



The  
Haemophilia  
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MINUTES OF A MEETING OF THE MEMBER SERVICES COMMITTEE  
HELD ON SATURDAY 2 NOVEMBER 1991 AT 11.00 AM  
AT CHARITYBASE, THE CHANDLERY, 50 WESTMINSTER BRIDGE ROAD, LONDON SE1

Minute No

Further Action

**Present:** Mr K Milne (in the Chair); Mr R Dickason; Mrs N Guy; Mrs C Hazlewood

**In attendance:** Mr D Watters (the General Secretary); Ms R Benson  
(Minutes Secretary)

Mr Cowe, Chairman of the Policy Committee, was present as  
a guest of the Member Services Committee

**MS91.35 Apologies**

Apologies were received for Mr J Miller, Dr M Winter and Mrs H Maynard.

Mr Milne welcomed Mr Cowe who was attending as a guest at this particular meeting of the Member Services Committee. Mr Cowe thanked the Committee for the invitation and said it was to be congratulated for initiating an excellent idea.

**MS91.36 Minutes of the last meeting held on Wednesday 10 July 1991**

Mr Milne observed that in the minutes of the meeting held on 10 July his remarks on the publishing in *Update* of the details of the Annual Service, M91.27.1, had appeared somewhat more forceful than he had intended. With this one reservation, the minutes of the meeting held on Wednesday 10 July 1991 were proposed for adoption by Mrs Guy, seconded by Mrs Hazlewood, as an accurate record of the proceedings and approved unanimously.

**37.1 MS90.12 (a) Annual Service/Feature**

Mr Milne expressed approval that the Annual Service, to be held later in the day, was taking place. Mr Watters reported that the names of those to be remembered were to be written on cards, including all those names that had been put forward through postal requests. After the Service the Chairman would dispose of the papers, ensuring that confidentiality was not breached.

Mr Milne mentioned the subject of the memorial, and the Committee agreed to await the findings of the Chairman and Dr Winter.

**37.2 MS90.13 Barnardo's Social Workers**

Mr Watters reported that the two Social Workers, Ms Teresa Janecka and Ms Liz Cox, working in Birmingham and London respectively, had had induction training and were now building up their case loads. He had seen them both recently and they were in touch with Centre Directors; they would be reporting back regularly to the Society and Mr Watters would keep the Committee informed. The reports would be generic in nature, and would not identify individuals. The Committee expressed interest and approval at the way in which the matter was proceeding.

DW

**37.3 MS90. 21 Bio Products Laboratory**

Mr Watters reported that, in a recent meeting with BPL, it had been agreed that they would inform immediately and simultaneously both the Society and Centre Directors of any future batch withdrawals. The Society would thus be in a position to answer any enquiries at the national office. The Committee expressed approval and Mr Milne said that BPL also supported the Society's high purity blood supplies policy.

**37.4 MS91.09 *Availability of Social Work Service in Haemophilia Care***

Mr Watters referred to Mrs Lovie's survey and said that it had highlighted the fact that funding for haemophilia care was becoming scarce. Any available resources were being channelled into HIV care. Hospital care was also being affected, especially in those changing to Trust status. Mr Milne observed that this was a further indication to the Society that service to the membership was of even greater importance if people were finding that they were not getting adequate care through the NHS and the Committee agreed to keep the matter under review.

MS Cttee

Mr Watters reported on a meeting of the British Association of Social Workers Special Interest Group he had attended on 31 October/1 November 1991, at which thirteen out of fifteen of the social workers present were, to his great pleasure, new faces. The occasion had been funded by the Society and had been very worthwhile and successful.

### **37.5 MS91.33.1 New Membership Application Forms**

Mr Watters said that the new forms would be worked on during 1992 for introduction in January 1993. It was felt that it could be unacceptable to burden people with the new forms as well as the proposed membership questionnaire, both in the same year. The Committee agreed that any comments on the initial draft of the form be submitted to Mr Watters by 31 December 1991.

All Cttees

## **MS91.38 Groups**

### **38.1 Birmingham Group**

Mr Dickason reported that there were no new developments. However, he had from Mr Watters a list of people to consult over procedures for asking Group Officers to leave their posts, and he would be writing to them shortly. The letter would list possible grounds for dismissal, such as failure to present accounts, failure to ask for approval of expenditure over £100, failure to hold a properly constituted AGM, failure to record proper minutes, and so on. A copy would be sent to Mr Watters. Mr Watters said that he had sent a letter a fortnight previously to the Treasurer asking for a financial report but had not yet had a reply. He would keep the Committee informed. Mr Milne expressed satisfaction that aconsensus was being sought from amongst the membership on reasonable procedures for management of Groups.

DW

### **38.2 Regionalization of Groups**

Mr Watters said that this issue was being considered by the Strategic Planning Group. Mr Milne felt that, while the Member Services Committee's general plans had been presented and ratified by the Executive Conference in October, the Committee could not proceed with those plans if it became apparent that it was at odds with the SPG. Mr Watters said that in the case of the nurturing and fostering of Groups the Committee had committed itself to the 1992 schedule of visits, approved previously. Mr Milne concurred, and the Committee agreed that the 1992 regional and area meetings was to be seen as an interim measure until the SPG had completed its brief and come up with recommendations. Mr Watters agreed to submit detailed costings of the meetings to both the Resources and Member Services Committees.

DW

### **38.3 Media Training for Groups:**

The Committee considered the paper, previously circulated, by Mr Simon Taylor on media training for Groups. While the Committee felt that the paper was useful, Health Network was in fact handling all media enquiries and would, in the near future, be meeting Groups with Mr Watters. Mr Watters said that in order to ensure a consistently high quality message reached the media at all times, Groups would be asked always to refer media enquiries to Health Network. Mr Cowe remarked that, while it was clear that Groups would need some help in coping with the media, it was known that the press preferred local accents. Mr Watters accepted this, but said that if the Society were to field someone it was important that the person be knowledgeable and informed. Mr Milne reflected that at the jumble sale level one of the questions always asked was on what was the money to be spent? Mr Dickason suggested that Health Network

supply A4 sheets to all Groups listing the Society's main concerns and the kinds of activities in which Groups might engage. The Committee approved this suggestion and Mr Watters agreed to put it to Health Network.

DW

### **MS91.39 Conferences**

#### **39.1 Haemophilia/HIV Family Weekend/Barnardo's:**

Mr Watters said that the Huddersfield Conference had been one of the best occasions that the Society had organized and it had also been most effective. Mrs Hazlewood felt that it would be beneficial if something similar could be set up every year to counteract the feelings of isolation faced by so many people who were affected by the problems of haemophilia and HIV. The Committee discussed briefly the problems of financing a family weekend. Mr Watters said that Barnardo's might help with funding and it was agreed that he ask them for advice on costings and whether they could assist financially. He would then present a proposal to the Macfarlane Trust at their next meeting on 21 November 1991 and make a request for a grant.

DW

Mr Watters said that four conferences were planned for 1992 at Preston, Bristol, Birmingham and in Newcastle and that sponsorship might be forthcoming.

#### **39.2 Adolescents/Young Men**

This issue was still being looked at by Dr Winter. Mr Watters reported that a similar event had been organized in Canada, taking the form of a camp attended by seventy five young men between the ages of fourteen and twenty four. He said that he had asked for a written appraisal, and the Committee expressed interest in hearing about it when the report arrived.

DW

### **MS91.40 Grants**

#### **40.1 Members**

i) **Car insurance:** Mr Watters asked the Committee to consider whether the Society should pay for car insurance. People with haemophilia had access to low cost car ownership through the Motability Scheme and it had never been Society practice to provide grants for car insurance. However, there had been instances when it was asked to do so. The Committee agreed that car insurance should not be paid, save in the most exceptional circumstances.

ii) **Driving lessons:** Mr Watters reported that applications for driving lessons were sometimes made either before or just after Mobility Allowance had been granted. If the Society paid for lessons and the person failed their driving test, then asked for a further grant, was the Society to agree? The Committee concurred that, unless special circumstances prevailed, the Society should not meet the costs involved in driving lessons.

iii) **Telephone deposits:** Mr Watters requested consideration of the Society's practice regarding payment of telephone deposits. Grants were made for telephone installation costs and after twelve months British Rail paid back the deposit to the subscriber, not the payee. However, if people did not pay their telephone bills regularly British Telecom deducted a sum from the original deposit. Mr Watters asked the Committee to endorse the system instituted by the Society of retrieving the telephone deposit from the subscriber after twelve months. The Committee agreed to this.

#### **40.2 Macfarlane Trust**

i) **Meeting:** Mr Milne recalled that a date for a proposed meeting with the Macfarlane Trust had not yet materialized, and it was agreed that Mr Watters would ask the Chairman to make enquiries.

DW

ii) **Trustees:** Mr Watters reminded the Committee that the Trust was still short of Trustees and that the Society should appoint new Trustees by March 1992.

iii) **Grants:** Mr Watters reported that, while the Society had not been flooded with extra requests for grants since the Trust had disbursed the money from the Government, nevertheless it was receiving telephone calls from people asking that it intercede with the Trust on their behalf over grant requests. This was a new development and it was agreed that the matter be mentioned to the Chairman.

DW

#### **MS91.41 Hepatitis**

Mr Dickason reported briefly on the findings of the Project Team. It had looked into the effectiveness of hepatitis vaccines, their availability and whether or not they were being used. It was probably acceptable to say that children under the age of five were safe from contamination from blood products by hepatitis C, but that all those who had been given unsterilized blood products would have been exposed to it. However, more research was needed. There seemed to be no problems with the supply of vaccines to Haemophilia Centres. A vaccine for hepatitis B was under consideration for the entire population. It was the Team's view that the Society need not take any action at present as the drug companies were working very hard on developing appropriate vaccines. However, the Team thought there was a need for a watching brief on the use of expensive drugs such as Interferon. The Committee received Mr Dickason's report with interest and he agreed to produce a resume for circulation. Mr Dickason reported that Christine Lee at the Royal Free had suggested a conference of hepatitis specialists and haematologists, and Mr Watters proposed that it might be done in conjunction with the British Liver Foundation. The Committee expressed approval of this idea, and Mr Watters agreed to look into it further.

DW

Mr Dickason mentioned that Dr Charlie Hay had suggested the publication of a fact sheet on hepatitis for distribution to Society members.

Mr Milne thanked Mr Dickason, Mr Taylor and Mr Barker for their excellent work on the subject.

#### **MS91.42 Strategic Planning**

Mr Milne said that the SPG would, in due course, provide clarification and guidance on the Society's plans for Groups and their possible regionalization.

#### **MS91.43 Any Other Business**

Mr Watters reported on a case of litigation that had recently come to his notice. A small group of people, using a US firm of lawyers, Wayne Spivee and Schraeger, were taking action in the US and Canada against Armour. This action would have relevance for only a very small number of people in the UK who would have to sue Armour in the US. On this basis it had been decided not to publish news of the action. Mr Watters asked the Committee for formal approval of this decision, which was granted. Mr Watters said that he had already put the US lawyers in contact with the UK-lead solicitors in the haemophilia/HIV litigation and that they had also contacted all Haemophilia Centre Directors.

#### **MS91.44 Date, time and place of next meeting**

The next meeting of the Member Services Committee will take place at the earlier time of 10.30 am on Saturday 18 January 1992 at Charitybase, The Chandlery, 50 Westminster Bridge Road, London SE1.

RB 06.11.91