**Your Name**

**Your Address, City, State, Zip Code**

Date

Senator (Full Name)

(Room #) (Senate Office Building)[[1]](#footnote-1)

United States Senate

Washington, D.C. 20510[[2]](#footnote-2)

Dear Senator \_\_\_\_\_\_\_\_\_:

I am writing to request your support for increased funding of **Prion Disease Surveillance** (*subcommittee: LHHS, agency: Centers for Disease Control and Prevention (CDC), account: Emerging and Zoonotic Infectious Diseases*).  This funding is critical to monitor cases of Creutzfeldt-Jakob Disease (CJD), an invariably fatal neurodegenerative disease. We are very grateful for the support of the House of Representatives in increasing **Prion Disease Surveillance’s** appropriation by $1 million for a total of $7.5 million.  We hope the Senate will support this long-overdue and much-needed increase. In addition, we request your help in encouraging the NIH to designate Prion Disease as one of the “Alzheimer’s Disease Related Dementias (ADRDs).”

Mention your personal story with CJD here.

CJD and other Prion Diseases are invariably fatal. A portion of the $7.5 million Prion Disease Surveillance funding requested for the CDC under Emerging and Zoonotic Diseases is used to fund the brain autopsy program at the National Prion Disease Pathology Surveillance Center (NPDPSC).  This provides families with answers about whether their loved one died of a sporadic, genetic, or acquired form of Prion Disease.  The program also monitors whether Bovine Spongiform Encephalopathy (commonly known as “mad cow” disease) and Chronic Wasting Disease (CWD) Prion Diseases in cow and in deer and elk, respectively, may have been transmitted to humans. With CWD now in 30 states, surveillance to assess whether it may be transmitting to humans is increasingly critical and is generating additional costs for the program. We request you ask the Appropriations Committee to:

1. **Increase prion disease surveillance’s appropriation through the CDC and NPDPSC from $6.5 million to $7.5 million to enable the CDC and NPSPSC to:**

* Monitor CJD cases and determine whether new strains are emerging
* Develop tests to determine whether CWD in deer and other cervids is spreading to humans
* In light of the rapid spread of CWD, provide increased surveillance, tissue collection, diagnostics, and diagnostic test development of prion disease cases from CWD endemic states.

2. **Encourage the NIH (NINDS and NIA) to include Prion Diseases (including CJD) in the definition of “Alzheimer’s Disease Related Dementias” (ADRD) Prioritized Research Milestones.** Prion Disease is clinically and scientifically similar to Alzheimer's Disease. Early discoveries about CJD were very valuable in studying other ADRDs, and this synergistic sharing of discoveries should continue, to benefit all protein-based diseases.

Thank you for reviewing this request. If you have questions, you may reach me at the number or email below.

Sincerely,

Your Name

Phone Number

Email

1. You can find senators’ room numbers and office building names [here](https://www.senate.gov/senators/index.htm). [↑](#footnote-ref-1)
2. Here is an example:

The Honorable Rob Portman

Hart Senate Office Building

United States Senate

Washington, D.C. 20510 [↑](#footnote-ref-2)