Dear Senator,

As a constituent, I am inviting you to join a number of stakeholders for a briefing on the Advancing Research for Neurological Diseases Act (S. 849). The briefing will be held on September 16 from 11:30 to 12:30 in the Senate Russell Building, room 485. The briefing is sponsored by the American Academy of Neurology, American Brain Coalition, Brain Injury Association of America, Epilepsy Foundation, International Essential Tremor Foundation, National Multiple Sclerosis Society, Parkinson's Action Network, Rare Disease Legislative Advocates, Research!America, Tourette Association of America, and United Spinal Association.

The bill would help advance neurological disease research by establishing a system to collect the size and makeup of different neurological disease populations. Currently, there is no accurate account of how many people in the United States have (INSERT SPECIFIC DISEASE) nor of the demographic characteristics of those living with (INSERT SPECIFIC DISEASE). As a result, (INSERT SPECIFIC DISEASE) researchers are working at a distinct disadvantage: lacking basic information about the disease. [Only use if appropriate to your diseases: This system could supply data that points to new environmental triggers, which could lead to a better understanding of the disease and new disease targets.]

The cause of (INSERT SPECIFIC DISEASE) is unknown, and a cure, so far, doesn't exist. Please join us to learn more about how S. 849 could help drive us closer to a cure for many neurological conditions!

Sample Facebook/LinkedIn Posts

Sample Post
Act Now for (INSERT SPECIFIC DISEASE): Contact your U.S. Senators and invite them to an important briefing on the Advancing Research for Neurological Diseases Act on September 16. Click here to send an invite and ask for their support of #neurodata S.849 today. [insert action alert link]

Sample Twitter Posts

Hashtags: #neurodata #MedicalInnovation

Sample Tweet
Contact your Senators and ask them to support #neurodata as an #MSactivist (INSERT YOUR HASHTAG) [insert action alert link]
Sample Tweet
Contact your Senators today and invite them to learn more about #neurodata and medical research [insert action alert link]

Sample Tweet
LIVE: #Congress is being briefed on the Advancing Research for Neurological Diseases Act. Urge your Senators to support the #neurodata bill[insert action alert link]

Sample Letter to the Editor or OpEd

[DATE]
To the Editor:

**First way to start the letter:** I want to thank Senator [ ] for his/her continued and strong support for biomedical research funding.

**A second way to start the letter:** As Congress continues to work on many challenging issues, I urge Senators [YOUR SENATORS’ NAMES HERE] to move forward the Advancing Research for Neurological Diseases Act this session.

**Body of the text:** This bill will mandate that the Centers for Disease Control and Prevention track the incidence and prevalence of neurological diseases, including (INSERT YOUR SPECIFIC DISEASE). This new data system could one day lead to a cure for diseases like (INSERT DISEASE), as information collected will provide a foundation for evaluating and understanding aspects of these diseases on which we currently do not have a good grasp – such as the geography of diagnoses, variances in gender, disease burden and changes in healthcare practices among patients.

I will be watching for our congressional delegation’s leadership on this issue and hope the U.S. Senate will prioritize medical research in FY 2016.

As a resident of [insert city of state] living with [insert disease], the neurological data bill means new research and the hope for a cure. [Give one concrete example of how the neurological data bill would improve your life]. That’s why I support the neurological data bill, and I hope you will too.

[Activist Name, Location]

Press Release

WASHINGTON, D.C. [insert date] - Today, 12 patient advocacy and research-oriented organizations will host a Senate briefing on the Advancing Research for Neurological Diseases Act (S.849). Together, The American Academy of Neurology, American Brain Coalition, Brain Injury Association of America, Epilepsy Foundation, International Essential Tremor Foundation, National Multiple Sclerosis Society, Parkinson’s Action Network, Rare Disease Legislative Advocates, Research!America, Tourette Association of America and
United Spinal Association have come together to educate the U.S. Senate about the benefits of neurological research and data.

[Insert quote from your organization CEO or President]

S.849 would create a centralized data collection system at the Centers for Disease Control and Prevention (CDC) that will track and collect data on the epidemiology of neurological diseases. The proposed data collection system will rely on existing databases to create permanent and separate national systems for each neurological condition. Information collected will provide a foundation for evaluating and understanding many factors, such as: geographic clusters of the disease; variability in racial and ethnic risk; changes in the gender ratio; disease burden; and health care practices and utilization. The bill also requires privacy standards at least as stringent as HIPAA.

The bill, which was introduced by Senator Isakson and Senator Murphy, establishes the National Neurological Diseases Surveillance System, which will collect data from people living with neurological conditions in an effort to better understand the nature, prevalence, and environmental factors related to neurological diseases so that researchers have more comprehensive data to use when investigating new treatments for those diseases. This surveillance system is especially important to people living with multiple sclerosis (MS), because the most recent national study of disease prevalence and incidence related to MS was conducted in 1975; now 40 years out of date. [REPLACE WITH DISEASE SPECIFIC DATA]

There has been broad, bipartisan support of the bill, and look forward to the eventual enactment of S.849, and the diverse advancements that it will bring into the field of research and development.

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**Activist Network Email**

**Pre-Briefing Email**

"Act Now: Help Gain Senate Support for #Neurodata"

This week, the (INSERT NAME OF YOUR ORGANIZATION) will join 11 of its closest allies to host a briefing on Capitol Hill to educate U.S. Senators about the importance of neurological data.

Education is the first step to understanding and supporting a bill. Will you join us as an activist and an educator today? Please contact your Senators and ask them to attend the briefing and cosponsor the Advancing Research for Neurological Diseases Act (S.849). Together, we can ensure the success of the Advancing Research for Neurological Diseases Act in both chambers of Congress. [insert action alert link]

**Sample Call Script**
The National MS Society is not organizing a central call-in number. However, if you have a call action center and would like to activate call alerts, please use the script below.

Hello, my name is [FIRST] ____ [LAST] _____. I am from [YOUR CITY & STATE] and am calling to support S.849- Advancing Research for Neurological Diseases Act.

- Additionally, I invite the Senator or a member of the Senators staff to attend the briefing on September 16 **September 16 from 11:30 to 12:30 in the Senate Russell Building, room 485** regarding the details of the bill.
- The bill will mandate that the Centers for Disease Control and Prevention track the incidence and prevalence of neurological diseases, including [YOUR DISEASE]. This new data system could one day lead to a cure for diseases like multiple sclerosis, as information collected will provide a foundation for evaluating and understanding aspects of these diseases on which we currently do not have a good grasp – such as the geography of diagnoses, variances in gender, disease burden and changes in healthcare practices among patients.

**Links:**
- National MS Society Action Alert
- National MS Society Neurological Data Website
- National MS Society S.849 Talking Points
- National MS Society S. 849 Leave Behind