



## 2024 CJD Foundation Family Conference

July 19-21, 2024, Hilton Washington DC Capitol Hill, Washington, DC

### AGENDA

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#### FRIDAY, JULY 19

**11:00 am – 7:00pm**      **Conference Registration – Bottom of Stairs, Lower Level**

**12:00 pm – 2:00 pm**      **Sporadic Prion Disease Meeting – Grand Ballroom, Lower 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

**12:00 pm – 2:00 pm**      **Genetic Prion Disease Meeting – Springwood, Lower Level**

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

Moderator:

**Debbie Yobs**, President and Executive Director, CJD Foundation

Expert Resources:

**Michael D. Geschwind, MD, PhD**, Professor of Neurology, University of California, San Francisco, San Francisco, CA

**Richard Knight, BA, BM BCh, FRCP(E)**, Chair, CJD Support Network, U.K.

**Simon Mead, BM BCh, FRCP, PhD**, Clinical Professor, MRC Prion Unit at UC London, Institute of Prion Diseases, London, England

**2:00 pm – 2:15 pm**      **Coffee Break**

**2:15 pm – 3:45 pm**      **Prion Disease Basics – Grand Ballroom**

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

**2:15 pm – 2:45 pm**      **Prion Disease Basics – Clinical**  
**Brian Appleby, MD**

**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**
- 4:00 pm – 5:00 pm      Bereavement Workshop**  
**Dr. Abigail Nathanson, LCSW, APHSW–C, ACS, New York, NY**
- 6:00 pm – 7:30 pm      Welcome Reception – Executive/Sagamore/Ashlawn, Lower Level**

**SATURDAY, JULY 20**

- 7:00 am                      Conference Registration – Bottom of Stairs, Lower Level**
- 7:00 am – 8:30 am      Continental Breakfast – Grand Foyer, Lower Level**
- 8:30 am – 8:40 am      Welcome – Grand Ballroom**  
**Debbie Yobs, President and Executive Director, CJD Foundation**
- 8:40 am – 9:05 am      Memorial Service**
- 9:05 am – 9:15 am      Opening Remarks and Introduction**  
**Brian Appleby, MD, Director, National Prion Disease Pathology Surveillance Center, Case Western Reserve University School of Medicine, Cleveland, OH**
- 9:15 am – 9:45 am      Keynote Address in Honor of Dr. Pierluigi Gambetti:**  
**Can Genetics Help in the Fight Against CJD?**  
**Simon Mead, BM BCh, FRCP, PhD, Clinical Professor, MRC Prion Unit at UC London, Institute of Prion Diseases, London, England**
- 9:45 am – 9:55 am      Question and Answer**
- 9:55 am – 10:15 am    The 2024 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**
- 10:15 am – 10:30 am      Question and Answer**
- 10:30 am – 10:45 am    Coffee Break**
- 10:45 am – 12:05 pm    CJD Foundation Research Grant Recipient Report Panels**

Participants will **choose one group** and view 4 or 5 presentations. Group A (5 speakers) and Group B (4 speakers) will present simultaneously in two different rooms. All 9 presenters will return to one room, the Grand Ballroom, for the Question and Answer panels and Moving Roundtables.

	<b>Room A – Grand Ballroom</b>	<b>Room B – Springwood</b>
	Group A – Moderator: <b>Joel Watts, PhD</b>	Group B – Moderator: <b>Richard Knight, BA, BM BCh, FRCP(E)</b>
<b>10:45 am – 11:00 am</b>	<b>Jason C. Bartz, PhD</b> Chair and Professor, Department of Medical Microbiology and Immunology, Creighton University School of Medicine, Omaha, NE “Detection of residual prions from decontaminated medical and laboratory surfaces”	<b>Dr. Thomas Cunningham</b> MRC Prion Unit at UC London, Institute of Prion Diseases, London, England “Generation of humanised STX6 overexpression mice to study prion disease genetic risk and as a model for therapeutic intervention”
<b>11:00 am – 11:15 am</b>	<b>Professor Parmjit Jat</b> MRC Prion Unit at UC London, Institute of Prion Diseases, London, England “Elucidating the factors required for propagating human CJD prions”	<b>Victoria Lawson, PhD</b> Department of Microbiology and Immunology, Peter Doherty Institute for Infection and Immunity, The University of Melbourne, Victoria, Australia “Risk of cancer from reduced expression of PrPC-implications for prion disease treatment”
<b>11:15 am – 11:30 am</b>	<b>Qiuye Li, PhD (CJDF Fellowship)</b> Department of Physiology and Biophysics, Case Western Reserve University School of Medicine, Cleveland, OH “High-resolution structure determination of MM1 and MM2 sCJD prions”	<b>Ignazio Cali, PhD</b> Department of Pathology, Case Western Reserve University School of Medicine, Cleveland, OH “Investigating prion protein seeding activity in Alzheimer’s disease and chronic traumatic encephalopathy”
<b>11:35 am – 11:50 am</b>	<b>Robert C.C. Mercer, PhD</b> Instructor, Department of Biochemistry, Boston University School of Medicine, Boston, MA “The identification of PrPSc interaction partners and the characterization of their role in prion infection and/or propagation”	<b>Dr. Sarah Vascellari</b> Department of Biomedical Sciences, University of Cagliari (UniCa), Cagliari, Italy “Development of a blood and urine prion diagnostic test for human prion diseases using the Real Time QuIC assays”
<b>11:50 am – 12:05 pm</b>	<b>Valerie L. Sim, MD, FRCPC</b> Centre for Prions and Protein Folding Diseases, University of Alberta, Edmonton, Alberta, Canada “Contribution of oligomeric prion populations to phenotypic heterogeneity in variably protease-sensitive prionopathy (VPSPr) versus silent prions”	<b>Change Rooms – Return to Grand Ballroom</b>

**12:05 pm – 12:30 pm    Research Grant Report Recipient Panel Debrief: Panel A Question and Answer – Grand Ballroom**

**12:30 pm – 1:25 pm    Lunch**

**1:25 pm – 1:35 pm    Group Photo – Hilton Washington DC Capitol Hill Hotel Lobby**

- 1:40 pm – 2:00 pm**      **Research Grant Report Recipient Panel Debrief: Panel B Question and Answer – Grand Ballroom**
- 2:00 pm – 4:00 pm**      **Moving Roundtables**
- 4:00 pm – 4:30 pm**      **Group Photo – Capitol Hill**  
Meet in Hilton Washington DC Capitol Hill Hotel Lobby
- 4:00 pm – 6:00 pm**      **Family Consultations (Optional) – Madison, Lower Level**  
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.  
**Danielle Jordan**, Autopsy Program Manager, National Prion Disease Pathology Surveillance Center  
**Meghan Lewis**, Autopsy Specialist, National Prion Disease Pathology Surveillance Center
- 7:00 pm – 7:30 pm**      **Reception – Grand Foyer**
- 7:30 pm**                      **Banquet – Grand Ballroom**

**SUNDAY, JULY 21**

- 7:45 am – 9:00 am**      **Continental Breakfast – Grand Foyer**
- 9:00 am – 9:15 am**      **CJD Foundation Report and Finance Report – Grand Ballroom**  
**Stuart Yaffa**, Chair, CJD Foundation Board of Directors  
**Patricia McGill**, Treasurer, CJD Foundation Board of Directors
- 9:15 am – 9:20 am**      **CJD Foundation Strides for CJD Announcements**  
**Lori Nusbaum**
- 9:20 am – 9:35 am**      **CJD Foundation Grants Program**  
**Debbie Yobs**  
**Joel Watts, PhD**
- 9:35 am – 9:45 am**      **Coffee Break**
- 9:45 am – 10:15 am**      **Drug Development**  
**Brian Appleby, MD**  
**Sonia Vallabh, PhD**, Senior Group Leader, Broad Institute, Cambridge, MA
- 10:15 am – 10:25 am**      **Question and Answer**

- 10:25 am – 10:55 am**    **National Prion Disease Pathology Surveillance Center Panel**  
**Brian Appleby, MD**  
**Katie Glisic, MA**, Administrative Lead  
**Danielle Jordan**, Autopsy Program Manager  
**Lateefa Russell**, Histologist  
**Tatiana Weaver, MEd, MLS (ASCP), CPHQ**, Laboratory Manager
- 10:55 am – 11:05 am**    **Question and Answer**
- 11:05 am – 11:35 am**    **CJD Foundation Family Panel: “Sharing My CJD Story In Art and Media”**  
**Debbie Yobs**, Moderator  
**Don Friedman**, Author, *Still Phyllis*  
**David Langan**, Author, *All is Well: Living Through Losing One You Love*  
**David Oliver**, Reporter, *USA Today*  
**Rosemary Vaswani**, Author, *Don’t Fade Away Starlight*, and Poet,  
@rosepoemsthebitterandthesweet Instagram Poetry Series
- 11:35 am – 11:45 am**    **Question and Answer**
- 11:45 am – 11:55 am**    **My CJD Story, a Film**  
**Lavonne C. Hall**, Member, CJD Foundation Board of Directors
- 11:55 am – 12:25 pm**    **Advocacy Update**  
**Anna K. Abram**, Senior Advisor, Akin Gump Strauss Hauer & Feld, LLP,  
Washington, D.C.
- 12:25 pm – 12:35 pm**    **Wrap-Up**  
**Debbie Yobs**
- 12:35 pm – 1:35 pm**    **Lunch**
- 1:00 pm – 2:00 pm**    **Advocacy Training**  
**Anna K. Abram**  
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 22

### **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 (by mail to 3634 West Market Street, Suite 110, Akron, OH 44333 or by email to [help@cjd.foundation.org](mailto:help@cjd.foundation.org)). Thank you for making your voice heard on Capitol Hill!