

## EDUCATION AND AWARENESS PROGRAM

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In an attempt to resolve many of the issues facing individuals suffering with suspected CJD, their families and those at increased risk of developing CJD, in early 2008 we launched our educational DVD 'Understanding CJD'.

With the assistance of notable Australian experts on prion disease and infection control experts in Australia, this DVD was produced as a tool for our national education and awareness program that is targeted at health care professionals. By sharing some of our experiences during our presentations we hope to dispel many of the myths and stigma associated with classical CJD (cCJD), promote better awareness and knowledge of this rare and fatal neurological disease and more informed care for CJD patients.

We hope that the information provided by our presentations and the DVD will assist health care professionals when dealing with an 'at risk of CJD' patient and that by working together we can create an environment where these patients feel comfortable and confident of receiving equity of care when disclosing their at risk status.

**For presentation enquires: 1800 052466 or [contactus@cjdsupport.org.au](mailto:contactus@cjdsupport.org.au)**

## THE FAMILY ACCESS PROJECT

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Access for carers and family members to counselling, education and support services.

The primary purpose of the ACCESS project is to extensively improve the experience of families caring for a loved one with suspected CJD by the provision of information regarding free or minimal fee services available. These include health, social and support services and information on genetic health services in each state of Australia.

Part of the ACCESS project has been the creation of a comprehensive data base that helps us to:

- \* Monitor the needs of families.
- \* Maintain a registry of services
- \* Establish a unique contact list of facilities and health care professionals knowledgeable about CJD.
- \* Maintain a network of genetic services around Australia which have an understanding of the issues facing CJD families.

Our contacts include medical staff who are knowledgeable and keen to assist our families and offer advice to other health care professionals as well as hospices and nursing homes experienced in caring for CJD patients and those able to offer respite.



## THE CJD SUPPORT GROUP NETWORK

is contracted to and funded by the Department of Health and Ageing to provide support, information and assistance to all Australians affected by Creutzfeldt-Jakob Disease (CJD) or other prion disease.

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### CONTACT US

**National Toll Free Number  
1800 052466**

**[contactus@cjdsupport.org.au](mailto:contactus@cjdsupport.org.au)**

**[www.cjdsupport.org.au](http://www.cjdsupport.org.au)**

## **WHAT IS (CJD)?**

CJD is a rare and fatal degenerative brain disease in humans. CJD is one of a group of diseases that affects humans and animals known as transmissible spongiform encephalopathies (TSE) or prion disease. CJD is unique in that it can be genetic and is transmissible. CJD is invariably fatal with no effective treatment or cure.

## **WHAT IS THE CJD SUPPORT GROUP NETWORK (CJDSGN)?**

The CJDSGN was established in 1994 to support recipients of human pituitary hormones. In 2004 the CJDSGN was restructured and funded to increase activities to provide support and information to all Australians affected by CJD or prion disease. The CJD Support Group Network is a founding member of the CJD International Support Alliance.

## **WHO WE CAN HELP**

- Families caring for or coming to terms with the loss of a loved one to CJD.
- People with a genetic predisposition to CJD and their families.
- Recipients of human pituitary hormones who have been identified as 'at increased risk of developing CJD', their families and other at risk groups.

## **SERVICES WE PROVIDE**

- Membership is free for people at increased risk of developing CJD and family and friends of CJD patients.
- A national toll free help line.
- An expansive website.
- An informative newsletter.
- Support, assistance and information packages for CJD families.
- Information packages for health care professionals caring for a CJD patient.
- An annual National CJD conference.
- Presentations at conferences and medical facilities.
- We advocate on behalf of our members experiencing delays or discrimination when accessing medical care and liaise with state health departments and the Australian National CJD Registry.
- We provide a mechanism for the DoHA to receive comments and concerns of human pituitary hormone recipients and CJD family members.
- We assist families to fundraise for CJD research.

- We are able to connect members to share experiences and provide mutual support.

- We promote awareness and knowledge of prion disease and represent the views of our members in other forums.

## **BECOME A MEMBER OR REGISTER AS AN INTERESTED PARTY**

Membership is free for family and friends of CJD patients and people at risk of CJD.

Health care professionals or others can request inclusion on our electronic 'Interested Party' List.

Contact 1800 052 466 or visit [www.cjdsupport.org.au](http://www.cjdsupport.org.au) for details.

## **TO MAKE A DONATION**

To make a donation to CJD Research [www.cjdsupport.org.au/donations.php](http://www.cjdsupport.org.au/donations.php)

To make a donation to support a fundraising event [www.cjdevents.org](http://www.cjdevents.org)

Information brochures and fact sheets are available on request. These can also be downloaded from our website.

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