



Creutzfeldt-Jakob Disease
Foundation, Inc.

The CJD Foundation Newsletter

JUNE 2011

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President's Message

Dear Friends,

We are looking forward to seeing many of you at *CJD 2011 and the Ninth Annual CJD Foundation Family Conference* being held in Washington D.C., July 8th-10th with Capitol Hill visits taking place on July 11th. This year we are expecting our largest attendance!

Suzanne Solvyns, David Ralston and I recently attended the NeuroPrion Annual meeting, May 16-19th in Montreal Canada. NeuroPrion is the European scientific organization launched in 2003 to bring prion disease researchers together to share their work. Suzanne and David are officers of the Australian CJD International Support Group Network, and Suzanne also serves as my co-chairman of the CJD International Support Alliance (CJDISA). We were honoured to be invited to present a 20 minute talk on behalf of the CJDISA. We divided it into two sections including short personal stories from affected families in 4 different countries.

This extremely well organized meeting was attended by almost 600 researchers. There were a lot of new faces and a lot of encouraging research work presented. Our talk was given a lunch time slot on Tuesday May 17. We were unsure if that would mean a large or small audience. To our delight lunch was a three course sit down meal meaning most if not all of the conference attendees were present. I began with a talk about you, our families, and the families around the globe served by our Alliance partners and talked about the feelings so many of you share with us. We then highlighted a few family stories from the United States, Australia, Italy and France.

Continued on page 2

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INSIDE THIS ISSUE:

President's Message	1-2
Golf Outing	3
Notes from Lori's Desk	4
Conference Sponsorships	4
HelpLine	5
Useful Information	5
Give Back America	5
Miscellaneous Information	6



Our aim was to bring the faces of the people we represent into the room and to touch the hearts of those present, as well as to thank them for their work and emphasize just how important they are to us all. If the reaction from the audience that day and during the next couple of days was anything to go by, with both of us constantly being stopped and thanked by people who were truly touched, I think we achieved our goals.

We had been asked not to use videos, only still photos as the NeuroPrion team wanted to film the presentation so that it could be added to their website with the research presentations. As it turned out we spoke in a different room so the talk couldn't be filmed. With perseverance on the part of Suzanne we have now managed to convert the whole presentation to a video but have run into technical problems trying to post it on our website. If you are interested in watching it please paste the link below into your browser and be patient. It takes approximately 4 minutes to download. The first portion is my overview and you can only hear my voice, the second part contains stories and photos from the 4 families with English translation for the French and Italian segments.

<http://www.cjdsupport.org.au/Videos/CJDISA%20Presentation%20%20Montreal%20May%202011.mp4>.

Please let me know what you think.

Our political advocacy work on behalf of the urgent need for renewal of the funding for the Surveillance Center's survival. Dr Gambetti, David Bell, Vice President of Government Relations for Case Western Reserve University, and I made our second trip to Capitol Hill on May 11th. We feel we are making some progress but the radical budget cuts being discussed for 2012 are definite threats to the free autopsy program. This will be the most critical item our families will be discussing during the Capitol Hill visits on July 11th.

Please know our most crucial work continues to revolve around the HelpLine. Each call means another family is in need of our help. Your generous response to our Spring Appeal ensures the continuation of the HelpLine as well as our many other important projects. I offer my heartfelt thanks, it means you are listening and caring.

I wish you all a peaceful and healing summer and greatly look forward to seeing many of you at our conference in a few weeks.

With Warmest Regards,

Florence

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

*The 10th Annual
Aaron Kranitz Memorial Golf Tournament
August 29, 2011
Firestone Country Club
North Course
Akron, Ohio*



This year we have once again secured Firestone's North Course and are hard at work to provide an even more spectacular event than in past years. We hope you will be able to join us for golf, lunch and the Post-Links Party, which includes a live and silent auction. This year is special as we are celebrating 10 years of golf tournaments and your support of the Creutzfeldt-Jakob Disease Foundation. If you are unable to golf with us, we hope you will support the CJD Foundation through one of our sponsorship opportunities and join us at the Post-Links Party. For more information, please call us at 330.665.5590 or email me at lori@cjd.foundation.org. *Click on the link on the front of our webpage for the full brochure.*

WE HOPE YOU WILL JOIN US FOR GIFTS, GOLF AND A GOOD TIME!

Notes From Lori's Desk.....

CJD 2011 and The Ninth Annual CJDF Family Conference is fast approaching. We hope that you are able to join us and we encourage you to attend the Capitol Hill visits on Monday. Advocacy visits are a way to tell your personal story and ask your elected official for their support. Nothing makes an impact like a personal story. Your Representatives want to hear your story. We will make the appointments for you and also provide a group training session on Sunday. At this meeting you will be given materials to leave with your representatives. We will arm you with the knowledge *and* the confidence you need. If you haven't already done so, please let me know that you are willing to participate by contacting me at 1-800-659-1991 or lori@cjd.foundation.org. I will set up the appointments around your travel schedule. I look forward to seeing you in Washington.



Conference Sponsorships

There are still Sponsorships available.

If you are considering a sponsorship, please contact Lori at 1-800-659-1991 or lori@cjd.foundation.org. Supporters will be acknowledged in our conference binders and signage at their sponsored event.

Thank you to those of you who have already contributed.

We appreciate your generosity.

HelpLine

The CJD Foundation's largest ongoing project is our toll-free HelpLine

(1-800-659-1991 or 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. Above you will find HelpLine statistics for January 2011 through May 2011.

2011	NEW CASES REPORTED	DEATHS REPORTED	CASES REPORTED FROM OUTSIDE THE U.S.	TOTAL HELPLINE CONTACTS	UNIQUE WEBSITE VISITORS
January	22	15	6	162	4,142
February	15	9	13	133	3,896
March	22	12	1	175	4,796
April	23	9	1	124	4,456
May	21	12	13	123	4,136
TOTALS =	103	57	34	715	21,426

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.

Useful Information

★ There is a 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!

★ Fundraising is a good idea any time of the year, but why not consider an event in your area while the weather is nice!

★ Remember to use GiveBackAmerica.com every time you shop online! Here is the link:



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

Please consider using GiveBackAmerica.com to help raise money for our organization. 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. There is no extra cost to our supporters.

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Miscellaneous Information

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

www.cjdfoundation.org.

Newsletter Subscription

If you are not on our email list and would like to receive our newsletter, please email 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 3rd parties.

Acknowledgements

Thank you, Volunteers! We appreciate all of your hard work!

Don't forget to "like" us on Facebook!



Comments/Suggestions

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

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