

NOTE OF A MEETING
RE: PLASMA PRODUCTS NOTIFICATION IN BCH
ON 14 SEPTEMBER 2004 AT 3.30pm

Present: Dr Miriam McCarthy DHSSPS
Dr Glenda Mock DHSSPS
Dr Frank Jones BCH
Dr David Edgar RVH
Dr Kieran Morris NIBTS
Dr Orla McNulty BCH
Dr Sid Dempsey RVH
Josephine Devlin DHSSPSNI

1. Dr Jones provided an update on progress and advised there were two teams currently searching patient records to identify those who had received plasma products between 1980 and 2001 and as a result may have been exposed to potential vCJD infections. He explained that some records will be incomplete as the procedures for collecting patient information back in 1980/1990 was different to those implemented today when the onus was on the patient to return relevant documentation. Plans remain unchanged and the Haemophilia Centre will issue letters to those patients suffering from haemophilia or some other congenital bleeding disorder that has been identified as "at risk" of vCJD on Tuesday 21 September 2004.

Dr Jones also said he had met with Michael Mc Bride, RVH to agree the content and format of a patient information sheet to issue to patients with the letter. The RVH are also planning on setting up a helpline to deal with any enquiries received from their patients.

2. Dr McCarthy explained the Chief Medical Officer plans to issue a letter to all GP's on Tuesday 21 September advising of the exercise being undertaken by the Health Protection Agency (HPA) Communicable Disease Surveillance Centre. This letter will provide general guidance to GP'S when providing general advice to patients.
3. Dr Edgar reported that RVH were also on track and would be issuing letters on 21 September to those patients with primary immunodeficiency disorders who

have been identified as potentially “at risk” of infection with vCJD. Dr Edgar suggested the letters should be copied to the patients GP’s and Dr McCarthy agreed. Dr Edgar asked what arrangements had been put in place for handling general enquiries from concerned patients and others who believe they may be at risk. Dr McCarthy explained there was information in the letters to patients and GP’s providing details and a telephone number of a general enquiries helpline operated by NHS Direct and its national colleagues. It had been hoped that Northern Ireland could share the Scottish helpline but she had been advised this was not going to happen and herself and Dr Mock were working on setting up an alternative helpline for Northern Ireland.

4. Dr McCarthy emphasised the need for consistency of the information and advice being given to patients and others who may be concerned. Dr Jones agreed and explained that was the main reason for BCH and RVH working together on the to patient information sheet. He advised a meeting of the Haematology Group was scheduled for 20 September and if the information sheet was complete he would table it at the meeting with the suggestion it be shared with all those directly involved in the exercise.
5. Dr McCarthy thanked everyone for their efforts to date and it was agreed provisionally another meeting be held week commencing 27 September, BCH at 3.30pm.