



NEWSLETTER

JANUARY 2017

Welcome to our first addition of the CJDISA Newsletter!

The purpose of this newsletter is to provide updates on the activities of the CJD International Support Alliance (CJDISA) and the Patient Member Organizations from around the world. As we continue to grow, and with the various time zones of the members, we are using this forum to stay connected and to provide information to all those that we support and advocate for.

Suzanne Solvyns & Deana Simpson

New Members: We are pleased to announce that we have two new Associate Member Organizations - Brazil and India! Patients and families will have access to individuals who can support and assist them within their native countries. Visit our website for contact information.

www.cjdisa.com

Other News: The CJDISA is pleased to announce that Deana Simpson accepted a nomination and will continue as co-chair of the Alliance, with Suzanne Solvyns, for another 2-years.

PRION 2017

The Prion 2017 Research Conference is scheduled for May 23 - May 26, 2017 in Edinburgh, Scotland. Members of the CJDISA will be in attendance to represent those affected by Prion Disease. The CJDISA will be presenting on Thursday, May 25 and will be submitting a poster abstract to highlight the work of the CJDISA. We will host a CJDISA meeting and a Friends & Advisors meeting during Prion 2017. Invitations will be emailed out with details.

Research Update - PRN100: Researchers at the Medical Research Council (MRC) Prion Unit, and other researchers around the world, have conducted long-term research to investigate potential antibody treatment for prion disease to see if such treatments might work and what side effects or other safety issues might be anticipated. The MRC Prion Unit has developed a potential antibody therapy which they are preparing to test clinically for the first time in a **small number of UK patients with sporadic CJD**. The Cure CJD Campaign is a group of individuals personally affected by prion disease who are raising funds to support this research (www.curecjd.com).

MEMBER REPORTS



Australia - Suzanne Solvyns

The CJD Support Group Network (CJDSGN) Australia held the 9th Annual National CJD Conference in Melbourne on 12th November 2016. Professor Richard Knight from Edinburgh UK, Dr Byron Caughey from Montana USA and Professor Michael Geschwind from California USA were keynote speakers from overseas. Professor Steven Collins, Professor Andrew Hill and Associate Professor Victoria Lawson and Professor Georges Grau also attended together with many others who are involved in research and surveillance in Australia. Attendees of over 100 represented CJD family members, recipients of human pituitary hormones, health care professionals and our research and surveillance community. Four very brave family members told their personal story emphasizing the need for research and the promotion of awareness of this rare disease.

The CJDSGN awards this year went to Professor Martin Delatycki, geneticist who recently chaired a working group initiated by the CJDSGN to produce guidelines for PRNP testing, and Dr Cathryn Haigh, an Australian researcher who has assisted the CJDSGN to develop processes that help identify priorities for the ever increasing amount of family donations we can offer to our researchers as memorial awards and grants. The legend award this year went to David Ralston, chair of the management committee of the CJDSGN, who has for over 20 years, as a volunteer assisted the development of our network, the establishment of our education program, our annual conference but more importantly the support we can offer to those personally affected by prion disease in Australia.

We were also able to acknowledge CJDSGN memorial donations totally \$181,300 that were provided, due to the generosity of CJD families and friends, to assist research in Australia. Some of this funding has gone to assist the establishment of the RT-QuIC diagnostic tool for Australia.

The Australian National CJD Registry (ANCJDR), our surveillance unit in Australia, has announced that Dr. Christiane Stehmann has been appointed to the role of coordinator of the registry. Christiane has been instrumental in assisting the development of a successful working relationship between the CJDSGN and the ANCJDR. We are confident that working with Christiane we will see ever more advancements that will benefit surveillance and support for CJD families.



France - JB Mathieu

MCJHCC was established in 1996 in response to a French health scandal, whereby 982 children were exposed to contaminated human growth hormones (hGH) in the 1980's. Among them, 120 have died and 862 have survived. The organization is aimed at providing mutual support, providing help to newly affected families, and leading legal actions against those responsible for this disaster. On December 8, 2016, the Paris Court of Appeal recognized the "prejudice of anxiety" of 22 of the survivors, belonging to the cohort of the 982 children that were exposed. Compensation in the range of € 10,000 - 50,000 have been granted to the plaintiffs. This is our first success at the judicial level.

India - Suhani Chhparwal

I have been personally affected by CJD with several members of my family having battled the disease with my father currently actively suffering. I am very committed to being the conduit in India to help Indian patients and families affected by prion diseases. I am in the process of establishing "CJD Care India" and will be working on a website soon. Dr. Annu Agarwal, a neurologist in India, has agreed to be the medical director for the group.



CJD Insight USA - Deana Simpson

Much of my time is spent supporting families with genetic CJD and my work with the CJD International Support Alliance. It is with a heavy heart that I share with you that my family has been stricken again by CJD - my cousin is currently in active disease at the young age of 58. Please pray for her and our family.



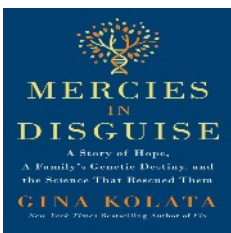
USA - Debbie Yobs

The October 2016 Strides for CJD was very successful. More than 1,000 people participated across the country. Funds raised will be applied to our vital programs in advocacy, family support, medical education, and research.

We hosted 15 Family Teleconferences which were attended by nearly 500 people. Families were able to ask questions and hear from various guest speakers who are experts in prion disease, genetic counseling, and grief support. Our HelpLine received 1,300 calls and emails and our website had more than 34,000 visits in 2016. We also held Grand Rounds in six states and Family Workshops in five states.

The Family Conference in July was well attended and featured five researchers who shared their work that was funded by families through the CJD Foundation Research Grant Program. In May 2017, we will be announcing our 2018 Research Grant Program - visit our website for more information.

www.cjdfoundation.org.



A new book is being released on March 21st by New York Times best selling author, Gina Kolata. The book, "Mercies in Disguise: A Story of Hope. A Family's Genetic Destiny, and The Science That Rescued Them" tells the story of CJD Foundation Board Member Amanda Baxley Kalinsky and her family, the path to diagnosing the disease (GSS) that affects multiple family members, and how Amanda changed the future of prion disease in her

family. You can purchase this book through smile.amazon.com using this line:

<https://smile.amazon.com/ch/65-0404623>. Amazon will donate 0.5% of the book price to Creutzfeldt-Jakob Disease Foundation Inc.



United Kingdom - Gillian Turner

The CJD Support Network's main role is to provide practical and emotional support for families and professionals affected by CJD. Our main service is our 24 hour Helpline, where we have answered over 13,000 calls. We have undertaken other complimentary tasks over the years. In December of 2015, the UK CJD Support Network celebrated its 20th year of providing support to those impacted by prion disease.

Since 1995 we have hosted 8 conferences, held family support meetings, and produced 23 newsletters. We have also written CJD guidelines for Social Workers and Nurses, prompted the Department of Health to produce CJD Health Guidelines, assisted the World Health Organization (WHO) to create the World Guidance for CJD, and sponsored research at the National Prion Clinic for sporadic CJD.

Our website is an integral part of our support to families and professionals, attracting five to six thousand unique visitors from all over the world each month. The Network has been recognized as a strong advocate for those affected by prion disease and, as such, participated on several important Government Committees ensuring that the patient and carer's views were considered in administrative, political, and medical decision making.

Along the way we have met and worked with some wonderful families, carers, committee members, and professionals, too many to mention here. We would like to thank them all.

We have given support and advice to similar Support Networks from around the world as they started up their organizations, including Japan, USA, and Germany. We are a proud member of the CJDISA. Since its formation, we have the confidence of knowing that when we are approached by families in European and other countries, including those where no support group exists, we can pass enquiries through its growing network, knowing they will get the support they require.

We would like to recognize and thank our Friends and Advisors (F&As). Their expertise and willingness to help guide our work and help those impacted by Prion disease is greatly appreciated. We are delighted to welcome Dr. Annu Agarwal, from India, as our 33rd F&A member. Thank you all; for always being there when we need you!

Australia

Professor Steven Collins

Professor Simon Hawke

Jennifer Cooke

Professor Andrew Hall

Canada

Professor Neil Cashman

Dr. Kevin Keough

Valerie Sim, MD, FRCPC

France

Dr. Jean Brugere-Picoux

Dr. Jean-Phillipee Brandel

Germany

Inga Zerr, MD

India

Dr Annu Agarwal

Israel

Ruth Gabizon, PhD

Italy

Professor Maurizio Porchiari

Professor Fabrizio Taliavini

Professor Gianluigi Forloni

Associate Professor Gianluigi Zanusso

Mexico

Victor Sanchez, MD

Spain

Professor Joaquin Castilla

United Kingdom

Professor Robert Will, MD

Professor Richard Knight FRCP(e)

Margaret Leitch, RN

Dr. Simon Mead

USA

Professor Pierluigi Gambetti

Paul Brown, MD

Associate Professor Brian Appleby, MD

Lawrence Schonberger, MD

Ermias Belay, MD

Associate Professor Michael Geschwind, MD, PhD

Jiri G. Safar, MD

Croine Lasmezas, PhD

Eric Minikel

Sonia Vallabh

Dr. Glenn Telling