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Minutes of the Twenty-seventh Meeting of the UK Haemophilia Centre Directors' held in Manchester on Friday 29th September, 1995.

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PRESENT: Dr. Brian T. Colvin - Chairman

Dr. A. Aronstam	Dr. J.M. Leslie
Dr. G. Barker	Dr. C.A. Ludlam
Dr. P. Bolton-Maggs	Dr. N. Mir
Dr. M. Chisholm	Dr. V.E. Mitchell
Dr. C. Costello	Dr. L.A. Parapia
Dr. S.V. Davies	Dr. H.F. Parry
Dr. S.I. Dempsey	Dr. J. Pasi
Dr. G. Dolan	Dr. A. Rejman
Dr. D.I.K. Evans	Dr. G. Savidge
Dr. K.K. Hampton	Sister A. Shaw
Dr. C.R.M. Hay	Dr. M.L. Shields
Dr. F.G.H. Hill	Dr. C.N. Simpson
Dr. R.M.I. Janmohamed	Miss R.J.D. Spooner
Dr. P.M. Jones	Dr. R.F. Stevens
Dr. D.M. Keeling	Dr. D.S. Thompson
Dr. H.C. Kershaw	Dr. C.H. Toh
Sister K. Khair	Dr. A.J. Vora
Dr. H.E.T. Korn	Dr. J.T. Wilde
Dr. C.A. Lee	Dr. M. Winter

1. Apologies

Dr. S. Al-Ismail	Dr. R.M. Ibbotson
Dr. B. Attock	Dr. M.W. Kenny
Dr. J. Beard	Dr. M. Laffan
Dr. J.B. Behrens	Dr. R. Lee
Dr. A.J. Black	Prof. G.D.O. Lowe
Dr. J.E. Chandler	Dr. E.E. Mayne
Dr. P.M. Chipping	Dr. E.J. Miller
Dr. V. Chowdhury	Dr. E.H. Moffat
Dr. J.A. Copplestone	Dr. P.J.F. McHugh
Dr. E.R. Craven	Dr. V. Neil
Dr. M.W. McEvoy	Dr. H. O'Brien
Dr. P.L.F. Giangrande	Prof. I.R. Peake
Dr. B.E.S. Gibson	Dr. M.N. Potter
Dr. D.S. Gillett	Prof. F.E. Preston
Dr. D.W. Gorst	Dr. C.D.L. Reid
Dr. P.J. Green	Dr. C.L. Rist
Dr. M. Hamon	Dr. J.A. Shirley
Dr. I.M. Hann	Dr. A. Thomas
Dr. J.P.L.A. Hayes	Dr. J. Thomas
Dr. M. Howard	Dr. A. Worsley

The Chairman welcomed everyone to the meeting and thanked Dr. Hay for organising it. The Chairman reported that Professor E.K. Blackburn, the first Chairman of the UKHCDO, had died and members stood for a moment in respect. The Chairman welcomed the new Directors or Co-Directors to the meeting. He

also welcomed Mr. Graham Barker and Dr. David Evans who were representing the Haemophilia Society, Dr. Rejman representing the Department of Health and Sister Alex Shaw representing the Haemophilia Nurses Association. The Chairman said that Professor Ian Temperley had recently retired and that Dr. Owen Smith would be replacing him in Dublin. He wished Professor Temperley a very happy retirement and he hoped that Dr. Smith would attend UKHCDO meetings in the future as an Observer in the same way that Professor Temperley had.

2. Minutes of the last Meeting

There were no comments and the minutes were approved.

3. Matters Arising from the Minutes

Dr. Giangrande had sent a letter to Dr. Colvin regarding the national database. He wondered to what degree the data should be released outside UKHCDO since Dr. Giangrande had received requests for information regarding individual patients. Dr. Keeling, representing Dr. Giangrande, said that he understood that the Directors were required by law to release data on individual patients. Dr. Colvin asked that Dr. Giangrande should send him a copy of the written legal advice that he had received regarding this matter. There were no other matters arising.

4. Chairman's Report

The Chairman's written report had been pre-circulated and was presented at the meeting. There was particular reference to a meeting held between the Officers of the Organisation and the Department of Health. Dr. Hay referred to Dr. Rejman's statement at the last Regional Centre Directors Meeting in which he suggested that Directors who were having difficulties regarding prescriptions for interferon should write to him for advice. Dr. Hill said that some purchasers had said that they did not want to buy interferon treatment and he felt that it was an on-going battle to persuade purchasers to pay for this material. Dr. Colvin suggested that Directors should contact Dr. Rejman if they were encountering difficulties. Regarding recombinant Factor VIII, the Chairman said that VAT was to be imposed on this product from the 1st November although it was likely that an appeal against the decision would be made. It was noted that VAT was already payable on porcine factor VIII. Concern was expressed at the lack of adequate funding for factor replacement therapy and it was acknowledged that UKHCDO should continue to press the Department of Health for increased resources. Dr. Lee presented a form regarding the use of recombinant Factor VIII and asked that Directors should return the completed form to her as soon as possible.

Hepatitis C Litigation

The Chairman said that there were still only a small number of patients seeking litigation and there was no need to co-ordinate the defence at present.

5. **Comprehensive Care Centres (CCCs), Haemophilia Centres and Audit and to discuss changes to the Constitution (*Appendix ii*)**

Dr. Colvin said that a revision of the Constitution of UKHCDO had been proposed and amendments had been pre-circulated for discussion at the meeting. It was very important that the Executive Committee of UKHCDO should not be too big to complete the business of the Organisation but he believed that the increase in numbers caused by the move from a regionally based to a CCC based Executive should not be too great. The question of the South West region was raised and their representative had objected to the proposals since a large part of the country might be excluded from Regional Centre Directors' Meetings/Executive Committee Meetings in the future. Dr. Colvin said that a maximum of two co-opted members would be invited to Executive Committee Meetings and that the South West could continue to be represented in this way. It was agreed that the revised Constitution should be reworded to allow a South West representative to be co-opted with voting rights. Dr. Bolton-Maggs was not happy that Liverpool Children's and the Royal Liverpool University Hospital were regarded as one Comprehensive Care Centre with only one representative attending the Executive Committee Meetings but the Chairman explained that this had already been discussed and agreed in the past. Following reorganisation in the Kent area Canterbury planned to apply for CCC status and would do so under the new rules. After further discussion the Chairman asked if the changes to the Constitution could be agreed. Dr. Jones proposed accepting the changes and Dr. Hill seconded this. There were no objections and so the changes were adopted. The Chairman agreed to prepare a full version of the revised Constitution as soon as possible.

6. **Treasurer's Report (*Appendix iii*)**

A written report was tabled and presented by Dr. Hay. He suggested that the membership fee should be kept at £20. Dr. Colvin thanked Dr. Hay for his hard work as Treasurer.

7. **Annual Returns for 1994 (*Appendix iv*)**

A written report was presented by Dr. Keeling on behalf of Dr. Giangrande. He said that Oxford Haemophilia Centre was financing the cost of changing the system from a main frame to a PC based system. Dr. Savidge raised the possibility of changing the Annual Returns over from a calendar year to a financial year basis. There was brief discussion about this and Dr. Colvin said that it had been decided that the data presented to the UKHCDO Annual Report should stay as calendar year data. The question of ownership of the data was also raised. Some Directors thought that it was wrong that Oxford Haemophilia Centre should pay for the system and there was also some anxiety that funding for UKHCDO data handling might be withdrawn from the Oxford Centre. Dr. Hay pointed out that if the UKHCDO paid for all the work done by Oxford Haemophilia Centre on their behalf it would deplete the funds of UKHCDO quite considerably. Dr. Colvin suggested that the matter should be discussed at an Executive Committee Meeting next year. Dr. Hill was concerned about the security of any genetic data held in the Oxford database and Dr. Colvin said that this had already been discussed by the

Genetics Working Party. Dr. Jones thought that there was a need for UKHCDO to have a Working Party on information technology and pointed out that one of the strands of the audit application was to obtain funding for Oxford. Dr. Rejman said that he would make informal soundings as to what was required for a further application for audit funding for UKHCDO. Dr. Jones raised the question of analysis of the data and the fact that for some data, there were differences between criteria used by UKHCDO and the World Federation of Haemophilia. An example was the factor level used to define severe haemophilia. He wondered whether the Directors should change their system to match that of the World Federation of Haemophilia. After further discussion it was agreed that a Working Party on Information Technology should be set up, preferably before the next Regional Directors' Committee Meeting.

8. Consent for Treatment

Dr. Colvin said that this matter had been raised at the Regional Directors' Committee meeting and agreement had been reached in principle to formal written consent for first treatments with concentrates and also that perhaps further consent should be obtained when there was a change in the product used for treatment. There was no uniform agreement about this. Dr. Hill said that consent needed to be informed consent and he thought that there was the need for a standard form. Dr. Colvin said that the Executive Committee could prepare a form if required to by the AGM but he had thought that it might be difficult as NHS Trusts have differing policies. Dr. Ludlam suggested that the matter should be reviewed again by the Executive Committee as it seemed that people might find it helpful to have a standard form and Dr. Savidge said that he felt that legal advice should be sought about this matter. Some Directors did not agree that written consent should be obtained as they felt that this could be held against them. It was agreed that the Directors accepted that informing patients was important but there was no agreement as to whether or not written consent should be obtained.

9. Haemophilia Society Report

A written report was presented by Mr. Graham Barker to the meeting. A copy of this report can be supplied on request to the Secretariat in Oxford. Following the presentation of the report several matters were raised and discussed. Dr. Hay asked Mr. Barker what the Society's attitude was to the hepatitis C litigation. Mr. Barker said that the Society had a list of approximately fifteen solicitors who knew about haemophilia and who would be willing to look into cases of any patients who wished to pursue litigation. The Society thought that patients would need to show that they had received inappropriate treatment if they were to succeed with litigation, for example, carriers who were given one dose of factor VIII instead of being given DDAVP. Dr. Hay said that he was concerned that the Society might be raising peoples hopes without justification and Mr. Barker replied that the Society was trying to be even-handed in this matter. Mr. Barker said that the Society would like the Government to provide funds for families of those who have died and those who are sick. One Director said that he had been asked by solicitors to provide Minutes of the UKHCDO meetings regarding hepatitis for a litigation case. Dr. Colvin said that the Executive Committee had already decided

that these Minutes are confidential and that the Directors should resist releasing them. Dr. Jones said that the World Federation of Haemophilia had had the same type of request and had also declined. Dr. Rejman pointed out that all documents had been made available for the HIV litigation and said that it might be necessary to release Minutes to solicitors within the UK.

10. Haemophilia Nurses Association Report

A report on behalf of the HNA was presented by Sister Alex Shaw, Chairman of the Association. A copy of the report is available on request from the Secretariat in Oxford. Dr. Savidge congratulated the Haemophilia Nurses Association for its integration within the Royal College of Nursing and Dr. Colvin thanked Sister Shaw for presenting the report.

11. Haemophilia Chartered Physiotherapists Association Report

There had been no reply to the invitation to the HCPA to send a representative and no report was available.

12. Macfarlane Trust Report (*Appendix v*)

Dr. Dempsey presented the report on behalf of Dr. Mayne. There was some discussion on IVF and AID and it was agreed that individual Haemophilia Centre Directors might write to the Trust about this matter if they wished to comment.

13. Reports from Working Party Chairmen

a) Genetics Working Party (*Appendix vi*)

A written report from Professor Ian Peake had been pre-circulated and was presented by Dr. Colvin. Dr. Jones wanted to know about the policy on testing of carriers and the Working Party would consider this. Some concern was expressed that Professor Giannelli had only wanted to release fully confirmed data to Directors but this problem had now been resolved. Professor Giannelli had obtained a grant from the Medical Research Council to develop a haemophilia A database and the Genetics Working Party would co-ordinate this work. The Oxford database would only hold a note that genetic data was available and where it was held, thus allowing Directors to obtain information with full preservation of confidentiality by doctor to doctor contact and with full consent.

b) Paediatrics Working Party (*Appendix vii*)

Dr. Hill said that the Working Party had met. They were liaising closely with the Inhibitor Working Party and were looking at the provision of information to parents and the use of Portacaths.

c) **von Willebrand's Disease Working Party (*Appendix viii*)**

Dr. Winter presented the report which had been pre-circulated. Dr. Colvin thanked Dr. Mayne and the Working Party members for their work. He felt that the production of the booklet was an immense achievement.

d) **HIV Working Party (*Appendix ix*)**

Dr. Lee presented the written report and invited comments. Dr. Colvin said that UKHCDO was very pleased that the Nature paper had been published although the media had not acknowledged that the work had been performed by UKHCDO.

e) **Inhibitors Working Party**

A written report was tabled and presented by Dr. Hay who said that Guidelines would soon be sent to Directors on the treatment of patients with inhibitors.

f) **Chronic Liver Disease Working Party**

No report had been received from Professor Preston but Dr. Ludlam was able to report that samples for HCV genotyping were being received for analysis in Edinburgh. Dr. Colvin said that a question had been raised at the Executive Committee Meeting about spouses of people with haemophilia being blood donors and the advice that they should not be blood donors had been repeated.

g) **Acute Adverse Events Working Party (*Appendix xii*)**

The written report from Dr. Giangrande, which had been pre-circulated, was presented by Dr. Keeling. In reply to a question, Dr. Keeling said that Dr. Giangrande liaised with the MCA so that if a yellow card report had not been sent to the MCA this would be picked up.

14. **Date of 1996 and 1997 Annual General Meetings**

1996

A Scientific Meeting would be held in the Spring in **Birmingham**. It was being organised by Professor Preston and full details would be circulated as soon as possible. The AGM would be held on the **4th October 1996** at the Royal Free Hospital.

1997

The AGM would be held in Cardiff and would be a two-day meeting.

15. Any Other Business

- a) **Factor XII.** Dr. Chisholm said that she would like to look at thrombosis in Factor XII deficient patients and their relatives and also at the incidence of spontaneous abortions in these patients. There were two ways of doing this. One would be for Dr. Chisholm to go via the Directors, the other would be to by-pass the Directors and for Dr. Chisholm to go direct to the General Practitioners. Miss Spooner reminded Dr. Chisholm that information regarding General Practitioners was not held in the Oxford database. Dr. Rejman advised against going to General Practitioners as they would probably charge for the information. Dr. Keeling thought that it would be very difficult for the UKHCDO to better the Leiden study. Dr. Winter suggested that Dr. Chisholm should join in with a study that Professor Machin was already doing. Miss Spooner suggested that she should write to Directors who have Factor XII deficient patients and inform them of Dr. Chisholm's interest. **This was agreed.**

There was no further business and the meeting closed at 2.56 p.m