

CJD Foundation Grants Update



CREUTZFELDT-JAKOB DISEASE
FOUNDATION, INC.

Supporting Families Affected by Prion Disease



Types of Memorial Grants

- Research
- Medical Education
- Family Programs
- Special Purpose (discussed with CJDF)
- General Fund (unrestricted)



Research Grant Cycle

- Call for Applications at Prion 2019 Scientific Meeting: May 2019
- Donor signs grant agreement: before September 1, 2019
- The CJD Foundation receives payment in full (or first of two payments for 2019 grant) by: **September 1, 2019**
- Notify grant recipients and disburse funds to researcher: **January 2020**
- Awarded researcher presents a mid-year research update (at conference): July 2020
- Awarded researcher provides a year-end research update: December 2020



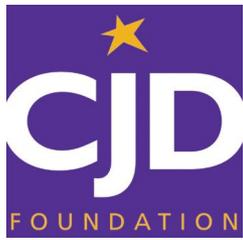
Already Funded 2019-20 Memorial Grants

**The James “Jim” Brown Memorial Grant,
contributed by Maridee Brown, Family & Friends**

**The Michael H. Cole Memorial Grant,
contributed by Jeanne Cole**

**The Katie Dopirak Memorial Grant, contributed by
The Pohl and Dopirak Family**

**The Diana Hunter Memorial Grant, contributed by
The Hunter Family and Byron Jones**



Already Funded 2019-20 Memorial Grants

**The José A. Piriz and Sonia E. Piriz Memorial Grant,
contributed by Karla Piriz and Lauren Piriz**

**The Eugene Riedel Memorial Grant,
contributed by Jacqueline Riedel**

**The Kenneth Wheat Memorial Grant,
contributed by Bebe Wheat and Family**



Grant Builders

- Have signed agreement to fund memorial grant
- Have begun (or completed) funding that grant



Grant Builders

The Robert Dodd Memorial Grant, contributed by Kathleen Dodd and Family

The Davey L. Kock Memorial Grant, contributed by Janine Kock

Mercies in Disguise Grant, in Memory of Dr. Buddy Baxley

**The Cheryl Molloy Memorial Grant,
contributed by Tim Molloy and Family**

The Paula Smart Memorial Grant, contributed by Jeff Moxie

The Tom Stivison Memorial Grant, contributed by Cookie Stivison



Additional Sources of Research Funding

- **Donations to the CJD Foundation**
- **Donations to Strides for CJD**
- **Families who host fundraisers**

Thank You!

- Families
- Businesses that support fundraisers
- Researchers
- Scientific Advisory Committee



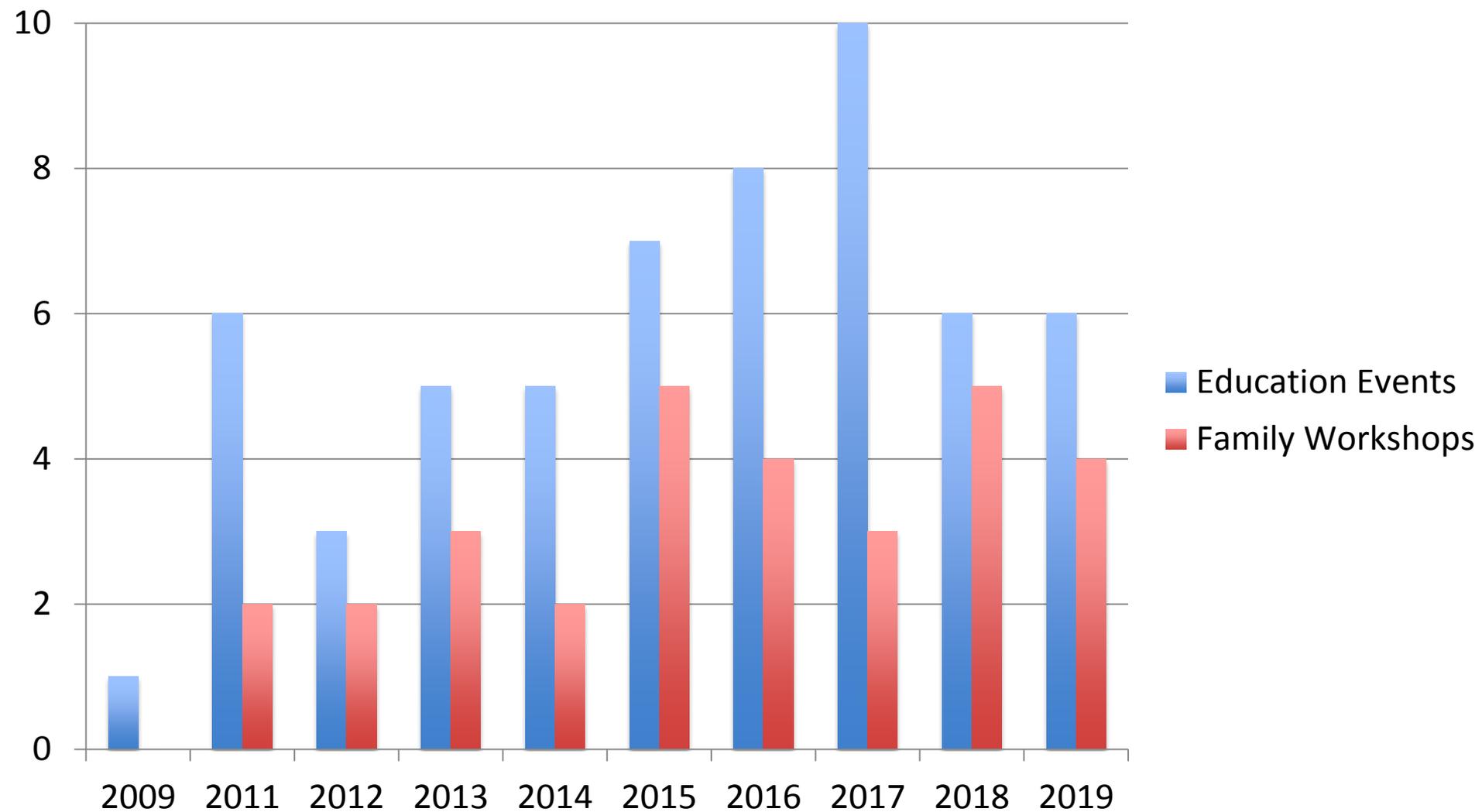
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Program Grants

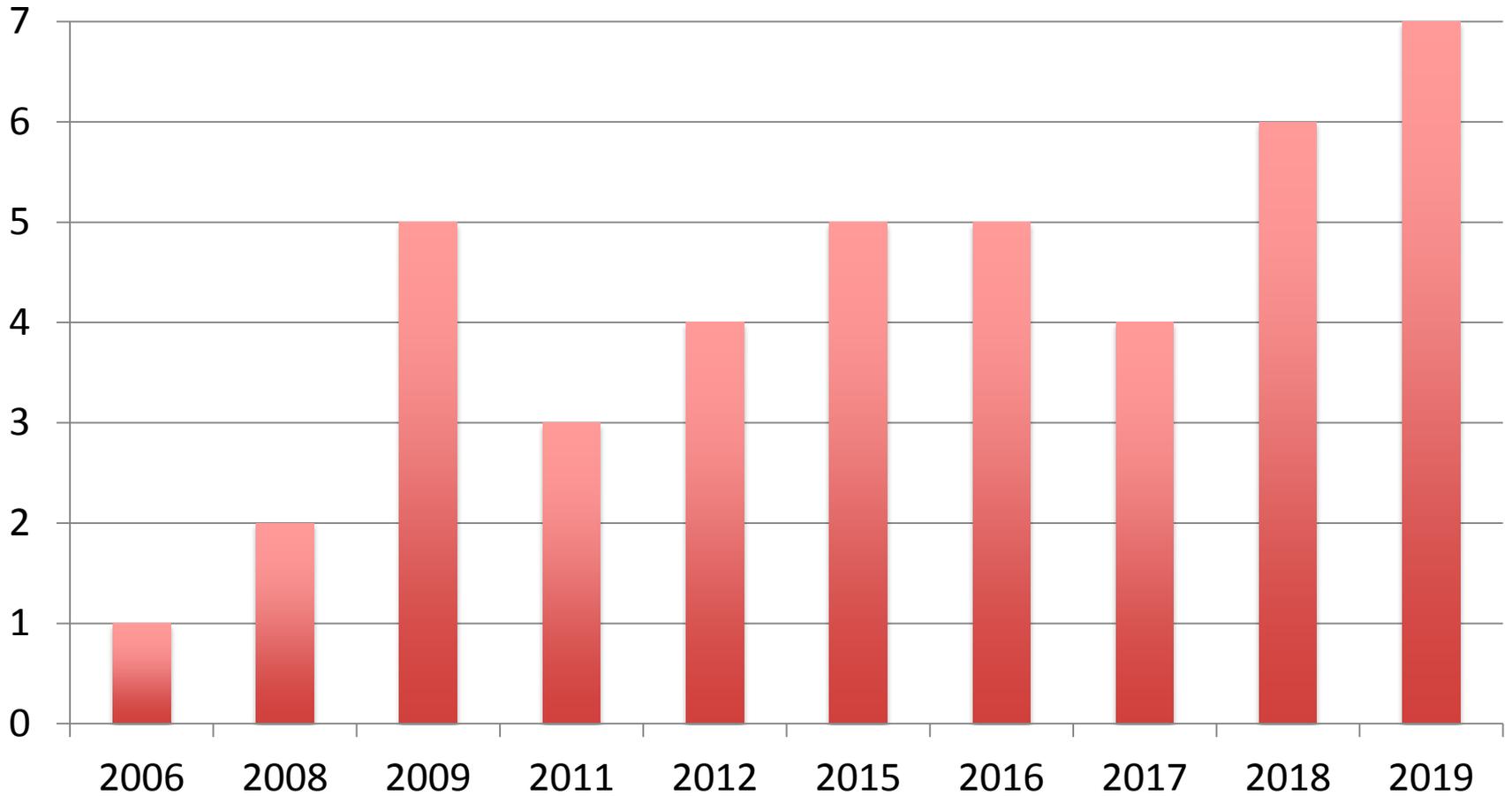
- Medical education
- Funeral Education
- Infection Control Education
- Family Workshops

Education/Family Workshops

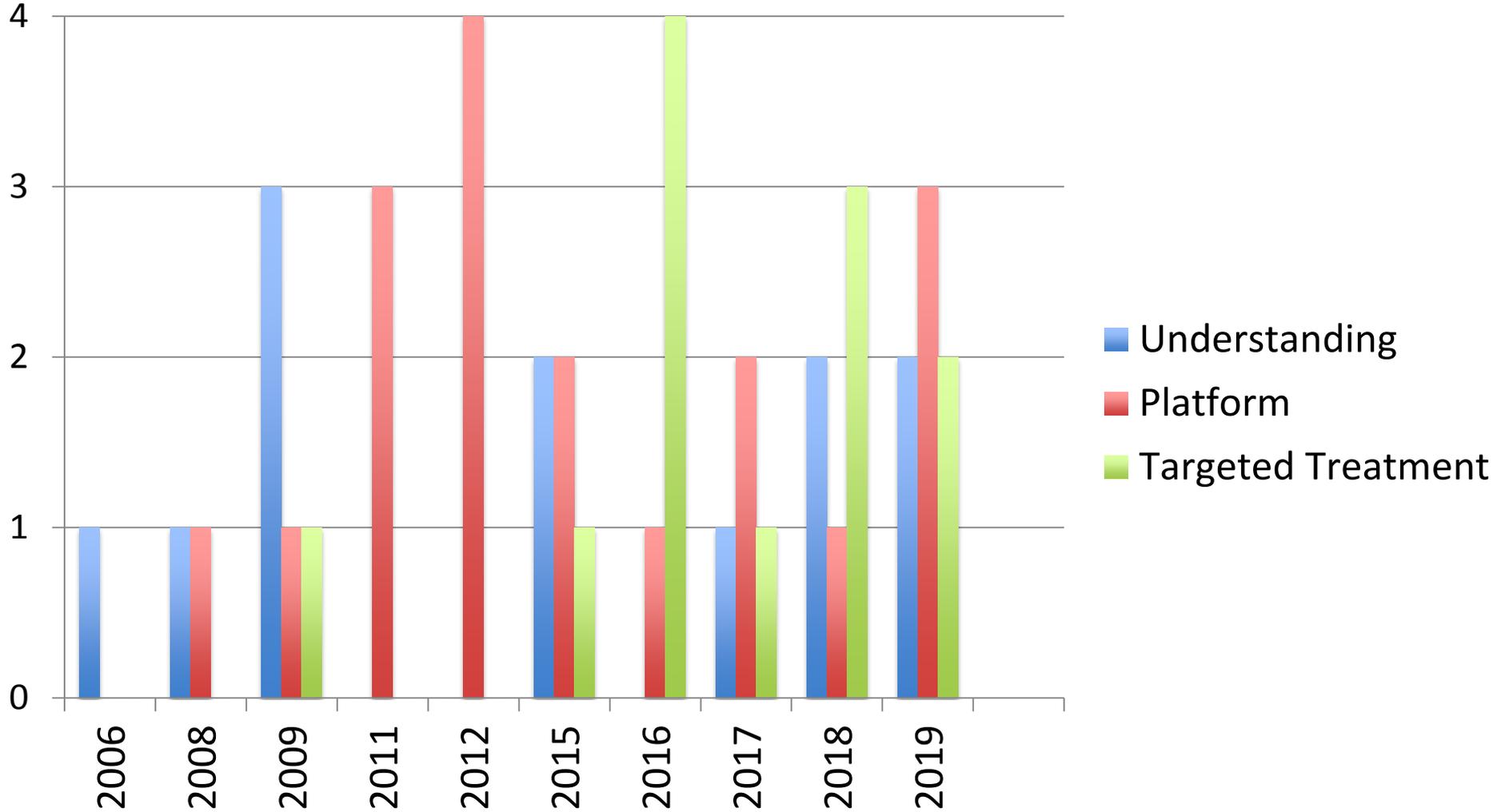


CJDF Research Grants

Research CJDF Grants by Year



CJDF Grants by Type



Increasingly More Multidomain Grants

- Arnold: Long term stability of CSF PrP
 - Understanding (normal & abnormal physiology)
 - Platform
 - Diagnosis/prognosis
 - Biomarker for treatment studies
 - Targeted treatment
- Foliaki: Neuronal dysfunction in prion disease
 - Understanding neuronal disruption in prion disease
 - Platform
 - Diagnosis/prognosis
 - Understand different mutations/strains
 - Platform to examine potential treatment responses

CJDF Grants

Research in Context for the Families +

- Family friendly
- Responsibility to the families
- Convey research findings in lay language
- Impact on human prion diseases
- Meet your researcher
- Develop relationships
- Foster motivation
- *Research in Context for the Families **by the Families***
 - Funded by the families
 - Chosen by the families
 - In some cases, research performed by the families (Joel, Eric, Sonia)

Research Grant Changes Since 2015

- No missed years
- More grants funded than all other prior years combined
- 11 fold more treatment related grants
- Family member on the scientific advisory committee (Hatte Blejer)
- Different avenues to fund grants (e.g., Strides)
- Continued changes and growth to come

Summary

- Contributions make a huge difference
 - Medical, infection control, and funeral home education
 - Family support in form of workshops
 - Research in context of human prion diseases
- CJDF Grants are unique. They are by the families and for the families
- Education/support events and research funding is approximating other patient advocacy groups with a larger affected population
 - Association for Frontotemporal Dementia (lifetime risk: 1/742)

Thank You!

- CJD Foundation Staff
- Families
- Supporting businesses of fundraisers
- Researchers
- Scientific Advisory Committee



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