President’s Message

Dear Friends,

I’m thrilled to be reporting on my first months as President of the CJD Foundation! We started 2015 in the most hopeful manner possible: by having the honor of awarding five significant research grants to outstanding researchers in the prion disease field. Their names and their project titles are listed on page three and four and on our website. All of the grant recipients plan to join us at our conference this July to share mid-year status reports on their exciting research projects. With 54 Letters of Intent to review, our Scientific Advisory Council had their work cut out for them.

We send our wholehearted thanks to the families who funded these research grants by donating Memorial Grants honoring their loved ones. Their names are listed on pages three and four. What a wonderful way to spark hope in all of us!

Our next cycle of research grants will be announced in May at the Prion2015 Conference in Fort Collins, Colorado. The CJD Foundation is a proud sponsor of this prestigious gathering of international scientists in the prion disease field.

We are so grateful that we have also received donations and memorial grants from families supporting medical education and family workshops. These programs are vital in spreading awareness of prion diseases, helping educate medical professionals who may be called upon to diagnose and treat patients, and providing families with much needed information and support.

It’s not too early to plan your summer visit to Washington, DC – a perfect antidote to the long winter we’ve encountered in many regions. You’ll soon receive an invitation to the 2015 CJD Foundation Family Conference, an important annual gathering of families and researchers, July 10-12 at the Washington Court Hotel. This year, for the first time, we’re offering a Sporadic CJD Meeting in parallel to the Familial Prion Disease Meeting on Friday afternoon, July 10.

Continued on page 2
President’s Message (continued)

On July 13, please also plan to visit Capitol Hill for Advocacy Day. Families who have participated say this is one of the most empowering experiences in the face of this unrelenting disease. We will provide advocacy training, materials, and appointments with legislative aids in the offices of your senators and representatives. You can educate your representatives about CJD and tell your story as only you can. Remember, your voice counts!

We are pleased to launch two teleconference support groups: A sporadic support group on the 2nd Tuesday of every month starting March 10 at 6:00 p.m. and a familial support group on the 3rd Tuesday of every month starting on March 17 at 7:00 pm. To register, email Melany@CJDFoundation.org or call 1-800-659-1991. If you are in the New York City or Cleveland area, you are also welcome to register for our in-person support groups in those cities.

We’re excited to announce the 2015 fall fundraiser benefiting the CJD Foundation general fund. Strides for CJD will feature a 5K run/2.5K walk in Morris County, New Jersey, as well as satellite walks in areas around the country. Details will be announced soon, as well as information on how you can participate. The fall fundraiser provides vital funds for every program the Foundation offers, including the Helpline, Medical Education, Family Workshops, Support Groups, research grant management, the annual conference, educational materials, DVDs, and many, many forms of family support.

We’re so inspired by the passion, generosity, and spirit of the families we come in contact with daily. Thank you for everything you do to further our shared cause: seeking treatments for prion diseases, supporting the families it affects, and increasing awareness and understanding.

With best wishes for a joyful Spring,

Debbie Yobs
President
CJD Foundation Family Research Grants

We are happy to announce through the generous support of family memorial grants five research grants have been awarded.

Emiliano Biasini, PhD
Pharmacological Chaperones for the Cellular Prion Protein
Center for Integrative Biology (CIBIO)
The University of Trento, Italy

Dr. Biasini is the recipient of:
The Robert J. Esposito Memorial Grant, contributed by Kathy Esposito
The Jon Fansler Memorial Grant, contributed by Rhonda Fansler
The Davey L. Kock Memorial Grant, contributed by Janine Kock
The Clay Parrish Memorial Grant, contributed by Linda Parrish
The Marsha Snively Memorial Grant, contributed by Ed Snively and Nikki Bland

Jean-Philippe Deslys, MD, PhD
Frank Yates, PhD
Human Mini-Brains as a New Platform to Identify and Validate Pharmaceutical Compounds for the Treatment of CJD
CEA/DSV/IMETI/SEPIA (Institute for Emerging Illnesses and Innovative Therapies)
Department of Prion and Atypical Infections Research,
Fontenay-Aux-Roses, France

Dr. Deslys and Dr. Yates are the recipients of:
The Tom Drymon and Lorraine Miller Memorial Grant, contributed by Karlene Duncan
The Cynthia Faber Memorial Grant, contributed by Peter Faber
The Joan Gill Memorial Grant, contributed by Lisa Marie Gill and Jennifer Gill
The Don Heestand Memorial Grant, contributed by Christine Heestand
The Barbara E.G. Holthouse Memorial Grant, contributed by Gary Holthouse
The Robert L. Packer Memorial Grant, contributed by Danielle Packer
The Gene W. Rockwell Memorial Grant, contributed by Irene Rockwell and Derek Widmayer
The Paula Smart Memorial Grant, contributed by Jeff Moxie
The Jeffrey A. Smith Memorial Grant, contributed by Mary Smith

Julie Moreno, PhD
The Role of Cellular Chaperones and the Unfolded Protein Response in Gerstmann-Straussler-Scheinker Syndrome
Prion Research Center, Colorado State University

Dr. Moreno is the recipient of:
The Keith Heinz Memorial Grant, contributed by Kathryn Heinz
The José A. Piriz Memorial Grant I contributed by Lauren Piriz
The José A. Piriz Memorial Grant II contributed by Lauren Piriz
The Patrick Yobs Memorial Grant, contributed by Debbie Yobs and Family
The Charles E. Ziants Memorial Grant, contributed by Phyllis D. Ziants
CJD Foundation Family Research Grants (continued)

We are happy to announce through the generous support of family memorial grants five research grants have been awarded.

Christina Sigurdson, DVM, PhD
Mechanisms of Selective Neuronal Vulnerability in Human Prion Disease
University of California, San Diego

Dr. Sigurdson is the recipient of:
The Neil W. Foster Memorial Grant, contributed by the Family of Neil W. Foster
The Raymond McGill Memorial Grant, contributed by Megan McGill
The Tom Stivison Memorial Grant, contributed by Cookie Stivison
The Al Tennant Memorial Grant, contributed by Marie Bauer
The Robert Zucker Memorial Grant, contributed by Jenna Zucker

Wenquan Zou, MD, PhD
Developing Therapeutics for CJD Using Patient-Specific iPSC-Derived Neurons
National Prion Disease Pathology Surveillance Center
Case Western Reserve University School of Medicine
Cleveland, Ohio

Dr. Zou is the recipient of:
The Michael H. Cole Memorial Grant, contributed by Jeanne Cole
The Robert J. Esposito Memorial Grant, contributed by Kathy Esposito
The Jon Fansler Memorial Grant, contributed by Rhonda Fansler
The Davey L. Kock Memorial Grant, contributed by Janine Kock
The Bryant Welch Memorial Grant, contributed by Keith Welch and Dianne Fox-Welch
HelpLine

The CJD Foundation’s largest ongoing project is our toll-free HelpLine (1-800-659-1991 or help@cjdfoundation.org). The HelpLine is available to families coping with a loved one’s suspected CJD diagnosis who are in need of support and information. We also receive many calls from medical professionals, funeral directors and embalmers, the general public, and the press and the media. We retrieve HelpLine messages seven days a week, and if the call is in reference to a patient in crisis, we return calls up until 10:00 p.m Eastern. The HelpLine statistics through January 2015 are below:

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<th>MONTH</th>
<th>NEW CASES REPORTED</th>
<th>DEATHS REPORTED</th>
<th>TOTAL HL CONTACTS</th>
<th>UNIQUE WEBSITE VISITORS</th>
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<tr>
<td>January</td>
<td>26</td>
<td>19</td>
<td>163</td>
<td>3,923</td>
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<tr>
<td>TOTALS*</td>
<td>26</td>
<td>19</td>
<td>163</td>
<td>3,923</td>
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</table>

The CJD Foundation is not a reporting agency and families are not required to report their loved one’s illness or death to us. These statistics are not intended to be scientific in nature, but instead to help validate the work we do on a daily basis.

Note 1: Not all new cases and deaths reported are confirmed by autopsy.

Note 2: Total HelpLine contacts include phone calls and emails from families, medical professionals and others.

*: Through January 31, 2015
Capitol Hill Advocacy Day

On Monday, July 13, you will have the opportunity to visit the offices of your Senators and Representatives on Capitol Hill. We will schedule all of the appointments for you, and prepare you at the Advocacy Day training session during our CJD Foundation Family Conference. Below are statements from two of the family members who have participated in the past:

“That first walk up the hill to the Senate office building was daunting and it is no surprise I was nervous and felt powerless and insignificant. Yet when I met with my representatives’ health issues liaisons, I found them to be receptive to our advocacy and knowledgeable about related issues. This made it so much easier to tell MY story, and why it was important to others, and what the related issues were to better inform them of how our concerns aligned with their positions and their constituency. I found the advocacy to inform our elected officials and participate in the democratic process satisfying. I highly recommend it.” - Stacey Ronczy

“…..Attending Advocacy Day made me feel like I really made a difference in this fight. I was able to speak to Congressmen and Congresswomen about my ordeal and why I believe so strongly in what the CJD Foundation is doing. This was no longer just a disease that affects such a small number of people. Together we showed it is a disease that affects US and OUR FAMILIES. I was no longer defeated, I was no longer hopeless – I had a VOICE and I was heard.” - Lauren Piriz

Please share your stories and photos with us! Join us on Monday, July 13 for 2015 Advocacy Day! #CJDAdvocacy
**Family Fundraisers**

Thank you to the following family members who are holding fundraisers. If you would like more information about any of these fundraisers, or would like to have your own fundraiser, please let me know. [lori@cjdfoundation.org](mailto:lori@cjdfoundation.org). We are so grateful to you for raising awareness about prion diseases, and for raising funds to support The CJD Foundation.

Megan McGill is holding a fundraiser to honor her brother:

*A Night of Comedy in Honor of SSG Timothy McGill*

Thursday, March 5, 2015
Teaneck, NJ

Joe Lozito will be running the *New York City Half Marathon to honor his sister Lorraine Marie Meys*

Sunday, March 15, 2015
New York, NY

Mike Hough is holding a fundraiser to honor his father:

*John Hough Memorial Benefit*

Saturday, April 4, 2015
Butler, PA

Mike Vitanza is holding a fundraiser to honor his brother:

*7th Annual Fundraising Concert in honor of Robert Vitanza*

Saturday, June 13, 2015
Bridgeport, CT

Rhonda Fansler is holding a fundraiser to honor her husband:

*3rd Annual Hunt for a Cure In memory of Jon Fansler*

Saturday, August 8, 2015
Shelbyville, IN

Kathy Esposito is holding a fundraiser to honor her husband:

*3rd Annual Espo's Night of Hope In memory of Bobby Esposito*

Saturday, November 14, 2015
Pittsburgh, PA
CJD Foundation Fall Fundraiser

Stay tuned for more information about Strides for CJD, our new fall fundraiser, scheduled for October 31, 2015. The event will feature:

- A 5K run and 2.5K walk in Morris County, NJ
- Raffles and silent auction
- Satellite run/walk groups participating anywhere in the country, wearing Strides for CJD t-shirts, FriendRaising, and sharing photos on social media

If you’d like to be a local captain for this fundraiser in your hometown or metropolitan area, please contact melany@cjdfoundation.org. Watch for more details!

#strides4CJD

Medical Education and Family Workshops—Lori

During the last few months, I have been contacting hospitals and medical facilities in an effort to schedule neurology grand rounds. On Friday, May 15, Dr. Brian Appleby and I will be traveling to Miami, Florida, where Dr. Appleby will give a Neurology Grand Round presentation at The Miami Miller School of Medicine. We will hold a Family Workshop that same evening (invitation on page nine of this newsletter), and we hope to see many of you there! Future Grand Round meetings are in the planning stages. In cases where we are unable to travel to because of limited resources, or because there is not a large audience, we are still able to provide the facility with educational resources. A Family Workshop has also been scheduled in Atlanta, Georgia, for Monday, April 20. Dr. Jim Lah and Debbie Yobs will facilitate this workshop. (Invitation on page 10 of this newsletter).

If you know of a hospital or facility in your city, please call me at 1-800-659-1991 with contact information. I will be happy to reach out.

Our Medical Education Program is made possible in part by funds made through a grant contributed by Janine Kock in memory of her husband, Davey Kock. Some of the funds also come from a Fundraiser by Mike Vitanza in honor of his brother Robert Vitanza, and in part by a grant from the Centers for Disease Control and Prevention. We are very grateful.
Miami, Florida Family Workshop

We cordially invite you to attend a 
CJD Foundation Family Workshop
As our guest

Hosted by
The Creutzfeld-Jakob Disease Foundation

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

Led By

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

Springhill Suites Marriott
Miami Airport East/Medical Center
1131 NW 10th Avenue
Miami, FL 33136

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 May 8, 2015 to melany@cjdfoundation.org or call us at 1-800-659-1991.
Registration is Required

There is no charge for this workshop
We cordially invite you to attend a
CJD Foundation Family Workshop
As our guest

Hosted by
The Creutzfeld-Jakob Disease Foundation

Monday, April 20, 2015
5:30pm - 7:30pm
5:30-6:00 Casual Reception
6:00-7:30 Question & Answer Session

Led By

Dr. Jim Lah, MD
Associate Professor, Emory School of Medicine
Associate Professor of Neurology, Emory University

Debbie Yobs
President, The CJD Foundation

Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30329-4027

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 April 13, 2015 to melany@cjdfoundation.org or call us at 1-800-659-1991.
Registration is Required

There is no charge for this workshop
Meet the Board of Directors

The past few months have seen a number of changes in our Board of Directors:

- We are pleased to welcome to the board Florence Kranitz! Thankfully, our tireless, inspiring, immediate past president is now sharing her time and wonderful talents with us as a board member.

- Dr. Pierluigi Gambetti resigned his longstanding role as Medical Director and CJD Foundation board member effective in February. We thank him for his many years of service, his guidance, and his dedication to the families and to the foundation. Joining us as co-Medical Directors are Dr. Jiri Safar, Director of the National Prion Disease Pathology Surveillance Center and Dr. Brian Appleby, Co-Director, National Prion Disease Pathology Surveillance Center and Associate Professor, Departments of Neurology, Psychiatry, & Pathology at Case Western Reserve University School of Medicine.

- As we also say farewell to Ana Betro, Tom Haught, Paul Paternoster, and Scott Paternoster and who have served on our board for many years, we welcome new board members Janine Kock, Jay Levy, and Jeff Yaffa. They are profiled below and continue on the next page.

![Jiri Safar, MD, PhD](image1)

**Co-Medical Director, The CJD Foundation**

Director, National Prion Disease Pathology Surveillance Center
Associate Professor, Department of Pathology, Case Western Reserve University

![Brian Appleby, MD](image2)

**Co-Medical Director, The CJD Foundation**

Co-Director, National Prion Disease Pathology Surveillance Center
Associate Professor, Departments of Neurology, Psychiatry, & Pathology
Case Western Reserve University School of Medicine
Janine is the owner, editor and publisher of two small weekly newspapers in Western Iowa, the Westside Observer and the Manilla Times.

*Why I joined the board:*
“
I joined the board because of my desire for something positive to come out of the CJD tragedy that has affected my family. My husband would want us to do our best to raise funds and awareness to help others.”

Jay is a CPA and Partner at CohnReznick LLP

*Why I joined the board:*
“A friend’s family was deeply affected by a prion disease, and I wanted to help. I’m based in New York and when the Foundation moved here, I thought this would be a great opportunity to apply my financial knowledge and my not-for-profit board experience to make a difference.”

Jeff is an Associate at Fox Rothschild LLP

*Why I joined the Board:*
“My grandfather passed away a number of years ago from CJD. The entire process was both traumatic and eye-opening because of all the unknowns related to this disease. When the opportunity to join the Board presented itself, I jumped at the chance to offer whatever I could to make a difference and help others going through the same process.”
Annual Fund Donors

As of March 4, the CJD Foundation’s Annual Fund Campaign has received over $55,000. Thank you to the following donors for their generous contributions.

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