A Letter from Debbie Yobs, CJDF President

Dear Friends,

Fostering connections remains at the heart of our work: connecting families with resources, and connecting them to researchers, peers, physicians, and legislators. We are grateful to have connected with so many of you this year through our programs and Helpline. Your involvement and support continue to enable all of our work including:

**Research Grants**
We opened 2017 by awarding CJD Foundation Research Grants to four researchers whose applications were top-ranked by our Scientific Advisory Committee. Each of the recipients spoke at our conference and all will be providing reports on their work in the next month. Then, at the International Prion Conference in Edinburgh, Scotland in May 2017, I was pleased to announce to the hundreds of assembled scientists that thanks to your donations and extraordinary fundraising efforts, we will again award a number of research grants in January 2018. Several of the researchers who were funded by CJD Foundation grants in past years have now published papers based on those projects. You can learn more at [https://cjdfoundation.org/grant-recipients](https://cjdfoundation.org/grant-recipients).

**Family Support Programs**
This year, more than 1,000 inquiries were answered via our Helpline. We reached over 350 callers through our evening teleconference series. Speakers included Dr. Byron Caughey, Dr. Brian Appleby, and Dr. Joel Watts. (Recorded portions can be heard at [https://cjdfoundation.org/interviews-with-experts](https://cjdfoundation.org/interviews-with-experts).) In addition, Dr. Katrina Hallmark hosted a Bereavement call and we initiated a GSS Support Group. Events are listed as they are scheduled on our website under About Us/Upcoming Events.

**Medical Education and Family Workshops**
The CJD Foundation hosted medical education sessions in Charleston, Cincinnati, Detroit, Houston, and multiple sessions in New York City. Professionals in neurology, psychiatry, and infectious disease received updates on diagnosing and caregiving for CJD. Family Workshops were held in Charleston, Cincinnati, Detroit, and Alabama. In addition, as part of our Medical Education program, we hosted funeral education sessions in Alabama and Cleveland. In New York, our support group continues to meet monthly.

**Annual Conference and Advocacy**
The CJD Foundation Conference in July featured esteemed speakers such as Dr. John Collinge, Dr. Neil Cashman, and all four recipients of 2017 CJD Foundation Research Grants. Presentations and recordings will be available on our website. Family workshops, Prion 101 sessions, moving roundtables, and other sessions enabled families to connect one on one with scientists, physicians, and other affected families and enhance their understanding of the disease and research progress.

(Continued on next page)
Advocacy Day is always an important part of our conference – and never more important than in 2017. CJD funding through the CDC and NPDPSC was marked for elimination in the Administration’s proposed budget, putting U.S. CJD surveillance at risk. Thankfully, after many of you contacted your representatives and shared your stories through letters, phone calls and visits at critical points in the legislative process, both House and Senate opted to include surveillance in the 2018 budget.

In Spring 2017, more than 40 of you wrote letters to your representatives. We brought all of those letters to Capitol Hill during our April visit. Families attending the conference in July visited their Senators and representatives, and then in September, we visited again and brought packets including excerpts from many of your letters, to convey the reach of prion disease across the U.S., and the impact it has on families. CJD may be a rare disease, but your voices were heard loud and clear in Washington!

Raising Awareness of Prion Disease

Mercies in Disguise, by NY Times science writer Gina Kolata, was released in March, and spread the word around the U.S. about prion disease and particularly its devastating affect on one family, the Baxleys of South Carolina. The book highlighted the decisions our board member Amanda Baxley Kalinsky made to ensure that the genetic mutation impacting her family would not be passed down to her children. During the book tour, Amanda has been invited to speak at multiple book events, including those in California, Florida, Georgia, and New York.

This year, Jeanne Cole and Brian Flynn shared their stories at our conference. You can access them here: 
Jeanne Cole’s story: https://cjdfoundation.org/jeannes-story
Brian Flynn’s story: https://cjdfoundation.org/brians-story-0

Strides for CJD

Our third annual Strides for CJD events hosted more than 1,700 walkers and runners in 12 cities, plus individuals who walked in their hometowns in support of the event. Families came together to pay tribute to their loved ones, support one another, and raise awareness of CJD in their communities. Funds raised will support the CJD Foundation’s general fund, including Medical Education, Family Support, and Research programs. Next year’s Strides for CJD events will be held on October 6 and 13, 2018. Committees are forming now – to volunteer, contact Abby@CJDFoundation.org. Registration will begin in Spring 2018. Visit www.strides4cjd.com for updates.

Approaching 2018 with Gratitude and Hope

In 2018, we will commemorate the 25th Anniversary of the CJD Foundation. Throughout the year, we will recognize the achievements of scientists in the prion field, and the accomplishments of the founders, leaders, and many dedicated volunteers and families who have supported the Foundation over those 25 years. In addition, we will renew our efforts to support research, educate medical professionals, and offer help and information to every family faced with a CJD diagnosis.

We wish you a very Happy Holiday Season and all the best in 2018. Thank you for your continued support!

With best wishes,

Debbie
CJD Foundation President Debbie Yobs and Program Director Lori Nusbaum attended Prion 2017 in Edinburgh, Scotland, May 23 to 26.

Prion experts from around the world shared updates on their work through presentations and posters. A number of scientists who have received past CJD Foundation grants were invited to present.

During the event, Debbie announced the CJD Foundation’s call for applications for the 2018 Research Grant Program.

**Did You Know?**

In 2017, CJD Foundation hosted …

**Family Workshops** in Birmingham, AL; Cincinnati, OH; Detroit, MI; Houston, TX, and Charleston, SC. *CJD Family Workshops are free of charge and open to all families affected by a prion disease. They are designed to provide support, education and the opportunity for open dialogue in a secure forum.*

**Grand Rounds** in Hershey, PA; Cincinnati, OH; Detroit, MI; Houston, TX; Charleston, SC; and New York, NY. *Grand Rounds provide medical education to physicians at hospitals at no cost to the institution. Led by CJD Foundation Medical Director Dr. Brian Appleby. These programs give medical professionals the most up-to-date information available about CJD and other prion diseases.*

**Funeral Education** in Birmingham, AL and Lorain, OH. *Funeral Education Seminars are provided at no cost and educate funeral directors, embalmers, and others in the funeral industry.*

**Teleconferences** with Dr. Brian Appleby; Byron Caughey, Ph.D.; Deana Simpson, RN; Katrina Hallmark, Ph.D.; and Dr. Joel Watts. *These evening conference calls allow families to ask questions of a prion disease expert, learn from the experience of other families, and lend support to one another.*
CJD Foundation July 2017 Family Conference in Washington, D.C.

Geneva and Luke Baxley, and Bradley Kalinsky at the Saturday evening banquet

Board member Janine Kock and Vickie Webb

Prion disease experts Dr. Alberto Bizzi and Dr. Michael Geschwind

Research Grant Recipients Dr. Stéphane Haik, from Paris, France, and Dr. Wen-Quan Zou, from Cleveland, Ohio.

Dr. Jiri Safar, Andrea Webb, Danielle Jordan, Janis Blevins and Dr. Dan Rhoads provide an overview of the work of the National Prion Disease Pathology Surveillance Center in Cleveland.

David Ralston, of the CJD Support Group Network Australia, and Steve Nivens, family member.

CJDF President Debbie Yobs presents a Volunteer of the Year award to Board Secretary Chuck Cash.

Left to right: Volunteer of the Year Trevor Baierl, Strides captains Pam Fear, Jeffrey Evans and Brandi Evans, and the Florence J. Kranitz Leadership Award winner Amanda Baxley Kalinsky.

Jeanne Cole and Dr. Katrina Hallmark
Advocacy is part of our mission at the CJD Foundation

This year, advocacy for continued funding of prion disease surveillance has been imperative — not only for the CJD Foundation and the families we serve — but also to the National Prion Disease Pathology Surveillance Center.

Thank you to all of you who wrote letters, which we delivered to your representatives in Washington, D.C.

During the Advocacy portion of the CJDF Family Conference in Washington, D.C., participants are armed with knowledge about prion disease and ready to take on Capitol Hill.

Nikki Bland and Ed Snively meet with West Virginia Congressman David McKinley (center).

The Joseph family, of Arizona, meets with legislative aides at Senator John McCain’s office on Capitol Hill.
BEVERLY HILLS, CA — The Foster family, Amanda Baxley Kalinsky and Beverly Hills Mayor Lili Bosse walk at the Beverly Hills High School track.

CLEVELAND, OH — Friends and family of Russ Ward walk the shores of Lake Erie at Edgewater Park.

JOPPA, MD — Runners hit the trail at Mariner Point Park.

MORRIS PLAINS, NJ — The “For the Love of Joyce” team participated in honoring of Joyce Rizzo.

ATLANTA, GA — The Cain family and their friends participate in memory of Johnny “Big Boss” Cain.

MINNEAPOLIS, MN — Walkers check out the raffle prizes at Lake Elmo Park Reserve.

FORT COLLINS, CO — Walking in memory of Jeffrey Shrout on the Colorado State University campus.

CHICAGO, IL — The family of Jorge Ascencio shows their team spirit despite the rainy weather at Waterfall Glen Forest Preserve.

TEMPE, AZ — A young walker participates in honor of Brandon Londer.

BOSTON, MA — Strides captain Victoria Costello and her friends participate in the city’s first-ever Strides for CJD event.

Watch for pictures from WASSAU, WI and PORTLAND, OR.
Calendar of Events

February 2018
★ Weds., Feb. 28: Rare Disease Day: www.rarediseaseday.us

July 2018

October 2018
★ Saturday, October 13: 2018 Strides for CJD
In 2017, we had 12 Strides run/walks throughout the U.S. and more than 100 people participating in individual events in their hometown. If you’d like to host a Strides event or join a local planning committee, call 1-800-659-1991.

New York Metro Area Support Group in 2018
★ January 8
★ February 12
★ March 5
★ April 9
★ May 7
★ June 4
For more information, email help@cjdfoundation.org.

Family Workshops Schedule 2018
★ March — Alabama
★ April — Louisville, KY and Philadelphia, PA
Stay tuned for additional Family Workshops!

Want to be added to our email list?
Drop us a line at help@cjdfoundation.org

Does your company offer a Matching Gift Program?
Please consider the CJD Foundation when making your 2018 Contributions!
Go to https://cjdfoundation.org/donate today!

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