



Creutzfeldt-Jakob Disease  
Foundation, Inc.

# The CJD Foundation Newsletter

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## From the President's Desk

As the CJD Foundation continues to grow, we feel the need to provide you with a vehicle better able to offer pertinent information relevant to CJD and to the Foundation's affected families and friends. Our goal with this new format is to provide more information on a wide range of topics. We will be including articles written by experts and friends who are interested in communicating ideas and information to you, our CJD Foundation family members. Marisa has designed this new format with high hopes that it will work, but we reserve the right to make changes as needed and/or suggested.

As with all new ventures, we are starting out small and hope to grow in relevance and in the ability to meet your needs and interests. Please send your feedback to [help@cjd.foundation.org](mailto:help@cjd.foundation.org).

Warmest Regards,

Florence Kranitz



## Free Subscription

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

## Conference Information

The 2008 Annual CJD Foundation Family Conference, to be held July 11-13 at the Washington Court Hotel, Washington D.C., is rapidly approaching. If you plan to attend, please register with us ASAP and the Washington Court Hotel directly if you are planning to stay there, we only have a few rooms left in our room block. Click on the following link for more information and a registration form:

[Conference Information](#).

*\*Please see pages 6-8 for the conference schedule.*

If you are interested in underwriting a meal at the conference, please contact Marisa at: 1-800-659-1991 or [marisa@cjd.foundation.org](mailto:marisa@cjd.foundation.org).

*The following sponsorships are available:*

Saturday Lunch - \$3,000

Sunday Breakfast - \$2,000

Sunday Lunch - \$3,000

Supporters will be acknowledged in our conference binders and with signage on the table of the meal you are sponsoring.

## The CJD Foundation Staff

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## From the Associate Director's Desk

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As I approach the one year mark of my time as Associate Director at the CJD Foundation (CJDF), I look back and I am humbled by my experience thus far. Throughout the past year, I have gained a great deal of knowledge about Creutzfeldt - Jakob Disease and the work of CJDF through the tremendous support of Florence, Ruthie, Wanda, Tracie, Carole Laderman and many others.

Upon joining the CJDF staff, I immediately realized how valuable the Foundation is to families going through a diagnosis or loss of a loved one. I came aboard at an eventful time, only two weeks before the 2007 Family Conference. I will never forget that first conference because meeting the families affected by CJD directly provided me with the motivation to do everything possible to support existing families, and sadly those families yet to come.

I can honestly say that my work at the Foundation is not just a job, it has become so much more and has helped me grow as a person mostly due to each of you, the families.

Best Regards,  
Marisa Boarman



## Advocacy

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By: Carole Laderman

Every year at the beginning of each conference we are always asked, "Will going up on Capitol Hill really make a difference? Can my one voice and one visit really make an impact?" My answer is always the same...YES! Just ask the families that have been doing advocacy visits year after year and finding it so rewarding.

Our elected officials need to meet our families first hand. They want to hear your stories and hear you speak from the heart. No speeches. Just your own personal family story. Believe me, you will be made to feel very welcome.

Advocacy visits are also our way to say thank you directly to offices for their support in the past of the CDC on behalf of the CJD Foundation. They need to know how much we appreciate this support. Nothing makes an impact as meeting face to face.

I urge all of you coming to the conference to try and give us some time on Monday and go up on the Hill to meet your representatives. We provide training and we send materials to leave with the office you are meeting. Please let us know if you are willing to participate by contacting us at 1-800-659-1991 or [marisa@cjd.foundation.org](mailto:marisa@cjd.foundation.org) so we can set up an appointment at your convenience. Thank you for your support!

## Questionnaire

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As many of you may know, Tracie Kedzierski, the CJD Foundation's volunteer questionnaire coordinator, conducts a questionnaire with any willing family member who has lost a loved one to CJD. We use this information to obtain an overview of case histories. In this way, we are able to look for possible trends or similarities in patient backgrounds. We never use names without the written permission of the families. At the present time, we are the only repository for anecdotal patient information in the United States. Recently, we received a generous grant to hire an epidemiologist to review the information we have compiled and hope to gain valuable insight from the collected data.

If you have not participated in a questionnaire, but are willing to do so, please contact either Tracie at [tracieked@gmail.com](mailto:tracieked@gmail.com) or contact us at 1-800-659-1991 or [help@cjd.foundation.org](mailto:help@cjd.foundation.org). Your help with this project is greatly appreciated.

## Genetic Information Nondiscrimination Act

Passage of the Genetic Information Nondiscrimination Act (GINA) will provide protection for those affected by familial CJD.

GINA was passed by both the House and the Senate and signed into law by President Bush on May 21, 2008. It will protect Americans against discrimination based on their genetic information when it comes to health insurance and employment. The bill passed the Senate unanimously and the House by a vote of 414 to 1. The long-awaited measure, which has been debated in Congress for 13 years, will pave the way for people to take full advantage of the promise of personalized medicine without fear of discrimination. It bans US employers from collecting genetic information from their employees and ensures that insurers can't request or require people to take genetic tests.

Meredith Wadman, in the May 1, 2008 issue of *Nature*, points out that this law may provide a boon for researchers, "the next generation of studies to identify gene culprits associated with complex diseases will involve tens of thousands of willing participants as cases and controls."



## CJD Foundation Online Guestbook Update

We recently implemented a new guestbook through a third-party website called WordPress. We have received feedback from guestbook users and have collectively decided that this is not the right format for us. Currently, our webmaster is working on implementing a new program that will hopefully be very similar to the old guestbook, but with increased security so we do not have spam postings. Stay tuned, we will keep you updated on the progress!



## HelpLine Statistics

The CJD Foundation's largest ongoing project is our toll-free HelpLine (1-800-659-1991) for any family who needs our help once a loved one is diagnosed with suspected CJD or any individual who has questions about the disease. Below you will find HelpLine statistics for January 1, 2008 – May 31, 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 to us. These statistics are not intended to be scientific in nature, but instead to validate the work we do on a daily basis.

2008				
MONTH	NEW CASES REPORTED	DEATHS REPORTED	TOTAL HELPLINE CONTACTS	UNIQUE WEBSITE VISITORS
January	35	22	203	6,424
February	24	9	212	6,848
March	19	18	164	7,492
April	36	14	231	8,427
May	26	14	191	8,839
<b>TOTALS =</b>	<b>140</b>	<b>77</b>	<b>1,001</b>	<b>38,030</b>

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.



## Good Search

**D**on't forget to use GoodSearch! Through GoodSearch.com, a search engine supported by Yahoo, the CJD Foundation can earn a penny for every time you search the internet, as well as a percentage of every purchase you make online at select stores. You use it just as you would any search engine, but you also earn money for the CJD Foundation in the process of browsing the internet.

To use GoodSearch, go to [www.goodsearch.com](http://www.goodsearch.com) and type in *CJD Foundation* under "WHO DO YOU GOODSEARCH FOR?" After entering the CJD Foundation, click verify. From there you can continue your search and we will receive a penny for each search. We have already earned over \$50 since mid-March 2008.

Also available is GoodShop.com. This is a new online shopping mall which donates up to 37% of each purchase to the CJD Foundation. Hundreds of great stores are involved in GoodShop, such as Amazon, Target, Gap, Best Buy, eBay, Macy's, Barnes and Noble and many more. Before you shop online, check GoodShop.com to see if that particular store will donate a portion of your purchase to the CJD Foundation.

This is a fast and simple way to earn money for the CJD Foundation, we hope you will GoodSearch!

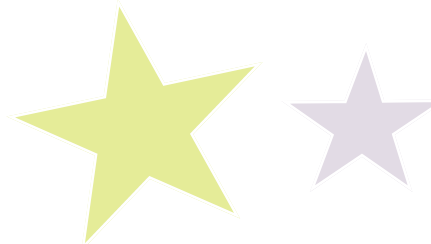
## Creutzfeldt-Jakob Disease International Support Alliance (CJDISA)

**T**he CJD International Support Alliance (CJDISA) was formed by a group of grassroots non-profit organizations that share one vital factor: a commitment to prion disease victims, their families and those at risk for prion disease.

CJDISA was founded to fill the gap that exists on an international level and to assure excellence in the service to individuals affected/at risk of prion disease, their families and caregivers. The participating organizations are dedicated to work together in meeting the educational, social, emotional, spiritual and practical needs of those they represent. Under the CJDISA umbrella, these organizations collaborate on educational initiatives, information dissemination, resource allocation, program design and implementation and advocacy.

CJDISA membership includes the following organizations from around the world:

- CJD Foundation, *USA*
- CJD Insight, *USA*
- CJD Support Group Network, *Australia*
- CJD Alliance, *UK*
- CJD Support Network, *UK*
- Associazione Italiana Encefalopatie da Prioni ONLUS (A.I.En.P.), *Italy*
- CJD Support Network, *Japan*



## NeuroPrion

NeuroPrion, formed in 2003, consists of prion researchers from 52 public research organizations in 20 European countries. With more than 120 individual research groups, the network involves more than 90% of the leading research groups in Europe. The NeuroPrion consortium's focus is on prevention, treatment, control and risks as they relate to prion diseases.

When the CJD International Support Alliance (CJDISA) was formed in July 2006, it attracted the interest of NeuroPrion. In September 2006 at their meeting in Torino, Italy, they invited us to speak about our fledging organization to an assembled group of more than 600 scientists. Since that meeting, NeuroPrion and their organizers, Dr. Jean Phillippe Deslys, Dr. Steve Simoneau and Jens Schell, all based in Paris, have become good friends and colleagues of both CJDISA and the CJD Foundation. Our DVD, "Confronting CJD and Other Prion Disorders" is available for viewing on a streaming feed on our website through a link to the NeuroPrion website.

NeuroPrion is sending two representatives to film the presentations at our CJD Foundation Family Conference next month. They plan to add the video to their website and thus again, allow us to provide a link to their website. You can read about NeuroPrion and their work, as well as their latest newsletter through their website, [www.neuroprion.com](http://www.neuroprion.com).



The following is a quote from their May 2008 newsletter "NeuroPrion News" (which hosts a section devoted to background and news from CJD Support Organizations around the world):

***"The University of Zurich celebrates its 175th birthday! An opportunity to interact with the public about prion diseases.***

*By: Mathias Heikenwalder*

*.....The goal of this exposition was to interact with non-scientists (children, students, elderly people, people from the street) to explain in lay-man terms what our daily and scientific work is about. Moreover, our current knowledge and possible treatment methodologies for various neurodegenerative diseases like sCJD, vCJD, fCJD, Alzheimers and Parkinson were discussed...*

*As a member of the NeuroPrion network we were especially grateful to be able to show a 60 minute video (provided by NeuroPrion but the property of the US CJD Foundation) with interviews and information about sCJD patients, their relatives and scientific background related to Creutzfeldt-Jakob Disease...."*

We thank NeuroPrion, Dr. Deslys, Steve, and Jens for helping us reach the world at large, their friendship, their support and their belief in us and in the families who have been affected by this tragic disease.



**CJD Foundation Family Conference**  
**Washington, D.C.**  
**Washington Court Hotel**  
**July 11-14, 2008**



**CJD Surveillance**  
National Prion Disease  
Pathology Surveillance Center

**Friday, July 11**

9:00-10:55 CJD Foundation Board of Directors' Meeting - Capitol Room  
11:00-12:30 Familial CJD Meeting - Capitol Room  
*(This meeting open only to those families affected by familial CJD)*

**National Prion Disease Pathology Surveillance Center and PrioNet Canada**  
**Early Diagnosis and Treatment Meeting**  
**Chairman, Pierluigi Gambetti, M.D.**  
**Montpelier Room**

*(This meeting directed at the research community, families may attend.)*

12:00-2:00 Registration  
**CSF, 14-3-3 and Other Markers**  
1:00-1:10 Introduction - Pierluigi Gambetti, M.D., USA  
1:10-1:40 Pierluigi Gambetti, M.D., USA  
1:40-2:10 Inga Zerr, M.D., Germany  
**Prions in Body Fluids**  
2:10-2:40 Jiri Safar, M.D., PhD, USA  
2:40-3:10 Claudio Soto, PhD, USA  
3:10-3:40 Neil Cashman, M.D., Canada  
3:40-4:00 Break  
**Neuroimaging: MRI**  
4:00-4:30 Inga Zerr, M.D., Germany  
4:30-5:00 Michael Geschwind, M.D., PhD, USA  
5:00-5:30 Alberto Bizzi, M.D., Italy  
5:30-5:50 General Discussion  
  
4:30-7:00 Registration - Atrium Foyer  
6:00-7:30 Casual Welcome Reception

**Saturday, July 12**

**CJD Foundation Family Conference  
National Prion Disease Pathology Surveillance Center and PrionNet Canada  
Joint Meeting  
Atrium Ballroom**

7:00-9:30 Registration - Atrium Foyer  
7:00-8:00 Continental Breakfast - Atrium Ballroom  
8:00-8:10 Welcome - Florence Kranitz, President, CJD Foundation  
8:10-8:40 Memorial Service

**Treatments  
Chairman, Neil Cashman, M.D.**

**Experimental Drug Studies**

8:40-8:50 Introduction - Neil Cashman, M.D., Canada  
8:50-9:20 Review - Valerie Sim, M.D., USA  
9:20-9:50 Report - Thomas Wisniewski, M.D., USA  
9:50-10:10 Break

**Human Drug Studies**

10:10-10:40 Review - Richard Knight, FRCP(E)  
10:40-11:10 Report - Fabrizio Tagliavini, M.D., Italy  
11:10-11:25 Update - Inga Zerr, M.D., Germany  
11:25-11:40 Update - Michael Geschwind, M.D., USA  
11:40-11:55 Update - Claudio Soto, PhD, USA  
11:55-12:20 General Discussion  
12:20-1:20 Lunch

**Surveillance Center Reports  
Chairman, Robert G. Will, M.D., FRCP(E)**

1:20-1:30 Introduction - Robert G. Will, M.D., FRCP(E), UK  
1:30-1:50 Review - Pierluigi Gambetti, M.D., USA  
1:50-2:10 Review - Robert G. Will, M.D., FRCP(E), UK  
2:10-2:30 Report - Inga Zerr, M.D., Germany  
2:30-2:50 Report - Maurizio Pocchiari, M.D., Italy  
2:50-3:10 Report - Gerard H. Jansen, M.D., FRCP, Canada  
3:10-3:20 Update - Victor Sanchez, M.D., Mexico  
3:20-4:00 Break  
4:00-5:30 Moving Round Table Discussion: Researcher and Families  
7:00-7:30 Reception - Atrium Foyer  
7:30 Dinner - Atrium Ballroom

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[www.cjdfoundation.org](http://www.cjdfoundation.org)

## Sunday, July 13

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### **Chairman, Marisa Boarman, Associate Director, CJD Foundation**

7:00-8:30 Continental Breakfast - Atrium Ballroom  
8:30-8:55 CJD Foundation Report - Mark Goldfarb, Ruthie George, Nick George  
8:55-9:15 CJD Foundation Questionnaire Report - Tracie Kedzierski  
9:15-9:40 Centers for Disease Control and Prevention Report - Ryan Maddox, MPH  
9:40-9:55 CJD Foundation Research Grant Recipient - Wen-Quan Zou, M.D., PhD  
9:55-10:25 Patient Report, Jonathan Simms - Mark McClean, M.D., UK  
10:25-10:45 Break

#### **CJD International Support Alliance Reports**

10:45-11:05 CJD Support Group Network - Suzanne Solvyns, Australia  
11:05-11:25 A.I.En.P. - Roberto Borgis and Raffaella Robello, Italy  
11:25-11:45 CJD Insight - Deana Simpson, RN, USA  
11:45-12:05 CJD Support Network - Minae Asakawa, Nobuhiko Ebisawa, Miyoko Nagatsuka, Japan  
12:05-1:20 Lunch  
1:20-2:20 Guided Discussion, Grief and Healing - Paul Tschudi, M.A., LPC, USA  
2:20-2:45 Break  
2:45-4:00 Advocacy Groups Prepare for Congressional Visits

## Monday, July 14

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9:00-4:30 Scheduled Congressional Visits

