President’s Message

I recently returned from the annual CJD Support Group Network (CJDSGN) Family Conference which was held in Melbourne, Australia and organized by Suzanne Solvyns, Director of the CJDSGN, with help from the organization’s Management Chairman, David Ralston and others. The CJD Foundation was well represented by Dr. Brian Appleby, Amanda Kalinsky and me, who were invited as speakers and American representatives. I was deeply honored to be presented with an award for our work with families. As always, Suzanne did an amazing job of organizing the meeting, which was well-attended by the Australian families and international researchers. Professor Richard Knight, Professor Maurizio Pocchiari, Professor Michael Alpers, Professor Andrew Hill and Professor Steve Collins also offered information about the latest science. Professor Alpers showed an amazing video produced by National Geographic about his work with the Fore tribe in Papua, New Guinea, and his group’s discovery that cannibalism was the root of their acquiring Kuru.

Our family research grant program is now mid process. In May we advertised the availability of four $50,000 grants from funds raised by families and received 53 Letters of Intent outlining individual prion disease research projects. Each of these letters was reviewed by our Scientific Advisory Committee, led by Dr. Pierluigi Gambetti, our Medical Director. The Letters literally came from all over the world, each one representing a very interesting and worthwhile project. The committee had an extremely difficult time narrowing the field, but subsequently invited 14 researchers to submit full applications. Successful recipients for the four grants will be announced at the end of January.

Our annual fund raising request, which was sent out this week, outlines a few of our very important projects, most of which would be impossible without your help. We ask that you please consider supporting us as you plan your annual donations.

As I announced at our annual conference in Washington and in the July newsletter, I will be stepping down on December 31st so this will be my last letter to you as President of the CJD Foundation! This extremely fulfilling role has allowed me to meet many of you, our brave families, who have continuously served as my inspiration. It has also afforded me the privilege of learning about prion disease science from some of the foremost world experts. Our Medical Director, Dr Pierluigi Gambetti, our advisor and steadfast champion over the last 13 years is a prime example. He has always made time to help and advise us no matter how busy his schedule may be. Dr. Ermias Belay, Dr. Lawrence Schonberger and Dr. Ryan Maddox from the Centers for Disease Control and Prevention have not only helped us receive a very generous CDC grant but have always responded.

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President’s Message

Professors Robert Will and Richard Knight from the CJD Surveillance Unit in the U.K. were among the first experts I met when I began this journey. I will never forget their kindness and willingness to meet with me at the Surveillance Unit in Edinburgh, no questions asked ahead of time. This meeting was one of the few that quite literally changed my life. They subsequently became good friends and loyal supporters of us and our work.

I will always treasure the wonderful friends I have made from all over the world. Suzanne Solvyns and I have served as co-chairs of the CJD International Support Alliance for many years and have watched it grow from a few member countries to 11 as of today. It has been an honor and an amazing experience to work with her and David Ralston. We have traveled to meetings all over the world together and have had many wonderful adventures which I will continue to treasure!

I am forever grateful to my three incredible children and their wonderful spouses who encouraged me every step of the way, and my “old” friends, Ruthie & Nick George, Ana Betro and Mark Goldfarb, all of whom became involved in the CJD Foundation to honor the memory of their dear friend and my husband Aaron, and honor him they did! Their commitment and devotion remained unwavering and because they were always willing to do the heavy lifting, we have been able to plan and implement some very important and successful programs, including our annual family conference in Washington D.C. I also want to express my gratitude to Lori Nusbaum, Associate Director extraordinaire! Because she is willing to take on almost any job and does them all so well she has truly eased my workload. And of course Wanda Culp-Lias who has been with us forever weaving her magic and keeping us on track and Melany Pritchard our newest staff member who brings passion, efficiency and a big smile to our office every day.

I know Debbie Yobs will be a strong and accomplished president and that she will lead the CJD Foundation with great skill and compassion. She has the passion and enthusiasm needed, and she knows the Board and I will be available to help whenever needed, just as Mayra Lichter, co-founder of the CJD Foundation has so generously done for me over the last 13 years.

I thank you all again and again for your continuing devotion to the CJD Foundation and wish you and yours a most healing and peaceful Holiday season.

With warmest regards,

Florence
The CJD Foundation and the International Alliance Reach Families Around the World

Amanda Baxley Kalinsky

At the age of 25, I was handed a death sentence. I was instantly faced with making decisions about my life I never imagined I would have to make...let alone at such a young age. I remember feeling like I was the only one...like I had lost myself somewhere in the darkness and there was no one there who could give me a flashlight. I remember when anger replaced my hope. When it felt like it was just me against the rest of the world...and the rest of the world was winning. I remember feeling so alone and so scared; so isolated and so vulnerable. I was in the midst of my darkest days.

But then I met Florence Kranitz. A woman with a tenacious yet gentle soul who taught me through example that my heartache could be someone else’s hope and that during those darkest days, we rise by lifting others. She gave me the opportunity to share my story for the first time during the Annual CJD Foundation Family Conference four years ago. I have spoken at every conference since and became a CJDF board member two years ago. Over the years, I have seen for myself how important it is to tell your story. Show your example. Tell everyone it’s possible, and others will feel the courage and use it to climb their own mountains.

A perfect example of this came a few weeks ago. Florence received an email from a man in Michigan who was contacting the Foundation on behalf of his brother in law, who lives in Brazil with the rest of his family. His family has been plagued by GSS for generations. After recently losing a sister to GSS at a very young age, his brother in law’s mother is now currently symptomatic. Needless to say, the family is overwhelmed with emotion and because he lives in the US, this family member felt compelled to reach out on his brother in law’s behalf. He wrote to the CJDF asking for help, desperate for information about GSS, any current studies they could participate in, and wanting to know what, if anything, they could do to stop this disease. Because of my experience with GSS and my willingness to share my story, Florence put him in touch with me. I wrote him a reply email that provided the answers to his questions, told him about my experiences, and gave him and his family the support they were so desperately searching for. After emailing back and forth with him as well as a few others, his family in Brazil was invited to participate in some very important research being done in the US. The family is so very grateful and incredibly encouraged by the help our foundation was able to provide.

The positive impact that the CJD Foundation has on people’s lives goes beyond our own borders. It has traveled across the world and given hope to those who thought all hope was gone. Robert F. Kennedy might as well have been referring to the people of the Creutzfeldt-Jakob Disease Foundation when he said,

“Each time a person stands up for an idea, or acts to improve the lot of others, or strikes out against injustice, he sends forth a tiny ripple of hope, and crossing each other from a million different centers of energy and daring, those ripples build a current that can sweep down the mightiest walls of oppression and resistance.”

Each one of us, through our own stories and our involvement with the CJD Foundation, creates our own ripples...and in time, the ripples that we have all created will become the current that drowns prion disease.
A Message From Lori

It was great seeing and meeting so many of you at our “Voices of Hope” concert in October. Special thanks go to Chairpersons Debbie Yobs and Mike Vitanza and their entire committee. They did an amazing job planning and executing this event. And thanks to so many of YOU as well - your participation, whether it was attending the event, donating, or becoming a sponsor, is what made this a huge success! We’ve posted photos from the event on our homepage at www.cjdfoundation.org.

CJD International Awareness day was November 12th and our families flooded social media with posts and tweets! I was in awe of the power of the internet!! I ran a quick statistical analysis and here are the results:

Facebook:
THIS WEEK we reached over 51,000 people and received 127 new “likes”. We proudly wore, posted and shared photos of ourselves wearing purple. CJD families shared their personal stories. Children, businesses, and other Facebook groups were involved, engaged, and showing their purple!

Our Website www.cjdfoundation.org:
THIS WEEK we received 3,124 NEW visitors to our website! By comparison, during the entire month of October we had a total of 3,573 new visitors.

Twitter:
I am fairly new to Twitter, so I haven’t figured out how to get official statistics, but there was A LOT of activity! Special thanks to family member Trevor Baierl and 44 Blue Productions, we received tweets from performers Donnie Wahlberg and Jenny McCarthy! They generated about 500 retweets and favorites. Everyone got in on the action!

Even as I sit here typing this message, I am continuously receiving notifications of new followers on Twitter and new “likes” on Facebook.

Thanks to everyone,

Lori
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 10:30pm. The HelpLine statistics January 2014 through October 31, 2014 are below:

<table>
<thead>
<tr>
<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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<tbody>
<tr>
<td>January</td>
<td>21</td>
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<td>3573</td>
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<tr>
<td>TOTALS</td>
<td>188</td>
<td>82</td>
<td>1,289</td>
<td>32,585</td>
</tr>
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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 October 31, 2014
Memory Quilt

With your donation of $100 we will create a “square” in memory or in honor of your loved one where you can place either a photograph or a star along with a tribute of 10-100 words. When you click the "submit" button, you will be taken to a special donations page and be asked to provide information. Your Memory Quilt entry will be sent to the CJD Foundation's webmaster for approval and posting, and once your memorial has been added you will be notified by email. When a CJD Memory Quilt "square" is created or a tribute is added to a square, a notification will be sent. If appropriate, an acknowledgment will also be sent to the family member listed on the donation form. Please consider establishing a CJD Memory Quilt square as a unique tribute. If you have any questions or need help accessing the Memory Quilt, just call our office at 1-800-659-1991.

Family Fundraisers

Thank you to the following families who recently held fundraisers to benefit the CJD Foundation:

Kathy Esposito, A dinner/auction in memory of her husband, Robert Esposito
Rhonda Fansler, A walk in memory of her husband, Jon Fansler
Associated Bank Colleagues, Jeans for a Cause, in memory of Ray Gardner
Lisa-Marie Gill, Various fundraisers in memory of her father, John Gill
Norma Grant, A dinner in memory of her husband, Dennis Grant
Megan McGill, Various fundraisers in memory of her father, Raymond McGill
Miranda Malichky’s six year old daughter, Cookies and Cocoa for CJD, in memory of her aunt, Tammy Dee Paulson
Lauren Piriz, Various fundraisers in memory of her husband, Jose’ Piriz
Lori Belcourt, a Bingo in memory of her sister, Tamrah Riley
Chris Snively, A golf outing in memory of his mother, Marsha Snively
Ed Snively, A golf outing in memory of his wife, Marsha Snively
Mike Vitanza, A concert in memory of his brother, Robert Vitanza
Tom Roach, Ran the Chicago Marathon in memory of his brother-in-law, Patrick Yobs
Jenna Zucker, Ran various marathons in memory of her father, Robert Zucker

Remember, you can use our FriendRaising page to fundraise for the CJD Foundation

Copy this link into your browser:  http://friendraising.towercare.com/Markslist/site/displaySite.do?siteIdCode=EQDSWICD
Save The Date

13th Annual CJD Foundation Family Conference
July 10 - 12, 2015
Washington Court Hotel
Washington, DC
Capitol Hill visit day is Monday, July 13, 2015
Mark your calendars!

Reminders

★ Don’t forget to use this link every time you shop online. A percentage of each purchase goes to The CJD Foundation. A few of the many retailers are: Target, Amazon, Walmart, Home Depot, Expedia, Staples). There is no extra cost to our supporters.


★ We have over 2,700 “likes” on our facebook page! Please log on to www.facebook.com and search for “CJD Foundation” to find us.

★ We are now on twitter! Follow us @CJDFoundation

★ We are now on LinkedIn! Connect with CJD Foundation there.

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 your loved one’s name who has been affected by CJD. Your information is confidential and never shared with any 3rd parties.

Comments/Suggestions

If you have any comments or suggestions, please email us at help@cjdfoundation.org.

341 W. 38th Street, New York, NY ★ 212.719.5900 ★ HelpLine 1.800.659.1991
help@cjdfoundation.org ★ www.cjdfoundation.org