

# Creutzfeldt-Jakob Disease Foundation 2023 Fly-In

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**Kendall B. Hussey**  
Senior Policy Advisor

khussey@akingump.com  
Washington D.C.  
+1 202.416.5207



# Agenda

Overview of Akin Gump's Public Law and Policy Practice and Core CJDF Team

2022 Advocacy Recap

118<sup>th</sup> Congress Advocacy Activity

Importance of Federal Advocacy

- Hill Day Tips
- Meeting Goals
- 118<sup>th</sup> Congress Dynamics

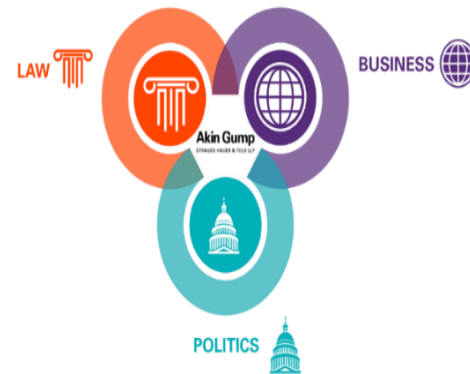
Questions

# Akin Gump's Public Law and Policy Practice

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# Public Law and Policy (PLP) Practice Overview

- More than 75 lawyers and other professionals who practice on legislative and policy matters.
- PLP is comprised of professionals who have served in elected office or as senior staff to members of Congress, congressional committees or in senior positions in the executive branch of the federal government.
- Strong substantive knowledge in all areas of policy. We can convincingly make arguments before Congress and regulatory officials based on who we know and what we know.
- We have a broad range of active representations before Congress and the executive branch, including federal departments and agencies.
- Consistently ranked as one of the top government relations practices in Washington, D.C., by both publications and our peers. Akin Gump's government relations practice is ranked Band 1 in *Chambers USA*.



“They have been excellent, given us great advice and have helped guide us through the channels and point us in the right direction. They know who the right people are to contact for various matters.

They have an all-around phenomenal government relations team.”

—*Chambers USA: America's Leading Lawyers for Business*

# PLP Range of Services

The public law and policy practice represents many Fortune 500 and Fortune 100 U.S. corporations. We also represent a wide range of individuals, small or medium-sized U.S. companies, nonprofit organizations, municipal governments and agencies, Native American tribes, foreign governments, foreign-based companies and organizations, foreign nationals and domestic and international coalitions and trade associations.

Akin Gump has organized its public law and policy practice in a way that affords clients the widest possible range of services, including the following:

- development of comprehensive strategic and tactical plans to achieve specific legislative, policy or regulatory objectives at all levels of government in the United States and abroad
- direct advocacy with government decision-makers
- formation and coordination of professional teams—including, for example, media, local counsel and/or other consultants—to advance client objectives at a single level of government or in multiple government venues (e.g., state/federal, multistate, international)
- support for advocacy by client government relations staff
- drafting, analyzing and monitoring of legislation, policy and regulations
- legislative and oversight investigation, including witness hearing preparation
- formation and management of coalitions
- management and organization of grass roots and grass tops lobbying efforts
- advocacy related to mergers and acquisitions
- planning and communicating public policy initiatives
- counseling on election law, ethics rules and political compliance
- advocacy and management of state referenda and initiatives
- Representation in regulatory rulemaking/enforcement proceedings.

“The top of everyone's list for lobbying. Subject experts actually reside within their government relations group, so there's a large number of people engaged in that work.”

—Chambers USA



# Akin Core Team

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



Kendall B. Hussey  
Senior Policy Advisor  
khussey@akingump.com  
Washington, D.C.  
+1 202.416.5207



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

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Derrick Stanfield  
Public Policy Specialist  
dstanfield@akingump.com  
Washington, D.C.  
+1 202.416.5051

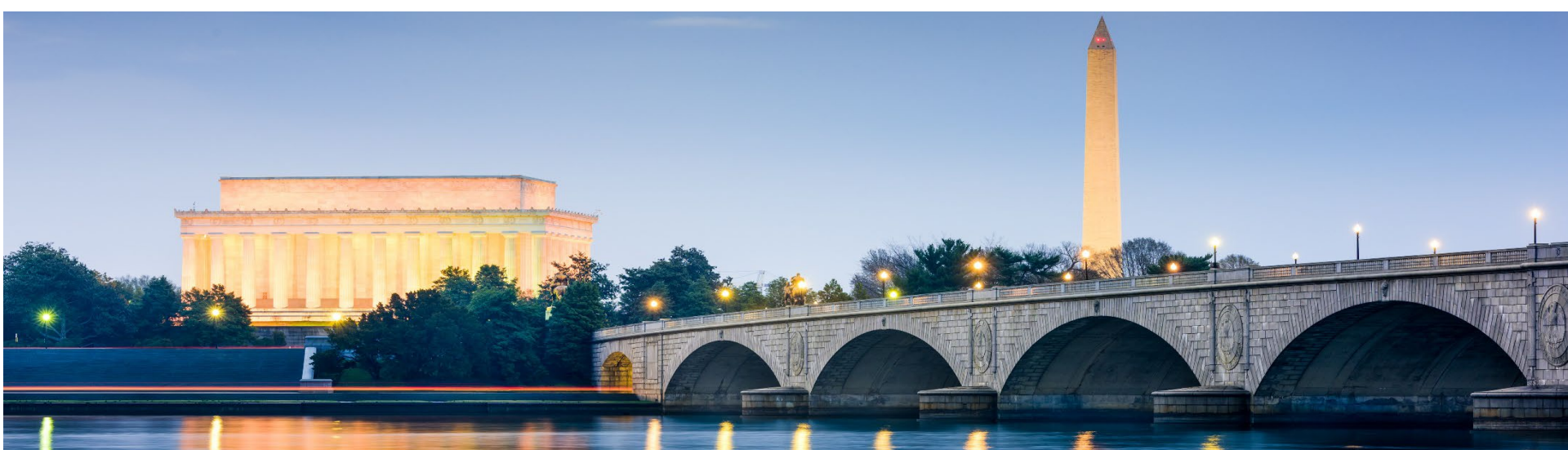
# 2022 Advocacy Recap

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# 2022 Advocacy Goals

CJDF previously identified the following advocacy objectives:

1. Adding Prion Disease, and specifically CJD, to the definition of Related Dementias under “Alzheimer’s Disease and Related Dementias”(ADRD) authorizing language for purposes of National Institutes of Health (NIH) research and funding;
2. Identifying opportunities for funding for surveillance and research of Prion Disease throughout the federal government;
3. Preserving the Centers for Disease Control and Prevention (CDC) funding for the Case Western Reserve University’s National Prion Disease Pathology Surveillance Center (NPDPSC).





# 2022 Advocacy Goals (cont.)

- CJDF began working with Akin Gump in September 2022 after the FY 2023 appropriations cycle had begun. However, both the Senate and House Appropriations Committees drafted report language offered an initial opportunity for CJDF to discuss its funding and policy recommendations and begin building relationships with Appropriations Committee staff ahead of the FY 2024 appropriations cycle.
  - The House Appropriations Committee approved the Labor-HHS explanatory report that included a \$ 1 million increase “to advance efforts on human prion diseases,” recognizing the critical work of the NPDPSC.
    - Also included report language that encourages NIH to recognize prion disease as an ADRD.
  - The draft Senate Appropriations Committee Labor-HHS report did not include increased funding and supportive report language, which provided an opening for CJDF to weigh in with Senate appropriators and their staff.

# Fiscal Year 2023 Appropriations

- In fall 2022, CJDF met with staff of the House and Senate Appropriations Committees to request changes to report language accompanying the Labor-HHS appropriations bill and to advocate for increased funding for prion disease surveillance at the National Prion Disease Pathology Surveillance Center in Fiscal Year (FY) 2023.
  - The House Labor-HHS report included a \$1 million increase; the draft Senate Labor-HHS report did not include a funding increase.
  - Under NIH, the House report included language that may have inadvertently excluded CJD from recognition as a prion disease under the Alzheimer's Disease and Alzheimer's Disease Related Dementias category and under the NINDS' BRAIN Initiative and the Alzheimer's disease research portfolio.
  - CJDF advocated that CJD should be specifically mentioned as a prion disease.

# FY 23 Omnibus Bill: Legislative Win for CJDF

- On Dec. 29, 2022, President Biden signed the Consolidated Appropriations Act, 2023 (P.L. 117-328).
- The legislation 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 will be 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.

# Additional Congressional Engagement

To complement appropriations advocacy, Akin Gump supported outreach to the Ohio congressional delegation in the House and Senate, select offices on the Senate Health, Education, Labor, and Pensions Committee and House Energy and Commerce Committee, and select members of the Rare Disease Caucus to strengthen CJDF's relationships with key Members.

# National Institutes of Health Outreach

- **2022 Goal:** Develop an allied relationship and improve communication with prion disease program director at the National Institutes of Health (NIH).
- On December 19, CJDF met with Dr. William Daley, NINDS Program Manager for Prion Disease Portfolio, and Rebekah Corlew, Office of National Institute of Neurological Disorders and Stroke (NINDS) Communication and Public Engagement.
  - This was the first direct contact between CJDF and Dr. Daley since he assumed this position and a big improvement over the prior NIH interaction.
  - Dr. Daley provided insight into language and wording that should be used in grant proposals to help make them applicable for monies earmarked under Alzheimer's disease.
  - Dr. Daley also outlined and recommended that CJDF develop an agenda and apply for an NIH R-13 grant to support a new CJD focused conference.
  - Dr. Daley stated that he will try to attend the summer 2023 CJDF conference.
- Akin Gump initiated contact with Dr. Dawn Beraud, Policy Director at the National Institute on Aging (NIA)/NIH to further facilitate relationships across institutes.

# 118th Congress Advocacy Activity

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# 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.

# Congressional Resolution on Creutzfeldt-Jakob Disease

Support for Introduction of Congressional Resolution recognizing “Creutzfeldt-Jakob Disease (CJD) Awareness Day” on November 12, 2023.

- 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 CJD Awareness Day Congressional Resolution.

# NAPA Reauthorization Outlook

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 (ARD) on people with the disease and their caregivers.
- The law defines Alzheimer's as "Alzheimer's disease and related dementias."
- The Advisory Council's 2022 report states that ARD 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."
- There is no mention or prion disease.

Ask: Support for updating what conditions constitute ARDs in annual report to Congress as part of NAPA Reauthorization legislation.

- Developing science from other neurodegenerative diseases indicates a connection between the prion paradigm and ARDs.
- 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

# 2023 NIH Outreach

**2023 Goal:** Pressure test and strengthen relationship with prion disease program director, Dr. William Daley

On June 28, CJDF submitted a draft R-13 grant proposal to NIH/NINDS for financial support of a CJD focused conference

- Proposal was met with significant enthusiasm from Dr. Daley who provided detailed feedback and internal assistance at NIH to support approval
- On June 30, the proposal was approved by NIH with broad support from NINDS and NIA including Alzheimer's Disease focused researchers
- Conference approval is a strong indication of a growing relationship between CJDF and NIH

Akin and CJDF also met with with Dr. Dawn Beraud, Policy Director at the National Institute on Aging (NIA)/NIH on January 23<sup>rd</sup>

- Meeting included multiple participants from NIA willing to partner with CJDF on grants and additional research
- Introductions provide an avenue to explore further cooperation with the AD research community

Ask: OH Delegation for letter of support for CJDF's R-13 grant proposal.

# Importance of Federal Advocacy

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# Why It's Important to Meet with Your Representatives and Senators

- Meetings are an effective way to inform and influence lawmakers (and their staff) and educate them about CJDF, Prion Disease, and the need for dedicated federal funding for human Prion Diseases.
- By meeting with Members of Congress, you can begin to build relationships helpful to CJDF's advocacy mission.
- Meetings present opportunities to educate, engage and gain Congressional support for your issue.
- It is their job to listen to YOU, their constituent.





# Tips for a Good Hill Day

- Review the Capitol Hill map and the Congressional office building names.
- Wear comfortable shoes (really...can you walk and stand in them for 8 hours?).
- Do not bring anything not allowed on an airplane (although food and beverages allowed).
- Arrive at Member office at scheduled time - not early and not late.
- Be kind to front office staff and help them by introducing yourself, telling them you are with CJDF, and which staffer the meeting is with and the scheduled time.
- Manage the clock - you need time to walk to your next meeting.
- Do not debrief on the meeting in the hallway.

# Conducting a Successful Hill Meeting

**Be prepared.** Research the Member of Congress you will be meeting with and note the Committee(s) on which he/she serves. Review the key points you want to make and coordinate with your Hill day team.

**Be on time.** Members of Congress and staff have limited time to meet, and are often on back-to-back virtual meetings or calls.

**Plan for a 15-30 minute meeting.** Ensure time to make the ask!

**Make clear introductions.** Introduce yourself and provide a short background on your connection to CJDF. Note if you are a constituent of the Rep/Senator.

**Personalize the issues.** The most persuasive appeal to Members of Congress will be your personal story but stay away from overly graphic descriptions of any medical issues.

**Questions?** Anticipate issues or questions. It is ok to say we will get back to you with an answer.

**Offer to be a resource on prion disease.** Let them know that if future questions arise on prion diseases or CJD, that you/CJDF can help!

**Say thank you.** Thank your Member of Congress/their staff for taking the time to speak with you and follow-up with a thank you email that reiterates CJDF's ask.

# Hill Meeting 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.

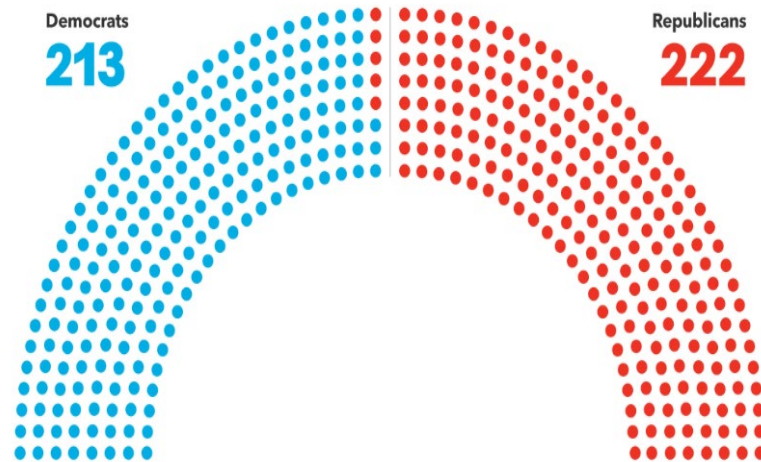
## Make the Ask(s)

- Support a \$1 million increase to prion surveillance funding for CDC and NPDPS
- Encourage Congress to influence the NIH to include CJD as a Prion disease within the ADRD category
- Support for a Congressional Resolution recognizing "CJD Awareness Day"

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

# A Divided Government

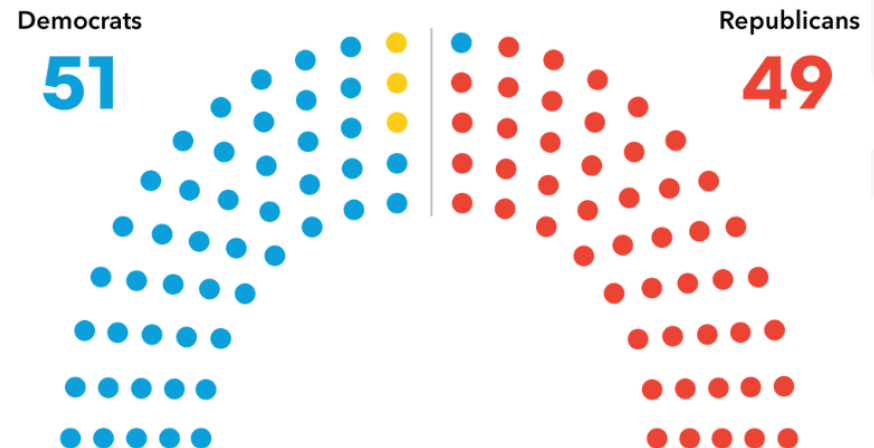
## House Balance of Power



- Upon election to House Speaker, Rep. Kevin McCarthy (R-CA), made several concessions to the conservative House Freedom Caucus, which has also made legislating challenging.

- House Republicans have a slim 4-vote slim majority (need 218 for bill passage).
- In the Senate, 60 votes are needed to pass a bill, making bipartisan support necessary.

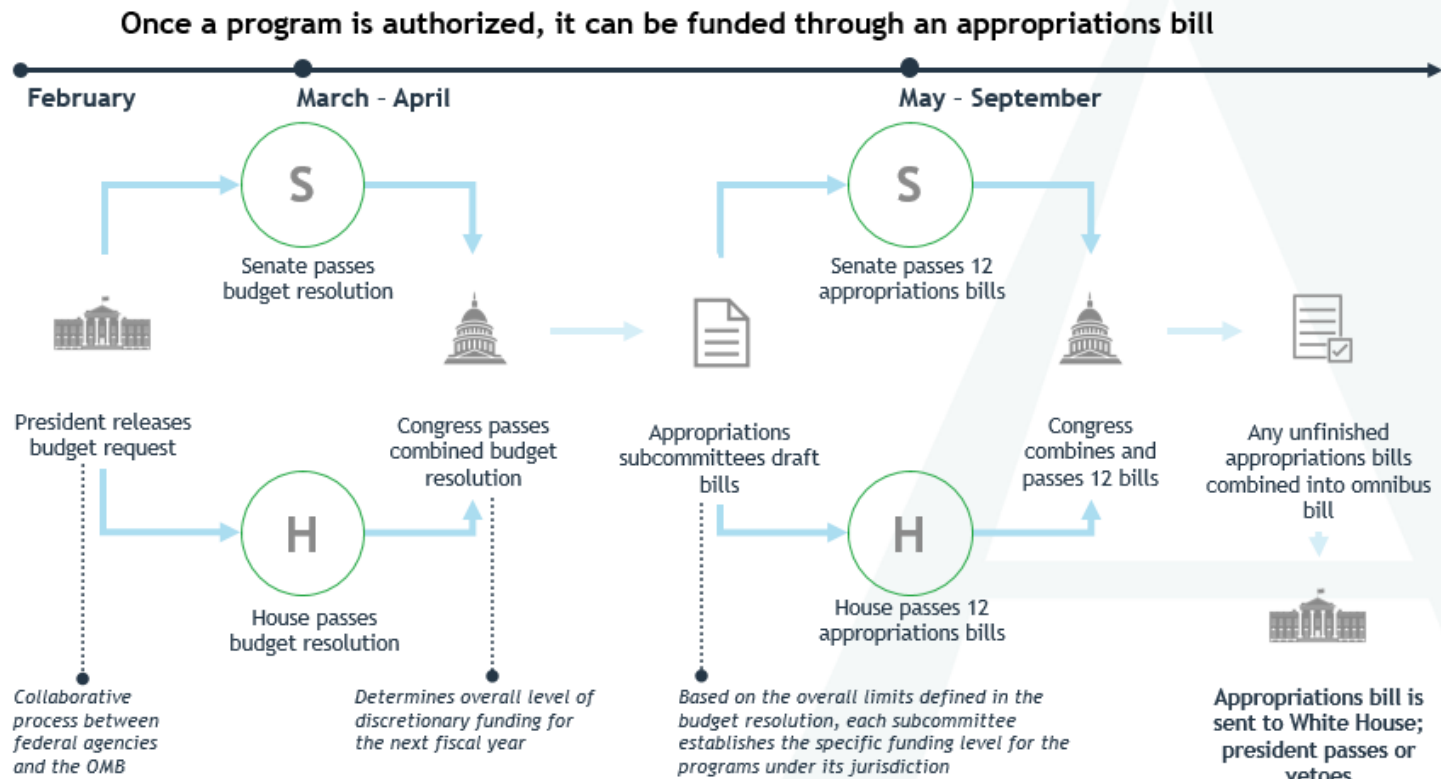
## Senate Balance of Power



Yellow indicates independents who caucus with Democrats.

# The Appropriations Process

- House and Senate Appropriations Committees are in the process of considering the 12 annual spending bills for FY 2024.
- The federal fiscal year ends on September 31, 2023, making that date the deadline for passing all 12 spending bills.



# 118<sup>th</sup> Congress Dynamics

- Upon election to House Speaker, Rep. Kevin McCarthy (R-CA) committed to House Freedom Caucus members that each individual spending bill will go to the House floor for a vote, rather than a multi-bill Omnibus package, which has become the norm at the end of the year.
- Speaker McCarthy also committed to setting spending allocations below FY 22 spending levels.
- The Fiscal Responsibility Act of 2023, the debit limit bill brokered by Speaker McCarthy and President Biden, addressed spending concerns by:
  - Capping nondefense discretionary spending for FY 2024 and FY 2025.
  - Ensuring a 1% spending cut if all 12 appropriations bills for FY 2024 are not passed by the end of 2023.
- Freedom Caucus members continue to push for deeper cuts and are threatening to withhold support for the spending bills.
- Congress only has two more weeks in session before the 6 week August recess, leaving little time to complete passage of all 12 spending bills upon their return after Labor Day.
- In the likely event that all the regular appropriations bills are not passed by the end of the fiscal year, a Continuing Resolution (CR) may be considered to avoid a government shutdown.



# Conclusion

- Don't forget to have fun - you are making a difference!



CREUTZFELDT-JAKOB DISEASE  
FOUNDATION, INC.

*Supporting Families Affected by Prion Disease*