# Minutes of the Fortieth Meeting of the
# UK Haemophilia Centre Doctors' Organisation Advisory Committee
# Held at 100 White Lion Street, London N1 9PF
# Friday, 1st July 2011

**Present**:

Dr Charles Hay – Chairman/Manchester Adults'
Dr Gerry Dolan - Vice Chairman/Nottingham
Dr David Keeling – Secretary
Dr Ri Liesner- Treasurer/GOS

Dr David Bevan – Guy's and St Thomas'
Janet Bevan - CMU
Dr Peter Collins – Cardiff
Professor Christopher Ludlam – Edinburgh
Dr Gillian Evans – Canterbury
Dr Paul Giangrande – Oxford
Dr Keith Gomez – Royal Free
Professor John Pasi – Royal London
Dr David Perry – Cambridge
Dr Campbell Tait - Glasgow
Dr Kate Talks – Newcastle
Dr Andrew Will – Manchester Children's
Dr Mike Williams - Birmingham Children's

Andrew Rose and Willem van'tHoff attended to talk about NIHR collaboration with NHD.

**1. Apologies for absence:**

Dr Paula Bolton-Maggs - Manchester Adults'
Dr Mike Makris - Sheffield
Dr Savita Rangarajan – Basingstoke
Professor Edward Tuddenham – Royal Free

**2. The minutes of the 39th meeting held on 8th April 2011 were approved with minor amendments.**

**3. HNA application to be affiliated to UKHCDO**. The formal proposal from the Haemophilia Nurses' Association was tabled. Those present agreed that in principle we would agree to an affiliation but that a meeting was needed to agree how the finances would be sorted out. Ri Liesner and Gerry Dolan will liaise with the HNA regarding this and also about the possibility of a joint meeting in 2012. It was not felt appropriate for a representative of the HNA to attend the Advisory Group as it was felt that the raison d'etre of the Haemophilia Alliance was to provide a forum for interaction between the UKHCDO, HNA and patients.

## 4. National procurement of clotting factor concentrates

**Contract Performance**. For wave 1 purchase of Helixate was always going to be a potential problem given the desire to be as close as possible to the minimum limit (as it is more expensive than Kogenate). However, it looks as though the Helixate commitment will be fulfilled. In Wave 2 there were no issues with performance.

**Consideration of roll-over of the contracts at the end of year two**. The current contract is a two-year agreement with two further options to roll the contract over for third and then a fourth year. Those present unanimously agreed that the contract should be rolled-over for a third year for both waves. It was felt that there was no realistic prospect of improving on current prices at the present time. Dr. Hay and Janet Bevan explained that there is a process of due diligence and there will be further stakeholder involvement.

**5. National Commissioning Board Timetable.** The National Commissioning Board (which is within the Department of Health) will be established for 2013/14 and have four regional offices. A replacement for HSG(93)30 will no longer be the responsibility of the Blood Policy Unit but will be under the auspices of the National Commissioning Board. A re-write of the National Service Specification has been devolved to the North-West Commissioners and it may be that the essentials of HSG(93)30 can be incorporated into this new document. It was suggested that the UKHCDO Executive should seek a role in the drafting of the National Service Specification and this should take laboratories (including genetics) into account. Christopher Ludlam asked for the devolved regions to be involved and this was agreed.

**6. Triennial Haemophilia Centre Audit.** The audit proforma is being redrafted for 2012 and there will be a separate proforma for the patient representative. It has been agreed that the UKHCDO audit and the genetics laboratory audit will be merged. It is hoped that the patient questionnaire can be available both on-line as well as in paper format. Networks will be audited as such. It was confirmed, as agreed in the last minutes, that non-Comprehensive Care Haemophilia Centres and spokes of networks should be audited by the Comprehensive Care Centres.

## 7. Hepatitis C

**Revised Skipton Fund compensation scheme for HCV**. There were 499 applications for forms on behalf of patients who had died before 29/08/2003. 347 of these have been returned to the Skipton Fund. 138 of these have been approved with a further 98 likely to be approved after checking. 28 have been declined and 47 are under further consideration. It is understood that appeals will be decided on a "balance of probabilities" basis.

**Hepatitis C Look-back Exercise.** The object of this exercise is to identify patients who are at risk and who have not been HCV tested. The exercise is being conducted at the request of the Department of Health and the devolved administrations and we have a year in which to collect this information. The NHD has received reports on 2,710 patients. All but 188 of these had a single report. It was agreed that we would now only ask the most recent Centre managing the patient to fill in the form. This change will require some alterations to the questionnaire software. Dr. Hay will contact Centres explaining the new arrangements.

**Penrose Enquiry**. Three blocks of evidence have been given in public. The open section on HIV is drawing to a close and this will be followed by a recess. It is expected that HCV will be considered in September.

**8. Annual Report.** Dr. Hay informed the meeting that most of the data was now in.

**9. NIHR Collaboration with NHD.** Peter Collins tabled a document regarding collaboration between the National Institute of Health Research (NIHR) and the National Haemophilia database (NHD). This collaboration will apply to studies that have applied for inclusion on the NIHR portfolio. Studies on the portfolio attract support and resources from the Comprehensive Clinical Research Network (CCRN) through Clinical Local Research Networks (CLRN). This support includes help with R&D, MREC and delivery of the objectives.

When a company or investigator applies for adoption on the NIHR portfolio assessment takes place by the Non-Malignant Haematology Specialty Group (NMHSG) and if children are involved also by the Medicine for Children Research Network (MCRN). Andrew Rose and Willem van'tHoff attended the meeting to explain how these arrangements work.

It was agreed by the Advisory Group that the NHD will facilitate this process. The NHD can establish the total number of patients of requiring age, diagnosis and appropriate inhibitor history in the UK. They will be aware of Centres taking part in competing studies and will be able to assess the potential eligible patients in the UK and where they are.

**10. Treasurers Report.** There is approximately £200K in the current account and Ri Liesner will pursue the possibility of investing a substantial proportion of these monies in COIF Charity Funds.

**11. Working Parties and Task Forces:**

i.) Obstetric Task Force. Dr. Hay will chair this Task Force which will include Dr Louise Byrd, Dr Liz Chalmers, Dr Rezan Kadir, Dr Will Lester, Dr Bella Madan, Dr Sue Pavord and Dr Rachel Rayment. It was agreed there is need for further obstetric input.

ii.) Musculoskeletal WP. This will be chaired by Dr Gerry Dolan and include Dr David Bevan, Dr Pratima Chowdary, Dr Desmond Creagh, Mr Nicholas Goddard, Dr Angela McKernan, Mr Paul McLaughlin and Dr John Hanley

iii.) Data management WP

  a) Clinical Outcomes sub-group. This group has agreed that data for individual bleeds should be collected through the Haemtrak system for the National Haemophilia Database. Patients would be encouraged to use Haemtrak either on PC or using a Smartphone. They will still have the option of filling out paper records but data would have to be inputted by the Data Managers at individual Centres. The Clinical Outcomes Sub-group is to recommend the use of the HJHS joint-score system. This was developed for 14 to 15 year-olds but could be extended to adults.

b) New "Green Card". The new card will shortly be available for Centres to print out locally.

c) Technical update. There needs to be a major technical up-date of the database.

iv.) Paediatric Working Party. Dr. Hay is to ask the previous Chair, Mike Richards, what the remit of a future committee might entail so we can consider whether it should be immediately reformed or lie fallow for a period.

v.) Inhibitor WP. The guidelines are rather long and it was discussed whether a way forward might be to separate acquired haemophilia. If the remaining guideline on congenital haemophilia were too long for the British Journal of Haematology, then it could be submitted to Haemophilia.

Inhibitor surveillance scheme is ongoing and particularly looking as to whether there is an increase in inhibitors associated with switching. Peter Collins emphasised that it is important that the National Haemophilia Database has genetic information for the analysis of inhibitors.

vi.) Morbidity and Mortality WP. Mike Makris was not present at the meeting but he had informed the meeting that the Hepatitis C guideline was now available on-line in Haemophilia.

vii.) Genetics WP. The Working Party is working on an up-date of the guidelines and on the process of adding genetic information to the National Haemophilia Database.

**12. Future Meetings**

AGM 3/10/11. Next Advisory meeting proposed for the first/second weeks of December.

**13. Any Other Business.** There was no other business.