President’s Message

Dear friends,

It’s hard to believe this is already October and that The CJD Foundation’s move to New York City is less than 3 months away and that my personal move is taking place in just a few days, as you might imagine, we are very busy! Although this move involves a great deal of planning and organizing the work of the CJD Foundation (CJDF) is continuing almost seamlessly. For this, and so much more, I owe a huge debt of gratitude to our Associate Director Lori Nusbaum, Office Manager Wanda Culp-Lias and Assistant Nancy DiGeroloma. Our HelpLine calls always take precedence and remain our most vital project. Everything else comes to a stop when a family needs our help. And we don’t only speak with American families, recently I spoke to a family in Israel and am currently working with a family in Singapore and a family in Mexico. How amazing is it that we can offer support, information, and referrals to specialists all over the world! We also continue to expand our series of Family Workshops which are held in different parts of the country. These Workshops are attracting a growing number of family members and glowing reviews! Our next Workshop is scheduled on October 23rd in St Louis MO. Currently we have 43 family members registered. They are not only from Missouri but are also traveling from Colorado, South Dakota, Illinois and Indiana! Lori and Veronica Oberdorf are doing an outstanding job organizing them.

We are deeply grateful to the many family members who have held or are holding fundraising events for the CJD Foundation. These events not only help by raising much needed dollars but also help by educating entire communities. If you are interested in information or in planning an event please contact Lori.

The CJD Support Group Network (CJSDSGN) headquartered in Australia is holding their 4th Annual Family Conference on Oct 20th and although I am not able to attend this year because of the two moves to New York City, Suzanne Solvyns, the Director and National Coordinator, asked me to record a speech revolving around our 10th Annual CJD Foundation Family Conference (which took place this past July) and our move to NYC. This speech will be a part of their Saturday evening program. It is deeply flattering and a great honor to be invited to shine a spotlight on our work to families and researchers living on the other side of the world!
Our new website looks great and will be launched very soon. We’ll let you know when it is up and running and look forward to hearing your comments.

In December two very special people in my life and the life of the CJDF will be leaving the Board of Directors. Nick George and Jim Simon have both been an integral part of the Foundation since our move to Akron 11 years ago. They have given most generously of their time and personal dedication, never too busy to take a phone call or to offer much needed advice. Nick has served as our Vice Chairman and Jim as our Attorney from the very beginning and both felt it was now time for them to focus on their many other obligations. They gave so much to us and we will greatly miss them on the Board but I know they will always be available if needed. As we say goodbye to Nick and Jim we welcome 3 new Board members, Chuck Cash from Bethesda, MD, Mike Vitanza from Stamford, CT and Amanda Kalinsky from Nashville, TN. All of them are family members and all have been dedicated to our work and to helping us grow in many different but important ways. We greatly look forward to working with them.

In my speech at the conference this past July I quoted words from a Beatles song which I think are most appropriate to repeat here (with apologies for my personal paraphrasing) “we say goodbye AND we say hello… hello hello”.

Our move to New York City not only means saying many goodbyes and many hellos but it also means we face many new challenges, but we at the CJD Foundation certainly know about taking on challenges (as do so many of you), just on the basis of what we do on a daily basis! We are looking forward with great enthusiasm to many new opportunities and promise to keep you informed every step of the way.

With my warmest personal regards,

Florence
A Message From Lori

As of this writing, Veronica and I are preparing to go to St. Louis for our fourth Family Workshop. The workshop is being held on Tuesday, October 23rd at the Renaissance St. Louis Airport Hotel. Please email me at lori@cjdfoundation.org or call 1-800-659-1991 if you would like to attend. The invitation is on the next page of this newsletter. We have 43 family members registered at this time, coming from many areas of the country. Future workshops are tentatively planned for: Cleveland in January, Orlando in February, Denver and Phoenix in April, Austin in May, Chicago in June, and Philadelphia in July. Again, these are tentative dates. I will keep everyone informed as plans progress.

If you plan to hold a fundraiser, please contact me for information. I will also make sure that your fundraiser is on our website and our facebook page.

Lori

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 Workshop – St. Louis

We cordially invite you to attend a

CJD Foundation Family Workshop

As our guest (no charge)

Hosted by

The Creutzfeld-Jakob Disease Foundation

Tuesday, October 23, 2012

5:30pm - 7:30pm

5:30-6:00 Casual Reception with wine & hors d'oeuvres
6:00-7:30 Presentations and Question & Answer

Dr. Beau Ances MD, PhD, Msc
Assistant Professor of Neurology with joint appointments in Neurosciences, Biomedical Engineering, and Microbiology as well as the Hope Center

Veronica Oberdorf
Chairman, Medical Education Program
The CJD Foundation

Lori Nusbaum
Associate Director, The CJD Foundation

Renaissance St. Louis Airport Hotel
9801 Natural Bridge Road
St. Louis, MO 63134
314-429-1100

Following the presentations you will have the opportunity to ask questions.

Please join us!

Please reply to lori@cjdfoundation.org or 1-800-659-1991.

There is no charge for this workshop
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 and 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 2012 through September 30, 2012 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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<tr>
<td>January</td>
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<td>February</td>
<td>20</td>
<td>15</td>
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<td>March</td>
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<tr>
<td>TOTALS</td>
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<td>91</td>
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<td>46,738</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 September 30, 2012
If you have recently moved or updated your contact information, please let us know! We want to keep information coming to you!

Reminders

★ Every time you shop online using the link below, a percentage of each purchase goes to The CJD Foundation. Here are just a few of the many retailers: Target, Amazon, Walmart, Home Depot, Expedia, Staples). There is no extra cost to our supporters.


★ We have almost 1,500 “likes” on our facebook page! Please log on to www.facebook.com and search for “CJD Foundation” to find us.

Newsletter Subscription

If you are not on our email list and would like to receive our newsletter, please email help@cjdfoundation.org. Type “NEWSLETTER” in the subject line and include your first and last name in the body of the email. 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 for this newsletter, please email us at help@cjdfoundation.org.

P.O. Box 5312, Akron, Ohio 44334 ★ 330.665.5590 ★ HelpLine 1.800.659.1991
help@cjdfoundation.org ★ www.cjdfoundation.org