

Creutzfeldt-Jakob Disease Foundation Advocacy Update

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Anna K. Abram
Senior Advisor

aabram@akingump.com
Washington, D.C.
+1 202.887.4151



Agenda

117th and 118th
Congress Advocacy

Importance of
Federal Advocacy

Questions

Akin Core Team



Anna K. Abram
Senior Advisor
aabram@akingump.com
Washington, D.C.
+1 202.887.4151



Mia Heck
Consultant
mheck@akingump.com
Washington, D.C.
+1 202.419.4612



Mario Luis Ramirez, M.D.
Consultant
mramirez@akingump.com
Washington, D.C.
+1 202.877.4000



Virgil A. Miller, M.P.H.
Senior Policy Advisor
vmiller@akingump.com
Washington, D.C.
+1 202.887.4590



June Nam
Public Policy Specialist
jnam@akingump.com
Washington, D.C.
+1 202.416.5051

2022 Advocacy Recap (117th Congress)

FY 23 Omnibus Bill: Legislative Win for CJDF

The Consolidated Appropriations Act, 2023 (P.L. 117-328) contained two key successes for CJDF: recognition under CDC as a prion disease, as well as a funding increase.

- The final FY 23 Labor-HHS explanatory statement included the following report language under CDC, which CJDF requested:
 - Prion Disease - The agreement includes an increase to advance efforts on human prion diseases, including Creutzfeldt-Jakob Disease, which are rapidly progressive and fatal neurodegenerative diseases that occur in both humans and animals, and recognizes the critical work of the National Prion Disease Pathology Surveillance Center.
 - Prion disease under CDC's Emerging and Zoonotic Infectious Disease account received a \$1 million increase and was funded at \$7.5 million in FY 23.

The language in the House Labor-HHS report under NIH regarding prion disease and brain health, and recognizing prion disease as an ADRD, was maintained in the final omnibus bill.

- The final omnibus bill did not specifically mention CJD under NIH.

**2023 - March 2024
Advocacy Recap
(118th Congress)**

Congressional Resolution on Creutzfeldt-Jakob Disease

118TH CONGRESS
1ST SESSION

H. RES. 821

Supporting the goals and ideals of “Creutzfeldt-Jakob Disease (CJD) Awareness Day”.

IN THE HOUSE OF REPRESENTATIVES

OCTOBER 26, 2023

Mr. VALADAO (for himself, Mr. COSTA, Ms. BROWN, Ms. SLOTKIN, Mr. JOYCE of Ohio, and Mr. MCCARTHY) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Supporting the goals and ideals of “Creutzfeldt-Jakob Disease (CJD) Awareness Day”.

Whereas Creutzfeldt-Jakob Disease (referred to in this resolution as “CJD”) is a rare, fatal brain disorder within a group of illnesses called prion diseases;

Whereas CJD occurs in approximately 1 to 2 cases per million individuals each year, resulting in approximately 500 cases annually in the United States, 85 percent of which are designated as sporadic, with no known causes, while 10 to 15 percent are deemed genetic and fewer than 1 percent are deemed acquired;

Whereas, in the early stages of the disease, CJD patients may exhibit failing memory, behavioral changes, impaired coordination, and visual disturbances, and as the illness

On Oct. 26, 2023, Reps. David Valadao (R-CA), Jim Costa (D-CA), David Joyce (R-OH), Shontel Brown (D-OH), Elissa Slotkin (D-MI) and Kevin McCarthy (R-CA) introduced the inaugural CJD Awareness Day Congressional Resolution (H.Res. 821). Additional co-sponsors have signed on: Reps. Jerrold Nadler (D-NY) and Josh Harder (D-CA).

“I’m proud to introduce this bipartisan resolution that would designate November 12, 2023 as CJD Awareness Day to honor Mayor Hall’s memory and help raise awareness for CJD patients and their families across the country.”

-Congressman David Valadao (R-CA),
October 30, 2023

CJDF's FY 2024 Appropriations Requests

Ask: Urge Congress to increase prion surveillance funding for CDC and NPDPSC by \$1 million in FY 2024, for a total of \$8.5 million, to support the following activities:

- Development of a comprehensive prion disease surveillance for more efficient detection methods; and
- Maintain appropriate tissue collection, diagnostics, and diagnostic test development of prion disease cases from CWD-endemic states.

Ask: Encourage Congress to influence the NIH to include CJD as a Prion disease within the ADRD category for FY 2024, to support the following activities:

- Further advance the study of CJD and other prion diseases by allowing AD/ADRD researchers to study the prion paradigm in other related conditions, enabling the use of more valid animal models; and
- Strengthen caregiver and health services research of AD/ADRD to be applied to prion disease, which shares many of the same challenges.

CJDF's FY 2024 Appropriations Wins

The FY 2024 House Labor-HHS bill included \$8 million for prion diseases.

The FY 2024 Senate Labor-HHS report included the following report language-

- **CDC:** Prion Disease Surveillance.—The Committee includes \$7,500,000 for surveillance efforts of human prion diseases, including Creutzfeldt-Jakob Disease, through the National Prion Disease Pathology Surveillance Center and CDC. Monitoring the prevalence of prion diseases, including whether a disease was acquired from animals or other humans, is particularly critical for Chronic Wasting disease endemic areas.
- **NIH:** Creutzfeldt-Jakob Disease.—The Committee encourages NIH to continue to fund projects investigating Creutzfeldt-Jakob Disease [CJD] and other prion diseases, which are rapidly progressive and fatal neurodegenerative diseases, including projects that are also relevant to Alzheimer's Disease and Related Dementias [ADRD]. CJD is caused by the abnormal folding of the prion protein in the brain, and closely resembles ADRDs.

The FY 2024 final minibus (P.L. 118-47) included \$8 million for prion disease, under CDC's Emerging and Zoonotic Infectious Diseases. The Senate report language carries the same weight as language included in the bill's accompanying explanatory statement.

Updates Since March 2024 Advocacy Visits

Hill Advocacy Goals

CJDF's mission is to advance research to optimize the prevention, early diagnosis and successful treatment of the life-threatening, degenerative brain disease that causes rapidly progressive dementia.

Educate Congress about CJD/prion disease and the need for funding to find treatments and cures for CJD/prion disease.

- CJD is a rare, 100% fatal, degenerative brain disease that causes rapidly progressive dementia.
- CJD is transmissible and presently has no treatment or cure, and diagnosis remains challenging.
- There are about 500 new cases of CJD annually in the United States.
- CJD falls within a group of illnesses called prion diseases, which are the result of misfolded proteins in the brain, called prions.
- Of the cases, 85% are sporadic, with no known causes, while 10-15% are deemed genetic and less than 1% are deemed acquired.
- CJD typically leads to death within a few months to one year following the onset of symptoms.

Make the Asks

- Support \$8.5 million for CDC/National Prion Disease Pathology Surveillance Center to fund prion surveillance in FY 2025.
- Encourage Congress to influence the NIH to include CJD as a prion disease within the ADRD category.
- Request support for passage of House version of the NAPA Act (H.R. 619/S. 133).
- Co-sponsor 2024 Congressional Resolution recognizing "CJD Awareness Day."

Offer CJDF as a resource for Members of Congress and their staff on prion disease issues.

FY 2025 Appropriations Requests

Ask: Support \$8.5 million for CDC and NPDPS to fund prion surveillance funding in FY 2025.

- Congress currently provides very limited funding for CJD research.
- Ongoing funding is limited to disease surveillance, including the National Prion Disease Pathology Surveillance Center (NPDPS), through the Centers for Disease Control and Prevention's (CDC) Emerging and Zoonotic Infectious Diseases account.
- NPDPS 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 meat from elk and deer affected by Chronic Wasting Disease (CWD).
- NPDPS is the primary line of defense in safeguarding U.S. public health against prion diseases.

Ask: Encourage Congress to influence the NIH to include CJD as a prion disease within the ADRD category.

- Encouraging NIH to further study CJD and other prion diseases within the "Alzheimer's Disease-Related Dementias" (ADRD) category would ensure integrated research that may benefit individuals suffering from CJD as well as other ADRDs, and encourage NIH to more equitably distribute funding to research CJD and other prion diseases.
- There are many similarities between AD/ADRDs and prion disease, and ADRDs have already benefited from prion disease research.

FY 2025 Appropriations Report Language Requests

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 over 30 states and all four regions of the country. Monitoring the prevalence of prion diseases, 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 Council report from 2023 that acknowledges the scientific connection between prion diseases and Alzheimer's Disease and Related Dementias [ADRDs] 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.

FY 2025 Appropriations - Latest State of Play

The FY 2025 House Labor-HHS bill included \$8.5 million for prion diseases.

The FY 2025 House Labor-HHS Report included:

- **CDC: *Prion Disease*.**—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 over 30 States and all four regions of the country. Monitoring the prevalence of prion diseases, 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 \$8,500,000 for surveillance efforts of human prion diseases, including Creutzfeldt-Jakob Disease, through the National Prion Disease Pathology Surveillance Center and CDC.
- **NIH: *Creutzfeldt-Jakob Disease*.**—The Committee commends the National Alzheimer’s Project Act Advisory Council report from 2023 that acknowledges the scientific connection between prion diseases and Alzheimer’s Disease and Related Dementias (ADRDs) 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. CJD is caused by the abnormal folding of the prion protein in the brain, and closely resembles ADRDs. Enhanced research of CJD, through the BRAIN Initiative and the Alzheimer’s Disease research portfolio, will be valuable to the study of ADRDs and vice versa, and further integration will benefit scientific pursuits in both fields with the goal of new treatments for neurodegenerative diseases.

The Senate Appropriations Committee has not yet released their FY 2025 Labor-HHS bill and related report.

The National Alzheimer's Project Act (NAPA) (H.R.619/S.133)

The National Alzheimer's Project Act (NAPA) Act (P.L. 111-375) was signed into law in 2011 and its authorization expires on December 31, 2025.

- Established the National Alzheimer's Project to create and maintain a national plan to overcome Alzheimer's; coordinate Alzheimer's research and services across all federal agencies; and accelerate the development of treatments and cures for Alzheimer's.
- Established an Advisory Council on Alzheimer's Research, Care and Services to provide advice on how to prevent or reduce the burden of Alzheimer's disease and related dementias (ADRD) on people with the disease and their caregivers.
- The law defines Alzheimer's as "Alzheimer's disease and related dementias."
- **The 2023 Advisory Council National Plan** states that ADRD includes "frontotemporal dementia (FTD), Lewy body dementia (LBD), vascular contributions to cognitive impairment and dementia (VCID), and mixed dementias -- especially AD mixed with cerebrovascular disease or Lewy bodies."
- **Noted that NINDS issued a funding opportunity to promote research on understanding why AD/ADRD shares certain features of prion diseases, and that this broader view of the basic biology of AD/ADRD could lead to potential breakthroughs.**

Ask: Support for the House Energy & Commerce Committee approved version of H.R. 619 which includes a provision that requires a summary of HHS' process for identifying and updating what conditions constitute ADRDs in the annual report to Congress as part of NAPA Act reauthorization.

- Developing science from other neurodegenerative diseases indicates a connection between the prion paradigm and ADRDs.
- Incorporating this knowledge ensures transparency around the most current scientific understanding of these diseases and how that understanding is evolving as informed by scientific advances

Congressional Resolution on Creutzfeldt-Jakob Disease

Support for Introduction of Congressional Resolution recognizing “Creutzfeldt-Jakob Disease (CJD) Awareness Day” on November 12, 2024.

- To highlight Creutzfeldt-Jakob Disease Awareness Day, Akin drafted a resolution to inform Members of Congress to learn more about CJD and consider how they may support affected patients, families, and communities.

Ask: Request Members of Congress to support the 2024 CJD Awareness Day Congressional Resolution.

March 2024 Hill visits

51 total Hill meetings

21 Senate meetings

30 House meetings

Leadership offices, committee staff, and personal offices

CJDF's sustained Hill advocacy has yielded results:

- ✓ FY 2023 Approps Wins
- ✓ FY 2024 Approps Wins
- ✓ Inaugural CJD Awareness Resolution
- ✓ Language in House NAPA Reauthorization bill
- ✓ FY 2025 House Approps Language

Advocacy

+

Cheerful
persistence

=

Results

Questions?

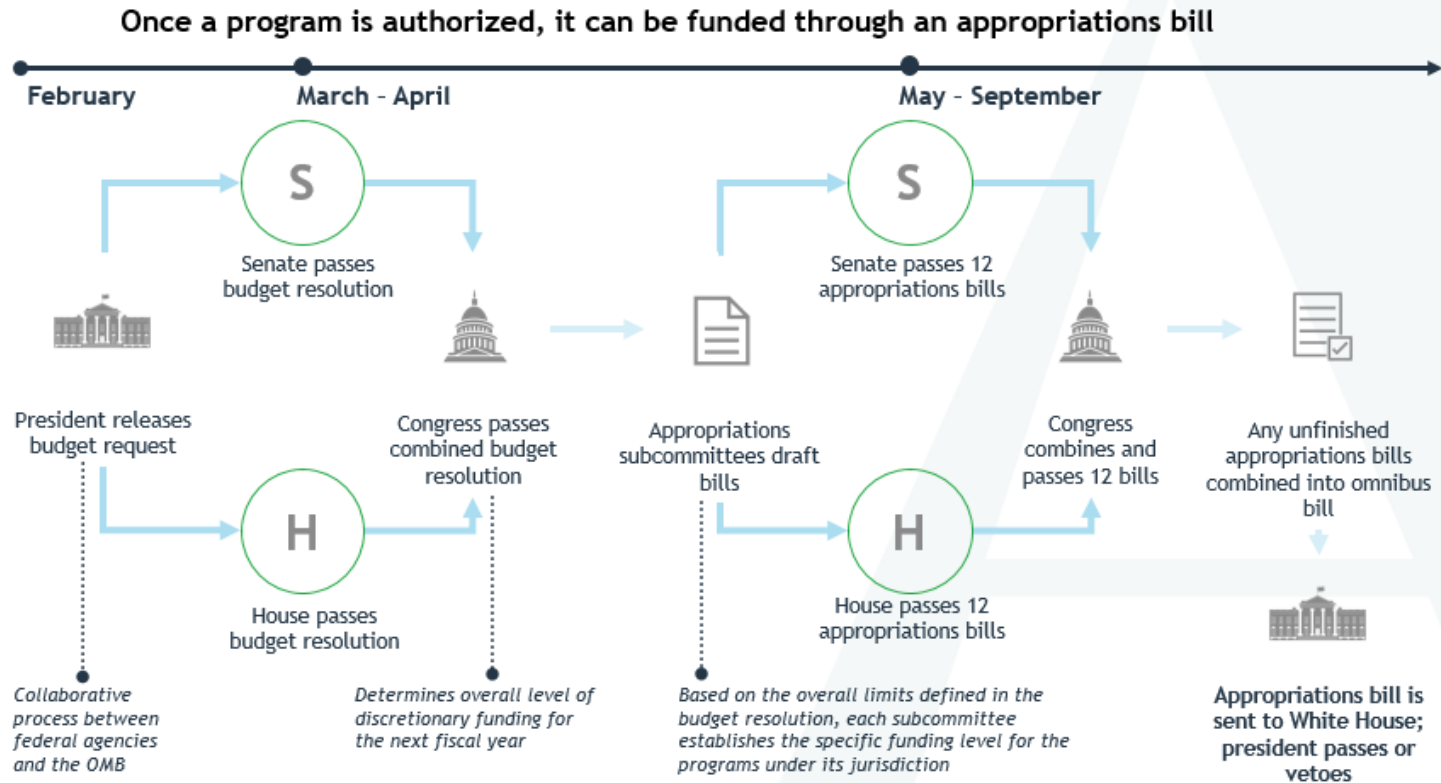


CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

Supporting Families Affected by Prion Disease

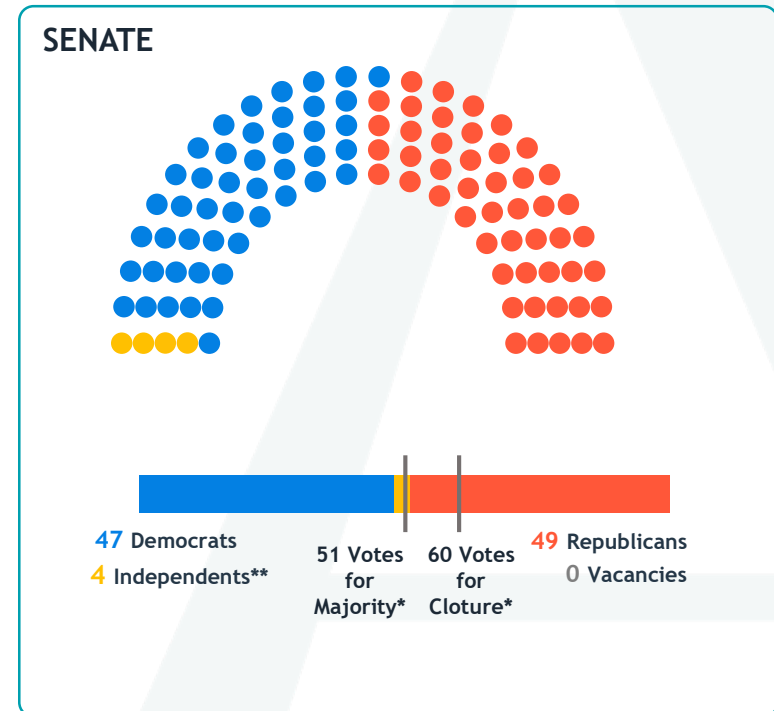
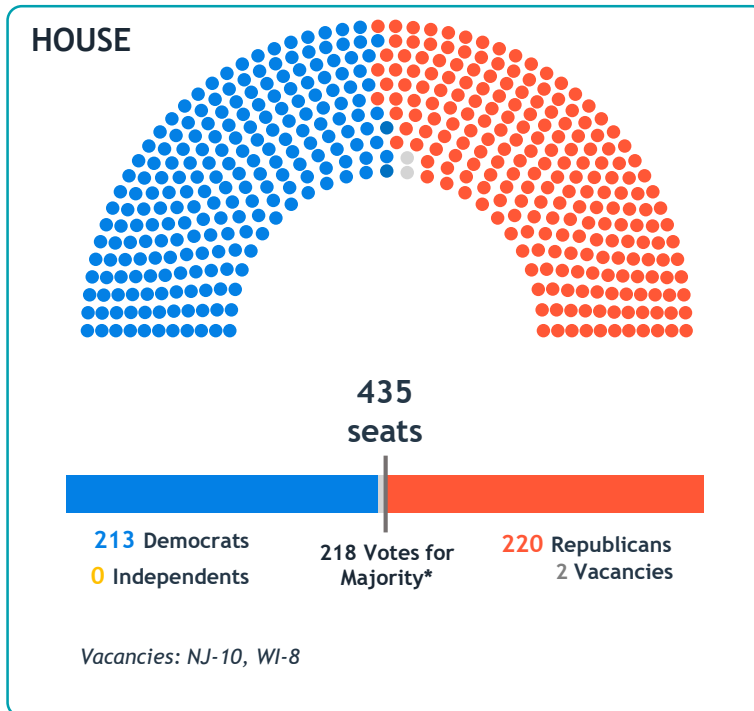
The Appropriations Process

- House and Senate Appropriations Committees are still in the process of considering the 12 annual spending bills for FY 2025. FY 2025 begins October 1, 2024.



A Divided Congress

- House Republicans have a slim majority (need 218 for bill passage).
- In the Senate, 60 votes are needed to pass a bill, making bipartisan support necessary.



*If no vacancies and all members vote

**Sens. Sanders (VT), King (ME) and Manchin (WV) caucus with the Democrats; Sen. Sinema (AZ) caucuses with neither party but receives committee assignments from Democrats