From the Minister of State
Caroline Flint MP

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Dear Mr Morrison

Thank you for your letter of 12 December to Patricia Hewitt about vCJD and the risk of transmission to patients through blood and blood products. I am replying as the Minister responsible for this policy area and I apologise for the delay in doing so.

I fully understand the concerns that many patients with haemophilia may have about the risk of vCJD. Following the identification of vCJD, we have introduced a number of measures to reduce the possible risk of infection being transmitted through blood and blood products. In the absence of a diagnostic test for vCJD we have adopted a highly precautionary approach, taking steps as new evidence becomes available.

You ask a number of questions about vCJD and the risks to haemophilia patients, which I have addressed below.

With regard to the progress of research into treatment of vCJD, as you know, there is currently no treatment for vCJD or related prion diseases. However, a small number of patients have been treated with quinacrine (a drug licensed for use against malaria). The Department has funded the Medical Research Council's (MRC's) clinical trial of quinacrine. It is expected that the results of this trial will be published in the near future. The Department and the MRC continue to support the drug discovery research programme developed by the National Prion Clinic and the MRC Prion Unit. Although no therapeutic treatments are available at the moment, the MRC has set up the New Therapies Advisory Group to identify possible new treatments as soon as possible. This group has already reviewed all the clinical research on treatments for all forms of CJD and has considered another review of all the laboratory-based research in this area. It is expected that these reviews will be published in the scientific literature later this year.

As you are aware, there is currently no validated diagnostic test that can be used before the onset of clinical symptoms to diagnose whether someone has contracted

vCJD. Research to support the development of diagnostic and screening tests is a priority for the Department. We have invested £7.5 million in a variety of novel approaches towards developing diagnostic tests. Several international groups of research workers are developing a blood test, and the National Blood Service is preparing to assess these if and when they become available.

The potential secondary routes of transmission of vCJD are through blood/blood products, and surgical procedures. We have taken a number of steps to minimise transmission through these routes. A list of the steps taken in relation to the blood supply is enclosed at Annex A.

You ask how likely it is that people with haemophilia and related bleeding disorders will develop vCJD. There have been no reported cases of vCJD associated with receipt of plasma products. However, as you know, all haemophilia patients who have received plasma products, between 1980-2001, sourced from UK donor plasma have been designated as "at risk of vCJD for public purposes". All plasma products are now sourced from non-UK plasma. The United Kingdom Haemophilia Centre Doctors' Organisation is collecting data which will provide an estimate on the number of haemophilia patients who have been exposed to plasma products which may be implicated with vCJD.

Further, you ask about the safety of plasma derived clotting factors. It is generally accepted by UK clinicians that recombinant and plasma-derived clotting factors are equally effective in treating clotting disorders. One advantage of recombinant products which are entirely free of human albumin is that they eliminate the risk from blood-borne viruses and the possible risk from vCJD.

However, plasma derived clotting factors are tightly regulated by European and United States authorities to minimise the risk of viral transmission. This is achieved by the screening of donor blood and the anti-viral measures taken during manufacture. In July 1998, we announced that plasma for the manufacture of blood products, such as clotting factors would be obtained from non-UK sources as a precautionary measure against the transmission of vCJD.

In light of concerns expressed by patients with Haemophilia about vCJD we have made funding available for treatment with recombinant products.

Support is available to people with haemophilia or related bleeding disorders who have been notified that they have been in contact with vCJD. At the time of the patient notification exercise, the Health Protection Agency sent out information to specialist clinicians treating people with haemophilia and other bleeding disorders in advance so that they could put in place support mechanisms for their patients. Clinicians were asked to ensure that patients were offered the opportunity for counselling if they wished. It was considered that individual clinicians are best placed to advise their patients, to counsel them and to present information about their individual risk.

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We will continue to ensure that full, up-to-date support is available for all patients who may be concerned, or potentially at risk, including patients with haemophilia or related bleeding disorders.

Finally, you ask that sufficient funds are available so that no treatment is denied or delayed to those who have been identified as at risk. The Department continues to keep all the evidence in relation to transmission of vCJD by blood and blood products under close review. We support policy which will lead to developing our understanding in this area and to ensure that patients receive the best medical treatment available.

It is now widely accepted that blood from an infected donor can transmit vCJD, but the probability of this happening is not known. Whatever the chance of infection, the likelihood of an infected person going on to develop vCJD symptoms is uncertain, and may depend on individual susceptibility.

You will have seen by now that a fourth instance of transfusion-associated vCJD infection has been identified. Three of these patients developed clinical vCJD, whilst the other patient did not develop clinical vCJD, and died of unrelated causes. All these individuals, who were in a small group of 66 patients known to have received blood from a donor who later went on to develop vCJD, have previously been informed of their potential exposure to vCJD. They have been asked to take precautions to reduce the chance of passing on vCJD on to other people via healthcare procedures, such as surgery.

We are concerned to ensure that all individuals notified of their potential exposure to vCJD are given appropriate access to specialist advice and support. We have asked Sir William Stewart to advise us on how this may be best provided, and we are expecting his final report shortly.

Although there have been reported cases of vCJD transmission from blood transmission, as mentioned earlier there are no reported cases of vCJD associated with the receipt of plasma products. Until a diagnostic test is available we will continue to adopt the precautionary approach.

I am copying this letter to Lord Morris, who tabled a Parliamentary Question about our response to your letter.

I hope this reply is helpful.

Yours sincerely

GRO-C

CAROLINE FLINT