



Creutzfeldt-Jakob Disease
Foundation, Inc.

The CJD Foundation Newsletter

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From the President's Desk

By: Florence Kranitz

The Sixth Annual CJD Foundation Family Conference and CJD 2008 was held on July 11-14 in Washington D.C and according to the feedback we've received, this was our most successful conference yet!

Any worries we had about our families being overwhelmed by the science or the larger attendance disappeared the first afternoon during the scientific meeting (held for scientists to present their work to each other). The room was set up for 70 people, before the meeting began two more rows of chairs were added and then the room became too crowded for additional chairs. We wound up with standing room only and most of the attendees were family members.

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Free Subscription

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

CJDF Research Grants

With the support of some of our families who have promised to donate \$2500.00 a year for five years, we are very excited to announce that we will be offering *two* \$20,000.00 research grants to be awarded in 2009.

By a unanimous Board of Directors decision, we will be renewing our first grant offered in 2006 to Dr. Wen-Quan Zou. Dr. Zou's research project is a comparative study of prion strains associated with iatrogenic and sporadic CJD.

We are also offering a second \$20,000.00 grant for new research projects. We will be posting this grant in the next few weeks and will be accepting applications through November. We hope to announce our new recipient by the end of the year. As before, the applications will be blinded (as much as possible) and reviewed by a panel having no affiliation with the CJD Foundation.

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From the President's Desk


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After this meeting, I asked a few family members what they took away from the experience, the answers, though phrased differently, were basically that although they didn't understand most of the science presented they felt that the isolation they lived with when CJD entered their lives disappeared when they entered the meeting room. It was, they said, an emotional experience to be surrounded by brilliant scientists who had devoted their careers to the terrible disease that had dramatically changed their lives, and yet few in their world had ever heard of.

One of the highlights is always the moving round table sessions, this year with so many more researchers in attendance we were able to have more tables and families were the beneficiaries.

For me, the conference memories have taken on a wonderful kaleidoscope-like effect which includes listening to fascinating research reports presented by brilliant scientists, hearing about new discoveries which may provide hope for those to come, and of being exhausted at the end of Saturday's sessions only to fully revive and delight, with everyone, at the wonderful surprise performance by Dr. Valerie Sim an MD, PhD researcher from The NIH Rocky Mountain Labs. Dr. Sim, also an accomplished concert violinist, played her "fiddle" after our banquet. She delighted us all with her running commentary and her dexterity and skill which included playing while lying on her back and holding the violin under her body and never missing a note!!

Sunday's presentations, which included those of our CJD International Support Organizations, were extremely special in a different and more personal way. The presenters are all friends I have developed through our mutual interest in speaking out to the world at large with one voice about CJD issues of concern.



Dr. Mark McClean, personal physician of Jonathan Simms, world's longest living CJD patient, gave perhaps the most poignant and moving presentation, ending with the statement that Jonathan's family has, over the past two years, attempted to offer his tissue, including blood and spinal fluid to any researcher without much success. (after his talk perhaps this will no longer be the case).

What always strikes me during our conference is the vast differences in those attending who all become one family for the weekend (and hopefully after as well) and the number of different accents indicative of the reach and draw this event produces and which is growing larger each year.

Please read some comments about the conference on pages 5-7.



New Research Publication

We extend our congratulations to Dr. Pierluigi Gambetti, our Medical Director and Director of the National Prion Disease Pathology Surveillance Center on the recent publication of a paper discussing his important research discovery, titled "A novel human disease with abnormal prion protein sensitive to protease." This paper was published in *The Annals of Neurology* on June 20, 2008. One of the contributors was Dr. Wen-Quan Zou, our 2006 grant recipient.



GoodSearch

Don't forget to use GoodSearch! Through GoodSearch.com, a search engine supported by Yahoo, the CJD Foundation can earn a penny for every time you search the internet, as well as a percentage of every purchase you make online at select stores. You use it just as you would any search engine, but you also earn money for the CJD Foundation in the process of browsing the internet.

To use GoodSearch, go to www.goodsearch.com and type in *CJD Foundation* under "WHO DO YOU GOODSEARCH FOR?" After entering the CJD Foundation, click verify. From there you can continue your search and we will receive a penny for each search.

Also available is GoodShop.com. This is a new online shopping mall which donates up to 37% of each purchase to the CJD Foundation. Hundreds of great stores are involved in GoodShop, such as Amazon, Target, Gap, Best Buy, eBay, Macy's, Barnes and Noble and many more. Before you shop online, check GoodShop.com to see if that particular store will donate a portion of your purchase to the CJD Foundation.

We have earned \$90 since March 2008, but it seems as though fewer people are taking advantage of this opportunity since it was first implemented. This is a fast and simple way to earn money for the CJD Foundation, we hope you will GoodSearch!

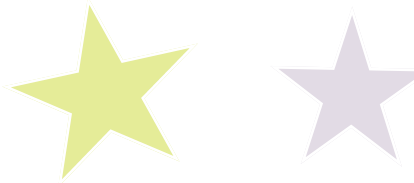
HelpLine Statistics

The CJD Foundation's largest ongoing project is our toll-free HelpLine (1-800-659-1991) for any family who needs support once a loved one is diagnosed with suspected CJD, or any individual who has questions about the disease. Below you will find HelpLine statistics for January 1, 2008 – July 31, 2008. 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 to us. These statistics are not intended to be scientific in nature, but instead to validate the work we do on a daily basis.

2008				
MONTH	NEW CASES REPORTED	DEATHS REPORTED	TOTAL HL CONTACTS	UNIQUE WEBSITE VISITORS
January	35	23	203	6,424
February	24	9	212	6,848
March	19	20	164	7,492
April	36	15	231	8,427
May	26	18	191	8,839
June	19	13	144	9,646
July	28	22	171	7,791
TOTALS =	187	120	1,316	55,467

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.



Comments/Suggestions

If you have any comments or suggestions for the newsletter, please email help@cjd.foundation.org.

Questionnaire Efforts

The CJD Foundation administers a questionnaire to any willing family member that has lost a loved one to CJD. The questionnaire collects information such as specifics on location, diagnosis, medical history, autopsy, eating habits, as well as other variables. Tracie Kedzierski, our Questionnaire Coordinator, began the questionnaire in 2000 after she lost her father to CJD. Since that time, the questionnaire has been edited twice with the help of our Medical Director and Director of the National Prion Disease Pathology Surveillance Center (NPDPS), Dr. Pierluigi Gambetti. The goal of these questions is to accumulate extensive clinical and patient level information from the family member's of suspected or confirmed cases of CJD to address the dearth of information in the United States in hopes of cultivating a resource that may provide new insight about the disease and future analyses.

Recently, we received a generous grant from the Homer Family Foundation to be used to assist us in analyzing and refining the questionnaire database. With this grant, we hired Steven Korzeniewski, an epidemiologist consultant. Mr. Korzeniewski is a PhD candidate in Epidemiology at Michigan State University. He has Masters degrees in epidemiology and health communication and his work has focused on neuroepidemiology. He became interested in CJD through his coursework and has been assisting the foundation for several months. He currently works as Michigan's newborn screening epidemiologist, has published nine papers in peer-reviewed journals, presented at numerous conferences, and is excited to help us in our efforts to learn more about CJD. With Mr. Korzeniewski's assistance, we have identified potential uses for the information that has been collected thus far. These include the following:

Quality Assurance

- Assess the rate of suspected CJD case samples being transmitted to NPDPS
- Identify barriers to specimen transmission to NPDPS
- Assess provider awareness of CJD and the CJD Foundation
- Assess the barriers to autopsy



Public Health Evaluation/Research

- Investigate method of diagnosis
- Track the rate of suspected/confirmed cases
- Learn about the clinical course of cases
- Track the location of suspected/confirmed cases

We hope to implement some or all of the above uses in the near future. Presently, we are working on cleaning up the database so that the information is analyzable. In addition, we are working on entering paper based surveys that are not yet in our database. We will keep you updated on our efforts.

If you have not filled out a questionnaire and would like to do so, please contact us at help@cjd.foundation.org or 1-800-659-1991. We appreciate your participation.



New Guestbook

We told you in the last newsletter that we would soon be implementing a new guestbook. The CJDF staff and the families have decided that the guestbook was not the best one for our needs. We are happy to report that the new guestbook is now up and running! It is very similar to the original guestbook in that you do not have to login to post. The security settings are much better and we hope this solves the spam problem we were having before. To post a new message, you simply fill out your name, email address and the message you wish to post. Your email address remains hidden from the public view, only the administrator can view it. We hope all of our old friends will post messages right away to encourage the new families to share their stories. Please visit: <http://www.cjdfoundation.org/guestbook.html> and post a message to ensure the success of our new guestbook!

Conference Reflections

Corrie Meyer, Virginia:

On February 11, 2008, I became a member of an exclusive club. This was not a club that I knew anything about and, upon coming on information, did I want to be a member. This was the day that my father, Paul Oberdorf, died of suspected CJD. The suspicion of sporadic CJD was confirmed several weeks later. The whole time he was sick, it was hard to handle because none of my friends really knew what he or I were going through. Even my mom and I had a hard time, seeing how this was her spouse and my father. It wasn't the same. During my father's illness, I had found out about the CJD conference and decided that I would like to attend. I am so glad that I did! It was extremely helpful to see and talk with others who had experienced the same things. I was able to find daughters who had lost one of their parents and talk with them. I found comfort in being able to talk to those who had especially experienced what I had (a full-time working mother with young children and traveling long distances several times a week to help take care of your dying parent). I finally knew I wasn't alone! The CJD conference had given me a new "family," of sorts. I am grateful for meeting everyone (families, researchers, and CJD staff)! I now know who I can turn to for comfort and know that they will understand! Thank you!



Mary Ruinaard and Etienne van Leeuwen, the Netherlands:

We visited the CJD Foundation Family Conference in Washington, DC and found it very helpful to meet with people who understand what we have been through. For the first time we felt as though we were not alone. We met fantastic families, doctors and professors from all over the globe.

What did we learn in Washington, DC at the CJD Foundation Family Conference? In one word, a lot! We recognized that there is a lot of work that needs to be

done in the Netherlands. We feel obligated to those families who will face CJD in the future, who need to be helped, recognized, heard and guided during the worst roller coaster ride of their lives. For us, the conference was the start signal to present a "wish list" of shortcomings to the Dutch CJD Surveillance Unit, and rectify issues in the Dutch health care system. They are listening and very helpful.

As for now, there is a lot of work to be done about awareness, education, empathy and guidance. Those who need it most are the families and victims who will be affected in the future with CJD.

For now, the tide is turning, we know we can't make it turn on our own, but with a little help we can!

Thanks to the staff of the CJD Foundation who organized the CJD conference very well. We were able to attend the conference at the very last minute, my compliments! Also, many thanks to the families and all of the professionals in the CJD community.

Thank you again!



Conference Reflections

Bonnie Johnson, Illinois:

With the loss of my baby sister Marcy Dee--actually 14 years younger than me and more like my daughter than sister--so recent, I found myself hesitant, yet excited about the CJD Conference. Marcy and I had spent a year and a half going from doctor-to-doctor in our frustrating search for a diagnosis. By the time we learned she had CJD, she could no longer walk or talk, and I had only four months left to love her. I promised Marcy I would tell her story and do everything I could to prevent others from suffering the lost time she and I did. I *know* she knew what I had said. Just like I know now she is still beside me, informing my every move. She, too, was at the CJD conference.

This Conference far exceeded my hopes and expectations. I thought it a brilliant strategy--and hopefully a new trend in medicine--to bring researchers from all over the world together with family members of victims. Here there were people who have lived firsthand the spiritual, emotional and physical impact of CJD, interacting with those on the cutting edge of the challenging biomedical fight against this formidable enemy. I feel certain the exchange between these two groups must have exponentially bolstered the fight against CJD. Further, I was not only truly inspired to talk with the researchers, but also with Florence Kranitz and her colleagues at the CJD Foundation. They became my role models.

Last, I learned that through activism--like our visits to Capitol Hill--you can empower yourself and memorialize your lost loved one in ways that, hopefully, will transcend time. I left the Conference knowing that my Marcy was smiling, and that I definitely had found the right people to help us in our struggle.

Tracey Miesner, Missouri:

This July was my first CJD conference, and to say I was nervous and overwhelmed is an understatement! I'm not quite sure what I was expecting, but I can safely say that I'll be returning. My family has been touched by a familial strain of CJD known as FFI and it has been rarely talked about outside our family. To come to this conference where we were able to speak openly and candidly about such a scary topic with people who actually understood what you were talking about was very therapeutic. It felt like coming home!! Where else can you find medical professionals and researchers who are the top in their fields, willing to not only share their research findings, but to sit and field questions from family members? It was extremely humbling and heartwarming. And to top it all off, I was able to meet Florence, the woman of many hats who has made all of this possible! She is such a wonderful transition between the professionals and the family members and I felt honored to meet her. What a truly amazing weekend: I headed home filled with hope and a sense of belonging to a special community, and have some new friends that I know will be life-long! Thanks for the life-changing opportunity!

Veronica Oberdorf, Virginia:

I didn't think anything good could possibly come from the death of 'my good man' and husband, Paul, to cjd (I prefer not to capitalize because it gives the disease more respect than it deserves). But... I found BLESSINGS at the Family Conference: others who had shared the same pain, no explanations necessary, an immediate kinship with wonderful warm individuals; one on one access to the researchers from around the world working on this disease; the opportunity to connect with those on the Hill that have the power to affect positive change; and the pleasure of meeting the voices at the Foundation who helped me during the darkest of days. While the gaping hole in my heart from the loss of my husband will never be closed, the Conference was a soothing salve, like aloe to a burn. Thank you to all who participated!

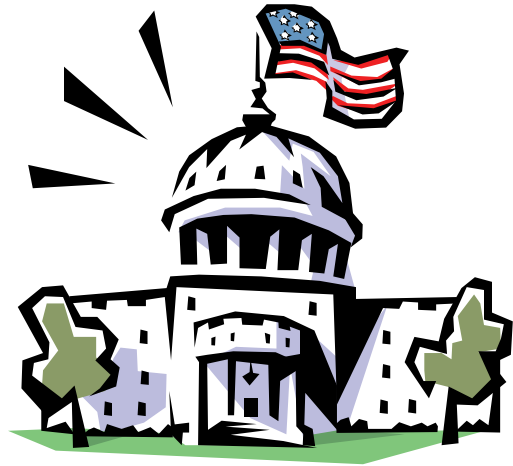
Advocacy Day Reflection

By: Julianne Prescop

I volunteered to do advocacy work for the CJD Foundation almost without thought. Speaking to congressional staffers on Capitol Hill about Creutzfeldt-Jakob disease seemed like a good culmination to the CJD Foundation Family Conference, so I signed up, without questioning what I would have to say or whether I would be able to make a difference.

As the day of the advocacy visits approached, I began to get more nervous and even thought about backing out. I imagined being questioned by hostile staffers and not knowing what to say. After all, just six months previously, I had only heard about CJD in newspaper articles about mad cow disease and I assumed that the United States had never had a case of CJD. How could I be expected to answer questions about CJD or the Foundation's legislative requests?

I didn't lose my nerves until halfway through my first advocacy visit. The staffer was kind, seemed interested in our policy proposals, and was eager to tell us of the work that the Senator was already doing to increase funding for disease research. When I realized that the staffer was just as concerned about impressing us, her constituents, as we were with impressing her, I began to relax. I realized that what we were asking for was less important than the fact that we were there, asking for it. I realized that congressional staffers, like myself, six months previously, had probably never met anybody who suffered from CJD and had probably never really thought of the disease as a real problem.



So, I told the staffer about my mom. I told them how, on her 53rd birthday in January, she had been perfectly healthy, vibrant, intelligent, and just plain wonderful. I told them how, over the next few months, she began to lose control over everything that made her who she was: her ability to walk, to speak, to communicate, and even her personality. I told them how hard it was for me and my family to care for her, and to know that the same thing will happen to other people – because if it could happen to her, it could happen to anybody. And, I gave them her picture.

While I doubt that I changed anybody's mind regarding the fundamental role of government in funding disease research or regulating industry, I know that the next time these issues come up for a vote, those staffers will remember me, remember my mom's story and her face, and remember that, whichever way they vote, they will be affecting real people who have suffered and are still suffering from this disease

