President’s Message

Dear Friends,

This message brings you news of some exciting developments at the CJD Foundation. Traditionally my year-end message gives you an overview of our projects, but I've been updating you all year ... and now we've got some brand new topics to talk about!

The first will be the launch of our new website…finally…almost! We've been working with a web designer for over a year. Lori Nusbaum -- our Associate Director who's been supervising this major project -- is doing her usual excellent job. The new website will let us easily add and edit our pages, which will make the site more timely and up-to-the-minute. The design looks somewhat different but all of the features of our old website are still smoothly included, especially the Guestbook. We are excited to share the new site with you and look forward to your comments. We are deeply grateful to Dr. Lawrence Schonberger and Dr. Ermias Belay of the Centers of Disease Control and Prevention for their continuing support and belief in us. They were instrumental in our having secured the critical CDC grant, which among other things, funded this project.

The second big event to share with you is our move to New York City. My own personal move was completed in late October; the Foundation’s should be completed in the next few weeks. As you can imagine, this has been a very busy time! But thanks to our hard-working staff, we've been able to make the transition practically seamless thus far. I am most grateful to all of them and to our Board of Directors for their support of our move and their continued dedication to the Foundation. Difficult as it is to say goodbye to Wanda and Nancy, Lori and I and the Board of Directors are very excited about all the new opportunities ahead.

Continued on page 2
Our third piece of "news" happened very recently in the form of an unusual proposal. The CJD Foundation was contacted by one of our family members and his songwriting partner who offered us a portion of the royalties from an original piece of music. “I Know,” a song of hope and inspiration, was written by internationally known choral music composer, conductor and humanitarian Jim Papoulis and BILLBOARD-charted lyricist Mike Greenly. It has just been published in memory of Jim’s wife Stephanie Martine Papoulis, who died tragically in 2007 at the age of 45 from CJD.

The song is performed by the Young People's Chorus of NYC -- an extraordinary group of multicultural young singers whose lives are positively transformed by being a part of it ... even as they earn awards for artistry around the world. The sheet music will be released in the spring.

Limited quantities of the CD are available for $10.00, which is tax deductible, and includes shipping and handling. This CD is a special limited edition just for us and will never be made available for retail sale to the general public. Please call us at 1-800-659-1991 if you would like to order a copy, or visit our website at www.cjdfoundation.org. You can also purchase it as a download music file on itunes.com https://itunes.apple.com/us/album/id586794802 or amazon.com http://tinyurl.com/d68htxq.

We are also privileged to make “I Know” available to you in a one-time only collectible edition. Each CD jacket is personally autographed by the song’s creators, Jim and Mike, with only 100 copies ever to be created. As long as our finite supply lasts, these hand-signed CDs are available for $25.00, which is also tax deductible and includes shipping and handling. Once these are depleted they will never be available again. These special edition CDs can be ordered by calling us or through our website store.

“I Know” is one of the most moving and beautifully sung pieces of music you will ever hear (I promise!). Knowing that it was written by someone experiencing the same pain we all have felt or are currently feeling, makes it in many ways, a song written and sung specifically for us. We hope you will listen to the clip through the link available on our Facebook page and choose to purchase or download a copy.

Although I try to say thank you to all of our supporters during the year I want to extend special appreciation to our Medical Director, Dr. Pierluigi Gambetti for his continuing dedication to us, to our work and to our families. No matter how busy his schedule, he is always available to offer help and insight whenever we ask. We also thank his staff -- Andrea, Katie, Danielle, Jeff, Janis and Natalie -- for their hard work and kindness at those very difficult and emotional times for our families.

Continued on page 3
Many of you have been part of our CJD Foundation family for a long time, and some have joined us very recently. We truly understand how difficult life is right now for our new members but we want you to know that most of us have walked in your shoes. We’ve left glowing lamps on the path for you and want you to know that, although the personal journey is yours, we are here to offer a hand to steady you at any time. We at the CJD Foundation, especially Veronica Oberdorf and Lori Nusbaum (who take turns volunteering with me on the HelpLine 365 days a year) continue to extend our hands and hearts to you for as long as you need us. On behalf of our CJD Foundation family, we send our most sincere wishes to all of you no matter where you are in your journey for a healing and peace filled New Year.

In my thank you letter to our Board of Directors of a few days ago, I said that for those of us who have lost a loved one to a prion disease, there is always a huge hole in our hearts ... but at this time of year, that hole seems to grow. I am keenly aware that each one of you came into my life because of that hole in my heart, so I thank you for being part of my personal “lemonade”.

In closing, I would like to add the anonymous reflection below. It was sent to me by Deana Simpson, one of our Board members and Director of CJD Insight, an organization formed to help those affected by familial CJD. These words express my personal sentiments exactly.

\[
\begin{align*}
I & \text{ want to say something to all of you} \\
& \text{who have become a part} \\
& \text{of the fabric of my life.} \\

\text{The color and texture} \\
& \text{which you have brought into my being} \\
& \text{have become a song,} \\
& \text{and I want to sing it forever.} \\

\text{There is an energy in us} \\
& \text{which makes things happen} \\
& \text{when the paths of other persons touch ours} \\
& \text{and we have to be there and let it happen.} \\

\text{When the time of our particular sunset comes} \\
& \text{our thing, our accomplishment,} \\
& \text{won’t matter a great deal.} \\

\text{But the clarity and care} \\
& \text{with which we have loved others} \\
& \text{will speak with vitality of the great gift of life} \\
& \text{we have been for each other.}
\end{align*}
\]

\(\text{(Author unknown)}\)
Dear Families and Friends,

As we close another year of activity all the members of the National Prion Disease Pathology Surveillance Center join me in extending the most heartfelt condolences to all the families who lost a loved one to prion diseases or related conditions. We know that you have been through tremendous pain. Unfortunately, the Center continues to have limited answers for patient’s families during the life of the patient. We hope the definitive detailed diagnosis following autopsy and tissue examination may have brought some sense of closure.

We are very grateful to all those families who have chosen to participate in our Autopsy Program. This program also provides much needed tissue and body fluids to our research as well as research pursued in several major laboratories in the U.S.A. and around the world. During 2012, tissues have been provided to eight laboratories for research which includes experimental drug treatment and early diagnostic testing.

The end of another year of activity offers the opportunity to reflect on the accomplishments and challenges of the past year as well as on the goals to be set for 2013. The Center’s major accomplishment of 2012 has been maintaining a high percentage of autopsies in cases of clinically suspected Creutzfeldt-Jakob disease (CJD) and other prion diseases in spite of continuous budget reduction. Maintaining the same percentage through 2013 will unquestionably be the biggest challenge. In spite of the reduced budget, we decided not to limit the number of autopsies performed by the Center at the beginning of the current fiscal year hoping that donations in support of the autopsy program will maintain the rate undiminished throughout the year. We are deeply grateful to those families who helped to fulfill this goal during 2012. Furthermore, in 2013 the Center will continue to work toward improving the diagnostic capabilities of CJD based on CSF examination. Limited but vital funding has been obtained toward this goal.

Another major challenge for 2013 will be to maintain the budget appropriation for prion disease by the US Congress. As soon as Congress is back to a normal schedule, Florence Kranitz, the President of the CJD Foundation and I will visit Congress to emphasize the need to support – albeit inevitably at a reduced budget – this vital program. We will keep you apprised of future developments, and continue to count on your continuous advocacy with your local Members of Congress regarding FY 2014 budget appropriation.

I close with the hope that 2013 will bring the much needed progress in early diagnosis and treatment, the two major issues that need to be solved before prion and other dementing illnesses can be defeated.

Also on behalf of all the members of the Center I send you our best wishes for a healthy and happy 2013!

Pierluigi Gambetti MD
Director, NPDPSC
As the new year begins, I will begin planning our future Family Workshops. These Workshops have been very successful and very well received. The workshops are get-togethers where family members have a chance to meet each other and also have the opportunity to hear about the latest research and ask questions in a very intimate setting. The next workshop is going to be in Cleveland, Ohio on January 17th. (See the invitation on the next page). Our Family Workshop in St. Louis, MO this past October had 60 participants! Some of the places we plan to visit in the future are Miami, Phoenix, Chicago, Austin, Philadelphia, New York to name a few. Veronica and I look forward to meeting you!

I am also very excited about our new website. All of the information will stay the same, but behind the scenes we will have more control of the site so that you stay well-informed more efficiently. Our launch is happening as I type this.

Also please plan to join us for **2013 and the 11th Annual CJD Foundation Family Conference** to be held July 12-15, 2013. Please save the date. Invitations will go out in March, and we hope to see you in Washington, DC.

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**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 - Cleveland, Ohio

We cordially invite you to attend a
CJD Foundation Family Workshop
As our guest (no charge)

Hosted by
The Creutzfeld-Jakob Disease Foundation

Thursday, January 17th, 2013
5:30pm - 7:30pm
5:30-6:00 Casual Reception
6:00-7:30 Presentations and Question & Answer

Dr. Pierluigi Gambetti
Director of the National Prion Disease Pathology Surveillance Center

Dr. Brian Appleby
Lou Ruvo Center for Brain Health, Neurological Institute
Cleveland Clinic Foundation

Florence Kranitz
President, The CJD Foundation

Lori Nusbaum
Associate Director, The CJD Foundation

InterContinental Hotel Cleveland
9801 Carnegie Avenue
Cleveland, OH 44106
216-707-4169

Following the presentations you will have the opportunity to ask questions.
We hope you will join us!

Please reply by January 9th 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 2012 through December 31, 2012 are below:

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<th>MONTH</th>
<th>NEW CASES REPORTED</th>
<th>DEATHS REPORTED</th>
<th>TOTAL HL CONTACTS</th>
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<td>December</td>
<td>10</td>
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<td><strong>TOTALS</strong></td>
<td><strong>208</strong></td>
<td><strong>120</strong></td>
<td><strong>1577</strong></td>
<td><strong>58,845</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 December 31, 2012
Annual Fund Donors

To date, the CJD Foundation’s Annual Fund Campaign has received over $55,000. Thank you to the following donors for their generous contributions.

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P.O. Box 5312, Akron, Ohio 44334 ★ 330.665.5590 ★ HelpLine 1.800.659.1991
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Save The Date

CJD 2013 and the 11\textsuperscript{th} Annual CJD Foundation Family Conference

Washington Court Hotel
Washington, DC
July 12 -15, 2013

Reminders

\textbullet \quad \textbf{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.

\url{http://www.givebackamerica.com/charity.php?b=1018}

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Comments/Suggestions

If you have any comments or suggestions for this newsletter, please email us at help@cjdfoundation.org.

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