

## *CJD 2010 and the Eighth Annual CJD Foundation Family Conference Schedule*

### **Friday, July 16th**

- 11:00 - 3:30**                    **Registration - Springwood Room, Lower level**
- 10:15 - 12:00**                **CJD Foundation Board of Directors Meeting - Capital Room,  
Mezannine Level**
- 12:30 - 2:30**                **Familial Prion Disease Meeting - Springwood Room, Lower Level**  
*\*This meeting is only for families affected by a familial prion disease*  
**Deana Simpson, RN - Chairman**  
*Macomb, Michigan*  
*Founder and Director, CJD Insight; Member, CJD Foundation Board of Directors*
- Pierluigi Gambetti, MD**  
*Cleveland, Ohio*  
*Director, The National Prion Disease Pathology Surveillance Center; Medical Director,  
The CJD Foundation, CJD Foundation Board of Directors*
- Thomas Wisniewski, MD**  
*New York, New York*  
*Professor, Departments of Neurology, Pathology and Psychiatry, New York University  
School of Medicine*
- 3:00 - 5:00**                    **Bereavement Workshop - Springwood Room**  
**Brian Appleby, MD - Chairman**  
*Baltimore, Maryland*  
*Director, CJD Program, The Johns Hopkins Hospital*
- Deana Simpson, RN**
- 4:30 - 7:30**                    **Registration, Atrium Ballroom Lobby**
- 6:00 - 7:30**                    **Welcome Reception, Atrium Ballroom**

**Saturday, July 17th Atrium Ballroom**

**7:00 a.m. Conference Registration**

**7:00 – 8:00 Continental Breakfast**

**8:00 – 8:10 Conference Welcome  
Florence Kranitz**

*Akron, Ohio*

*President, The CJD Foundation; Co-Chairman, The CJD International Support Alliance*

**8:10 – 8:35 Memorial Service**

**Co-Chairmen: Pierluigi Gambetti, MD  
Neil Cashman, MD, FRCP(C), FCAHS**

Overviews

**8:35 – 9:00 The Future of Prion Disease Research and Treatments  
John Collinge, MD, FRCP, FRS**

*London, England,*

*Director, UK Medical Research Council's Prion Unit; Director, UK National Prion Clinic*

**9:00 – 9:10 Q&A**

**9:10 – 9:35 CJD World Overview and Difficulties in Making A CJD Diagnosis  
Robert Will, MD, FRCP(E)**

*Edinburgh, Scotland,*

*Professor of Neurology, University of Edinburgh; Former Director and Founder, National CJD Surveillance Unit, Western General Hospital*

**9:35 – 9:45 Q&A**

**9:45 - 10:00 Coffee Break**

Diagnosis and Treatment

**10:00 – 10:20 The Current State of Prion Disease Diagnostics  
Jiri Safar, MD**

*Cleveland, Ohio*

*Co-Director, The National Prion Disease Pathology Surveillance Center*

**10:20 – 10:25 Q&A**

**10:25 – 10:45 The Future of Prion Disease Diagnostics  
David Wishart, PhD**

*Alberta, Canada*

*Principal Investigator, Nano Life Sciences, National Institute for Nanotechnology, National Research Council*

10:45 - 10:50	<b>Q&amp;A</b>
10:50 - 11:10	<b>Human Prion Disease Vaccine</b> <b>Thomas Wisniewski, MD</b>
11:10 - 11:15	<b>Q&amp;A</b>
11:15 - 11:35	<b>Doxycycline Clinical Trial Update</b> <b>Fabrizio Tagliavini, MD</b> <i>Milan, Italy</i> <i>Director, Divisions of Neuropathology and Neurology, Fondazione IRCCS Istituto Neurologico Carlo Besta</i>
11:35 - 11:40	<b>Q&amp;A</b>
11:40 - 11:55	<b>The National Prion Monitoring Cohort Study</b> <b>Simon Mead, PhD</b> <i>London, England</i> <i>Head, Human Genetics Program, MRC Prion Unit; Lead Clinician, National Prion Clinic</i>
11:55 - 1:10	<b>Lunch</b>
<u>Surveillance</u>	
1:10 - 1:30	<b>Prion Disease Surveillance in the United States</b> <b>Pierluigi Gambetti, MD</b>
1:30 - 1:50	<b>Prion Disease Surveillance in Canada</b> <b>Gerard Jansen, MD, FRCP(C)</b> <i>Ottawa, Canada</i> <i>Principal Investigator, CJD Surveillance System, Public Health Agency of Canada</i>
1:50 - 2:10	<b>Prion Disease Surveillance in the United Kingdom</b> <b>Richard Knight, MD, FRCP(E)</b> <i>Edinburgh, Scotland,</i> <i>Deputy Director, UK National CJD Surveillance Unit, Western General Hospital</i>
2:10 - 2:30	<b>Prion Disease Surveillance in China</b> <b>Xiao-Ping Dong, PhD</b> <i>Beijing, China</i> <i>Director, Division of Science and Technology, Chinese Center for Disease Control and Prevention</i>
2:30 - 2:50	<b>Prion Disease Surveillance in France</b> <b>Jean-Philippe Brandel, MD</b> <i>Paris, France</i> <i>Researcher and Neurologist, National Network for Disease Surveillance of Creutzfeldt-Jakob and Related Diseases, Groupe Hospitalier Pitié-Salpêtrière</i>

2:50 - 3:05                    **Coffee and Cookie Break**

3:05 - 5:00                    **Moving Round Tables**

7:00 - 7:30                    **Reception**

7:30                              **Banquet**

**Sunday, July 18th**

**Co-Chairmen:**                *Ruthie George*  
                                      *Lori Nusbaum*

7:30 - 8:45                    **Continental Breakfast**

8:45 - 9:00                    **CJDF Updates**  
**Mark Goldfarb**  
*Akron, Ohio*  
*Chairman, Board of Directors, The CJD Foundation*

**Ruthie George**  
*Akron, Ohio*  
*Treasurer, Board of Directors, The CJD Foundation*

9:00 - 9:15                    **CJDF Questionnaire Statistical Report**  
**Carlos Alzola**  
*Vienna, Virginia*  
*Statistician, Data Insights*

9:15 - 9:20                    **Q&A**

9:20 - 9:35                    **The Centers for Disease Control and Prevention Report**  
**Ryan Maddox, MPH**  
*Atlanta, Georgia*  
*Epidemiologist, Prion Disease Office, CDC*

9:35 - 9:40                    **Q&A**

9:40 - 9:55                    **Searching for Custom Dominant Negative PrPs by In Vitro Prion Replication Studies**  
*2008 CJD Foundation Human Prion Disease Grant Recipient\**  
**Joaquin Castilla, PhD**  
*Bizkaia, Spain*  
*Principal Investigator, Prion Lab, Proteomic Unit, CIC bioGUNE*

9:55 - 10:00                   **Q&A**

- 10:00 - 10:15**                    **Analyses of the Protein Tau to Help Determine Whether the Newly Discovered Protease-Sensitive Prionopathy is the Sporadic Form of Gerstmann-Sträussler-Scheinker Disease (GSS)**  
*2009 Patrick Yobs GSS Memorial Fund Grant Recipient\**  
**Gianfranco Puoti, MD, PhD**  
*Cleveland, Ohio*  
*Neurologist and Research Associate, The National Prion Disease Pathology Surveillance Center*
- 10:15 - 10:20**                    **Q&A**
- 10:20 - 10:35**                    **Coffee Break**
- 10:35 - 10:50**                    **Etiology of Sporadic CJD: Somatic Mutations of the Human Prion Protein Gene in Brain Cells**  
*2009 CJD Foundation Human Prion Disease Grant Recipient\**  
**Qingzhong Kong, PhD**  
*Cleveland, Ohio*  
*Researcher, The National Prion Disease Pathology Surveillance Center*
- 10:50 - 10:55**                    **Q&A**
- 10:55 - 11:10**                    **Adult Neurogenesis in Prion Diseases: A New Lead for Therapeutics?**  
*2009 CJD Foundation Human Prion Disease Grant Recipient\**  
**Sylvain Lehmann, MD, PhD**  
*Montpellier, France*  
*Research Group Leader, Department of Molecular and Cellular Pathologies, Institut de Génétique Humaine*
- 11:10 - 11:15**                    **Q&A**
- 11:15 - 11:25**                    **PrioNet Canada Overview**  
**Neil Cashman, MD, FRCP(C), FCAHS**  
*Vancouver, British Columbia*  
*Scientific Director, PrioNet Canada, a Network of Centres of Excellence*
- 11:25 - 11:40**                    **Alberta Prion Research Institute (APRI)**  
**Kevin Keough, PhD, FCAHS**  
*Alberta, Canada*  
*Executive Director, The Alberta Prion Research Institute*
- 11:40 - 1:00**                    **Lunch**

*\*The 2008-2009 Human Prion Disease Research Grants were made possible through funds established by the families of Stephen Able, John Kelley, Paul Oberdorf and Al Tennant. The GSS grant was funded by the family of Patrick Yobs.*

## Support Organization Reports

- 1:00 - 1:15**                    **CJD Support Group Network, Australia**  
**Suzanne Solvyns**  
*Glenhaven NSW, Australia*  
*National Coordinator, CJD Support Group Network; Co-Chairman, The CJD International Support Alliance*
- 1:15 - 1:30**                    **Associazione Italiana Encefalopatie da Prioni (A.I.En.P.), Italy**  
**Roberto Borgis**  
*Torino, Italy*  
*President, A.I.En.P.*
- 1:30 - 1:45**                    **CJD Support Network, Japan**  
**Yumiko Uchiyama**  
*Japan*  
*Counselor, CJD Support Network, Japan*
- 1:45- 2:00**                    **CJD Support Network, United Kingdom**  
**Richard Knight**  
*Medical Director, CJD Support Network*
- 2:00 - 2:15**                    **CJD International Support Alliance report**
- 2:15 - 2:30**                    **Coffee and Cookie Break**
- 2:30 - 4:00**                    **Advocacy Training**  
**Michael Beer and Jenny DiJames**  
*Washington, D.C.*  
*Principals, Williams & Jensen, PLLC*

**Monday, July 19th**  
Capitol Hill Visits