



2026 CJD Foundation Family Conference

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

DRAFT AGENDA

FRIDAY, JULY 10

11:00 am – 7:00pm Conference Registration – Grand Ballrooms 1-4, Foyer

12:00 pm – 1:00 pm Genetic Prion Disease Workshop Part 1 – Salons 8-10, Main Level

Short discussions with speakers 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

Amanda Kalinsky, Family Member

Eric Minikel, PhD, Director, Prion Therapeutic Science, Broad Institute of MIT and Harvard, Cambridge, MA

Krista Savage, MS, CGC, Grey Genetics

Other speaker to be named

1:00 pm – 3:00 pm Genetic Prion Disease Workshop Part 2 – Salons 8-10, Main Level

This workshop is for families affected by a genetic prion disease only.

Debbie Yobs, President and Executive Director, CJD Foundation

Other speaker to be named

1:00 pm – 3:00 pm Sporadic Prion Disease Workshop – O'Hare Ballroom, Terminals 1-3, Main Level

This workshop 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, Akron, OH

3:00 pm – 3:15 pm Break – Grand Ballrooms 1-2, Foyer

3:15 pm – 4:45 pm Prion Disease Basics – Grand Ballrooms 1-4

These sessions provide an excellent foundation for Saturday's scientific presentations.

3:15 pm – Prion Disease Basics – Clinical

3:45 pm

Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH

3:45 pm – Prion Disease Basics – Research

4:15 pm

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 Ballrooms 1-2, Foyer**

5:00 pm – 6:00 pm **Bereavement Workshop, Grand Ballrooms 1-4**

Tessa Garcia McEwen, AM, LCSW, Certified Dementia Practitioner, Certified Grief Educator, The Memory Center, University of Chicago Medicine, Chicago, IL

Danielle Jordan, Autopsy Program Manager, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH

6:00 pm – 7:30 pm **Welcome Reception – O'Hare Ballroom, Terminal 5**

SATURDAY, JULY 11

7:00 am **Conference Registration – Registration Booth B**

7:00 am – 8:30 am **Continental Breakfast – Grand Ballrooms 1-2, Foyer**

8:30 am – 8:40 am **Welcome – Grand Ballrooms 1-4**

Debbie Yobs, President and Executive Director, CJD Foundation

8:40 am – 9:00 am **Memorial Service**

9:00 am – 9:30 am **Keynote Address in Honor of Dr. Pierluigi Gambetti**

Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH

9:30 am –
9:40 am

Question and Answer

9:40 am – 10:50 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

9:40 am –
9:50 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

9:50 am –
10:00 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

10:00 am –

Engineering human cells to propagate fluorescent prions for live

- 10:10 am** **monitoring of prion infection and high-resolution in situ prion structure determination**
Ellie Hanzi, Imperial College London, England
- 10:10 am – 10:20 am** **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, Rocky Mountain Laboratories, Division of Intramural Research, National Institute of Allergy and Infectious Diseases, National Institutes of Health
- 10:20 am – 10:30 am** **Engineered biosensors for improved prion detection**
Joel Watts, PhD, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
- 10:30 am – 10:50 am** **Research Grant Recipient Reports, Group A Debrief**
- 10:50 am – 11:05 am** **Break – Grand Ballrooms 1-2, Foyer**
- 11:05 am – 11:55 am** **CJD Foundation Research Grant Recipient Reports, Group B**
Moderator: **Joel Watts, PhD**, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
- 11:05 am – 11:15 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
- 11:15 am – 11:25 am** **Assessing retinal function as a potential early biomarker for Creutzfeldt-Jakob Disease (CJD)**
Dr. Pei Ying Lee, Department of Optometry and Vision Sciences, The University of Melbourne, Melbourne, Victoria, Australia
- 11:25 am – 11:35 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
- 11:35 am – 11:45 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
- 11:45 am – 12:05 pm** **Research Grant Recipient Reports, Group B Debrief**
- 12:10 pm – 12:25 pm** **To Come**
- 12:25 pm – 1:15 pm** **Lunch – Grand Ballrooms 1-2, Foyer**

- 1:15 pm – 1:25 pm Group Photo – Hotel Lobby**
- 1:30 pm – 4:00 pm Moving Roundtables – Grand Ballrooms 1-4**
 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) – OO’Hare Ballroom, Terminal 3**
 National Prion Disease Pathology Surveillance Center staff will be available for individual family consultations regarding status of autopsy results and/or the NPDPS’s autopsy program.
- 7:00 pm – 10:00 pm Banquet – Grand Ballrooms 1-4**

SUNDAY, JULY 12

- 7:45 am – 9:00 am Continental Breakfast – Grand Ballrooms 1-2, Foyer**
- 9:00 am – 9:25 am CJD Foundation Report: Programs, Finance, Advocacy, and Strides for CJD – Grand Ballrooms 1-4**
- 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 – Grand Ballrooms 1-4**
Brian Appleby, MD, Director
- 10:05 am – 10:15 am Question and Answer**
- 10:15 am – 10:30 am Break – Grand Ballrooms 1-2, Foyer**
- 10:30 am – 10:50 am 2026 Centers for Disease Control and Prevention Report**
 Invited to Speak: **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
- 10:50 am – 11:05 am Question and Answer**
- 11:05 am – 11:35 am CJD Foundation Family Panel: “My Story, My Mission”**
 Moderator: **Debbie Yobs**, President and Executive Director, CJD Foundation
Nikki Bland, Denise Chainey, Jeanne Cole, Shannon Romano, Mike Vitanza
- 11:35 am – 12:25 pm Drug Development Panel**
 Moderator: **Brian Appleby, MD**, Director, National Prion Disease Pathology

Surveillance Center, Case Western Reserve University School of Medicine,
Cleveland, OH

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,
Tarrytown, NY

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

**12:25 pm –
12:40 pm**

Question and Answer

12:40 pm – 1:30 pm **Moving Roundtables with Drug Development Panel – Grand Ballrooms
1-2, Foyer**

1:30 pm

Conference Concludes