



Creutzfeldt-Jakob Disease  
Foundation, Inc.

# The CJD Foundation Newsletter

MARCH 2011

VOLUME 7, ISSUE 5

## President's Message

Dear Friends,

*It is with great personal sadness that I report the death of Jonathan Michael Simms, Belfast Northern Ireland on Friday, March 4th. Jonathan was the world's longest living vCJD patient. He became symptomatic in May, 2001 at the age of 17 just as he was about to fulfill his dream of becoming a soccer player for the Northern Ireland's National Soccer Team.*

*After a year long court battle, spearheaded by his father Don, Jonathan became the first vCJD patient to be treated with the drug Pentosan Polysulphate (PPS). PPS was delivered from a pump under his stomach wall to his brain via an intraventricular catheter.*

*Jonathan was lovingly cared for at home by his adoring family for almost 10 years. His parents, Karen and Don and his 6 siblings and niece lived each day with the hope that although Jonathan was very ill when PPS was begun, each positive step, however slow, would be of help and a source of encouragement to other CJD patients and families. Although each of Jonathan's milestones (and there were many) were met by roadblocks the Simms family continued to fight unselfishly for recognition in order to help others.*

*On a personal note, Don, Karen and their children and granddaughter are close personal friends who for many years provided me with inspiration and hope. When my son Mitch and I visited them in their home in Belfast in 2006 we were treated to a remarkable day. We were warmly greeted by the entire family and had a visit with Jonny in his large sun filled room at the back of the house. Jonny's bedroom walls were covered with football awards and his framed soccer jersey, photos and multitudes of messages of encouragement from all over the world. In nine years I never heard a word of self pity, only the expressions of deep desire to use their personal experience to help as many people as possible.*

*I fervently hope that the memory of Jonathan Simms, his courage and that of his family will continue to inspire and provide hope.*

*Continued on page 2*

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In September, 2010 The CJD Foundation with the contributions of four families offered three \$40,000 research grants. These families either completed or promised to complete a \$10,000 grant donation within four years.

In mid January, after carefully reviewing the nine applications selected from thirty seven submitted Letters of Intent, our Scientific Advisory Committee notified us of their decision for the recipients of our three research grants.

The grantors and recipients are as follows:

The David and Peter DeMaggio Memorial Grant given by the Paternoster Family was awarded to Dr. Yuri O. Chernoff, Professor, School of Biology, Georgia Institute of Technology, Atlanta, Georgia. The project is titled *Yeast Model for Studying Heritable Mammalian Prion Disease*. In the long term, these results should pave a way for developing anti-prion treatments.

The Bryant Welch Memorial Grant given by Keith Bryant Welch and the Paula Smart Memorial Grant given by husband Jeff Moxie was awarded to Dr. Joaquin Castilla, Principal Investigator, Prion Lab, CIC bioGUNE, Bizkaia, Spain. Dr Castilla's project will focus on developing a prion susceptible human neuronal cell line, his objectives are:

To obtain a cell line capable of replicating human prions in culture cells. Fibroblasts from biopsies from patients who carry mutations in the PrP will be reprogrammed to neurons. Patients are being selected in the Basque country, a Spanish region where in recent years have been identified several families with mutations in the codon 218 and 178. The reprogrammed fibroblast to neurons will be used for infecting with human prion obtained from the same donors of the fibroblasts or his/her relatives who are carrying the same mutation and are developing the disease. In addition, human prions used as inocula will be adapted previously *in vitro* to increase the chances of success. If success, the cells will be used directly in: diagnosis, searching for antiprionic therapies and as a tool for studying the molecular mechanisms involved in the transmissible spongiform encephalopathies.

The Carlton Maddrey Wilson Grant given by Deborah Wilson and Children was awarded to Dr. Emiliano Biasini and Dr. David Harris, Boston University School of Medicine. Boston MA. Their project is titled *TARGETING THE FUNCTIONAL ACTIVITY OF PrPC AS A NOVEL STRATEGY FOR DRUG DISCOVERY IN PRION DISEASES* which will be, as you can see, focused on finding a drug treatment for prion diseases.

All of the Grant recipients will be presenting reports on their work at CJD 2011 and the Ninth Annual CJD Foundation Family Conference. The Conference information was sent out last week. The schedule can be found on our website [www.cjdfoundation.org](http://www.cjdfoundation.org). Please call Wanda, 800-659-1991 or check our website if you didn't receive a notice.

With My Warmest Regards,

*Florence*

P.O. Box 5312, Akron, Ohio 44334 ★ 330.665.5590 ★ HelpLine 1.800.659.1991  
[help@cjdfoundation.org](mailto:help@cjdfoundation.org) ★ [www.cjdfoundation.org](http://www.cjdfoundation.org)

## The CJD Foundation, Inc.

We would like to formally announce our partnership with:



We have partnered with GiveBackAmerica.com to help raise money for our organization, all at no extra cost to our supporters.

GiveBackAmerica.com is an online shopping mall created to raise money for local and national charities. The concept is simple, every time you shop online from one of the participating retailers on GiveBackAmerica.com (ex. Target, Amazon, Walmart, Home Depot, Expedia, Staples); a percentage of each purchase goes to The CJD Foundation, Inc. To begin raising money go directly to:

<http://www.givebackamerica.com/charity.php?b=1018>

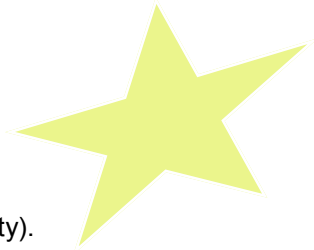
*How can I help? Follow these simple suggestions!*

### INDIVIDUALS:

- 1 - Use GiveBackAmerica.com every time you shop online!
- 2 - Tell your friends about our shopping mall using the GiveBackAmerica.com *"Six Degrees of Giving Program."*
- 3 - Save your organization's personal shopping page to your favorites.

### WORKPLACE:

- 1 - Encourage co-workers to use GiveBackAmerica.com.
- 2 - Book company travel online through our mall (Ex. Expedia, Travelocity).
- 3 - Order office supplies online (Ex. Staples, OfficeMax, and Office Depot).
- 4 - Tell your community partners about GiveBackAmerica.com.



To see the list of Participating Retailers and to get to Give Back America copy and paste this link into your browser:

<http://www.givebackamerica.com/charity.php?b=1018>

**Participating Retailers and the Percentage of Each Purchase Donated to Charity**

*"Changing the Way America Gives, One Purchase at a Time"*

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

Welcome to the 21st century and the power of Facebook! I am so pleased with the overwhelming response to my facebook posts. I received many calls and emails in addition to your facebook postings. If you haven't done so already, please friend us on facebook. You will be seeing more of us in the future.



Our questionnaire has recently undergone a few changes. We hope that you will be willing to fill out a new one and include your loved one's information. For those of you who have already filled out an earlier version, and would be willing to complete our newest version, you can either call me at 800-659-1991 to receive one by mail, or you can print the one on our website, and mail it back to me. If you have never filled out a questionnaire, we ask that you consider doing so now as a way to honor the memory of your family member. This will allow us to include your loved one's information in the statistical report which will be presented at our conference in Washington, D.C., being held July 8-10. This extremely important information is only available through you.

The fundraising bug has bitten! It seems since spring is on it's way, many of you have fundraising on your mind! I've been receiving several inquiries asking for information. If there is anything I can do to help make your fundraiser happen, please let me know. Your support is very much appreciated and necessary! You are putting knowledge to work by raising awareness and we are very grateful!

*Lori*

### HelpLine

The CJD Foundation's largest ongoing project is our toll-free HelpLine (1-800-659-1991 or [help@cjd.foundation.org](mailto:help@cjd.foundation.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. We listen to HelpLine messages seven days a week, and if necessary, we return calls up until 10:30pm. To the right you will find HelpLine statistics for January 2011 and February 2011.

2011	NEW CASES RE-PORTED	DEATHS RE-PORTED	TOTAL HL CON-TACTS	UNIQUE WEBSITE VISI-TORS
January	19	9	149	4,142
February	15	4	111	3,896
<b>TOTALS =</b>	34	13	260	8,038

*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.*

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The tentative CJD Foundation Family Conference 2011 Schedule is on the front page of our website:

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

### Conference Information at a Glance

*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. If you haven't received an invitation, please call Wanda at 1-800-659-1991.

### Acknowledgements

We would like to thank all of our wonderful volunteers. Without your help we would not be able to do our jobs! Thank you!

### Newsletter Subscription

If you are not on our email list and would like to receive our newsletter, please email [help@cjdfoundation.org](mailto:help@cjdfoundation.org). Type "NEWSLETTER" in the subject line and include your first and last name in the body of the email. It is optional to 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 3<sup>rd</sup> parties.

### 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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