



CJD 2011 and the Ninth Annual CJD Foundation Family Conference **Tentative Schedule**

Draft, March 7, 2011

Friday, July 8th

- 11:00 – 3:30** **Registration**
- 10:00 – 11:00** **CJDISA Friends & Advisors meeting**
- 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
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
- Michael Geschwind, MD, PhD**
San Francisco, California
Assistant Adjunct Professor of Neurology, Memory and Aging Center, University of California at San Francisco
- 3:00 – 5:00** **Bereavement Workshop – Springwood Room**
Deana Simpson, RN, Co-chairman
- Katrina Hallmark, PsyD, Co-chairman**
San Antonio, Texas
Neuropsychologist, Southwest Medical Center

Brian Appleby, MD
Cleveland, Ohio
Cleveland Clinic Foundation

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
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
Vancouver, British Columbia
Professor & Scientific Director, PrionNet Canada, a Network of Centres of Excellence

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

- 9:45 - 9:50** **Q&A**
- 9:50 - 10:10** **Ryuichiro Atarashi**
Specificity of Human Prion Detection in CSF
Nagasaki, Japan
Department of Molecular Microbiology and Immunology, Nagasaki University
Graduate School of Biomedical Sciences.
- 10:10 - 10:15** **Q&A**
- 10:15 - 10:35** **John Collinge, MD, FRCP, FRS**
Detection of Prion Infection in vCJD: A Blood Based Assay
London, England
Director, UK Medical Research Council's Prion Unit; Director, UK National Prion
Clinic
- 10:35 - 10:40** **Q&A**
- 10:40 - 11:00** **David Wishart, PhD**
The Future of Prion Disease Diagnostics
Alberta, Canada
Principal Investigator, Nano Life Sciences, National Institute for Nanotechnology,
National Research Council
- 11:00 - 11:05** **Q&A**
- Treatment
- 11:05 - 11:20** **John Collinge, MD, FRCP, FRS**
Overview of Treatments
- 11:20 - 11:25** **Q&A**
- 11:25 - 11:45** **Gianluigi Forloni, PhD**
Doxycycline Clinical Trial results
Milan, Italy
Head of the Neuroscience Department and Laboratory of Biology of
Neurodegenerative Disorders (BND), Mario Negri Institute in Milano.
- 11:45 - 12:45** **Lunch**
- 12:45 - 1:05** **Paul Brown, M.D**
The Discovery of Kuru
Bethesda, Maryland
Senior Scientist Retired, National Institutes of Health

1:05 - 1:10 Q&A

Surveillance

1:10 - 1:30 **Pierluigi Gambetti, MD**
*US Prion Disease Surveillance and the Importance of Autopsy;
Tests Conducted*

1:30 - 1:35 Q&A

1:35 - 1:55 **Maurizio Pocchiari, MD**
European Surveillance Overview
Rome, Italy
*Research Director and Head, Clinical, Diagnosis and Therapy of
Neurodegenerative Disorders Unit, Department of Cell biology and Neurosciences,
Istituto Superiore di Sanita*

1:55 - 2:00 Q&A

2:00 - 2:20 **Daniel Krewski, MHA, MSc, PhD**
Summary
Ottawa, Ontario
*Professor and Director of the R. Samuel McLaughlin Centre for Population Health Risk
Assessment, University of Ottawa*

2:20 - 2:35 **Coffee & Cookie Break**

2:35 - 4:30 **Moving Round Tables**

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

7:30 **Banquet**

Sunday, July 10th

Co-Chairmen: **Ruthie George**
Akron, Ohio
Treasurer, Board of Directors, The CJD Foundation

Lori Nusbaum
Akron, Ohio
Associate Director, CJD Foundation

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

8:45 - 9:00

Mark Goldfarb

CJDF Updates

Akron, Ohio

Chairman, Board of Directors, The CJD Foundation

Ruthie George

Akron, Ohio

Treasurer, Board of Directors, The CJD Foundation

9:00 - 9:15

Carlos Alzola

CJDF Questionnaire Statistical Report

Vienna, Virginia

Statistician, "Data Insights"

9:15 - 9:20

Q&A

9:20 - 9:35

Ryan Maddox, MPH

Centers For Disease Control and Prevention Report

Atlanta, Georgia

Epidemiologist, Prion Disease Office, CDC

9:35 - 9:40

Q&A

9:40 - 9:55

Kevin Keough, PhD, FCAHS

Alberta Prion Research Institute (APRI)

Alberta, Canada

Executive Director, The Alberta Prion Research Institute

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

Joaquin Castilla, PhD

Developing a prion susceptible human neuronal cell line based on reprogramming fibroblasts from CJD affected patients

Bizkaia, Spain

Principal Investigator, Prion Lab, Proteomic Unit, CIC bioGune

10:40 - 10:45

Q & A

- 10:45 - 11:00** **Yury O. Chernoff, PhD**
Yeast Model for Studying Heritable Mammalian Prion Diseases in Mammals
Atlanta, Georgia
Professor, School of Biology, Georgia Institute of Technology
- 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
Boston, Massachusetts
Instructor, Harris Laboratory, Boston University
- 11:20 - 11:25** **Q&A**
- 11:25 - 11:40** **Bradley Kalinsky, MD & Amanda Baxley Kalinsky**
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 - 1:00** **CJD International Support Alliance report**
- 1:00 - 1:15** **Suzanne Solvyns**
CJD Support Group Network, Australia
Glenhaven NSW, Australia
National Coordinator, CJD Support Group Network; Co-Chairman, The CJD International Support Alliance
- 1:15 - 1:30** **Roberto Borgis**
Associazione Italiana Encefalopatie da Prioni (A.I.En.P.), Italy
Torino, Italy
President, A.I.En.P.
- 1:30 - 1:45** **J.B. Matthieu**
MCJ-HCC, France
Paris, France
President, MCJ-HCC
- 1:45 - 2:00** **Coffee and Cookie Break**

2:00 – 4:00

Florence Kranitz , Ruthie George, Lori Nusbaum
Advocacy Training

Monday, July 11th

Capitol Hill Visits