Dear friends,

I hope you are all moving in a positive direction especially now that the calendar says spring is here (even though it hasn’t quite arrived in NYC).

We have an amazing speaker list scheduled for our 11th Annual CJD Foundation Family Conference including our 4 grant recipients. The conference is, once again, being held in Washington D.C, July 12-14, the 15th is set aside for Capitol Hill visits. Letters of invitation and registration forms were mailed on March 28th. If you didn’t receive the mailing please know all family members are welcome. You can print out the registration form on our website and send it to us either email, fax or snail mail. The conference is always a fulfilling and healing event, please try to join us.

On March 13th Dr Gambetti and I met in Washington and met with most of the members of the House Appropriations Subcommittee and Ohio Senator Sherrod Brown’s staffer to request continuation of funding for the National Prion Disease Pathology Surveillance Center (NPDPSC). This funding comes from the CDC budget but, once again, is at risk. As you all know the budget problems are especially painful this year but if the funding isn’t renewed the NPDPSC will not be able to keep its doors open. If you are willing to visit your Congressional representatives in your district and add your voice to ours please let me know.

Continued on page two
Dr Brian Appleby and I serve as members of the FDA TSE Advisory Committee. We both attended the meeting held in Rockville MD on March 14th. The meeting was called by the FDA to seek advice from the 15 Committee members on the model structure and interpretation of its draft Risk Assessment for possible transmission of vCJD from red blood cells in the U.S. Unfortunately only 2 out of 15 voted against the assumption that the low prevalence estimate was the most likely predictor of future cases of blood borne vCJD. Another FDA issue, not addressed by this committee but one we as a Foundation are concerned about relates to allowing the distal ilium to continue to be used in processed meats. This is a very important food safety issue because it has been shown that this part of the small intestine can, under certain circumstances, be infectious. The FDA has opened a rare public comment period. Please look at the information posted on our website under “Latest News and Information” and consider making your voice heard.

I send all of you my best regards and hope to see you at the Family Conference in July.

Florence Kranitz
President
From Lori

The Cleveland Family Workshop was held on January 17th and was once again a huge success. Dr. Gambetti, Director of the National Prion Disease Pathology Surveillance Center, presented to an audience of about 45 people. These workshops provide an excellent opportunity to meet other families affected by CJD, and are also a great opportunity to ask questions and hear about some of the latest research in a relaxed, small environment. Our plans to hold workshops in Florida and in Colorado are still in the works, as well as other states.

In the course of settling into our new offices in New York, we are also experiencing intermittent US Mail issues. If you mailed us your registration form for CJD 2013 and the Eleventh Annual CJD Foundation Family Conference, and did not receive an email confirmation, please call us at 1-800-659-1991.

I look forward to seeing you in Washington, DC in July, and as always, if you have any questions or concerns, please don’t hesitate to call or email me at lori@cjdfoundation.org.

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 USPS 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 Fundraiser

The following fundraiser in honor of Bob Vitanza will benefit the CJD Foundation. Everyone is welcome.

5th Annual CJD Benefit Concert in Honor of Robert (Bob) Vitanza
Saturday, June 1, 2013 8PM

Featuring Musical Performances by

Simple Jim
(with Mike Vitanza)
11-Close

Bad Boy
10-11PM

sPUNK!
9-10PM

T-shirts, raffles, etc.

Captain's Cove Seaport
1 Bostwick Avenue
Bridgeport, CT 06605

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 March 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>2886</td>
</tr>
<tr>
<td>February</td>
<td>18</td>
<td>11</td>
<td>126</td>
<td>2968</td>
</tr>
<tr>
<td>March</td>
<td>13</td>
<td>5</td>
<td>87</td>
<td>3316</td>
</tr>
<tr>
<td>TOTALS</td>
<td>55</td>
<td>18</td>
<td>326</td>
<td>9170</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 March 31, 2013
CJD 2013 and the 11th Annual CJD Foundation Family Conference

The Creutzfeldt-Jakob Disease Foundation and The National Prion Disease Pathology Surveillance Center cordially invite you to attend *CJD 2013 and the Eleventh Annual CJD Foundation Family Conference*, July 12-14, 2013, to be held at the Washington Court Hotel, Washington, D.C. Capitol Hill visits will be scheduled on July 15th.

The highlights of the conference include the opportunity to:

- Meet other families affected by a prion disease
- Attend workshops
- Learn about the latest prion disease research directly from the researchers
- Hear about the work of support organizations around the globe from the leaders of these organizations
- Participate in Capitol Hill advocacy visits

We strongly encourage you to stay and participate in Capitol Hill advocacy visits on Monday, July 15th. This unique opportunity to meet with your elected representatives will be organized for you by the CJD Foundation. We will also provide advocacy training and equip you with materials to share. This is your chance to tell your personal story, educate your representatives about CJD and draw attention to the issues all of us care about. You will gain a better understanding of how our government works and the true sense that together we can make a difference.

The registration fee covers all conference sessions and materials, the Bereavement Workshop on Friday, the casual welcome reception Friday evening, a continental breakfast and lunch on Saturday and Sunday and the banquet Saturday evening. Please mail or fax your registration with payment as soon as possible, as in previous years, we expect a full turnout.

We are again offering the opportunity for an individual or a group to sponsor a meal or coffee break. You will find this information on the tri-fold. Please call us if you have questions.

Hotel reservations must be made separately with the Washington Court Hotel by calling 202.628.2100. Our special conference rates are available on a first-come, first-served basis. Be sure to inform the Washington Court Hotel that you are with the CJD Foundation when making your reservation. If you choose a different hotel you will still be required to register for the conference.

We look forward to seeing you at this very special event and feel confident you will find the conference both valuable and healing.

Sincerely,

Florence Kranitz, President, CJD Foundation

Pierluigi Gambetti, Director, NPDPSC


help@cjdfoundation.org ★ www.cjdfoundation.org
Save the date

The 12th Annual Aaron Kranitz Memorial Golf Tournament
Tuesday, August 13, 2013
Firestone Country Club
North Course
Akron, Ohio
Conference Information

Please visit our website for more information
www.cjdfoundation.org
or call us at 1-800-659-1991

CJD 2013 and the 11th Annual CJD Foundation
Family Conference

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 over 1,700 “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.

help@cjdfoundation.org ★ www.cjdfoundation.org