COMBINED 41ST ADVISORY COMMITTEE AND 12TH ANNUAL GENENRAL MEETING of the UK HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

Brighton Dome,
29 New Road, Brighton BN1 1UG

Monday, 3rd October 2011

Present:
Dr. Charles Hay, Outgoing Chairman, Manchester Adults
Dr. Gerry Dolan, Incoming Chairman, Nottingham
Dr. David Keeling, Incoming Vice Chairman, Oxford
Prof Mike Laffan, Incoming Secretary, Hammersmith
Dr. Ri Liesner, Treasurer, Great Ormond Street

Dr. Jayanthi Alamelu, Guy's & St Thomas' NHS Foundation Trust
Dr. David Bevan, Guy's & St Thomas' NHS Foundation Trust
Dr. Myles Bradbury, Cambridge
Dr. Carole Cairns, Belfast Children's
Dr. Pratima Chowdary, The Royal Free
Dr. Desmond Creagh, Truro
Dr. Gillian Evans, Canterbury
Dr. John Hanley, Newcastle
Christine Harrington, Haemophilia Nurses Association
Dr. Dan Hart, The Royal London
Dr. Hussain Hirri, Portsmouth
Dr. Lishel Horn, Leeds
Chris James, Haemophilia Society
Dr. Will Lester, Birmingham Adults
Prof Christopher Ludlam, Edinburgh
Dr. Hamish Lyall, Norfolk & Norwich
Dr. Christine Macartney, Belfast Children's
Dr. Bella Madan, Guy's & St Thomas' NHS Foundation Trust
Dr. Mike Makris, Sheffield Adults
Paul McLaughlin, Haemophilia Chartered Physiotherapists Association
Dr. Carolyn Millar, Hammersmith Hospital, Imperial College London
Dr. Akeel Moosa, Dorchester
Dr. Mary Morgan, Southampton
Dr. Andrew Mumford, Bristol
Dr. Bethan Myers, Lincoln
Dr. John Pasi, The Royal London
Dr. John Rowell, Royal Brisbane and Women's Hospital
Julia Spires, Haemophilia Nurses Association
Dr. Campbell Tait, Glasgow
Dr. Kate Talks, Newcastle
Dr. Henry Watson, Aberdeen
Dr. Andrew Will, Manchester Children's
Heather Williams, UK Haemophilia Data Managers Forum

1. **Apologies for Absence:**

Dr. Rowena Jecock, Head of the Blood Policy Group at the Department of Health – England
Karen Simpson, Health Protection DHSSPS– Ireland
Edwina Hart, Minister for Health and Social Services – Wales
Angela Westoby, Haemophilia Nurses Association

Dr. Mike Williams, Birmingham Adults
Dr. Jonathan Wilde, Birmingham Adults
Dr. Paul Giangrande, Oxford
Dr. Jason Mainwaring, Southampton
Dr. Rhona Maclean, Sheffield
Dr. Julia Anderson, Edinburgh
Dr. Julie Blundell, Truro
Dr. Peter Collins, Cardiff
Dr. David Perry, Cambridge
Dr. Rosie Dennis, Edinburgh
Dr. Vanessa Martlew, Liverpool R.I.
Dr. Keith Gomez, Royal Free
Dr. Oliver G Chapman, Coventry
Dr. Tim Nokes, Plymouth
Dr. Steve Austin, St. Georges'

2. **Election of New Members:**

Dr Raza Alikhan, Consultant Haematologist,University Hospital of Wales
Dr. Joanne Craig, Consultant Haematologist , Inverness
Dr. Daniel P Hart, Senior Lecturer and Honorary Consultant in Haemostasis, Barts and The London Medical and Dental School

The above were unanimously approved as new members.

Dr. Beatrice Nolan, Consultant Haematologist, Our Lady's Children's Hospital, Dublin

was approved as an honorary member.

It was reported that three doctors from Cork may be applying for honorary membership. The Annual General Meeting agreed that the Advisory Committee would be allowed to approve their application for honorary membership.

3. **Minutes of the 11th AGM held on 12th November 2010 and matters arising:** The minutes were approved. There were no matters arising.

4. **Minutes of the 40th Advisory Committee meeting held on 1st July 2011 and matters arising:** The minutes were approved and there were no matters arising.

5. **Chairman's report:** The full Chairman's report appears on pages 1 – 5 of the 2011 Annual Report. Dr. Hay reflected on progress made during the last six years including the further development of the UKHCDO Secretariat and National Haemophilia Database which is now reporting in a timely fashion. There has been the development of several guidelines and the National Service Specification. The constructive working relationship with the Department of Health has continued to be nurtured and has led to two successful national procurement programmes. There are still significant demands and challenges including vCJD, the Skipton Fund, inhibitor surveillance and the HCV look-back exercise.

   Having been run very successfully by Jonathan Wilde, David Perry is now taking over responsibility for the audit programme and there will be a root and branch review including representation from the HNA, the Haemophilia Society, patient representatives and commissioners.

   There is a need to revise HSG (93) 30 and the National Service Specification and this will have to be agreed with the new national commissioning board which will not come into existence until April 2012. Dr. Hay thanked all those who had given him help and support during his six years as Chairman and received a warm round of applause. He was given a gift on behalf of the membership.

6. **National Procurement of clotting factor concentrate:** The contract running from April 2010 lasts for two years with the option of renewing for one year followed by a further year if parties agreed. The UKHCDO Advisory Board has recommended rolling over the contract for recombinant factor VIII for a year but the final decision is between the Department of Health and the manufacturers. The Commissioners from wave 1 are also keen to roll over the contract although there was more discussion from wave 2. The south-east commissioners agreed to roll over, the Scottish commissioners were more reluctant. They have agreed to roll over for one year but for one year only. The Scots will therefore have to have a new contract from April 2013 whilst the rest of the UK may decide to roll over the current contract for a further year to 2014.

   It was agreed that a small Task Force will be set up to consider how to approach commissioning next time in what will be very different circumstances with more products, perhaps including those with a longer half-life.

   There was discussion about the contract for prothrombin complex concentrates. It was agreed that the contract had been undermined by the withdrawal of CSL Behring and the continuing purchase of Beriplex outside the contract. It was agreed that UKHCDO would not be involved with PCC procurement in future as most is used for warfarin reversal.

7. **Triennial Haemophilia Centre Audit/Accreditation:** David Perry was not at the meeting but a report regarding Triennial audit begins on p.114 of the Annual Report.

8. **HCV:**

   i) **HCV Look-back exercise:** the aim is to identify all patients affected with hepatitis C and to calculate the burden of disease for planning. There were 15,057 patients registered during the period of risk (mostly with mild bleeding disorders). 11,567 are still alive. The number of forms received is 3,266. Of these 2,547 are still alive and 719 deceased. 1,493 patients have been exposed to either blood components or concentrate (284 to blood components only, 349 to concentrate only and 860 to both).

It is generally agreed that the burden being placed on Centres is too great. It has been agreed that forms will only be submitted by the Centre who saw the patient most recently. It was also agreed to stop collecting data on dead patients which will reduce the number of forms in total from 15,000 to 11,000. For these 11,000 patients we will collect HCV status so the patients will need an HCV test if they have not had one unless we can be certain they have not been exposed to blood or blood products. Data for planning will come from a randomised cohort. Professor Ludlam asked if the requirement to involve the Caldicott Guardian could be waived but Dr. Hay responded that he could not give this assurance.

ii) **Skipton Fund:** this continues to be major work for some Centres. Dr. Hay reported that where information was missing there was a tentative agreement that cases would be decided on the balance of probabilities.

iii) **Penrose Inquiry:** Professor Ludlam reported that the Penrose Inquiry was moving on to HCV. It will consider HCV testing and its introduction in 1991. Patients will give evidence in December. The transcripts are on the website. The Inquiry should publish next year.

iv) **HCV up-date**: Mike Makris

a) UKHCDO guidelines on the management of HCV in patients with bleeding disorders have been published.

b) Fibroscans are not widely available but patients can get a higher level of compensation if they score >13.

c) New antiviral therapies including HCV nucleotide protease inhibitors (telaprevir and boceprevir) are under consideration by NICE for patients with genotype I.

d) Liver centres are transplanting some HCV positive livers into HCV positive patients requiring urgent liver transplant.

9. **Treasurer's Report and finances:** Ri Liesner presented the Accounts for the year. Total income was £107,252, total expenditure £33,606 giving a net income of £73,646.00. With total funds brought forward of £225,789 this gives a total of £299,435. Ongoing discussions are taking place as to how to invest these. Dr. Hay proposed the Accounts were accepted; this was seconded by David Bevan and agreed by the meeting.

10. **UKHCDO Limited:** Dr. Dolan confirmed that Drs. Hay, Dolan and Professor Ludlam are Directors.

11. **Publications and guidelines:** It was agreed that all the guidelines need to have a review date and we must have a mechanism in place to ensure review of the guidelines so that their life can either be extended or they can be archived if that is appropriate.

12. **Annual report of statistics from the National Haemophilia Database:** Delegates to the meeting received a comprehensive report. Dr. Hay went through some key highlights for the meeting, median usage data with inter quartile ranges and full ranges presented as a box and whisker plots were shown for patients with haemophilia A and B respectively split into those under eighteen and those above eighteen years old. Median usage of factor VIII shows little variation with product. Total use increased over the year by 3.8%, the smallest increase for many years.

    In the future collecting data through HAEMTRACK has the potential to significantly improve our data collection.

13. **Working parties:** The working party reports are included in the full Annual Report. Reports will not be repeated here but a few issues will be highlighted.

    Dr. Andrew Mumford made two proposals; that a small writing group be set up to update the guidelines on inherited platelet disorders and that, separately, the **Rare Bleeding Disorders Working Party** should be re-established. Both were agreed.

    Dr. Pasi spoke about the work of the **Clinical Outcomes sub-group of the Data Management Working Party**. They have been working hard to define minimum datasets for collection. They have developed a standardised patient return form which collects the same data as Haemtrak and he encouraged all Centres to use this. He also spoke about the development of an agreed joint score to be used in adults.

    Dr. Hart gave the **Inhibitor Working Party** report on behalf of Peter Collins. A new guideline is coming to completion. As switching products is becoming such an important issue the Inhibitor Working Party has recommended that when patients switch they need a test before switching and then at least two inhibitor screens in the following six months before they go back to once a year surveillance.

    Dr. Makris, chair of the **Morbidity and Mortality Working Party** said that there will be new recommendations on vaccination and that these would no longer be required if patients were not expected to receive plasma products. He also said that we will need to confirm that we have informed patients regarding their "at risk" status for vCJD.

14. **Reports from Associated Societies:** Reports from the UK Haemophilia Data Management forum, the Haemophilia Chartered Physiotherapist Association, the Haemophilia Nurses' Association, the Haemophilia Alliance, the MacFarlane Trust and the Haemophilia Society are all part of the annual report.

    An important point to highlight is that the physiotherapists have developed an induction pack for a new physiotherapist coming into the area. Dr. Dolan suggested that the physiotherapists might want to organise a workshop and there is an agreed joint score system to be used nationally.

Chris James presented a report on behalf of the Haemophilia Society and all present at the meeting agreed that it is important that the UKHCDO and Haemophilia Society work as closely together as possible.

15. **Future meetings:** The format of future meetings will be discussed at the next Advisory Board.

16. **Any other Business:** There was no other business.