
- Purpose was to gain momentum in the Senate
- Nearly half of Senate offices in attendance
- Since the briefing, these orgs have joined the coalition:
 - Hydrocephalus Association
 - National Stroke Association

House Bill – H.R. 292

- Led by Reps. Burgess (R-TX-26) & Van Hollen (D-MD-8)
- 126 bipartisan cosponsors
- Included in the 21st Century Cures Act (H.R. 6), which passed the House on July 10, 2015

Senate Bill – S. 849

- Led by Sens. Isakson (R-GA) & Murphy (D-CT)
- 25 bipartisan cosponsors
- HELP Committee passed the bill on February 9, 2016 with some changes:
 - Removed authorized funding
 - No longer mandated to start the system
 - 5 diseases to start with

Moving Forward

- Want the Senate bill to pass so that the House and Senate can work together
- Want strong language—closer to House bill—that sets the data collection system up for success