



**United Kingdom Haemophilia Centre Doctors' Organisation**

**Our ref:** FGHH/PAM (Dictated 09.09.04.)

9 September 2004

**To: All Haemophilia Centre Doctors in the UK**

**FOR URGENT AND IMMEDIATE ATTENTION**

Dear Everyone,

**Re: Notification of patients with haemophilia and bleeding disorders of the changed perception of risk of vCJD by British sourced plasma products and institution of health protection measures**

I have been requested by the Health Protection Agency to notify you of the above. The attachments (Toolkit) about vCJD risks with British plasma sourced products are self-explanatory. Please read the letter to clinicians and then proceed with the requested actions to make every effort to post letters, plus patient information sheets, to patients by first class post on 20 September 2004. I am fully aware that the time scale is extremely short and I have expressed my concerns. There will have been a written statement to Parliament from the Secretary of State for Health today (9 September), which I will copy to you when I receive it.

The first actions required are to brief Centre staff, to ensure that we can get the letters out to all patients so that they are given comprehensive information at the same time.

The letter to patients needs some insertions, telephone numbers, etc. and should go to all patients/or parents of children with haemophilia and other bleeding disorders (that excludes platelet disorders). If possible, use the letter as sent but some may wish to adapt because of local reasons. Ensure you file copies in each patient's notes. It is felt that all patients need to be informed, even those not affected so that they are informed about the events and understand the implications.

The press are to be briefed on 21 September by the Department of Health.

**Cont'd...**

The Haemophilia Society plan to do a mail shot to their members about the issue, including their fact sheet on vCJD on 21 September.

Patients will be advised to contact their Centres if they contact NHS Direct or The Haemophilia Society.

I have arranged an open session for the afternoon of Monday 4 October 2004 at the UKHCDO Annual General Meeting in Edinburgh, with speakers (Patricia Hewitt, James Ironside, Don Jeffries and another from the HPA) on vCJD, epidemiology, risk assessment and health precaution measures. I hope you will all be able to attend the AGM.

I realise this notification will require significant effort on everyone's part, in particular to meet these time scales. I am sure everyone will do their best to achieve the near impossible in the interest of their patients.

If anyone has any queries, please contact me by email ([frank.hill@GRO-C](mailto:frank.hill@GRO-C)) or telephone (work: GRO-C or mobile: GRO-C)

Yours sincerely,

GRO-C

**F.G.H. Hill**  
**Chairman – UKHCDO**

**Encs.**

**Chairman:** Professor Frank G H Hill, Department of Clinical & Laboratory Haematology, Birmingham Children's Hospital NHS Trust, Steelhouse Lane, Birmingham, B4 6NH  
Tel: GRO-C Fax: GRO-C Email: [frank.hill@GRO-C](mailto:frank.hill@GRO-C)

**Vice Chairman:** Dr. Charles R M Hay, University Department of Haematology, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL  
Tel: GRO-C Fax: GRO-C Email: [chay@GRO-C](mailto:chay@GRO-C)

**Treasurer:** Dr Angela E Thomas, Department of Haematology, Royal Hospital for Sick Children, 9 Sciennes Road, Edinburgh, EH19 1LF  
Tel: GRO-C Fax: GRO-C Email: [angela.thomas@GRO-C](mailto:angela.thomas@GRO-C)

**Acting Secretary:** Dr. Gerry Dolan, Department of Haematology, University Hospital, Queen's Medical Centre, Nottingham, NG7 2UH  
Tel: GRO-C Fax: GRO-C Email: [gerry.dolan@GRO-C](mailto:gerry.dolan@GRO-C)

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