



2026 CJD Foundation Family Conference

July 10-12, 2026, Chicago Marriott O’Hare, Chicago, IL

AGENDA

FRIDAY, JULY 10

- 11:00 am – 7:00pm** **Conference Registration – Grand Ballroom, Foyer**
- 12:00 pm – 1:00 pm** **Genetic Prion Disease Workshop Part 1 – Grand Ballroom 1-4**
Short talks regarding genetic counseling, testing, caregiving, treatment development, and studies. *This workshop is for families affected by a genetic prion disease only.*
Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
Michael D. Geschwind, MD, PhD, Professor of Neurology, University of California, San Francisco, San Francisco, CA
Eric Minikel, PhD, Director, Prion Therapeutic Science, Broad Institute of MIT and Harvard, Cambridge, MA
Krista Savage, MS, CGC, Genetic Counselor, Grey Genetics, Orting, WA
Amanda Kalinsky, RN, BSN, Family Member
- 1:00 pm – 3:00 pm** **Genetic Prion Disease Workshop Part 2 – Chicago Ballroom F-G**
This support group-like session is for families affected by a genetic prion disease only.
Moderator: **Debbie Yobs**, President and Executive Director, CJD Foundation
Panel from Part 1
- 1:00 pm – 3:00 pm** **Sporadic Prion Disease Workshop – O’Hare Ballroom, Terminals 2-3**
This support group-like session is for families only.
Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
Lori Nusbaum, Program Director, CJD Foundation
- 3:00 pm – 3:15 pm** **Break – Grand Ballroom, Foyer**
- 3:15 pm – 4:45 pm** **Prion Disease Basics – Grand Ballroom 1-4**
These sessions provide an excellent foundation for Saturday’s scientific presentations.
- 3:15 pm – 3:45 pm** **Prion Disease Basics – Clinical**
Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH

- 3:45 pm – 4:15 pm** **Prion Disease Basics – Research**
Joel Watts, PhD, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
- 4:15 pm – 4:45 pm** **Prion Disease Basics Question and Answer**
- 4:45 pm – 5:00 pm** **Break – Grand Ballroom, Foyer**
- 5:00 pm – 6:00 pm** **Bereavement Workshop, Grand Ballroom 1-4**
Tessa Garcia McEwen, AM, LCSW, DCCS, CDP, Certified Dementia Practitioner, Certified Grief Educator, The Memory Center, University of Chicago Medicine, Chicago, IL
Danielle Jordan, Grief Recovery Specialist and Autopsy Program Manager, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
- 6:15 pm – 7:30 pm** **Welcome Reception – O’Hare Ballroom, Terminal 5**

SATURDAY, JULY 11

- 7:00 am** **Conference Registration – Grand Ballroom, Foyer**
- 7:00 am – 8:30 am** **Continental Breakfast – Grand Ballroom, Foyer**
- 8:30 am – 8:40 am** **Welcome – Grand Ballroom 1-4**
Debbie Yobs, President and Executive Director, CJD Foundation
- 8:40 am – 8:55 am** **Memorial Service**
- 8:55 am – 9:25 am** **Keynote Address in Honor of Dr. Pierluigi Gambetti: Why There Is Reason to be More Hopeful About the Field of Prion Disease**
Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
- 9:25 am – 9:35 am** **Question and Answer**
- 9:35 am – 11:00 am** **CJD Foundation Research Grant Recipient Reports, Group A**
Moderator: **Jason Bartz, PhD**, Chair and Professor, Department of Medical Microbiology and Immunology, Creighton University School of Medicine, Omaha, NE
- 9:35 am – 9:45 am** **Refined transgenic approaches to investigate selective adaptation of human prions during intracranial and peripheral transmissions**
Alyssa Block, PhD, Postdoctoral Fellow, Prion Research Center, Colorado State University, Fort Collins, CO
- 9:45 am – 9:55 am** **Characterization of synaptic abnormalities in iPSC-derived neurons from E200K carriers**
Jose Andres Alepuz Guillen, PhD, Postdoctoral Researcher, Chobanian and Avedisian School of Medicine, Boston University, Boston, MA

- 9:55 am – 10:05 am** **Engineering human cells to propagate fluorescent prions for live monitoring of prion infection and high-resolution in situ prion structure determination**
Ellie Hanzi, Imperial College London, England
- 10:05 am – 10:15 am** **Engineered biosensors for improved prion detection**
Joel Watts, PhD, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
- 10:15 am – 10:30 am** **Break – Grand Ballroom, Foyer**
- 10:30 am – 10:40 am** **Higher-resolution visualization of prion fibrils in neurons and extracellular vesicles using state-of-the-art Cryo-TEM and FIB-SEM Imaging – Grand Ballroom 1-4**
Jakub Soukup, PhD*, Rocky Mountain Laboratories, Division of Intramural Research, National Institute of Allergy and Infectious Diseases, National Institutes of Health
- 10:40 am – 11:00 am** **Research Grant Recipient Reports, Group A Debrief**
- 11:00 am – 12:00 pm** **CJD Foundation Research Grant Recipient Reports, Group B**
Moderator: Joel Watts, PhD, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
- 11:00 am – 11:10 am** **Assessing retinal function as a potential early biomarker for Creutzfeldt-Jakob Disease (CJD)**
Pei Ying Lee BOptom, PhD, Department of Optometry and Vision Sciences, The University of Melbourne, Melbourne, Victoria, Australia
- 11:10 am – 11:20 am** **Assessing efficacy of a PrP-lowering Molecular Gate as a therapeutic for prion disease**
Nina Oberbeck, PhD, Vice President of Translational Sciences, Gate Bioscience, Brisbane, CA
- 11:20 am – 11:30 am** **Multi-center assessment of olfactory swab procedure performed by non-otolaryngologists for improving and simplifying human prion disease diagnosis**
Gianluigi Zanusso, MD, PhD, Associate Professor, Department of Neuroscience, Biomedicine and Movement Sciences, University of Verona, Verona, Italy
- 11:30 am – 11:40 am** **Investigating prion protein seeding activity in non-prion disease dementia**
Ignazio Cali, PhD*, Department of Medicine and Surgery, University Kore of Enna, Enna, Sicily, Italy and Associate Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
- 11:40 am – 12:00 pm** **Research Grant Recipient Reports, Group B Debrief**
- *Scheduled to speak remotely
- 12:00 pm – 12:10 pm** **Memorial Tribute to Byron Caughey, PhD**
- 12:10 pm – 12:20 pm** **Teleneurology Assessment Program for CJD (TAPCJD)**
Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH

- 12:30 pm – 1:20 pm** **Lunch – Grand Ballroom, Foyer**
- 1:20 pm – 1:30 pm** **Group Photo – O’Hare Ballroom, Foyer**
- 1:30 pm – 4:00 pm** **Moving Roundtables – Grand Ballroom 1-4 and 5-6**
 Rotate among tables and sit for informal question and answer with speakers, research grant recipients, and other professionals.
- 4:00 pm – 6:00 pm** **Family Consultations (Optional) – O’Hare Ballroom, Terminal 3**
Danielle Jordan will be available for individual family consultations regarding status of autopsy results and/or the National Prion Disease Pathology Surveillance Center’s autopsy program.

Danielle Jordan, Autopsy Program Manager, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
- 7:00 pm – 10:00 pm** **Banquet – Grand Ballroom 1-4**

SUNDAY, JULY 12

- 7:45 am – 9:00 am** **Continental Breakfast – Grand Ballroom, Foyer**
- 9:00 am – 9:25 am** **CJD Foundation Report: Programs, Finance, and Strides for CJD – Grand Ballroom 1-4**
Stuart Yaffa, Chairman, CJD Foundation Board of Directors
Jacob Schwister, Treasurer, CJD Foundation Board of Directors
Lori Nusbaum, Program Director, CJD Foundation, Akron, OH
- 9:25 am – 9:40 am** **CJD Foundation Grants Program**
Debbie Yobs, President and Executive Director, CJD Foundation
Joel Watts, PhD, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
- 9:40 am – 10:05 am** **National Prion Disease Pathology Surveillance Center Panel**
Brian Appleby, MD, Director
Eriton Cunha, PhD, Tissue Lab Scientist
Gabriella DelPrete, Research Assistant II-Tissue Coordinator
Danielle Jordan, Autopsy Program Manager
Keisi Kotobelli, MS, GStat, Data Manager II
Liam Wissinger, Digital Pathology Manager
- 10:05 am – 10:15 am** **Question and Answer**
- 10:15 am – 10:35 am** **2026 Centers for Disease Control and Prevention Report**
Ryan Maddox, PhD, Epidemiologist, Prion and Public Health Office, Division of High-Consequence Pathogens and Pathology, National Center for Emerging and Zoonotic Infectious Diseases, Atlanta, GA

10:35 am – 10:50 am **Question and Answer**

10:50 am – 11:20 am **CJD Foundation Family Panel: “My Story, My Mission”**
Moderator: **Debbie Yobs**, President and Executive Director, CJD Foundation
Panel: **Nikki Bland, Denise Chainey, Jeanne Cole, Shannon Romano, Mike Vitanza**

11:20 am – 12:10 pm **Drug Development Panel**
Moderator: **Brian Appleby, MD**
Kiyoshi Arita, MSc, Project/Product Manager, Research and Development Division, International Clinical Development Department, Nobelpharma Co., Ltd., Tôkyô, Japan
Andreja Avbersek, MD, Executive Medical Director, Regeneron Pharmaceuticals, Inc., Tarrytown, NY
Kathy Meyer, MPH, PhD, DABT, Vice President of Nonclinical Development, Sangamo Therapeutics, Inc., Richmond, CA
Eric Minikel, PhD, Director, Prion Therapeutic Science, Broad Institute of MIT and Harvard, Cambridge, MA
Nina Oberbeck, PhD, Vice President of Translational Sciences, Gate Bioscience, Brisbane, CA
Rob Pulido, PhD, Director, Clinical Development, Ionis Pharmaceuticals, Inc., Carlsbad, CA

12:10 pm – 12:25 pm **Question and Answer**

12:25 pm *Pick Up Pizza in Hallway and Return for Drug Development Moving Roundtables*

12:25 pm – 1:30 pm **Moving Roundtables with Drug Development Panel**

1:30 pm **Conference Concludes**