

CJD Foundation Update

Stuart Yaffa, Board Chair

Patricia McGill, Treasurer

July 2024



CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

Supporting Families Affected by Prion Disease



CJD Foundation Update

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



Family Conference 2023 and 2024





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	9
Western Region	Current and past caregivers; sporadic and genetic	10
Genetic	People at risk; current and past caregivers	8
Other	Guest speakers, bereavement series	10
Total Sessions/12 months		48



Advocacy

- Partnered with Akin
- Fall 2023: CJD Awareness Day / Resolution
- March 2024: Advocacy Day on Capitol Hill
- Submitted request forms to Appropriations Committee member offices each Feb./March
- Submitted written testimony to Senate and House each April/May



Advocacy

Recent updates:

- Report language in FY2025 appropriations bill, including requested increase in CDC line item for Prion Disease surveillance to \$8.5 million
- Language about Prion Disease in NAPA reauthorization bill



Scientific Conference and NIH Application

Conference: Mechanisms of Neurodegeneration in Human Prion Diseases and Their Intersection with AD/ADRD

Home Register Program Sponsorships Poster Abstracts and Travel Grants Childcare

Conference: Mechanisms of Neurodegeneration in Human Prion Diseases and Their Intersection with AD/ADRD

November 12 - 14, 2024

Bethesda Marriott
5151 Pooks Hill Road
Bethesda, MD 20814

Register Sponsor



Launched New Website

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

CONTACT US

✓ Supporting Families Affected by Prion Disease



Select Language ▼

DONATE



CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

About Prion Disease ▼

For Families ▼

For Professionals ▼

About Us ▼

Take Action ▼

2024 CJD Foundation Family Conference

Conference Deadlines

Monday, June 9th: T-Shirt Guarantee

Monday, June 17th: Hotel Block Reservation

Sponsorship Opportunities

Reserve a Room at Hilton
Washington DC Capitol Hill



View Tentative Agenda

Register or Sponsor Today



Strides for CJD 2024



Get Help Now



View Upcoming Events



Learn More About Prion Disease



Launched New Website

The screenshot shows a web browser window with the address bar displaying 'cjd.foundation.org/caregiver-support/'. The page has a purple header with the text 'TOLL-FREE HELPLINE: 1-800-659-1991' and 'CONTACT US'. Below this is a navigation bar with links: 'About Prion Disease', 'For Families', 'For Professionals', 'About Us', and 'Take Action'. A yellow 'DONATE' button is on the right. The main content area has a purple background with the title 'Manage Visitors' and two paragraphs of text. On the left, there is a photograph of a woman hugging an elderly man.

Caregiver Support - CJD Found. X

cjd.foundation.org/caregiver-support/

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

✓ Supporting Families Affected by Prion Disease

f t y

DONATE

CJD FOUNDATION

CREUTZFELDT-JAKOB DISEASE FOUNDATION, INC.

About Prion Disease ▼ For Families ▼ For Professionals ▼ About Us ▼ Take Action ▼

Manage Visitors

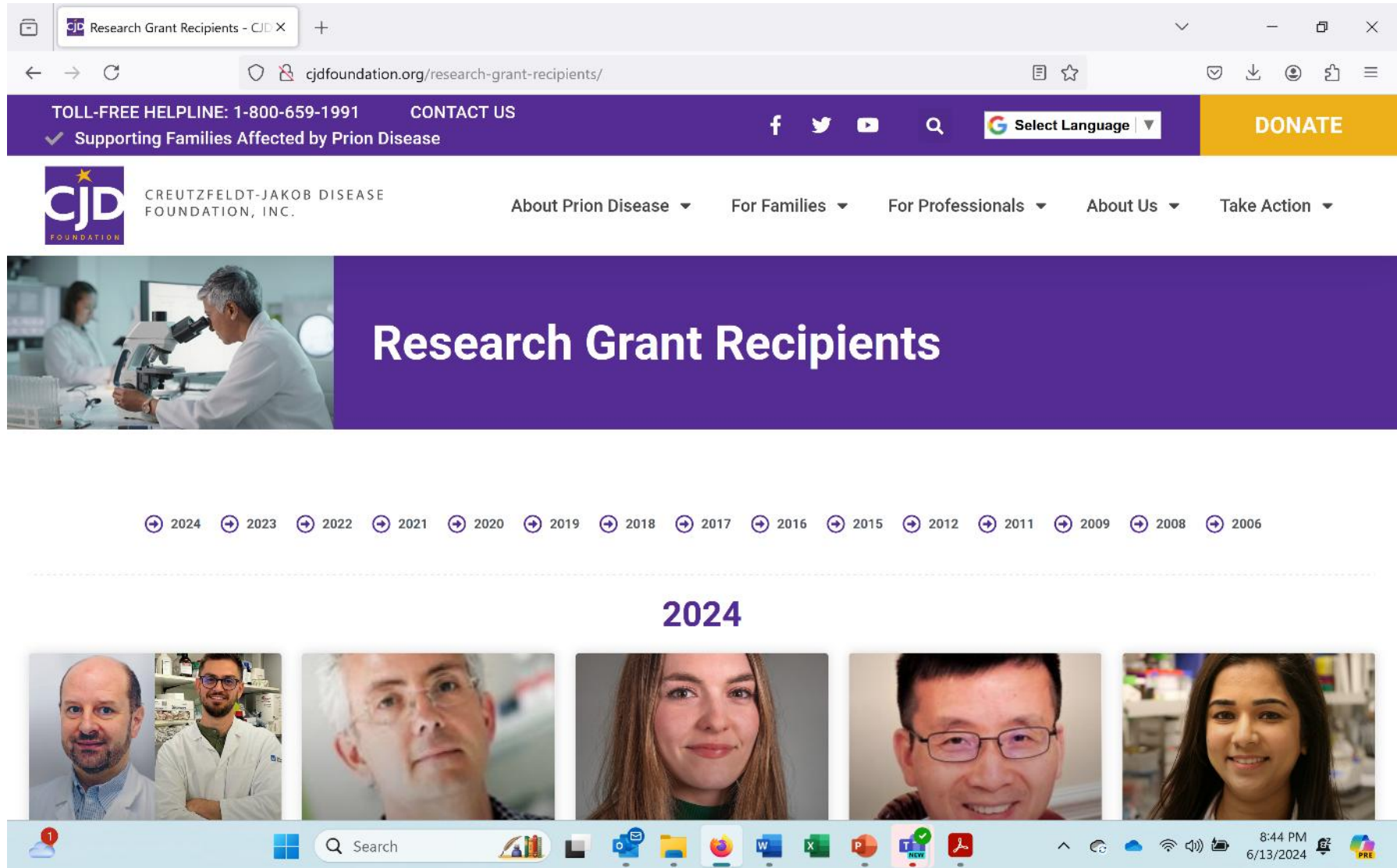
After a prion disease diagnosis, your family may feel compelled to invite large groups to your home to visit the patient or say goodbye to them. Before inviting a large group, assess whether the patient might adjust well to the group. If visits make the patient restless or agitated, it is best to ask visitors to come in pairs or small groups, keep the visit short, and have low expectations for the patient's level of involvement in the discussion.

Although the patient may be confused or even unable to communicate, you can try to include them in conversations, and speak to them kindly about your shared history, your love for them, pride in their accomplishments, and happy memories together.

Take Care of the Caregiver

Relieving your exhaustion and stress is crucial for both you and the patient. You may have little time to care for yourself while caring for the patient, but self-care is vital. Exercising, getting adequate sleep, and eating healthfully will benefit you and enable you to continue the grueling tasks of caring for your loved one.







Medical Education

September 2023:

- Cape Cod Falmouth Hosp – Grand Rounds
- Baystate Univ. of Mass Med School – Grand Rounds

November 2023.

- Marion County Funeral Directors Association

December 2023:

- Intermountain Health Utah – Grand Rounds

January 2024:

- NYU Presby-Weill Cornell Medicine – Grand Rounds
- NYU Langone – Grand Rounds
- Nassau Suffolk Funeral Directors Association

February 2024:

- Syracuse SUNY Upstate Medical University – Grand Rounds

March 2024:

- Beth Israel Deaconess Medical Center

May 2024:

- Cornell and Mem. Sloan Kettering – Infectious Disease/Grand Rounds
- Oregon Funeral Directors Association
- Harbor-UCLA Medical Center – Grand Rounds



Strides for CJD 2023



- 23 Locations
- 2,740 Registrants
- Raised almost \$600,000



Charity Navigator Rating

CJD Foundation has earned a **fifth consecutive 4-star rating**

“This is our **highest possible rating** and indicates that your organization adheres to sector best practices and executes its mission in a financially efficient way...”

“**Only 21% of the charities** we evaluate have received at least 4 consecutive 4-star evaluations, indicating that Creutzfeldt-Jakob Disease Foundation outperforms most other charities in America.”





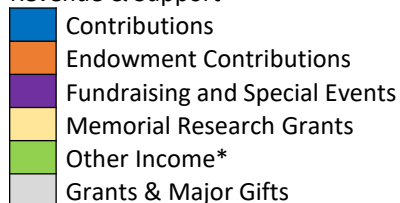
Finance report



2023 Revenue & Support

*Draft Audit Numbers

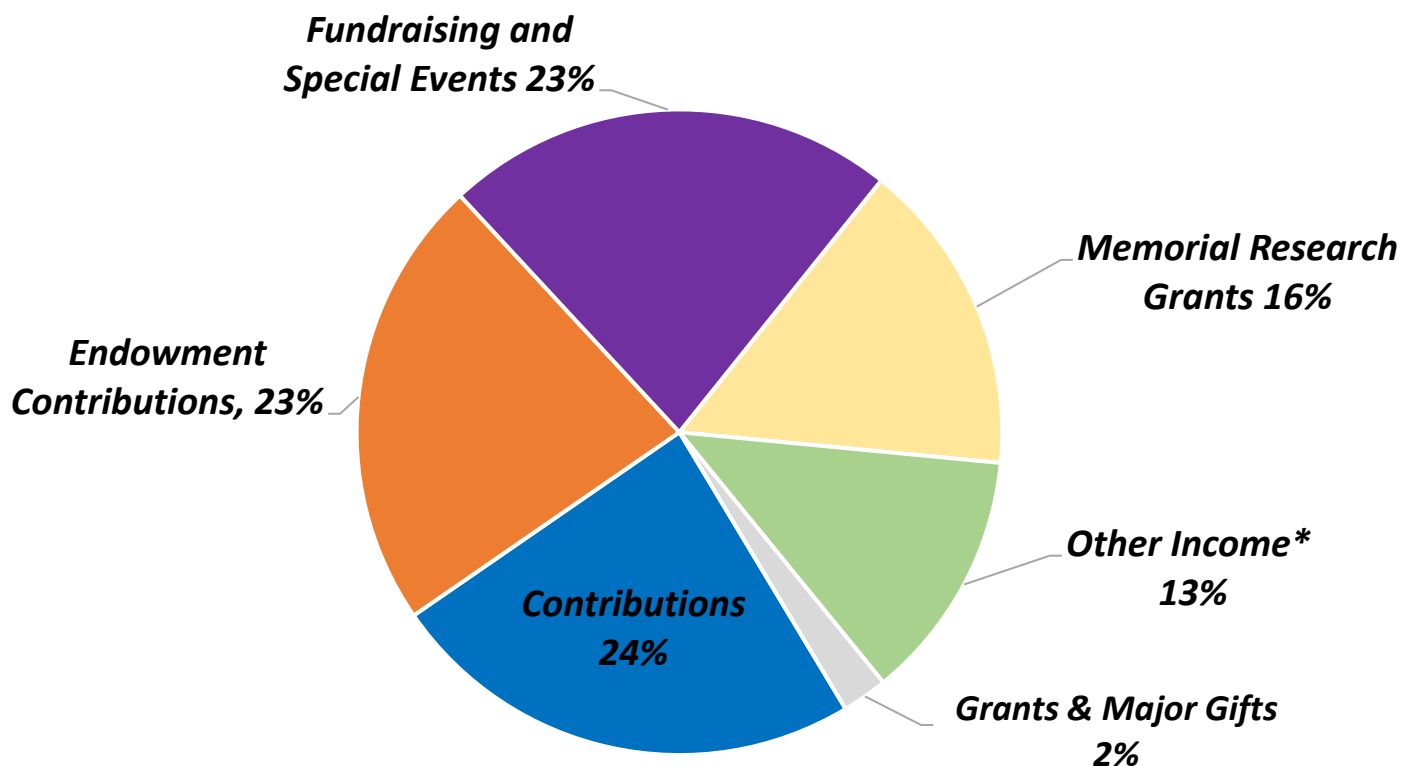
Revenue & Support



Total Revenue & Support

2023
790,279
747,809
746,062
518,856
414,726
74,890
<hr/> 3,292,622

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





2023 Expenses

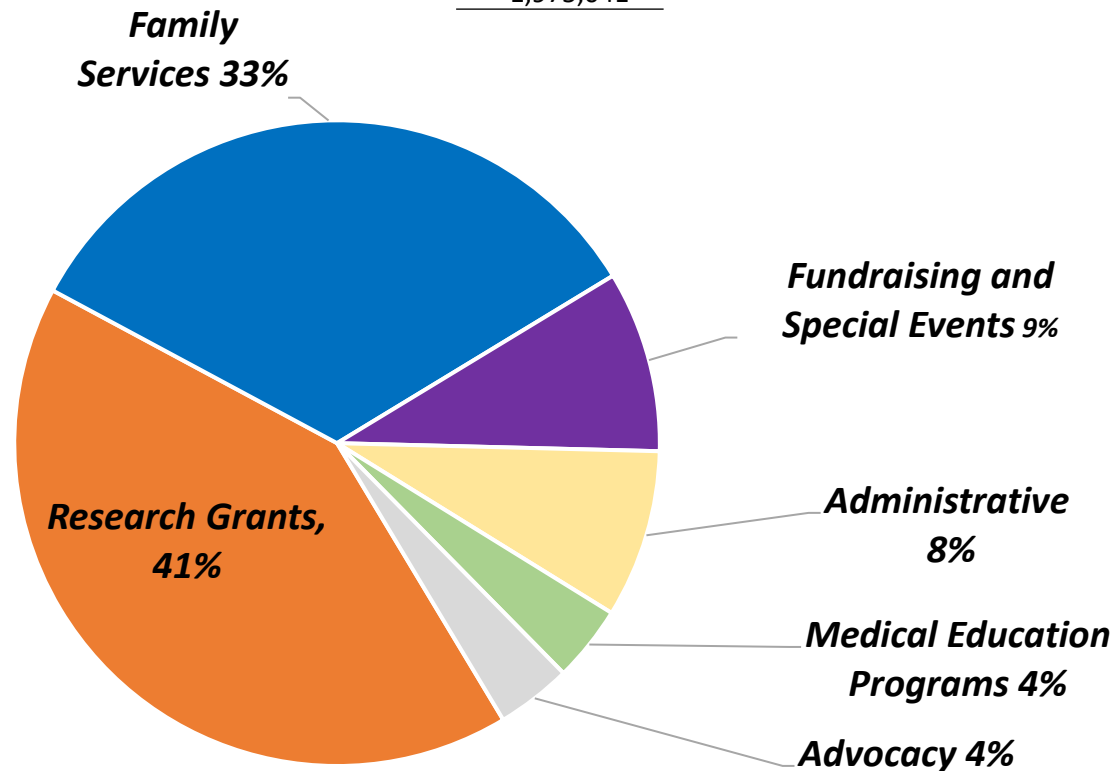
*Draft Audit Numbers

Functional Expenses

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

Total Expenses

2023
818,782
661,092
179,355
166,228
75,257
74,328
<hr/> 1,975,041





Strides for CJD Update