



Creutzfeldt-Jakob Disease
Foundation, Inc.

The CJD Foundation Newsletter

MARCH 2009

VOLUME 2, ISSUE 1



President's Message

For the second year in a row we are honored to be working in partnership with Dr. Pierluigi Gambetti, Director of the National Prion Disease Pathology Surveillance Center and Dr. Neil Cashman, Director of PrionNet Canada to present a joint Conference in Washington, DC, *CJD 2009 and the CJD Foundation Family Conference*, which will be held at the Washington Court Hotel, July 10-13. We are currently finalizing the list of speakers and are very fortunate to have received acceptances from many of the world's leading CJD experts. We will be posting the information on our website shortly, invitations to all of the families in our database will be mailed out the week of March 23. We hope to see you in Washington, DC!

I want to share one example of how our conference can provide much more than you might otherwise imagine. This past July, Veronica Oberdorf, one of our new family members, met Mary van Leeuwen-Ruinaard and her son Etienne, who traveled from the Netherlands to attend our conference, also as new family members. We were recently surprised and delighted to learn that

Continued on page 2

ARC Look Back Study

In 1995, the American Red Cross (ARC) initiated a "Look Back" study to determine whether or not sporadic or acquired CJD can be transmitted through blood. They elicited the help of the CJD Foundation in 2004 and this partnership continues to provide very important information for this study.

The ARC Look Back Study paper, "Lack of evidence of transfusion transmission of Creutzfeldt-Jakob disease in a US surveillance study" was recently published in Transfusion. The abstract can be viewed through the following link: <http://www.ncbi.nlm.nih.gov/pubmed/19170987>.

We are continuing to ask any family whose loved one died of CJD and was either a blood donor or recipient to contact the ARC.

Many family members are also unaware that any blood relative of a CJD patient is not allowed to donate blood. Although, thus far, the only type of CJD known to be transmitted through blood transfusion is variant CJD (vCJD), the one contracted from eating contaminated beef, this donor restriction continues to provide a measure of safety for our U.S blood supply.

Continued on page 3



Board of Directors

Florence Kranitz, President
Pierluigi Gambetti, MD, Medical Director
Mark Goldfarb, Chairman
Nick George, Vice Chairman
Ruthie George, Treasurer
Sybil Willen, Secretary
Ana Betro
Tom Haught
Tracie Kedzierski
Carole Laderman
Mayra Lichter
Scott Paternoster
Rhonda Rutledge
Tom Sawyer
Jim Simon
Deana Simpson
Chris Szuch
Stuart Yaffa
Cecile Sardo, Emeritus

Staff

Marisa Boarman
Associate Director
Wanda Culp-Lias
Office Manager
Nancy DiGeroloma
Administrative Assistant

INSIDE THIS ISSUE:

President's Message (cont'd)	2
Questionnaire Update	2
ARC Look Back Study (cont'd)	3
Reflections - Marcia Gaddis	3
HelpLine Statistics	4
Fundraisers	4
Consumer Federation of America	5

President's Message, continued from page 1

Mary and Etienne had accepted Veronica's invitation to visit the U.S and to stay with Veronica for a few weeks. On February 16, joined by Dr. Brian Appleby, Director of the new CJD program at Johns Hopkins Hospital, they drove to Akron to visit and discuss the possibility of starting a CJD Foundation in the Netherlands. We met at the CJD Foundation office in the morning and spent the afternoon in Cleveland at the National Prion Disease Pathology Surveillance Center (NPDPS). Dr. Gambetti graciously gave us a mini-lecture on the work of the Center, answered questions and spoke privately to some of the group. Sally Berri, NPDPS's Manager, then led a tour of the Center explaining the purposes of many of the laboratories and how they work together to provide valuable information to families and researchers. We were most grateful to Dr. Gambetti and Sally for their hospitality. We all agreed that it was a wonderful day and an incredible opportunity on so many levels.

Soon we will be on the move again, literally! Our office building was sold and although we have a long term lease, we were asked to vacate 7 years early so they could turn the building into a daycare center. In a few months, we will be moving to our new office that is just down the street. We are not looking forward to once again packing up (after only two years at this location!) and moving, but we are very happy with the design of the new space. We're keeping the same post office box number and the same phone numbers which, we hope, will avoid confusion and/or down time. The new space is being remodeled to suit our needs and although the moving date is not yet final, we have been promised an early May move-in date.

We are seeing a slight increase in CJD symptom recognition by neurologists and hope that the CJD Foundation's education program has contributed somewhat to this trend. In conjunction with our medical education Grand Round meetings, we continue to send letters of appreciation to physicians who have been helpful to one of our patients/families. We also send educational information, including a copy of our DVD and a pamphlet, to those physicians reported to have been unable to recognize possible CJD symptoms.

We hope you will continue to email us your comments, suggestions and offers of help and sincerely hope you will consider attending our conference in July.

I send all of you my warmest regards,

Florence

P.S. Mary van Leeuwen-Ruinaard sent me an email today to say that she and Etienne will be hosting the first CJD Foundation meeting in the Netherlands on March 22!

CJDF Questionnaire Update

The CJD Foundation's questionnaire efforts continue to be successful. Since September 2008, we have received 305 completed questionnaires! All of the collected information has been entered into our database and is currently being analyzed by our epidemiologist consultant, Steven Korzeniewski. He is busy preparing an overview of the data which he will be presenting at the 2009 Conference in July.

Our questionnaire is used to obtain an overview of case histories. We are looking for possible

trends or similarities in patient backgrounds. The questionnaire offers each family, who is willing to share their story, a safe and meaningful way to do so. At the present time, we are the only repository for anecdotal CJD patient information in the United States. If you have not yet filled out a questionnaire and are willing to do so, please contact us at 1-800-659-1991 or help@cjd.foundation.org.

Thank you to all of the families who have taken the time to fill out a questionnaire, your information is extremely valuable and greatly appreciated!

ARC Look Back Study, continued from page 1

We hope you are willing to help. If so, please contact Kerri Dorsey, MPH, at (301) 738-0592 or via email at dorseyke@usa.redcross.org. Please identify CJD donor or recipient in the “subject” line.

Thank you for your consideration. Your participation, if necessary, will greatly help to make a difference.

Family Member Reflections

By: Marcia Gaddis

The quiet view from a chairlift elevating one to 11,000 feet is breathtaking on a clear day. The Lodgepole Pines and the Quaking Aspens (rightly named), spiking tall out of newly fallen snow, beckon onward to the top of the world. And once at the top, gliding around to the slope, you see it – mountain peaks in very direction. Grandeur. Beauty. A hushed reverence for Creation. We take a few pictures, adjust our equipment and tighten our boots. We take a deep breath and point our skis downhill.

It’s always the steepest at the top– that first few hundred feet seem to be the most threatening to me, but how else can you experience those wonderful runs about midway down the mountain? There is no turning back. Then you begin to make a few good turns and your confidence grows and before you know it you’re back at the lift, going up again to experience the thrill of it all over and over again.

There is a fine line between skiing in control and skiing out of control. There is sheer exhilaration shushing down the slopes, making clean turns and gliding to smooth stops. Allowing yourself to pick up a little more speed takes you to a new level of skill requirements and much concentration. It’s risky, thrilling, and at the same time a little scary. It’s thrilling when things go well and you manage to stay on top of your skis. It’s scary when you lose control and feel yourself falling (was it confidence or skill – or both?).

The grief process is a little like skiing – in control one minute, out of control the next. A good example was shared with me last week from one of Megan’s friends. She was sitting in a lab class in med school and the professor started talking about unusual diseases - in fact, the very disease that took Megan’s life. She was caught off guard by the lecture topic relating so closely to her good friend and she had to leave the classroom. I know that feeling. It’s called emotional ambush. You are participating in an event and out of the blue, something pulls a trigger, grabs your heart, and you are caught in your grief once again, exposed and vulnerable. I felt it at the restaurant. It was the perfect restaurant with best friends and great food, everyone having so much fun sitting at the community table. The “everyone having so much fun” seems to always ambush me. I thought I might have to run from the table, but if I started I might not stop. I tried to bring myself back mentally by looking for something to distract me - the tomato label trick – anything that would bring me back to the moment. The tears came anyway and I blamed it on the spicy food.

Grieving, like skiing, takes practice. I haven’t had much practice skiing, but I do know that both require the most powerful muscle in the body – the mind – to exercise belief in the ability to withstand and conquer “the mountain” at hand. Even the pines and the aspen trees are given survival properties. They both are first to invade an area after a wildfire, requiring extreme heat to release new seeds for growth. The needles of the pine are paired and often twisted together offering support to the tree, and the aspens maintain an extensive root system, encouraging growth, “lending a hand” if you will to surrounding saplings. For skiers and grievers, sometimes the slope seems daunting. Sometimes you cannot even see the way. Both require staying alert, watching out for the dangers or ambushes along the way. Both benefit from being with others, who ski alongside or behind you and help you up when you fall, who share an exhilarating run, who offer a hand-warmer, or to carry your skis at the end of the day. It is the support of those around you –like the pines with the aspens - that keeps you looking back up at the mountain peaks, looking up.

Marcia and Mike Gaddis lost their daughter Megan to CJD September 12, 2008

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

HelpLine Statistics

The CJD Foundation's largest ongoing project is a toll-free HelpLine (1-800-659-1991). The HelpLine is available to families coping with a loved one's suspected CJD diagnosis and in need of support and information, and to the general public who may have questions about prion diseases. Below you will find HelpLine statistics for January 1, 2009 – February 28, 2009. 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 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.

2009	NEW CASES REPORTED	U.S. DEATHS REPORTED	HELPLINE (FAMILY) CALLS	HELPLINE (FAMILY) EMAILS	GENERAL INQUIRY CONTACTS	MEDICAL PROF CONTACTS
January	26	17	84	76	8	12
February	15	8	67	70	3	12
TOTALS =	41	25	151	146	11	24
	FUNERAL PROF CONTACTS	DoH CONTACTS	NPDPS CONTACTS	CDC CONTACTS	MEDIA CONTACTS	UNIQUE WEBSITE VISITORS
January	1	2	21	4	1	4,788
February	6	5	14	2	-	4,993
TOTALS =	7	7	35	6	1	9,781

Note 1: Not all new cases and deaths reported are confirmed by autopsy.

Note 2: "Contacts" include emails and phone calls.

Fundraisers

The CJD Foundation will be holding its Eighth Annual Aaron Kranitz Memorial Golf Outing on August 31, 2009 at Firestone Country Club in Akron, Ohio. We are looking forward to another successful golf outing!

We would like to acknowledge families who have held fundraisers to benefit the work of the Foundation. Abby and Nick Webb and the 2nd Annual Captain Bill's Bike Squad participated in America's Most Beautiful Bike Ride around Lake Tahoe on June 1, 2008 in memory of Bill Davis. The Lanciotti Family held a golf outing on July 14, 2008 in Mt. Sinai, NY in memory of John Lanciotti.

The Yaffa Family held their 3rd annual golf outing in memory of Jerry Yaffa on August 11, 2008 in Cherry Hill, NJ. The Heestand Family held a golf outing on September 26, 2008 in Cleveland, Ohio in memory of Don Heestand. The Snively Family held the first "Footwork for CJD" event on November 15, 2008 in memory of Marsha Snively. Marcia Gaddis and friends recently held a Daffodil Dance in Atlanta, GA in memory of Megan Gaddis. In February, Deer Park Elementary School in Texas donated a portion of their talent show proceeds to the CJD Foundation in memory of Randy J. Rodrigue, Sr.

A special thank you to the Webb, Lanciotti, Yaffa, Heestand, Snively, Gaddis and Rodrigue families for their support!

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

www.cjdfoundation.org



Consumer Federation of America

Consumer Federation of America's Response to New Appointment at USDA

February 25, 2009

President Obama's appointment of Kathleen Merrigan to be Deputy Secretary of Agriculture sends a strong and positive message of change at USDA. Dr. Merrigan has been a high ranking Senate aide, a USDA official and is currently director of the food, agriculture and environment program at Tufts University's Friedman School of Nutrition.

In the Senate she helped develop the Organic Standards Act. As AMS Administrator she charted the course for successful implementation of the law.

As AMS Administrator she took steps to assure the safety of ground beef used in school lunch programs, protecting our kids from foodborne illness. In 2000, Dr. Merrigan instituted a new policy establishing a zero tolerance for both *E. coli* O157:H7 and *Salmonella* in ground beef purchased for use in federal feeding programs and requiring testing to assure the standard is met. USDA purchased hundreds of millions of pounds of ground beef products for child nutrition and other programs each year. Although the Department had detailed requirements for packaging, it had no pathogen standards. This standard not only reduced the chance of school children getting sick from federally purchased food, it also raised the overall quality of USDA's ground beef purchases.

The Deputy Secretary traditionally takes on day to day oversight of USDA operations. Dr. Merrigan's history indicates she will bring a new perspective to this role. Her appointment sends a message that the Obama Administration intends to chart a new path for the U.S. Department of Agriculture. American consumers applaud this appointment.



Free Subscription

If you are not on our email list and would like to receive our newsletter, please email help@cjdoundation.org. Include your first and last name, email address and "Newsletter" in the subject line.



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

www.cjdoundation.org