President’s Message

Dear Friends,

We’re pleased to share some highlights from the 2015 CJD Foundation Family Conference, held July 10-13 in Washington, DC. It was wonderful to see the many connections our attendees made, with each other and with the professionals who so generously shared their time and insights with us. Attendance was at top capacity, and those who joined us heard from an outstanding slate of speakers. With feedback from all of you, the conference weekend keeps evolving and growing!

The weekend started with some excellent Friday workshops. As always, Deana Simpson and her team offered an insightful and compassionate workshop for families affected by Familial Prion Disease. This year, for the first time, we simultaneously offered a Sporadic Prion Disease workshop hosted by Dr. Brian Appleby and Lori Nusbaum. Following the Bereavement session hosted by Deana Simpson and Dr. Katrina Hallmark, families joined Dr. Appleby for a Prion Disease Overview, a chance to learn the basics of prion diseases and the science behind them, in preparation for Saturday’s scientific presentations. Dr. Appleby’s presentation, “Prion Disease Overview” and his summary of “Prion Disease 101” are available on our website here.

We were fortunate to have a keynote presentation by Dr. Byron Caughey, focused on the evolution of prion disease research and the development of RT-QuIC as an early diagnosis tool. Dr. Glenn Telling spoke about the role played by transgenic mouse models in studying prions and the implications for developing and testing therapeutics, and Dr. Thomas Wisniewski addressed his work on a vaccine for Chronic Wasting Disease (CWD). The five recipients of the CJD Foundation Family Memorial Research Grants shared their objectives and the mid-year status of their projects. All of these presentations are posted on our website at www.cjdfoundation.org. The moderated panel discussions following each set of presentations, and the Moving Roundtables, gave families multiple opportunities to pose questions to our esteemed speakers.

Continued on page 2
President’s Message (continued)

Sunday's Fundraising workshop spotlighted the dedicated work of a number of families who have raised funds for the CJD Foundation’s programs. We applaud them all! Dr. Bradley and Amanda Kalinsky shared their moving story and their insights about reproductive options. Several of us represented the CJD International Support Alliance, sharing the stories we had presented to hundreds of researchers at the Prion2015 conference in Ft. Collins, Colorado in May. Dr. Jiri Safar shared the goals and structure of the National Prion Disease Pathology Surveillance Center. Dr. Ryan Maddox updated us on the activities of the CDC and the epidemiology data. Kevin Keogh provided an overview of the studies in progress at the Alberta Prion Research Institute. And Lori Nusbaum shared data from the CJD Foundation’s questionnaire. The weekend ended with advocacy training. For more on Advocacy Day, go to page 10.

We hope you will plan to join us for next year’s conference. In fact, we’ll soon be auctioning on eBay a weekend stay at the Washington Court Hotel, which can be used at next year’s conference. If you can’t make it to DC, check our schedule of teleconferences and Family Workshops in this newsletter.

Raising awareness about prion disease is high on the agenda for all of us, and this fall’s Strides for CJD events offer an outstanding opportunity to support the programs of the CJD Foundation, while educating others about CJD and other prion diseases. On the weekend of October 31, groups will be walking or running in different locations around the country (see page 8). But you can participate anywhere by registering at strides4cjd.com then walking wherever you are that day. Posting photos of yourself wearing your Strides for CJD t-shirt will help others to see the number of families affected … and our mutual determination to make a difference.

Thank you to all who are working to bring this new event to the forefront, and for our sponsors! There’s still time to sponsor, and to purchase raffle tickets. This event will raise vital funds to support all of the CJD Foundation’s programs, including family support, medical education, advocacy, and research.

2016 research grants: Letters of Intent for our next round of research grants have been sent to our Scientific Advisory Committee for review. This fall, a short list of applicants will be selected by the Committee to provide full proposals, with the grants being awarded in early 2016. If you’d like to donate a family memorial research grant to honor your loved one, contact us soon. Family Memorial Grants received by September 2015 will be eligible for the 2016 cycle. We also offer a two-year option to fund 2017 or 2018 grants. Your fundraising and donations toward prion disease research are helping to advance the field, and providing hope to all.

Thank you for everything you do to raise awareness of prion diseases!

With gratitude,

Debbie Yobs

Debbie Yobs
Conference Awards

At our Family Conference in July, Debbie Yobs presented awards to three very deserving individuals. Below are excerpts from her speech.

“I’m so pleased to present volunteer of the year awards to two individuals who set a standard we can all follow. They represent the many individuals who support the important activities of the Foundation on a daily basis. One has been a long-time volunteer and one much more recent but with a tremendous impact.

First, I’d like to present the Volunteer of the Year award to a woman who has faithfully staffed our nighttime and weekend Helpline for many years. She is a member of our board and has also supported the grand rounds, family workshops, and other programs, and has been a wonderful supporter of family members on a one-on-one basis. We send wholehearted thanks to Veronica Oberdorf for all she does!

Next, a woman who energetically approached me one year ago tonight, urging me to find a role for her in supporting the families of the foundation. Since then she has had an impact on so many programs. She has helped us with social media and promotion, and she was instrumental in making the Atlanta family workshop an extraordinary experience. She has been a valuable member of our fundraising committee and our Board, and she plans to host a Strides4 CJD event in Atlanta. She recently designed and launched the Strides4 CJD website and is working on electronic registration system for the event. Maria Thacker, thank you for all you do!

Finally, I’m very pleased to announce that the board has voted to establish an annual leadership award in honor of Florence Kranitz. The Florence J. Kranitz Leadership Award will be given each year to an individual who demonstrates leadership in achieving the Foundation’s missions, in a volunteer or other role. To someone who embodies the vision, dedication, and goal-oriented leadership Florence has demonstrated. This year, in its inception year, I’m very pleased to present the Florence J Kranitz Leadership Award to ... Florence Kranitz.”
Letter from Lori

I hope all of you have been having a relaxing and restful summer. It’s hard to believe it’s almost over!

Our Medical Education Program has been keeping us very busy!! Since our last newsletter in June, we have updates to report:

Dr. Brian Appleby presented an Infection Control Seminar at North Shore University Hospital in New York.
Dr. Michael Geschwind presented at a Grand Rounds at Northridge Hospital in California.

Upcoming Medical Education and Family Workshops:

September 15 - Family Workshop, Indiana (see invitation on page 5)
September 16 - Neurology Grand Rounds - Indiana University School of Medicine - Dr. Brian Appleby

October 14 - Neuroscience Grand Rounds, Intermountain Medical Center, Murray, Utah - Dr. Brian Appleby
October 14 - Family Workshop, Utah (see invitation on page 6)

December 9 - Neurology Grand Rounds, Duke University Medical Center, NC - Dr. Brian Appleby
December 10 - Psychiatry Grand Rounds, Duke University Medical Center, NC - Dr. Brian Appleby
December 10 - Grand Rounds, Central Regional Hospital, Butner, NC - Dr. Brian Appleby
Family Workshop - Date to be announced, North Carolina

More Family Workshops are being scheduled for 2016.

Some more dates to remember:

October 31—Strides for CJD
November 12 - CJD International Awareness Day
December 1 - Giving Tuesday

Newsletter Subscription

If you would like to be on our email list please email Lori at lori@cjdfoundation.org. Please also include your mailing address for other CJD Foundation updates, including conference information and invitation, and the name of your loved one who has been affected by CJD. Your information is confidential and never shared with any 3rd parties.
INDIANA

We cordially invite you to attend a
CJD Foundation Family Workshop
As our guest (no charge)

Sponsored in part by
The Centers for Disease Control and Prevention
and
Rhonda Fansler in Memory of her Husband, Jon Fansler

Tuesday, September 15, 2015
5:30pm - 7:30pm
5:30-6:00 Casual Reception
6:00-7:30 Question & Answer Session

Dr. Brian Appleby, MD
Co-Director, National Prion Disease Pathology Surveillance Center
Co-Medical Director of the Board of Directors, CJD Foundation
Associate Professor, Departments of Neurology, Psychiatry, & Pathology
Case Western Reserve University School of Medicine

Lori Nusbaum
Associate Director, CJD Foundation

Residence Inn, Indianapolis Carmel
11895 North Meridian Street
Carmel, IN  46032

This group is open to all families affected by a prion disease
and is designed to provide support, education and
the opportunity for open dialogue in a secure forum.

Please join us!

Reply to melany@cjdfoundation.org or call us at 1-800-659-1991.
Registration is Required

There is no charge for this workshop
Family Workshops Continued

UTAH

We cordially invite you to attend a
CJD Foundation Family Workshop
As our guest (no charge)

Sponsored in part by
The Centers for Disease Control and Prevention

Wednesday, October 14, 2015
5:30pm - 7:30pm
5:30-6:00 Casual Reception
6:00-7:30 Question & Answer Session

Dr. Brian Appleby, MD
Co-Director, National Prion Disease Pathology Surveillance Center
Co-Medical Director of the Board of Directors, CJD Foundation
Associate Professor, Departments of Neurology, Psychiatry, & Pathology
Case Western Reserve University School of Medicine

Debbie Yobs
President, CJD Foundation

Residence Inn Salt Lake City Murray
171 E. 5300 S.
Murray, Utah 84107

This group is open to all families affected by a prion disease
and is designed to provide support, education and
the opportunity for open dialogue in a secure forum.

Please join us!

Reply by October 5, 2015 to melany@cjdfoundation.org or call us at 1-800-659-1991.
Registration is Required

There is no charge for this workshop
Family Fundraisers

Since our last newsletter, there have been some family fundraisers. Thank you to all of you! We very much appreciate it!

Family fundraisers are also being held through our FriendRaising page. To learn more about FriendRaising, visit https://friendraising.donorpro.com/campaigns/139.

Linda Parrish held a fundraiser in memory of her husband Clay - May, 2015, in Kentucky.
Mike Vitanza held the 7th Annual Fundraiser in honor of his brother Bob - June, 2015, in Connecticut.
Rhonda Fansler held the 3rd Annual Hunt for a Cure, in memory of her husband Jon - August, 2015, in Indiana.
Lauren and Karla Piriz held the First Annual Piriz Family Prion Disease Fundraiser in memory of José and Sonia Piriz, August, 2015, in New York.
The Snively Family held the Marsha K. Snively Memorial Golf Outing in memory of Marsha K. Snively - August, 2015, in West Virginia.

Upcoming Fundraisers:
September 27 - The Marsha K. Snively Golf Outing, in memory of Marsha K. Snively - Latrobe, PA
September 27 - A Miniature Golf Tournament in memory of Scott Mullenix - Colorado Springs, CO
November 14 - Espo’s Hope in memory of Bobby Esposito - Pittsburgh, PA; www.esposhope.com.

You Can Raise Money for the CJD Foundation Just by Shopping!

If you shop at any of the places below, the CJD Foundation receives a portion of the proceeds:

- givebackamerica.com - http://www.givebackamerica.com
- Amazon Smile - http://smile.amazon.com
  on facebook https://www.facebook.com/amazonsmile?fref=ts
- Facebook - Follow us The Creutzfeldt-Jakob Disease Foundation
Strides for CJD

We are in full swing with the planning of our upcoming fundraiser, Strides For CJD, which is scheduled for October 31. There are several satellite locations holding events, with the main event being held in New Jersey: The satellite locations are Atlanta, Arizona, Chicago, Cleveland, Maryland, and Minneapolis. Thank you to the team captains who are doing a great job organizing their teams, securing sponsors, and selling raffle tickets. If you are able attend one of these fundraisers please contact a team captain (below). If you can’t be at any of these locations, please walk in your hometown to raise awareness. All you have to do is register as an individual at www.strides4cjd.com, wear your tshirt, take photos, and post them on social media.

Additional ways you can participate:

- **Sponsor:** go to [http://www.strides4cjd.com/#/sponsor-or-donate/c69w](http://www.strides4cjd.com/#/sponsor-or-donate/c69w)
- **Walk/run:** register at [http://www.strides4cjd.com/#/register/c227](http://www.strides4cjd.com/#/register/c227)
- **Sell Raffle Tickets:** [http://www.strides4cjd.com/#/raffleauction/c1a3n](http://www.strides4cjd.com/#/raffleauction/c1a3n)
- **Promote the Event to your Friends**
- **Donate:** [https://friendraising.donorpro.com/campaigns/139/personal/5327](https://friendraising.donorpro.com/campaigns/139/personal/5327)

Listed below are the local captains and their contact information:

- **Atlanta:** Maria Thacker Goethe - strides4cjdatlanta@gmail.com
- **Chicago:** Molly Nocerino - strides4cjdcchicago@gmail.com
- **Cleveland, Ohio:** Kristin May - strides4cjdcleveland@gmail.com
- **Maryland:** Maryann Forgan - strides4cjdmd@gmail.com
- **Minneapolis, Minnesota:** Pam Fear - strides4cjdmn@gmail.com
- **Morris County, NJ:** Melany Pritchard - melany@cjdfoundation.org
- **Phoenix/Scottsdale, Arizona:** Corby Foster - strides4cjdaz@gmail.com

**Contact Melany to attend one of the following informal strides locations:**
- San Diego, CA
- Fort Collins, CO
- Fairmont, WV

#strides4CJD #cureCJD

341 W. 38th Street, New York, NY ★ 212.719.5900 ★ HelpLine 1.800.659.1991
[help@cjdfoundation.org](mailto:help@cjdfoundation.org) ★ [www.cjdfoundation.org](http://www.cjdfoundation.org)
Support Groups

Teleconferences and Support Groups: Held monthly by phone, sporadic and familial teleconferences allow families to share their stories and get answers to their questions. Many thanks to Dr. Brian Appleby, our co-Medical Director, for sharing his time and knowledge through these programs. In addition, we continue to host monthly support groups in Cleveland and New York.

Cleveland Area Support Group - First Monday of every month - The next meeting is scheduled for Monday, October 5.
New York Area Support Group - Please call Melany to register 1-800-659-1991. The scheduled meetings for the New York Area Support Group are:

- Monday, September 28
- Monday, October 19
- Monday, November 9
- Monday, December 7

Scheduled Teleconference Dates:
Sept. 29: Interview with Corinne Lasmézas
October 20: Combined Sporadic/familial
November 10: Sporadic
November 17: Familial (Amanda Kalinsky, RN, to speak about reproductive options, including PGD before IVF)
December 8: Sporadic
December 15: Familial

The next teleconference is scheduled for Tuesday, September 29 at 7p.m. Eastern
Please call the CJD Foundation at 1-800-659-1991 to register

Guest: Corinne Lasmézas

Topic: Dr. Lasmézas will discuss her study on the anti-prion activity of the drugs Astemizole and Tacrolimus

Dr. Corinne Lasmézas, DVM, Ph.D. is Professor at The Scripps Research Institute. Since Dr. Lasmézas' appointment at Scripps in 2005, she has focused on how misfolded proteins lead to neuronal dysfunction and loss in diseases including Alzheimer’s, Parkinson’s and prion diseases. Dr. Lasmézas is a multiple TED speaker and is an internationally recognized expert in the field of neurodegenerative diseases. She has published more than 60 original scientific papers. She has been a Member of Scientific Advisory Board at Anavex Life Sciences Corporation since March 2015. Dr. Lasmézas holds a PhD in Neurosciences from the University Pierre & Marie Curie in Paris and obtained her Doctorate of Veterinary Medicine and Diploma of Aeronautic and Space Medicine from the University of Toulouse, France.
On Monday, July 13, 2015, as part of the CJD Foundation Family Conference, several family members went to Capitol Hill and had the opportunity to tell their story to key policymakers and talk about CJD. We know that all of you had an impact and your actions made a difference. One of those family members, Karlene Duncan, has been to Capitol Hill many times and she talks about her Capitol Hill experience here:

by, Karlene Duncan

Dottie Weller, Rusty Schenk and I visited Capitol Hill on July 13, 2015 at the conclusion of the CJD Foundation Conference. We visited the offices of Senator Michael Bennet and Senator Cory Gardner, and dropped off a packet of information with our Congressional requests with the office of Representative Doug Lamborn.

At both Senators Bennet and Gardner’s offices we met with aides who see constituents and gather information to pass along to the Senators. We took a few minutes to talk to them about CJD, and to relate how it has personally affected us. We advocated for continued funding of the Surveillance Center, and also talked about how strides in research for CJD could benefit many related prion diseases.

We learned of two new programs that could potentially provide funding for CJD research. One is the Peer Reviewed Medical Research Program. The other is the 21st Century Cures Program. The House has already passed this program, and only takes two Senators to back adding a disease for research in the program. The aides urged all of us associated with CJD to write, call or visit our Senators to advocate getting CJD and related prion in this program for funding.

For those of you who haven’t been to Capitol Hill, I urge you to go. Talk to your Senators and Congressional Representatives. Their aides are friendly and receptive and eager to know their state’s constituents’ concerns. All information is passed on to the Senators or Representatives for their review. I also encourage you to visit your Senators or Representatives local offices; or to write, call or fax them with our message about CJD. It’s an empowering feeling to take positive strides against this horrible disease.
Meet the Board of Directors

Here are the newest of our hardworking Board Members!

Carol Kluge-Mitts, New York

Why I participate in the CJD Foundation:

I participate in the foundation for two reasons: to support my friend in her mission to build more awareness and advocacy for the CJD Foundation and prion disease as well as a personal commitment to volunteerism and service.

Maria Thacker-Goethe, Atlanta

Why I participate in the CJD Foundation:

I participate in the CJD Foundation in memory of my father and to support all those families devastated by this disease. I am proud to be part of an organization working to find a cure for this fatal disease.

Molly Nocerino, Chicago

Why I participate in the CJD Foundation:

I want to do anything I can to support the work of the CJD Foundation and families affected by CJD. Working on the strides4cjd fundraiser has already given me the opportunity to meet so many amazing people. I feel lucky to be part of this organization.