

## *CJD 2011 and the Ninth Annual CJD Foundation Family Conference*

### **Friday, July 8th**

- 11:00 – 3:30**                    **Registration**
- 10:00 – 11:00**                    **CJDISA Friends & Advisors meeting**  
*\*This meeting is open only to the members of the CJDISA Friends & Advisors Committee*
- 11:30 – 12:30**                    **CJD Foundation Board of Directors Meeting – Capitol Room, Mezzanine Level**  
*\*This meeting is open only to the members of the CJD Foundation Board of Directors*
- 12:30 – 2:30**                    **Familial Prion Disease Meeting – Springwood Room**  
*\*This meeting is only for families affected by a familial prion disease*  
**Deana Simpson, RN - Chairman**  
*Founder and Director, CJD Insight; Member, CJD Foundation Board of Directors  
Macomb, Michigan*
- Pierluigi Gambetti, MD**  
*Professor, Case Western Reserve University School of Medicine, Department of Pathology  
Director, The National Prion Disease Pathology Surveillance Center; Medical Director,  
The CJD Foundation, CJD Foundation Board of Directors  
Cleveland, Ohio*
- Michael Geschwind, MD, PhD**  
*Assistant Adjunct Professor of Neurology, Memory and Aging Center, University of California at San Francisco  
San Francisco, California*
- 3:00 – 5:00**                    **Bereavement Workshop – Springwood Room**  
**Deana Simpson, RN, Co-chairman**
- Katrina Hallmark, PsyD, Co-chairman**  
*Neuropsychologist, Southwest Medical Center  
San Antonio, Texas*

**Brian Appleby, MD**  
*Lou Ruvo Center for Brain Health, Neurological Institute  
Cleveland Clinic Foundation  
Cleveland, Ohio*

**4:30 – 7:30**                    **Registration, Atrium Ballroom Lobby**

**6:00 – 7:30**                    **Welcome Reception, Atrium Ballroom**

## **Saturday, July 9th - Atrium Ballroom**

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

**7:00 – 8:00**                    **Continental Breakfast**

**8:00 – 8:10**                    **Welcome**  
**Florence Kranitz**  
*President, The CJD Foundation; Co-Chairman, The CJD International Support Alliance  
Akron, Ohio*

**8:10 – 8:35**                    **Memorial Service**

**Co-Chairmen:**                **Pierluigi Gambetti, MD**

**Neil Cashman, MD, FRCP(C), FCAHS**  
*Professor & Scientific Director, PrionNet Canada, a Network of Centres of Excellence  
Vancouver, British Columbia*

### **Keynote Address**

**8:35 - 9:05**                    **Neil Cashman, MD, FRCP(C), FCAHS**  
*How Prion Disease Research is Leading to New Inroads for  
Alzheimers Disease and Parkinsons Disease*

**9:05 – 9:10**                    **Q&A**

**9:10 – 9:25**                    **Coffee Break**

### **Diagnostics**

**9:25 – 9:45**                    **Professor Richard Knight, MD, FRCP(E)**  
*The Difficulties of Making a CJD Diagnosis*  
*Professor, Director, UK National CJD Surveillance Unit, Western General Hospital  
Edinburgh, Scotland*

- 9:45 - 9:50**                    **Q&A**
- 9:50 - 10:10**                **Ryuichiro Atarashi, MD, PhD**  
*Specificity of Human Prion Detection in CSF*  
*Department of Molecular Microbiology and Immunology, Nagasaki University*  
*Graduate School of Biomedical Sciences*  
*Nagasaki, Japan*
- 10:10 - 10:15**                **Q&A**
- 10:15 - 10:35**                **Joel Watts, PhD**  
*Spontaneous Prion Disease in Transgenic Mice and Implications*  
*for Sporadic CJD*  
*Institute for Neurodegenerative Diseases at University of California San*  
*Francisco*  
*San Francisco, California*
- 10:35 - 10:40**                **Q&A**
- 10:40 - 11:00**                **David Wishart, PhD**  
*The Future of Prion Disease Diagnostics*  
*Principal Investigator, Nano Life Sciences, National Institute for Nanotechnology,*  
*National Research Council*  
*Alberta, Canada*
- 11:00 - 11:05**                **Q&A**
- Treatment**
- 11:05 - 11:25**                **Neil Cashman**  
*Urine Derived Pharmaceuticals: Risk of CJD?*
- 11:25 - 11:30**                **Q&A**
- 11:30 - 11:50**                **Gianluigi Forloni, PhD**  
*Doxycycline Clinical Trial results*  
*Head of the Neuroscience Department and Laboratory of Biology of*  
*Neurodegenerative Disorders (BND), Mario Negri Institute in Milano.*  
*Milan, Italy*
- 11:50 - 12:50**                **Lunch**

## Surveillance

- 12:50 - 1:10**      **Pierluigi Gambetti, MD**  
*U.S. Prion Disease Surveillance and the Importance of Autopsy;  
Tests Conducted*
- 1:10 - 1:15**      **Q&A**
- 1:15 - 1:35**      **Maurizio Pocchiari, MD**  
*European Surveillance Overview*  
*Professor and Research Director and Head, Clinical, Diagnosis and Therapy of  
Neurodegenerative Disorders Unit, Department of Cell Biology and Neurosciences,  
Istituto Superiore di Sanita  
Rome, Italy*
- 1:35 - 1:40**      **Q&A**
- 1:40 - 2:00**      **Daniel Krewski, MHA, MSc, PhD**  
*Summary*  
*Professor and Director of the R. Samuel McLaughlin Centre for Population  
Health Risk Assessment, University of Ottawa  
Ottawa, Ontario*
- 2:00 - 2:05**      **Q&A**
- 2:05 - 2:10**      **Coffee Break**
- 2:10 - 4:15**      **Moving Round Tables**
- 4:15-6:30**      *Sally Berri, Manager of the National Prion Disease Pathology  
Surveillance Center will be available for family consultations  
regarding status of autopsy results and/or the autopsy program.*
- 7:00 - 7:30**      **Reception, Atrium ballroom lobby**
- 7:30**              **Banquet, Atrium**

## Sunday, July 10th

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

**7:30 – 8:45** Continental Breakfast

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

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

**9:00 - 9:15** Lori Nusbaum  
***Questionnaire Report***  
*Associate Director, CJD Foundation*  
*Akron, Ohio*

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

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

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

**9:40 – 9:55** Kevin Keough, PhD, FCAHS  
***Alberta Prion Research Institute (APRI) Report***  
*Executive Director, The Alberta Prion Research Institute*  
*Alberta, Canada*

**9:55 - 10:10** Coffee Break

### CJD Foundation Family Research Grant Recipient, 2009

**10:10-10:25** Maurizio Pocchiari, MD  
***Pentosan Polysulphate: A Friendly Delivery System for Therapy in Prion Diseases***

## CJD Foundation Family Research Grant Recipients, 2011

- 10:25 - 10:40**      **Yury O. Chernoff, PhD**  
*Yeast Model for Studying Heritable Mammalian Prion Diseases in Mammals*  
Professor, School of Biology, Georgia Institute of Technology  
Atlanta, Georgia
- 10:40 - 10:45**      **Q & A**
- 10:45 - 11:00**      **Joaquin Castilla, PhD**  
*Developing a Prion Susceptible Human Neuronal Cell Line Based on Reprogramming Fibroblasts from CJD Affected Patients*  
Principal Investigator, Prion Lab, Proteomic Unit, CIC bioGune  
Bizkaia, Spain
- 11:00 - 11:05**      **Q&A**
- 11:05 - 11:20**      **Emiliano Biasini, PhD**  
*Targeting the Functional Activity of PrPc as a Novel Strategy for Drug Discovery in Prion Diseases*  
Instructor, Harris Laboratory, Boston University  
Boston, Massachusetts
- 11:20 - 11:25**      **Q&A**
- 11:25 - 11:40**      **Bradley Kalinsky, MD & Amanda Baxley Kalinsky, RN, BSN**  
*In Vitro Options, A Personal Story*  
Charleston, South Carolina
- 11:40 - 11:45**      **Q&A**
- 11:45 - 12:45**      **Lunch**

### Support Organization Reports

- 12:45 - 2:00**      **CJD International Support Alliance Panel Presentation**
- Introduction, Florence Kranitz & Suzanne Solvyns**  
*Co Chairmen, The CJD International Support Network*
- Suzanne Solvyns**  
*CJD Support Group Network, Australia*  
Director, CJD Support Group Network,  
Co chairman the CJD International Support Group Network  
Sydney NSW, Australia

**David Ralston**  
*CJD Support Group Network, Australia*  
Chair, CJD Support Group Network  
Sydney NSW, Australia

**Roberto Borgis**  
*Associazione Italiana Encefalopatie da Prioni (A.I.En.P.), Italy*  
President, A.I.En.P.  
Torino, Italy

**J.B. Matthieu**  
*MCJ-HCC, France*  
President, MCJ-HCC  
Paris, France

**Professor Richard Knight**  
*CJD Support Network, U.K.*  
Co Chair, CJD Support Network, U.K.  
Edinburgh, Scotland

**Deana Simpson**  
*CJD Insight*  
Founder and Director, CJD Insight  
Macomb, Michigan

2:00 - 2:15

**Coffee Break**

2:15 - 4:00

**Florence Kranitz , Ruthie George, Lori Nusbaum**  
*Advocacy Training*

**Monday, July 11th**

**Capitol Hill Visits**