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NORTHERN IRELAND HAEMOPHILIA & THROMBOSIS CENTRE

5th November 2002

Dr K Fullerton Medical Director Belfast City Hospital Trust A Floor Belfast City Hospital

Dear Dr Fullerton

On Friday, 1st November 2002, I was made aware of new developments regarding the SNBTS Factor VIII and Factor IX vCJD Notification Strategy in Scotland. I understand that the question of the Notification Strategy has been raised at Ministerial level within the Scottish Parliament and that the Chief Medical Officer for Scotland has agreed that haemophilia patients in Scotland may be informed of their exposure to affected batches of concentrate. I enclose a copy of a letter dated 29th October 2002 from Dr A Keel, Deputy CMO for Scotland.

I attended an urgent meeting of the Scotland and Northern Ireland Haemophilia Directors Group yesterday in Glasgow. Although the Scottish Office was urging the Scottish Directors to send out pre-prepared letters last Friday, there were practical difficulties in doing so, and it would appear that letters will be sent out within 7-10 days in Scotland.

There are Northern Irish patients who were treated with affected concentrate in Northern Ireland, now resident in Scotland, and my understanding from the meeting was that these patients will be offered the opportunity to know of their exposure. In addition, patients now living in England will be informed by their local English Haemophilia Director.

I would be grateful if you could inform me the most appropriate action to take in view of the above. As you are aware, in March 2002, Dr Campbell wrote to me advising the need to follow advice from the variant CJD Panel.

Yours sincerely

GRO-C

Julia A M Anderson Consultant Haematologist

C c Dr Glenda Mock, DHSSPSNI





SCOTTISH EXECUTIVE

Health Department

Professor G D O Lowe Co-Director Scotland and Northern Ireland Haemophilia Directors Group Haemophilia and Thrombosis Centre Glasgow Royal Infirmary 84 Castle Street Glasgow G4 OSF St Andrew's House Regent Road Edinburgh EH1 3DG

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29 October 2002

Dear Gordon

SNBTS FACTOR VIII AND FACTOR IX VCJD NOTIFICATION STRATEGY

Thank you for copying me into your letter of 24 October to CMO. In his absence on leave this week I am responding on his behalf. The reason that CMO has not responded to your previous letter is that he is awaiting a response from the Incidents Panel. My understanding as of this week is that Professor Banner will be writing to CMO on this issue.

As you are probably aware, Christopher raised the matter with me a couple of weeks ago. My advice to him was that if Haemophilia Directors feel from a clinical and professional point of view that patients should be told about the SNBTS concentrate used for treatment between 1987 and 1989, then they should proceed to inform them, with appropriate counselling. On the basis of the information available to me, it seems unlikely that the Incidents Panel's view will be at variance with this advice.

It would therefore seem entirely appropriate that you write out to haemophilia patients in a similar manner to last year's communication on the BPL concentrates. Given that this will alert all potential recipients to the issue, I see no reason to use any other mechanism, either at Trust or Scottish level, as suggested in your letter, to make the issue public.

I hope this is helpful.

Kind regards,

Yours sincerely

GRO-C DR A KEEL Deputy Chief Medical Officer

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