



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

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

## **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 - Lower Level**

**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 - Atrium Ballroom**  
*\*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 - Springwood Room, Lower Level**  
*\*This meeting is only for families affected by a genetic prion disease*

#### **Deana Simpson, MSN, 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 – Atrium Lobby**
- 3:00 – 4:30**                    **Prion Disease Overview – Atrium Ballroom**  
*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 – Atrium Ballroom**  
**Katrina Hallmark, PsyD, Co-chairman**  
*Neuropsychologist*  
*San Antonio, Texas*
- 6:00 – 7:30**                    **Welcome Reception – Executive/Sagamore/Ashlawn – Lower Level**

**Saturday, July 14 - Grand Ballroom – Lower Level**

- 7:00am**                        **Conference Registration – Lower Level**
- 7:00 – 8:30**                    **Continental Breakfast**
- 8:30 – 8:40**                    **Welcome**  
**Debbie Yobs**  
*President, CJD Foundation*
- 8:40 – 9:10**                    **Memorial Service**  
*Mayra Lichter, Chairman, CJD Foundation Board of Directors*  
*Veronica Oberdorf, CJD Foundation Board of Directors*  
*David Ralston, CJD Support Group, Sydney, Australia*  
*Suzanne Solovyns, CJD Support Group, Sydney, Australia*

## Program

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

### Keynote Address

**9:10 – 9:15**

**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*

**9:15 – 9:45**

**Robert G. Will, MD, FRCP(E)**

***Keynote Speaker***

***Why Do People Get CJD?***

*Department of Clinical Neurosciences, Western General Hospital, Edinburgh, UK*

**9:45 – 9:50**

**Q&A**

### CJD Foundation Research Grant Recipient Reports

**9:50 – 10:05**

**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**

**10:05 – 10:20**

**Hermann Clemens Altmepfen, 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. Altmepfen 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**

- 10:20 – 10:35**      **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
- 10:35 – 10:50**      **Question & Answer Panel (Kraus, Altmeppen, Harris)**  
**Moderator**      **Brian Appleby, M.D.**
- 10:55 – 11:10**      **Coffee Break**
- 11:10 – 11:25**      **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
- 11:25 – 11:40**      **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
- 11:45 – 12:45**      **Lunch**

- 12:45 – 1:00**                    **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**
- 1:00 – 1:15**                    **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*
- 1:15 – 1:35**                    **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**  
*Efforts to Develop a Preventive Therapeutic for Prion Disease*  
*Prion Scientists, Broad Institute, Cambridge, Massachusetts*
- 1:40 – 1:55**                    **Coffee Break**
- 1:55 – 4:00**                    **Moving Roundtables – Grand Ballroom**
- 4:00 – 6:00**                    *Crissy Moskal, Administrative Manager of The National Prion Disease Pathology Surveillance Center; Katie Glisic, Research Coordinator; and Meghan Lewis, Autopsy Specialist, will be available in the Madison Room for individual family consultations regarding status of autopsy results and/or the autopsy program.*
- 7:00 – 7:30**                    **Reception - Grand Foyer - Lower Level**
- 7:30**                                **Banquet - Grand Ballroom - Lower Level**

## Sunday, July 15 – Grand Ballroom, Lower Level

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

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

**9:00 – 9:15**            **CJD Foundation Report**  
**Mayra Lichter**  
*Chairman, CJD Foundation Board of Directors*  
*Miami, Florida*

**9:15 – 9:30**            **CJD Foundation Grants Program**  
**Marie Kassai, Dr. Brian Appleby**  
*CJD Foundation Grants Committee,*  
*Members, CJD Foundation Board of Directors*

**9:30 – 9:45**            **National Prion Disease Pathology Surveillance Center Overview**  
**Dr. Brian Appleby**

**9:45 – 10:00**        **National Prion Disease Pathology Surveillance Center Panel**  
**Moderator**            **Dr. Brian Appleby**

**Panel:**

**Mark Cohen, MD**  
*Co-Director, NPDPS*  
*Professor, Departments of Pathology and Neurology, Case Western Reserve University*

**Crissy Moskal**  
*Administrative Manager*

**Katie Glisic, MA**  
*Research Coordinator*

**Meghan Lewis**  
*Autopsy Specialist*

**10:00 – 10:15**        **Q&A**

**10:15 – 10:30**        **Coffee Break**

**10:30 – 10:45**        **Alberta Prion Research Institute (APRI) Report**  
**Kevin Keough, PhD, FCAHS**  
*Executive Director, Alberta Prion Research Institute (APRI)*  
*Alberta Innovates*  
*Alberta, Canada*

**10:45 – 10:50**        **Q&A**

- 10:50 – 11:05**      **The 2018 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  
Centers for Disease Control and Prevention  
Atlanta, Georgia*
- 11:05 – 11:10**      **Q&A**
- 11:10 – 11:20**      **American Red Cross**  
**Lauren Crowder, MPH, CPH**  
**Whitney Steele, PhD, MPH**
- 11:20 – 11:50**      **Family Stories – Outreach and Education**
- **Amanda’s Story** by Amanda Baxley Kalinsky, RN, BSN
  - **Family Stories**
- 11:50 – 12:30**      **Lunch**
- 12:30 – 1:15**      **The CJD International Support Alliance**  
**Suzanne Solvyns & Deana Simpson**  
*Co-Chairpersons, CJD International Support Alliance*
- 2:00**                      **Advocacy Training**  
*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!*