



Creutzfeldt-Jakob Disease  
Foundation, Inc.

# The CJD Foundation Newsletter

DECEMBER 2010

VOLUME 6, ISSUE 4

## President's Message

Dear Friends,

On behalf of The CJD Foundation Board of Directors and Lori, Wanda, Nancy and Michelle, I wish each one of you a most peaceful, meaningful holiday season and a very healing year ahead.

We have had a very busy and productive year. Below is a brief overview of highlights of work in 2010 and some of the plans in place for 2011.

- Our grant from the Centers for Disease Control and Prevention was not only renewed but increased for the next five years! We are extremely grateful to Dr. Lawrence Schonberger and Dr. Ermias Belay for their continued belief in our work and in us, without them this grant and the programs it underwrites would not be possible.
- In 2010 we awarded four research grants, three \$20,000 awards and one GSS research grant for \$10,000. In January 2011 we will be awarding three new grants and have increased award amounts of each to \$40,000. The families of Paula Smart, David and Peter DeMaggio, Bryant Welch and Carlton Wilson have each contributed \$10,000 and the CJD Foundation will underwrite the remaining amount. We advertised the grants and received thirty nine Letters of Intent from all over the globe, each of them worthy of funding making it very challenging for our Scientific Advisory Committee to choose only nine finalists to submit their application. The committee will notify us of their three selections on January 15<sup>th</sup>.

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- In October we implemented two new programs, a Medical education program chaired by Veronica Oberdorf, a registered nurse and educator, and a Funeral Director and Embalmers education program chaired by Bob and Marie Kassai. Bob is a funeral director and embalmer and a past member of the Board of Directors of the New Jersey Funeral Directors Association, Marie is an Infection Control nurse who helped write prion disease infection control guidelines for the World Health Organization.
- With the renewal of the Homer Foundation Family Grant we can continue our Questionnaire project with the goal of publishing the results in the very near future.
- CJD 2010 and the Eighth Annual CJD Foundation Family Conference held this past July exceeded our expectations! We are honored, once again, to be working with the most amazing group of partners. We have already had our first planning meeting with Dr. Pierluigi Gambetti, Dr. Neil Cashman, Dr. Michelle Wong and Janie Toth. CJD 2011 and The Ninth Annual CJD Foundation Family conference will be held July 8-11<sup>th</sup> in Washington, D.C. Please mark your calendars. Although I say this every year (but it always seems to be true) this one promises to be our best one yet! Letters with registration information will be mailed to everyone in our database in early March.
- The CJD International Support Alliance continues to work together and to speak out on issues affecting prion disease patients and those at risk all over the world. Presently our membership consists of representatives from Australia, France, Israel, Italy, Japan, the United Kingdom and the United States. This year many of us met in person in Australia, Austria and Washington, D.C. We also meet monthly via teleconference.
- We will be participating in the Consumer Federation of America's food policy committee again this year.
- We recently installed a new database which, while testing our patience and computer skills, promises to be of huge benefit. It will allow us to merge our bookkeeping program, our patient and donor databases and utilize a time saving mail merge program.

I extend my personal gratitude to the CJD Foundation Board of Directors who not only take great interest in our work but also care deeply. We are truly fortunate to have Board members who give of themselves and offer to help not only when asked, but also volunteer their services whenever they see the need. My thanks as well to Lori Nusbaum our Associate Director for her excellent work and dedication and to Wanda, Nancy and Michelle our outstanding support staff.

The CJD Foundation continues to be immensely grateful to our Medical Director Dr. Pierluigi Gambetti. He is always willing to offer valuable help and advice no matter how busy his schedule may be. His staff, Sally, Danielle, Jeff and Katie reflect his philosophy and his kindness to us and our families.

*Continued on page 3*

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Once again, I extend my heartfelt wishes for peace and healing to each one of you. In closing, I quote from one of my favorite poems written by E.E. Cummings. It has very special meaning to me, especially at this time of year, and I hope it will to you as well.

“I carry your heart with me (I carry it in my heart)

I am never without it...

And here is the deepest secret nobody knows

(here is the root of the root and the bud of the bud

And the sky of the sky of a tree called life which grows

Higher than the soul can hope or mind can hide)

And this is the wonder that's keeping the stars apart

I carry your heart (I carry it in my heart)”

With My Warmest Regards,

*Florence*

### Letter from Dr. Gambetti

Dear Families and Friends,

The theme that continually stands out as we reflect upon the year is gratitude and appreciation. We deeply appreciate the dedication of those families who devote themselves to the care of their affected loved ones and to ensure that proper diagnosis is achieved by consenting to autopsy. 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.

2010 has been an exciting year in research as it has been shown in the scientific presentations at the Eighth Annual CJD Foundation Family Conference in Washington, D.C. this past July. The opportunity of meeting many of the family members was, as always, inspiring to all of us involved in research and surveillance. We look forward to interacting with all the family members at the next conference in July 2011.

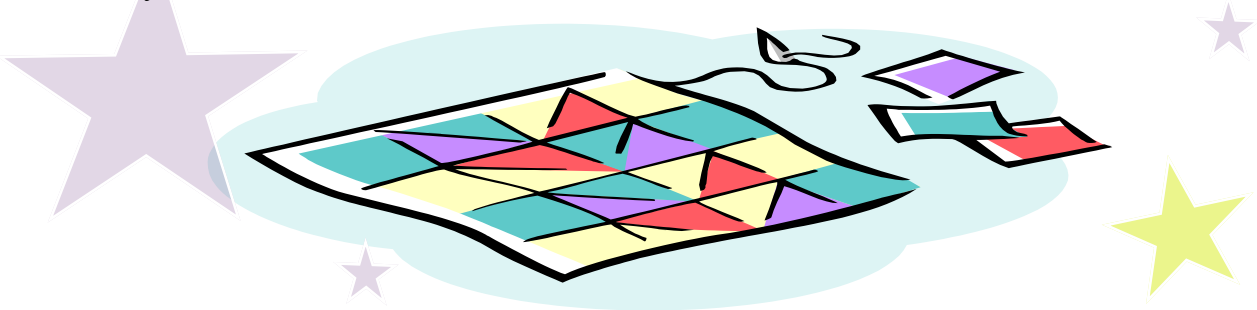
On behalf of the Center I send you our gratitude for all your support and best wishes for the incoming holidays and for a bright new year!

Pierluigi Gambetti

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## Notes From Lori's Desk.....

- ★ The Memory Quilt provides an opportunity to honor or memorialize a loved one or a friend. The purchase of a "square" on the quilt allows you to place a photograph and tribute which will then be permanently posted on our website. You can access the Memory Quilt through the following link: <http://www.cjdfoundation.org/memorial.html>. If you have any questions, please contact us at [help@cjdfoundation.org](mailto:help@cjdfoundation.org) or 1-800-659-1991.
- ★ Remember to keep the fun in *fundraising*! Email me at [lori@cjdfoundation.org](mailto:lori@cjdfoundation.org) to get started.
- ★ Minor Glitch in Guestbook - When posting to the Guestbook on our website, you need to type your message into Microsoft Word (or your favorite word processor) *without* apostrophes, then copy and paste your message into the guestbook. Our webmaster is working on this problem! We are sorry for the inconvenience!



## HelpLine Statistics

The CJD Foundation's largest ongoing project is our toll-free HelpLine (1-800-659-1991 or [help@cjdfoundation.org](mailto: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, medical professionals, funeral directors and embalmers, the general public, the press and the media. To the right you will find HelpLine statistics for January 2010 through November 2010.

*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.*

2010				
MONTH	NEW CASES REPORTED	DEATHS REPORTED	TOTAL HL CONTACTS	UNIQUE WEBSITE VISITORS
January	28	19	126	3996
February	23	22	132	4313
March	20	23	145	4816
April	15	19	76	5233
May	18	19	106	4711
June	21	13	23	3031
July	26	14	88	4142
August	16	21	60	4382
September	24	13	82	4097
October	29	16	95	5285
November	15	6	99	4915
<b>TOTALS =</b>	<b>235</b>	<b>185</b>	<b>1,032</b>	<b>48,921</b>

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## 2010 Family Fundraising Events

*We are grateful to these families for holding a fundraising event and donating the proceeds to the CJD Foundation. These generous donations are one more reason we can continue to support those who turn to us each day for help.*

- ★ A concert in memory of Bob Vitanza, organized by Mike Vitanza with the help of many friends.
- ★ The 3<sup>rd</sup> Annual Footwork for CJD in Memory of Marsha Snively, organized by the Snively Family.
- ★ The 3<sup>rd</sup> Annual John A. Lanciotti Memorial Golf Outing, organized by the Lanciotti Family.
- ★ The 3<sup>rd</sup> Annual Don Heestand Memorial Golf Outing, organized by family and friends of Don Heestand.
- ★ Golf Tournament in memory of Lionel Edgar Laplante Jr., Sponsored by Chelo's Restaurants, Inc.
- ★ Snaggletail Book Sales, in memory of Dovie St. Peters.
- ★ Nancy Schepis Mallon Golf Outing, organized by Stephen Mallon.
- ★ Hannah's Hope for a Cure, organized by Hannah Carlson, Age 10, in memory of her grandfather, Richard Carlson
- ★ Manausa Fundraiser, in memory of Gary Manausa.
- ★ Ongoing fundraising by Mary Lou Jubin, in memory of her sister Eileen Sears.

### Conference Update

*The CJD Foundation Family Conference 2011 will be held July 8 - 11, 2011 at the Washington Court Hotel in Washington, D.C. Advocacy Day on Capitol Hill will be on Monday, July 11<sup>th</sup> for interested families. We are delighted to report that this will be our fourth consecutive conference held in partnership with the National Prion Disease Pathology Surveillance Center and PrionNet Canada. The conference will, once again, feature speakers from around the world. Further details will be provided in the coming weeks on our website and Facebook page! Letters and registration information will be mailed in early March.*

## Annual Fund Donors

To date, the CJD Foundation's Annual Fund Campaign has collected a total of \$46,205.00! Thank you to the following donors for their generous contributions.

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## Acknowledgements

No matter what language you speak, the



message from us is clear!!!

Thank you to our many



ありがとうございます Families, friends and



volunteers!



## Comments/Suggestions

If you have any comments or suggestions for this newsletter, please email us at [help@cjdfoundation.org](mailto:help@cjdfoundation.org).

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