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Minutes of the Twenty-Fourth Meeting of the UK Haemophilia Centre Directors, held in the Main Lecture Theatre at the University of East Anglia, Norwich on Friday 18th September 1992

Chairman: *Dr. Elizabeth Mayne*

<u>Present</u>

Dr. M.I. Adelman
Dr. S. Al-Ismail
Mr. G. Barker
Dr. O.H.A. Baugh
Dr. J. Behrens
Dr. D. Bevan
Prof. A.L. Bloom
Dr. P. Bolton-Maggs
Dr. M.A. Boots
Mrs. B. Buzzard
Dr. M. Chisholm
Dr. B.E. Gilliver
Dr. B.T. Colvin
Dr. C. Costello
Dr. H.M. Daly
Dr. S.I. Dempsey
Dr. G. Dolan
Dr. M. Dudley
Sister M. Fearns
Dr. Forman
Dr. P.L.F. Giangrande
Dr. B. Gibson
Dr. B.E. Gilliver
Dr. H. Hambley
Dr. I.M. Hann
Dr. C.R.M. Hay
Dr. J.P.L.A. Hayes
Dr. F.G.H. Hill
Dr. R.I. Ibbotson
Dr. M.W. Kenny
Dr. D.J. King
Dr. H.E.T. Korn
Dr. Laffan
Mrs. P. Latimer
Dr. R. Lee
Dr. J. Leslie
Dr. Dr. C.A. Ludlam
Dr. J.A. Maitland
Dr. E.E. Mayne
Dr. S. Mayne
Dr. P.J.F. McHugh
Dr. E. Miller
Mr. K. Milne
Dr. V.E. Mitchell
Dr. D.C. Mitchell
Dr. D.A. Montgomery
Dr. D.G. Oscier
Dr. L.A. Parapia
Prof. F.E. Preston
Dr. C.D.L. Reid
Dr. A.J. Rejman
Dr. C.R. Rizza
Dr. J.R.Y. Ross
Dr. G. Savidge
Dr. Sawers
Dr. G.L. Scott
Dr. J.A. Shirley
Dr. C.N. Simpson
Miss R.J.D. Spooner
Dr. R.H. Stevens
Dr. Thomas
Dr. D.S. Thompson
Dr. I.D. Walker
Dr. E.J. Watts
Dr. M. Winter
Dr. A. Worsley

<u>Apologies</u>

Dr. A. Aronstam, Alton
Dr. T. Baglin, Cambridge
Dr. J. Beard, Hastings
Dr. P. Jones, Newcastle
Dr. G. Lucas, Manchester
Dr. A.G. Prentice, Plymouth
Dr. C.L. Rist, Worthing

The Chairman welcomed everyone to the meeting and thanked Dr John Leslie for making the excellent arrangemtns for both the scientific meeting and the business meeting.

2. Minutes of the last Meeting

It was pointed out that the document was entitled HC76(4), not HS76(4) as printed in the minutes. After this correction the minutes were approved and signed.

3. Matters arising from the Minutes

P.7: 11. The Haemophilia Society's Booklet

The Chairman pointed out in addition to the Essentials of Haemophilia produced by the Society, it was intended that the Haemophilia Centre Directors "Guidelines on haemophilia treatment" would be prepared by the end of 1992. In the interim the Chairman recommended an article in Blood Reviews on Haemophilia Care which had been written by Dr Mark Winter. She thought it particularly suitable for junior staff undertaking haemophilia care for the first time.

P.3 (ii) HC76(4) was in the process of being re-written by the Department of Health in conjunction with the Chairman of the Haemophilia Centre Directors' Organisation and the Haemophilia Society. Later Dr Rejman from the Department would present the most recent draft document.

P.3 (iv) Adverse Reactions

Inhibitors

The Chairman reported that the CSM had indicated that if an inhibitor developed in a patient whilst being treated with a licensed product, they requested that a yellow card be filled in and sent to them, in addition to the internal arrangements within the Organisation.

P.4: Constitution

The Chairman indicated that it was the intention to issue a printed version of the Constitution to be circulated to all Haemophilia Centre Directors. She indicated that since the last AGM changes had taken place in the office-bearers of the Organisation. Dr Christopher Ludlam had accepted the position of Vice Chairman. The Chairman thanked his predecessor, Dr Charles Rizza, who had stepped into the breach following the illness of Dr Peter Kernoff, for all the work and organisation he had done for the Directors during his Vice Chairmanship. Dr Richard Stevens had replaced Dr Richard Wensley as the Manchester Representative on the Committee. Dr Charles Hay had succeeded Dr Wensley as Treasurer. Thereafter the Chairman reminded members that their personal membership fee for the Organisation, namely £20, was now due to be paid to the Treasurer, Dr Hay. At a recent Regional Directors meeting it had been agreed to send a regular sum of money to the Oxford Haemophilia Centre to offset the costs of the Secretariat. It was agreed that the income generated from the personal membership fee should fulfil this sum of money. At presnet the bank balance for the Organisation was of the order of £7,000. This was achieved by a profit from the scientific meeting held in Sheffield in 1990. The only outgoing payment had been for reprints of the Recommendations on therapeutic materials. At this point Dr John Leslie indicated he felt there would be similar profit generated from the current scientific meeting.

P.4: Charitable Status

The Chairman indicated that she had applied to the Charity Commissioners for the Organisation to achieve charitable status. The application had been written in July and she would let the Haemophilia Centre Directors know as soon as a decision was made.

P.5: NBA

The Chairman said she had responded to the consultation document and requested that the Haemophilia Centre Directors' Organisation be represented on the new National Blood Authority. Dr Rejman informed the meeting that it was probable the authority would be set up early in 1993.

4. Chairman's Report

a) The Chairman suggested that a Peter Kernoff Lecture might be inaugerated to acknowledge the contribution made by Dr Kernoff to haemophilia care, both in the UK and on a worldwide basis. She suggested that such a lecture might serve as the climax to the scientific meetings. The matter was discussed briefly and the idea approved.

b) The regular meetings of the Regional Directors had been concerned largely with the therapeutic recommendations. The publication of the Recommendations had provoked much response and indeed criticism. In reply to criticism it had been reiterated that the document expressed a concensus viewpoint. It was felt that each Haemophilia Centre Director would need to use his or her own judgement in the prescribing of blood products. Furthermore it was agreed that the Directors needed to monitor constantly the situation and update the document as necessary.

c) The Chairman reported that the Regional Directors' Audit for England and Wales should be completed by December 1992. She indicated that experience from the pilot study in Scotland and Northern Ireland had revealed that a signed auditor's report seemed to have a beneficial effect on administrators. They seemed more inclined to implement improvements when they saw that the recommendations had been made from an outside Centre. It was felt that if the England Wales audit was productive and helpful, all Centres might wish to participate in audit. The Chairman indicated that she had received an audit programme from Dr Mark Winter which she felt was an excellent example of inter-Centre audit. Funding of the audit was questioned. The Chairman indicated that no problems had been encountered; in fact the local Audit Committee of each Centre had willingly, paid for the auditor's travel expenses.

d) HC76(4)

Dr Colvin raised the question of the concept of "Holding Centres" which had been put forward previously; he asked if this had been discarded. The Chairman replied in the affirmative and said it was now proposed that there should be a two-tier system, namely Haemophilia Centres and Comprehensive Care Centres. The latter would be required to treat 40 or more severely affected patients annually. The small Centres were to be retained as they provided an essential service in many geographical regions. **The composition of the Regional Directors'Committee was not intended to change.** The question of designation or re-designation as a Comprehensive Care Centre required careful consideration. It was suggested a committee of "Three Wise Men", not directly involved in the day-to-day care of haemophilics, should decide on the designations. Possible nominees to become the "Three Wise Men" were Dr Michael Rawlins, the incoming Chairman of the CSM; Professor Charles Forbes, Professor of Medicine in Dundee; and one other, perhaps a retired Haematologist with a broad experience in haemophilia care. It was suggested they might draw up a questionnaire to help in the designation of Comprehensive Care Centres.

5. Annual Returns for 1991

Dr Rizza presented the report which had been pre-circulated. He said that an additional figure (figure 1) had been included as it indicated the number of patients treated by each Centre. This was important in the light of the revision of HC76(4). He reported that von Willebrand's disease patients showed the largest increase in registration. There had been an unexpected increase in the usage of Factor VIII. There had been the usual "predicted" increase in Factor IX usage. Regarding mortality figures, Dr Rizza drew attention to the fact that the majority of cancer deaths had occurred in HIV negative patients. Thereafter discussion followed and it was suggested that high purity material should be analysed separately and **this was agreed.** Additionally it was suggested that the usage of product should be subdivided into that used for HIV positive and HIV negative patients. **This was agreed.** Further discussion occurred regarding the reasons for the unexpected increase in Factor VIII usage. The Chairman suggested a simple questionnaire be sent to all Centres to ascertain the reason for the increase. **This was agreed.**

6. HIV Statistics

Dr Rizza presented the data which had been pre-circulated. A brief discussion followed but no specific action was taken.

7. HC76(4) Re-Write

Dr Rejman introduced the draft document. He indicated that the Secretary of State, then William Waldegrave, had been instrumental in the decision of the Department to rewrite the document. Following the decision, a committee had been formed comprising the UKHCDO Chairman, Mr David Watters representing the Haemophilia Society, Dr Rejman and an administrative civil servant from the Department of Health. Several drafts had been made of the revised document. The Department indicated that there would no longer be a regional system of haemophilia funding. It was the intention that the circular would be addressed to public health directors and then copied to other departments. The final draft would go out for consultation to the Royal Colleges, etc, and it was hoped to issue the document by the end of the year.

The aim of the document was to inform and remind purchasers that haemophilia care is both expensive and unpredicatable. It would indicate to purchasers that they should always consult with the professionals. In the document it was hoped to give three example contracts and the Haemophilia Society agreed to provide the examples, as they already collected this information. When the contracts had been received from the Haemophilia Society, it was intended that the draft document would go to the management executive for approval. Within the document there would be clearcut definitions of a Haemophilia Centre and a Comprehensive Care Centre. The designation of Centres would not come under the jurisdiction of the Department of Health but would emanate from the peer group. The Department of Health document covered England only but Dr Rejman assumed that Scotland, Northern Ireland and Wales would issue similar documents at a later date. A lively discussion ensued. Dr Mitchell (Leicester) queried the figure of 40 plus patients for the designation of a Comprehensive Care Centre. Dr Mayne said that the Regional Committee had felt it inadvisable to set a lower figure because the figure of 40 severely affected patients would indicate and guarantee that a Centre would have full experience of all the complications of haemophilia care. However she indicated that the figure was not rigid at the present time. Dr Mitchell was concerned about the relationship between a Haemophilia Centre and a Comprehensive Care Centre; he felt that it could result in a loss of funds to Haemophilia Centres. Dr Rejman replied that this would depend on the district and region; every patient must have access to Comprehensive Care. Standard Haemophilia Centres might not be able to provide for example, orthopaedic surgery. Every Director of Public Health (DPH) would need to make arrangements for all Haemophilics to have comprehensive care. The Department of Health had decided that the document was incomplete without the examples of contracts and therefore could not be circulated to all Directors before the Annual General Meeting. Dr Mayne indicated that the Regional Representatives had been asked to discuss the document and many had circulated it to Haemophilia Centres in their region. She had received many responses in this respect; however it was regrettable that not all members present at the meeting had been able to see the draft document. Dr Rejman indicated that it would be sent to all Haemophilia Centres at a later stage. He reiterated that the object of the circular was to remind purchasers that they needed to provide comprehensive care for haemophilics and that it should be planned; the Department of Health did not approve of ECRs, they were to be the extreme exceptions for treatment. Dr Hill raised the question of haemophilics going on holiday; he thought that this needed to be flagged within the document as one could not always judge how much therapy a patient should take with him when going on holiday. Dr Rejman indicated that Directors had to allow for predictable events. Dr Daly (Truro) indicated that her Centre received many holiday patients but they had encountered no problems. They simply increased their stock of Factor VIII and Factor IX during the summer months. Dr Savidge (London) asked if the Department was planning to write similar documents for other specialties. Dr Rejman replied in the negative. Dr Mayne indicated that she would try to ensure that everyone concerned would see the document in the near future.

8. Reports from Working Party Chairmen

a) Paediatric

Dr Hill indicated that a group of Directors interested in prophylaxis met earlier in the year. They had co-opted a radiologist and an orthopaedic surgeon to review x-ray joint changes. At the present time a protocol for prophylaxis was being drafted. It was indicated that good venous access was essential for participation. However, the working party had decided that indwelling Port-a-Caths should not be used, due to the difficulty with infection.

b) Chronic Liver Disease

(i) HCV and Alpha Interferon - Professor Preston reported that the working Party had sent out a questionnaire and received 100 returns. 77 Centres carried out HCV testing, 46% indicated that they discussed the results with their patients but 8% said that the results were not discussed. He had some information regarding deaths of 341 patients, 34 of whom had chronic liver disease. There had been an autopsy carried out on 80 and 30% of these showed evidence of chronic liver disease. Professor Preston reported that the members were particularly interested in the instance of Hepatocellular carcinoma. He referred to the publication by Professor Mannucci in 1991. Professor Preston indicated that alcohol abuse seemed to be a relevant aetiological factor, and he suggested that the UK data should be published as soon as possible. Thereafter was discussion on the use of alpha interferon for treating hepatitis C cases. Members were reminded that alpha interferon was unlicensed for this indication. Professor Preston recommended that Haemophilia Centre Directors should enter patients with hepatitis C into trials with interferon and they could contact him for further information. Dr Al-Ismail 9Swansea) asked regarding the frequency of testing patients for hepatitis C. **It was agreed that patients should be tested annually.** He also asked for recommendations for treatment of patients who had significant hepatitis. Dr Savidge said he would use interferon, Professor Bloom agreed but the concensus of opinion seemed to be that the use of an unlicensed product was not justified. In conclusion Professor Preston referred members to a paper by Dr Dusheiko of the Royal Free Hospital which recommended the use of alpha interferon.

(ii) HAV - Dr Savidge(London) asked if hepatitis A derived from concentrates was a problemn. Professor Preston referred to the cases which had occurred in Italy and also to some that had occurred in Ireland. Dr Mayne said that she had been told that the Irish hepatitis cases were not thought to be related to concentrate use. The Chairman and Vice-Chairman had been invited to Octapharma (Vienna) to inspect the plant and discuss the problem of Hepatitis A infection. Dr Colvin (London) asked for the indications for hepatitis A vaccination. Professor Preston replied that he had written to Dr Richrd Tedder for advice.

d) Von Willebrand's Disease

Dr Savidge presented his report by showing slides of the registered data kept by Oxford. He referred to an earlier questionnaire on how Centres diagnose von Willebrand's disease. He presented a summary of the tests necessary to establish the diagnosis. He thought that the information currently registered was not very useful and suggested that the Directors should stop sending in von Willebrand Working Party forms for new registrations. He also suggested that a new von Willebrand Working Party should be formed and he would draft proposals for this.

c) Adverse Events Working Party

Dr Savidge (Chairman) introduced members to present the various reports. Dr Colvin reported on the detection of five inhibitors during 1991/92. Two were in children aged three years and 18 months and the other three were in adults. None of the patients had had relatives with antibodies and no one product was involved.

Dr Hay said he had received 16 reports of transfusion reactions, including one reported for a second episode. Three reactions were not related to blood products. There were no incidences of more than one Centre having problems with any one batch.

Professor Preston said that he had information regarding nine episodes of thrombosis since the formation of the Working Party; all related to Factor IX. There were several major episodes involving DIC and DVT, and all but one related to surgery. One appeared to be related to an infected Port-a-Cath. One patient had low ATIII and Professor Preston queried whether liver disease was involved as a risk factor.

The Chairman thanked Dr Savidge and his collegues for their reports. She thought the information regarding the thrombotic episodes should be published. **This was agreed.**

9. Date and place of Future Meetings

a) The 1993 Annual General Meeting would be held in London in October and would be a one-day meeting.

b) The 1994 Annual General Meeting would be held in Birmingham, organised by Dr Hill, and would be a two-day meeting. This meeting would include the Kernoff Lecture.

10. World Federation of Haemophilia

Dr Ludlam presented a paper on the World Federation oNnbehalf of Dr Jones. The document referred to the strategic plans of the WFH and the UK Haemophilia Centre Directors were invited to help the World Federation with this project.

11. Haemophilia Society

Mr Ken Milne presented a short report on behalf of the Society. He said that the Haemophilia Society shortly would be sending out another questionnaire to the Haemophilia Centre Directors. There was some discussion about the low patient membership of the Society. The

Chairman suggested that membership of the Society paralleled other similar patient organisations e.g., cystic fibrosis. Mr Milne said he was not worried about the numbers of patients who joined. Dr Colvin asked Mr Milne what views the Society had on hepatitis C litigation. Mr Milne said that the Society had put a small number of people in touch with lawyers.

12. Haemophilia Nurses Association

Sister Maureen Fearns presented a short report on behalf of the Association. She said that membership of the Association was now restricted as full membership of the RCN was required of all members. Dr Mayne paid tribute to the HNA and thanked them for all the work they had done. Dr Lee asked about courses being run by the HNA. Sister Fearns said that 10-day induction courses in haemophilia care were now being run for newly appointed haemophilia sisters.

13. Haemophilia Chartered Physiotherapists' Assocation

Mrs Brenda Buzzard presented a brief report on behalf of the Association which now had 40 members. They had produced a new booklet which would be issued by the Haemophilia Society. The Chairman thanked Mrs Buzzard for the report.

14. Haemophilia Special Interest Group Report

Mrs Latimer presented a report on behalf of the group. She said that there were problems with the new disability living allowance form which was not assessed by the DSS instead of by a medical doctor. The Chairman thanked Mr Latimer for her report.

15. Macfarlane Trust Report

Dr Mayne stressed that although the Trust would continue to make regular payment to Haemophilics it would continue to consider single grant applications. Short respite breaks were being financed and these were not limited to convalescence following hospital admission. There had been increasing demands for single payments. Clearly there was still a need for the Trust. The Trust had four meetings per year. The Senior Social Worker Tudor Williams would be happy to visit any Centres to talk to small groups of patients about the work of the Trust. Dr Mayne was impressed by the careful administration of the Trust. Sister Fearns queried the Trust's insistence that Haemophilia Centre Directors signed forms. Dr Mayne said that the Trust would accept another signature if the reason for this was explained.

The Chairman thanked Dr Leslie once again for arranging the meeting which closed at 3 p.m.