Dear Friends,

We hope to see many of you at the 2016 CJD Foundation Family Conference, July 8-10 in Washington, DC. The conference sessions are designed to inform, support, and uplift you.

The schedule kicks off on Friday at 12:45 with Familial and Sporadic Prion Disease Workshops, followed by a Prion Disease Overview (to help families prepare for the scientific presentations), and a Bereavement Workshop. Saturday’s presentations include talks by several prominent prion disease scientists as well as updates from the five scientists who received CJD Foundation grants this year. A moving roundtables session will allow families to speak personally with the scientists.

Sunday’s agenda includes updates from the CJD Foundation, National Prion Disease Pathology Surveillance Center, CDC, APRI, CJD International Support Alliance, and an inspiring panel of family members affected by prion disease who will share what they’re doing to make a difference. You can view the presentations on our website after the conference.

If you join us in Washington, DC, please stay until Monday and join CJD Foundation families who will visit Capitol Hill to share their stories and our concerns about prion diseases in the offices of our legislators. Training and all materials are provided.

This May, we look forward to representing CJD Foundation families at Prion 2016, an international gathering of prion scientists in Tokyo, Japan. We’re pleased to be able to once again announce an invitation for scientists to apply for 2017 research grants. Your fundraising efforts are attracting the attention of top prion disease scientists worldwide!

Thank you for all you do to support families affected by CJD.

Debbie Yobs
President
2016 CJD Foundation Family Conference

July 8-10, 2016
Capitol Hill Advocacy Day: Monday, July 11
Washington Court Hotel
Washington, DC

Click the following links for information:

- Invitation Letter
- Registration Form
- Information Trifold

If you have any questions, please call us at 1-800-659-1991 or email melany@cjdfoundation.org

We hope you can join us!

Family Workshops

We may soon be scheduling a family workshop in your area, however the locations below have already been scheduled. Registration is required by calling or emailing melany@cjdfoundation.org or 800-659-1991. Please let us know if you have any questions.

Bloomington, Minnesota - April 14 (click here to view invitation)
New York City - May 17 (click here to view invitation)
Denver, Colorado - August 2 (invitation coming soon!)
Los Angeles area - September 13 - (invitation coming soon!)
Research Grant Recipients

We are so pleased to have awarded five significant research grants to outstanding researchers in the prion disease field. All of these grant recipients plan to join us at our conference this July to share mid-year status reports on their exciting research projects.

Dr. Hermann Clemens Altmeppen
Targeting the Endogenous Proteolytic Processing of PrPc as a Therapeutic Strategy Against Prion Diseases
Institute of Neuropathology, University Medical Center
Eppendorf, Germany

Byron Caughey, PhD
Antisense Oligonucleotides to Delay or Prevent Onset of Prion Disease in Mice
Laboratory of Persistent Viral Diseases
NIH/NIAID Rocky Mountain Laboratories
Hamilton, Montana

Roberto Chiesa, Ph.D.
A New Anti-Prion Compound that Reduces PrPc Levels and Inhibits PrPsc Replication
Istituto di Ricerche Farmacologiche Mario Negri
Milano, Italy

Zuzana Krejciova, Ph.D.
Human Stem Cell Derived Neural Models for sCJD Prion Propagation and Drug Discovery
Institute for Neurodegenerative Diseases, University of California
San Francisco, California

Valerie Sim, MD, FRCPC
Combination Therapies for Human Prion Disease
Centre for Prions and Protein Folding Diseases, Department of Medicine, University of Alberta,
Edmonton, Alberta, Canada
Upcoming Family Fundraisers

Norma Grant - Dinner Fundraiser in Memory of her husband Dennis, May 7, Coconut Creek, Florida

The 7th Annual Nancy Schepis Mallon Golf Outing, in Memory of Nancy Schepis Mallon, May 21, Hookstown, Pennsylvania

Jill Butterman Canuel - Jill is participating in the Tough Mudder in memory of her brother Garry, June 11, Sparta, Kentucky

Mike Vitanza - 8th Annual Fundraising Concert in Memory of his brother Robert, June 11, Bridgeport, Connecticut

Rhonda Fansler - 4th Annual Hunt for a Cure, in Memory of her husband Jon, August 6, Shelbyville, Indiana

Kathy Esposito - 4th Annual Espo’s Night of Hope, in Memory of her husband Bobby, August 20, Pittsburgh, Pennsylvania

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Teleconference Support Groups

The following support groups are open to all families affected by a prion disease and are designed to provide support, education and the opportunity for open dialogue in a secure forum. Please join us!

* Tuesday, April 12 - Teleconference with Guest Speaker: Dr. Michael Geschwind, UCSF
  8pm EASTERN time
* Tuesday, May 10 - Teleconference with Katrina Hallmark, PhD.
  TOPIC: Bereavement and CJD - 7 pm EASTERN time
* Watch for upcoming June dates with Dr. Brian Appleby

New York Support Group

The New York Support Group sessions will be held at 6pm Eastern time. Please call or email Melany for more information: melany@cjdfoundation.org 1-800-659-1991.

Monday, April 4
Monday, May 2
Monday, June 6
Monday, August 1
Thank you all for helping to make Strides for CJD 2015 such a huge success! We are excited for STRIDES 2016! Mark your calendars!!!

**Saturday, October 1, 2016**

If you would like to organize a Strides event in your community or support the planning of any of the events below, please contact Melany@cjdfoundation.org or 800-659-1991

Registration information and details on each location coming soon.

Atlanta, GA - **Sunday, October 2**
Chicago, IL
Cleveland, OH
Fort Collins, CO
Westside, IA

Los Angeles, CA
Joppatowne, MD
Minneapolis, MN
Morris Plains, NJ
Phoenix, AZ

[Strides4cjd.com](http://www.strides4cjd.com)
Here’s a video from Arizona

https://www.dropbox.com/s/lse8gg2cqh4coed/Strides%20for%20CJD%20AZ%20-%20202015.mp4?dl=0

And even though it was hot and sunny, they proudly wore their long sleeved t-shirts in the desert!

Atlanta
Facts along the way in Iowa

New Jersey

Colorado

Maryland