President’s Message

Dear friends,

In July we hosted our most successful CJD Foundation Family Conference yet. For the first time in eleven years we closed registration! We feel that the increased attendance was due to the information being more accessible through our new website rather than an increase in the number of cases. I can’t tell you how many times families told us that attending this conference changed their lives. Just knowing they were not alone and that they were able to hear about the latest science directly from those doing the work seemed to rekindle a spark and provide a measure of hope. The power point presentations are on our website, the video should be posted in the next 10 days.

We are very grateful to Dr. Pierluigi Gambetti, our Medical Director and conference partner, Lori Nusbaum, Associate Director and our volunteers Ruthie George, Veronica Oberdorf, Debbie Yobs and our Australian partners Suzanne Solvyns and David Ralston. Their help was invaluable, especially this year when we were working with a very limited staff.

During my speech at the conference I stressed the importance of our research grants program. Over the past 10 years with the help of our Scientific Advisory Committee we have awarded a total of 21 research grants. These one year human research grants are underwritten by families and by the CJD Foundation. To establish a grant and name it in memory of a loved one families pledge a total of $10,000 which can be paid out over a 4 year period. The CJD Foundation adds to each grant. This year three $40,000 research grants and one $10,000 grant were awarded. Unlike other organizations we charge no administration costs assuring that every dollar raised for research is used specifically for this purpose. To establish a grant many families combine efforts to host a fund raising event. It is also important to check with employers to see if they have a matching gifts program. Please call Lori for fund raising suggestions and further information. Our goal is to reach $250,000, a lofty one, but we know, with your help this is entirely possible. We look forward to working with you!

With Warmest Regards,

Florence
From Lori

It was so nice seeing so many of you at this year’s conference. We had about 160 people in attendance! I wish I had more time to spend with each of you. It’s a very busy time!

The PowerPoint presentations from the conference are posted on our website. They are posted in several areas:

On the homepage:
In the square labeled “Foundation Updates”
Under the “About Us” tab, under “CJD Foundation Family Conference”
Under the “Info” tab, click on “CJD Foundation Family Conference”

Let me know if you have any questions.

Lori

On Line 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. To purchase a "square":

- Go the to "Store" tab and click on "Store Items".
- Next to "Memory Quilt" click on "Add to Cart".
- Enter your text into the "Order Contents" area.
- Complete the checkout process.
- Email your photo to lori@cjdfoundation.org in a .jpg format or send it by USMAIL to:

  The CJD Foundation
  341 W. 38th Street, Suite 501
  New York, NY 10018

Once your memorial has been added to the website, you will be notified by email.

Please consider establishing a CJD Memory Quilt square as a unique tribute. If you have any questions, call Lori at 1-800-659-1991.
Upcoming Family Fundraisers

The following fundraisers will benefit the CJD Foundation. Everyone is welcome.

For additional information please email Kathy Esposito at esposhope@comcast.net

Saturday, September 14, 2013
For additional information please email Rhonda Fansler at jrfansler43@sbcglobal.net
Golf Fundraiser

For many reasons we have decided to forego our annual golf outing this year, but are pleased to report that we have already begun working on our 2014 event.

Over the last 11 years the Aaron Kranitz Memorial Golf Outing has been our largest fundraiser, underwriting many of the CJD Foundation’s crucial projects. Each year we have been able to raise enough money in golf tournament sponsorships to assure that our programs continue without having to make any cuts. Although the event won’t be held in the traditional way this year, we hope you will still consider making a donation. The money we raise will go towards our Research Grants program, our Medical Education program and our Discretionary Fund program. Our goal is $250,000.

We plan to recognize and thank this year’s major donors by posting names and levels of support on our website. In addition, we will send email recognition to our previous year’s golf supporters and participants and follow up with a second tier of thanks in our Newsletter.

Although we are disappointed about the unforeseen series of events that led to the cancellation of this year’s golf tournament, we hope you will continue to be a generous contributor to our cause. Please follow the link below to our fundraising site to make an online donation or send your check to The CJD Foundation, 341 W. 38th Street, Suite 501, New York, NY, 10018. Thank you very much.

https://friendraising.towercare.com/Markslist/campaign/viewDetails.do?campaignId=17232

Friendraising

What does it mean to be a FriendRaiser?

We are so happy to see that many of you are utilizing our fundraising module on our website. It’s very easy to do and self explanatory. Anyone can become a “FriendRaiser” for the CJD Foundation. Just click on the “Fundraising” button on our homepage and follow the instructions. When you add your fundraising information to our website link we will create a homepage for you where you will be able to share your story, upload photos, and invite your friends, family and co-workers to support your efforts to raise money for the CJD Foundation. Through your personal homepage your friends and family will be able to register, join a team, make a donation and so much more. If you have any questions, please call Lori at 1-800-659-1991 or email lori@cjdfoundation.org. All events are subject to pre-approval by the CJD Foundation.
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 2013 through June 2013 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>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>24</td>
<td>2</td>
<td>113</td>
<td>2,886</td>
</tr>
<tr>
<td>February</td>
<td>18</td>
<td>11</td>
<td>126</td>
<td>2,968</td>
</tr>
<tr>
<td>March</td>
<td>13</td>
<td>5</td>
<td>87</td>
<td>3,316</td>
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<tr>
<td>April</td>
<td>32</td>
<td>13</td>
<td>135</td>
<td>3,872</td>
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<tr>
<td>May</td>
<td>24</td>
<td>12</td>
<td>145</td>
<td>3,690</td>
</tr>
<tr>
<td>June</td>
<td>16</td>
<td>6</td>
<td>103</td>
<td>3,583</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>127</strong></td>
<td><strong>49</strong></td>
<td><strong>709</strong></td>
<td><strong>20,315</strong></td>
</tr>
</tbody>
</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 June 30, 2013
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 2,000 “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.