

2026 CJD Foundation Family Conference – Evaluation Form

Thank you for attending the CJD Foundation Family Conference. Your feedback is very important to us. Please take a few minutes to fill out this evaluation form and return it to a CJD Foundation staff member or complete it online at www.tinyurl.com/2026-family-conference (navigate to the Attendee Portal).

Scale: 5 – Excellent 4 – Very Good 3 – Good 2 – Fair 1 – Poor N/A – Not Applicable

Venue and Resources

Venue	5	4	3	2	1
Catering	5	4	3	2	1
Registration and Check-In	5	4	3	2	1
Print Resources	5	4	3	2	1
Attendee Portal (Online Resources)	5	4	3	2	1
Store (Products and Inventory)	5	4	3	2	1

Comments on Venue and Resources: _____

Friday Programs

Genetic Prion Disease Workshop Part 1, Brian Appleby; MD; Michael D. Geschwind, MD, PhD; Eric Minikel, PhD; Krista Savage, MS, CGC; Amanda Kalinsky, RN, BSN	5	4	3	2	1	N/A
Genetic Prion Disease Workshop Part 2, Debbie Yobs and Panel	5	4	3	2	1	N/A
Sporadic Prion Disease Workshop, Brian Appleby, MD and Lori Nusbaum	5	4	3	2	1	N/A
Prion Disease Basics – Clinical, Brian Appleby, MD	5	4	3	2	1	N/A
Prion Research Basics – Research, Joel Watts, PhD	5	4	3	2	1	N/A
Bereavement Workshop, Tessa Garcia McEwen, AM, LCSW, DCCS, CDP and Danielle Jordan	5	4	3	2	1	N/A

Comments on Friday Programs: _____

Saturday Programs

Keynote Address: Why There Is Reason to Be Moore Hopeful About the Field of Prion Disease, Brian Appleby, MD 5 4 3 2 1 N/A

Research Grant Recipient Reports, Group A

Moderator: **Jason Bartz, PhD** 5 4 3 2 1 N/A

Refined transgenic approaches to investigate selective adaptation of human prions during intracranial and peripheral transmissions, Alyssa Block, PhD (Fellowship) 5 4 3 2 1 N/A

Characterization of synaptic abnormalities in iPSC-derived neurons from E200K carriers, Jose Andres Alepuz Guillen, PhD (Fellowship) 5 4 3 2 1 N/A

Engineering human cells to propagate fluorescent prions for live monitoring of prion infection and high-resolution in situ prion structure determination, Ellie Hanzi 5 4 3 2 1 N/A

Engineered biosensors for improved prion detection, Joel Watts, PhD 5 4 3 2 1 N/A

Higher-resolution visualization of prion fibrils in neurons and extracellular vesicles using state-of-the-art Cryo-TEM and FIB-SEM imaging, Jakub Soukup, PhD (virtual) 5 4 3 2 1 N/A

Research Grant Recipient Report, Group A Debrief 5 4 3 2 1 N/A

Research Grant Recipient Reports, Group B

Moderator: **Joel Watts, PhD** 5 4 3 2 1 N/A

Assessing retinal function as a potential early biomarker for Creutzfeldt-Jakob Disease (CJD), Pei Ying Lee, BOptom, PhD 5 4 3 2 1 N/A

Assessing efficacy of a PrP-lowering Molecular Gate as a therapeutic for prion disease, Nina Oberbeck, PhD 5 4 3 2 1 N/A

Multi-center assessment of olfactory swab procedure performed by non-otolaryngologists for improving and simplifying human prion disease diagnosis, Gianluigi Zanusso, MD, PhD 5 4 3 2 1 N/A

Investigating prion protein seeding activity in non-prion disease dementia, Ignazio Cali, PhD (virtual) 5 4 3 2 1 N/A

Research Grant Recipient Report, Group B Debrief 5 4 3 2 1 N/A

Teleneurology Assessment Program for CJD (TAPCJD), Brian Appleby, MD 5 4 3 2 1 N/A

Moving Roundtables 5 4 3 2 1 N/A

Comments on Saturday Programs: _____

Sunday Programs

CJD Foundation Report: Programs, Finance, and Strides for CJD, Stuart Yaffa, Jacob Schwister, and Lori Nusbaum	5	4	3	2	1	N/A
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CJD Foundation Grants Program, Debbie Yobs and Joel Watts, PhD	5	4	3	2	1	N/A
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National Prion Disease Pathology Surveillance Center Panel, Brian Appleby, MD; Eriton Cunha, PhD; Gabriella DelPrete; Danielle Jordan; Keisi Kotobelli; Liam Wissinger	5	4	3	2	1	N/A
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2026 Centers for Disease Control and Prevention Report, Ryan Maddox, PhD	5	4	3	2	1	N/A
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CJD Foundation Family Panel: "My Story, My Mission" Moderator: Debbie Yobs, Panel: Nikki Bland, Denise Chainey, Jeanne Cole, Shannon Romano, Mike Vitanza	5	4	3	2	1	N/A
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Drug Development Panel, Moderator: Brian Appleby, MD; Kiyoshi Arita, MSc; Andreja Avbersek, MD; Kathy Meyer, MPH, PhD, DABT; Eric Minikel, PhD; Nina Oberbeck; PhD; Rob Pulido, PhD	5	4	3	2	1	N/A
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Moving Roundtables with Drug Development Panel	5	4	3	2	1	N/A
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Comments on Sunday Programs: _____

Why Attend Conference

Please rate how much of a factor each of the following was in choosing to attend Conference, 5 meaning it was a significant factor in choosing to attend and 1 meaning it was not a significant factor in choosing to attend.

Location	5	4	3	2	1
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Speakers/Agenda	5	4	3	2	1
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Cost	5	4	3	2	1
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Other (please specify) _____	5	4	3	2	1
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Were there any other factors that impacted your decision to attend Conference? Please explain. _____
