A LETTER FROM **DEBBIE YOBS, CJDF PRESIDENT**

Dear Friends,

Thank you for your continued advocacy, support, and passion about our shared cause. We launched 2018 with a very full schedule of activities, and we thank you for supporting all of them!

**25 Years of Making a Difference**

This year marks the 25th Anniversary of the founding of the CJD Foundation. We thank all who have contributed to the development of the Foundation, created its programs, and supported other families throughout those years. There is still a great deal of work to do to achieve our mission, but we have already achieved so much together. Thank you for all you do to raise awareness, support one another, and contribute to all of our programs!

**Research Grants**

In January, we were honored to award research grants to six outstanding scientists whose applications were top rated by our Scientific Advisory Committee.

**Hermann Clemens Altmeppen, Ph.D.**
Institute of Neuropathology
University Medical Center – Eppendorf, Hamburg, Germany

“How Investigating the Potential of the Neuroprotective N1 Fragment of the Prion Protein as a New Treatment Against Prion Diseases”

**Leonardo Cortez, Ph.D.**
Centre for Prions and Protein Folding Diseases,
University of Alberta, Edmonton, Alberta, Canada

“Isolation and Strain-Specific Characterization of Pathogenic CJD Prion Particles”

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LETTER *(Continued on Next page)*
LETTER (Continued from Previous page)

David A. Harris, M.D., Ph.D.
Department of Biochemistry, Boston University School of Medicine
“Highly Synergistic Combination Therapy for Prion Diseases”

Allison Kraus, Ph.D.
Rocky Mountain Laboratories, Montana
“Investigation of Prion Inactivation by Reactive Oxygen Species in Vivo”

Sylvain Lehmann, Ph.D.
Institute for Regenerative Medicine and Biotherapy, University of Montpellier, France
“Innovative Human 3D Neural Network Model for the Efficient Propagation of Human Prions”

Rodrigo Morales, Ph.D.
Mitchell Center for Alzheimer’s Disease and Related Brain Disorders
Department of Neurology, University of Texas-Houston Medical School
“Systematic Evaluation of the Zoonotic Potential of Different CWD (Chronic Wasting Disease) Isolates”

To learn more about each of these studies, visit https://cjdfoundation.org/grant-recipients or join us at the 2018 CJD Foundation Family Conference. We thank all of you for supporting these six exciting studies through your donations to the CJD Foundation, to Strides for CJD, and to Family Memorial Grants.

Advocacy

In February, many of you helped us to communicate to members of Congress the importance of continuing to fund Prion Disease Surveillance in both Fiscal Year 2018 and 2019. Given the overlap between two budget cycles this year, we needed to double our efforts to make legislators aware of the devastating effects of prion disease, and the compelling need to fund CJD Surveillance. Thank you to all who called and emailed their representatives and senators, and who filed an appropriations request form for their district.

If you are willing to assist with advocacy in the future, please:

• **Attend Advocacy Day in July** – At our annual conference, you will hear about the issues and the science of CJD, receive advocacy training, and have the opportunity to visit your representative and Senators’ offices (Monday, July 16). We schedule meetings with your legislators’ offices, and provide you with talking points and materials for your meetings. Join us for this opportunity to share your story and educate your representatives about CJD.

• **Join our advocacy mailing list** – Email us at Help@CJDFoundation.org with subject line “Add me to advocacy list.” We will alert you when there is an advocacy deadline, and provide you with information on how to contact your representatives and suggested requests.

Teleconferences and Family Workshops

Our full schedule of teleconferences and family workshops is listed on page 8. If you are not receiving these invitations by email, email us at Help@CJDFoundation.org with subject line “Add me to mailing list.”
LETTER (Continued from Previous page)

Conference
The CJD Foundation Family Conference will be held July 13 to 15, 2018, in Washington, DC. We are so pleased to welcome as our Keynote Speaker Professor Robert Will of the UK National CJD Research and Surveillance Unit. In addition to presentations by the six scientists who received grants in January, we will host Sporadic and Genetic Family Workshops, roundtable discussions with the speakers, updates from past research grant recipients and from the CDC and NPDPSC, report on the CJD Foundation questionnaire program, and more. To register, visit cjdfoundation.org/conference.

We thank the sponsors and donors who contribute each year and make it possible for us to host this important gathering. Watch your mail and email for registration and sponsorship information, and join us in Washington, DC!

Strides for CJD
Captains have already been meeting and working to schedule their dates (October 6-13, 2018) and locations. This year’s prospective locations include:

Atlanta  Joppa, MD
Beverly Hills  Minneapolis
Boston  Morris County, NJ
Charleston, WV  Pittsburgh
Chicago  Seattle
Cleveland  Tempe
Denver  Wausau, WI

If you are interested in joining the committee in these locations or in hosting an event in your area, please contact help@CJDFoundation.org.

Thank you for all you do to raise awareness and battle CJD!

Debbie Yobs
President

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If you missed our March 20 teleconference with Dr. Valerie Sim (or any of our other Interviews with Experts), you can find them here: https://cjdfoundation.org/interviews-with-experts

2017 ANNUAL FUND DONORS
We are very grateful to those of you who have contributed to our Annual Fund.

To view a list of our 2017 Annual Fund Donors, visit https://cjdfoundation.org/2017-annual-fund-donors
HARDING ACADEMY REMEMBERS TEACHER, RAISES FUNDS TO SUPPORT CJD FOUNDATION

Every year since 2001, Harding Academy in Nashville, TN (PreK to 8th grade), hosts a fundraiser to support a charity chosen by the student body through an essay competition.

This year, fifth-grader Katherine Thomas wrote an essay in memory of her fourth-grade teacher, Camille Gift, who passed last March from CJD.

At the school’s Jump and Hoop It Up fundraiser on March 15, the younger students jumped rope for 30 minutes, and the older students competed in basketball events. The event concluded with a student-versus-faculty basketball game. This year’s event — which involved 600 children and adults — raised more than $10,000, which will be donated to support the programs of the CJD Foundation.

We are thankful to the students, parents, staff and faculty of Harding Academy for their contributions in memory of Camille, a beloved mother, grandmother, teacher and friend.

Remembering Mrs. Gift
by Katherine Thomas, Fifth-Grader, Harding Academy, Nashville, TN

Have you ever heard of Creutzfeldt-Jakob Disease [pronounced kroits-felt yah-kawp]? You will be shocked to learn that it is a terrible disease that is always fatal to whoever acquires it. Creutzfeldt-Jakob Disease, or CJD for short, is from a family of diseases called "prion diseases." These diseases are brain disorders. CJD is the most well-known of all the prion diseases. Once a person is diagnosed with CJD, there is not much one can do to stop it. The Creutzfeldt-Jakob Disease Foundation, however, is an organization that helps to support families of people with CJD and promotes research to try to find a cure for this currently incurable illness. In my opinion, the money raised during Harding’s Jump and Hoop It Up fundraiser should go to this foundation. There are three reasons why I believe Harding should support this organization. First, CJD is always fatal. Second, there is currently no cure for this disease, but our money can help the doctors and scientists continue to try to find one. Finally, last year, my beloved teacher, Mrs. Camille Gift, passed away from this disease. Her passing led me to discover this foundation and fuels my desire to support it.

CJD is invariably fatal to anyone who falls ill with it. Usually CJD victims die in less than eight months, which is shocking. Almost all cases of CJD are what's called "sporadic," meaning they are unprovoked. If you get CJD, it doesn't matter if you were in great health before you acquired it. Usually CJD occurs in people over 60 years old. Even a former Olympic athlete who is in fantastic health could get CJD and die from it very quickly. Nothing can stop CJD.

There is also currently no cure for CJD, though there are a few medications that people can take that relieve their pain just a little bit. Nothing can really and truly protect you from CJD, and it can affect anyone, since most of the

MRS. GIFT (Continued on Next page)
cases aren’t caused by a particular reason. When a disease is fatal, it is difficult to have hope. Hope is that "thing" that families rely upon in order to get through tough times. Because a CJD diagnosis is fatal news, hope is often lost. This disease deserves more recognition because it is so terrible and there is currently no way to stop it.

Finally, last year, I had a teacher named Mrs. Gift. Prior to my fourth grade year, I was wishing and hoping and doing everything to try to ensure that I was assigned to her homeroom. I was thrilled to learn that I was, indeed, going to be in her class! I had an amazing first trimester with her. We read books in class, she recommended books to me, she even lent me her personal copies! I also was ecstatic to attend Mrs. Gift's legendary book clubs, and I had so much fun talking about books and eating the free candy she gave us. But a month before winter break, Mrs. Gift started not feeling so well. She had frequent sick days, and often told us she felt dizzy and tired. She went to the hospital to have herself checked out, and her doctors couldn't diagnose anything. They told her to rest and take lots of time off. She did, and then started feeling really bad. She pushed through until winter break, and on the last day she hugged us all and told us, "I'll see you in two weeks!"

Once winter break started back up again, we were told we would have a substitute teacher for about two weeks because Mrs. Gift needed to rest and relax. We all carried on with our lives, preoccupied with schoolwork and other things. We weren’t really worried about her, because we had been told it wasn’t serious, just a bad case of winter sluggishness. But apparently it was not. She and her family went to a specialist in another state, who told her she had Creutzfeldt-Jakob Disease. Everyone in our class was devastated, although we had no idea what this disease was. Because we didn't know much about it, we underestimated it, thinking, Oh, it can't be that bad. She was really healthy before she got it, so of course she'll be fine. We powered through and made infinite cards and "get well soon" packages. About three months had passed, with no sign of improvement. We were still hopeful and kept believing in miracles and took anything as a sign of recovery.

It soon became clear there was no hope. Mrs. Gift didn't have much more time. Her health was rapidly deteriorating. We all knew that, but somehow couldn’t accept reality, pushing the subject away whenever it was mentioned. Mrs. Gift couldn't die. She just couldn't. But we were wrong. Only a few months after winter break started and Mrs. Gift promised us we would see her again, CJD finally took her away from us. Mrs. Gift powered through until the end, but Creutzfeldt-Jakob Disease is powerful, and no one ever wins against it.

The memory of Mrs. Camille Gift is one of the memories I hold closest to my heart. I don't want anyone else to go through the pain of having a loved one diagnosed with this disease. No one deserves it. This is why the money for Jump and Hoop It Up needs to go to the Creutzfeldt-Jakob Disease Foundation. We can help find a cure for this terrible disease.
Learning the facts about CJD takes real effort. Sharing your personal story and educating others takes courage. Kudos to these family members who have been invited to share their stories and raise awareness about CJD in their communities, or who found a way to blend information about CJD into their work communities!

Jeffrey Evans, Director of Nespresso’s flagship store in Beverly Hills, recently hosted an event for the Association of Celebrity Personal Assistants. The ACPA often features non-profit organizations at their meetings, and Jeffrey had the honor of speaking for 10 minutes on CJD and the Foundation. CJD was also featured in the member email sent by the ACPA following their meeting.

Right: Paul Kelleher appeared on television’s Jeopardy on Feb. 27, 2018, and wore a purple Cure CJD ribbon in memory of his sister, Robin Parinello, who died of CJD. In their photograph together, Jeopardy host Alex Trebek wore a purple tie as well!

Debbie Yobs was interviewed about CJD on radio station KRMS, on the Ozarks Today show in the 5 pm hour on March 15, 2018: http://www.krmsradio.com/show-archive-podcast/

Roberta Solimene, who lost her husband Robert to CJD, was invited to represent the CJD/Prion Disease community at Rare Disease Day at Quinnipiac University in Connecticut in February 2018. Roberta has been an adjunct professor in the Occupational Therapy Department of the University and was pleased to help the university community learn more about CJD.

In addition, Roberta was a guest on the Connecticut Public TV show, “Got Girlfriends,” on March 15. She spoke about CJD and her personal experience with her husband. She also provided the CJD Foundation website and helpline number. The episode will air soon and will be available on Vimeo.

Left: Amanda Baxley Kalinsky spoke at Nova Southeastern University in Florida, as part of the university’s Distinguished Speakers Series. During her visit, Amanda did a meet-and-greet event with her mother, Kathy Baxley; Nova students and Professor Robert Speth in the university’s Health Professions Division.

How have you spread the word about our fight against CJD? Share your story today at Help@CJDFoundation.org. To learn more about Prion Diseases, so you can help educate others, visit:

https://cjdfoundation.org/cjd-foundation-literature
https://cjdfoundation.org/about-cjd
https://cjdfoundation.org/faq
Our website features synopses, in layman’s terms, of two recent research studies published by CJD Foundation Research Grant Award winners.

“Prion seeding activity and infectivity in skin samples from patients with sporadic Creutzfeldt-Jakob disease” by Christina Orrú, Ph.D., Science Translational Medicine

Detecting CJD in skin cells as a potential diagnostic
Among the questions families often ask about CJD is whether someone can develop the disease from contact with their loved one’s skin, either through caretaking or casual touch. To date, multiple studies have shown there is no evidence that family, friends or healthcare professionals are at any increased risk of prion disease compared to the general population.

To learn more about how skin cells could be used as a diagnostic in CJD, go to https://cjdfoundation.org/synopses-recent-studies.


An important step forward in finding treatments for CJD
“There are no treatments and no cure.”

These are devastating words for a CJD patient and their families to hear. And while scientists have attempted for decades to understand the mechanisms of prion disease and to identify potential treatments, brain diseases like CJD present special challenges for the research community.

Until now, the only way to study the human form of CJD has been in animal tests. These studies have yielded important information, but the relevance of the findings for CJD in humans has been unclear and have not led to new drugs or other treatments. Efforts to investigate how prions are passed between brain cells have been hampered by an inability to replicate the proteins in human cells in lab models. Such experimental models approximate or mimic a disease in human cells and are an early step in the discovery of new medicines. Molecules are tested in human cell models to assess any impact on a particular disease or disorder. If the results are promising, the molecule may advance to further testing, and ultimately, to trials in humans.

To read the full summaries, go to https://cjdfoundation.org/synopses-recent-studies.
April 2018
Thurs., April 5, 7 p.m. Eastern
Genetic Prion Disease Teleconference with Eric Minikel and Sonia Vallabh
Sonia and Eric will discuss their efforts to develop a preventive therapeutic for prion disease and the prospects for preventive clinical trials in people at risk for genetic prion disease. To register, call 1-800-659-1991 or email help@cjdfoundation.org.

Tues., April 17, 7 p.m. Eastern
Teleconference Speaker Series with Ryan Maddox, Ph.D.
Dr. Maddox will lead a Q&A discussion about prion disease, including types of CJD, frequency of occurrence, methods of counting CJD cases, Chronic Wasting Disease, and more. To register, call 1-800-659-1991 or email help@cjdfoundation.org.

May 2018
Tues., May 15, 7 p.m. Eastern
Bereavement Teleconference with Katrina Hallmark, Ph.D.
Dr. Hallmark will share the messages she presents in the bereavement workshop at the CJD Foundation Family Conference each year, and what she learned through her personal loss of a loved one to CJD. To register, call 1-800-659-1991 or email help@cjdfoundation.org.

June 2018
Tues., June 12, 7 p.m. Eastern
Teleconference Support Group with Dr. Brian Appleby
Open to all families affected by prion disease and is designed to provide support, education and the opportunity for open dialogue in a secure forum. To register, call 1-800-659-1991 or email help@cjdfoundation.org.

July 2018
July 13 to 15, (Advocacy Day, July 16)
2018 CJD Foundation Family Conference in Washington, D.C.
This annual event brings together prion disease experts and families affected by prion disease. The conference fee until June 11 is $195 per person. After June 11, it will be $215 per person. To register online, visit cjdfoundation.org/conference.

October 2018
Sat., October 6 (October 7 and 13, in some locations)
Strides for CJD
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
April 9, May 7, and June 4, at 6 p.m. For more information, email help@cjdfoundation.org.