UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

Ref: CRMH/LD/H Lewis

Tuesday, 08 August 2006

Please file in Haydn's notes

Mr Haydn W. Lewis
GRO-C
Cardiff
GRO-C

Dear Mr Lewis,

Re: Query abstracts from the National Haemophilia Database

Thank you for your enquiry. I am sorry that I have been a little slow to respond to this, but I have been on holiday. I will deal with your queries as numbered in your original letter:-

1. Prior to the building of the BPL fractionation plant at Elstree, UK factor VIII was manufactured at the Lister Institute in Oxford. British factor VIII was therefore often referred to as either Oxford factor VIII or Lister. This continued to some extent even after the BPL plant was built. For that reason Oxford, who were running the database at that time coded your BPL product as Oxford Factor VIII, since these terms were used synonymously.

2. Our records show that prior to 1974 you were treated exclusively with plasma or cryoprecipitate. In 1974 you appear to have had your first exposure to factor VIII concentrate with Travenol / Hyland / Hemofil, an American commercial product. Epidemiological evidence published much later would suggest that, if you had not already contracted hepatitis C from plasma or cryoprecipitate, that you would almost certainly have contracted it on your first exposure to this concentrate.
   The reference to Dr Craske has puzzled us since we took over the database in 2002, since Dr Craske was a Virologist who was based in the North West of England but who has long since retired. We believe that in the late 1970's the UKHCDO Liver Disease Working Party conducted a retrospective survey of non-A, non-B hepatitis and that the data from this survey was kept in a file labelled treatment centre code 39 Dr Craske for the sake of convenience. Understandable, this has caused quite a lot of confusion since. The issue of consent to receive this concentrate is between you and your centre and is nothing to do with the database, but it would not have been normal to have asked for consent at that time, and this treatment anti-dates the first description of non-A, non-B hepatitis in patients with haemophilia by 12 months.

3. As you say, your centre reported a factor VIII inhibitor in you for the first time in 1973. It is incorrect to state that you did not receive any factor VIII until 1974, since you received cryoprecipitate and plasma in 1969, 1970 and 1971.

4. I am puzzled by your question here since Koate is not a Scottish product. The printout that we sent you quite clearly shows, in agreement with your notes, that you received Koate in 1984 and 1985. This is an American product manufactured at that time by Cutter.

5. I can only speculate why you were first informed of your HIV status on the 2nd February 1985, whereas we have been told that the date of your first positive test was 15th July 1984. We have a record of two HIV positive tests, one dated 15/02/1985, actually taken after you were told of your status, and the other dated 15/07/1984. This information comes from a form G completed on 5/11/1987. HIV testing was not widely available until late 1984 and early 1985. Some of the better organised centres kept stored plasma samples from their patients and were therefore able to test them retrospectively when a test became available, to better establish the time at which their patients had contracted the infection. It is therefore possible that the 1984 test was a retrospective test, but we have no way of knowing that for sure.

In answering the above queries I have examined the original records sent to us by Cardiff from our archive. If you have any further questions please ask.

With best wishes.

Yours sincerely

GRO-C

Dr CRM Hay
Chairman, UKHCDO

c.c. Dr PW Collins, Consultant Haematologist, Department of Haematology, Haemophilia & Thrombosis Laboratory, University Hospital of Wales, Heath Park, Cardiff, CF14 4XW.

UKHCDO Executive Committee

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: GRO-C

Vice Chairman: Dr Garry Dolan, Nottingham Haemophilia Comprehensive Care Centre, University Hospital, Queen's Medical Centre, Derby Road, Nottingham, NG7 2UH
Tel: GRO-C Fax: GRO-C Email: GRO-C

Treasurer: Dr Angela F Thomas, Department of Haematology, Royal Hospital for Sick Children, 9 Sciennes Road, Edinburgh, EH9 1LF
Tel: GRO-C Fax: GRO-C Email: GRO-C

Secretary: Dr David Keeling, Oxford Haemophilia Centre and Thrombosis Unit, Churchill Hospital, Oxford, OX3 7LJ
Tel: GRO-C Fax: GRO-C Email: GRO-C

Secretariat: Lynne Dewhurst, N.H.D Co-ordinator & UKHCDO Administrator, Haemophilia Dept., Manchester Royal Infirmary, Oxford Rd, Manchester, M13 9WL
Tel / Fax: GRO-C Email: GRO-C

Registered Charity No: 1052808