

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392178



MINUTES OF A MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY
HELD ON SATURDAY 27 FEBRUARY 1993 AT 11.00 AM
AT CHRIST CHURCH AND UPTON CHAPEL, KENNINGTON ROAD, LONDON SE1

Minute No

Present: The Rev Prebendary A J Tanner, Chairman; Mr K Milne, Mr A Cowe, Vice Chairmen; Mr G Clarke, Acting Treasurer; Mr R Dickason; Mr J Lander; Mr S Taylor; Professor L Evans.

Representatives from the following Groups

Cambridge, Derby, E Kent, Grampian, Hampshire, Leicester, Lewisham, Lincoln, Merseyside, Norfolk and Norwich, North Wales, North West, Northampton, Northern, Oxford, Southern, West of Scotland.

In Attendance: Mr D Watters, General Secretary; Ms S Archer, Resources Manager; Ms R Benson, Minutes Secretary.

AGENDA

- C93.01 Chairman's remarks and welcome
- C93.02 Apologies for absence
- C93.03 Minutes of the meeting held on 21 November 1992
- C93.04 Matters arising
- C93.05 Questions to the Executive Committee on any matter
- C93.06 Workshop/presentation
- C93.07 Lecture by Dr C Hay
- C93.08 Discussion
- C93.09 AGM matters
- C93.10 Any other business
- C93.11 Date, time and place of next meeting

Lecture by Dr Charles Hay, Royal Liverpool Haemophilia Centre
on High Purity Blood Products

C93.01 The Chairman's remarks and welcome

The Chairman welcomed all those who had managed to come, despite bad weather. He observed that the gathering was a more compact, homely one, and that this was the first Council meeting at which only one representative from each Group was attending, rather than two. This decision had been taken in line with general economies the Society was taking. The Chairman said that it had also been decided at an Extraordinary General Meeting in 1990 to reduce the number of times Council met to twice a year. He said that with such economies and having taken hold generally of the situation, the Society was in a much better financial position, and he paid tribute to Mr Watters and Ms Archer for helping to put the Society's financial affairs on a steady course.

C93.02 Apologies

Apologies for absence were received from the representatives of the Jersey, Perth, South East Scotland, Northern Ireland, Tayside, Cornwall and South Essex Groups, and from Mr K Colthorpe, Mr N Lawson, Mrs J Hodgson and Mrs N Guy.

C93.03 Minutes of the meeting held on Saturday 21 November 1992

The minutes of the meeting held on 21 November 1992 in Grantham had been circulated in advance. They were proposed as an accurate record of the proceedings by Mr Tony Harding, Derby Group, seconded by Mr Simon Taylor, and agreed unanimously.

C93.04 Matters Arising

04.1 Re-draft of HC (76)4

Mr Watters reported that the Department of Health's paper HC (76)4 was in the final stages of re-drafting and was under consideration by various professional bodies. It was hoped that this would be published in April 1993. The paper would recommend that there be two tiers of haemophilia centres, Comprehensive Haemophilia Care Centres and Haemophilia Centres. The status of existing centres would be in the hands of Centre Directors. Mr Watters said that eighteen months earlier comprehensive care guidelines had been sent to all contractors and purchasing authorities by the Society and local Groups should try to enforce the comprehensive care message at a local level.

The Chairman welcomed these developments for haemophilia care and said that it had been the then Minister of Health, Mr William Waldegrave, who, despite civil servants' feelings to the contrary, had ordered the re-draft. He said people with haemophilia could feel comforted and reassured that standards of medical treatment were to be maintained.

04.2 Travel to the USA

Mr Watters reported that while there had been no material change to the rules for travel to the US, things looked more hopeful with official recognition of the difference between immigrants and visitors. It seemed likely that before long people who were HIV positive would be granted unimpeded entry. He would keep Council informed.

04.3 Publications

Mr Cowe reported that another booklet in the Society series on various aspects of haemophilia had been launched, entitled *Joint Care and Exercises*. It was published jointly with the Chartered Institute of Physiotherapists and the Society. The Chairman welcomed this latest addition to what was a helpful and informative collection of booklets about haemophilia.

05.1 Europe

Mr Taylor reported that a recent move in the European Community could have meant the introduction of a European-wide ban on imported blood products. This would have been disastrous for the UK as 30% of blood product usage was commercially based. The UK did not want to have to rely on a single source of supply; other countries, for instance, had found a high incidence of inhibitors in products they used, and the Society felt that it was important to have a wide range of supplies. Three weeks earlier a report had gone before the European Parliament calling for an immediate ban on all commercial blood products in Europe. The Society received a copy of the report four days before its presentation and had quickly drafted objections and amendments. Mr Taylor said that he and Mr Watters had also hurriedly rallied European opposition to the report, and he remarked that the Society's careful building up of good relations with sister organisations had paid off as the response had been whole-hearted and swift. The result of all this effort had been that amendments had been passed, thereby emasculating the report. Those concerned with European legislation in this area would be aware that in future patient opinion would be voiced, and Mr Taylor said that meetings were to be set up to gather forces so that this message might be reinforced.

05.2 Charities Act

The Chairman raised the subject of the 1992 Charities Act and the importance it gave to responsible and proper management of charity business. Mr Watters said that the Act emphasised Trustee responsibility and this included the necessity of Trustees knowing what was happening throughout the charity they served. In the case of the Society this had particular application to activities of Groups, especially where fundraising was concerned. Mr Watters reminded the meeting that Society forms were available for Groups to report their fundraising events, and he said that in order to satisfy the auditors at the end of each financial year these forms would have to be produced for each of the fundraising events Groups held, as they were programmed. Mr Watters urged Groups to use the forms if the Society was to remain within the law. He also distributed important material on the Charities Act 1992 that emphasised the burdens on the Trustees.

05.3 Centralised banking

Continuing with legal and financial matters, Mr Watters mentioned that 24 out of the Society's 28 local Groups were in, or about to be in, centralised banking. He reported that at the latest annual auditing of Society accounts, the auditors had suggested that the accountability of Groups should be tightened up. In fact, at the most recent Executive Committee meeting it had been agreed that joining centralised banking be made compulsory for all Groups by the end of June 1993. Mr Milne added that the Society was not only subject to charity law but also, as a limited company, to company law. Mr Dolan, West of Scotland, suggested that a note should go into *The Bulletin* giving this information and setting out guidelines for Groups; this idea was approved.

05.4 Acting Treasurer

At this juncture the Chairman introduced Mr Gordon Clarke who was already well known to Council prior to his election to the Executive Committee through his involvement with the Northern Ireland Group. He had very kindly agreed to become Acting Treasurer up to the 1993 Annual Meeting. This had become necessary on account of Mr Lawson's continued absence due to GRO-A The Chairman expressed the gratitude of the Society to Mr Clarke for taking on this highly responsible and onerous task.

C93.06 Workshops/presentation

Standing in for Mr Barker who was not able to be present because of GRO-A, Mr Watters asked the Group representatives to discuss progress made on the implementation of Proposal One of the Strategic Plan, ie Monitoring and Influencing Local Care. The company was divided into three groups, and Mr Watters asked that representatives talk about what progress their Groups had or had not made on the idea of establishing a local contact person, about identifying the Centres and also the District Health Authorities in the areas covered by each Group, and, finally, about any problems encountered with haemophilia care. Mr Watters requested that notes be taken at each of the three discussions and that these be passed on to Mr GRO-A at the national office during the coming week.

The groups met for approximately 90 minutes after which lunch was served.

C93.07 Lecture

Dr Charles Hay, Royal Liverpool Haemophilia Centre, gave a lecture on high purity blood products, their various merits including results of different studies and clinical trials, and the technologies involved in their manufacture. The audience received the lecture with much interest and asked a number of questions afterwards. The Chairman thanked Dr Hay warmly, and this was reflected in the applause of those present.

C93.07 Discussion

There was a brief discussion and difficulties over the role of local contact people for each Group were raised. Mr GRO-A suggested that a map of Local Health Authorities would be appreciated, and this was noted. It was also clear that many Groups recognised that the majority of haemophilia patients were not Society members. Groups represented only a minority of those attending treatment Centres. Arising from this there was a possible conflict in the Society's representation of itself, ie, as a local contact organisation or as an alternative to Reference Centres, mainly offering information. The Chairman said that the workshops and their findings had provided valuable feedback and he thanked all those who had taken part.

C93.08 AGM matters

The Chairman asked the meeting to consider AGM matters, namely the nominations of President of the Society, Vice-Presidents and the Medical Advisory Panel.

08.1 Nomination of Presidents

The Chairman reported that Dame Catherine Cookson, OBE MA had expressed herself willing to continue in the office of President of the Society and he recommended that she be re-elected. This was proposed by Mr GRO-A, West of Scotland Group, seconded by Mr GRO-A, Leicester Group, and agreed unanimously.

08.2 Nomination of Vice-Presidents

The Chairman reported that the following persons had agreed to act as Society Vice-Presidents:

Dr Rosemary Biggs MA MD FRCP
Dr S H Davies MB CLB FRCP FRCPath
Mr Frank Field MP
Professor G I C Ingram MD FRCP FRCPath
Baroness Masham of Ilton
Sir Geoffrey Johnston Smith MP
Dr J F Wilkinson Phd Msc MC FRCP FRIC

The Chairman recommended them to the meeting; they were proposed by Mr Ben Lewis, Leicester Group, seconded by GRO-A, Derby Group, and agreed unanimously.

The Chairman mentioned that it was hoped, before long, to make a re-assessment of the office of Vice-President and its place in Society affairs. Professor Evans suggested that when this took place it might be worth considering having persons who were more in the public eye and likely to donate money. This was noted.

08.3 Nomination of Medical Advisory Panel

The Chairman reported that the Medical Advisory Panel was now reduced in size and those serving on it were specialists in their own fields. He recommended for election:

Dr C Hay MD MRCP FRCPath
Dr C A Ludlam Phd FRCP FRCPath
Dr E Mayne MC FRCP (Glas) FRCPath
Professor F E Preston MD MRCP FRCPath
Dr E G D Tuddenham MC MBBS MRCP MRCPath

The Chairman recommended, further, that Dr Christine Lee of the Royal Free Hospital be asked to fill the vacancy created by the recent death of Professor Arthur Bloom. The names were proposed by Mr G Clarke, seconded by Mr GRO-A, Lewisham Group, and agreed unanimously.

C93.09 Any other business

There was no further business to report.

C93.10 Date, time and place of next meeting

The next meeting of the Council of the Haemophilia Society will take place on Saturday 20 November 1993 at a venue to be announced.

Approved as an accurate record

Signed the Reverend Prebendary A J Tanner

AJT/DW/RB 08.03.93