

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392215



**The
Haemophilia
Society**

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**MINUTES OF THE
COUNCIL OF THE HAEMOPHILIA SOCIETY**

**held on Saturday 3 October 1987, at the
Hawkstone Hall, Kennington Road**

Those present:

Reverend A J Tanner, Mr K Milne, Mr K Colthorpe, Mr A Cowe, Mrs D Daniel, Mr T Fitton, Mr G Kirman, representatives from the following Groups; Birmingham, Cambridge, Derby, Hampshire, Jersey, Leicester, Lewisham, Lincoln, Norfolk, North Eastern, North West, North Wales, Northampton, Northern, Northern Ireland, Oxford, Perth, Scottish, Sheffield, South Wales, Southern and Tayside.

In attendance: Mr David Watters (General Secretary) and
Miss Linda Matthews (Administrative Secretary)

AGENDA

- 87.19 Apologies for absence
- 87.20 Minutes of the meeting held on 30 May 1987
- 87.21 Matters arising
- 87.22 Reports from Working Parties
- 87.23 World Federation of Hemophilia
- 87.24 Any other business
- 87.25 Date and place of next meeting

87.19 **APOLOGIES FOR ABSENCE** were received from John Prothero, Clive Knight, Simon Taylor, Peter Stevens, and Dr Kuttner, Merseyside, Cornwall, East Kent and South Essex Groups and Mrs [GRO-A] (Aberdeen representative).

87.20 **MINUTES** of the meeting held on 30 May 1987 had been circulated in advance and were unanimously approved as an accurate record of proceedings at that meeting, having been proposed by [GRO-D] and seconded by Keith Colthorpe.

87.21 **MATTERS ARISING:** Mrs [GRO-A] enquired about the Brendan Foster and Catherine Cookson Awards. The General Secretary replied that the response in recent years had been disappointing but that an attempt would be made to publicise them in a future Bulletin.

87.22 **REPORTS FROM WORKING PARTIES**

- (a) **Finance and General Purposes:** In the absence of John Prothero, the Treasurer, the Chairman reported that work with the new Auditor was proceeding apace with the production of forecasts of income and expenditure for future years. While the income of the Society continued to grow it was equally important to note that expenditure was also growing; increased income did not imply increased wealth.

Computerisation of the Society's accounts was going ahead and Linda Matthews, Administrative Secretary, now handled all the Treasurer's day-to-day work.

The potential income from the London Rubber Company's AIDS Initiative was noted.

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- (b) Blood Products: Ken Milne reported that he had made a visit to BPL during July and noted the continued expectation that self sufficiency in factor VIII was imminent. A clinical trial of 8Y and 9A was about to be conducted and BPL had applied for a clinical trial certificate in this connection. Mr Milne also reported that it had now been possible to clear most of the 'unscreened' batch of plasma held at Elstree; the material had been held in individual batches and tracing to donors had been comparatively simple. Mr Milne also spoke of newer products coming onto the market - in particular monoclonal factor VIII and genetically engineered concentrate. Both products were undergoing clinical trials in the United States and good results were indicated in both cases. It was not clear whether Elstree would have the capability to adapt to those new and exciting changes brought about by improved technology.

Mr Milne had, along with the General Secretary, attended the Annual Meeting of the Haemophilia Centre Directors on Friday 25 September 1987. Dr Charles Rizza had been elected the new Chairman, following the appointment of Dr Charles Forbes to the Chair of Haematology at Dundee University. The Working Party, which had met under Dr G F Savidge, on the subject of reorganisation of haemophilia care in the United Kingdom, had finalised its work and its recommendations were in line with those proposed by the Haemophilia Society. A new 'Yellow Book' would be produced in the near future and a new Health Circular was being drafted to take account of reorganisation. Other matters covered at the Centre Directors' Meeting included a survey of heat treatment on concentrates from which it was clear that hepatitis risk was substantially reduced, if not eliminated, and also a survey on inhibitor patients and their treatment.

The Annual Meeting had been without its normal statistical returns as a result of Miss [GRO-A]'s illness. It was agreed that the General Secretary send Miss [GRO-A] the good wishes of the Society along with flowers.

- (c) Treatment and Care: Ken Milne reported on this Working Party, with particular reference to its work on Mobility and Attendance Allowances. Mention was made of the importance of winning Attendance Allowance prior to April 1988 and the revision of Social Security structures. It was also noted that HIV antibody status, when declared, could assist considerably in obtaining Attendance Allowance. The facility for private interview at Social Security offices was also highlighted. It was agreed that the General Secretary should attempt to draw together the various useful points for people claiming benefits and present them in a HAEMOFACT or other publication.

Mr Milne also mentioned his employment survey which, it was thought, would be launched in the New Year.

- (d) Case Committee: In the absence of Dr Kuttner, the Chairman reported on the continuing high demand on funds from the Case Committee, particularly in cases where HIV was leading to financial distress. The monthly level of grants had now reached £3,000 and it was noted that this was likely to continue to be the case until the issues related to Recompense were sorted out. It was also noted that the restructuring of DHSS benefits from April 1988 could lead to even higher demands on the funds in view of changes that would be introduced.
- (e) Overseas: The Chairman reported that triple-bags to the value of approximately £500 had been procured and were awaiting dispatch to New Delhi. New Delhi had received a large quantity of needles, etc, earlier in the year and, through the good offices of Mrs [GRO-D], a very much reduced rate of tax payable in India had been negotiated.

The Chairman also mentioned his forthcoming visit to India as part of a WFH Taskforce. The Chairman undertook to procure photographs and other relevant information for reports and fundraising.

- (f) Publications and External Relations: Andy Cowe reported on the work of the External Relations Working Party, first of all in relation to the Parliamentary Campaign. Mr Cowe outlined the demand which was to be made to the Government, through our Submission which was to be lodged within a few days. The demands were as follows:-

1. A fund to underwrite insurance - both life and mortgage protection
2. A weekly non-means tested benefit payable to widows and dependants of people with haemophilia who die from AIDS. This should extend to elderly parents dependent on their children as well.
3. A disability premium high enough to cover HIV-related costs. The estimate submitted by the Haemophilia Society is in the region of £70 per week.
4. A fund for lump-sum payments which could cope with additional costs such as anxiety, fear, distress, discrimination, etc.

In the case of all those benefits the importance of confidentiality and anonymity was of paramount importance.

Mr Cowe also outlined the timetable of the campaign as follows:-

Tuesday 13 October:	Press Conference
Tuesday or Wednesday 3 or 4 November:	Meeting with John Moore, Secretary of State
5 November:	Meeting of Parliamentarians at House of Commons

Mr Cowe outlined the importance of this being an all party issue and not only one from the opposition benches. It was therefore of the greatest importance that members of the majority party be lobbied extensively in their constituencies. Mr Cowe thanked all those who had already written to their MPs - pointing out that the response to the Department was already quite substantial.

Mr Cowe also reported on work related to publications, etc. Work had been done on a Society audio/visual presentation, as well as the Bulletin and Update publications. A major decision had been taken regarding Dr Peter Jones book LIVING WITH HAEMOPHILIA - this will now be given, free of charge, to all new members of the Society.

Mr Cowe had also received representations from the Haemophilia Nurses Association expressing an interest in the proposal to have a children's publication.

In response to questions Mr Cowe agreed to produce notes for people giving lectures on the Society and its work. Discrepancies brought about by the editorial service were also noted and Groups were asked to report any such, in writing, to the General Secretary so that they could be followed up. The importance of keeping copies of articles sent in was stressed and the advisability of supplying hard copy rather than last minute telephone calls.

- (g) Seminar: Diane Daniel reported that the venue of the 1988 Seminar would be in Liverpool on the weekend March 18-20 at the Crest Hotel. No programme or topic details were yet available.

- (h) Sales: Mr Colthorpe reported that Christmas card sales were going well and reported, further, that many items in the gift catalogue were now out of stock.
- (i) Group Liaison: George Kirman reported that, although there had not been much activity during the summer months, he had a busy time ahead and if any Group wished him to attend any meetings before the end of the year early contact was advised.

Mr Kirman also reported that there was a proposal for a new Grampian Group under the aegis of [GRO-A]. Under the new arrangement this proposal was announced for consideration at the November meeting of the Council.

Mr Kirman announced that since the work of the Group Liaison Officer was growing Terry Fitton had already been incorporated into his small Working Party by the Executive Committee. They now wished to propose that [GRO-A] (Northampton) be co-opted to assist with the work. This was agreed unanimously.

- (j) Research Grants: Delegates had received outline details of all applications in advance. Consideration of the applications was as follows:-

- (i) Dr Elizabeth Mayne, Belfast The Chairman reported that the Executive Committee had approved a grant of £500 for work on immune response to multiple skin test antigens in people with haemophilia. The application had received the support of the Northern Ireland Group and had been agreed under the emergency powers available to the Executive Committee. It was therefore reported to this meeting.
- (ii) Professor Ecclestone, Newcastle This application had been withdrawn. It was also noted that this application, for an extension of a grant agreed in November 1986, related to a grant agreed twelve months ago which had not been claimed and it was agreed that this raised questions about time expired grants.
- (iii) Dr D N Whitmore, Lewisham The Lewisham Group and the Executive Committee recommended a grant of up to £1,500 to provide patient comforts in the new treatment area recently made available at the Lewisham Hospital. This was proposed by [GRO-A] seconded by [GRO-A] and agreed with three abstentions.
- (iv) Dr M I Adelman, Lincoln Lincoln had also recently achieved a new Haemophilia Centre and applied for two items costing a total of £2,985 as follows:-

1. A Combi-Mixer CM-9 with multiple flask tray and a 12 month service contract - £485
2. An Accuwash Microtitre plate washer/dispenser - £2,500

That the application succeed was proposed by [GRO-A] seconded by Ken Milne and agreed with three abstentions.

- (v) Professor M E J Curzon, Leeds Professor Curzon had applied for a grant in the sum of £14,623, spread over two years, to study dental disease in children with chronic disorders - the money applied for being in respect of children with haemophilia, the total work also embracing children with cerebral palsy and heart conditions. The Executive Committee, after careful consideration and the benefit of advice from a dental practitioner who is Secretary of a Group of the Society, recommended that no grant be paid in response to this application. The Chairman therefore proposed that no grant be paid and this was agreed nem con.

- (vi) Mr D J Lamb, Charles Clifford Dental Hospital, Sheffield Mr Lamb sought a grant of £3,000 to cover the cost of treating ten patients with haemophilia suffering from candida - an unpleasant aspect of HIV infection. The aim was to reduce the unpleasantness of candida by inserting a 'plate' in the mouth of patients. The Executive Committee recommended that no grant be made in respect to this application, largely in view of the fact that people with haemophilia have enough to contend with at present. It was felt that if a cohort of immune suppressed patients was required there were groups other than those with haemophilia. It was therefore proposed by the Chairman that this application fail and this was agreed with one abstention.

87.23 **WORLD FEDERATION OF HEMOPHILIA:** The Chairman, speaking in his role as Chairman of the World Federation, spoke of the difficulties facing the Federation following the death of Frank Schnabel. In the meantime, and up to the Madrid Congress in 1988, the work of the President had been shared out between a number of the Vice-Presidents.

In connection with the 1988 Congress in Madrid the Chairman reported that the final selection of candidates would be made in the next few weeks. Despite unduly high registration fees, which would be in excess of £450 per delegate, six delegates would still be sent.

87.24 **ANY OTHER BUSINESS**

- (a) Mrs M I Britten: The Chairman reported that, on the previous evening, the Executive Committee had, at their own expense, entertained Mrs Britten to dinner in recognition of her long service to the Haemophilia Society. The Chairman felt, in view of Mrs Britten's long standing commitment and dedication to the Society, and her continued interest in its work, she should be invited to attend Council meetings, as an observer, in the future. This was agreed with overwhelming support.
- (b) The Haemophilia Society Award: The Chairman reported that, following mention during the last few years, agreement had now been reached that a new Award should be made by the Society and that this should take the form of an inscribed parchment and be known simply as The Haemophilia Society Award.
- (c) The Chairman proceeded to receive cheques from local Groups as follows:-

Northern	£2,000
Perth Charity Shop	£1,000
Perth	£1,000
Northern Ireland	£4,000
Norfolk and Norwich	£ 500
Northampton	£1,500
Birmingham	£1,000
Scottish	£ 800

The Chairman expressed the gratitude of the Haemophilia Society to everyone involved in raising those excellent donations for the work of the Society.

87.25 **DATE AND PLACE OF NEXT MEETING:** The General Secretary stressed that on the evening prior to the next meeting of Council the International Airlines Charity Ball would be held at the Royal Albert Hall. Negotiations were being made by the Ball Committee for cheap hotels in the area of the Albert Hall and details of this would be forwarded to all Groups as soon as possible. In the meantime the General Secretary wished it to be known that free admission tickets to the Royal Albert Hall would be made available to all Council members who wished to attend this special fundraising event. Because of the Ball the meeting on Saturday 28 November would begin at 2 pm and include formal business only.

Approved as an accurate record of the proceedings

GRO-C

The Reverend Alan Tanner (Chairman) 28 November 1987