



CJD SUPPORT GROUP NETWORK NEWSLETTER

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www.cjdsupport.org.au

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DEPARTMENT OF HEALTH & AGEING

General information for human
pituitary hormone recipients.

Toll Free 1800 802 306

CJD Support Group Network (CJDSGN)

The last 6 months have been extremely busy with Infection Control problems effecting recipients of hPH commencing prior to the year even beginning. As the time progressed so did the number of health care related issues that were, not only extremely stressful for the recipient involved and their family, but on the main completely unnecessary. We did note however, that although last year we were assisting several Victorian recipients with outstanding Infection Control issues that no new problems have been reported to us from that state this year. We can only assume that the CJD consensus workshop held in November 2004 has been extremely beneficial in educating health care workers about the implementation of the Infection Control Guidelines (ICG's) that were endorsed in 2004.

Following years of contact from families of victims of CJD, the committee of CJDSGN has decided to assist and encourage support for other groups affected by CJD to develop as part of our network. This period has seen a lot of work undertaken by the committee together with Alison Boyd from the Australian National CJD Registry (ANCJDR) on the beginnings of a support group for families of familial CJD (fCJD).

Electronic Medical Records are under trial in several states and we will be attempting to keep current with the progress especially in relationship to privacy issues. As an organisation we are joining the Consumer Health Forum and via this newsletter and state meetings we aim to bring you current information on what is developing in each state.

Following a meeting with representatives of the CJD Support Network Japan last year in Brisbane we have continued to build on contacts with overseas CJD Support Networks. Already in contact with CJD Support Network UK, we have also established contact with BSE Foundation in UK, CJD Foundation and CJD Aware in USA.

Carol and Suzanne are flying out the first week of July 05 to Washington DC to attend the CJD Foundation of USA annual conference. We have been asked to give a presentation on our CJD Support Group work in Australia and also hope to establish contact, on behalf of familial CJD families in Australia, with Deana Simpson who is involved with support for families of fCJD families in USA.

We welcome the families of victims of CJD and hope that this newsletter can develop to be supportive and informative for all whose lives are touched by CJD in Australia. Our aim is to present articles that are of interest to all members and hope that you will appreciate the content that those with knowledge have agreed to contribute to this and future newsletters.

Frequently Asked Questions- Creutzfeldt-Jakob Disease (CJD)

What is CJD?

CJD is a rare and fatal disease of the nervous system. CJD is one of a group of diseases that affects humans and animals, known as the transmissible spongiform encephalopathies (TSE) or prion diseases.

Are there different forms of CJD?

Yes there are. Classical CJD (cCJD) may be sporadic, familial or iatrogenic

Sporadic (sCJD) is a rapidly progressive disease that occurs at random in approximately one in a million of the general population. (About 20 cases each year in Australia) Sporadic CJD accounts for 85% - 90% of all cases and effects mainly people in the 50 to 70 age group. Sporadic (sCJD) is not inherited and does not effect or put family members at risk of CJD.

Familial/inherited (fCJD) is very rare and only accounts for about 10% of all cases. Included in this group are familial CJD (fCJD), Gerssstmann Straussler Scheinker Syndrome (GSS) and Fatal familial insomnia (FFI).

Genetic prion disease is usually recognised from a family history of the illness in siblings and parents and/or positive prion protein gene (PRNP) testing. It is passed at conception via the bodies genetic material, DNA. A child born from a parent carrying genetic CJD has a 50% chance of inheriting the disease causing mutation. Not all mutations prove to be transmissible during a lifetime.

Iatrogenic/health care associated (iCJD), although rare, has occurred worldwide as a result of a number of medical treatments.

The use of human pituitary hormones has resulted in 5 deaths in Australia – 3 definite (hPG), 1 probably (hPG) and 1 possible (hGH) No recorded cases in Australia since 1991. Worldwide approximately 178 cases

Dura Mater grafts – a tissue that covers the brain, is used in brain surgery and some other operations, to repair damaged membrane. 5 cases recorded in Australia, worldwide the figures stand at approximately 170 cases.

Cornea grafts – Three cases worldwide (no recorded cases in Australia).

Exposure to contaminated neurosurgical equipments. – Five cases worldwide but none since the 1970's. (no recorded cases in Australia)

Variant CJD (vCJD), the human form of bovine spongiform encephelopathy (BSE) commonly known as "mad cow disease" has not occurred in Australia, although there are approx 160 cases worldwide with the majority of those recorded in UK.

VCJD was first recognised in 1996 in the UK after the first death occurring in England in 1994.

Variant CJD is probably related to the consumption of bovine spongiform encephalopathy (BSE) contaminated meat products following the epidemic of BSE (a prion disease that occurs in cattle) in UK cattle during the 1980 and 1990's. Australia is a BSE free country with no case ever reported in our cattle.

Is Variant CJD different to other forms of CJD?

Yes, vCJD sounds the same as CJD but they are different diseases and present differently.

CJD FOUNDATION- USA: CJD Family Conference Washington D.C. 9– 12th July 2005

By the time you receive this newsletter Carol and Suzanne should be winging their way to Washington DC to contribute to a section on "Support Organisations around the World".

Our appreciation goes to the CJD Foundation in USA for the invitation and to the Department of Health & Ageing (DoHA) for their approval of this trip which should be a very moving and educational experience.

Speakers at the conference include:

- Florence Kranitz, President CJD Foundation
- Dr Robert Will National CJD Surveillance Unit, Edinburgh, Scotland
- Dr Paul Brown – former Medical Director, NIH – USA
- Dr Pierluigi Gambetti, National Prion Disease Pathology Surveillance Centre USA
- Dr Nicolai Rainov, Department of Neurological Science UK
- Dr Robert Rohwer, Molecular Neurovirology Unit USA
- Deana Simpson – familial CJD
- Graham Steel – BSE Foundation UK
- Don Simms – father of Jonathan first PPS patient.

Support group meetings will be held in all states during August and September to provide members with the wealth of information that should come out of this conference.

FAMILIAL CJD (fCJD) SUPPORT GROUP

The CJDSGN, originally established as a support service for recipients of human pituitary hormones who are at low risk of health care associated CJD, acknowledges the need for support for all who are affected by various forms of CJD in Australia.

The CJDSGN has for many years been regularly contacted by family and friends of CJD victims in Australia who have been seeking information and support.

Committee members have been working closely with Alison Boyd of the Australian National CJD Registry (ANCJDR) and familial family members to discuss ways of developing a support group particularly for members of families affected by fCJD.

It is our aim to encourage and assist such a group to develop and become part of the CJD Support Group Network so that familial family members can share experiences and support others who are caring for, or coming to terms with the loss of a loved one to CJD, especially the inherited/ familial form.

The CJDSGN will continue to encourage other such groups to develop so that the usefulness of the grant, structure and information network can be extended to support all Australian whose lives are touched by CJD. We thank the DoHA for being positive and supportive of this new endeavour and subsequent changes to our structure and purpose.

A new section is to be added to our Website www.cjdsupport.org.au and we thank members of the Brown family, particularly Mandy, for their contribution and willingness to share their experiences to help other family members who are looking for information on our website.

MANDY'S STORY

My family and I were first acquainted with the CJD Support Network Australia last year after losing my father, Graham Brown, to familial CJD (fCJD) on August 23rd. The preceding 2 to 3 weeks were spent conducting invariably fruitless searches for information on fCJD and other groups or individuals in Australia that may have been able to offer advice or information about a disease we had no prior knowledge of.

A particularly frustrating discovery for us during the final weeks of Dad's life, as he continued to deteriorate at a rapid rate and we continued our seemingly futile search for information, was that unfortunately there was no support group in Australia at all for families like ours.

I noticed however that the CJD Support Network web site, which I understood was specifically for the support of recipients of Human Pituitary Hormone (hPH) who may be at low-risk of contracting Creutzfeldt-Jacob Disease (CJD), mentioned that it was more than happy to speak to people who may have been affected by other variations of CJD, such as familial. This seemed like a good place to start and I eventually established quite frequent contact with Suzanne Solvyns, who was extremely helpful and most sympathetic regarding the lack of support for individuals affected by other variations of CJD. This "gap" in the support structure led to discussions between committee members of CJD Support Group Network and Alison Boyd of the National CJD Registry, who all agreed that the expansion of the CJD Support Network to an extensive group, inclusive of all people personally affected by CJD would be a logical "next step".

Naturally my mother, sisters and I were delighted when we were advised that we were able to launch our own "arm" or sub-section on the CJD Support Network web site that specifically addressed issues that may confront family members who, like us, were desperate to find information and support as they cared for their loved one dying of CJD. Specifically, we wanted to address particular issues we had personally confronted, such as the difficulty of obtaining a diagnosis during the onset of the illness, palliative care, grief and genetic counselling.

We are very wary that much of what we discuss on the fCJD arm of this web site may be particularly confronting to those of you who are hPH recipients. It may not be easy to read about the CJD experience and its effect on the families left behind. We would encourage you then to approach the content of the fCJD arm of this website with thoughtful consideration and should you choose not to read its contents, we ask for your respect and understanding that as members of the Australian CJD community, we believe that every 'voice' of CJD – iatrogenic, sporadic, familial– should be heard, regardless of their personal circumstances.

Thank you for hearing us! Mandy

THE AUSTRALIAN NATIONAL CREUTZFELDT-JAKOB DISEASE REGISTRY

The CJD Support Group Network committee has asked for information about CJD research performed in Australia. Along with research performed by the Australian National Creutzfeldt Jakob Disease Registry (ANCJDR) based at The University of Melbourne, CJD research is performed by 3 separate laboratory groups that together combine to form the Prion Research Group (PRG). The PRG are focused on prion protein diseases. A fourth group is planning to establish in Sydney.

Prion diseases of humans are neurodegenerative disorders which currently have no cure. They are associated with the build up of a misfolded (disease causing) form of an otherwise normal protein, called the prion protein. Prion protein is normally found throughout the body, but it is most abundant in the brain. Prion diseases share similarities with other neurodegenerative diseases such as Alzheimer's and Parkinson's disease, which also involve the accumulation of misfolded proteins. Prion diseases are unique in that the misfolded form of the prion protein has infectious properties which can transmit the disease.

The major aim of the PRG is the development of diagnostic and treatment strategies for this group of diseases. We aim to achieve this by studying the disease at several levels, including:

- understanding the normal function of the prion protein.
- examining the key events or steps involved in forming the change from the normal protein to the rogue form of the prion protein
- identifying what happens to a cell when it is infected with the abnormal protein.

In the past the group has developed several experimental systems for looking at these aspects of prion diseases and has published many publications in leading international journals. One recent significant development for the group has been the purchase of a fluorimeter, a significant piece of equipment made possible by a generous donation from one family. The fluorimeter will open new areas of research to be explored by the PRG, expanding research techniques available to the group.

Alison Boyd ANCJDR

Donations to CJD Research in Australia can be made by contacting the Australian National CJD Registry at the University of Melbourne 03 834419

MEDICAL IN CONFIDENCE LETTER

For recipients of hPH there is now a revised version of this letter that relates to the current Infection Control Guidelines. This does explain your risk status and gives contact details for health care professionals/workers.

The latest version is dated February 2005, so if you have not received your updated version or would like to register to receive this and future versions please contact Jennifer Wall at the DoHA. 1800 802306/ email Jennifer.wall@health.gov.au

ELECTRONIC MAILING LIST

This has proved to be very successful for those of you who like to be kept informed and are interested in information that comes our way. We have two systems:

1. You receive all information electronically. Newsletters invitations and extra articles of interest.
2. You can receive all of the above but still receive mail-outs of the newsletter and invitations.

To subscribe to our electronic mailing list please email us: Contactus@cjdsupport.org.au

WEBSITE

We are very pleased to report that our new website in the first 6 months has recorded almost 4500 visits with over 13500 hits. This is a long way from recorded reports for the previous website for 6 month period during the 2003/2004 period of 112 visits. We once again thank Matt Smith for his assistance and expertise.

Recipients of hPH are always keen to be kept informed of any developments in the field of CJD and are reassured to know that independent expert bodies are monitoring matters of particular concern. In this article, Professor Ryan gives an overview of the committee he chairs.

NHMRC Special Expert Committee on Transmissible Spongiform Encephalopathies (SECTSE)

In December 2000, the National Health and Medical Research Council established SECTSE with the following major objective: "To provide independent, expert and timely scientific analysis and advice to Australian governments, drawing on contemporary scientific data and knowledge, on all matters necessary to prevent and limit the spread of variant Creutzfeldt-Jakob Disease (vCJD) and other transmissible spongiform encephalopathies (TSEs) in Australia."

SECTSE is an interactive committee, regularly inviting updates from the various government departments and agencies involved with the committee and other interested parties. Its work is wide-ranging and encompasses the following:

1. Assessing and minimising the potential risk of TSEs
2. Infection control
3. Ethical and legal issues
4. Linkages with national and international committees
5. Contingency planning / risk management planning
6. Advice to governments and non-government agencies.

SECTSE is accepted as the peak national body for the provision of expert scientific advice regarding bovine spongiform encephalopathy (BSE) and CJD (including vCJD). Its key achievements include:

- advice that supported the development of safer animal feeding practices (eg ruminant feed ban), stronger approaches to surveillance, and the national BSE contingency plan;
- advice and community consultation that supported implementation of blood donor deferral decisions;
- advice that has supported decisions in relation to human therapeutic goods (eg vaccines, plasma products, insulin, Lyodura);
- advice that has supported decisions in relation to the importation of human food products;
- advice in relation to organ and tissue donation;
- advice in relation to infection control practices;
- advice in relation to ethical and legal issues, particularly regarding the operation of the Australian National CJD Registry;
- advice supporting the listing of CJD as a notifiable disease;
- advice in relation to the BSE outbreak in Canada and USA;
- advice that supported the development of the Commonwealth contingency plan should a case of vCJD be confirmed in Australia;
- advice leading to the establishment of the National CJD Incident Panel.

The major current issues of consideration for SECTSE relate to preserving the integrity of the blood supply in Australia, particularly in view of the recent reports in the UK of two instances in which variant CJD (vCJD) may have been transmitted by blood transfusion.

SECTSE maintains a "watching brief" across the spectrum of important TSE issues in Australia, including matters of concern to the CJD Support Group Network. Fortunately, as time extends since the (hopefully) last occurrence of CJD following human pituitary hormone exposure in Australia, the ongoing risks of such exposure should be lessening in our community.

The CJDSGN merits congratulation and encouragement for the superb role that it performs in keeping hPH recipients and others well updated about important CJD-related issues such as through its excellent website and newsletter.

Professor Graeme Ryan, Chair SECTSE.

INFECTION CONTROL ISSUES FOR "LOW RISK" PATIENTS

As already mentioned this year the CJDSGN has been involved assisting and supporting several recipients of hPH who have experienced problems when accessing dental and medical health services. These problems, causing emotional and stressful times for those involved and their families, have been for the most part completely unnecessary. The Infection Control Guidelines (ICG's) that were published in June 2004 are sometimes being misinterpreted by health care workers resulting in "low risk patients" being treated as "high risk patients" or "low infectivity tissue" being treated as "high infectivity tissue".

The current ICG's basically state that a "low risk patient" (recipients of hPH come into this category) should be treated with standard precautions with routine reprocessing of instruments unless high infectivity tissue, including brain, spinal cord, eye (retina and optic nerve) and pituitary are involved and in dentistry additional precautions are only recommended for maxillofacial and endodontic procedures.

These guidelines are much less stringent than the previous NHMRC guidelines so why are so many problems occurring now?

- We can also assume that media coverage of "mad cow disease" overseas and media coverage of the Royal Melbourne Incident have increased awareness of CJD but not knowledge.
- The ICG's are only recommendations and cannot be enforced, so if a health care worker decides to treat anyone at risk as high risk to be on the safe side then we are discriminated against.
- The problems are also occurring in Private Hospitals and centres and advice we have received is that they do not have to take us on as a patient if they have concerns.
- There is a lot more screening (questions about CJD) on forms that are required to be filled in at hospitals, dentists rooms etc.
- The new version of the Medical in Confidence letter (MICL) that is available for recipients of hPH to present to health care workers was only sent out in March, so presentation of the previous MICL that referred to NHMRC guidelines did cause some confusion.

What can CJDSGN do to assist?

- We have contacts and experts who can advise health care professionals of correct procedures so we are able to assist you with any problems or questions you may have.
- We have put together a proposal, with the assistance of A/Prof Paul Johnson, Deputy Director, Infectious Diseases, Austin Health in Victoria, that has been sent to the Department of Health and Ageing (DoHA) in Canberra, and has subsequently been brought to the attention of the ICG Working Group. This suggests a series of information sheets covering various procedures (Medical, dental and optical) for both high and low infectivity tissues, outlining the infection control guideline recommendations for various procedures. These could be obtained from the DoHA to be attached to the MICL, and would be a quick and effective way of informing the Infection Control Nurse and others of what is required. A/Prof Johnson has offered to trial such a scheme at his hospital.
- We are currently working on establishing contacts in each State/ Territory who can assist with problems. After attending the CJD consensus work shop organised by Victorian Health in November 2004 we now have a good network of contacts in Victoria. Following representation to Mr Michael Richardson and his speech in NSW Parliament on 22nd March 2005 we have been contacted by a representative of NSW Health who has already assisted us with a NSW health problem and we have been invited to write an article for the "In Control" newsletter that is distributed to around 3,500 health care professionals in NSW. In SA a contact has now been established and we have a possible contact in QLD.

Cecile Wise hPH recipient from NSW writes...

In the past few years I have had to undergo a number of medical in and out patient procedures in hospitals. Inevitable my "low risk of CJD" status has presented as a mammoth problem to hospital and medical staff. An example of this is that three years ago I found myself barrier nursed in a major Sydney hospital.

"The squeaky wheel gets the oil with the aid of the CJD Support Group Network"

Being set up with this type of treatment I employed the aid of CJDSGN to fight my battle. Suzanne and her contacts were sensational and I am in awe of the commitment and energy that Suzanne and Carol put into my cause.

My advise to any person who finds themselves in a position where hospital and/or medical staff are treating them "differently" because of their risk status, is to contact their support group coordinator and ask for their assistance. Unbeknown to me CJDSGN has resources at its figure tips with a network of contacts and experts to assist, and consequently due to the Support Group's involvement, my issues were resolved.

ICG WORKING PARTY IS CURRENTLY REVISING INFECTION CONTROL GUIDELINES.

A departmental representative on the ICG Working Party has advised:

"At the ICG Working party meeting in March 2005 the recent experiences of hPH recipients were raised. Of particular concern were situations where the current guidelines are clear that treatment other than neurosurgery and some major dental procedures should not require additional precautions. At the meeting, the ICG working party agreed that an education strategy should be developed to accompany the ICG revisions.

Supporting materials, such as the information sheets suggested by CJDSGN, would be considered as part of such a strategy. It is anticipated that a revised structure of the CJD component will make it easier for infection control practitioners to navigate the document itself and locate relevant information."

ELECTRONIC MEDICAL RECORDS

HealthConnect is a National system that is not scheduled to be up and running until 2008. Trials have however been occurring in Tasmania, SA, Northern Territory and Queensland (Townsville and South Brisbane).

Tasmania is due to begin implementation in November 2005 closely followed by SA. These trials are being conducted by State/Territory Departments in conjunction with the Commonwealth.

NSW is currently piloting an electronic health records system called Healthelink, which is planned to be rolled out statewide by June 2006. This we understand will eventually work in conjunction with the National HealthConnect. It is also our understanding that WA may be working on a system in line with what NSW is doing.

There is a lot of debate going on between consumer groups and by joining the Consumer Health Forum we will be kept current with the developments.

There would seem to be a lot of logical reasons for such a system to be of benefit but also a lot of questions regarding privacy issues and in our case what our records would disclose about our CJD risk status.

Plans do indicate that there will be ways to protect delicate information and restrictions on who can access what information. CJDSGN is making contact with consumer representatives in each state/territory.

Suzanne Solvyns attended a forum in April in Sydney on Healthelink organised by NSW Health in conjunction with NCOSS, followed by a half day session on HealthConnect.

The biggest debate that will continue for some time to come is the Opt-In or Opt-Out option. HealthConnect, will work on Opt-In so consumers request the option of electing to be involved with electronic medical records. During the trials in Tasmania consumers were interviewed and explained the system. In NSW Healthelink is planned to be an Opt-out option. This means that once you attend a practitioner or hospital your records will be recorded electronically but will not be able to be accessed by other health care professionals/workers for a period of 30 days. During this time you have the right to Opt-out.

The whole electronic medical record debate will certainly be on the agendas of state meetings and we will endeavour to bring you as much information on your state as possible.

OVERSEAS SUPPORT NETWORKS

"CJD is a rare and to date, a globally invariably fatal brain disease. There are now a number of CJD Support Groups across the world. Namely though the use of the Internet, it has been possible for important connections to be established between them. Through the global unity that continues to grow, I firmly believe that by forming such a Global Alliance, these groups combined voice and strength for those who have lost, those current suffering from, and those sadly still to come in the future is and will always be really important. "

Graham Steel- Vice-Chair, Human BSE Foundation www.hbsef.org

Graham Steel is a native of Glasgow, Scotland, United Kingdom and works as a personal injury claims manager. Graham's brother, Richard, was diagnosed with variant Creutzfeldt-Jakob Disease (vCJD) in April 1999 and died in November 1999 at the age of 33.

Graham joined the committee of the Human BSE Foundation as a volunteer in September 2001. Since then, he has acted as Vice-Chair. One of his main initial foci has been to develop and maintain the foundation's website. He is also a Board Director of CJD Foundation as of December 2003.

Over the last year, Graham has devoted much time learning more of the background of TSE's and prion disease, the current rationale of treatment issues and maintaining contact with many researchers in several Continents.

Graham Steels writes for us about vCJD in UK and PPS.

A new form of CJD emerged in the mid 1990's in the United Kingdom. It was initially named New Variant CJD, now commonly referred to as vCJD.

The Human BSE Foundation was created in 1995 - 1996 by family members of some of the early victims. Graham Steel has acted as their Vice-Chair since 2001. Graham lost his brother to vCJD in 1999. Due to the dedicated work of the Foundation in its early years, this resulted in the public BSE Inquiry published in 2000, a National Care Package for sufferers of all forms of CJD and a compensation scheme for vCJD victims and their families. Irwin Mitchell Solicitors had previously been involved in raising Court Proceedings (resulting in compensation in 1997) for hGH CJD victims & families and were chosen by the Foundation as their legal representatives. The vast majority of (not all) claims have now been settled. To date there have been 150 victims in the UK, about a dozen in other Countries (mainly France). At the present time (June 05), there are 6 vCJD patients in the UK, three of whom are receiving experimental treatment.

With hindsight, one issue (out of 16 volumes and 4000 pages) that was raised in the BSE Inquiry was why there was insufficient and indeed no revisited research in relation to a compound called Pentosan Polysulphate (PPS).

In 2001, a 16 year old boy called Jonathan Simms was diagnosed as having vCJD. It is most likely that he caught the disease by eating meat/meat products that was/were contaminated with BSE. His parents, Don and Karen, were told that nothing could be done to save their son's life. Not content with that advice, Don started his search for information on what could be done. He was briefly treated with a compound called Quinacrine, but the treatment was short lived due to adverse side effects. After finding out about PPS through the Internet and Microbiologist Dr Steve Dealler, he found a Neurosurgeon to provide him with advice on how PPS could potentially be injected directly into Jonathan's brain. This form of delivery is nothing new and is a common form of brain surgery. Whilst this was experimental treatment, this was not for experiments sake. After a 9 month Court battle, and a positive judgement, the 'all clear' was given for Jonathan and another vCJD patient to get the treatment. Sadly, the other patient (a young girl) who's condition was not dissimilar to Jonathan's died before she could be treated. Jonathan's condition continued to deteriorate during this time.

After he first received PPS in January 2003 uncharted waters were truly entered into. Thankfully, the "expected" side effects (seizures or even death) did not occur. Small but positive important changes have been seen in his condition and not only is he the longest surviving vCJD patient, he is in a stable condition and a number of observations (objective and subjective) do appear to indicate that PPS has either halted or slowed down the progression of the disease.

Don and Karen would like to accept the advice of their son's GP (Dr Mark McClean) who has said on record that Jonathan is no longer terminally ill.

"The general consensus is that Jonathan Simms is no longer terminally ill - he is no longer in the last days or weeks of life - we hope they are right said Don Simms."

In the UK, apart from 3 vCJD patients, 5 patients with other forms of Prion disease are also receiving PPS. The 8 families collectively are campaigning for proper assessment and data collection and comparison of their loved ones. The overall outcome is unclear in such an unprecedented situation.

CJD SUPPORT NETWORK UK

The following articles have been supplied to us by the CJD Support Network UK and we thank Gillian Turner, CJD Support Network Co-ordinator for permitting us to bring you these articles of interest that recently appeared in the CJD Support Network Newsletter (UK), Issue 14 dated March 2005.

Blood test offers hope for earlier diagnosis

Health news in the *Daily Mail* online 13 October 2004 reported that a new blood test, developed by Proteome Sciences, a company specializing in protein research, could be widely available with twelve months. Proteome Sciences are working with the CJD Surveillance Unit on the test which is devised to target specific protein changes in blood which will allow doctors to diagnose vCJD years ahead of a patient developing symptoms.

Infection Control

The *Journal of General Virology* (2005) 86, 869-878 described research by Professor John Collinge et al at the MRC Prion Unit detailing 'an enzyme-detergent method for effective prion decontamination of surgical steel'.

Effective sterilization procedures for surgical instruments to protect transmission of CJD and other prion diseases have been a concern and a high priority for the Department of Health.

The research showed that the prion-degrading reagents identified in the study are readily available, in expensive, non-corrosive to instruments, non-hazardous to staff and compatible with current equipment and procedures used in hospital sterilization units.

SPECIAL THANKS

Professor Graeme B Ryan AC

Chair NHMRC Special Expert Committee on Transmissible Spongiform Encephalopathies (SECTSE). For time and effort in supplying us with an article of interest and a commitment to keep us all informed of the work of SECTSE.

Alison Boyd

For her article on research but even more for her devotion to the CJD community of Australia and her enthusiasm for the establishment of a fCJD support group, and constant assistance with Infection Control Issues.

Our overseas contacts for networking and sharing:

- **Florence Kranitz**- CJD Foundation USA
- **Chris Brom**- CJD Aware USA
- **Graham Steel**- Human BSE Foundation
- **Gillian Turner**- CJD Support Group Network UK

Jennifer Cooke – Sydney Morning Herald and author of *Cannibals, Cows & The CJD Catastrophe*. For her article SMH 14th March 2005 "Hospitals misreading CJD Risk" (copy available on request).

Mr Michael Richardson – NSW Member of Parliament for taking our Infection Control Issues to NSW Parliament (copy of NSW Legislative Assembly Hansard available on request).

To the special people at the Commonwealth Department of Health and Ageing in Canberra who support and assist us to assist you. **Fiona Brooke, Anna Bauze** and last but certainly not least **Jennifer Wall**, who is always there for us.

Nadine Solvyns, PeachStar Productions for assistance with the production of this newsletter.
newsletter

Committee CJDSGN

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