



Creutzfeldt-Jakob Disease  
Foundation, Inc.

# The CJD Foundation Newsletter

OCTOBER 2010

VOLUME 5, ISSUE 3

## President's Message

Dear friends,

I hope you are able to enjoy the beautiful autumn weather (in some parts of the country). Watching the leaves change color is almost magical!

The CJD Foundation office is in the process of transitioning to a new data base designed specifically for non profits. After 6 months of training we are, hopefully, going live today. This program promises to make all of our lives easier, especially Wanda's, and we are all in favor of that. It combines our patient/family records, bookkeeping and special project information into one program. We are grateful to Stu Yaffa and Mitch Kranitz for their professional advice and guidance during the decision making process.

Our Ninth Annual Aaron Kranitz Memorial Golf Tournament was held on August 30<sup>th</sup> at Firestone Country Club in Akron, Ohio. The weather was beautiful and the energy generated by the golfers and the Foundation volunteers contributed to a completely spectacular day. Our incredible Chairmen were Ana Betro, Ruthie George, Mark Goldfarb and Tom Haught and, once again they donated an unbelievable number of hours to help make this event a success. Ana and Ruthie, along with coordinating the entire day, collected the amazing items for the live and silent auctions and Mark and Tom did a great job signing up 89 golfers, including a number of corporate teams. We express our gratitude to them and to the large group of wonderful volunteers, many who came from out of state as a tribute to family members or friends. This year during the auction we initiated "Fund a Fund" asking for donations to the CJD Foundation Discretionary fund. The auctioneer started "bidding" at \$1,000.00 and moved down by increments-we raised \$6,000.00 to add to our fund to help families pay medical and/or funeral expenses, how amazing!!

September 8-12<sup>th</sup> I attended "Prion 2010", the European scientific meeting held, this year, in Salzburg Austria. NeuroPrion, The European

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Network of Excellence, the conference organizers, once again invited the members of the CJD International Support Alliance (CJDISA) to attend. Our registration fees were paid by Alliance Biosecure which is an umbrella organization for international pharmaceutical companies. They provide a number of large grants for prion disease research. The patient/family CJDISA members in attendance with me were Suzanne Solvyns, my Alliance Co-chairman and National Coordinator of the CJD Support Group Alliance, Australia, Roberto Borgis, President of A.I.En.P, Italy, Dr Francois Labenere representing MCJ-HCC, France, and Alice Anane, The CJD Foundation, Israel. Suzanne and I were invited, once again, to speak to the assembled scientists on behalf of the Alliance.

Along with a small group of researchers, the CJDISA was invited to a workshop “Prion Risk 2010” organized by PrioNet Canada held the day before the conference began. The purpose of this very interesting meeting was to form a global risk consensus as presented by experts studying TSE infectivity of urine and blood both human and animal. I have taken the liberty of greatly simplifying the conclusions presented by two of the world’s leading experts, Professor Pierluigi Gambetti whose research leads him to conclude that concentrated urine from patients with sporadic CJD delivered to transgenic (humanized) mice by intracerebral injection (directly into the brain) does not transmit the disease, and Professor Robert Will discussed the United Kingdom’s discovery a few years ago that the blood of variant CJD patients presents a high risk of transmission. The incubation period for transfused blood can be up to five years.

The “Prion 2010 from Agent to Disease” Congress was held September 9-11, coordinated by NeuroPrion and consisted of scientific presentations by the world’s leading prion disease experts who were each invited to discuss their newest research. There was time for Q&A at the end of each presentation, (which was one of my favorite parts), many presenters were challenged to defend their work by colleagues. My overall sense is that we are getting closer, and there have been many promising new developments, but we don’t yet have a viable treatment or cure. Having said this, I think I can speak for my colleagues, when I say we definitely came away very hopeful.

The CJD Foundation is growing and expanding our programs including the addition of a new Education Program led by Veronica Oberdorf. Veronica is an RN with a strong healthcare and organizational skill set. She is a member of our Board of Directors, a HelpLine volunteer and conducted an in-service Hospice meeting for us and received rave reviews from those in attendance. She will be organizing prion disease educational seminars in hospitals and hospices. We are delighted to have this important project placed into such capable hands. If you are interested in volunteering to help her please contact us.

Please take time to read the information about Family Grant opportunities. I hope you will consider this very meaningful way to honor the memory of a loved one.

I thank all of you for continuing to support the CJD Foundation with your ideas, your dollars and your willingness to reach out to families in need of support when we ask for your help.

With my warm regards,

*Florence*



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

## A Message From Lori

[lori@cjd.foundation.org](mailto:lori@cjd.foundation.org)

Fundraising is fun and easy to do! Step one is to call me at 1-800-659-1991. During this initial phone call we'll discuss different options and I'll give you some ideas. Once you decide on what fundraiser is right for you, you will need to complete an Event Planner Consent Form, which I will email or fax to you. When the form is signed, you need to fax it back to me at 330-668-2474. When I receive it, I will email you the remaining necessary forms to make your event a success.

One event, currently in its 3rd year, is Footwork for CJD in West Virginia. This year, the event will be held on November 6th, 2010, at Fairmont State University. This event raises awareness for CJD and funds for the CJD Foundation. If you'd like, you can send a picture of someone you lost to CJD to [cure\\_cjd@yahoo.com](mailto:cure_cjd@yahoo.com), along with their name, age, city and state where they lived. Their picture will be displayed in a frame on a memorial table and carried during the memorial lap. If you have any questions about this event, or would like to learn more, you can contact Nikki Bland at [cure\\_cjd@yahoo.com](mailto:cure_cjd@yahoo.com). They also have a fan page on facebook that you can join. It is: Footwork for CJD in West Virginia.

Another opportunity to honor the memory of a loved one is to underwrite a grant project. More information about our Family Research Grant is on page 4 of this newsletter.

Warm Regards,

*Lori*

## HelpLine Statistics

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. Below you will find HelpLine statistics for January 2010 through July 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	18	126	3996
February	23	17	132	4313
March	20	22	144	4816
April	15	16	76	5233
May	18	14	106	4711
June	21	11	23	3031
July	26	6	88	4142
August	16	16	56	4382
September	24	8	80	4097
<b>TOTALS =</b>	<b>167</b>	<b>120</b>	<b>751</b>	<b>34,624</b>

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# Family Research Grant Guidelines



Creutzfeldt-Jakob Disease  
Foundation, Inc.

The mission of the Creutzfeldt-Jakob Disease (CJD) Foundation is based on serving the needs of the patients and families we represent. We all know that the only hope we have to find a treatment or a cure is through research.

In 2006, at the request of a few family members and with the approval of the CJD Foundation Board of Directors, we established the Family and CJD Foundation Human Prion Disease Research Grant project. Thus far we have offered a total of seven one year research grants. Each is underwritten by both the CJD Foundation and one of our families and bears the name of the loved one being remembered.

The grant opportunities are advertised through the NeuroPrion Network of Excellence, the European prion research community, PrioNet Canada, the Canadian prion research community and the CJD Foundation. Our scientific advisory committee evaluates the applications and determines the most promising projects.

This program has evolved over the years as interest and participation has grown. Each participating family agrees to contribute a total of \$10,000.00, either in one payment or in \$2500.00 installments each year for 4 years. In the past, the CJD Foundation has matched the \$10,000 to offer a one year grant of \$20,000.00. This year the Board has increased the total to \$40,000.00 with families still responsible for only \$10,000.00. Presently we have three grants available to be awarded in January 2011.

We encourage you and your family to consider this meaningful and important opportunity to honor the memory of your loved one.

Please contact us if you are interested or need further information.

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# Footwork for CJD



Many of you have expressed an interest in helping The Creutzfeldt-Jakob Disease Foundation. Those of us at the Foundation greatly appreciate your desire to help. We have found a fun way for you to do so and collectively call attention to Creutzfeldt-Jakob Disease.

November 12<sup>th</sup> is International CJD Day and we would like your assistance in planning a local fundraiser on or near this date. The name of the event is *Footwork for CJD*. This can be a walking or running event in your neighborhood or local park. You will be asked to organize the type and length of event, date, time and the route. The Foundation will provide you with a downloadable checklist to help you plan your event, as well as a CJD fact sheet, consent form, registration form, pledge sheet, a press release template and signage. From there you can print off as many copies as you need. In addition, the Foundation will mail a purple "Cure CJD" bracelet for you and each participant in the fundraiser.

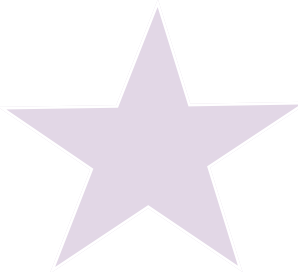
If you would like to plan *Footwork for CJD* in your community, please fax an Event Planner Consent Form to 330.668.2474. To receive this form, call Lori at 1-800-659-1991 or email [help@cjd.foundation.org](mailto:help@cjd.foundation.org). From there we will email you all of the downloadable information you will need.

Thank you for helping us with our fundraising efforts and we wish you success in creating your own *Footwork for CJD*! Please email or call me if you have any questions. Together we can bring awareness on International CJD Day...one step at a time.

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Don't Forget! We are now on  
Facebook!

Search "CJD Foundation" and  
click "like" to join our group!



### Newsletter 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). 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.

### Acknowledgements

#### Many Thanks....

To the many volunteers,  
friends, and families  
who support the CJD  
Foundation.



### Comments/Suggestions

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

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