



United Kingdom Haemophilia Centre Doctors' Organisation

Date 27 August 2002

Dear Colleague

**RE: The National Haemophilia Database: Your Questions Answered.**

Please find enclosed the above leaflet for patients and their relatives. This leaflet has been drawn up by the UKHCDO Data Management Working Party, in consultation with the Haemophilia Society.

In accordance with the Data protection act of 1998, and subsequent modifying acts, this leaflet must be distributed to patients as the opportunity arises. Please display the leaflet in your Haemophilia Centre, and give a copy of the leaflet to patients as they present to the Haemophilia Centre and when they are seen in clinic. Where possible, the leaflet should be given to the patient prior to consultations so that they have the opportunity to ask questions about it should they wish to do so. Please also make a note in the patient's notes that they have been given the leaflet. Make a note of any questions that they raise.

Recent presentations both at the Haemophilia Alliance meeting, and at the Haemophilia Society meeting, which was held in Manchester, lead me to expect that the patient will view the National Haemophilia Database in an extremely positive light and that the leaflet itself will not generate a lot of questions.

Should you require further copies of the leaflet, please contact the Manchester Haemophilia Centre on 0161 276 4810 and we will send them.

Yours sincerely

GRO-C

Dr CRM Hay  
Chairman, UKHCDO Data Management W.P.

**Chairman:** Dr. F. G. H. Hill, Department of Clinical & Laboratory Haematology, The Birmingham Children's Hospital, Steelhouse Lane, Birmingham B4 6NH  
Tel: GRO-C Fax: GRO-C Email: frank.hill@GRO-C

**Vice-Chairman:** Dr. C. 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

**Treasurer:** Dr. G. Dolan, Department of Haematology, University Hospital, Queen's Medical Centre, Nottingham NG7 2UH  
Tel: GRO-C Fax: GRO-C Email: gerry.dolan@GRO-C

**Secretary:** Dr. R. F. Stevens, Department of Haematology, Royal Manchester Children's Hospital, Pendlebury, Nr. Manchester M27 1HA  
Tel: GRO-C Fax: GRO-C Email: Richard.Stevens@GRO-C