A Letter from Debbie Yobs, CJDF President

Dear Friends,

We at the CJD Foundation wish you a peaceful holiday season. This year has passed quickly, but we have much to appreciate as we look back on 2016! Here are just a few highlights.

Our appreciation and praise go to all who supported the very successful Strides for CJD events this past October! More than 1,000 people participated across the country. Thanks to the hard work of our captains, their committees, and all who assisted, Strides for CJD raised awareness in eight communities and gave families a venue to meet each other and pay tribute to loved ones affected by prion disease. Funds raised will be applied to our vital programs in advocacy, family support, medical education, and research.

Our thanks go to the eight wonderful committees and to:
- Goodyear and Scottsdale, Arizona team captain Corby W. Foster
- Beverly Hills, California team captain Brandi Evans
- Chicago, Illinois team captain Molly Nocerino
- Fort Collins, Colorado team captain Julie Moreno
- Joppa, Maryland team captain Maryann Forgan
- Minneapolis, Minnesota team captain Pam Fear
- Cleveland, Ohio team captain Kristin Horomanski; and
- Mike Vitanza, Shawn Welty, Casey Conner and the New Jersey committee.

We’re pleased to have been able to connect with so many families through our programs this year.

Nearly 500 people have registered for our 15 family teleconferences over the past year, to engage in Q&A, to support other families, and to hear speakers including Dr. Brian Appleby, Dr. Katrina Hallmark, Eric Minikel, Dr. Paul Brown, Sonia Vallabh, and Professor John Collinge. Recordings of the Speaker Series calls are on our website. We also received more than 1,300 calls and emails to our HelpLine, and more than 34,000 visits to our website this year.

During 2016, the CJD Foundation sponsored Grand Rounds presentations in six states and Family Workshops in five states. Our Family Conference in July featured five researchers whose work was

(Continued on next page)
funded by you through the CJD Foundation Research Grant Program. These recipients of the 2016 CJD Foundation research grants have worked all year, in your name. They will report on their projects at the end of the year.

Along with Dr. Jiri Safar (our Scientific Director and the Director of the NPDPSC) and Dr. Brian Appleby (our Medical Director and co-Director of the NPDPSC), we made three visits to Capitol Hill this year, raising awareness among legislators, sharing the impact of prion disease on our families, and reinforcing the vital importance of continued funding for CJD surveillance.

A highlight of our year was announcing to the 400 researchers gathered at the international Prion 2016 conference in Tokyo that the CJD Foundation would once again offer research grants, thanks to your generous donations. After evaluating the more than 50 applications we received in August, our Scientific Advisory Committee selected a small group for the next review round. In January we will announce those selected to receive 2017 CJD Foundation Research Grants. Early in 2017, we will share the reports of the five researchers funded through our 2016 Research Grants. And in May 2017, we look forward to announcing the 2018 Research Grant program, all made possible by your donations to the CJD Foundation, to Strides4CJD, and to Family Memorial Grants. Together we are having a measurable impact on prion disease research!

As the year wraps up, we express our profound gratitude to Dr. Safar, Dr. Appleby, and the hard-working team at the NPDPSC for all they are doing for the CJD community. We also send tremendous gratitude to each of you – our volunteers, board members, Strides captains, and all who work tirelessly to support those affected by CJD and to make a difference. Thank you for your involvement and passionate support of our shared cause. We commit to continue our drive to educate professionals, advocate for families, and support advances in prion disease research in the year ahead.

Best wishes,

Debbie
Dear Families and Friends,

The National Prion Disease Pathology Surveillance Center (NPDPSC) would like to extend our most sincere condolences to all the families who have lost a loved one to prion disease or a related neurodegenerative disorder. There are no words we can offer that will console you, only those that express our understanding for the heartache your family is going through.

We know that the Center has limited answers for patient’s families during the difficult and often confusing time of the initial diagnosis of your loved one, but hope that the definitive detailed diagnosis we provide following autopsy and tissue examination may have brought some sense of closure.

We are very grateful to all those families who have chosen to participate in our Autopsy Program and for their Capitol Hill advocacy on our behalf. This program provides much needed tissue and other specimens for our research, which is crucial for experimental drug treatments and early diagnostic testing. In spite of budgetary constraints, we have decided not to limit the number of autopsies performed by the Center, hoping that donations in support of the autopsy program will allow us to keep the rate of autopsies performed undiminished throughout the years to come. We are deeply grateful to those families who help to fulfill our goals, and continue to work towards improving the diagnostic capabilities of CJD based on cerebrospinal fluid (CSF) examination.

On behalf of all the members of the Center I send you our warmest wishes for a healthy and happy 2017!

Jiri Safar, M.D.,
Director, NPDPSC

Please consider the CJD Foundation when making your End-of-the-Year Contributions!

If your company has a Matching Contribution Program, be sure to let us know.

Go to www.cjdfoundation.org today!
A Note from Lori Nusbaum, CJDF Program Director

Dear Friends,

It’s hard to believe that 2016 is almost behind us! It’s been a busy year! Our Medical Education Program has been in full swing, and this year we’ve been to nine communities including: Tucson, Arizona; Los Angeles, California (3); Minneapolis, Minnesota; New York, New York (2); Denver, Colorado; and Columbus, Ohio. Many thanks to Dr. Brian Appleby of the National Prion Disease Pathology Surveillance Center and Case Western Reserve University School of Medicine, and Dr. Michael Geschwind, UCSF, for educating the many professionals about CJD and other prion diseases on our travels. Combined this year, we have reached several hundred neurologists, other medical professionals, and in some cases, infection control specialists who were present during these Grand Round presentations. Many were not only from the hospital where the presentation occurred, but from surrounding hospitals as well. What a great opportunity to reach a large number of medical professionals! If you have a contact at a hospital in your area, please let me know, and I will try to schedule a medical education program at that facility.

We were also able to hold Family Workshops in most of these places. Family Workshops are open to all families affected by a prion disease and designed to provide support and education, and a place where your questions and concerns can be addressed.

None of this would be possible without the generous sponsorships of: Cookie Stivison, in memory of her husband Tom; Nancy Cypert, in memory of her husband Ed; Marlene Honig, in memory of her husband Dr. Herbert Honig; and Janine Kock, in memory of her husband Davey.

They were also funded in part by grants from: The Centers for Disease Control and Prevention, and The Wells Fargo Van Houten Memorial Grant.

We’re in the process of scheduling additional Medical Education for 2017. In just a few weeks, Dr. Appleby; Aaron Koeth, a mortician at Case Medical Center; and I will be presenting at the Alabama Funeral Directors Association’s Mid-Winter Conference. This is an opportunity for us to speak to a group of funeral directors about CJD and other prion diseases. There are so many misconceptions on this topic in the funeral industry, and this is a great opportunity for us to address them. We’ll be looking for more of these conferences to attend in 2017.

While we’re in Alabama, I’ve scheduled a Family Workshop at the Hyatt Regency in Birmingham on Saturday, January 14. Please join us for the Family Workshop – we’d love to meet you! See page 11 for more details.

The date has been set for the 2017 Family Conference. Please mark your calendars! CJDF Foundation Family Conference, The Washington Court Hotel in Washington, D.C., July 14 – 16 (July 17, Capitol Hill Visits)

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

Lori Nusbaum, CJDF Program Director

This fascinating book tells the story of CJDF Board Member Amanda Baxley Kalinsky and her family, the path to diagnosing the disease (GSS) that affects multiple family members, and how Amanda changed the future of prion disease in her family.

Remember, when you purchase items through smile.amazon.com using this link [https://smile.amazon.com/ch/65-0404623], Amazon will donate 0.5% of the price of your eligible purchases to Creutzfeldt-Jakob Disease Foundation Inc.!

The CJDF has established the “Mercies in Disguise” Research Grant, which will fund research programs to find a cure for prion diseases, in honor of the Baxley Family. To make a donation to this grant, call 1-800-659-1991.

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HelpLine Statistics for January 2016 through October 31, 2016

Our toll-free HelpLine, 800-659-1991, and email at help@cjdfoundation.org, are monitored 7 days a week offering answers, resources, referrals and a listening ear to families who are struggling to confirm a diagnosis, overwhelmed by caregiving, or mourning the loss of a loved one from CJD. We also receive many calls from medical professionals, funeral directors and embalmers, the general public, the press and the media.

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<th>MONTH</th>
<th>NEW CASES REPORTED</th>
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<td>21</td>
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**TOTALS** | **157** | **105** | **1,229** | **34,510**

The CJDF 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.

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

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

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Coming to Bookstores & Amazon.com, March 21!


This fascinating book tells the story of CJDF Board Member Amanda Baxley Kalinsky and her family, the path to diagnosing the disease (GSS) that affects multiple family members, and how Amanda changed the future of prion disease in her family.

Remember, when you purchase items through smile.amazon.com using this link [https://smile.amazon.com/ch/65-0404623], Amazon will donate 0.5% of the price of your eligible purchases to Creutzfeldt-Jakob Disease Foundation Inc.!

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2016 ~ Celebrating our 2nd annual Strides for CJD event

GOODYEAR, AZ

Strides Team Captain Corby W. Foster and his family

Adam and Kristin Valente take a walk under the palm trees at Estrella.

SCOTTSDALE, AZ

Kristina Davis shows her support for the CJD Foundation.

Melanie Foster, Tiffany Eiben, Moaki Durkee and Gwen Durkee welcome walkers to the Troon North Golf Club.

Esther Angelus Grabowsky and her pup, Mordy, walk in honor of Esther’s mother, Rochelle Angelus.

BEVERLY HILLS, CA

Enthusiastic members of Team Reiss

Jake Schreiner, Greg Curry and Julie Schreiner, with family and friends

The Foster and Blatchley families gather at the Beverly Hills High School track.

CHICAGO, IL

Despite the wet weather, the Schwister family (left) and other passionate Chicagoans came out to support Strides4CJD.

(Continued on next page)
2016 ~ Celebrating our 2nd annual Strides for CJD event

FORT COLLINS, CO

Students and researchers from Colorado State’s Prion Research Center and community members get ready to walk. The family of Lesa Curtis walks in her memory.

Dr. Lindsay Parrie and raffle winner Traute Parrie

JOPPA, MD

Above: Team captain Maryann Forgan (far right) and the Strides4CJD participants
Right: Anna Kozlosky and Zach Dixon take part in Strides to honor their mother, Mary Dixon.

Matt and Carolyn Platania walk in honor of Carolyn’s grandmother, Mary Connaghan.

MINNEAPOLIS, MN

Photo booth fun with Nancy Koller, Susan Sanderson, Julie Selberg and Sara Thompson

Nancy Phelps and Steve Skold

Kaitlin Fear and Lindsay Goetsch, with Strides Team Captain Pamela Fear

MORRIS PLAINS, NJ

Runners take off from the starting line. Erma Terrezza Ogar with a raffle prize donated by Donna Welty

The family of Robin Parinello walks in her memory.

(Continued on next page)
The clouds parted and the sun came out just in time for the Strides walkers at Valley View Woods Park.

The Pugh Family

Judge Bean, Katie Fuchs and Shady

Family and friends walk in memory of Bill Davis

Corallo’s Crusaders walk in memory of Chris Corallo. During their walk through Glasgow Park, a purple butterfly landed on the baby’s blanket, which the family believes was a sign from their loved one.

Strides4CJD participant MaryAnn Nguyen

Stay tuned for more information about Strides4CJD 2017.

To be a team captain, contact Lori at 1-800-659-1991.
Annual Fund Donor List, as of 12/13/16

We are very grateful to those of you who have already contributed to our Annual Fund. To date, we have raised more than $60,000.

If you haven’t already done so, please consider supporting our work though an Annual Fund donation by calling 1-800-659-1991.

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Carlyn Zubin

Calendar of Events

January 2017

★ Mon., Jan. 9, 6 p.m. — **NY Support Group**: Families of loved ones with CJD are invited to participate in our free, monthly face-to-face support group in New York City. To make your reservation and for venue info, call 1-800-659-1991 or send an email to help@cjdfoundation.org.

★ Sat., Jan. 14, 5 p.m. — **CJD Foundation Family Workshop: Birmingham, Alabama**. Sponsored in part by The Centers for Disease Control and Prevention and a generous donation by Cookie Stivison, in memory of her husband Tom Stivison. Featuring guest speakers Dr. Brian Appleby and Lori Nusbaum. Registration for this event is required; call 1-800-659-1991.

February 2017

★ Mon., Feb. 6, 6 p.m. — **NY Support Group**: Families of loved ones with CJD are invited to participate in our free, monthly face-to-face support group in New York City. To make your reservation and for venue info, call 1-800-659-1991 or send an email to help@cjdfoundation.org.

★ Tues., Feb. 28 — **Rare Disease Day**: This annual awareness day is dedicated to elevating public understanding of rare diseases and calling attention to the special challenges people face.

Looking Ahead

★ July 14 to 16, (Capitol Hill visits, July 17): **The CJD Foundation’s annual Family Conference**, in Washington, D.C., brings together prion disease experts and families who have lost a loved one to CJD. To register, call Lori at 1-800-659-1991 or email help@cjdfoundation.org.