Minutes of the Thirty Eighth Meeting of the
UK Haemophilia Centre Doctors' Organisation Advisory Committee
Held at 100 White Lion Street, London N1 9PF
Monday, 17th January 2011

Present:

Charles Hay	Chairman/Manchester
Gerry Dolan	Vice-Chairman /Nottingham
Ri Liesner	Treasurer/Great Ormond Street
David H Bevan	St Thomas'
Elizabeth Chalmers	Glasgow RHSC
Peter W Collins	Cardiff
Gillian Evans	Canterbury
Paul Giangrande	Oxford
John Hanley	Newcastle
Christopher Ludlam	Edinburgh
Mike Makris	Sheffield
John Pasi	Royal London
Mike Richards	Leeds
Jonathan T Wilde	Birmingham Adults
Mike Williams	Birmingham Children's
Thynn Thynn Yee	Royal Free, London

1. Apologies for absence:

Dr David Keeling	Secretary / Oxford
Dr David Perry	Cambridge
Dr Vanessa Martlew	Liverpool

2. The minutes of the 37th meeting held on 12th November 2010 were approved.

3. National procurement of clotting factor concentrates Dr CRM Hay

a) National Procurement for home delivery

A number of centres have contracted with a provider outside the national contract, presumably on the basis of price. This is a concern because their service specification may be lower and this sector has a poor record for information technology and handling. BUPA appear to have priced itself out of the market. Their basic price is very expensive and, although they discount heavily in exchange for early payment, is very difficult for hospitals to comply with.

b) Waves 1 and 2 Contract Performance

Dr Hay had reviewed the latest data on performance of the contracts. The contracts appeared to be on target. The main concern in Wave 1 being that the 10% volume awarded to Helixate may not be achieved and that this would trigger a penalty. It was clear that there was significant variation in use across the country but the combined use was within the predicted volume.

Figures for the third quarter for wave 1 will soon be available and should give a better indication of the year-end forecast and whether any corrective action needs to be taken.

For Wave 2, the concern had been that there was a slow response to the contract; largely because this coincided with summer holiday season and patients/staff were not available.

It was agreed that a survey would be conducted to assess:

i. The experience of patients on information received about the contracting process, the arrangements for switching and their satisfaction with their new therapeutic product.

ii. The experience of the Haemophilia Centres with regard to communication of the discussions on the contract, the nature of the contract, necessary actions and response of the suppliers

4. Triennial Haemophilia Centre Audit **Drs. D Perry & CRM Hay**

David Perry had taken over as UKHCDO Lead for Triennial audit.

a) 2009 Audit update

The Audit of the Comprehensive Care Centres is complete. The results have been reviewed by a committee led by Dr Hay and Dr Wilde. Dr Hay as Chairman of the UKHCDO was in the process of writing to the Comprehensive Care Centres asking for their response to the audit reports. There will be a final audit report and this will be prepared following the next meeting of the audit review group on the 4 March. In addition to producing a final report, there would be discussion on UKHCDO accreditation following audit and review of feedback from the patient representative.

It was noted that there had been plans to incorporate the result of the Triennial Audit into the designation process but this process was now suspended by the commissioners and there was no information on whether there were any plans to proceed at a future date. It was proposed that the experience and outcome from the Triennial Audit process should be reported. It was agreed that consideration should be given to publishing the experience of the UKHCDO Audit and it was agreed that this would be discussed by the Audit Review Group on the 4th March.

b) Audit of non-CCC centres

It was agreed that the audit of non CCCs should be the responsibility of the Regional Networks. It was confirmed that Dr David Perry should keep a register of the audits of non CCCs as well as CCCs.

5. Review of HSC 93(30) **Dr CRM Hay**

It was acknowledged that HSC 93(30) was out of date and the Committee supported a revision of this document. The Department of Health have also confirmed that they support updating the document and confirmed that it should be a multi-disciplinary process including commissioners and Department of Health representatives. As HSGs no longer exist, there was a discussion on which body would ratify the document. There is a new national commissioning counsel and advice would be sought from DH as to whether this body should approve the document or whether DH had another mechanism for doing this. There was discussion on the relationship between HSC 93(30) and the forthcoming review of the service specification. It was agreed that the process for review HSC 93(30) should proceed and would hopefully inform the service specification review process. It was agreed that the document should be a United Kingdom document but it is likely there would be some differences between the four countries constituting the United Kingdom. It was suggested that the main document should be generic and would be appendices relevant to each country. The document should include standards that may be audited.

6. Hepatitis C **Dr CRM Hay & Prof CA Ludlam**

a) Revised compensation scheme for HCV

The new Health Secretary had launched a short review on the compensation for hepatitis C. An Advisory Committee was convened which met once and conducted further business by email and telephone. The UK was invited to send three representatives and these were Dr Hay, Dr Makris and Dr Dolan. The rest of the Advisory Group was very similar to that set up to advise on the formation of the Skipton Funds including hepatologists, virologists, Department of Health (DH) representatives and blood transfusion specialists. There was a long discussion on the recommendations made by this Advisory Group. It was acknowledged that there would be a recurrent annual payment for those considered eligible and there would be one off payments for those with evidence of chronic liver disease and an additional sum for those with more advanced liver disease. A concern was expressed about the eligibility criteria for payments and it was noted that there was some differences between these and the criteria used by the Skipton Fund. It was agreed that urgent clarification would be sought with DH and that when the exact criteria were clear, a letter would be sent by Dr Hay to all Haemophilia Centres informing them of the process. In order to help Haemophilia Centres identify relevant patients, a summary document would be prepared by Dr Makris listing the eligibility criteria and the recommended actions. The biggest concern was the deadline for patients to register for compensation. At present this was set at the 31st March 2011 and there was unanimous agreement that this was unrealistic.

Dr Hay as Chairman of UKHCDO agreed that he would write to DH asking for urgent clarification on the criteria for compensation and request that the deadline of the 31st March be extended to a more reasonable time period.

b) NICE Scoping Exercise

NICE had launched a scoping exercise to examine new treatments for hepatitis C. UKHCDO were invited to send two representatives and it was agreed that these should be Dr Thynn Thynn Yee and Dr David Bevan.

c) Hepatitis C Look-back Exercise

Dr Hay reminded the Committee that this project was funded by the Department of Health and that money had been transferred to the National Haemophilia Database for this exercise. He outlined the main aims of the study which were:-

i. To document the current situation with regard to the number of patients that had been tested for hepatitis C, were still with hepatitis C, with complications and treatment status.

ii. To identify those individuals who may have been exposed to hepatitis C but had not been formally tested.

There was considerable discussion on the process of conducting this exercise. It was agreed that all individuals who had been treated by factor concentrate or pooled products such as cryoprecipitate would be eligible for inclusion in this study. It was agreed that this exercise would be a significant amount of work for haemophilia centres and in order to ensure that the process runs as smooth as possible, a clear summary outlining the aims of the study, patients eligible for the look-back exercise, suggested process for examining records would be sent out with a covering letter by Dr Hay. Dr Hay informed the Committee that the National Haemophilia Database would provide lists for all eligible patients who had been registered on the National Haemophilia Database.

d) Penrose Inquiry

Professor Ludlam updated the Committee on this process. He outlined the issues which were that the Committee was examining in detail the deaths of five individuals who had contracted hepatitis C and died from complications of this. The cases would be reviewed in detail and all the main issues would be identified and discussed. There would be a public hearing to take evidence and it was likely that there would be considerable controversy involved in this process. There was some discussion on the time frames involved in the evidence that would be considered by the Penrose Inquiry. It is thought that there would be little examination of any data beyond 1992 and concerns expressed by the Committee that a more complete assessment of the evolution of transfusion transmitted infection and response to this would best be obtained through review of data up to the present day.

7. Treasurers Report **Dr R Liesner**

Dr Liesner presented the Accounts to date. The current account for UKHCDO as of 1 November 2010 and Treasury Reserve Accounts totalled £212,977.66. It was agreed that advice would be sought on investing some of the money held on account.

8. Working Parties

i.) Data management WP *Dr G Dolan*

a) Clinical Outcomes Sub-Group

Dr Dolan informed the Committee that this was identified as a priority by the Data Management Working Party following a meeting in Newcastle to discuss QUIPP. The Secretary of State for Health and DH have identified clinical outcomes as a key priority and this has been taken up by the Commissioners. The UKHCDO Data Management Working Party had convened a Task Force – The Clinical Outcomes Sub-Group, Chaired by Professor John Pasi, to set the achievable clinical outcome measures for haemophilia care. This group is to focus, first on what is achievable easily in the short term and secondly to focus on outcome measures which are desirable but which, by virtue of their resource implications, may not be immediately achievable. This group will report back to the DMWP.

b) Data for Industry

The committee were asked if they were happy for the database to provide data to industry which they may use for regulatory purposes or for market planning. Such data would be anonymised and would not be at a centre level. Industry is increasingly looking to NHD to provide data which may be used for pharmaco-surveillance or which may be used as supporting data for regulatory submissions or for market planning. With those caveats, the committee agreed that it would be acceptable to provide industry with such data.

The last meeting with Industry was judged by participants to be very useful. It is proposed to have a further Industry meeting at some stage later in the year.

ii.) Paediatric Working Party *Dr M Richards*

The PWP has not had a meeting since the last advisory committee / AGM but the neonatal guideline is going through the BCSH process and will be submitted to BJH. A meeting is scheduled for early spring. The group is about to reach its three year lifespan and will have to consider whether it should regenerate and review its remit and membership.

iii.) Inhibitor Working Party *Dr P Collins*

a) New Membership

This WP has been reformed. There were more people applying to be on it than is a reasonable number for a working party. Confirmations will be sent out within a week.

b) Working Party Program

The new inhibitor guidelines are nearly there but 1/2 sections need completing.

A manuscript has been submitted to Blood Analysing inhibitor development throughout life based on the last 20 years of inhibitor reports. This is in the process of alterations to address the reviewers concerns.

The next edition of the Inhibitor Guidelines need to be reviewed and finished and submitted for publication. I revised version will be circulated in advance of the next meeting of this group, which is scheduled for April.

c) Inhibitor surveillance scheme

The WP will continue to work with the NHD to collect more data on inhibitor surveillance over a 3 year period, asking centres to submit data and looking particularly at inhibitor frequency related to switching and those in older age. This will tie into the PTP data collection work that is already underway. We may move towards central testing of samples in the future but meanwhile the NHD has received some financial support from the Baxter and Pfizer for the first year of the Project. Further submissions will be made for subsequent years.

iv.) Morbidity and Mortality Working Party *Dr M Makris*

The guideline on hepatitis C management is in draft form. The paper on vCJD has been accepted by Haemophilia. There was discussion on the inconsistencies of surgery and instruments on high risk vCJD patients, e.g. for liver transplant.

v.) Genetics Working Party

The guideline is being revised as it is 5 years old following BCSH process. The lab network is still very active.

9. Future Meetings

Dates of future Advisory Committee Meetings are:-

Friday 8th April 2011
Friday 1st July 2011
Friday 14th October 2011 – Possible merge with AGM

10. Any Other Business

a) UK Comprehensive Research Network *Dr P Collins*

Peter Collins discussed the importance of the UK CRN (non-malignant haematology section) and how it important it may become in accessing research funds. He thinks there should be collaboration between the NHD and the CRN to help simplify the process whereby companies who want to do trials can find out easily where they would be done. It was agreed that a representative of UK CRN should attend the next DMWP meeting and that we should explore ways of collaborating with this group further. He also thinks that 'Medicines for Children' should be included in that collaboration.

b) Temporary overseas visits by UK Patients Professor K J Pasi

John Pasi raised the issue of patients who leave the country temporarily for >3/12 to travel, e.g. on a gap year. The UKHCDO agreed that as a body it supports visits abroad such as this and would provide them with the drugs/treatment that they require to do so.

11. Date and time of next meetings

Dates of future Advisory Committee Meetings are:-
Friday 8th April 2011
Friday 1st July 2011
Friday 14th October 2011
At the Joint UKHCDO/BSHT Meeting