



2025 CJD Foundation Family Conference

July 11-13, 2025, Chicago Marriott O'Hare, Chicago, IL

DRAFT AGENDA

FRIDAY, JULY 11

- 11:00 am – 7:00pm** **Conference Registration – Registration Booth B, Main Level**
- 12:00 pm – 2:00 pm** **Sporadic Prion Disease Meeting –O'Hare Ballroom, Terminals 1-3, Main Level**
**This is a workshop 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
- 12:00 pm – 2:00 pm** **Genetic Prion Disease Meeting – Salons 8-10, Main Level**
**This workshop is only for families affected by a genetic prion disease*
Moderator: **Debbie Yobs**, President and Executive Director, CJD Foundation
Family Panel:
Trevor Baierl, Nicholas De Maggio, Pamela Fear, Amanda Kalinsky, Vicki Qualley
Expert Resources:
Michael D. Geschwind, MD, PhD, FANA, FAAN, Professor of Neurology, University of California, San Francisco, San Francisco, CA
Richard Knight, BA, BM BCh, FRCP(E), Chair, CJD Support Network, U.K. and Emeritus Professor of Clinical Neurology, The University of Edinburgh, Edinburgh, Scotland
- 2:00 pm – 2:15 pm** **Break – Grand Ballrooms 1-2, Foyer**
- 2:15 pm – 3:45 pm** **Prion Disease Basics – Grand Ballrooms 1-4**
These sessions provide an excellent foundation for Saturday's scientific presentations.
- 2:15 pm – 2:45 pm** **Prion Disease Basics – Clinical**
Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
- 2:45 pm – 3:15 pm** **Prion Disease Basics – Research**
Joel Watts, PhD, Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada

3:15 pm – 3:45 pm	Prion Disease Basics Question and Answer
3:45 pm – 4:00 pm	Break – Grand Ballrooms 1-2, Foyer
4:00 pm – 5:00 pm	Bereavement Workshop, Salons 8-10 Tessa Garcia McEwen, AM, LCSW, DCCS, CDP , Center for Comprehensive Care and Research on Memory Disorders, University of Chicago Medicine, Chicago, IL
6:00 pm – 7:30 pm	Welcome Reception – O’Hare Ballroom, Terminal 5

SATURDAY, JULY 12

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 – 9:10 am	Opening Remarks and Introduction Brian Appleby, MD , Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
9:10 am – 9:40 am	Keynote Address in Honor of Dr. Pierluigi Gambetti Glenn Telling, PhD , Director, Prion Research Center, Colorado State University, Fort Collins, CO
9:40 am – 9:50 am	Question and Answer
9:50 am – 10:30 am	CJD Foundation Research Grant Recipient Reports, Group A
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 – 11:35 am	CJD Foundation Research Grant Recipient Reports, Group B
11:35 am – 11:55 am	Research Grant Recipient Reports, Group B Debrief
11:55 am – 12:25 pm	James Mastrianni, MD, PhD , Professor of Neurology, Director, Center for Comprehensive Care and Research on Memory Disorders, University of Chicago, Chicago, IL
12:30 pm – 1:30 pm	Lunch – Grand Ballrooms 1-2, Foyer

1:30 pm – 1:40 pm	Group Photo – Hotel Lobby
1:45 pm – 4:00 pm	Moving Roundtables – Grand Ballrooms 1-4
4:00 pm – 6:00 pm	Family Consultations (Optional) – O’Hare Ballroom, Terminal 3 Katie Glisic, MA and Meghan Lewis, MA will be available for individual family consultations regarding status of autopsy results and/or the National Prion Disease Pathology Surveillance Center’s autopsy program. Katie Glisic, MA , Administrative Lead, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH Meghan Lewis, MA , Autopsy Specialist, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH
7:00 pm – 7:30 pm	Reception – O’Hare Ballroom, Terminal 5
7:30 pm	Banquet – Grand Ballrooms 1-4

SUNDAY, JULY 13

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 Stuart Yaffa , Chair, CJD Foundation Board of Directors Patricia McGill , 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 – 9:55 am	Break – Grand Ballrooms 1-2, Foyer
9:55 am – 10:25 am	National Prion Disease Pathology Surveillance Center Panel – Grand Ballrooms 1-4 Brian Appleby, MD , Director Eriton Cunha, PhD , Tissue Lab Scientist Katie Glisic, MA , Administrative Lead Meghan Lewis, MA , Autopsy Specialist
10:25 am – 10:35 am	Question and Answer
10:35 am – 10:55 am	2025 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

10:55 am – 11:10 am Question and Answer

11:10 am – 11:40 am CJD Foundation Family Panel: “My Story, My Mission”

Debbie Yobs (Moderator), Karen Adams, Pat Elliott, Elizabeth Rodriguez, Tim Schwister

11:40 am – 12:25 pm Drug Development Panel

Kiyoshi Arita, MSc, Project/Product Manager, Research and Development Division, International Clinical Development Department, NobelPharma Co., Ltd., Tōkyō, Japan

Elizabeth McNeil, MD, MSc, Global Clinical Program Lead in Neurology, Sangamo Therapeutics, Inc., Richmond, CA

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

Nina Oberbeck, PhD, Senior Director of Translational Sciences, Gate BioScience, Brisbane, CA

Anne Smith, PhD, Vice President of Clinical Development, Ionis Pharmaceuticals, Inc., Carlsbad, CA

12:25 pm – 12:40 pm Question and Answer

12:40 pm – 1:30 pm Informal Roundtable Lunch with Drug Development Panel – Grand Ballrooms 1-2, Foyer

1:30 pm Conference Concludes