

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392092



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MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE
HELD ON SATURDAY 16 MAY 1992 AT 10.00 AM
AT CHARITYBASE, 50 WESTMINSTER BRIDGE ROAD, LONDON SE1

Minute No

Present: The Rev Prebendary A J Tanner (Chairman), Mr N Lawson (Treasurer),
Mr K Milne, Mr A Cowe, Mr J Lander, Mr S Taylor, Mr R Dickason, and
Mrs N Guy.

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

AGENDA

- E92.12 Mrs Caroline Hazlewood
- E92.13 Apologies for absence
- E92.14 Minutes of the meeting held on 8 February 1992
- E92.15 Matters arising
- E92.16 Reports from Committees
- E92.17 General Secretary's Report
- E92.18 World Federation of Hemophilia
- E92.19 The Macfarlane Trust
- E92.20 Any other business
- E92.21 Date and place of the next meeting
- E92.22 Strategic Planning

E92.12 Mrs Caroline Hazlewood

The Chairman spoke of Mrs Caroline Hazlewood who had been a member of the Executive Committee for many years, and who had recently resigned. The Chairman spoke warmly of Mrs Hazlewood's contribution to the work of the Committee, saying that she had always been forthright in expressing her views, and had on occasion reminded the Committee that it existed to serve the wider membership of the Society. She had been instrumental in the planning and promotion of the Women's Weekends, to which she had devoted much time, and been most attentive in order to turn them into the success that they had proved to be. The Committee was unanimous in its appreciation of the part Mrs Hazlewood had played in its work, and wished her well.

E92.13 Apologies for absence

Apologies for absence were received from Mr K Colthorpe, Mrs J Hodgson and Dr **GRO-A**

E92.14 Minutes of the meeting held on 14 November 1992

The minutes of the meeting held on 8 February 1992 were proposed as an accurate record of the proceedings by Mr Milne, seconded by Mr Lawson, and agreed unanimously.

E92.15 Matters arising

15.1 1992 Annual General Meeting

Mr Watters noted for the Committee that the AGM was to be held at the John Radcliffe Hospital in Oxford on 6 June 1992 and that he hoped he would receive nominations for the various elections due to take place. According to the rules these should be received not more than three weeks or three days in advance of the meeting.

15.2 Awards

Mr Watters reported that £5,000 had been offered to the Society by the widow of Mr Philip Morris, with the suggestion that income from this invested amount be used to help people with haemophilia advance their studies in the arts, particularly in music, from which Mr Morris had derived much pleasure. The Chairman expressed reservations about accepting the gift in the form of an award, saying that the proliferation of awards should be avoided. Mr Taylor submitted that it be accepted in the form of a scholarship, given out every few years when there was someone who needed it. Mr Watters thought there should be a time limit of twenty years to such an arrangement since inflation would reduce the value of the gift, and Mr Lawson suggested that nominations for the scholarship should come from Groups. There was general approval of these ideas, and the Chairman proposed that Mrs Morris be approached and consulted.

15.3 Vice Presidents

Mr Watters recalled that at the previous year's AGM a revision of the Society's Vice Presidents had been promised, but that other pressing matters had intervened. It was agreed that an approach be made by Mr Watters to Sir Geoffrey Johnson-Smith.

Mr Watters reported that regular contact was being made with the office of the Society's patron, the Duchess of Kent. The Society was being considered for events two or three years hence.

E92.16 Reports from Committees

16.1 Member Services Committee

Mr Milne reported on the Member Services Committee's activities under the following headings:

(i) **Hepatitis:** The first draft of the fact sheet had been circulated, and the revision was due shortly.

(ii) **Grants and enquiries:** The Committee was well within its budget for the first quarter of 1992, having agreed to an expenditure of approximately £2,500.

(iii) **Medical Advisory Panel Meeting:** This had taken place and Dr Tuddenham's report on Gene Therapy had been particularly interesting.

(iv) **Local Groups:** Mr Watters' visits to Scotland had been most successful, but the proposed Northern meeting had been cancelled because of apparent lack of interest by many of the Group Committees.

(v) **Haemophilia Days:** Mr Milne announced with pride that the Days were running within budget and proving popular.

(vi) **Other matters:** Mr Milne reported that Mr Watters was having to operate without a fully functioning Member Services Department. This was noted by the Committee.

Mr Cowe raised a query over the cancellation of Mr Watters' visit to the North and Midlands [(iv) Local Groups], saying that he was concerned that this programme had been abandoned. Mr Watters said that only seventeen people from the Groups concerned had indicated that they would attend, and ten of those were from one Group. He had been working over weekends and there was pressure on his time; he felt that there should be a greater return for his efforts. Mr Dickason supported Mr Watters, saying that if Group Officers showed no interest in attending the meeting would not be as worthwhile an occasion, and the Society had to cut its losses. Mr Watters said that he had regretted the cancellation, and had taken the precaution of writing to Groups in the south west (Bristol, London and Exeter) where his next series of meetings was due, alerting them to this recent event. Mr Cowe accepted their explanation of the position.

16.2 Policy Committee

Mr Cowe reported on the Policy Committee's activities:

(i) **NHS Reforms, HC (76)4:** The General Election had relegated the reforms to the back burner, but these were once again receiving the Department of Health's attention. A further meeting between the Department and the Society was scheduled for Monday 18 May 1992.

(ii) **Gene Therapy, Clothier Report:** The Committee had considered its response to the issue of Gene Therapy, having been helped by the work of the Genetic Interest Group. The consensus had been one of broad approval, but it had been felt that the situation should be watched. The Chairman observed that it was important for the Society to be concerned with developments in this field, to be seen to be involved and showing an informed interest.

(iii) **Blood Products Policy:** A paper on the Society's policy would be available soon.

(iv) **Cost/benefit studies:** Although the Committee would have liked to commission a cost/benefit study of the treatment of people with haemophilia, the project had had to be shelved for the time being because of the expense. However, Dr Peter Jones had offered to look through the available literature, located primarily in the US, for relevant data. Mr Milne remarked that such data would be particularly valuable since the Society had adopted a policy favouring prophylaxis.

(v) **European Haemophilia Consortium:** The Consortium would be meeting in Dublin over the weekend of 22/25 May 1992 and Mr Watters, Mr Taylor and Mr Barker would be attending.

(vi) **World Federation of Hemophilia Decade Plan:** The Society had responded to the Decade Plan through Mr Taylor. A revision of the Plan would be circulated before the Congress in Athens, at which its adoption would be proposed. There had been only one personal response to the Plan, and that had come from Mr Watters, and just one response from a member organization, from the Society.

16.3 Resources Committee

Mr Lawson reported on the Resources Committee:

(i) **Approval of audited accounts and financial position:** The Society's reserves showed a marked drop for the financial year 1990-91 and expenditure had increased slightly. During 1992 no research grants would be made, and research grants that had been approved previously would not be paid. Mr Watters said that bequests to the Society had been more substantial, and the fundraising programme would be run earlier during the year. It was hoped that the Annual Report, accompanied by the new corporate brochure, would prove to be an inducement to the making of donations to the Society. The Chairman said that the Executive Committee carried the responsibility for the Society's financial affairs and that these should be monitored closely. Mr Taylor suggested that all members of the Executive Committee receive monthly financial reports, and Mr Dickason said it would be helpful if there was a brief commentary attached. In this way the achieving of goals such as those recommended by the Strategic Planning Group might be more realistically assessed.

Mr Watters reported that the Fundraising Committee would meet on 19 May 1992 under the chairmanship of Mr David Miller; the activities of the Committee had been delayed by the illness of Mr Julian Miller. Mr Taylor said that it was important for the Society to be positive about the future; it had experienced a high profile during the period of the campaign, and a re-orientation was now needed, a fresh look at the way forward. The professionals whom the Society had called in to help over this period of transition would be laying the grounds for success, and while the results of fundraising might take a while to come through the Society should be confident of reaping the rewards. Mr Lawson remarked that Mr McDonald had not been an expense to the Society as he had raised enough money to cover his fees. Mrs Guy said that she felt Groups were perhaps not fully aware of the fundraising possibilities available to them, despite the publicizing of fundraising ideas suitable for use at a local level; they had not seen any examples of successful fundraising activities. The Chairman said that solidarity was needed in the present difficulties, and a conviction too, that goals were realisable and would be achieved. Fundraising would be concentrating on the big money rather than pitching at local Groups. Mr Watters and Mr Lawson had the matter in hand and in concert with the auditors the situation would be stabilized.

(ii) **123 Westminster Bridge Road:** Solicitors acting for the Society and British Rail were negotiating the lease; rent had not been paid for two and a half years, the sum owed being in the region of £50,000. The Society had made a proposal to pay this off. VAT was also under negotiation.

E92.17 **General Secretary's Report**

The Report had been circulated previously. The following points were discussed:

17.1 **Medical Advisory Panel**

The membership of MAP was discussed; it was agreed that gene therapy should be amongst the Panel's considerations, and therefore Dr Tuddenham should be asked to become a member. The following names were also agreed: Dr E Mayne, Dr C Ludlam, Dr C Hay, Professor A Bloom and Professor E Preston.

17.2 Recommended Blood Products

Mr Watters raised the issue of likely trends in the use of blood products with the advent later in the year of a markedly cheaper resin chromatography product. Mr Watters remarked that it could be argued that there were some Centre Directors who regarded any of the new technology products as high purity. There was some discussion and Mr Milne stated that he would be unhappy at not distinguishing between the resin chromatography product and the high purity monoclonal product. It was agreed that monoclonal products should be used for HIV patients, and that resin chromatography should be favoured over intermediate products such as 8Y. Above all, there should be freedom of choice for clinicians to supply high purity products. It was generally felt that the issue should be kept on the MAP agenda.

17.3 Haemophilia Days

Mr Watters asked for help from Committee members for the forthcoming Haemophilia Days.

17.4 XX Congress; Athens, October

There was a short discussion about Professor Mandalaki's proposal for a shrine to doctors who had contributed to the field of haemophilia; the Committee felt that if there were to be a shrine it should be to those with haemophilia and HIV who had died, not the doctors.

Mr Watters drew attention to the fact that only two members of the Executive Committee would be going to Athens. Mrs Hazlewood had been the third member but as she had resigned she would not, of course, be in the party and with costs in mind, Mr Watters had not suggested replacing her.

17.5 Visits to Centres

Mr Watters reported that he had found his visits to Centres in Glasgow, Aberdeen and Manchester most fruitful, especially in promoting physiotherapy as a vital part of haemophilia care.

E92.18 World Federation of Hemophilia

Mr Taylor raised the subject of the elections of the WFH Council and Executive at the Congress in Athens. It was agreed that the names of candidates should be known in advance, and what election procedures were to be followed. The possibility of nominations from the floor should be avoided.

E92.19 The Macfarlane Trust

19.1 Meetings

Mr Watters reported that the meeting with the Macfarlane Trust on 2 March 1992 had been successful; there had been subsequent informal communications and relations between the two organizations were happy.

19.2 The Chairman's Report

The Chairman reported that all but one or two payments had been made from the two Special Payments Trusts. The remainder were proving difficult as the next of kin could not be traced.

19.3 Other matters

The Chairman reminded the Committee that a promise of continuing support for the Trust had been given by the Government, and that this was to be reviewed in the autumn. Plans for this meeting were being laid with a view to the Trust's funding being fortified for the future. The Trust's main concerns were the maintenance of regular payments. Single payments were now made less frequently, and were given for hospital visits, nursing and similar treatment-related needs.

The Chairman reported that Mr Hodgson had agreed to become a Trustee.

E92.20 Any Other Business

Mr Cowe announced that Mr Gordon Clarke had joined the Policy Committee as a co-opted member.

E92.21 Date and place of next meeting

The next meeting of the Executive Committee will take place on Wednesday 1 July 1992 at 5.50 for 6.00 pm at Charitybase in Room 701.

The meeting adjourned for lunch.

E92.22 Strategic Planning

22.1 The Plan

(i) **The Proposals:** Mr Taylor introduced the first part of the Strategic Planning Group's proposals, saying that the Plan itself was a process to help the Society focus its activities and a way of deciding in which direction it wanted to go and how to set off along its chosen route. The Plan was emphatically not a solution to the Society's problems, it pointed the way forward. The reason this re-evaluation was happening at this moment in the Society's history was because in the last few years there had been a clear focus to the work of the Society, resulting in a greater professionalism and higher ambitions. With this focus gone, the time was right to pause and take stock, and to use the expertise gained to achieve more for people with haemophilia.

Mr Taylor continued by asserting that the Society needed to be well-informed on two critical issues, that of the Health Service Reforms and the treatment and care of people with haemophilia. This was outlined in Proposal 1 of the Draft Strategic Plan. It would be necessary, said Mr Taylor, to have up to date information about what was happening at the national level, involving the Department of Health and Centre Directors, and at the Regional and District levels, involving the Centres themselves. Networks of communication would need to be established to monitor developments and changes in the way patients were being treated.

Proposal 2 suggested that the Society acquire a better understanding of the needs of people with haemophilia and their families. Mr Taylor said that current perceptions were biased and hazy, and influenced by those who could shout loudest. Many people with haemophilia had no means of making their voices heard, and local Groups did not reach them. A study should be undertaken to identify the needs of people with haemophilia. This could be achieved by two methods; an analysis of existing material, and through a fresh survey of that section of the population with haemophilia. It was hoped that, when completed, the study would provide the Society with a better understanding of what services were required and how those services might be matched to need.

Following on from Mr Taylor, Mr Dickason stated that Proposal 3 outlined the development of these new services and how they might be achieved. He said that the Society would need to be clear about its targets; there was a variety of proposals and priorities would have to be established. The costs and benefits of each proposal would need to be considered.

Mr Dickason outlined Proposal 4 which looked at the question of membership. This would look not only at different membership categories but at the future work of Groups and Council.

Mr Milne continued the resume of the Plan, saying that the Strategic Planning Group wished to ask the Executive to put its weight behind the principle that sufficient funds would be raised to make the Plan a reality. This would initially involve requesting that Mr Watters make fundraising a higher priority. Secondly, implementation would require clear targets and a process for reviewing progress. It was thought that the Executive Committee was not perhaps the best forum for this, and that a co-ordinating body operating between the existing Committees might be a good way of carrying out this task. Thirdly, the allocation of responsibility for executing the action plan in each proposal required careful consideration.

A discussion ensued on the Proposals contained in the Plan and the issues surrounding implementation. Mr Barker said that it would be necessary to set up a process for making decisions about which areas of work were to be done as the wherewithal became available through the Society's fundraising activities. Priorities contained within the different elements of the Plan would need to be established, and these would also need to be considered in relation to existing activities.

The Committee welcomed the Draft Plan and agreed that it be launched without major amendments for consultation at the AGM. However, it was agreed that implementation could take place only as funding and the staff became available.

The following additional recommendations made by the Strategic Planning Group and set out in the Draft Paper were considered:

- (a) The proposals set out in *Consultation on the Draft Plan* were agreed.
- (b) The sending of a questionnaire to the membership, presented in draft form to the Committee, was agreed in principle. The Committee was asked to send any comments on the questionnaire to Mr Barker.
- (c) The proposals previously circulated on annual budgeting and planning were agreed.
- (d) The paper entitled *Proposals for Evaluation of Services* was agreed.
- (e) The setting up of a membership development Project Team was approved, to include the Chairman, Mr Dickason, Mrs N Guy, one member of staff and one Council member. It was agreed that a draft remit be submitted to be considered at the first meeting of the Project Team.
- (f) It was agreed that Mr Watters and Mr Dickason should discuss Mr Watters' priorities.
- (g) It was agreed that Mr Watters should produce a paper for the next Executive Committee meeting on the implementation of the Plan. It was suggested that an outline of proposals might be helpful for airing at the AGM.
- (h) It was agreed that the question of the handling by the appropriate Committees of the Plan's proposals be addressed in Mr Watters' paper (g).

The Committee thanked the members of the Strategic Planning Group, Mr Dickason, Mr Taylor, Mr Watters and Mr Barker for the considerable time and effort they had given to the work entailed in the process of Strategic Planning. In particular, gratitude was expressed to Mr Barker for shouldering the main burden of writing and producing the Plan.

AJT/DW/GB/RB 08.06.92

Approved as an accurate record of the proceedings

GRO-C

..... The Revd Prebendary A J Tanner