President’s Message

Dear Friends,

Our Twelfth Annual CJD Foundation Family Conference, held July 11-13th in Washington D.C. (Capitol Hill visits were held on Monday, July 14th) was a success! Once again we filled the ballroom at the Washington Court Hotel and were privileged to hear about the latest research from an outstanding group of prion scientists (the presentations will be posted on our website soon). Many of our families and researchers stayed for the Capitol Hill visits on Monday. The evaluations were overwhelmingly positive proving once again that the conference and the Hill visits were gratifying and productive for everyone. Our Congressional requests can be found on our website, http://www.cjdfoundation.org/current-year.

We are extremely grateful to Mike Vitanza, a family member and CJD Foundation Board Member who, for the past six years, has sponsored an annual concert in honor of his brother Bob. We are extremely grateful to him for his efforts which cumulatively has raised over $100,000 for the CJD Foundation!

Please look at the fundraising page on our website http://friendraising.towercare.com/Markslist/site/displaySite.do?siteIdCode=EQD5WICD which allows families to set up an individual fundraiser connecting it to an event or email campaign to honor a loved ones’ memory.

Families have been sponsoring research grants in memory of a loved one since 2006. Through this project we are proud to have supported some very important prion disease research projects and to see our name appear when the papers are published and/or presented. The availability of four $50,000 CJD Foundation Family Research grants was advertised in the registration packets at the May, 2014 NeuroPrion scientific meeting in Trieste Italy, and after review by our Scientific Advisory Committee will be awarded in January, 2015. If you are interested in learning more about these grants please contact us.

Continued on page 2
President’s Message

And speaking of fundraising events, please reserve October 5th to join us for “Voices of Hope”, a concert to benefit the CJD Foundation, featuring the Young Peoples Chorus of New York City. Debbie Yobs and Mike Vitanza are co-chairmen of this event which will be held from 4pm-7pm at New York University’s Kimmel Auditorium. If you can’t join us, we hope that you will consider participating in other ways. For more information please see Lori’s article on page three.

Those of you who attended our conference know that I will be stepping down as President of the CJD Foundation on December 31st. After writing and re-writing my speech, (many times) I put my feelings into the following words:

“For the last dozen years, MY life and that of the Foundations have been bound and intertwined in the most SATISFYING of ways. This work that I love has clearly defined me and given me more than I could ever have expected or hoped for. From day one, this hasn’t been a “job” it’s been a calling. And other than the pride I feel for my own children and grandchildren, there is no greater pride I’ve ever felt in my life than what I feel for this incredible organization. On December 31st I will be stepping down as President, and once again, experiencing a huge life change… but the important difference is, this one is by choice. I know it is time and that this change is good for the Foundation as well as for me, new leadership will bring fresh ideas, new strategies and new hope.”

I am extremely happy to announce that Debbie Yobs has accepted the Board of Director’s offer to become the next CJD Foundation President. Debbie has served as Director of Marketing for a large accounting firm for many years, is a member of the CJD Foundation Board of Directors and is also a family member. I know she will be a wonderful leader and will take the CJD Foundation to the next level! Mayra Lichter, Founder and first President and I will always be available to help Debbie and the Foundation in any way possible. I plan to continue to be an active member and supporter and will look forward to seeing many of you at our concert and future conferences.

With warmest regards,

Florence

President
A Message From Lori

It was great seeing so many of you at the CJD Foundation Family Conference, and hopefully I will see you again at “Voices of Hope”, a fundraiser benefitting the CJD Foundation, at New York University’s Kimmel Auditorium in New York City on October 5th. Chairpersons Debbie Yobs and Mike Vitanza and their committee have been busy planning this event and have made it easy for everyone to be involved even if you cannot be there. We will soon have a dedicated website with all of the information, but in the meantime, here are some important details.

- If you would like to be a sponsor (i.e., flower sponsor, beverage sponsor, event sponsor, etc.) at the event, **Click here to see available sponsorships.**
- To purchase an ad in our advertising booklet **click here.** (Note: A full page ad is included with a sponsorship (above)). You can also create a memorial ad and include a picture of your loved one. Please note this on the ad form.
- We also need items for the silent auction. Space is somewhat limited, so gift certificates are a great idea. We have also set up a wish list on amazon.com. You can purchase the items already chosen on this site. Once purchased, the item is then shipped to the CJD Foundation and will be used in the silent auction. You don’t have to worry about picking the item up, delivering it or wrapping it. All you have to do is go to [http://www.amazon.com/gp/registry/wishlist/8BGK2LGVSQKIDQ/ref=cm_wl_rlist_go_v?](http://www.amazon.com/gp/registry/wishlist/8BGK2LGVSQKIDQ/ref=cm_wl_rlist_go_v?) and purchase the item! What a great (and easy!) way to contribute!
- If you are able to obtain auction items from a company or a store, here is a letter which includes our tax ID# and an explanation of the event and the CJD Foundation. You will also need to complete the Auction Donation Form.

  **Click here for "Solicit Auction Prize Donations" from Businesses**

  **Click here for the “Auction Donation Form”**

And if I haven’t lost your attention at this point….. Keep reading…

Some suggestions for items are, but not limited to:

- Airline tickets
- Vacation homes
- Sports memorabilia
- Anything signed by a musician/actor/artist/athlete/etc
- Jewelry
- Spa Items (NY area)
- Restaurant Gift Cards (NY area)
- Electronics
- Movie Passes (NY area)

We are confident that with your participation, this event will be a huge success! And as always, call me or email me lori@cjdfoundation.org if you have any questions or suggestions.

Lori
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 2014 through June 30, 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>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>21</td>
<td>7</td>
<td>146</td>
<td>3211</td>
</tr>
<tr>
<td>February</td>
<td>13</td>
<td>6</td>
<td>148</td>
<td>3838</td>
</tr>
<tr>
<td>March</td>
<td>15</td>
<td>7</td>
<td>175</td>
<td>2557</td>
</tr>
<tr>
<td>April</td>
<td>22</td>
<td>3</td>
<td>127</td>
<td>2972</td>
</tr>
<tr>
<td>May</td>
<td>17</td>
<td>6</td>
<td>127</td>
<td>3733</td>
</tr>
<tr>
<td>June</td>
<td>15</td>
<td>7</td>
<td>114</td>
<td>2558</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>103</strong></td>
<td><strong>36</strong></td>
<td><strong>837</strong></td>
<td><strong>18,869</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, 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.

Upcoming Family Fundraisers

We are so grateful to the following families for holding these fundraiser events. If you are in their areas, the families would love to have your support! To get more information, please email me at lori@cjdfoundation.org.

- Golf Outing in Memory of Marsha Snively - Saturday, August 9, 2014 - Bel Meadow Golf Club, Clarksburg, West Virginia
- Golf Outing in Memory of Marsha Snively - Sunday, September 28, 2014 - Pennsylvania
- Hunt for a Cure in Memory of Jon Fansler - Saturday, September 14, 2014 - Whispering Hope, Shelbyville, Indiana
- Espo's Night of Hope in Memory of Bobby Esposito - Saturday, November 8, 2014 - Georgetown Centre, Pittsburgh, PA
- Tom Roach—Running the Chicago Marathon in memory of Patrick Yobs—October, 2014

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

"Voices of Hope"
A Fundraiser benefiting the CJD Foundation

October 5, 2014, 4 p.m. – 7 p.m.
New York University’s Kimmel Center
60 Washington Square South
New York

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 2,300 “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

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.

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