

## Letters

# Iatrogenic Creutzfeldt–Jakob disease in Australia: time to amend infection control measures for pituitary hormone recipients?

Suzanne L Solvyns and David W Ralston

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TO THE EDITOR: Although we welcome Boyd and colleagues' recommendations for changes to infection control guidelines for Australian recipients of human growth hormone (hGH) and human pituitary gonadotrophin (hPG),<sup>1</sup> we are concerned about the accuracy of the history provided and do not want it misrepresented.

Boyd and colleagues refer to recipients living with anxiety since 1985, when the Australian Human Pituitary Hormone Program (AHPHP) was halted. However, Australian recipients were not aware of the risk until 1991–1992. After the first two recorded deaths from Creutzfeldt–Jakob disease (CJD) of women treated with hPG, their husbands fought for official recognition of the link between their deaths and the AHPHP. In 1992, media attention alerted recipients to the risk and initiated contact from treating doctors. Knowledge that this information had been withheld since 1985 angered recipients.

Boyd et al's article is contradictory in mentioning a possible single, discrete contamination event but also claiming that a higher-risk period is unknown. We challenge this — particularly on behalf of recipients who were informed they had received hormones from a batch identified as likely to have contained the transmissible agent that causes CJD.

We dispute the stated lack of availability of detailed treatment information, as the Australian Government Department of Health and Ageing has meticulously obtained and archived patient notes of recipients from their treating doctors, which provide the most accurate source of data. Boyd and colleagues had access to records of the four

women whose deaths resulted from AHPHP treatment. The records seem consistent with published data,<sup>2,3</sup> confirming that the four women were treated between 1973 and 1978. This surely indicates a high-risk period and gives extra confidence to those treated outside this timeframe.

Further, two of the three patients on whom autopsies were performed received treatment from an identical batch of hormones (44); one was treated with this batch only. The third patient received hormones from batches 43 and 45.<sup>2</sup> Batch 44 was identified as contaminated, and it was theorised that tainted material was transferred to batch 45 via production equipment. The patient who did not undergo an autopsy received only batch 25, which was produced earlier and indicates another possible contamination event within the 1973–1978 period.

Risk estimate percentages do not provide more confidence for recipients than is currently already growing. They do not bring back those who died, take away the guilt of the parents who consented to hGH therapy for their children, or change a history of suicides, broken marriages, anxiety, disgrace and despair.

It is important that Boyd and colleagues do not blur the implications of their findings with the continued need for the Australian Government to maintain the Human Pituitary Hormone Trust Account, which was established to provide funding for counselling and support services for recipients, and ongoing support for this group of citizens whose lives changed forever and who continue to battle discrimination and delays when accessing health care. The recommendations inspire hope but provide no immediate relief. The passing of time brings confidence, but the record needs to respect the enormous impact on the lives affected.

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1. Boyd A, Klug GMJA, Schonberger LB, et al. Iatrogenic Creutzfeldt–Jakob disease in Australia: time to amend infection control measures for pituitary hormone recipients? *Med J Aust* 2010; 193: 366-369. [<eMJA full text>](#) [<PubMed>](#)
2. Allars M. Report of the inquiry into the use of pituitary derived hormones in Australia and Creutzfeldt-Jakob disease. Canberra: AGPS, 1994.
3. Cooke J. Cannibals, cows and the CJD catastrophe. Sydney: Random House Australia, 1998: 224.

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*IN REPLY:* We thank Solvyns and Ralston for their thoughtful and heartfelt comments and their assistance in ensuring historical accuracy regarding the issues surrounding iatrogenic Creutzfeldt–Jakob disease (CJD) risk and recipients of the Australian Human Pituitary Hormone Program (AHPHP).

Whether there is a need for ongoing support of AHPHP recipients for the foreseeable future was not considered in the scope of our report,<sup>1</sup> but we unequivocally support provision of optimal health care services for them, which we believe relaxation of infection control measures will assist.

The delays and manner in which many AHPHP recipients learned of their risk of CJD is certainly regrettable, but this was not the universal experience of recipients. Some were made aware of the risk by their treating practitioner in 1985,<sup>2</sup> with their heightened personal anxiety commencing from that time.

As stated in our report, we agree that the close temporal development of CJD in the four Australian human pituitary gonadotrophin recipients appears consistent with a single, significant contamination event,<sup>1</sup> such as from tainting of a limited number of treatment batches — an observation broadly in keeping with the existence of a higher-risk treatment window. However,

despite assertions to the contrary, data acquired from various sources by the Australian National Creutzfeldt–Jakob Disease Registry for analysis did not permit confident and consistent delineation of a higher-risk treatment group. This is not synonymous with saying that a higher-risk period was unknown to us.

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1. Boyd A, Klug GMJA, Schonberger LB, et al. Iatrogenic Creutzfeldt–Jakob disease in Australia: time to amend infection control measures for pituitary hormone recipients? *Med J Aust* 2010; 193: 366-369. [<eMJA full text>](#) [<PubMed>](#)
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