

HAEMATOLOGY

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NORTHERN IRELAND HAEMOPHILIA COMPREHENSIVE CARE CENTRE

20th December 2002

STRICTLY PRIVATE & CONFIDENTIAL

Professor Frank Hill
Chairman – UKHCDO
Department of Clinical & Laboratory Haematology
The Birmingham Children's Hospital
Steelhouse Lane
Birmingham B4 6NH

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Re: Update on SNBTS notification regarding blood donor diagnosed with vCJD

Dear Professor Hill

Thank you for your recent letter about the notification of patients regarding implicated batches of FVIII from a donor since diagnosed with vCJD. In total around half of the patients have replied to my letter and have been counselled and informed of the exposure to the implicated batch if necessary.

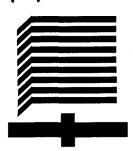
With regards to the media interest, there was a very intense morning on 28th November when my Medical Director fielded around eight 'phone calls from local TV stations and the Northern Irish and Southern Irish papers. There was quite considerable interest from the Republic of Ireland. One of our patients felt it appropriate to go on TV but was really voicing concerns about hepatitis C and compensation issues rather than issues regarding vCJD itself.

Interestingly, the Department of Health in Northern Ireland had not wished to be involved in fielding any media calls, nor had the Northern Ireland Blood Transfusion Service. This had left our own individual Trust at the Belfast City Hospital to deal with all media enquiries. Luckily, my Medical Director has been extremely supportive and prior to the letters being sent out, we had tried to cover every eventuality and this certainly helped on the day. Since that particular time there have been no other calls from the media.

The local Northern Ireland Haemophilia Society was not involved, but I liaised closely with Karen Pappenheim about the UK Society's letters.



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Professor Frank Hill, Chairman, UKHCDO

It is of interest that it was stated quite clearly on the TV by my Medical Director that all patients in Northern Ireland receive recombinant treatment and unfortunately this is certainly not the case. There is, however, renewed interest from the Chief Medical Officer in attempting to fund recombinant therapy for all adults. Half-a-million pounds were found in the June funding for recombinant therapy. However, in a meeting held on 18th December 2002 at the Health Board headquarters in Belfast, it appears that this money will now be used to cover, in part, the cost of two inhibitor patients receiving immune tolerance and one particularly expensive adult patient with inhibitors. We therefore need a further £0.8 million to address the issue of converting patients currently receiving plasma derived therapy on to recombinant therapy. The next meeting will be in early February 2003 but I think I have impressed upon the various Principal Officers acting on behalf of the CMO about the need for a written answer regarding recurrent funding for recombinant product. They seem quite committed to funding recombinant product and it does look promising.

I will certainly keep you informed about recombinant issues in Northern Ireland as I know it may have an impact on the situation in England.

In the meantime, I have a myriad of questions about the vCJD Incident Panel's advice regarding decontamination of surgical instruments/dental instruments in patients exposed to implicated batches of product. This is causing a large amount of anxiety at the Northern Ireland School of Dentistry who wish me to supply a list of affected patients names to enter into dental records. I was anxious to learn more about the handling of such situations in other regions of the UK and how other Haemophilia Directors are dealing with this problem.

Thank you for your letter and with best wishes for Christmas.

With kind regards,

Yours sincerely

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Juffa A M Anderson

Consultant Haematologist/Centre Director

