

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392182**

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The  
Haemophilia  
Society  
123, Westminster Bridge Road  
London SE1 7HR

Telephone: 071-928 2020

Fax: 071-620 1416

MINUTES OF A MEETING OF THE MEMBER SERVICES COMMITTEE  
HELD ON SATURDAY 18 MAY 1991 AT 11.00 AM  
AT 123, WESTMINSTER BRIDGE ROAD, LONDON SE1

Minute No

Further Action

**Present:** Mr K Milne (in the Chair); Mr R Dickason; Dr M Winter

**In attendance:** Mr D Watters (the General Secretary); Mrs H Maynard (Member Services Manager); Ms R Benson (Minutes Secretary)

Mr Milne recalled Mr George Kirman, whose passing was a sad loss, and who would always be remembered by those who had known him for his good humour and courage.

Dr Winter's performance in the London Marathon on behalf of the Society was noted, with pleasure.

**M91.13 Apologies**

Apologies were received from Mr J Miller.

**M91.14 Minutes of the last Meeting**

The minutes of the meeting held on Saturday 26 January 1991 were proposed for adoption as an accurate record of the proceedings, and approved.

**M91.15 Matters Arising**

**15.1 M90.12 (a) Annual Service/Feature:** Mr Milne reported that the Rev Prebendary Tanner was willing to conduct an Annual Service at Bishopsgate, perhaps in the autumn. Mr Watters said that once a firm date had been agreed the event could be announced in *The Bulletin* and/or *Update* and people could be sent details of time and place on request. This would ensure that the Service was a private affair, and would allay fears regarding unwanted publicity. It was agreed that the Macfarlane Trust would also be asked to notify people.

Mem Serv  
Ctee

Mr Milne mentioned the National Feature, and after a brief discussion the Committee agreed that this should be fixed, rather than mobile, and that the matter should be presented to the Executive Committee on Thursday 6 June 1991.

Mem Serv  
Cttee

**15.2 M90.13 Barnardo's Social Worker:** Mr Watters reported that two Social Workers had been appointed, working in London and Birmingham respectively. The Society had been involved in the design of the induction programme, and as soon as they were established in their jobs the Committee would be meeting them.

**15.3 M90.21 Bio Products Laboratory Correspondence:** Mr Milne reported that he had written to Dr Richard Lane expressing concern over two issues, namely BPL's manufacture of two products with the possible creation of a two tier system, and the matter of product licences for new material. Dr Lane had replied, and on the second point had said that although 8Y had not yet been licensed, there were no impediments to its being sold.

The Committee agreed that the Society should pursue its policy favouring monoclonal or solvent/detergent treated blood products, and Mr Dickason suggested that a paper on the latest developments be written and circulated to the Executive. It should outline the current position, listing the various products on the market, and their prices. The Committee agreed this, and Dr Winter said that the Society ought to keep a close eye on the activities of Regional Centres and BPL.

DW

**15.4 M91.05 Teaching Children with Bleeding Disorders:** Mr Watters reported that the publication was in the hands of the Editor, photographs had been commissioned and it should be out by August.

**15.5 M91.09 Availability of Social Work Service in Haemophilia Care:** Mr Milne raised the matter of this paper, written by Mrs GRO-D, which a Project Team would consider. Mrs Maynard reported that aspects of the paper would be included by Mr Barker in the section on standards of treatment and care in the Policy Document.

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**15.6 M91.06 Women's Weekend:** Mr Milne reported that the Weekend at Durham University had been a success, despite a lower number of participants. He paid tribute to Mrs GRO-D, Mrs Hodgson and Mrs Maynard for their parts in its organization. Mr Watters announced that there had been requests for similar weekends to be held in Scotland and Northern Ireland. It was agreed that options be kept open for possible future weekends.

**15.7 Publications Editor and Committees:** The Committee discussed briefly the relationship between the Editor and other Committees, and how articles and publications were initiated. Mr Milne had discussed the matter with Mr Cowe. It was thought that the Editor could either commission a paper, or a Committee could decide to produce one, and in any event all publications would be submitted to the Editor who would tailor them to the Society's house-style.

**16.1 Birmingham Group:** Mr Dickason reported on the current situation, which appeared to have reverted back to an earlier position. A number of previously agreed courses of action had not been accomplished, and it was generally felt that the Group's abilities were being stretched beyond their resources. The Group was not fulfilling its legal obligations, nor was it supplying a service in the area for those with haemophilia. The Committee agreed that Mr Dickason would attend the Group's next meeting to be held in mid June, and report back. It was further agreed that the Executive would be asked on Saturday 6 June 1991 to give the Member Services Committee the authority to close the Group, if it became necessary.

RD

**16.2 Mr Watters' visits:** Mr Watters reported that his programme of visits to local Groups was proceeding apace. In February he had had a constructive day with East Kent and Lewisham Groups. Mr Watters observed that when several Groups were present at such a meeting, a closer bonding resulted. Groups could see how other Groups operated. Developing this idea, Mr Watters said that meetings incorporating a number of Groups in a particular area should be considered for 1992; such meetings would be a better use of Society resources in terms of time and money (he was working twenty three weekends in 1991), and would benefit the Groups themselves who would undoubtedly gain much from inter-Group connections. The Society would be greatly strengthened, since at present any Group contact took place only during Council meetings. There was concern, also, that some Groups might feel insignificant and unimportant, and it was felt that this would be helped through a better system of direct communication by way of area meetings. Later on Regional Group meetings could be contemplated. The Committee endorsed Mr Watters' views.

Mr Watters reported on his recent attendance, with his Personal Assistant, Mr P Burba, at the opening of the new Northern Ireland office. This was situated on the ground floor of a terraced house close to the centre of Belfast, looking out on to a park. During the course of the day, which was informal and relaxed, around sixty people had dropped in and there had been a feeling of general goodwill and enthusiasm. Health Network was attending to publicity in the local press.

Mr Dickason raised the issue of even-handed treatment of all Groups, and said that the Society should be particular about not seeming to favour one Group over another. Mr Watters agreed, and suggested the establishment of further regional offices, perhaps another four, which could maintain close contacts with Groups within their regions.

**16.3 Media Training for Groups:** Mr Milne reported that at the recent Policy Committee Meeting on Saturday 27 April Mr Simon Taylor had agreed to re-write a package he had produced at an earlier date on media training. It had been suggested that this might be used to help members of Groups deal with the media. The Committee welcomed the suggestion, but was uncertain about exactly what was envisaged; it was thought that a low key approach involving talking to the local press at fêtes and coffee mornings would be accepted by members of Groups, but that they might be somewhat intimidated if television interviewing, for instance, was on the agenda. Mr Watters said that much could be learned from Mr Taylor's experience in relations with the media, especially for those members of the Society who had dealings with press, radio and television.

The Committee felt that it would like further clarification from the Policy Committee on what was intended. It was also suggested, and agreed, that a specific policy be established, for inclusion in the Policy Document, on how the Society should manage its contacts with the media.

Policy  
Document

**16.4 Group Minutes:** Mr Milne brought up the subject of procedure regarding Group Minutes. It was agreed that Mrs Maynard would read through all Group Minutes and discuss any problems therefrom with Mr Watters. If necessary they could then be addressed at Member Services Committee meetings.

HM

**16.5 Group Attendance at Council Meetings:** Mr Milne enquired whether there were any persistent non-attenders at Council meetings. Swansea and Jersey Groups were mentioned, and Mr Watters announced that he would be seeing both soon, and would talk to them. It was thought that there were no major problems over which to be concerned.

DW

#### **M91.17 Conferences**

Mrs Maynard reported on progress on the Regional One-Day Conference to be held at Huddersfield. Thirty people were coming, but late bookings might still arrive. Posters advertising the conference were being sent to Groups and Centres in the area. Mr Dickason observed that if the Society was moving towards a regional structure, it might be judicious to wait for a period before arranging any more conferences, and the Committee concurred.

#### **M91.18 Medical Advisory Panel**

There was a discussion of a paper by Mr Barker, previously circulated, on the findings of a Project Team set up to review the workings of the Medical Advisory Panel. It was generally agreed that the function of MAP needed to be redefined, but that its structure should not necessarily be changed as radically as had been suggested. For instance, it was felt that the inclusion of nurses, social workers and physiotherapists was unnecessary and would prove to be unworkable in practice. The Committee agreed the following points:

- i) MAP should continue to exist.
- ii) MAP should not contain non-medical members.
- iii) Members should have specific areas of interest.
- iv) The Panel should serve a broader function, including education and conferences. Members could be asked to give a seminar on hepatitis, for example, or organize a conference on a specific subject.
- v) A document detailing how MAP should be run might be a more suitable way of structuring the Panel's activities than individual job descriptions or contracts for members.
- vi) The AGM should be asked to give responsibility for appointment of medical advisers to the Executive Committee.

- vii) The Society would hold the right to co-opt any new members it wished.
- viii) Consultation on other health care issues would not be required by the constitution.

These views would be presented to the Project Team for further discussion before submission to the Executive Committee on 6 June 1991.

#### **M91.19 Grants**

It was agreed that reference to a Case Committee was no longer appropriate; the Member Services agenda and minutes would refer simply to "Grants". A report summarizing grants made in the period 1 January 1991 to April 1991 was circulated, showing an increase in awards over the last four months of 1990.

Mr Milne raised the fact that the Macfarlane Trust had recently decided not to accede any longer to certain requests for funds. The Committee was disappointed and expressed regret at the decision.

#### **M91.20 Policy Document**

It was agreed that Mrs Maynard would read through past Member Services Committee minutes and extract any items for the Policy Document.

HM

#### **M91.21 Adolescents**

Mr Milne reported that [GRO-D] in Margate had suggested that HIV positive boys in their adolescence or late teens needed help and support from the Society in facing up to and coming to terms with possible difficulties they might meet. A weekend had been proposed during which problems could be aired. There was some discussion, and it was recognised that it was a complex subject and that there were various obstacles to the successful running of such a weekend, namely that sufficient numbers of adolescents wanting to attend a group gathering were doubtful, that they probably would not want to come with their parents, and that some parents might object to the kind of subject matter that was up for discussion. Dr Winter agreed to discuss the idea with both Mrs [GRO-D] and Mrs [GRO-D], and Mr Dickason suggested that he speak to Mrs [GRO-D] in Leeds. Mr Watters proposed that he pick brains at Barnardo's, who had many years of experience in working with teenagers. It was agreed that once ideas had been pooled, Mrs Maynard would present a report to the Committee.

MW  
RD  
DW  
HM

#### **M91.22 Member Services Manager**

A paper outlining the work of the Member Services Manager had been circulated. This revealed that 75 - 80% of Mrs Maynard's work involved dealing with individual members' needs, problems and queries. The Member Services workload was only being carried because the major part of the Society's work with Groups was being shouldered by Mr Watters. Mr Watters said that it would not be possible to advance into new areas such as hepatitis, blood products and AIDS/HIV without changes being made at the national office. Another member of staff

would be required, as well as extra floor space, and the Resources Committee would be alerted to the fact.

Resources  
Cttee

**M91.23 Any Other Business**

**11.1 Hepatitis:** Mr Milne reported that a Project Team consisting of Mr Taylor, Mr Dickason and Mr Watters had been set up to look at ways in which the Society's work in the field of hepatitis could be furthered. Dr Winter agreed to being consulted if necessary.

**11.2 Prophylaxis:** The Committee agreed that Society policy on prophylactic treatment should be that it believed it to be central to haemophilia care that all people with severe haemophilia under the age of eighteen, or those with target joints, should be given prophylaxis and should remain on it for the duration of their lifetimes. This proposal would be put to the Policy Committee for further discussion.

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It was further agreed that this should be an item for inclusion in the Policy Document, and that policy on blood products should also be incorporated.

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**M91.24 Date, time and place of next meeting**

The next meeting of the Member Services Committee will take place at the Haemophilia Society on Wednesday 10 July 1991 at 6.00 - 8.30 pm.

RB 29.05.91