

CJD Foundation Update

Stuart Yaffa, Board Chair

Jacob Schwister, Finance Committee

July 2025



CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

Supporting Families Affected by Prion Disease



CJD Foundation Update

- Family Conference
- HelpLine
- Support Groups
- Website
- Advocacy
- Research Grants
- Scientific Conference
- Strides for CJD



Family Conference





Helpline

- 7 Days
- More than 1,000 contacts each year
- Patient families, professionals, media, public
- Referrals to professionals, studies, programs, caregiving materials, web content and recordings

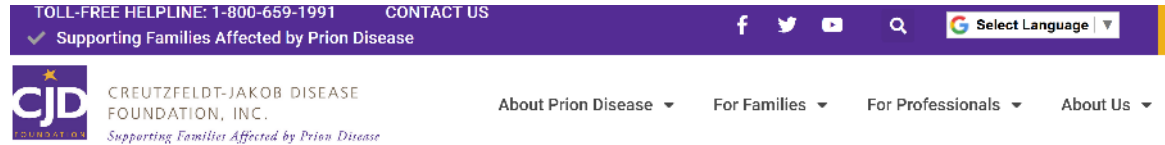


Support Groups

Group	Type	Sessions
Current Caregiver	Current caregivers; co-led by volunteers	11
Eastern Region	Current and past caregivers; sporadic and genetic	8
Western Region	Current and past caregivers; sporadic and genetic	8
Genetic	People at risk; current and past caregivers	7
Other	Guest speakers, bereavement series	10
Total Sessions/12 months		44



Website



Sporadic CJD (sCJD) occurs for no apparent reason and accounts for 85% of the cases.

Cause: Unknown

Distinguishing Features: Affects mainly people over the age of 60. Common symptoms include ataxia and dementia. Short course. Upon tissue examination there is spongiform change, but plaques are rarely present.

Sporadic Fatal Insomnia (sFI) is an extremely rare form of Sporadic CJD representing less than 1% of all cases. sFI has clinical and histopathologic features indistinguishable from those of Fatal Familial Insomnia (FFI), but does not have the mutation on the prion gene that characterizes FFI.

When receiving a diagnosis of prion disease, a family will need to quickly consider several issues:

- ▶ Is it safe for the patient to be alone at any time? If the patient lives alone, who will monitor them daily to determine when this assessment changes? (This can change rapidly as the disease progresses.)
- ▶ If the patient is about to be released from the hospital, should they be in their home, at another home, or at a hospice or other care facility?
- ▶ Should the patient be moved to another community or another state where more family or friends are available? Is the patient still able to travel comfortably and safely?
- ▶ Which family members or friends are available to help? Can a schedule be arranged for them to care for the patient, or serve as companions, in shifts?
- ▶ Can private health aides be hired if needed?



Family Conference Recordings

Past Presentations

➔ 2024 ➔ 2023 ➔ 2022 ➔ 2021 ➔ 2020 ➔ 2019 ➔ 2018 ➔ 2017 ➔ 2016 ➔ 2015



Advocacy

- Partner with Akin all year
- Fall 2024: CJD Awareness Day / Resolution
- March 2025: Advocacy Day on Capitol Hill
- Feb/March: Submit request forms to Appropriations Committee member offices
- May: Submit written testimony to Congress
- Constituent campaigns - continuous



To Participate in Advocacy

- Email Help@CJDfoundation.org
Subject line: Add Me to Advocacy List
- Learn your Senators/Rep's staff email addresses
- When you receive email campaign request:
Copy/Paste/Personalize/Send
- Call your Congressional offices
- Build a relationship
- Attend **Advocacy Day, March 2-3, 2026,**
Washington, DC



Awarded 7 Research Grants and 2 Fellowships in 2025



Alyssa Block, PhD

Grant Title: Refined



Ignazio Cali, PhD

Grant Title: Investigating



**Jose Andres
Alepuz Guillen,
PhD**



Dr. Pei Ying Lee

Grant Title: Assessing



**Szymon W.
Manka, PhD**



**Nina Oberbeck,
PhD, Vice
President of
Translational
Sciences**



**Jakub Soukup,
PhD**

Grant Title: Higher-
resolution visualization of
prion fibrils in neurons and



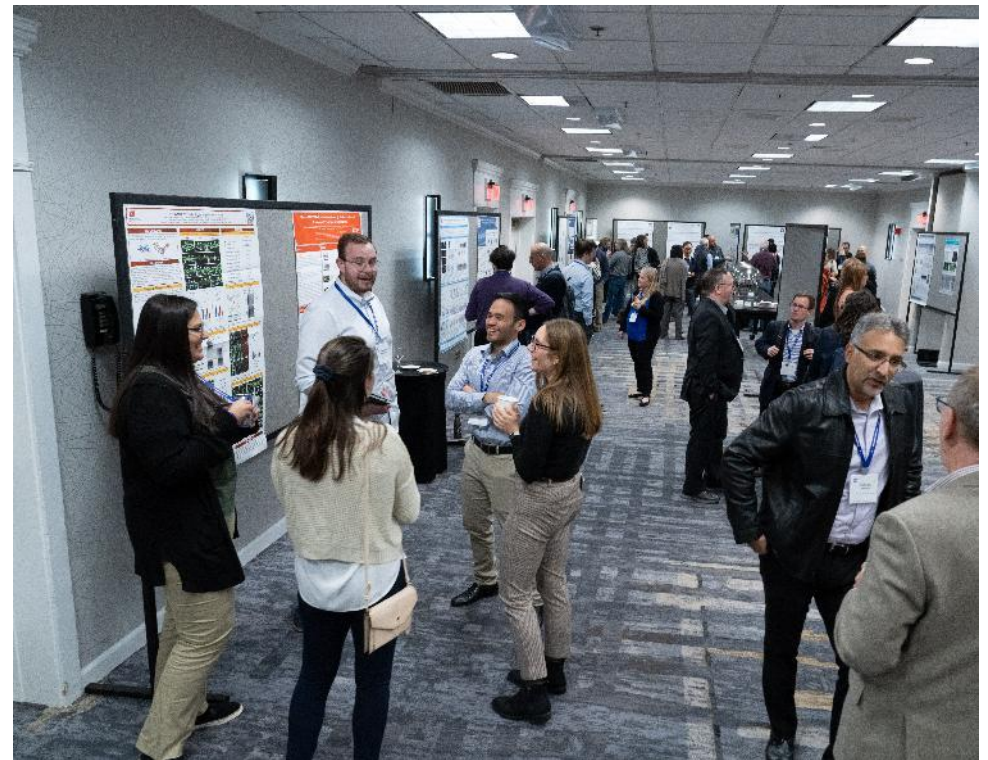
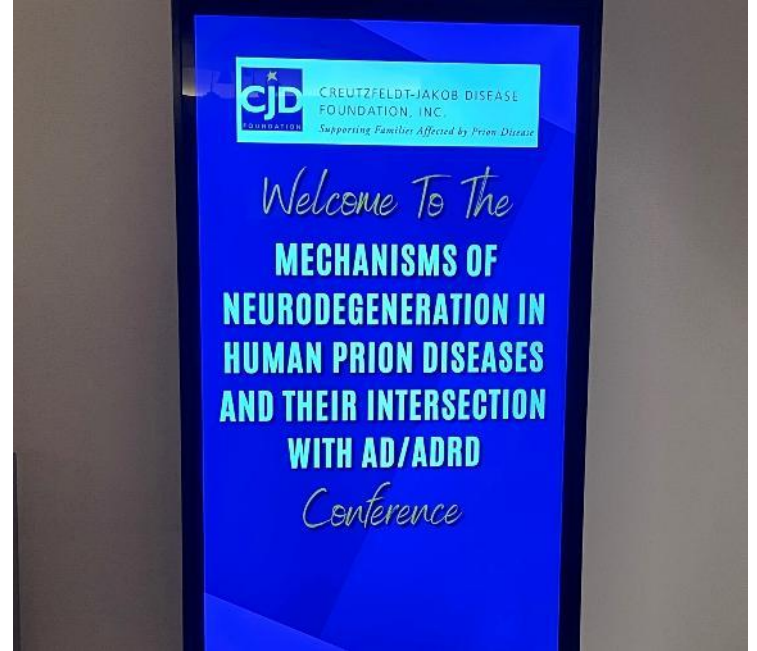
Joel Watts, PhD

Grant Title: Engineered
biosensors for improved
prion detection
Location: Tanz Centre for



**Gianluigi
Zanusso, MD, PhD**

Grant Title: Multi-center
assessment of olfactory
swab procedure performed





Medical Education

September 2024:

- University of Kansas Medical Center – Grand Rounds

October 2024:

- St. Joseph's University Medical Center – Grand Rounds
- CareOne, NJ – Grand Rounds

March 2025:

- University of Virginia – Grand Rounds
- University of Washington, Seattle – Grand Rounds

April 2025:

- Center for Infectious Disease Research and Policy
- Association for Professionals in Infection Control and Epidemiology Ohio
- Vermillion County Funeral Directors Association (Virtual)

May 2025:

- Oregon Department of Health
- Texas Epidemic Public Health Institute – Grand Rounds



Strides for CJD 2024

21 Locations

2,750

Registrants

Raised over
\$600,000





Charity Navigator Rating

 Charity Navigator

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Accountability & Finance

Score

100

Most Recent Fiscal Year:
FY 2023

This beacon provides an assessment of a charity's financial health (financial efficiency, sustainability, and trustworthiness) and its commitment to governance practices and policies.

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100%



Four-Star Charity 

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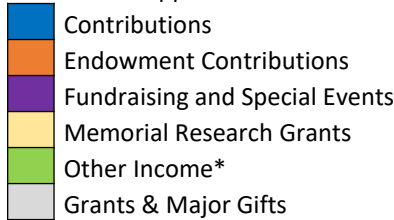
Finance report



2024 Revenue & Support

*Draft Audit Numbers

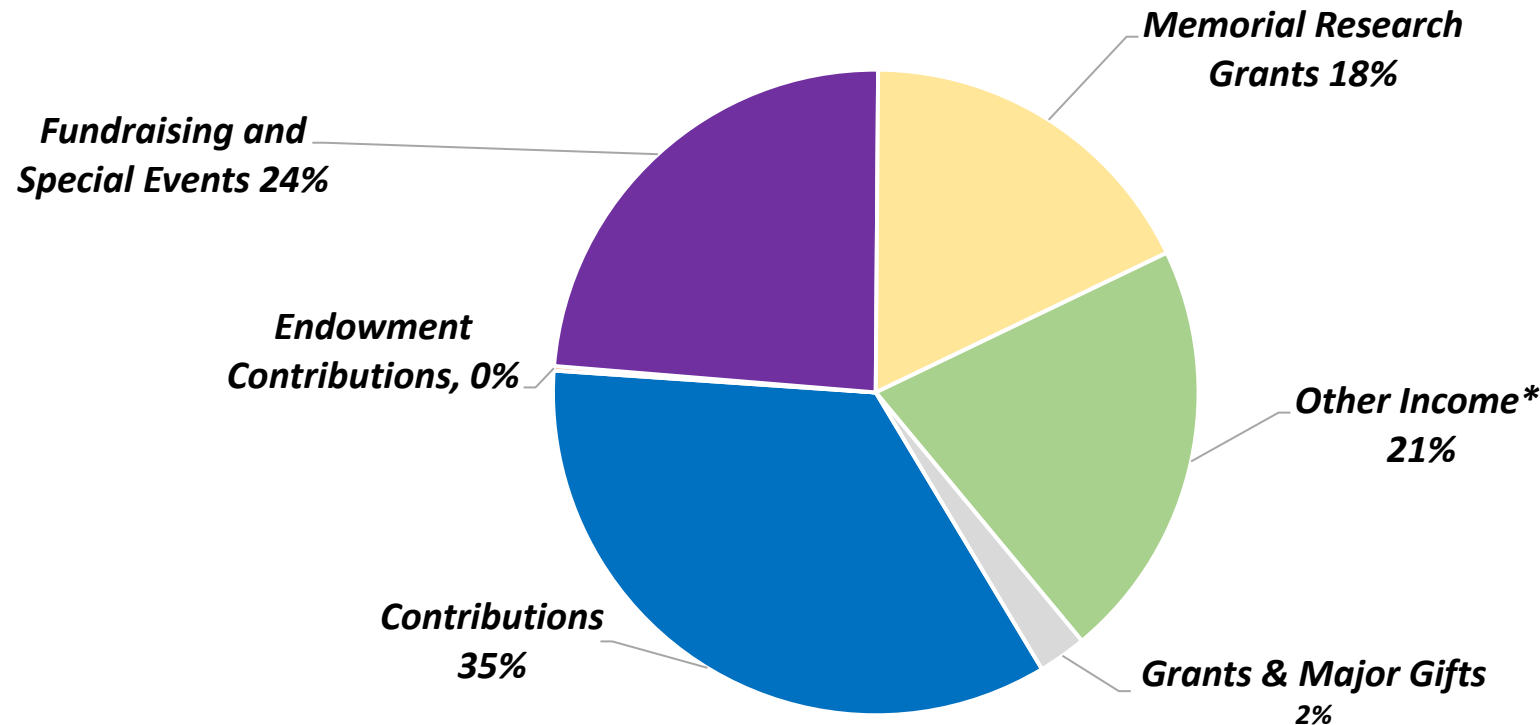
Revenue & Support



Total Revenue & Support

2024
1,083,256
7,000
743,496
554,637
658,715
75,325
3,122,428







*Other income is comprised of conference income, miscellaneous income and in-kind contributions.





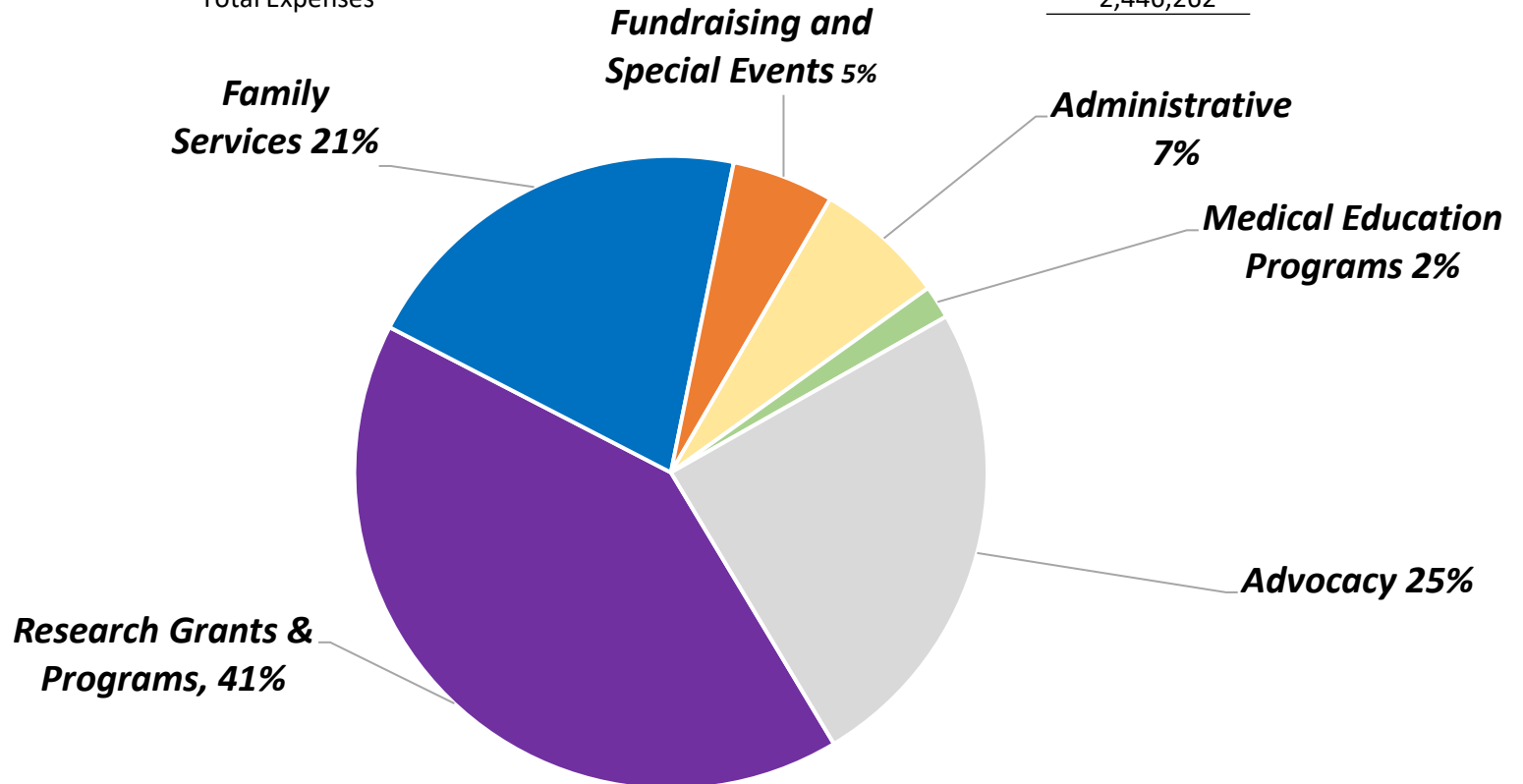
2024 Expenses

Functional Expenses

	Research Grants & Programs
	Family Services
	Fundraising and Special Events
	Administrative
	Medical Education Programs
	Advocacy

Total Expenses

2024
1,007,819
503,902
127,425
163,899
41,571
601,646
<hr/> 2,446,262





Strides for CJD Update



Strides for CJD 2025

- Akron, OH ● Arlington, TX ● Boston, MA ● Brownton, MN
- Charleston, WV ● Chicago Area, IL ● Denver, CO
- Fairfax, VA ● Johnsonburg, PA ● Morris County, NJ
- Portland, OR ● Rockwall County, TX ● San Diego, CA
- Saratoga Springs, NY ● Seattle, WA ● St. Louis, MO

