



Creutzfeldt-Jakob Disease
Foundation, Inc.

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A Message from Florence

I want to send my most sincere and heartfelt wishes to each of our family members for peace and healing. I know how difficult the holidays can be for those of us who have been touched by this tragic disease, and I hope that each of you will be surrounded by supportive and loving family and friends. Please know that you, both old and new friends, have carved out a special place in the hearts of each of us at the CJD Foundation. You make our daily work more worthwhile than you can ever imagine.

And to everyone, families and friends alike, I hope 2009 brings each of you a sense of renewal, contentment and good health. Without our partner patient/family advocacy organizations around the world, our researchers, and our devoted friends at the National Prion Disease Pathology Surveillance Center, the Centers for Disease Control and Prevention, the FDA, and PrioNet Canada, we could not even begin to accomplish our important work. Our gratitude and sincerest thanks to all of you, and again, my best wishes for a meaningful holiday season.

My warmest regards,

Florence



From Dr. Gambetti

As this year comes to an end, I want to take the time, on behalf of the National Prion Disease Pathology Surveillance Center and personally, to honor those whose lives have been affected by CJD. The fierce dedication of many, many families and the uncompromising commitment of the CJD Foundation continue to inspire us at the Surveillance Center to work as fervently as we can to provide quick and accurate diagnoses with the hope that it will bring closure to a very painful process. And it is for all of those who suffered because of these diseases that we, among other scientists around the world, carry on the fight for early detection and treatment.

Many of you were able to get a first look at some of this research at the CJD Conference in Washington, D.C., this past July. It was a humbling experience to personally meet many of the family members and friends that our Center staff helped over the phone. It was inspiring to see everyone come together as a community at that conference and we thank you all for your courage and spirit.

My most sincere wishes,

Pierluigi Gambetti



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Tragic Loss: A Key to Personal Growth and Resilience

By: Regan MacBain Traub, CPC, SPHR

A profound journey for me began in August of 2003. It has endured more than five years later. Losing my husband to Creutzfeldt Jakob Disease (CJD), only 3 years after we married and only two months after the first symptoms appeared, detonated my entire world. It also brought me more than I could have possibly imagined in invaluable insight, knowledge and skills for my life, as well as in my work to guide people and businesses to go forward through their challenges.

After four decades of searching for the love of my life, I met Carl in 1986. After twelve years of friendship and four years of dating, we made the leap of faith into marriage. We were continuously intertwined and alongside each other 24/7 – by mutual choice. I saw his existence in my life as far exceeding my dreams of what happiness could possibly be.

With the undeniable news that I could not save the love of my life, six weeks into the onset of this incurable disease which was devouring my husband's brain at lightning speed, and only two weeks before I would ultimately lose his physical being, my sense of reality and blissful marriage was exploding. I had lost the most important battle I had ever fought – no reprieve, no remission, no choice.

While lamenting my plight as a choice-less victim, a simple concept crystallized in my mind. I did have a choice – in fact, a very important choice. I could choose how my husband would be able to live his last days and we would spend our last days together. This concept charted a path down which I would find comfort – I could do something that was meaningful, do it well, and keep me from falling apart being little or no help to the man who meant more to me than my own life. I vowed that during our remaining days, to the best of my ability, I would ensure that Carl would consistently feel loved, live without pain, maintain his dignity, and be surrounded by that which he loved. In those few moments, I began using a practice that ultimately became a key to my survival and healing, then teaching others to be resilient and withstand the challenges that life deals into our hands.

- Whenever you feel choice-less, remember there are *always* choices - look for, and make them, with courage;
- Returning to a state of choiceful-ness (from a sense of choiceless-ness) is a process by which enlightenment and resilience develops; and
- The act of “choosing” contributes heavily to restoring one's personal dignity and confidence in the face of heart-breaking challenge while enabling clear thinking and sound judgment with a path down which to proceed.

I have always believed that life is meant to present us with many challenges for us to face, from which to grow. For it is not *what* we face but the *way in which we face* those challenges that defines us. When facing tragic loss, our role as survivor may include:

- Keeping our loved one's memory and meaning alive;
- Living in a way which would make our loved one proud - look for special qualities/lessons/values that he/she would have wanted you to embrace and live them to the extent to which they are true for you;
- Exploring how the experience of their loss has enriched your life and personal perspective; and
- When sought by others, sharing your insights to help others feel supported and not alone. Knowing that someone else has survived a significant loss and has found a way to live happily and productively after loss, can provide needed hope for someone that the overwhelming sense of loss will dissipate in time and that someday, they too can become happy once again.

While experiencing and healing from a horrific tragedy, it is hard to begin to imagine ever being able to be whole again, much less, a better person for it. Five years later, I am stronger, wiser, and more resilient. I only hope that some of which I have learned will someday inspire and benefit others to move forward in life, appreciating and learning from gifts of the past in order to be ready to receive the special gifts of the future.



P.O. Box 5312, Akron, Ohio 44334 ★ 330.665.5590 ★ HelpLine 1.800.659.1991 ★ help@cjdfoundation.org

www.cjdfoundation.org

CJD 2009 and the CJD Foundation Family Conference Update

The CJD Foundation will, once again, partner with The National Prion Disease Pathology Surveillance Center and PrioNet Canada to present CJD 2009 and the CJD Foundation Family Conference.

The conference will be held at the Washington Court Hotel, Washington DC, July 10-13, 2009. We will begin with a casual welcome reception on Friday evening. Saturday morning we will hold a memorial service and continue the program with presentations by some of the world's leading prion disease experts, a panel discussion and moving round table sessions. During the moving round tables, families will have an opportunity to speak more privately with many of the presenters.

Sunday we will hear reports from the leaders of CJD support organizations from around the world, all of whom are members of the CJD International Support Alliance. We will also hear progress reports from our grant recipients. In the afternoon, we will have the opportunity to participate in political advocacy training sessions in preparation for Monday's meetings.

On Monday, those families who would like to visit their representatives on Capitol Hill will be able to take advantage of this rare opportunity. Our Political Advocacy Committee will make appointments for each family who has indicated a willingness to participate. Family members will meet with their Congressional Representatives to briefly tell their story (if they wish) and to review the important CJD issues we will outline during the training meeting on Sunday.

We are presently discussing the option of repeating the meeting on Friday afternoon, specifically set up as a venue for researchers to present their recent work to each other. Of course, our families would be invited to attend as well.

Please visit our website in the coming weeks for further conference information.



Educational Mailings

During the past two months, the CJDF has sent out two educational mailings and is presently planning a third. The first mailing included a letter and a copy of our DVD, "CJD Information for Funeral Directors and Embalmers," to each crematorium in Virginia. Our partners in this effort were Drs. Lawrence Schonberger and Ermias Belay of the Centers for Disease Control and Prevention, Dr. Pierluigi Gambetti, Director and Sally Berri, Manager of the National Prion Disease Pathology Surveillance Center and Dr. Carl W. Armstrong, State Epidemiologist, Virginia Department of Health. This mailing was carried out as a direct response to our notification that one of our families had been refused cremation services by any crematorium in Virginia. Sally Berri was finally able to locate a crematorium in North Carolina willing to carry out the family's wishes.

The second mailing was sent to the state Funeral Directors Association in all 50 states. A letter and an educational DVD were also included in this mailing. In direct response to this mailing, The North Carolina Funeral Director's Association contacted us requesting 20 more copies of the DVD to give to Funeral Directors. They will also be utilizing the DVD in continuing education sessions.

The third mailing will be our largest. We are planning to send our medical education DVD "Confronting CJD and Other Prion Disorders" to more than 650 medical libraries around the United States. A poster produced by PrioNet Canada in collaboration with Dr. Gambetti and the CJDF will be included.

These educational mailings are made possible through the generous support and encouragement of Drs. Gambetti, Schonberger and Belay and so many of you, our families. With your help we not only see the problems, but we are able to take the appropriate measures to address them. Together we ARE making a difference!

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HelpLine Statistics

The CJD Foundation's largest ongoing project is a toll-free HelpLine (1-800-659-1991). The HelpLine is available to families coping with a loved one's suspected CJD diagnosis and in need of support and information, and to the general public who may have questions about prion diseases. Below you will find HelpLine statistics for January 1, 2008 – December 23, 2008. Please keep in mind that 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.

2008	NEW CASES REPORTED	DEATHS REPORTED	TOTAL HELPLINE CONTACTS	UNIQUE WEBSITE VISITORS
January	35	24	203	6,424
February	24	8	212	6,848
March	19	18	164	7,492
April	36	13	231	8,427
May	26	24	191	8,839
June	19	18	144	9,646
July	28	17	171	7,791
August	27	24	150	5,323
September	16	12	140	5,698
October	20	17	160	4,974
November	22	11	120	5,293
December*	12	8	178	3,876
TOTALS =	284	194	2,064	80,631

* December statistics are only through December 23, 2008

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.

Memory Quilt

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 or 1-800-659-1991.

CJDF Scientific Grant

In October, we issued an invitation for researchers to apply for our 2nd research grant. We advertised through our website, our email list of researchers and a notice placed in the welcome packets at the *Prion 2008* meeting in Madrid. The first step in the process was to invite any scientist conducting human prion disease research to send a Letter of Intent outlining their project. We expected to receive six or seven responses, but instead received 33! These letters were turned over to our Scientific Advisory Committee on Tuesday, December 2. The committee will decide which researchers will be invited to submit applications by December 29. We were both overwhelmed and gratified by this response.

The CJDF Board of Directors met on December 10 and voted to offer two more new research grants, making a total of 4 - three new awards and one renewal grant to our 2006 recipient, Dr. Wen-Quan Zou.

Through generous donations and careful budgeting, we are able to offer these grants without affecting our other important projects.

CJDF Questionnaire

In September 2008, the CJDF began mailing our updated questionnaire to family members. Over 140 questionnaires have been filled out and returned to us. We are very appreciative and thank all of the families who have taken the time to complete one. We are currently in the process of entering the information in our new database. After this process is completed, our epidemiologist will review the data entries and create an anonymous overview.

The questionnaire is used to obtain an overview of case histories, look for possible trends or similarities in patient backgrounds and offer each family who is willing to share their story a safe and meaningful way to do so. At the present time, we are the only repository for anecdotal CJD patient information in the United States.

If you have not filled out a questionnaire and would like to, please contact us at 1-800-659-1991 or help@cjd.foundation.org.

Free Subscription

If you are not on our email list and would like to receive our newsletter, please email help@cjd.foundation.org. Include your first and last name, email address and "NEWSLETTER" in the subject line.

Skype

One of our families recently sent Florence an email suggesting we tell families who are nursing a loved one about "Skype," a simply installed computer camera used for free internet calling and video. The following paragraph is the description of her usage:

I had my Step-Dad set it up on my Mom's computer and we have been using it daily so that she can see me and my husband and our dog when we call. I mention this because it has been really good for her to see us each day. We can chat and she can see us smiling and blowing her kisses. I can hear her smiling and laughing. Since each day is so precious to the family of people suffering, I am hoping you can help others connect this way. I can't tell you how much we have come to rely on it. It is our lifeline. It is easy to set up and use. It also comes with IM so you can have conversations without "calling."

Social Security - Compassionate Allowances

The following article includes information about obtaining immediate social security coverage for CJD patients, a battle won with the help of Congressman Robert Aderholt of Alabama, his staff, and many of you, our family members. For more information on Social Security compassionate allowances, including contact information, please visit the following website:

<http://www.socialsecurity.gov/compassionateallowances/>

Social Security speeds disability claims review

By: Jim Abrams

WASHINGTON (AP) — People with cancers and other severe medical conditions will get quicker action on disability claims under a new Social Security program.

The time needed to decide claims could trim from 100 days or more to as few as two, said Michael J. Astrue, who heads the Social Security Administration. The Compassionate Allowances initiative will apply to 25 rare diseases and 25 cancers, and may be expanded later, the agency said Monday.

"This is something that I've believed in for a long, long time," Astrue said in an interview before the announcement. His father received disability benefits because of a rare form of brain cancer.

The program focuses on diseases where the conditions are so severe or the treatment so difficult that the person making the claim obviously cannot continue working. Astrue said the agency can approve many claims solely on confirmation of the diagnosis. Those include acute leukemia, amyotrophic lateral sclerosis (ALS) and pancreatic cancer.

Among others on the list are inoperable forms of breast, bladder, kidney and bone cancer; Creutzfeldt-Jakob disease; Gaucher disease; and Rett Syndrome.

At a public hearing on the program last spring, Dr. Edward Benz, president of the Dana-Farber Cancer Institute, said 1.4 million cases of cancer are expected to be diagnosed this year and a significant number of cancer patients are uninsured or underinsured.

"Coupled with an inability to perform work given the disabling impact of their diseases, the financial impacts to these patients and their families are enormous," he said.

Depending on the nature of the claim, a decision from the agency can take months. Getting a hearing for an appeal may take longer, more than a year at times.

This year the agency began a rapid action process whereby computers scan for key terms that make it 95 percent certain a claim will be accepted.

Together with the new program based on specific diseases, the agency estimates the two-track system will result in a decision for 6 percent to 9 percent of disability cases, for as many as 250,000 people, in a matter of days.

Even with the speedier processing, there will be no change in the law under which claimants must wait five months before getting benefits. Those receiving approval may have shorter periods to wait because the five-month period begins from the onset of the disability.

The Social Security Disability Insurance program for the past half-century has paid monthly benefits to disabled workers and certain family members who have worked long enough and paid Social Security taxes. The Social Security Administration this year will receive about 2.6 million disability claims.

