

CJD Foundation Update

Stuart Yaffa, Board Chair

Jacob Schwister, Finance Committee

July 2026



CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

Supporting Families Affected by Prion Disease



CJD Foundation Update

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

Family Conference



We decided to collaborate on dissemination of TFI with Stanley Prusiner, who seemed to have the best transgenic (Tg) mice expressing human PrP.

*Piero Turchi, a talented and productive postdoctoral fellow from Bologna, and I could not believe our eyes: Tg mice inoculated with ACJD200 on TFI brain homogenates displayed *scnPrP* type 1 or 2 mimicking those of the ACJD200 and TFI patients. This finding showed that human *scnPrP* types were reproducible despite the different (mouse vs human) brain microenvironments.*

*From quickly observed that type 1 and 2 reproductive time occurred in the absence of the pathogenic mutation of TFI and ACJD200, which the Tg mice did not carry. Therefore, the inoculated human *scnPrP* types 1 and 2 carried all the information needed to reproduce themselves in the Tg mice with no need for nucleic acid intervention.*

In 1996, the results of that study published in 1996 strengthened the pre-existing 10 years hypothesis in which brain directly seeded the 1980/1981 NCHS.

Prusiner
2018
21KDa
18.5

CJD
FFI



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	10
Western Region	Current and past caregivers; sporadic and genetic	9
Genetic	People at risk; current and past caregivers	2
Other	Guest speakers, bereavement series	10
Total Sessions/12 months		42



Website

TOLL-FREE HELPLINE: 1-800-659-1991

CONTACT US

✓ Supporting Families Affected by Prion Disease



Select Language ▼

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CREUTZFELDT-JAKOB DISEASE
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Supporting Families Affected by Prion Disease

About Prion Disease ▼

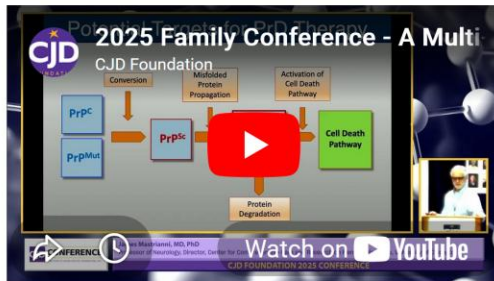
For Families ▼

For Professionals ▼

About Us ▼

Take Action ▼

2025 Family Conference Presentations and Recordings



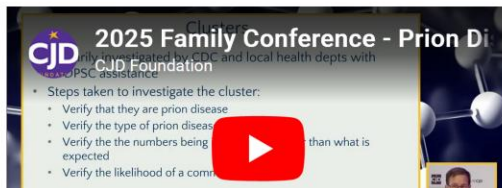
Link: [A Multi-Targeted Approach in Search of Prion Disease Therapy](#)



Link: [Drug Development Panel](#)



Link: [Drug Development Panel Question and Answer](#)





Advocacy

- Partner with Akin all year
- Fall 2025: CJD Awareness Day / Resolution
- March 2026: 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 8-9, 2027,**
Washington, DC



Awarded 8 Research Grants and 2 Fellowships in 2026

2026



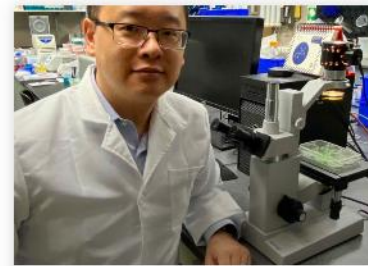
Joaquín Castilla,
PhD



David A. Harris, MD,
PhD



Vanessa
Laversenne, PhD



Jingxin Wang, PhD



Prof. Neil A. Mabbott



Daniel Ojeda-Juarez,
PhD



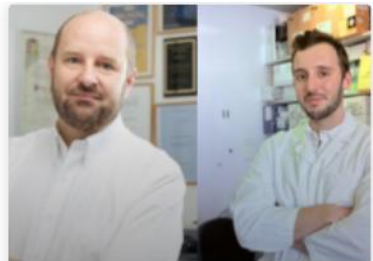
Paulina Soto, PhD



Thomas J. Trainer



Simon Mead, PhD



Adriano Aguzzi, MD
and Vangelis Bouris,



Medical Education

October 2024:

- St. Josephs Univ Med. Ctr., NJ: Grand Rounds
- CareOne, NJ: Grand Rounds

March 2025:

- Univ. of WA, Seattle: Grand Rounds

April 2025:

- IN Funeral Directors Association: Funeral Education

September 2025:

- (HAI/AR) Prevention Program, KY: Infection Prevention

February 2026:

- John Carroll University, OH: Grand Rounds
- VHC Health, VA: Grand Rounds
- University Hospital Cleveland Medical Center, OH: Grand Rounds

March 2026:

- Houston Methodist, TX: Grand Rounds

April 2026:

- Wisconsin Dept. of Health Services, WI: Grand Rounds



Strides for CJD





Charity Navigator





Finance report



2025 Revenue

*Draft Audit Numbers

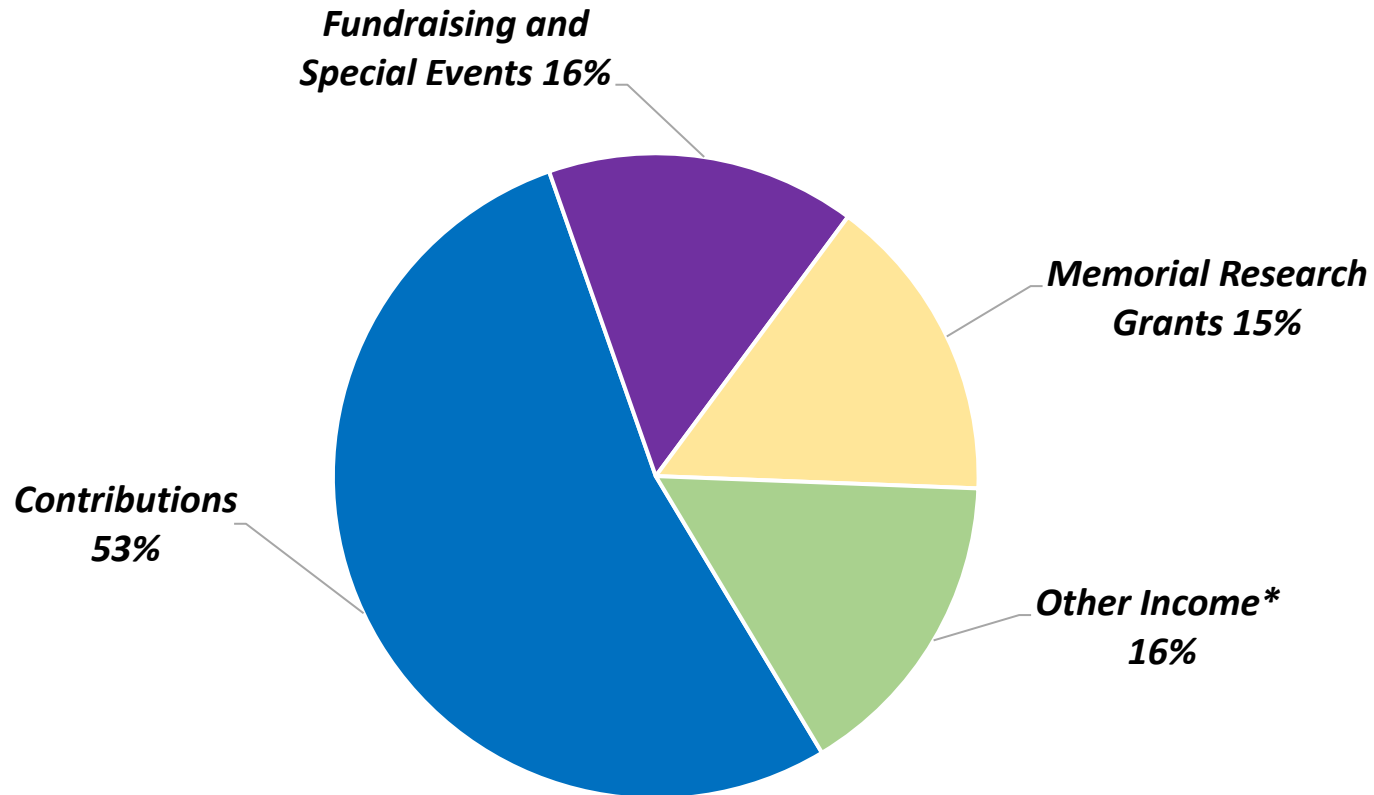
Revenue

Contributions
Fundraising and Special Events
Memorial Research Grants
Other Income*

Total Revenue

2025
2,025,571
589,989
587,908
600,244
3,803,712

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





2025 Expenses

Functional Expenses

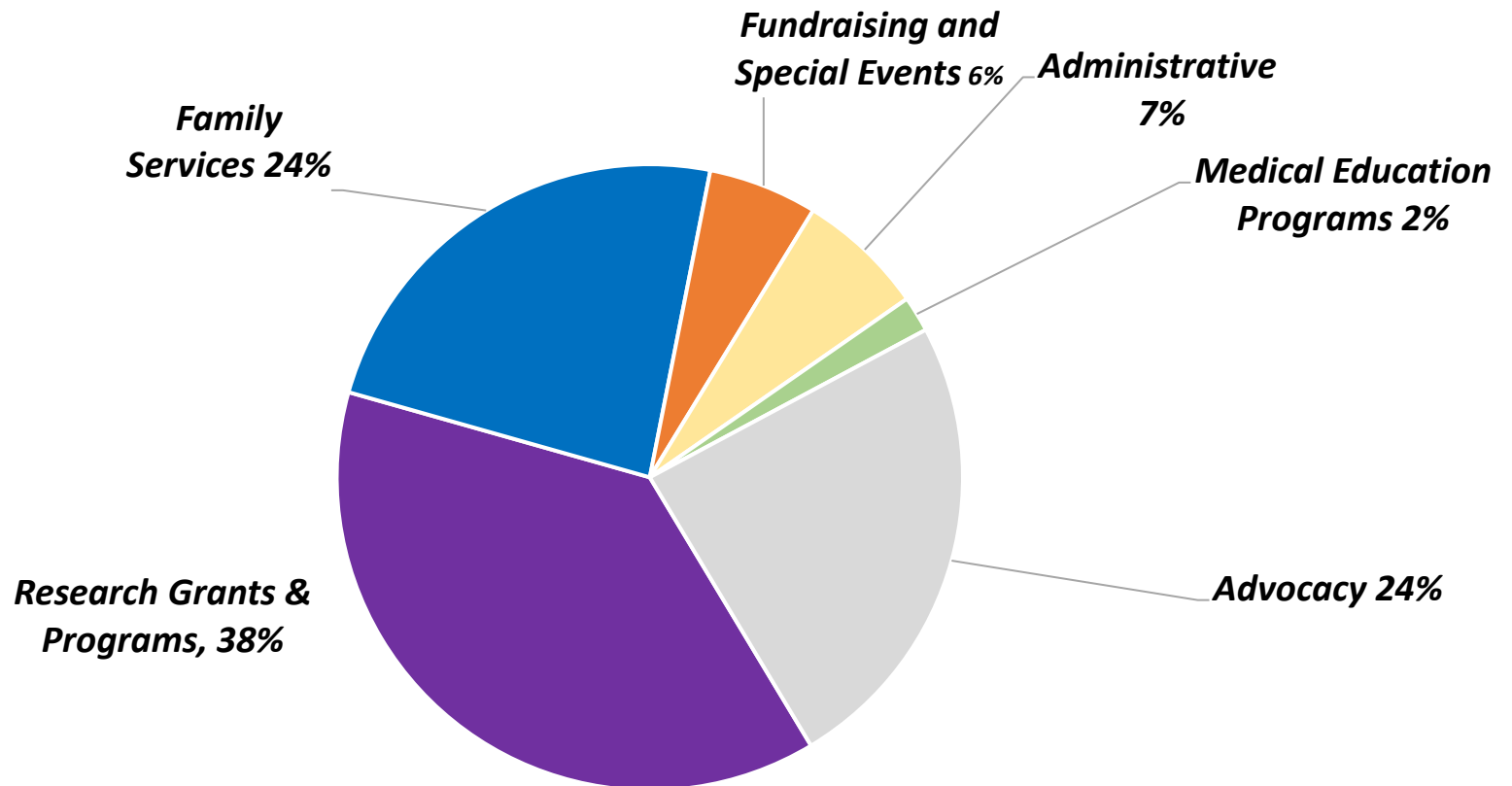
Research Grants & Programs
Family Services
Fundraising and Special Events
Administrative
Medical Education Programs
Advocacy

2025

911,495
568,894
135,317
158,279
44,300
580,574

Total Expenses

2,398,859





Strides for CJD Update