



CJD SUPPORT GROUP NEWSLETTER

December 2004

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DEPARTMENT OF HEALTH & AGING

General information for human
pituitary hormone recipients.

Toll Free 1800 802 306

CJD Support Group Network (CJDSGN)

The newly structured support group is up and running. We are now known as the CJD Support Group Network Pty. Ltd. (CJDSGN)

As advised in the last edition of the HPH Newsletter sent to you by the department, we have had to restructure to enable us to take over the role of providing services and support to recipients of human pituitary hormones (hPH), and their family members and are currently contracted to, and funded by the Department of Health and Ageing.

In NSW/ACT, Suzanne Solvyns remains as coordinator and will also take on that role in QLD. Carol Wilson, who is the current coordinator for Tasmania will now also become coordinator of Victoria and WA and David Mullan will remain as coordinator of SA and NT.

We welcome a new member to the Management Committee. David Ralston will fill the vacancy that has come about with the departure of the Victorian coordinator. David is a growth recipient, he was a member of the National Pituitary Hormone Advisory Committee, NPHAC, and although David has always been committed to assisting other growth hormone recipients, he is now officially on the committee as a voice and a representative of hGH recipients. We feel that this is a very overdue but very positive move. David has attended several of the state meeting giving hGH recipients a chance to meet and talk with him.

We are implementing some positive changes but initially we have had to sort out our database and mailing lists. Unfortunately the Victorian coordinator, who was also coordinator for QLD and WA has not passed on mailing lists for those states, and consequently we are unable to automatically transfer members in those states to the current support group mailing list. We apologise to those who are affected and thank those of you who have already contacted us and re-established your membership.

If you are receiving this newsletter via the department of Health and Ageing, with a note attached, you are not currently on the support group mailing list and we would ask you to please contact us by mail, email or toll free numbers to register if you would like to continue to be a member, or join the support group, and receive future newsletters, information and invitations.

Our first committee meeting for CJDSGN was held in Adelaide in July 2004 and a SA state meeting was also held at this time. In early August 2004, a QLD state meeting was held in Brisbane to coincide with members of the committee meeting with representatives of the Japanese support group who were attending an International Conference in Brisbane (1st to 8th August, 040. NSW/ACT meetings were held in Sydney and Canberra at the end of August, followed by Victorian and WA meetings in Melbourne and Perth in October.2004. During November, Tasmanian meetings followed in Hobart and Launceston

Website

Our Website has now been updated and revamped. Visit our new and informative site:
www.cjdsupport.org.au

We now have a section called "Articles of Interest" and this will be updated as information comes to hand. We have also included a "FAQ" section. This covers CJD generally and then frequently asked questions from recipients of hPH (also included in this newsletter)

We would especially like to thank our web director, Matthew Smith, for all his work and expert advise. We would also like to thank the department of Health and Ageing for providing a link directly to section 31 (Section on CJD) of the Infection Control Guidelines (ICG), and Alison Boyd from the CJD Case Registry, for the first article in a series of articles on topics of interest. These articles will also be included in each addition of our newsletter.

We hope you find the revised website helpful and easy to navigate. If you have any suggestions, criticism, praise or comments please contact us:
contactus@cjdsupport.org.au

Please note that all committee members have new CJD Support Group email addresses. The personal email addresses that you may have been using will still reach us.

Join Our Electronic Mailing List

If you would like to be included in our electronic mailing list please send your email address to:
s.solvyns@cjdsupport.org.au .

We are now in the position to send bulk emails of newsletters, invitations and information of interest to you via email. You have three choices.

- You can elect to only receive information, newsletters and invitations from us only via email (you will need to advise us of your email address).
- You can receive all information via email but still receive your newsletters and invitations by mail .
- Remain on our mailing list as before. If you do not contact us this is the way we will continue to inform and contact you.

Bulk emails will **not** make your name or email address available to be viewed by any other members of CJDSGN. If you are already receiving information from us via email it is not necessary to re-register for this service.

Articles of Interest

Discussion at support group meetings and questions asked of coordinators show that many members of the recipient community are keen to know that they are up to date with developments in the area of CJD. Alison Boyd of the Australian National Creutzfeldt-Jakob Disease Registry (ANCJDR) has agreed to provide a series of short articles for our support group newsletters. Below is the first of Alison's contributions, an introductory article that we hope will be followed in the future by updates that will continue to provide information that is current, accurate, and we hope interesting.
David Ralston- CJDSGN

The Australian National Creutzfeldt-Jakob Disease Registry

The Australian National Creutzfeldt-Jakob Disease Registry (ANCJDR) was established in October 1993 in response to the four CJD deaths in recipients of gonadotrophin (hPG). The ANCJDR is headed by co-directors Professors Colin Masters and Steven Collins. The ANCJDR was established to perform surveillance of CJD and prion diseases, with an emphasis on monitoring for medically acquired CJD cases in Australia. The ANCJDR is designated a referral centre for human Transmissible Spongiform Encephalopathies (TSE) by the World Health Organization, offering laboratory based TSE diagnostic services.

Current Australian CJD figures for the period 1993-2004 report an overall incidence rate of 1.15 deaths per million people, per head of population, per year. This rate is consistent with anticipated numbers in a population of the size found in Australia. For this introduction, I will provide numbers on the medically acquired Australian CJD cases. In total 10 cases have occurred between 1987 and 2000; four of these were recipients of hPG (3 cases were confirmed with CJD and one case is classed as clinically probable CJD) and a single possible case is recorded in a recipient of growth hormone (hGH). There was insufficient supporting evidence to elevate this case to a firm diagnosis of probable CJD, consequently it is classed as suspicious for CJD only. A further five people have also died confirmed with CJD, with histories of dura mater grafts during neurosurgery in Australia. The risk for medically acquired CJD generates much interest, but the ANCJDR can report there have been no medically acquired CJD cases arising from corneal transplants or through contaminated neurosurgical instruments in Australia, and no cases of medically acquired CJD have occurred after 2000.

Frequently Asked Questions

As a recipient of human pituitary hormones, human growth hormone hGH or human pituitary gonadotrophins.

Can I donate Blood?

No. Currently the blood bank questionnaire identifies and defers recipients from donating blood or blood products.

Can I donate Organs?

Yes you can register as an Organ Donor. Registration forms can be collected at all Medicare offices or you may register on line by visiting:

www.hic.gov.au/organ

The Australian Organ Donor Register (AODR) does prefer that you register as an Organ donor only (not tissues), or flag that you are a hPH recipient. Any organs donated to a organ recipient would be offered on a informed consent basis.

Can I be a bone marrow donor?

Not as this stage. A criteria for becoming a bone marrow donor requires that you are able to donate blood. We are hopeful that this may be changed in the future.

Can my children donate blood and organs?

Yes. There is absolutely no reason why children of hPH recipients cannot donate blood, organs or tissues. Children of recipients of hPH are at no further risk of CJD than the general public.

What is my health risk status?

"Low risk" of CJD

Have there been any more death of recipients of hPH from CJD in recent years?

No – the last case was in 1991.

What is a Medical in confidence letter (MICL) and how do I receive one?

The Medical in Confidence Letter (MICL) is available for recipients of hPH by either requesting a copy from the department of Health and Ageing (1800 802306) or by contacting your support group coordinator. The MICL is just to assist you if you want to advise a medical practitioner of your low risk status. It is personalised and gives details of treatment and contact numbers for health workers to be able to obtain more information.

A new copy, in line with the new Infection Control Guidelines, will be available early 2005 and automatically forwarded to all recipients who have a current copy.

The use of MICL should not be necessary for general surgery or routine dental procedures, only operations involving high infectivity sites. High infectivity sites for low risks patients are the brain, pituitary gland, spinal cord, eye (retina and optic nerve) and in dentistry, maxillofacial surgery or endodontic procedures (root therapy).

There is no obligation to carry or provide this letter. If you have a MICL but are unsure if it is current contact the department of Health and Ageing 1800 802306

Infection Control Guidelines (ICGs)

Revised guidelines were endorsed at the Australian Health Ministers Advisory Committee in January 2004 and were published by the Department of Health and Ageing in June 2004. For the last four years the ICGs have been extensively revised by the Communicable Diseases Network of Australia (CDNA) and the NHMRC Special Expert Committee on Transmissible Spongiform Encephalopathies (SECTSE).

To access the full document visit the ICG website www.icg.health.gov.au

Section 31 and appendix 9 are the sections that relate to CJD. For your convenience, The Department of Health and Ageing have provided a direct link to section 31 on our website: www.cjdsupport.org.au use the ICG Link.

If you are interested in obtaining a copy of Section 31 but have no possible way of accessing a copy from the internet, please contact your coordinator and request a photocopy by mail.

The ICGs are a living document and will be updated from time to time. The department of Health and Ageing is currently establishing a working group to review the CJD components of the ICGs. Recent developments/events indicate that an update is necessary and it is anticipated that the updated text will be ready for endorsement mid 2005 by CDNA.

Note" 31.18 refers to "low risk" people (this includes recipients of human pituitary hormones) should be excluded from the routine donation of organs and tissues. This situation has changed. (See section Organ Donation – FAQ)

Report on meeting with the Japanese Support Group



Held at The Manor Apartments. . Queen Street, BRISBANE Sunday 1st August, 2004 3pm

Present:

Carol Wilson – Director – Coordinator
Suzanne Solvyns – Director –Coordinator

CJD Support Network – Japan
Dr Muneto Ueda M.D - Chairman CJD Support Group Network
Professor Kiyohilo Katahira PhD – Department of Social Welfare, The Toyo University
Mr Akira Nakajima – Lawyer
Mr Ibuki Yamamura – Family member of CJD Victim
Miss Katharina Gauchel – Interpreter

Carol and Suzanne met with the Japanese members of the CJD Support Network at their hotel in Brisbane at 3pm and returned to the apartment in Queens Street for a meeting as previously organised via email. The meeting was conducted with the assistance of an interpreter.

The members of the CJD Support Network from Japan were very interested in finding out details of the support group in Australia and also an overview of the CJD situation in Australia. Suzanne and Carol explained the support group; it's purpose, present role, and future aims.

Discussed

Topics discussed included; the new Infection Control Guidelines in Australia, Health Care Associated CJD cases in Australia (including Dura Mater which was of particular interest to the Japanese CJD Support Network), background information on the hPH program in Australia, the establishment of support services including counselling services, legal actions undertaken by recipients, and information on the ex gratia payments.

Japanese support network members explained the involvement of the support network in Japan. The support network was originally established to support victims and family members of health care related (Iatrogenic) CJD, following people receiving dura mater grafts during neurological procedures, but is now assisting victims and families of all forms of CJD and prion disease. Dura mater continued to be used in Japan until 1997, although usage ceased in most countries around 1990 after evidence of a death. In Japan, as the incubation period ranges from 3 – 30 years, they fear many more case may occur directly connected to dura mater grafts. (20,000 people a year were treated with dura mater in Japan approx 400,000 in total).

In Japan, the use of dura mater grafts until 1997 has so far been responsible for 113 deaths due to health care associated CJD. In Australia this figure is 5 with only 5000 –10,000 recipients of dura mater grafts.

In Japan, ongoing compensation for victims of cases of Health Care associated CJD due to dura mater continues following previous legal action.

The Japanese CJD Support Network advised that with continuation of research in Japan, they are hopeful of leading the world with a test or cure.

"Carol and I found this meeting to be a very special learning experience. We knew very little about the risks of CJD due to dura mater transplants and even less about the death toll associated to this form of Iatrogenic CJD in Japan. We have had no contact with family members of victims of this medically acquired form of CJD in Australia. We therefore appreciated what we could learn from our Japanese counterparts. The Japanese members in turn, having no deaths relating to hPH treatment, were keen to learn from us and our experiences here.

We have committed to stay in touch, to share experiences and knowledge. This can only be beneficial to all of us who are at lowrisk of Iatrogenic CJD around the world."

Suzanne. And Carol

Royal Melbourne Hospital Incident – September 2004

A 56 year old man, who had undergone surgery for brain tumors in January and November 2003 at the Royal Melbourne Hospital (RMH), died in June 2004. Shortly prior to the man's death there was some indication that he may be suffering with CJD but it was thought highly unlikely that he could be suffering from two serious neurological conditions. Following an autopsy, it was confirmed on 7th September 2004 that this man had died from the fatal brain disease, CJD.

It was also confirmed that he had suffered from sporadic CJD (sCJD) and not vCJD, the newest strain that is linked to eating beef products contaminated with bovine spongiform encephalopathy (BSE), or the inherited form of CJD, familial CJD. Sporadic CJD (sCJD), occurs at random and accounts for 85% of all classical CJD cases. sCJD occurs at approx 1.15% cases per million per year in Australia (approx 20 cases per year).

There were some concerns amongst recipients of human pituitary hormones (hPH) that this man may have also been a recipient of hPH but this was not the case.

The National CJD Incidents Panel recommended advising 1056 patients, who had undergone brain or spinal surgery within 18 months of the man's surgery, that they may have been exposed to a possible remote risk of CJD. As there was no instrument tracking system in place at the time, all 1056 patients had to be advised. This number was later reduced to approximately 300. Those patients who had **not** been treated within a 3 months window of either of the man's operations, and patients whose dura mater (membrane that covers the brain) **had not** been penetrated during their operation were all advised that their health status was no longer considered to be at "Low risk" of CJD. The remaining 300 have been advised that they are at "low risk" but that this risk is minimal. CJD has never been transmitted via medical instruments in Australia and worldwide there has not been a case of transmission in this way since the 1970's. Of the 1056 patients initially advised most were from Victoria, with a few from NSW and Tasmania and a small number from SA and overseas.

One who received such a letter was also a recipient of hPH, fortunately she was not one of the 300 who are still considered to be at remote risk due to the surgery, but remains at "low risk" due to hPH treatment.

We had advice, on the situation at the RMH by a teleconference with the Department of Health and Ageing (DoHA) on Monday morning 13th September 2004, prior to a press release. For the next few days our phones rang hot, firstly calls from the media, then from recipients of letters from RMH and also from others how had been operated on at a different time or hospital but still felt concerned.

We worked closely with staff at the RMH during a very stressful time for those patients involved.

Creutzfeldt-Jacob Disease Preventing Transmission in the Health Care Setting Consensus Workshop

Following the experience with the RMH, the Office of Chief Clinical Advisor, together with the Victorian Advisory Committee on Infection Control, facilitated the Consensus Conference on Friday 26th November 2004 in Melbourne. This conference was aimed at addressing the practical issues associated with implementing the Infection Control Guidelines (see section on ICGs).

Invitations went out to hospitals in Victoria, and other appropriate organisations and bodies. Representatives were invited from other states, Fiona Brooke attended on behalf of the DoHA and several members of the NHMRC special Expert Committee on Transmissible Spongiform Encephalopathies (SECTSE) were present. Members of The Australian National CJD Registry (ANCJDR), Professor, Steve Collins and Dr Victoria Lawson were both speakers on the day and Carol Wilson and Suzanne Solvyns were invited to represent the CJD Support Group Network. We understand that the interest in this workshop was overwhelming, with final attendance numbers exceeding the original expectations and many others wanting to attend being turned away because of lack of space.

A very well run day, with an informative agenda, followed the opening of the conference by The Honourable Bronwyn Pike MP, Minister for Health, Victoria.

Other speakers included Dr Michael Gonzales, Melbourne Health; Professor Graeme Ryan, Chair of SECTSE; Professor Andrew Kaye, Neurologist from the RMH; Assoc Professor Paul Johnson (Screening and Risk Assessment); Dr Bill Shearer (Adverse Event Management) and Ms Michele Cullen (Equipment Processes).

Many of you have asked over the years

- "How is it possible to have more education and information on CJD available to the various health institutions and health care workers?"
- "Why do we always have to explain our situation and often suffer from unnecessary stigma, due to our low risk status, when accessing various forms of health care?"

We are optimistic that this sort of conference will go a long way to improve our situation when seeking health services. The interest was positive and the standard of the information and the involvement of the participant at the conference was excellent. We can only hope that the other states of Australia will follow the lead taken by Victoria Health and consider holding similar conferences.

Well, we have finally put to bed the first edition of our newsletter. We are not posting this newsletter on the website as this is a newsletter exclusively for members only. This is your newsletter and we welcome any ideas, editorials or comments.

We would like to say a very special thank you to a few people:

- Fiona Brooke and Jennifer Wall – Department of Health and Ageing. For assisting us with the website but more importantly for being there to assist whenever there is a problem or issue that affects a recipient. They care and they really help.
- Rita Jensen – Department of Health and Ageing for just doing anything possible to assist recipients with the ICGs.
- Jennifer Cooke –author of “*Cannibals, Cows & The CJD Catastrophe*” by Random press, and journalist with the SMH. Thank you for all the information your book has supplied, the interesting meetings you have provided for recipients and most of all for the trust we all have in you as a journalist.
- Alison Boyd, Australian National CJD Registry, for the firsts of many interesting articles to come and for her support during the years.

- Matthew Smith for making our new website happen.
- Nadine Solvyns, for making our logo come to life, for formatting and designing the newsletter and for technical support along the way.
- Special thanks to our families for their support, it has been an incredibly busy but productive year and we could not have done it without all the above support and assistance.

Committee
CJDSGN

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