



2025 CJD Foundation Family Conference

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

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, 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, Grand Ballrooms 1-4 Tessa Garcia McEwen, AM, LCSW , Certified Dementia Practitioner, Certified Grief Educator, The Memory Center, 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: Novel Mouse Models of Prion Diseases 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 – 10:50 am	CJD Foundation Research Grant Recipient Reports, Group A Moderator: Joel Watts, PhD , Associate Professor, Department of Biochemistry, University of Toronto, Toronto, Ontario, Canada
9:50 am – 10:00 am	Investigation of Glycoprotein Nonmetastatic Melanoma protein B (GPNMB) as potential therapeutic target in Prion Diseases Elena De Cecco, PhD , Senior Researcher, University of Zürich, Zürich, Switzerland
10:00 am – 10:10 am	Development of ADAM8-based Gene Therapy for CJD Qingzhong Kong, PhD , Associate Professor of Pathology and Neurology and Assistant Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH

10:10 am – 10:20 am	Understanding the molecular mechanism of spontaneous prion emergence in knock-in mouse models Surabhi Mehra, PhD, MSc* , Postdoctoral Fellow, Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto, Toronto, Ontario, Canada
10:20 am – 10:30 am	Bridging the pre-clinical gap for a small brain-penetrant molecule that reduces PrPC levels Gerold Schmitt-Ulms, PhD* , Professor and Graduate Faculty Member, Department of Laboratory Medicine and Pathology, Tanz Centre for Research in Neurodegenerative Diseases, 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: 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
11:05 am – 11:15 am	Exploring the efficacy of dominant negative protein-based gene therapy for different prion diseases: in vivo proof-of-concept study Joaquín Castilla, PhD* , IKERBasque Research Professor, Center for Cooperative Research in Biosciences (CIC bioGUNE), Basque Research and Technology Alliance (BRTA), Derio, Spain
11:15 am – 11:25 am	Generating cerebral organoids from donors with sporadic Creutzfeldt-Jakob Disease Arielle Hay, PhD , Postdoctoral Research Fellow, Prion Cell Biology Unit, Laboratory of Neurological Infections and Immunity, Rocky Mountain Laboratories, Division of Intramural Research, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Hamilton, Montana
11:25 am – 11:35 am	Validation of a non-invasive diagnostic test for prion diseases using tear fluid Matthias Schmitz, PhD , Dementia Research Unit, Department of Neurology in Göttingen, National Reference Center for TSE and German Center for Neurodegenerative Diseases (DZNE), Göttingen, Germany
11:35 am – 11:55 am	Research Grant Recipient Reports, Group B Debrief
12:00 pm – 12:15 pm	A Multi-Targeted Approach in Search of Prion Disease Therapy James Mastrianni, MD, PhD , Professor of Neurology, Director, Center for Comprehensive Care and Research on Memory Disorders, University of Chicago, Chicago, IL
12:15 pm – 12:25 pm	Question and Answer
12:30 pm – 1:30 pm	Lunch – Grand Ballrooms 1-2, Foyer

*Scheduled to speak remotely

1:30 pm – 1:40 pm	Group Photo – Hotel Lobby
1:45 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) – 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 – 10:00 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 Jacob Schwister , 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 Elliot , 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., Tôkyô, 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 , Vice President 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