

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392218



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MINUTES OF A MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY
HELD ON SUNDAY 25 NOVEMBER 1990 AT 11.30 AM
AT ST GEORGE'S HOTEL, LIVERPOOL.

Minute No

Further Action

Present: The Rev A Tanner (Chair); Mr J Lander; Mr K Colthorpe; Mr R Dickason; Mrs C Hazlewood; Mrs J Hodgson; Mr J Miller. Representatives from the following Groups: Cambridge, Cornwall, Derby, East Kent, Grampian, Hampshire, Lewisham, Leicester, Lincoln, Merseyside, Norfolk & Norwich, North East, North West, Northampton, Northern, Northern Ireland, Nottingham, Oxford, Perth, Sheffield, South East Scotland, South Essex, South Wales, Southern, Tayside, West of Scotland.

In Attendance: Mr D Watters (General Secretary); Mr G Barker (Policy Manager); Ms L Matthews (Resources Manager); Ms H Maynard (Member Services Manager)

AGENDA

- C90.20 Apologies for absence
- C90.21 Minutes of the Meeting held on 2 June 1990
- C90.22 Matters arising
- C90.23 Reports from Committees
- C90.24 World Federation of Hemophilia
- C90.25 The Chairman's Residential Weekend
- C90.26 Any other business
- C90.27 Date, time and place of next meeting

C90.20 Apologies

Apologies for absence were received from Jersey Group and Mr K Milne, Mr A Cowe, Mr G Kirman, Mr C Knight and Mr M Lawson.

C90.21 Minutes of the meeting held on 2 June 1990

The minutes had been circulated in advance and their adoption as an accurate record of proceedings was proposed by Mrs Guy, seconded by Mr Colthorpe, and agreed unanimously.

C90.22 Matters Arising

- a) **Running vests:** After a prolonged discussion about the Society's need to provide running vests, and consideration of a number of proposals, it became clear that Northern Group held a supply which could be made available to other local Groups at a charge. In the meantime the Society nationally will look again at the question and report as appropriate.
- b) **Compensation update:** Mr Watters reported that, as the result of a meeting held in the House of Commons on Wednesday 21 November 1990, an All Party Group of MPs had been formally established. This will be an ad hoc group under the Chairmanship of Patrick Cormack MP, and Vice Chairmen Rosie Barnes, Alf Morris and Jim Wallace. 28 MPs had attended the meeting despite it being a highly fraught day in the House, being the day preceding the resignation of the Prime Minister and the meeting occurring at the same time as a re-scheduled debate on the Disability Bill. It was agreed that, as soon as the new Prime Minister was appointed, everyone should make all possible efforts to write to the new Prime Minister and to the new Secretary of State for Health, William Waldegrave. Mr Watters also paid tribute to the work done by GJW, the Health Network, and his colleagues on the staff at the national office for the work they undertook in connection with the campaign and in supporting his role.
- c) **Financial limit available to Groups for expenditure:** Mrs [GRO-D] raised this matter. She had been under the impression that this had been extended to £100 at the earlier meeting of the Council held in Sheffield. It was pointed out that the arrangement was that £50 was the limit available to all Groups although this could be extended, on request, to £100 or, by referral to the Resources Committee, to a higher, but justifiable sum.

C90.23 Reports from Committees

- a) **Member Services Committee:** On behalf of Mr Milne, who was absent, Mr Dickason reported on behalf of the Committee. He made particular reference to the concern felt by the Member Services Committee to give resources and strength to local Groups in the Society and, further, it had been agreed that Mr Watters should visit all local Groups during the course of 1991. Local Group Officers present at this meeting of the Council had received a copy of the *Local Group Resource File* and Mr Dickason paid tribute to Mr Kirman for his help in preparing this very important loose leaf file for local Groups. Additional material would include Notes for Treasurers.

Mr Dickason also reported on progress being made with Barnardo's on a pilot project to appoint a Social Worker to work in the London RHAs with families where HIV was present alongside haemophilia. The Committee were also concerned with producing a new education booklet which would be entitled *Teaching Children with Bleeding Disorders*. This would be ready during 1991.

Providing day-long conferences throughout the country was another matter which had received the attention of Member Services Committee. More news about this would be forthcoming early in 1991.

Mr Milne had concerned himself very much with the provision of blood products and had been involved in discussions with BPL regarding the packaging and size of bottles available from the Elstree plant.

The Committee were also looking into some tangible object to mark the tragedy which had occurred to people with haemophilia in the United Kingdom and thought and negotiations and discussions on that would continue into 1991.

- (b) **Resources Committee:** The Chairman reported that the Resources Committee continued to monitor income and expenditure. He highlighted the appointment of McDonald and Associates as professional fundraisers for the Society and, in doing so, he acknowledged that this was a new departure in the life of the Society. However, it was no longer possible to sustain all the work of the Society and the fundraising with present staff resources.

Resources Committee were also looking at the role of the Executive Committee as responsible employers of staff and particular attention had been given to conditions of employment, pensions and the fact that we were working towards becoming an equal opportunities employer.

The Chairman highlighted a Christmas Carol Concert to be given in his church in London on Thursday 6 December and the International Airlines Ball at the Commonwealth Institute on Friday 7 December.

The Treasurer, Mr Lander, made a particular plea to Groups to submit their accounts to 31 December 1990 as quickly as possible and, further, asked that all Groups notify Ms Matthews of the names of the signatories to all bank accounts.

In discussion Mr [GRO-A] (Cardiff) questioned whether the Executive Committee had the right to embark upon engaging fundraisers. There was general agreement among those present that it was necessary to take this step and, further, the Chairman reminded those present that the 1989 Chairman's Conference, in interpreting the CERT Report, had clearly established that such responsibility lay firmly with the Executive Committee who, in the last analysis, were responsible for the financial conduct of the Society.

- (c) **Policy Committee:** In the absence of Mr Cowe, Mrs Hazlewood reported on behalf of the Policy Committee. She mentioned, in particular, work that had been carried out in connection with the HIV compensation campaign by Mr Watters and the current heavy work load which he was bearing.

A great deal of time had been spent on the NHS Review and the Executive Committee gave this matter such a high priority that Mr Barker, the Policy Manager, had devoted much of his time and energies to it. Mr Barker reported on the NHS Review and its likely implication for people with haemophilia and their treatment, particularly in relation to service delivery in the "purchaser/provider" ethos of post April 1991. A special edition of *Group News* would be produced carrying full details of this so that local Groups could become fully involved in this important issue.

Mrs Hazlewood also reported on the likely implications of the Disability Living Allowance which would come into effect in 1992. The Policy Committee would keep all members informed of developments on this and, again, Groups would be kept particularly well informed through *Group News*.

Policy Committee had been concerned with the USA immigration legislation and while it appeared at the moment that the matter was about to be resolved another problem was beginning to emerge in that it would not be possible to get travel insurance if HIV positive after January 1992. Mr Watters was involved in negotiations in that connection.

While the Society remained a member of the World Federation of Hemophilia the continued involvement was under review and Mrs Hazlewood drew particular attention to a letter in the current edition of *THE BULLETIN* from Dr Peter Jones seeking new ideas for the future of the World Federation.

In dealing with publications Mrs Hazlewood highlighted the video which the Society hoped to produce during 1991 and the *Haemophilia Centre Directory* which was being sponsored by Blood Products Laboratory and which, also, would be available in early 1991. Investigations were taking place into the layout of *THE BULLETIN* and varying formats were currently being presented. The overall corporate image of the Society was under review in conjunction with McDonald and Associates, the fundraisers. Mrs Hazlewood highlighted the success of our latest Safer Sex publication sponsored by the Health Education Authority. Of 20,000 copies printed only 1,200 remained at the national office. HEA were considering reprinting the publication on account of the very high demand. *Treatment News* was also mentioned and highlighted.

The Independent Broadcasting Authority had also granted a television appeal which would be broadcast during the spring of 1991.

Looking ahead the Policy Committee were most concerned about the NHS Review, the purity and supply of Factor 8 products, hepatitis and its implications for people with haemophilia and securing the highest standards of treatment and care for patients with haemophilia in the United Kingdom. The Chairman thanked Mrs Hazlewood for her comprehensive report.

C90.24 World Federation of Hemophilia

This had already been mentioned in C90.23 (c).

C90.25 The Chairman's Residential Weekend

In response to an invitation for comments from the Chairman about the arrangements for, and the value of, the Conference, the weekend was welcomed as a success and described as cost effective. There was some concern that the Agenda had been rather heavily loaded and one delegate enquired whether it might be possible to hold the Council Meeting earlier in the weekend rather than the last event. This suggestion attracted no support but the Chairman said consideration would be given to it. The nine Workshop leaders were invited to present their suggested priorities for the coming year. In these presentations, it was generally agreed that the campaign for HIV compensation should continue as the highest priority of the Society although concern was expressed that we should not become "the HIV Society" and that we should remember our basic commitment to all people with haemophilia.

The compensation campaign apart, it was agreed that the quality of care offered to people with haemophilia in the United Kingdom was the top priority for the Society. A close second priority was the NHS Review and the way in which it would affect treatment and care for people with haemophilia. Almost sharing third place came the support to local Groups envisaged in Mr Watters' programme for 1991 and the problems of hepatitis for people with haemophilia who were suffering severe liver damage. It was agreed by the Chairman that those, and other subjects, would continue to be reviewed by the Executive Committee and he expressed particular thanks to Mr GRO-D, Mrs GRO-D, Mrs GRO-D, Mr GRO-D, Mrs GRO-D, Mrs N Guy, Mr GRO-D, Mr GRO-D and Mrs GRO-D who had each led two workshop Groups during the course of the weekend in order to establish priority areas of activity for the Society for the coming year.

C90.26 Any other business

Grampian Group drew attention to the fact that the Scottish Adventure Holiday would be held in the week beginning 11 August 1991.

The Chairman received cheques of £500 from Northern Group and £1,500 from Northampton Group. The receipt of both cheques was met with acclamation.

In closing the Chairman paid tribute to Mr Watters for the work he had done in organizing the conference, and in particular, in relation to the campaign. He drew attention to the fact that the Resources Committee were directing Mr Watters to take an additional eight weeks leave during 1991 in order to compensate him for the hours worked during evenings and weekends for which it had not been possible to take time off in lieu.

C90.27 Date, time and place of next meeting

The Chairman announced that the next Council Meeting would take place in London on Saturday 16 March 1991. Details of programme and venue will be supplied.

DW/RB 30.11.90

GRO-C

16 March 1991.