



The
Haemophilia
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MINUTES OF A MEETING OF COMMITTEE B
HELD ON THURSDAY 15 JULY 1993 AT 4.00 PM
AT MABELDON COURT HOTEL, 10 MABELDON PLACE, LONDON WC14

Minute No

Further Action

Present: Mr K Milne (Chair), Mr R Dickason, Mr S Taylor, Mrs N Guy,
Mr J Pepper

In Attendance: Mr D Watters (General Secretary), Mr G Barker (Deputy General
Secretary), Ms R Benson (Minutes Secretary)

Mr A Cowe, Chairman of Committee A, and Ms S Archer, Resources
Manager, attended at the invitation of the Committee.

Papers on items 93.05, 08 and 09 had been submitted in advance.

B93.01 Apologies for absence

Apologies were received from Mr Lawson. Mr Watters reported that the Chairman
would attend meetings of both Committees A and B when requested.

B93.02 Minutes of last meetings

The minutes of the last meetings of the Member Services Committee, 20 April 1993,
and the Policy Committee, 8 May 1993, were proposed for adoption by Mr Taylor,
seconded by Mr Dickason, as an accurate record of the proceedings and were
approved.

B93.03 Membership

Membership of the Committee was discussed briefly and it was proposed that
Dr Mark Winter be asked to join as a co-opted member, that staff members and
members of the Executive should be invited to attend on occasions when they might
contribute to the agenda, and that Ms Liz Cox also be asked to attend when the
occasion demanded.

It was further proposed that representatives from the Society's local Groups and also
from different interest groups, such as parents of young children, be invited to attend
specific meetings. Mr Dickson suggested that the agenda for the coming year be
planned so that the Committee could be active in pushing forward the needs
assessment programme. He said this would be a way of including groups who might

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be feeling left out in the cold.

The Committee agreed these proposals.

B93.04 Terms of reference

Terms of Reference for Committee B had been previously circulated. Mr Barker asked that comments be sent to him by 20 July 1993. Mr Milne proposed that the Terms be put before the Executive Committee meeting on 29 July 1993 for ratification, and that they be reviewed twelve months from that date.

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The Committee agreed this proposal.

B93.05 Report on recent activities

A report on the Committee's recent activities had been circulated and the following items were considered.

05.1 Dr Jean Pierre Allain: The Committee agreed that there was no need for the Society to make comment on the outcome of Dr Allain's appeal. His continued employment in the UK was no longer an issue.

05.2 Blood products for HIV+ patients: There was some discussion and it was proposed that the Society's position on high purity blood products for HIV patients should be that it strongly recommended monoclonal and recombinant products, rather than ion exchange products. A batch of the latter had recently been withdrawn from use in Scotland since the discovery that one patient receiving ion exchange product had developed inhibitors. It was suggested that the Society should push this policy regardless of the opinion of MAP.

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The Committee agreed these proposals.

05.3 Implications for patients regarding product switches: It was felt by Committee members that patient's confidence in their medical treatment would be undermined by the practice of switching the products they received. In some circles this had been justified on the grounds of expense, rather than for clinical reasons.

The Committee agreed that while the Society was unhappy with the practice of switching patients from one product to another, this would not be pursued as a priority.

05.4 Publications

4.1 Haemophilia Briefing: The Committee agreed that a Task Group consisting of Mr Taylor and Mr Barker should produce and circulate a first draft to Committee B of the new in-house publication for opinion formers. Production of the first issue was due in September.

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4.2 Introduction to Haemophilia; Teaching Children with Bleeding Disorders: The Committee agreed that the Committee approach the Treasurer for funds to reprint the former. The position on the other publication would be reviewed later.

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4.3 Benefits Publication: It was reported that the East Kent Group had produced a booklet on benefits and the Committee felt that the Society should seek sponsorship to reproduce it, after editing, for a wider circulation. It was also suggested that information on benefits for people with HIV should also be included, the Terence Higgins Trust having produced a booklet on the subject.

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The Committee **agreed** these proposals.

Mr Dickason proposed that back issues of *The Bulletin* be looked through for articles that might be informative and useful on a variety of subjects. He suggested that, if necessary, these be edited for reader accessibility and produced in-house on A4 sheets. An index could be assembled and circulated at intervals.

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The Committee **approved** this proposal.

05.5 HSG (93) 30: The Department of Health's paper on haemophilia treatment and care had been published and circulated within the NHS. It had been sent to local Groups with the suggestion that it would be useful campaigning tool. The Society had also written to all District Health Authorities.

The Committee **approved** these developments.

05.6 London Implementation Group: Mr Barker reported that following the Tomlinson Report, LIG had produced a report of an independent review of specialist paediatric services in London. The recommendations contained in the report would be considered by the Secretary of State and decisions were expected in the autumn. The report seemed to suggest that only those hospitals with comprehensive paediatric services, including in-patient services, should provide haemophilia care. The Report claimed that the Royal Free was not able to provide the appropriate in-patient services. Mr Barker reported that he would be attending a meeting at the Royal Free to discuss this issue and would monitor the issue.

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The Committee **noted** these developments.

5.7 Invalidity Benefits: Mr Barker reported on changes proposed by the Government to Invalidity Benefit. He had written to Mr Peter Lilley, the Secretary of State for Social Security, and had received a reply confirming that these proposals were in the pipeline. Mr Barker said that the Society was in touch with other organisations over the issue.

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The Committee **noted** these developments.

5.8 Haemophilia Days 1993: Mr Watters reassured the Committee that the Society was acting in conjunction with the Macfarlane Trust over the organising of the three Haemophilia Days planned for late 1993, and that the agendas were the Society's responsibility. Mr Watters asked that a member of the Executive be present on each occasion. Mr Taylor, Mr Dickason and Mrs Guy volunteered.

DW

B93.06 Hepatitis:

Mr Milne proposed that a Task Group be formed to examine the hepatitis issue. Mr Taylor said that the Society should establish itself as an authoritative source of information. He felt it would be unwise for the Society not to be active on the issue at this early stage; people were not yet alert to the implications of hepatitis, but would be before long. Mr Dickason informed the Committee that there was the possibility of the setting up of a clinical trial on an unethical basis. Invasive techniques were to be used and those taking part would not be informed of the various implications. Mr Watters reported that he had been in touch with Professor Eric Preston.

The Committee **agreed** that a Task Group on hepatitis be set up consisting of Mr Dickason, Mr Taylor and Mr Watters. On the above immediate issue they would await Professor Preston's opinion, and on the broader front they would consider the best way forward.

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B93.07 HIV

Mr Milne said that there appeared to be a need for the Society to take a more active role over HIV. At a recent meeting of the Birchgrove Group, established as an HIV support group, there had been disappointment that the Society had not done more to counteract feelings of isolation and rejection. There was a range of issues connected with HIV, such as variations in treatments offered across the country, variations in the kinds of support offered by Centres, complementary medicine, immigration, all of which might be addressed by the Society, and help and information offered to those who needed it.

The Committee **agreed** that a Task Group consisting of Mr Milne, Mr Barker, Mrs Guy and Ms Cox be formed to look at HIV related matters. A member of the Birchgrove Group might be invited to serve on the Group.

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B93.08 Needs assessment: progress report

Mr Barker reported that in connection with the Strategic Plan questionnaires had been sent to ten different categories of Society member. Disappointingly, the overall response rate had been about 25%, but of those who had responded and who had ticked a box agreeing to a follow-up telephone call would be contacted. It was hoped to discuss further what people wanted and expected from the Society. The findings from both the questionnaire and the follow-up calls would be analysed and a report circulated to the Committee in the latter part of September. Mr Barker said that he felt the Society should keep the subject of services offered to members under constant review.

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20.09 **Budget and plans for 1994**

Mr Barker said that the paper circulated previously listed a number of issues and areas of work with which the Society might wish to engage in 1994. A rough idea of costings had been provided based on figures for the previous financial year. The Committee discussed briefly each possible area of work and Mr Barker asked everyone to complete a table rating each area according to degrees of importance. On the basis of the information received a costed work programme for 1994 would be drawn up by Mr Barker and Ms Archer and submitted at the next meeting of the Committee.

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B93.10 Grants to Centres

Mr Milne raised the subject of grants. He proposed that the original Grants Committee consisting of the Chairman, Mr Cowe, Mr Clarke, himself, Mr Watters should continue with the initial assessing of grant applications followed by recommendations to the Executive Committee. Any changes to the Society's policy on grants should be discussed by Committee B for submission to the Executive.

The Committee agreed this proposal.

Mr Dickason reported that the handling of a recent application for equipment for Lincoln County Hospital had caused discontent within the local Group. He proposed that the following categories of guidelines relating to the entire grants procedure be written down and formalised: (a) application procedures and how to go about them, (b) anticipated times the Grants Committee took to make responses, (c) directions for Groups on how to go about fundraising for grants, and (d) guidance for Groups about what sort of support they might expect from the Society. Mr Dickason suggested that the above proposals be sent in draft to Lincoln Group in order to bring them back into the fold and to get a grass roots response.

The Committee agreed that a Task Group consisting of Mr Dickason, Ms Archer and Mr Watters be set up to develop these guidelines.

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B93.11 Any other business

There was no further business.

B93.12 Date and time of next meeting

The next meeting of Committee B will take place on Saturday 9 October 1993 at 10.30 for 11.00 am at a venue to be decided.

AC/GB 20.07.93