



Creutzfeldt-Jakob Disease
Foundation, Inc.

The CJD Foundation Newsletter

SEPTEMBER 2011

VOLUME 9 ISSUE 7

President's Message

Dear Friends,

Once again we had perfect weather for our golf outing at Firestone Country Club on August 29th. This year was the 10th Anniversary of the Aaron Kranitz Memorial Golf Tournament and we were delighted to welcome 92 golfers. We would have had 104 if Hurricane Irene hadn't decided to arrive in NY two days before the Tournament, making it impossible for 12 of our very loyal golfers to arrive (fortunately they suffered very minimal damage). The Tournament was a big success and I can say without a doubt that everyone, golfers and non-golfers (like me) had a wonderful day. We are very grateful to our chairmen Mark Goldfarb, Tom Haught, Ruthie George and Ana Betro. With these four at the helm doing such an amazing job there could be no doubt that the weather would cooperate and the event would be a huge success!

Not pausing to take a breath we are now in the process of planning a second Family Workshop in partnership with Dr. Gambetti and the National Prion Disease Pathology Surveillance Center (NPDPS). The Workshop will be held on October 18th in Portland Maine. Please see Lori's article on page three for information. Our first Family Workshop held in May, in Eugene, Oregon, was a wonderfully meaningful event for all of us who attended. Families had an opportunity to meet each other, tell a little of their personal stories, learn about the work of the NPDPS from Dr. Gambetti and about the work of the CJD Foundation with lots of time allotted for questions. We hope families in or near Portland will be able to join Dr. Gambetti and Lori. I will be in Australia at this time attending the CJD Support Group Network conference being held this year in Melbourne.

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As many of you know, The CJD Foundation in conjunction with some of our families, offers research grants each year. These grants consist of a total of \$10,000 from a participating family and a matching or larger amount from the CJD Foundation. To set up this grant, which will bear the name of your loved one, we ask that you agree to make one payment totaling \$10,000.00 or to contribute \$2500.00 per year for four years which will be used for one grant in the next calendar year. We advertise the availability of these grants on our website, through the European scientific association (NeuroPrion), in professional journals and via email notification to past applicants and those who have contacted us during the year. The grants will be awarded after careful review by our scientific advisory committee. We limit the applications to research projects benefiting humans only and impose a time limit of one year for the project to be completed. We ask successful recipients to submit progress reports at six months and then a final report at one year and we invite our recipients to report on their work at our July conference in Washington D.C. Each family is given the name of the researcher and the project they are helping to underwrite. The successful recipient is notified of the family who has helped the CJD Foundation with the funding of their award..

Thus far we have offered nine research grants in amount of \$20,000.00 over a four year period and three \$40,000.00 research grants in 2011. We are very proud to have contributed to many important scientific advances, many of which have been published in prestigious scientific journals. If you are interested in participating or would like more information please contact me, Florence@cjd.foundation.org.

We have added a new page to our website titled "Prion Disease Research News". Please visit our website and look for this link to some of the latest research papers and information, in the index on our homepage www.cjd.foundation.org . Our first paper discusses some potential anti-prion agents. Dr. Thomas Wisniewski (one of our longtime friends and conference presenters) is one of the authors. Our thanks to Rob Alvo for sending this the day it was published in PLoS ONE. I look forward to your feedback.

Thank you for your continued support and interest in our work.

I wish you all a gentle and healing fall.

Hope is like the sun, which, as we journey towards it, cast the shadow of our burdens behind us-Samuel Smiles

With Warmest Regards,

Florence

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help@cjd.foundation.org ★ www.cjd.foundation.org

**Request from Dr. David Wishart and Dr. Heather Graves
University of Alberta,
Department of Biological Sciences and Computer Science**

**Knowledge Mobilization: Studying knowledge needs
of patients and families.**

In April 2011, PrioNet Canada, a sponsor of the CJD Foundation Family conference, awarded a grant to Dr. Heather Graves and Dr. David Wishart at the University of Alberta to study the impacts of prion research beyond the laboratory. The aim of this “Knowledge Mobilization” study is to examine how the knowledge developed in scientific research projects can be shared with and used by others. There are many people who may be interested in this research, including policy makers, doctors, academic researchers, but of course, those most directly affected are patients and their families.

As a member of the research team for this project, I had the opportunity to attend the CJD Foundation Family conference, held in Washington DC this past July. Thanks to the conference, I got to meet some of you, the families who have been affected by this terrible disease. Through our discussions, I have begun to learn a little bit about the experience of being a family member of someone with CJD, the unique challenges around diagnosing, understanding, explaining and coping with the disease, and your hopes and concerns for the future. But we want to learn more: The tragedy of CJD is what motivates scientific research into drug leads and the biology of prion disease, so it is crucial for us to improve our understanding of what kinds of information patients and families want and need, and what the best ways are to communicate about it.

As part of the knowledge mobilization project, we are therefore inviting all patients and families who are interested in this project to contact us. We would be happy to talk with you more about the project and we are eager to get families' feedback in the form of informal discussions/ interviews (by phone or in person). We would also be happy to use a more open-ended approach to work with any stories, surveys or other materials that you are willing to share with us. These discussions will help us judge whether or not research groups' current communication strategies are meeting families' needs and will guide future strategies for knowledge sharing. We will also prepare a summary report for PrioNet. If you are interested, please contact Dr. Heather Graves (the project lead, hgraves@ualberta.ca) and/or me (Connie Sobsey, csobsey@ualberta.ca). We look forward to hearing from you!!!

Message from Lori

As some of you may know, The CJD Foundation has been collecting data since 2000 with the help of our families. Our questionnaire has undergone major revisions. Each revision has made the process of collecting statistical analysis easier and more accurate. The most current, up to date questionnaire can be found on our website, or you can call me at 1-800-659-1991, or email lori@cjd.foundation.org for a copy to be mailed to you. We truly appreciate your willingness to participate in our questionnaire project. Without you it would not be possible. At our CJD 2011 and the 9th Annual CJD Foundation Family Conference, I gave a report on the questionnaires we have received. The power point slides for this report and all of the other presenter's power point slides are on our website for your viewing. If you weren't able to attend, and you haven't done so already, it is definitely worth your time to look at these very informative slides. Go to the homepage of www.cjd.foundation.org and click on the "Presentations" link.



On October 18th I will be joining Dr. Pierluigi Gambetti in Portland, Maine for a **CJD Family Workshop**. We will begin with a casual reception from 5:30-6:00. From 6:00-7:00 I will give a brief report on the work of the CJD Foundation then turn the Workshop over to Dr. Gambetti who will discuss the work of the National Prion Disease Pathology Surveillance Center and conduct a question and answer session. See invitation on page 4. We would love to have you join us if at all possible! RSVP to lori@cjd.foundation.org by October 5th.

Lori



We cordially invite you to attend a
CJD Family Workshop

Hosted by
The Creutzfeldt-Jakob Disease Foundation
And the
National Prion Disease Pathology Surveillance Center

Tuesday, October 18th, 2011
5:30pm - 7:30pm
5:30-6:00 Casual Reception
6:00-7:30 Presentations and Question & Answer

Dr. Pierluigi Gambetti
Director of the National Prion Disease Pathology Surveillance Center

Lori Nusbaum
Associate Director, The CJD Foundation

Holiday Inn By The Bay
88 Spring Street
Portland, Maine 04101

Dr. Gambetti will present an overview of the work of the Surveillance Center.
Lori Nusbaum will discuss the work of the CJD Foundation.

Following the presentations you will have the opportunity to ask questions.
Please join us!

Please reply by October 5th to lori@cjd.foundation.org or call us at 1-800-659-1991.

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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. The HelpLine statistics for January 2011 through August 2011 are seen here.

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.

2011				
MONTH	NEW CASES REPORTED	DEATHS REPORTED	TOTAL HL CONTACTS	UNIQUE WEBSITE VISITORS
January	22	15	165	4142
February	15	9	138	3896
March	22	12	176	4796
April	23	10	126	4456
May	21	12	121	4136
June	17	10	138	4105
July	16	15	125	3910
August	13	15	110	4100
TOTALS =	149	98	1099	33,541

Fundraising

Having a fundraiser means that you are putting knowledge to work by raising awareness. I am here to assist you and to provide you with whatever you need to get you started. International CJD Awareness Day is in the month of November so many families choose to hold a fundraiser during this month. Whatever date you choose and whatever kind of fundraiser you choose, you've made the right choice! Contact Lori at 1-800-659-1991 or lori@cjd.foundation.org for information or ideas.

★ Don't feel like organizing your own fundraiser?

There are easy options to contribute already in place! Here are a few:

1. Go to our website, www.cjd.foundation.org and click on "Give Back America" on the left-hand side of the page. Shop as you normally would through this site, a percentage of the proceeds will go to The CJD Foundation.
2. Log on to Facebook and search for "Causes CJD" or "CJD Causes". From there, you can donate and you can tell all of your facebook friends to join "Causes" too.
3. Go to our website, www.cjd.foundation.org and click on "Contribute" on the left-hand side of the page. From there, click on "Make a Donation".

It's that easy! If you have any questions, please call Lori.

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Thank You For Your Support – Fundraisers

We are grateful to these families for holding fundraising events and donating the proceeds to the CJD Foundation. These generous donations are one more reason we can continue to support those who turn to us each day for help.

- ★ A Concert in Memory of Bob Vitanza, organized by Mike Vitanza
- ★ A Birthday Celebration in Memory of Howie Burdon, organized by Christy Jones
- ★ An Online Fundraising Event in Memory of Susana Jarque, organized by Gisela Martinez
- ★ An Outdoor Fishing Event in Memory of a Good Friend, organized by Sandra Lacey
- ★ A Vendor Booth at an Outdoor Concert Event, organized by Rebecca at Nelson Plant Food, TX
- ★ A Birthday Celebration in Memory of Thomas Hawkins, organized by Marianne Sabrier
- ★ “Daffodil Dance” in Memory of Megan Gaddis, organized by Marcia Gaddis and the Club Estates Garden Club of Atlanta, Georgia
- ★ Annual Footwork for CJD in Memory of Marsha Snively, organized by the Bland/Snively Family
- ★ Annual John A. Lanciotti Memorial Golf Outing, organized by the Lanciotti Family
- ★ Music Sales in Memory of Eileen Sears, organized by Mary Lou Jubin
- ★ Snaggletail Book Sales, in Memory of Dovie Marie St. Peters, Donated by Tommy St. Peters and family

Newsletter Subscription

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

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@cjd.foundation.org.

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