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27 February 2006

Dear John and Stephen,

**Clinical care and management of recipients of blood transfusion from  
donors who developed vCJD**

Thank you for your letter of 14 February which followed my recent telephone conversations with John concerning recipients of blood from donors who developed vCJD. I am replying to your joint letter and on behalf of Sir Liam Donaldson to the previous letters of 23<sup>rd</sup> and 26<sup>th</sup> January from John.

During my recent telephone conversations with John, I had hoped that I was able to provide reassurance that the Department's top priority has been to ensure that the needs of the individuals identified as 'at-risk' are met and that any further potential public health risk is minimised. To this end, we asked the Health Protection Agency to lead on the follow up of this group of people, liaising with other relevant bodies.

This approach was taken to ensure, as far as possible, comprehensive co-ordination with all of the other key players, such as your clinic, so that the best possible practical and consistent advice would be given. I have asked the HPA to consider the points you raised in your letter and I append their detailed response.

As some time has now passed since the HPA first made contact with this group of people through their GPs, I have agreed with the Chief Medical Officer that an independent group should be set up to review the current arrangements and make recommendations for future follow-up care and support to these individuals. We will want to ensure that the work of this group is fully transparent and that they report speedily.

The implication from your letters is that the group of people contacted in this exercise have not been supported previously. Whilst I fully understand your concerns, I am afraid I cannot agree with this view. The information sent to patients' GPs during the notification exercise (conducted in late 2003/early 2004, and in mid-2005) asked explicitly for the GP to provide information and support to the individuals to help them understand their risk and to take precautions to limit any risk to others. Contact details for the National Prion Clinic (called the MRC Prion Unit during the 1st notification in late 2003/early 2004) were included, alongside contacts details for other relevant organisations including the CJD Support Network and the National CJD Surveillance Unit (NCJDSU). I am aware also the HPA have been in consultation with you for some months to secure your input into the updated information pack for this group.

On the question of whether it is in the best interest of 'at risk cohort' individuals for the GP contact details to be provided to the NPC, the Department's view is that the patients' interests and right to make an informed choice must be uppermost in our minds. They have been informed of the risk to themselves and asked to take steps to protect others. The GPs have been encouraged to refer their patients for specialist care, and provided with details of how to do this. The GP is responsible for the overall clinical care of the person, and is best placed to act as their impartial adviser. The information pack sent from HPA on 6 February makes the options for referral very clear, and the processes to be followed should the individual opt for that choice.

We understand from the HPA that in fact 16 GPs had responded by 20 February, and the HPA are actively following up the outstanding responses. There may be cases where the GP/patient's choice is considered to warrant further discussion with the GP, and I hope that you and others will assist the HPA in reviewing available data to identify such cases and in providing the GPs with further advice through the HPA, as appropriate.

I hope that by replying to you at some length I have clarified a number of key issues. I, and colleagues here including the Chief Medical Officer, want to ensure that the patients receive the best possible coordinated care. We recognise the valuable contribution that your Unit and the other key players make in delivering care and support to patients and families of CJD sufferers. The proposed independent group, which I mentioned above, to advise on these issues will be central to ensuring the best long-term approach.

Regards,

Yours sincerely,

GRO-C

David R Harper

cc: Sir Liam Donaldson