



CREUTZFELDT-JAKOB DISEASE  
FOUNDATION, INC.  
*Supporting Families Affected by Prion Disease*

**CJD Surveillance**  
National Prion Disease  
Pathology Surveillance Center

## 2023 CJD Foundation Family Conference

July 14–17, 2023, Hilton Washington DC Capitol Hill

### AGENDA

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#### FRIDAY, JULY 14

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|--------------------|---|
| 11:00 am – 7:00 pm | Conference Registration – Atrium Lobby  |
| 12:00 pm – 2:00 pm | <p><b>Genetic Prion Disease Meeting – Springwood, Lower Level</b></p> <p><i><u>*This workshop is only for families affected by a genetic prion disease.</u></i></p> <p>Moderator:<br/><b>Debbie Yobs</b>, President/Executive Director, CJD Foundation</p> <p>Panelists:<br/><b>Michael D. Geschwind, MD, PhD</b>, Professor of Neurology, UCSF<br/><b>Jill Goldman, MS, MPhil</b>, Columbia University Medical Center<br/><b>Richard Knight, BA, BM BCh, FRCP(E)</b>, Medical Director, CJD Support Network, U.K.<br/><b>Shashi Shetty, PhD</b> CLIA Lab Director, National Prion Disease Pathology Surveillance Center<br/><b>Sonia Vallabh, PhD</b>, Broad Institute</p> |
| 12:00 pm – 2:00pm  | <p><b>Sporadic Prion Disease Meeting – Atrium Ballroom</b></p> <p><i><u>*This is a workshop for families only.</u></i></p> <p><b>Brian Appleby, MD</b>, Director, National Prion Disease Pathology Surveillance Center<br/><b>Lori Nusbaum</b>, Program Director, CJD Foundation</p>  |
| 2:00 pm – 2:15 pm  | Coffee Break  |
| 2:15 pm – 3:45 pm  | <p><b>Prion Disease 101 – Atrium Ballroom</b></p> <p>These sessions provide an excellent foundation for tomorrow's scientific presentations.</p>  |
| 2:15 pm – 3:00 pm  | <p><b>Brian Appleby, MD</b></p> <p><b>Prion Disease Basics – Clinical</b></p>   |
| 3:00 pm – 3:45 pm  | <p><b>Joel Watts, PhD</b>, Associate Professor, Department of Biochemistry, University of Toronto</p> <p><b>Prion Research Basics – Research</b></p>  |

3:45 pm – 4:00 pm	Coffee Break
4:00 pm – 5:00 pm	Bereavement Workshop – Atrium Ballroom Dr. Abigail Nathanson, LCSW, APHSW–C, ACS
6:00 pm – 7:30 pm	Welcome Reception – Executive/Sagamore/Ashlawn, Lower Level

## SATURDAY, JULY 15

7:00 am	Conference Registration – Bottom of Stairs, Lower Level
7:00 am – 8:30 am	Continental Breakfast – Grand Foyer
8:30 am – 8:40 am	Welcome – Grand Ballroom Debbie Yobs
8:40 am – 9:05 am	Memorial Service
9:05 am – 9:15 am	Opening Remarks and Introduction Brian Appleby, MD
9:15 am – 9:45 am	Keynote Address in Honor of Dr. Pierluigi Gambetti Richard Knight, BA, BM BCh, FRCP(E) A Long and Winding Road: 45 Years of CJD History
9:45 am – 9:55 am	Question & Answer
9:55 am – 10:00 am	CJD Foundation Research Grant Recipient Report Panels – Change Rooms for Breakout

Participants will **choose one group** from this session and view 3 presentations. Group A (3 speakers) and Group B (3 speakers) will present simultaneously in two different rooms.

	Room A – Grand Ballroom	Room B – Springwood
	Group A, Part 1 – Moderator: <b>Joel Watts, PhD</b>	Group B, Part 1 – Moderator: <b>Brian Appleby, MD</b>
10:00 am – 10:15 am	<b>Leonardo Cortez, PhD</b> Centre for Prions & Protein Folding Diseases, University of Alberta, Edmonton, Alberta, Canada “Prion protein aggregate size distribution drives clinical phenotype”	<b>Marcelo Barria, PhD</b> National CJD Research & Surveillance Unit, Centre for Clinical Brain Sciences, University of Edinburgh, Edinburgh, UK “Assessing the replication properties of prion protein aggregates found in archived formalin-fixed, paraffin embedded appendix tissue collected from the asymptomatic population by the highly sensitive in vitro prion amplification assay”

10:15 am – 10:30 am	<b>Bradley Groveman, PhD</b> National Institutes of Health, Rocky Mountain Laboratories, Laboratory of Neurological Infections & Immunity “Regional tropism of sporadic CJD subtypes in human brain organoids”	<b>Joaquín Castilla, PhD</b> Center for Cooperative Research in Biosciences (CIC bioGUNE), Basque Research & Technology Alliance (BRTA), Derio, Spain; IKERBASQUE, Basque Foundation for Science, Bilbao, Spain “Development & characterization of the fastest animal model able to propagate GSS prions faithfully”
10:30 am – 10:45 am	<b>Shashirekha Shetty, PhD</b> National Prion Disease & Pathology Surveillance Center, Case Western Reserve University, University Hospitals, Cleveland, OH “Examining copy number variants as a possible phenotype modifier in prion disease”	<b>Jaime Noguez, PhD</b> National Prion Disease Pathology Surveillance Center, Case Western Reserve University, University Hospitals Cleveland Medical Center, Cleveland, OH “Improving the sensitivity of CSF RT-QuIC in humans by examining cases with indeterminate results”

**10:45 am – 11:00 am      Coffee Break**

Participants will **choose one group** from this session and view 2 presentations. Group A (2 speakers) and Group B (2 speakers) will present simultaneously in two different rooms. All 10 presenters will return to one room, the **Grand Ballroom**, for the Question & Answer panels and Moving Roundtables.

	<b>Room A – Grand Ballroom</b>	<b>Room B – Springwood</b>
	Group A, Part 2 – Moderator: <b>Joel Watts, PhD</b>	Group B, Part 2 – Moderator: <b>Richard Knight, BA, BM BCh, FRCP(E)</b>
11:00 am – 11:15 am	<b>Hermann Clemens Altmeyen, PhD</b> Institute of Neuropathology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany “Enzymatic PrP shedding in humans: Biomarker potential & therapeutic target”	<b>Zerui Wang, MD, PhD</b> Department of Pathology, Case Western Reserve University “Assessing Prophylactic & Therapeutic Efficacy of a Cellulose Ether Compound TC-5RW on CJD”
11:15 am – 11:30 am	<b>Maria Letizia Barreca, PhD</b> Department of Pharmaceutical Sciences (DPS), University of Perugia-Italy “Blocking the Neurotoxic Activities of Mutant Prion Proteins by a Novel Class of Therapeutic Agents”	<b>Rodrigo Morales, PhD</b> Department of Neurology. The University of Texas Health Science Center at Houston “Development of a high throughput system for screening anti-prion molecules”

**11:30 am – 11:35 am      Change Rooms –Grand Ballroom**

**11:35 am – 11:55 am      Research Grant Report Recipient Panel Debrief: Panel A-1 Question & Answer**

**11:55 am – 12:15 pm      Research Grant Report Recipient Panel Debrief: Panel B-1 Question & Answer**

**12:15 pm – 1:10 pm      Lunch**

**1:10 pm – 1:15 pm      Group Photo – Hilton Washington DC Capitol Hill Hotel Lobby**

**1:15 pm – 1:35 pm      Research Grant Report Recipient Panels Debrief: Panels A-2 and B-2 Question & Answer**

1:35 pm – 3:30 pm	Moving Roundtables
3:30 pm – 4:00 pm	Group Photo – Capitol Hill
4:00 pm – 6:00 pm	<p><b>Family Consultations (<i>Optional</i>) – Madison, Lower Level</b>  Danielle Jordan and Meghan Lewis will be available for individual family consultations regarding status of autopsy results and/or the National Prion Disease Pathology Surveillance Center’s autopsy program.</p> <p><b>Danielle Jordan</b>, Autopsy Program Manager, National Prion Disease Pathology Surveillance Center  <b>Meghan Lewis</b>, Autopsy Specialist, National Prion Disease Pathology Surveillance Center</p>
7:00 pm – 7:30 pm	Reception – Grand Foyer
7:30 pm	Banquet – Grand Ballroom

## SUNDAY, JULY 16

7:45 am – 9:00 am	Continental Breakfast – Grand Foyer
9:00 am – 9:15 am	<p><b>CJD Foundation Report &amp; Finance Report</b>  <b>Mayra Lichter</b>, Chair, CJD Foundation Board of Directors  <b>Patricia McGill</b>, Treasurer, CJD Foundation Board of Directors</p>
9:15 am – 9:20 am	<p><b>CJD Foundation Strides for CJD Announcements</b>  <b>Lori Nusbaum</b>, Program Director, CJD Foundation</p>
9:20 am – 9:35 am	<p><b>CJD Foundation Grants Program</b>  <b>Clarence Hunter</b>, CJD Foundation Grants Committee, Members, CJD Foundation Board of Directors  <b>Brian Appleby</b>, MD</p>
9:35 am – 9:55 am	<p><b>The 2023 Centers for Disease Control and Prevention Report</b>  <b>Ryan Maddox</b>, PhD, Epidemiologist, Prion and Public Health Office  Division of High-Consequence Pathogens and Pathology</p>
9:55 am – 10:10 am	Question & Answer
10:10 am – 10:20 am	Coffee Break
10:20 am – 10:30 am	<p><b>CJD Lookback Study Update</b>  <b>Lauren Crowder</b>, PhD, MPH, CPH, Executive Scientific Officer, American Red Cross</p>

10:30 am – 11:00 am	<b>National Prion Disease Pathology Surveillance Center Panel</b> Brian Appleby, MD Tatiana Weaver, Lab Manager Shashi Shetty, PhD, CLIA Lab Director Jamie Noguez, PhD, CSF Section Head Danielle Jordan, Autopsy Coordinator
11:00 am – 11:10 am	<b>Question &amp; Answer</b>
11:10 am – 11:25 am	<b>The CJD International Support Alliance</b> Suzanne Solvyns, Co–Chair, CJD International Support Alliance
11:25 am – 11:55 am	<b>CJD Foundation Family Panel</b> Trevor Baierl, Member, CJD Foundation Board of Directors Amanda Kalinsky, Member, CJD Foundation Board of Directors Sonia Vallabh, PhD, Broad Institute
11:55 am – 12:25 pm	<b>Advocacy Update</b> Kendall Hussey, Senior Policy Advisor, Akin Gump Strauss Hauer & Feld, LLP
12:25 pm – 12:35 pm	<b>Wrap–Up</b> Debbie Yobs
12:35 pm – 1:35 pm	<b>Lunch – Grand Ballroom</b>
1:35 pm – 2:30 pm	<b>Advocacy Orientation – Grand Ballroom</b> This session will prepare families to make advocacy visits on Monday. Families not visiting Capitol Hill are also encouraged to stay and learn how to advocate from home!

## MONDAY, JULY 17

### Capitol Hill Visits

Family members who have registered for advocacy visits will receive their packets on Sunday. On Monday, stop in the lobby to check in before visits. After visits, drop off advocacy evaluation forms in lobby or send to CJD Foundation. Thank you for making your voice heard on Capitol Hill!