



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

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

## **TENTATIVE SCHEDULE**

### **2018 CJD Foundation Family Conference**

July 13 - 15

Washington Court Hotel, 525 New Jersey Avenue, NW, Washington DC 20001

#### **Friday, July 13**

**11:00am – 7:00pm**    **Registration - Atrium Lobby**

**9:00 – 10:30**            **CJDISA Friends & Advisors Meeting - Capitol Room**  
*\*This meeting is open only to the members of the CJDISA Friends & Advisors Committee and the International Alliance Members*

**10:45 – 12:15**            **CJD Foundation Board of Directors Meeting - Capitol Room**  
*\*This meeting is open only to the members of the CJD Foundation Board of Directors*

**12:45 – 2:45**            **Sporadic Prion Disease Meeting - Springwood Room, Lower Level**  
*\*This is a workshop for families only*

#### **Brian Appleby, MD - Chairman**

*Director, National Prion Disease Pathology Surveillance Center  
Associate Professor, Departments of Neurology, Psychiatry, & Pathology  
Case Western Reserve University  
Medical Director, CJD Foundation Board of Directors  
Cleveland, Ohio*

#### **Lori Nusbaum**

*Program Director, CJD Foundation*

**12:45 – 2:45**            **Genetic Prion Disease Meeting - Executive Room, Lower Level**  
*\*This meeting is only for families affected by a genetic prion disease*

#### **Deana Simpson, RN - Chairman**

*Member, CJD Foundation Board of Directors  
Macomb, Michigan*

#### **Michael D. Geschwind, MD, PhD**

*Professor of Neurology, Memory and Aging Center  
University of California at San Francisco (UCSF)  
San Francisco, California*

- 2:45 – 3:00**                    **Coffee Break – Sagamore, Lower Level**
- 3:00 – 4:30**                    **Prion Disease Overview – Executive Room, Lower Level**  
*Whether you are attending your first conference or seeking a clearer understanding of the science of prion disease, join us for these sessions – an excellent preparation for tomorrow’s scientific presentations.*
- 3:00 – 3:45**                    **Brian Appleby, MD**  
*Prion Disease Basics*
- 3:45 – 4:30**                    **Richard Knight, BA, BM BCh, FRCP(E)**  
***Diagnosis and Treatment of Human Prion Diseases***  
*Medical Director, CJD Support Network, U.K.*  
*Director, The CJD Surveillance Unit*  
*Edinburgh, Scotland, United Kingdom*
- 4:30 – 5:30**                    **Bereavement Workshop – Executive Room, Lower Level**  
**Deana Simpson, RN, Co-chairman**  
**Katrina Hallmark, PsyD, Co-chairman**  
*Neuropsychologist, Clarity Child Guidance Center*  
*San Antonio, Texas*
- 6:00 – 7:30**                    **Welcome Reception – Atrium Ballroom**

**Saturday, July 14 - Atrium Ballroom**

- 7:00am**                        **Conference Registration – Atrium Lobby**
- 7:00 – 8:30**                    **Continental Breakfast**
- 8:30 – 8:40**                    **Welcome**  
**Debbie Yobs**  
*President, CJD Foundation*
- 8:40 – 9:00**                    **Memorial Service**  
*Lori Nusbaum, Program Director, CJD Foundation*  
TBD

## Program

**Chairpersons:** **Brian Appleby, MD**  
**Debbie Yobs**

### Keynote Address

- 9:00 – 9:05** **Brian Appleby, MD**  
**Opening Remarks**  
*Director, National Prion Disease Pathology Surveillance Center*  
*Associate Professor, Departments of Neurology, Psychiatry, & Pathology*  
*Case Western Reserve University*  
*Medical Director, CJD Foundation Board of Directors*  
*Cleveland, Ohio*
- 9:05 – 9:35** **Robert G. Will, MD, FRCP(E)**  
**Keynote Speaker**  
*Department of Clinical Neurosciences, Western General Hospital Edinburgh, UK*
- 9:35 – 9:40** **Q&A**

### CJD Foundation Research Grant Recipient Reports

- 9:40 – 9:55** **Allison Kraus, PhD**  
***Investigation of Prion Inactivation by Reactive Oxygen Species in Vivo***  
*Rocky Mountain Laboratories, Montana*  
**Dr. Kraus is the recipient of:**  
**The Jon Fansler Memorial Grant, contributed by Rhonda Fansler**  
**The John Gill Memorial Grant, contributed by Lisa Marie Gill Braun**  
**The Eugene A. Riedel Memorial Grant, contributed by Jacqueline Riedel**  
**The Tom Stivison Memorial Grant, contributed by Cookie Stivison**  
**The Vincent Walsh Memorial Grant, contributed by Sue Walsh**
- 9:55 – 10:10** **Hermann Clemens Altmeyen, PhD**  
***Investigating the Potential of the Neuroprotective N1 Fragment of the Prion Protein as a New Treatment Against Prion Diseases***  
*Institute of Neuropathology, University Medical Center – Eppendorf, Hamburg, Germany*  
**Dr. Altmeyen is the recipient of:**  
**The Garry Buttermann IV Memorial Grant, contributed by Jill Canuel**  
**The Davey Kock Memorial Grant, contributed by Janine Kock**  
**The Jeffrey A. Smith Memorial Grant, contributed by**  
**The Jeffrey and Mary Smith Family Foundation**  
**The Strides for CJD Grant, contributed by the Families of the CJD Foundation**

- 10:10 – 10:25**                    **David A. Harris, MD, PhD**  
*Highly Synergistic Combination Therapy for Prion Diseases*  
*Department of Biochemistry, Boston University School of Medicine*  
**Dr. Harris is the recipient of:**  
The Marcos Amongero Memorial Grant, contributed by  
    Lauren Amongero and Family  
The Michael H. Cole Memorial Grant, contributed by Jeanne Cole  
The Robert Dodd Memorial Grant, contributed by Kathleen Dodd and Family  
The Eugene A. Riedel Memorial Grant, contributed by Jacqueline Riedel  
The Jeffrey A. Smith Memorial Grant, contributed by  
    The Jeffrey and Mary Smith Family Foundation
- 10:25 – 10:40**                    **Coffee Break**
- 10:40 – 10:55**                    **Question & Answer Panel (Kraus, Altmeppen, Harris)**  
Moderator                         **Brian Appleby, M.D.**
- 10:55 – 11:10**                    **Carole Crozet, PhD (on behalf of Sylvain Lehmann, PhD)**  
*Innovative Human 3D Neural Network Model for the Efficient*  
*Propagation of Human Prions*  
*Institute for Regenerative Medicine and Biotherapy, University of Montpellier, France*  
**Dr. Lehmann is the recipient of:**  
The Marcos Amongero Memorial Grant, contributed by  
    Lauren Amongero and Family  
The Ricki/Rivka Angelus Memorial Grant, contributed by Debbie Callif  
The Al Tennant Memorial Grant, contributed by Marie Bauer  
The Davey L. Kock Memorial Grant, contributed by Janine Kock and Family  
The Eugene A. Riedel Memorial Grant, contributed by Jacqueline Riedel
- 11:10 – 11:25**                    **Leonardo Cortez, PhD**  
*Isolation and Strain-Specific Characterization of Pathogenic CJD Prion*  
*Particles*  
*Centre for Prions and Protein Folding Diseases, University of Alberta*  
*Edmonton, Alberta, Canada*  
**Dr. Cortez is the recipient of:**  
The Christopher “Dutch” Grammel and Michael Roll Memorial Grant,  
    contributed by Scott and Beth Grammel  
The “Mercies in Disguise Grant in Honor of the Baxley Family,” contributed  
    by Kathy Baxley and Family  
The José A. Piriz and Sonia E. Piriz Memorial Grant, contributed by  
    Karla Piriz and Lauren Piriz  
The Patrick Yobs Memorial Grant, contributed by Debbie Yobs and Family  
The Strides for CJD Grant, contributed by the Families of the CJD Foundation
- 11:25 – 12:30**                    **Lunch**

**12:30 – 12:45**                    **Rodrigo Morales, PhD**  
*Systematic Evaluation of the Zoonotic Potential of Different CWD Isolates*  
*Mitchell Center for Alzheimer’s Disease and Related Brain Disorders, Department of Neurology, University of Texas-Houston Medical School*  
**Dr. Morales is the recipient of:**  
**The Eugene A. Riedel Memorial Grant, contributed by Jacqueline Riedel**  
**The Jeffrey A. Smith Memorial Grant, contributed by**  
    **The Jeffrey and Mary Smith Family Foundation**  
**The Tom Stivison Memorial Grant, contributed by Cookie Stivison**  
**The Strides for CJD Grant, contributed by the Families of the CJD Foundation**  
**The CJD Foundation Grant, contributed by**  
    **The Families of the CJD Foundation**

**12:45 – 1:05**                    **Question & Answer Panel (Crozet, Cortez, Morales)**  
**Moderator**                    **Richard Knight, BA, BM BCh, FRCP(E)**  
*Medical Director, CJD Support Network, U.K.*  
*Director, The CJD Surveillance Unit*  
*Edinburgh, Scotland, United Kingdom*

**1:05 – 1:25**                    **Antisense Oligonucleotides (ASOs) and Prion Disease**  
**A message from Dr. Byron Caughey, 2016 recipient of CJD Foundation grant for “Antisense Oligonucleotides to delay or prevent onset of prion disease in mice”**  
  
**Eric Minikel and Sonia Vallabh**  
**An update on working toward a future clinical trial (on potential future clinical application)**  
*Prion Scientists, Broad Institute*

**1:25 – 3:25**                    **Moving Roundtables**

**3:25 – 5:55**                    *Crissy Moskal, Administrative Manager of The National Prion Disease Pathology Surveillance Center; Katie Glisic, Program Director; and Meghan Lewis, Autopsy Specialist, will be available in the Montpelier Room for individual family consultations regarding status of autopsy results and/or the autopsy program.*

**7:00 – 7:30**                    **Reception - Capitol/Senate Rooms**

**7:30**                              **Banquet - Atrium**

**Sunday, July 15 – Atrium Ballroom**

*Chairpersons:*                **Mayra Lichter**  
                                      **Lori Nusbaum**

**7:45 – 9:00**                    **Continental Breakfast**

- 9:00 – 9:15**                    **Mayra Lichter**  
*CJD Foundation Report*  
*Chairman, CJD Foundation Board of Directors*  
*Miami, Florida*
- 9:15 – 9:30**                    **Dr. Brian Appleby**  
*CJD Foundation Grants Program*  
*CJD Foundation Grants Committee,*  
*Members, CJD Foundation Board of Directors*
- 9:30 – 9:45**                    **Dr. Brian Appleby**  
*National Prion Disease Pathology Surveillance Center Overview*
- 9:45 – 10:00**                    *National Prion Disease Pathology Surveillance Center Panel*  
**Moderator**                    **Dr. Brian Appleby**
- Panel:**  
**Mark Cohen, MD**  
*Co-Director, NPDPSC*  
*Professor, Departments of Pathology and Neurology, Case Western Reserve University*
- Crissy Moskal**  
*Administrative Manager*
- Katie Glisic, MA**  
*Program Director*
- Meghan Lewis**  
*Autopsy Coordinator*
- 10:00 – 10:15**                    **Q&A**
- 10:15 – 10:30**                    **Coffee Break**
- 10:30 – 10:45**                    **Kevin Keough, PhD, FCAHS**  
*Alberta Prion Research Institute (APRI) Report*  
*Executive Director, Alberta Prion Research Institute (APRI)*  
*Alberta Innovates*  
*Alberta, Canada*
- 10:45 – 10:50**                    **Q&A**
- 10:50 – 11:05**                    **Ryan Maddox, PhD**  
*The Centers for Disease Control and Prevention Report: A CDC CJD Q&A*  
*Epidemiologist, Prion and Public Health Office*  
*Division of High-Consequence Pathogens and Pathology*  
*National Center for Emerging and Zoonotic Infectious Diseases*  
*Centers for Disease Control and Prevention*  
*Atlanta, Georgia*
- 11:05 – 11:10**                    **Q&A**

- 11:10 – 11:20**      **Lauren Crowder and Whitney Steele**  
*American Red Cross*
- 11:20 – 11:30**      **Lori Nusbaum**  
*Questionnaire Report*
- 11:30 – 11:55**      **Amanda Baxley Kalinsky, RN, BSN**  
*Family Stories – Outreach and Education*
- 11:55 – 12:00**      **Q&A**
- 12:00 – 12:40**      **Lunch**
- 12:40 – 1:25**      **The CJD International Support Alliance**  
**Suzanne Solvyns & Deana Simpson**  
*Co-Chairpersons, CJD International Support Alliance*
- 2:00**      ***Advocacy Training***  
*Legislative Staff, U.S. Senate*  
*Washington, DC*  
*This session will help prepare families who will hold advocacy visits on Monday.*  
*Families NOT attending Capitol Hill are also encouraged to stay for this informational meeting. This will help prepare you for advocating in your hometown.*

## **Monday, July 16**

### **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 evaluation forms in lobby or send to CJD Foundation.*

*Thank you for making your voice heard on Capitol Hill!*