CJD Foundation Grants Update
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

CREUTZFELDT-JAKOB DISEASE FOUNDATION, INC.

Supporting Families Affected by Prion Disease
Program Grants

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

- Education Events
- Family Workshops


Graph showing the number of Education Events and Family Workshops from 2009 to 2019.
CJDF Research Grants
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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Supporting Families Affected by Prion Disease