President’s Message

Dear Friends,

As the end of the year approaches I am amazed at the changes that have occurred since last January. Our move to NY is, as we expected, proving to be very positive. The Akron and NY staff have meshed almost seamlessly, instead of talking to each other in person we are constantly communicating through intercom. In 2013 we sponsored a total of 14 educational meetings including Grand Rounds, Infection control Seminars, and Family Workshops. We are very grateful to Beth Nivin from the New York City Department of Health for helping us plan seven Grand Round meetings and one Infection Control seminar in NYC, Jeannie Druckenmiller from the Wisconsin Department of Health for her help with the Wisconsin Grand Round meeting and Family Workshop in Madison, WI. Exciting plans are underway for 2014, including increased medical education seminars and Family Workshops around the country, the introduction of our first NYC signature event scheduled for next fall featuring a concert by the Young Peoples Chorus of New York City directed by family member Jim Papoulis and his lyricist and marketing director Mike Greenly and, of course our 12th Annual CJD Foundation Family Conference.

I want to offer my sincerest gratitude to our devoted and hardworking staff. Associate Director Lori Nusbaum who, in addition to her other numerous duties, continues to oversee the growing number of family fundraising events (please check the Fundraising link on our website-you, the families, are doing an incredible job!!) and to plan and coordinate the medical meetings and Family Workshops around the country. Melany Pritchard, our new Office Manager, is quickly learning the many diverse tasks that come with the job and is a pleasure to work with and we are very happy to welcome our “new” bookkeeper, Wanda Culp-Lias who is starting her 10th year with the CJD foundation but in a different role! Wanda rejoined our team two months ago as our bookkeeper and is doing her usual outstanding job.

Continued on page 2
President’s Message

On behalf of The CJD Foundation, I want to express our heartfelt gratitude to our Medical Director Dr. Pierluigi Gambetti who, over the years, has been our mentor and advisor and has made himself available whenever we need him. His kindness, support and friendship have helped us grow in ways that wouldn’t have been possible to imagine! We also owe a debt of gratitude to his hard working staff Andrea Webb, Katie Glisic, Danielle Jordan, Jeff Negrey and Janis Blevins. When our families need kindness the most, they are there to help.

Without the generous grant we receive from the Centers for Disease Control and Prevention (CDC) our programs would either have to be severely cut back or completely eliminated, and without Dr. Lawrence Schonberger and Dr. Ermias Belay this grant would not be possible. We are deeply grateful to them and our friends at the CDC for believing in us and our work and in turn allowing us to help you, our families.

Our Officers and Board of Directors are an inspirational group. Following the example set by Mark Goldfarb, Chairman of the Board, each member takes their role very seriously making sure our work continues to follow the high standards set by Founders Mayra Lichter and Cele Sardo. We participated in our first Board Retreat in October. It was led by an outstanding expert, Marty Coyne, who helped us to look at where we are today, where we want to be in a year’s time and in the future, and how to implement the steps needed to achieve new goals.

There are so many others “behind the scenes” without whom my work as President would, at times, be very difficult. I wish there was space to tell you more about the people who are always there to help but it would take up the entire newsletter! We are a very fortunate and grateful organization.

2014 Family Conference
Our twelfth Annual CJD Foundation Family Conference will be held July 11-14th, once again at the Washington Court Hotel in Washington, D.C. Conference information and registration will be sent out in late March, but mark your calendars now so you can participate in the very special event.

Annual Fund
We are very grateful to those of you who have already contributed to our Annual Fund. Thus far we have raised over $21,000 which will be used to help underwrite our crucial programs and to provide help for families in need financial assistance with a medical or funeral bill. If you haven’t already done so please consider supporting our work though an Annual Fund donation.

Continued on page 3
President’s Message

Research
The opportunity to fund a research grant in memory or honor of a loved one is, for many families, a unique way to be a part of the solution. 2014 will mark the tenth year we have offered family supported grants to researchers conducting new human prion disease research. Each grant stipulates that recipients complete their work in one year and submit reports at six months and at one year. We have been privileged to have helped fund groundbreaking projects which are, in turn, leading to important new discoveries. Each year the CJD Foundation grant recipients are invited to discuss their work at our Family Conference in July. If you are interested in information about establishing a grant, please contact me or Lori for more information.

All in all, considering the huge changes, we are finishing the year on a strong financial and organizational footing.

On behalf of the CJD Foundation, I wish each of you a peace filled holiday season hope that the New Year, no matter where you are in your journey, brings you further healing surrounded by the love of your family and friends and that the memory of your loved one brings you strength and inspires your life.

With warmest personal regards,

Florence
Letter from Dr. Gambetti

Dear Families and Friends,

The theme that continually stands out as we reflect upon the year is our deep appreciation of the family members and their dedication and devotion to the care of their affected loved ones and consent to autopsy allowing for a confirmed diagnosis. Our gratitude towards the CJD Foundation for all their support to the families affected by this disease is boundless. We are very grateful to all the family members and friends who rally to promote fundraising for the continued success of the Center’s surveillance and research efforts in these economically trying times. Finally, we want to extend our gratitude for the kind words expressed to us by the families to whom we have been able to give closure by providing the answers they need during a very difficult time.

Other major accomplishments in 2013 include maintaining the budget appropriation for prion disease by the US Congress, improving the diagnostic capabilities of CJD, and maintaining a high percentage of cases examined as compared to cases expected. Furthermore, we have developed and expect to introduce soon the new CSF test RT-QuIC (Real Time Quaking –Induced Conversion). RT-QuIC has a high sensitivity, therefore when positive allows for the definite diagnosis of CJD. We are excited and proud of these accomplishments and hope to carry the momentum forward to 2014.

As always, we look forward to the Foundation conference where we have the privilege of meeting so many families and sharing the podium with the most prestigious prion researchers in the world. In closing, all of us at the National Prion Disease Pathology Surveillance Center in Cleveland Ohio send you our best wishes for a happy and healthy 2014.

Sincerely,
Pierluigi Gambetti MD
Director, NPDPSC
A Message From Lori

Two family workshops are scheduled for the coming year. The first in Pittsburgh, Pennsylvania on January 15th, and the second on April 2nd in Austin, Texas. We are honored that Dr. Paul Brown will be joining us at the Pittsburgh workshop and will participate in the question and answer session. The invitation to the Pittsburgh workshop is on the next page. I hope to see many of you there. I will be making arrangements to hold workshops in other cities as well, and will keep you informed. Feedback is always appreciated - whether it be by phone, email, our website or Facebook.

The FriendRaising page on our website is quite active. This year families have raised a total of over $165,000 using our FriendRaising site. You are all doing an excellent job! Please let me know if you have any questions or need help starting a page.

Have a Wonderful Holiday and a Happy New Year,

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.
Pittsburgh, Pennsylvania

We cordially invite you to attend a free 
CJD Foundation Family Workshop

Hosted by
The Creutzfeldt-Jakob Disease Foundation

Wednesday, January 15, 2014
5:30pm - 7:30pm
5:30 - 6:00 Reception
6:00 - 7:30 Presentation and Q&A

Deana Simpson, RN
St. John Providence Health System

Lori Nusbaum
Associate Director, The CJD Foundation

Springhill Suites Pittsburgh Airport
239 Summit Park Drive
Pittsburgh, PA 15275

We hope you can join us!

Please reply by January 8th to lori@cjdfoundation.org or call us at 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 2013 through November 30, 2013 are below:

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<th>MONTH</th>
<th>NEW CASES REPORTED</th>
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<th>TOTAL HL CONTACTS</th>
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<td>2</td>
<td>113</td>
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<td>15</td>
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<td>March</td>
<td>12</td>
<td>5</td>
<td>87</td>
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<td>April</td>
<td>32</td>
<td>13</td>
<td>135</td>
<td>3,872</td>
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<td>May</td>
<td>24</td>
<td>12</td>
<td>145</td>
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<td>June</td>
<td>16</td>
<td>7</td>
<td>103</td>
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<td>23</td>
<td>8</td>
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<td>22</td>
<td>13</td>
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<td>18</td>
<td>3</td>
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<td><strong>TOTALS</strong></td>
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<td><strong>93</strong></td>
<td><strong>1,310</strong></td>
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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 November 30, 2013
Annual Fund Donors

As of December 10th the CJD Foundation’s Annual Fund Campaign has received over $21,000. (we will publish the entire list in our February Newsletter.) Thank you to the following donors for their generous contributions.

Abraham, Rochelle and Rhonda
Albers, Kirsten
Bacchetti, Bruna J.
Bach, Robert and Karen
Batten, Vernon and Carolyn
Beard, Bonita
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Karnman, Mitchell
Kelley, Anne
Kline, Katrina
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Lang, Suzanne
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Livreri, Gerald and Francine
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Lovelace, Barbara
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Manchess, Eileen
Mandina, Kathleen
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Martin, Mary Ann
Matthews, Wendy and Roy
Maxen, James and Charlene
McCarthy, Bob
McCarry, James
McMullen, Jane
Milano, Evelyn
Miller, Aimee
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### Annual Fund Donors

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Save The Date

CJD 2014 and the 12th Annual CJD Foundation Family Conference

Washington Court Hotel
Washington, DC
July 11-14, 2014

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 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.

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help@cjdfoundation.org ★ www.cjdfoundation.org