

# Creutzfeldt-Jakob Disease Foundation Advocacy Tips

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**Anna K. Abram**  
Senior Advisor

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



## Agenda

Importance of  
Federal Advocacy

Advocacy Tips

# Akin Core Team

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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

# Importance of Federal Advocacy



# 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 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 Representative/Senator.

**Personalize the issues.** The most persuasive appeal to Members of Congress will be your personal story but we recommend staying 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 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 and NPDPSA to fund prion surveillance funding 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.



# Building on March 2024 Momentum

CJDF's sustained Hill advocacy is yielding 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*