



The
Haemophilia
Society

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MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE
HELD ON THURSDAY 14 NOVEMBER 1991 AT 6.30 PM
AT CHARITYBASE, THE CHANDLERY, 50 WESTMINSTER BRIDGE ROAD, SE1

Minute No

Present: The Rev Prebendary A J Tanner (Chairman), Mr K Milne, Mr N Lawson (Treasurer), Mr J Lander, Mrs C Hazlewood, Mr K Colthorpe, Mrs J Hodgson, Mrs N Guy, Dr GRO-A and Mr S Taylor.

In attendance: Mr D Watters (General Secretary), Ms S Archer (Resources Manager), Mr G Barker (Policy Manager), and Ms R Benson (Minutes Secretary).

AGENDA

- E91.33 Apologies for absence and welcome to new members
- E91.34 Minutes of the meeting held on 6 June 1991
- E91.35 Matters arising
- E91.36 Reports from Committees
- E91.37 General Secretary's Report
- E91.38 World Federation of Hemophilia
- E91.39 The Macfarlane Trust
- E91.40 Any other business
- E91.41 Date of next meeting

E91.33 Apologies for absence

Apologies for absence were received from Mr J Miller, Mr R Dickason, Mr A Cowe and Mrs H Maynard.

Minutes of the meeting held on Friday 4 October 1991

Mr Milne suggested that minute E91.28.6, first paragraph, should read "Having read them, a few Society members had approached their Centre Directors with requests for the products and this had caused a certain amount of consternation to a few Directors."

Mr Lander pointed out minute E91.31.2 in which it stated that he had been Chairman of the Resources Committee: he had not, and this was amended.

Otherwise the minutes of the meeting held on Friday 4 October 1991 were proposed as an accurate record of the proceedings by Mr Colthorpe, seconded by Mr Lawson, and agreed unanimously.

E91.35**Matters arising**

35.1 Plans for the Chairman's Conference: Mr Watters reported on plans for the Chairman's Conference to be held over the weekend of 22/24 November 1991 in Sunderland. He said that the occasion would be, amongst other things, an attempt to get local Groups to own and be part of the Society's strategic plans for the future. It was hoped, also, that the membership at large would be able to feel that they could play a greater part in the affairs of the Society and that they could have some effect on the decision and policy making processes in the coming year.

35.2 Medical Advisory Panel: A paper had been circulated beforehand. Mr Watters said that it introduced a set of proper terms of reference for the re-organized Panel, and he requested that these be formally adopted by the Committee. This was proposed by Mr Lander, seconded by Mr Colthorpe, and agreed unanimously. On behalf of the Committee the Chairman thanked the Project Team, consisting of Mr Milne, Mr Cowe, Mr Watters and Mr Barker, for all their hard work.

35.3 Strategic Planning: The Chairman asked Mr Milne to report on the Project Team's progress. Mr Milne said that the assignment undertaken at the Executive Committee's meeting on 4 - 5 October 1991, with Compass Partnership, was on course: the Group was in the process of assessing what information it needed, what information it already had and what resources might be necessary. Haemophilia Centres and the Society's membership would be the main sources of information and the method for acquiring that information had still to be decided. Mr Milne said that, while it was desirable that the membership be involved, the Group was in the process of balancing the degree to which it felt that people could be pestered with questions and forms. It was hoped that early in 1992 decisions would have been made regarding the categories and extent of the information required, and that it would be possible to advance to the production of a questionnaire.

Mr Milne raised the problem of Committees being able to proceed with their particular issues when those issues were under consideration by the Strategic Planning Group. Mr Watters said that the Group would be discussing the issues with the individual Committees as its work progressed.

Reports from Committees**36.1 Member Services Committee**

(i) **Hepatitis:** Mr Milne reported that the Project Team consisting of Mr Dickason and Mr Taylor, along with Mr Barker and Mr Watters, had completed the brief on hepatitis. Mr Taylor told the Committee that, having contacted experts in the field and having received comprehensive reports on the current thinking on the subject, the Team had concluded that hepatitis should not be a major concern for the Society. 80% of people infected with HCV and HBV would show no clinical signs and the treatments available were limited; the understanding of the progression of liver disease could only be established through liver biopsies, now considered unethical. The team felt that the Society was in danger of creating concern and worry where they need not exist. Publicity and high profile coverage would be out of proportion to the threat that actually existed. Mr Taylor proposed that a fact sheet on hepatitis be prepared and a request made that the Project Team be discharged from its duties; the Committee agreed, and thanked Mr Taylor and Mr Dickason for the useful work they had accomplished.

(ii) **Medical Audit:** Mr Watters reported that on 7 October 1991 he had attended a meeting of Centre Directors at which medical auditing had been discussed. While the process was well advanced in Scotland and Northern Ireland, England and Wales lagged behind. The Committee re-affirmed their support for medical audit, and agreed that a watching brief be kept on it with a view to its rapid implementation south of the border.

(iii) **Service of Thanksgiving:** Mr Milne reported that the Service of Thanksgiving had taken place on Saturday 2 November 1991 at St Botolph's. About one hundred and forty people had attended and the main credit was due to the Chairman for making it such an uplifting, moving and hopeful occasion. The Chairman thanked Mr Milne, and said he was grateful to all those concerned, including the Member Services Committee for their support and motivation, the Phoenix Singers, who had given their services free of charge, and the staff in the national office, especially Mr GRO-D, who had all worked very hard. The Chairman observed that there had been a few people who had been concerned about the possibility of unwanted publicity, but this obstacle seemed to have been overcome; there had been no-one from any branch of the media there, and the service had been well attended. Mr Milne mentioned that another occasion to build upon the achievement of the Service would be discussed in the new year.

36.2 Resources Committee

(i) **Financial position:** Mr Lawson reported that, while the Society's financial position was fairly constrained for the time being, income for the financial year had increased.

(ii) **123 Westminster Bridge Road:** Mr Lawson said that the Society had attempted to buy the premises at auction on 31 October 1991, the reserve being set at £190,000. The property had been withdrawn at £187,500. Ownership was still in the hands of British Rail, and the Society would persevere with its bid. It was in possession of a twenty year lease, in itself a valuable asset.

36.3 Policy Committee

A written report had been circulated in advance summarizing the Policy Committee's main concerns and activities. These related to the NHS Review, standards of care and treatment, blood products and the Society's response to the recent Government consultative document *The Health of the Nation*. The Committee noted the Policy Committee's paper.

(i) **Meeting with Mr Waldegrave, Secretary of State for Health:** A meeting had taken place on 12 November 1991 between Mr Waldegrave and the Chairman and Mr Watters. The Chairman recounted that the meeting had been constructive and helpful: he and Mr Watters had described the condition of haemophilia to Mr Waldegrave and had expressed disquiet over the implications for funding of treatment under the NHS reforms. The document *Essentials of Haemophilia Care* had been shown to Mr Waldegrave. Mr Waldegrave had listened receptively throughout and had indicated that he was minded to have the circular HC 76/4 re-written; this could be achieved by the end of January 1992. Mr Watters remarked that the Society had done well to have seen Mr Waldegrave; it was a privilege to see a Secretary of State, not just ministers, and the Committee expressed satisfaction and approval. Mr Waldegrave's decision to review the circular was a significant achievement for the Society, reversing the position previously adopted by his Department. The Chairman thanked Mr Watters and Mr Barker for their clear and detailed briefings before the meeting.

E91.37

General Secretary's Report

37.1. Professional Management Staff Committee Meeting: Mr Watters reported that the meeting had been successful and worthwhile. It had been agreed to explore economies by making documents interchangeable throughout different countries. It had been useful to meet and share common problems.

37.2 Recombinant Symposium: Mr Watters, reporting in a pessimistic mood, said that there seemed little prospect of the development of commercial quantities of a synthetic factor before 1994, nor in the near future. There were problems related to the development of inhibitors, and costs. No-one had been prepared to answer questions related to expenditure and time-scales.

37.3 European Consortium: Mr Watters reported that a meeting of the European Consortium was to take place in Prague on 30 November – 1 December 1991. The UK would be represented by Mr Taylor, Mr Barker and Mr Watters. Thirteen European countries would be attending. Amongst topics for examination and discussion were the problems faced by central European countries and a demand from Spain that all communication be in the language of the country concerned with simultaneous translation at all meetings.

37.4 McDonald and Associates: Mr Watters reported that letters would be sent to all those who had responded to the TV Appeal and to the End to End Bike Ride. These two mailings were planned to go out shortly. Another batch of letters was due to go out to those companies, Trusts and foundations that had not responded to a letter sent out in June, and an entirely new approach was to be made to companies and Trusts that the Society had not contacted before. Other matters on McDonald's agenda were Christmas Cards for 1992, the 1992 Prison Art show, a legacies campaign and a revised, more accessible, Annual Report. Another fundraising idea under consideration was Mr Lawson's suggestion of a chain letter asking for £20 for the Groups' adventure holidays or another specific project.

37.5 Visits to local Groups: Mr Watters reported that his programme of visits to local Groups would conclude on Sunday 17 November with a meeting in Plymouth with Southern, Cornwall and Hampshire Groups. A recent visit in the Nottingham area had been most successful.

E91.38

World Federation of Hemophilia

38.1 Working Party Report: Mr Taylor reported that the World Federation was to produce a paper unveiling a strategic plan for the organization; the Society would have an opportunity to discuss and offer suggestions before final presentation at the XX International Congress of the World Federation of Hemophilia on 12/17 October 1992 in Athens. Mr Watters said that he had seen the paper at the PMSC meeting and had thought it promising. Mr Taylor said that the Society should have it by the end of the year, and promised to keep the Committee informed. Mr Watters reminded everyone that those wanting to attend the Athens conference should make their wishes known either to himself or to the Chairman; the closing date for nominations was 31 December 1991.

38.2 Other matters: Mr Watters asked the Committee to consider two World Federation postal ballots that had recently come to his attention.

(i) **Mexico:** A new national organization had been established in Mexico fulfilling WFH criteria for membership. This would be the only Mexican National Member Organization. It was resolved unanimously to vote in favour of the admission of the new NMO.

(ii) **XXI World Federation of Hemophilia Congress:** The new Mexican NMO was seeking to sponsor the 1994 Congress. Doubts were expressed on three points: entry to Mexico by HIV positive people with haemophilia; the ability of a new NMO to sponsor such an event; travel problems from the UK to Mexico, there being no direct flights. It was agreed that these points should be raised with WFH before the matter was taken further. Doubt was expressed, also, about whether it was appropriate to make this decision by postal ballot rather than at a General Assembly.

E91.39

The Macfarlane Trust

39.1 Report: The Chairman reported that only a very small number of payments had still to be settled, and they had been held up mainly due to legal difficulties. The problems with making payments to those in Scotland had been overcome, and payments to Northern Ireland had been mostly completed. The next issue was that of applying to the Government to top up the Trust's money, and an argument to be used would relate to the fact that countries such as Australia and Ireland had provided much higher settlements.

39.2 Trustee nominations: The Chairman recalled for the Committee that there were Trustee vacancies still to be filled. Mr Watters said that Mrs GRO-D from Oxford was agreeable to giving further consideration to one of the positions: Mrs Guy proposed Mrs GRO-D's appointment; she was seconded by Mr Milne, and the Committee agreed unanimously. The Chairman asked that members of the Committee think about the other appointment, and also the re-election or otherwise of the present Trustees. Trustees would serve for two years from March 1992. Any suggestions should be offered either to the Chairman or Mr Watters.

01.40

Any Other Business

There was no further business.

E91.41

Date of next meetings

The next meeting of the Executive Committee will take place on Thursday 6 February 1992 at 5.00 for 5.30 pm at Charitybase, The Chandlery, 50 Westminster Bridge Road, SE1.

DW/RB 04.12.91

PETER MORRISMAN
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