Dear (XXXX),

I hope this email finds you well. As the Fiscal Year (FY) 26 budget and appropriations process continues, I am writing on behalf of the Creutzfeldt-Jakob Disease Foundation (CJDF) to underscore the importance of maintaining the Centers for Disease Control and Prevention (CDC) funding for human prion disease surveillance at the National Prion Disease Pathology Surveillance Center and recognizing prion diseases under the Alzheimer’s Disease and Related Dementias (ADRD) category.

Thank you for your consideration of these two timely asks:

* Please reach out to HHS and ask that the Department continue prion disease surveillance by the National Prion Disease Pathology Surveillance Center (NPDPSC) which is currently funded through the CDC, but was proposed to be zeroed out in the President’s FY26 budget
* Please request Rep./Sen. \_\_\_\_\_’s support for related FY 26 appropriations and report language requests to ensure essential surveillance and research funding for prion diseases, including CJD, continues. Specific requested report language is included below.

By way of background, CJD (a form of prion disease) is a degenerative brain disease that progresses rapidly and is always fatal. There is no treatment, and people with CJD usually die within one year of becoming ill. CJD occurs when a folded protein in the brain called a “prion” folds abnormally, causing large parts of the brain to be destroyed. Individuals with CJD often exhibit symptoms similar to other degenerative brain diseases like Alzheimer’s and Parkinson’s, making diagnosis difficult. The only true way to diagnose the disease and determine its source is through a postmortem examination. While rare, CJD ravages families, and because there is no treatment or cure, it is extremely difficult for caregivers who know that their loved ones are facing certain death.

The National Prion Disease Pathology Surveillance Center (NPDPSC), is funded by the Centers for Disease Control and Prevention’s (CDC) Emerging and Zoonotic Infectious Diseases account, conducts diagnostics on suspected cases of prion disease to determine their cause and is the only laboratory-based organization in the U.S. that monitors human prion diseases and is able to determine whether a patient acquired the disease through the consumption of prion contaminated beef (known to cause Bovine Spongiform Encephalopathy (BSE) or “mad cow” disease) or is due to a novel prion disease, such has transmission of chronic wasting disease (CWD) from deer/elk to humans. CDC prion disease surveillance funding is also used for epidemiology and select state public health departments to assist in investigations of possible outbreaks. Continued funding is vital to human prion disease surveillance efforts and we urge Rep./Sen.\_\_\_ to support maintaining at least the current level for the NPDPSC in FY 26. The NPDPSC is the primary line of defense in safeguarding U.S. public health against prion diseases and reducing or eliminating funding would jeopardize comprehensive prion disease surveillance, which is an important safety net to U.S. public health.

I am also writing to request Rep./Sen.\_\_\_\_’s support for report language in the FY 26 Labor-HHS Appropriations Committee Report encouraging the National Institutes of Health (NIH) to recognize prion diseases under the Alzheimer’s Disease and Related Dementias (ADRD) category. The National Alzheimer’s Project Act (NAPA) Advisory Council has acknowledged the scientific connection between prion diseases and ADRDs, but does not include prion diseases in the ADRD category. Clarification on how diseases are selected for the ADRD category, and inclusion of prion disease as an ADRD, would ensure integrated research that may benefit individuals suffering from CJD as well as other ADRDs.

[Option to insert a few sentences to customize any personal connection to CJD the advocate would like to share.]

Thank you for your consideration of these requests which are particularly timely as the President’s FY 2026 Budget proposed eliminating funding specific to CDC human prion disease surveillance. As the House and Senate Appropriations Committees are moving forward with the FY 2026 appropriation process, I hope you will weigh in and convey your support for both maintaining this critical surveillance funding and research focus on CJD. Please do not hesitate to reach out with any questions.

For additional reference, below please find the specific report language being requested:

**Centers for Disease Control and Prevention Account**

Prion Disease Surveillance.—The Committee is concerned that Chronic Wasting Disease (CWD), a fatal condition in cervids (deer, elk, and moose) caused by misfolded prions, has been detected in 36 states and all four regions of the country. Monitoring the prevalence of human prion disease, including determining a disease’s incidence and whether it was acquired from animals or other humans, is critical. In light of scientific observations regarding the nationwide spread of CWD and concerns about the potential for cross-species transmissions to humans and food production animals, the Committee includes $8.5 million for surveillance efforts of human prion diseases, including Creutzfeldt-Jakob Disease, through the National Prion Disease Pathology Surveillance Center and CDC.

**National Institutes of Health Account**

Creutzfeldt-Jakob Disease.—The Committee commends the NAPA Advisory Committee report from 2023 that acknowledges the scientific connection between prion diseases and Alzheimer's Disease and Related Dementias [ADRDs], and the 2024 Update that specifically mentioned CJD, and continues to encourage NIH to recognize prion diseases as ADRDs and fund more research for prion diseases, like Creutzfeldt-Jakob Disease [CJD]. ADRDs have already benefited from prion disease research, and further integration of the fields could lead to beneficial new treatments and improve our scientific understanding of these devastating diseases.

Sincerely,