

Appendix B

Ref: BP/LD/Data clean last treated/ 3 - Northampton

Dr Sonia Swart Clinical Haematology Northampton General Hospital NHS Trust Cliftonville Northampton NN1 5BD

U.K.H.C.D.O NATIONAL HAEMOPHILIA DATABASE -Wednesday, 16 July 2008

Dear Dr Swart.

NHD - Data Cleaning Exercise - Severe Haemophilia A and B not treated since 2006

As part of the UKHCDO Data Quality Accreditation Programme, the National Haemophilia Database is reviewing its definition of a 'Registered Patient'. The definition will contain the following:

- A patient who is treated at a haemophilia centre on a regular basis
- A patient who is reviewed at a haemophilia centre on a regular basis

There may be circumstances where a patient may not be seen at their registered centre for extended periods, for example where the haemophilia centre is part of a 'hub and spoke' model, or when the patient is a student registered in a centre close to their home whilst also being registered at a centre near their university or college.

The initial data clean-up will focus on severe Haemophilia A and B patients.

Please find enclosed list of patients registered at your centre who, according to the records on the National Haemophilia Database, have not been treated since 2006.

Please log onto the National Haemophilia Database website (http://nhd.cmmc.nhs.uk/) and amend the patient's record. At the main menu, choose "Report Event Menu", then choose "remove patient".

Please indicate on the attached list those patients who you wish to remain registered at your centre, providing justification. If the patient is no longer seen at your centre, please give a date and the reason for discharge. If the patient is no longer at your centre, please indicate which centre the patient attends (if known).

Please fax the completed list to Lynne Dewhurst at the National Haemophilia Database on GRO-C

Yours sincerely

GRO-C

Ben Palmer Research Analyst Statistician

National Haemophilia Database

Chairman:

Dr Gerry Dolan, Nottingham Haemophilia Comprehensive Care Centre, University Hospital, Queen's Medical

Centre, Derby Road, Nottingham, NG7 2UH

GRO-C Fax GRO-C Email: gerry.dolan@ GRO-C

Research Analyst Statistician:

Ben Palmer, National Haemophilia Database and U.K.H.C.D.O. Secretariat, Haemophilia Dept., Manchester Royal

Infirmary, Oxford Rd, Manchester, M13 9WL

GRO-C Fax GRO-C Email: Ben.Palmer@ GRO-C

Administrator:

Lynne Dewhurst, National Haemophilia Database and U.K.H.C.D.O. Secretariat, Haemophilia Dept., Manchester

Royal Infirmary, Oxford Rd, Manchester, M13 9WL Tel / Fax. GRO-C Email Lynno Dewhurste

Head of Data Services:

Dr Rob Hollingsworth, M.D.S.A.S., The Works Business Centre Ltd, Union Street, Ardwick, Manchester, M12 4JD Tel GRO-C Fax GRO-C Email: Rob Hollingsworth GRO-C