

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392180



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MINUTES OF A MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY
HELD ON SUNDAY 24 NOVEMBER 1991 AT 11.30 AM
AT THE SWALLOW HOTEL, QUEENS PARADE, SEABURN, SUNDERLAND

Minute No

Present:

The Rev Prebendary A J Tanner, Chairman; Mr A Cowe, Vice Chairman;
Mr K Milne, Vice Chairman; Mr N Lawson, Treasurer; Mr R Dickason;
Mr S Taylor; Mr K Colthorpe; Dr [GRO-A]; Mrs N Guy.

Representatives from the following Groups

Birmingham, Cambridge, Cornwall, Derby, East Kent, Grampian, Hampshire,
Leicester and Rutland, Lewisham, Lincoln, Merseyside, Norfolk and Norwich,
Northampton, North East, North Wales, North West, Northern, Northern
Ireland, Nottingham, Oxford, Sheffield, South East Scotland, South Essex,
South Wales, Southern, Tayside, West of Scotland.

In Attendance:

Mr D Watters, General Secretary; Mr G Barker, Policy Committee Manager;
Ms S Archer, Resources Committee Manager; Ms R Benson, Minutes
Secretary.

AGENDA

- C91.20 Apologies for absence
- C91.21 Minutes of the meeting held on Saturday 1 June 1991
- C91.22 Matters arising
- C91.23 Reports from Committees
- C91.24 World Federation of Hemophilia
- C91.25 The Chairman's Residential Weekend: Summary and Resolutions
- C91.26 Any other business
- C91.27 Date, time and place of next meeting

C91.20 Apologies

Apologies for absence were received from the Jersey, Perth and Swansea Groups, and from Mr J Miller, Mr J Lander, Mrs J Hodgson and Mrs C Hazlewood.

C91.21 Minutes of the meeting held on Saturday 16 March 1991

The minutes had been circulated in advance and were proposed as an accurate record of the proceedings by Mrs C Robertson, seconded by Mrs L Reynolds, and agreed unanimously.

C91.22 Matters Arising

22.1 Travel to the USA

Mr Watters reported that, to travel to the US, a waiver was still necessary for people who were HIV positive and had to be applied for from the US embassy. The waiver took the form of a removable sheet placed in the traveller's passport. The Society was continuing its boycott of all travel to the US. This took the form of not attending any conferences in that country and refusing travel funds for any individual intending to visit it.

22.2 National Health Service Reforms

The Chairman reported that a meeting had taken place between Mr William Waldegrave, Secretary of State for Health, and the Society, represented by the Chairman and Mr Watters. The meeting had been useful and constructive, and as a result Mr Waldegrave had indicated that the Department of Health's document on haemophilia care, known as HC 76/4, would be looked at again by his Department, in consultation with the Society. The Chairman said that this was a valuable achievement. The successful outcome of the meeting was due largely to the work put in beforehand by Mr Watters and Mr Barker, and the Chairman thanked them both for briefing him so well.

22.3 Compensation Update

The Chairman reported that the money from the Government for those people with haemophilia infected by HIV had nearly all been settled. Final delays were due mainly to legal difficulties. The Macfarlane Trust was planning to return to the Government to request more money to maintain its funds; these were being depleted by the maintenance of regular payments and the erosion of capital was accelerating. The Chairman promised to keep the Council informed.

22.4 Medical Advisory Panel (paper circulated)

Mr Watters reminded the meeting that the Medical Advisory Panel had been due for election at the Annual General Meeting in June 1991, but that the matter had been deferred to allow further consideration to be given to the subject. The Executive Committee had appointed a Project Team to review the Panel's role and responsibilities. It had been felt, said Mr Watters, that the Panel was too big and unwieldy and that it did not always produce entirely satisfactory results. The Panel had no terms of reference from which to work and members seemed, at times, unable to re-adjust to their appointed roles as advisors to the Society. The Project Team had produced a paper, previously circulated, recommending that the Panel be reduced to six members; that the members be re-appointed on an annual basis; that the Panel members be appointed on the basis of their involvement with the Society's main concerns and, finally, that it operate within the proposed terms of reference outlined in the paper. The Chairman observed that the Panel represented a useful

resource and that it was important to take advantage of the skills and expertise it made available to the Society. He asked the Council to approve the Project Team's recommendations; this was proposed by Mrs Dickason, seconded by Mrs Robertson, and agreed unanimously.

C91.23 Reports from Committees

23.1 Policy Committee (paper circulated)

Mr Cowe, reporting on the current membership of the Policy Committee, said that while Mrs Hazlewood had transferred to another Committee, Dr GRO-A and Dr Brian Colvin had accepted an invitation to join the Policy Committee, and he welcomed them both. Mr Colthorpe and Mr Taylor were still members. Mr Barker, Policy Manager, carried out most of the work of the Committee and Mr Watters attended all the meetings, including those of the other Committees, and so kept the Policy Committee abreast with what was happening in other areas of the Society.

Referring to the Committee's report circulated previously, Mr Cowe said that the Committee's attention had been focussed particularly on the NHS reforms and what these would signify in terms of haemophilia treatment and care, and the cost thereof. The Committee was considering ways of researching the cost-effectiveness of haemophilia care, and would keep the Council informed of progress.

Other matters listed in the Committee's report were the policy on blood products, and the Society's response to the Government's recent consultative paper *The Health of the Nation* and disability benefits. The Committee was considering, also, the Society's overseas links, including those with the World Federation of Hemophilia, the European Consortium, the European Commission, Eastern Europe and India. Again, Mr Cowe said that the Committee would report in due course on developments within all these fields.

23.2 Member Services Committee (paper circulated)

Mr Milne said that Mrs Hazlewood had joined the Member Services Committee. Another new member, by way of co-option, was Dr Mark Winter, whom he welcomed. The other members were Mr Miller, Mr Dickason and Mrs Guy. Mr Watters attended meetings.

Mr Milne reported that Mrs Maynard, Members Services Manager, spent a large part of her time dealing with problems and queries brought to her by the Society's membership; in consequence she was unable to attend to other Committee matters. In order to alleviate the situation it was hoped to appoint another staff member in 1992.

Mr Milne referred to the Committee's report, already circulated, and said that current concerns included local Groups, their relationships with the national office and each other, and that the purpose of Mr Watters' visitations in 1991 had been to help Groups revitalize and reorientate themselves. The possibility of establishing a regional structure for Groups was being looked into.

The Committee was occupied, also, with a programme of meetings and conferences, including the feasibility of a family weekend and an event for teenagers and young men with HIV. A Project Team had looked at hepatitis and related matters.

Mr Milne reported that the Society's Thanksgiving Service had taken place at St Botolph's, Bishopsgate on Saturday 2 November 1991. Conducted by the Chairman, it had been a moving service for all those present, and an immense success. It was hoped that there would be similar services in the future. Mr Milne urged those present at the meeting to tell others that there had been no unwanted publicity, and that future services would continue to be very much family

affairs. On behalf of all those who had attended the service Mr Milne expressed appreciation and thanks for the tea laid on afterwards by the Chairman's family. He also declared admiration and gratitude for the way in which the Chairman had made the service such an uplifting and hopeful occasion. Mr Milne proposed a vote of thanks to the Chairman for all the work he carried out on behalf of the Society and this was acknowledged by prolonged applause. The Chairman thanked Mr Milne for his words, saying that the Service had been a significant occasion for him too, and that he looked forward to the next one.

23.3 Resources Committee

Mr Lawson, who had taken over the Chairmanship of the Resources Committee earlier in the year, welcomed Ms Susan Archer as Resources Manager. Other members were Mrs Hodgson and Mr Lander.

Mr Lawson reported that the Society had done well in 1991, and, unlike many other charities, had increased its income. However, it was necessary to plan for the future and build up financial reserves with long-term goals in mind. The Chairman said the Society was fortunate to benefit from Mr Lawson's wide experience of business and financial affairs, and was grateful that he managed to find the time to take on the Chairmanship of the Committee.

23.4 Grants Committee

Mr Watters reported that the Grants Committee, meeting twice annually, with deadlines at the beginning of January and July, had considered the following applications for funding:

23.4 (i) Dr B A McVerry, Leeds: A grant of £2,000 for a further year to enable a part-time physiotherapist to remain in post. This was agreed. It was noted that the local Group had already funded £1,000 through centralized banking for this purpose.

23.4 (ii) Karen Beeton, Haemophilia Chartered Physiotherapy Association: A grant of £4,500 for two booklets on physiotherapy exercises for people with haemophilia, one for adults and one for children. This was granted on condition that the Association publish the booklets in the Society's new livery, and with its logo on the covers next to that of the CPA. This condition had been accepted.

23.4 (iii) Dr Bernadette Modell, University College: Funding for research related to thalassaemia; this was not agreed since the Committee rated it as a low priority in the current climate.

23.4 (iv) Dr Mark Winter, Margate: £1,000 to improve patient amenities at the Margate Centre. This request had been received through the East Kent Group, and it was granted.

23.4 (v) Dr T G Truscott, University of Keele: Research on the photochemistry of viral inactivation, for which £9,500 was requested. The Committee felt that the immediate benefit to people with haemophilia was remote, and the application was turned down.

23.4 (vi) Professor A L Muggleton-Harris, MRC: Support for sponsorship of a conference for geneticists in the UK in September 1992. It was recommended that no grant be made.

23.4 (vii) Dr Charles Hay, Liverpool: A grant of £1,200 for the purchase of a number of TENS machines; this was approved.

23.4 (viii) Professor E F Preston, Sheffield: £5,000 was requested to fund improvements to patient amenities at the Royal Hallamshire. The application was couched in broad terms, and in the absence of further details and costings the Committee recommended a grant of £2,500.

23.4 (ix) Dr Christine Lee, London Royal Free: A large grant of £26,000 was applied for to fund research into hepatitis and HIV in people with haemophilia. The Committee thought that while the project was important, the Society could not meet the full amount asked for. It was agreed, however, that £10,000 should be offered including help with securing the balance.

23.4 (x) Mr A Inman, Dental Practitioner, Oxford John Radcliffe: £2,500 was requested to meet a shortfall at the Nuffield Hospital Dental Department. The upgrading of facilities was necessary to safeguard those likely to be exposed to viral infections. The Committee recommended that this grant be successful.

It was noted that grants at 23.4 (i), (iv), (vii) and (viii) were made possible as a result of income from the End to End Bike Ride.

C91.24 World Federation of Hemophilia

24.1 XX World Federation of Hemophilia Congress

Mr Watters reporting on XX World Federation of Hemophilia Congress to be held in Athens on 12 - 17 October 1992, said that the Executive Committee had approved sponsorship of six places. These would be split equally, three each at local and national levels. The deadline for all nominations, to be made in writing, was 31 December 1991.

Mr Taylor said that, since the Council meeting in June at which he had undertaken to report back on the Project Team investigating the Society's relationship with WFH, that organization had announced the development of a strategic plan. A document was to be produced and the Society would have the opportunity at an early stage, certainly before the end of 1991, to discuss it and offer recommendations. The final draft of the strategic plan was to be presented at the Athens Congress, and if approved would be formally adopted.

24.2 Other matters

Mr Taylor observed that 1992 and the European context was, for the treatment and care of people with haemophilia, very important. The European Commission had issued a directive on blood supply and the Society needed to take a close interest. The Society was working with the European Haemophilia Consortium to develop a co-ordinated response to the European Commission. Mr Taylor said the Society had a wealth of expertise and knowledge, and it was keen to share this with other Non-Member Organizations, especially those in eastern Europe.

C91.25 The Chairman's Residential Weekend

The Chairman raised the subject of the Society's proposal to embark upon a strategic planning process with the help of a professional organization, Compass Partnership. This had been introduced to the Council on the previous day, Saturday 23 November, when Mr Dickason had outlined what it might mean and what it could entail. Compass Partnership would assist the Society in the identification of goals and possible future directions and trends. It would help in the development of an overview of the work of the Society, enabling it to take a considered and measured approach to those issues affecting the lives of people with haemophilia. The estimated cost was £10,000. The Chairman recalled the engaging of CERT and although that had cost a

smaller amount, it had at the time seemed large; the Council's decision to go ahead had been made with some trepidation. The Society had, however, benefitted enormously from the CERT recommendations, and the Chairman felt that while the sum presently under discussion might seem a large figure, the Society stood to acquire once again great advantage through working with external professionals. After some discussion it was proposed by Mrs Dickason, and seconded by Mr GRO-A, that the Society proceed with the strategic planning process in conjunction with Compass Partnership. This was agreed unanimously.

C91.26 Any other business

The Chairman reported with sadness that Dr Kernoff, Director of the Haemophilia Centre at the Royal Free, London remained severely incapacitated as a result of illness. It seemed unlikely that he would be returning to his duties at the Centre; in the meantime Dr Christine Lee was standing in for him. The Chairman recalled that Dr Kernoff had made a very significant contribution to the treatment and care of haemophilia, and had managed an important research team at the Royal Free. In addition to these achievements, on a human level, he had always been most kind and attentive both to his patients and to the Society.

The Chairman observed that the Conference weekend had provided an opportunity for Council members, the Executive and Society's staff to meet each other in relaxed surroundings, making it an agreeable and worthwhile occasion for all concerned. It was a valuable consultative exercise and had been well served by excellent lectures. The Chairman thanked all those involved; the various professionals from different fields who had given up time to attend, and all those who had represented the Society's Groups from across the country. He expressed gratitude, in particular, to Mr Watters whose work had made the weekend such a success; there was warm applause.

C91.27 Date, time and place of next meeting

The next meeting of the Council of the Haemophilia Society will take place on Saturday 29 February 1992; the venue will be announced.

DW/RB 16.01.92

Approved as an accurate record of the proceedings on 29 February 1992

Signed

GRO-C

..... The Rev Prebendary A J Tanner, Chairman