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INFECTED BLOOD INQUIRY

WITN6392219

**MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE OF THE
HAEMOPHILIA SOCIETY**

held on Thursday 8 February 1990 at the Bloomsbury Crest Hotel, London WC1

Present: Revd Alan Tanner, Mr J Lander, Mr A Cowe, Mr K Colthorpe, Mr R Dickason
Mr T Fitton, Mrs C Hazlewood, Mrs J Hodgson, Mr G Kirman, Mr C Knight and
Mr J Miller.
In attendance: Mr D Watters (General Secretary) and Miss L Matthews (Administrative
Secretary).

A G E N D A

- 90.10 Apologies for absence
- 90.11 Minutes of the meeting held on 11 January 1990
- 90.12 Matters arising
- 90.13 CERT
- 90.14 Reports from Working Parties
- 90.15 World Federation of Hemophilia
- 90.16 General Secretary's Report
- 90.17 The Macfarlane Trust
- 90.18 Any other business
- 90.19 Date and place of next meeting

- 90.10 **Apologies for absence** were received from Mr K Milne.

The Chairman extended a warm welcome to Mr Richard Dickason, attending his first meeting of the Executive Committee as a co-opted member.

- 90.11 **Minutes of the meeting held on 11 January 1990**, having been circulated in advance, were proposed for adoption as an accurate record of proceedings at that meeting by Mr Kirman, seconded by Mr Colthorpe, and agreed unanimously.

- 90.12 **MATTERS ARISING**

(a) Compensation:

- (i) Campaign - The General Secretary reported that, with the help of GJW, the tactics and likely results of our future campaign later in the year were being assessed. A series of parliamentary lunches for small groups of MPs had started and would continue throughout February and into March. The first one had been held the previous day and had proved most valuable.

It was also noted that future strategies would form a major part of the agenda at the forthcoming Spring meeting of the Council.

- (ii) Litigation: The General Secretary reported that it appeared that a large number of people had been enabled to start their legal actions using their £20,000 from the Government. In addition, it was hoped that the trial of main issues would commence in the High Court in London on 14 January 1991.

- (b) 123 Westminster Bridge Road: The General Secretary outlined the proposed rent increase being submitted by those acting for British Rail and the counter proposal being put by those representing the Haemophilia Society. Whatever the outcome it appeared that our rent would, as previously reported, be at least doubled. This posed fundamental questions about whether the offices should remain in central London since it did not appear likely that lower rentals would be obtained within the immediate London area. There was a great deal of virtue in the offices being in central London, near to the Houses of Parliament and convenient for travel to and from all parts of the country. The newly formed Resources Committee will consider this matter at their next meeting.
- (c) The General Secretary drew the attention of the Executive Committee to the fact that consideration should be given to the recipient(s) of the 1990 Haemophilia Society Award and, if appropriate, the R G Macfarlane Award. It was agreed that since there had been no interest shown in the Catherine Cookson or Brendan Foster Awards for some time this matter should be allowed to lie on the table.

90.13 CERT: The Chairman outlined matters discussed at a meeting held on Saturday 27 January 1990 between himself, Mr Cowe, Mr Knight and the General Secretary. Mr Milne had been unable to attend. The Chairman emphasised how important it was, when considering the implementation of the CERT Report, to regard the exercise as a fresh start. In that connection one had to look at staffing arrangements as well as the personnel represented on each of the new Committees which would in future fulfil much of the function currently exercised by the Executive Committee.

In that connection the following matters were discussed, and approved:-

- (a) The following staff positions were approved, subject to the final agreement of the staff concerned:-
- (i) Administrative Secretary - Linda Matthews
 - (ii) Policy and Development Secretary - Jonathan Cooper
 - (iii) Member Services Secretary - Heather Maynard

It was noted that the term 'Secretary' is by no means a final term and will be the subject of further discussion and negotiation.

It was also be recognised that the General Secretary will, of course, require a new Personal Secretary to replace Heather Maynard.

Having been proposed by the Chairman, those items were approved unanimously.

- (b) In connection with the structure of each Committee it was agreed formally that there be four Committees of the Executive Committee - Resources, Policy and Development, Member Services and Grants.

It was further agreed that the Reverend Alan Tanner, Chairman, would chair Resources; that Mr Cowe would chair Policy and Development; Mr Milne would chair Member Services and the Grants Committee would, as now, be constituted by the Officers.

In addition it was agreed that each Committee would be serviced primarily by the staff person mentioned above. The General Secretary would attend all Committee meetings.

In connection with membership of each Committee it was agreed that the membership would be as follows with individual variations to be considered:-

Resources	Policy & Development	Member Services
Terry Fitton	Keith Colthorpe	Richard Dickason
Jane Hodgson	Caroline Hazlewood	George Kirman
Julian Lander	Clive Knight	Julian Miller

Having been proposed by the Chairman, those items were approved with one abstention

- (c) In considering the resources available to the staff it was agreed that a part-time minute secretary be appointed along with a part-time assistant to the Administrative Secretary. This, having been put by the Chairman, was agreed unanimously.
- (d) The meeting went on to consider the pattern of Executive Committee meetings. It was proposed by the Chairman that the Executive Committee should meet four times in each year - two meetings being on Saturdays (for the whole day), one over the Residential Weekend and one on a Thursday - or possibly Friday-evening. This was agreed unanimously.
- (e) In relation to the new pattern of Council meetings, it was proposed, as agreed at the Chairman's Conference in Newcastle in October 1989, that the Council would meet twice during the year - once on a Saturday as at present and once in Residential Conference. This was agreed unanimously.

It was noted that there was a need for a minor amendment to the Memorandum and Articles of Association in order to accommodate this matter since, at present, the Council was required to meet on four times in each year. This matter will be considered at the forthcoming meeting of the Council.

90.14 **REPORTS FROM WORKING PARTIES**

- (a) Finance and General Purposes: Mr Lander reported on the end of the year accounts which showed, conveniently, a very small surplus. He emphasised how important the budgetting exercise was in preparing for the future. There were now some eight Groups within the centralised banking system but, following the receipt of bank statements from most Groups there appeared to be a number of Groups who were holding far in excess of the £500 limit allowed by unanimous resolution of the Council of the Society. In particular problems were arising when 'internal' transactions took place whereby Groups and the Society paid each other money - effectively taking money from one pocket and putting it in the other since all funds are, by definition, Society funds. This related particularly to a decision taken at the January meeting of the Executive Committee when it had been agreed, in the absence of all the facts, to pay a sum of £1,300 to the North Wales Group in respect of the North Wales Adventure Holiday. The Executive Committee had been under the impression that the Group faced a deficit, or alternatively were unable to pay the bill, for the North Wales Adventure Holiday, without receipt of the requested £1,300. In the event this had proved not to be the case and, accordingly, it was proposed by Mr Lander, seconded by Mr Cowe, that the Society should withdraw the shortfall agreed at the previous meeting of the Executive Committee in respect of the North Wales Adventure Holiday but reaffirm the Society's commitment to the North Wales Adventure Holiday and authorise Mrs GRO-D to act on the Society's behalf in all matters relating to the holiday and its future. The North Wales Group should be assured that the full backing of the Haemophilia Society was available at all times, in all respects, pertaining to the holiday itself. This resolution was agreed unanimously.

Another problem which had arisen related to the difficulty of gaining access to information from local Group accounts. While local Groups could only open accounts in the name of the Haemophilia Society with the authority of the Haemophilia Society that did not, under banking law, give the Society itself access to individual Group banking records. It was clearly the easiest method of retaining a picture of the overall financial situation of the Society and a number of local Groups had in fact proposed that the national office should be in a position to obtain this information directly from their banks. Accordingly it was proposed by Mr Lander, seconded by Mrs Hodgson, that each Group be required to authorise its bank to supply records of its accounts and balance to the national office on the request of the national office. This was agreed unanimously.

It was also agreed that the General Secretary should establish the precise nature of the failed negotiation between the North Wales Adventure Holiday and the Macfarlane Trust which led to the Trust being unable to make an allocation in respect of the Holiday.

- (b) Treatment and Care: Mrs Hazlewood reported on the overwhelming response to the forthcoming Women's Weekend. It had filled very quickly with a further long waiting list. The Executive Committee agreed that consideration should be given to the planning of another Conference but recognised the problems with finance of a two day Residential Conference and invited the new Member Services Committee to consider alternative arrangements for that programme.
- (c) Publications and External Relations: Mr Cowe reported that the 'Children's Haemophilia Book' was now available and was being distributed by post to all member families with children aged twelve or under. In addition Haemophilia Centres could obtain multiple copies at £1.50 each.

The third edition of 'Introduction to Haemophilia' was also available. An order for one thousand copies has already been met and copies are available for distribution free of charge. Again, a copy has been circulated to Haemophilia Centres. A forth, improved, edition is already under consideration. Ideas for further improvements to the publication will be welcomed.

'Safer Sex - The Choice is Here' is the name of the publication being funded by the Health Education Authority. HEA have now approved the text following a very supportive report from the independent researchers who carried out a readership reaction survey. Illustrations and graphics are now in hand and publication is expected in April. It is proposed to hold a launch for health care professionals and the medical press.

The Society had provided a leading article for the Royal Medical Society's AIDS Newsletter.

A copy of the video produced by HEA has been received and reviewed. It contains interviews with three families in which the children have haemophilia and presents a confident, optimistic view of living with haemophilia. Mr Cowe expressed his satisfaction with the production and stressed the Society's involvement with HNA in producing a set of guidance notes to accompany the tape which is, essentially, designed for use by Health Care Professionals.

Finally, Mr Cowe, reported that, along with the General Secretary, he would be spending Saturday working on the initial draft of the 1989 Annual Report. Ideas and comments are warmly welcomed.

- (d) Group Liaison and Training: Mr Kirman reported on a particular problem regarding a Group which appeared to be holding well in excess of £2,000 in its accounts. Mr Kirman formally asked that all Groups should be reminded that their cash holding limit was £500 unless by prior arrangements. The Group concerned will be written to by the General Secretary.
- (e) Case Committee: The General Secretary had circulated a report on the activities of the Case Committee covering the months of November, December 1989 and January 1990. This showed that over the three month period a total of twenty grants were approved in the total sum of £4,003.00 - an average grant of £200.15.

During the course of the year a total of £22,477.95 had been paid in welfare grants. This compared to a total of £15,935 in 1988 and was seen as a part of the effect of the Government's review of the Social Security system.

- (f) Overseas: The Chairman reported that Ashok Verma, the Secretary of the Indian Federation of Haemophilia, had spent some time in London in the early part of January. He had stayed as the guest of the UK Society and had been entertained by a number of people, including Jonathan Cooper and the General Secretary. He had also been able to meet Mrs GRO-D for the first time after communication for some twenty years in writing.

A number of members expressed concern about the situation of people with haemophilia in Eastern Europe and the General Secretary reported that he was in contact with European Consortium countries in this connection.

(g) Grant Applications:

- (i) Dr H Daly, Royal Cornwall Hospital, Truro: Dr Daly sought a grant of £2,500, on a one-off basis, to enable her to incorporate haemophilia treatment records into a system part funded by the Cornwall Leukaemia Trust. The Executive Committee felt that this was an exceptional application, largely on account of the exceptional work carried out by Dr Daly in Truro, as well as a means of recognising the hard work of the Cornwall Group of the Society. It was, accordingly, proposed by Mr Lander, seconded by Mr Kirman, that the application succeed. This was approved with one abstention.
- (ii) David Jerwood, University of Bradford: This application, in the sum of £4,500 in the first instance and £3,500 in two subsequent years, was connected with a computer based project to assess the amount of factor VIII to be administered to each patient in each set of circumstances. The Committee felt that there was little merit in this project and it was proposed by Mr Kirman, seconded by Mr Knight, that no grant be made. This was agreed unanimously.
- (iii) Dr Paul C Winter, Belfast: This application was for a grant of £200 for the purchase of an additional electrophoresis gel tank to be used in connection with DNA/carrier detection techniques in Northern Ireland. That this application succeed was proposed by Mr Cowe, seconded by Mr Colthorpe and agreed unanimously.
- (iv) Nuffield Department of Orthopaedic Surgery: The General Secretary reported that he had received a preliminary application seeking help towards the establishment of a national orthopaedic service for people with haemophilia, based at the Nuffield Department of Orthopaedic Surgery. It had been anticipated, from the initial document received in September, that the annual cost of this project would be in the region of £40,000. The General Secretary had suggested that consultations should be held with the Haemophilia Centre Directors Organisation before any formal application was made to the Haemophilia Society.
- (v) Dr Paula Bolton-Maggs, Liverpool: Dr Bolton-Maggs had applied for a grant of £3,000 for the current and following year to enable her to complete a study on factor XI deficient patients. Applications had been made to other sources and it was resolved that the Society should help Dr Bolton-Maggs to explore those sources of funding prior to considering the matter further.

90.15

WORLD FEDERATION OF HEMOPHILIA: It was noted with regret that Mr Charles Carman, President of the World Federation of Hemophilia, had not found it possible during his European Tour to meet the UK Haemophilia Society Executive Committee.

90.16 **GENERAL SECRETARY'S REPORT**

- (a) Use of Volunteers: It was agreed that, certainly in connection with HIV and AIDS, the Society did not have the resources at present to cope with the selection and training of volunteers.
- (b) AGM Venue and Topic: It was proposed that the 1990 AGM be held in Sheffield and that the subject of the afternoon lecture be 'Stress'. This was proposed by Mr Kirman, seconded by Mr Colthorpe, and agreed unanimously.
- (c) Staff Training Costs: It was noted that the office would be closed on March 13 and 14, 1990, for staff Management Training and the total cost of that would be £1,075 plus VAT, plus accommodation costs.
- (d) UK AIDS Declaration: The General Secretary reported that during the last month a number of organisations which had not previously reached a decision on whether or not to attend conferences in the USA had, in fact, decided not to attend. In view of this, the small number of organisations involved in the drafting of the declaration who had yet to make up their minds, and the importance of the declaration itself, it was proposed by Mr Miller, seconded by Mrs Hazlewood, and agreed unanimously, that the UK Society now sign the declaration.
- (e) Dr Robb-Smith: It was noted that Dr Robb-Smith was writing a pamphlet marking the life of our late President, Dr R G Macfarlane. It was again resolved that no funding be made available for this project.
- (g) European Citizen Action Service: The General Secretary withdraw a proposal that the UK Haemophilia Society should join the European Citizen Action Service (ECAS) until costs involved became clearer. It was generally agreed that the organisation could provide a useful function to the European Consortium.

90.19 **THE MACFARLANE TRUST:** The Chairman reported that the Trustees were due for renomination, having reached the end of their first two year period. It was noted, that due to pressures of business, Mr Taylor had been unable to attend meetings. Accordingly it was agreed that Mr Taylor should not be renominated. It was proposed by the Chairman that the Society confirm the appointment of the other five Trustees and, subject to the agreement of the Charity Commissioners, leave one place vacant until a point regarding the possibility of Trustees receiving benefit from the Trust be answered by the Charity Commissioners. In the event of an unsatisfactory reply from the Charity Commissioners further consideration would be given to the point. This resolution attracted five votes in favour, one against and four abstentions.

It was also agreed that the General Secretary should write to the Macfarlane Trust stressing the need for the Trust to take no account whatsoever of the payment of £20,000 when assessing grant applications for single payments. This course was proposed by Mr Knight, seconded by Mr Cowe, and agreed unanimously.

90.18 **ANY OTHER BUSINESS:** There were no items of other business.

90.19 **DATE AND PLACE OF NEXT MEETING:** Thursday 8 March, 1990 at 6 pm for 6.30 pm at the Elizabeth Room of the Bonnington Hotel, London WC1.