Australian Government
Department of Health and Ageing

HPH newsletter

Providing information on the Australian Human Pituitary Hormone Program

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If you would like to receive the *HPH newsletter*

or if you have any queries about treatment with human pituitary hormones

please contact us

- **by telephone 1 800 802 306 (free call)**
- **by fax on (02) 6289 2500**
- **by e-mail CJD@Health.gov.au**
- **or post to**

Zoonoses, Foodborne & Emerging Infectious Diseases Section
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News from the Department of Health and Ageing

Review of the Human Pituitary Trust Account

Since the Human Pituitary Hormone Program ceased in 1985, the Commonwealth has provided funds for counselling for recipients and their families, a support group network for recipients, and a number of medical research projects from the Pituitary Hormone Trust Account (PHTA). The Department also provides funding to support the Australian National CJD Registry (ANCJDR).

In 1994, Professor Margaret Allars conducted the *Report of the Inquiry into the use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob (CJD) disease* known as the Allars Report. The Allars Report recommended that the PHTA and the Creutzfeldt-Jakob Disease Support Group Network (CJDSGN) be reviewed by 2010. A review is currently underway and the reviewer has been in contact with both the ANCJDR and the CJDSGN. The review will assess the appropriateness, effectiveness and efficiency of support to the CJDSGN and Registry and make recommendations regarding future funding.

CJD Nationally Notifiable

In September 2003, the Communicable Disease Network Australia endorsed the latest version of the list of communicable diseases to be notified nationally which included Creutzfeldt-Jakob Disease (CJD). Tasmania, Victoria, Western Australia, South Australia and New South Wales have included CJD in their State notifiable diseases list, the remaining States and Territories are expected to follow. In some jurisdictions this has meant a lengthy process associated with amendment to existing legislation.

The reporting of diseases such as CJD enables monitoring and investigation of these diseases in the community in order to prevent the spread of these diseases and reduce their impact on others.

Medical in confidence letter

The *'Medical-In-Confidence - To Whom It May Concern Letter'* letter was developed to assist recipients in accessing medical care, this letter was revised in 2008 to reflect the changes to current infection control standards and best practice. Just as a reminder if you would like to receive the updated *'Medical-In-Confidence - To Whom It May Concern Letter'* please contact the free call line 1800 802 306 and a copy will be sent to you.

When this letter is updated in future to reflect infection control standards, the Department will automatically send the latest version to recipients who have previously requested a copy.

Infection Control Guidelines (ICGs)

The ICGs are available to the public and provide guidance on infection control strategies, environmental cleaning and protection of health care workers in health care facilities. The ICGs cover all kinds of transmissible diseases including viruses (eg. hepatitis C, rotavirus), bacteria (eg. staphylococcus, tuberculosis) and other diseases like classical CJD (cCJD).The ICGs are designed to be used by all health care workers, such as hospital and clinic infection control staff, nurses, clinicians and dentists. Chapter 31 of the ICGs relates to cCJD, including sporadic CJD, inherited CJD and iatrogenic CJD, but excluding variant CJD (vCJD).

During 2007, the cCJD Chapter of the ICGs was reviewed by an expert panel and revised to ensure a more concise format. The procedures and processes which infection control staff use to evaluate a patient and determine the best way to protect them and subsequent patients has been simplified into a dichotomy for classification of transmission risk based on the tissues exposed during a procedure and the risk status of the patient. The precautions which need to be taken when a patient at risk of cCJD is identified have also been simplified to minimise the risk of transmission of cCJD and minimise occupational hazards for health care workers. The result is more user-friendly ICGs.

The entire ICGs are currently undergoing further review by the National Health and Medical Research Council on behalf of the Australian Commission for Quality and Safety in Healthcare and expect to be finalised this year.

If you are undergoing a procedure, your healthcare provider can download a copy of the cCJD Chapter of the ICG free of charge from the Department of Health and Ageing website (www.health.gov.au). The CJDSGN or the State or Territory Health Department can also provide further advice on infection control in your situation.

CJD Support Group News

2010 'Understanding CJD' Conference

The CJD Support Group Network (CJDSGN) is currently organising the third annual conference to be held in Melbourne in May 2010.

The first conference was held in Melbourne in 2008 followed by the conference this year in Sydney. Attendance at the annual conference is free for all members of the CJDSGN, their families and friends. All recipients of human pituitary hormones and their families, who are not currently members of the CJDSGN, are also welcome to attend the conference free of charge.

Since the restructure of the CJDSGN in 2004 the focus and work of the network has grown. The funding agreement with the Department of Health and Ageing has been expanded to support all Australians affected by CJD or other prion diseases. This includes other 'at risk of CJD' groups and families who are dealing with or have lost a loved one to CJD.

It has been encouraging at meetings to see how supportive recipients have been of families affected by sporadic or genetic forms of CJD. As CJD occurs at random in about one person per million of the population each year there are about 25 – 30 families each year who lose a family member to this devastating disease.

The support and resources available for families has been crucial and the expansion has meant that the CJDSGN continues to provide for recipients needing advice and assistance, an active and well connected network. The CJDSGN provides an informative website, resource material and an education/awareness program for health care professionals aimed at reducing the infection control problems that we often face when accessing health care.

At the 2008 and 2009 conferences we were fortunate to have Australia's leading researchers and experts attending as speakers giving our audience the opportunity to learn

more about research on prion disease being conducted in Australia and overseas as well as information on many topics of interest including infection control, experimental treatments for CJD patients and the management of CJD.

Professor Colin Masters, Associate Professor Steven Collins, Professor Andrew Hill and Dr Victoria Lawson from the University of Melbourne, Professor Simon Hawke from the University of Sydney and Ms Alison Boyd from the Australian National CJD Registry gave freely of their time to present current information for our members.

This year we were also honoured to welcome Professor Richard Knight from the National CJD Surveillance Unit, Edinburgh UK, and for the second year Ms Margaret Leitch, who is the national coordinator for CJD patients in the UK. Both Professor Knight and Ms Leitch funded their travel to Australia to share information on surveillance, research and the situation in the UK.

For the 2010 conference we are delighted to have the interest of a number of overseas experts keen to attend and to provide a variety of information for you all. We are hopeful of welcoming representatives of the member organisations of the CJD International Support Alliance (CJDISA). The CJDSGN was a founding member of the CJDISA in 2006 and working with, and sharing resources, with like organisations around the world has greatly enhanced the services that we are now able to provide as well as encouraging and giving us the confidence to hold an annual conference.
For the past two years attendees at the conferences have included people from every state and territory in Australia as well as from New Zealand. Although the conference is designed to supply information for members we do encourage any interested health care professionals to attend providing they cover the cost of their attendance.

In order to provide availability for as many people as possible we are planning in 2010 to hold a full day meeting in Perth prior to the Melbourne conference and we are hopeful that we can encourage several of the speakers to join us for this meeting. Following the Melbourne conference there will also be an information afternoon held in Sydney. If we are able to continue to provide an annual conference in the future we will be mindful of providing access for members in other areas of Australia.

If you are not already a member but would like to receive an invitation to the conference please email contactus@cjdsupport.org.au or ring our toll free number 1800 052466.

Copies of our DVD 'Understanding CJD' are available free of charge for members. The DVD provides an excellent resource tool for your GP or any other health care professional and covers the current infection control guidelines.

We have an extensive electronic 'Interested Party' list of health care professionals interested in receiving up to date information or resources to which you are welcome to add your doctor or dentist.

Suzanne Solvyns
Director
The CJD Support Group Network

Incident Panel Report for 2009 activities

Over 2009, the National CJD Incident Panel (CJDIP) was convened to assess and advise on a number of issues. The first was in relation to surgery after a suspect CJD diagnosis had been made. The remaining six requests were made for advice before surgery, when medical staff were planning to undertake procedures and were seeking clarification of patient's CJD risk status and the appropriate infection control measures needed. The following summarise the Incident Panel's requests and the advice provided.
1. A patient with recurrent eye infections underwent draining of intra-ocular fluid on two occasions for diagnosis and treatment. Several weeks after the eye procedures, an acute illness which involved cognitive impairment emerged, which led to the clinical suspicion of CJD shortly before death. There

was no referral for autopsy. A routine medical risk assessment identified the ocular procedures during the patient's possible CJD illness. The procedure was reviewed and the instruments involved identified as a part of the risk assessment, and promptly placed in quarantine by the hospital. The local health authority concerned sought the CJD Incident Panel's advice on the assessment of the CJD risk for these instruments. The assessment revealed the procedure only involved the anterior chamber of the eye, and as a consequence no additional infection control measures were necessary. The quarantined instruments were safely returned to general use.

2. Four patients presented separately over 2009 for either spinal or cranial surgery after previously being notified by a local health department about a possible CJD exposure from previous surgery they have undergone. The initial CJD risk notification by the hospital and local health authority had alerted several hundred patients treated by the health service of their "low risk" CJD status when the potential for a surgical exposure to CJD had been identified, several years earlier. The risk status advice was based on the Australian infection control guidelines and current scientific knowledge about CJD. The local health authorities and /or treating medical staff requested the Incident Panel advise on these four patients' current risk status for CJD, and also for sterilisation advice for the management of any neuro-surgical equipment used in their future surgical procedures. The Incident Panel reported that the risk assessment to these four patients' could be downgraded from a "low risk" status, to a background population risk level. Consequently, after careful review of the initial CJD patient surgery event, the dates involved for all these patient's surgeries, and the sterilisation of the surgical equipment, these four patients were considered to require only routine sterilisation measures for all their future surgery.

3. Hospital medical staff requested advice from the Incident Panel in relation to clarifying the risk group classification for a further two patients requiring surgery involving the central nervous system. One patient had reported a suspicion of a family history of CJD and a second raised the possibility of a growth hormone treatment when younger. The Incident Panel was able to clarify the CJD risk levels and advised on appropriate infection control measures.

Infection control developments for surgery

Pre-surgical assessment of patients according to either a high, low or background population risk for CJD has been relied on around the world, to assist hospitals and health care services manage CJD transmission risks, particularly for patient's undergoing neuro-surgical procedures. Because the disease associated transmissible agent causing CJD is difficult to destroy by routine hospital sterilisation methods, additional management methods of patients with a higher or lower risk for CJD will need to continue. Consequently, the pre-surgical risk assessment will continue as an important basis for minimising the surgical transmission of CJD in hospitals.

During 2009, the Australian bio-pharmaceutical group Novapharm Research P/L released two new products that they claim are prionicidal agents. These new enzymatic cleaning products are released under the trade-names Asepti RAPIDZYME Pr and Asepti AUTOZYME Pr. They are designed to augment routine cleaning and sterilisation methods already used on surgical and endoscopic equipment in the health care setting. The Novapharm Research P/L Asepti solutions are claimed to be the first prionicidal cleaning products that can be easily incorporated into hospitals routine sterilisation procedures on surgical and endoscopic equipment. These products are intended to provide a greater level of reassurance for the management of routine sterilisation methods and for inadvertent surgical transmission events, when higher level infection control sterilisation methods are needed.

Authors:
ANCJDR/CJDIP