

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392211



DGW

**The
Haemophilia
Society**

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**MINUTES OF THE MEETING OF THE EXECUTIVE COMMITTEE OF THE
HAEMOPHILIA SOCIETY**

**held on Thursday 8 January 1987, at
123 Westminster Bridge Road, London SE1**

Those present: Revd A J Tanner, Mr K Milne, Dr L Kuttner, Mr J Prothero,
Mrs M I Britten, Mr K Colthorpe, Mrs [GRO-A], Mr [GRO-A]
and Mr D Watters

AGENDA

- 87.01 Apologies for absence
- 87.02 Minutes of the meeting held on 13 November 1986
- 87.03 Matters arising
- 87.04 Working party reports
- 87.05 Treasurer's report
- 87.06 World Federation of Hemophilia
- 87.07 General Secretary's report
- 87.08 Any other business
- 87.09 Date and place of next meeting

87.01 APOLOGIES FOR ABSENCE were received from Mr C Knight, Mr A Cowe,
Mr S Taylor and Mr [GRO-A]

87.02 MINUTES of the meeting held on 13 November 1986, which had been
circulated in advance were approved unanimously after minor textual
amendment. This was proposed by Mr [GRO-A] and seconded by Mr Prothero.

87.03 MATTERS ARISING

- (a) AIDS: Reference was made to some regrettable remarks made by a
Haemophilia Centre Director at an inquest in Birmingham and the
subsequent inaccurate press reporting. A letter from the General
Secretary had been published in The Times on New Year's Day as a
result.

Under this heading the Executive Committee also discussed a proposal
from Dr Peter Jones, namely that an award should be established for
the newspaper correspondent who covers AIDS reporting most responsibly
each year. This idea had been mooted by Dr Jones at the Newcastle
AIDS Conference last February and had been referred to the Society
when the Department of Health and Social Security effectively granted
the Society the 'underspend' on that Conference. The members of the
Executive Committee were unanimous in their view that this should not
happen.

- (b) 123 Westminster Bridge Road: The Executive Committee noted how
very pleasant the new offices were for their first meeting to be held
at the Society's offices for many years.

87.03

MATTERS ARISING

- (c) International Airlines Charity Ball: The Executive Committee recorded their thanks to the Committee of the International Airlines Ball for a wonderful evening on Friday 28 November 1986. The Committee also recorded their thanks to Dave Parker of Qantas Airlines for his generosity in donating the proceeds from his sponsored slim to the Society at the Ball - a total of £2,429. It was noted that the Airlines Ball Committee would decide in the near future whether or not we would benefit from their event in coming years.
- (d) 1986 Annual Draw: The Executive Committee noted with pleasure that the 1986 Annual Draw had made a net income in the region of £14,000 - approximately £1,000 up on 1985. It was also noted that Birmingham Group had organised an evening fundraising event for the Draw which had been a very great success.

87.04

WORKING PARTY REPORTS:

- (a) Finance and General Purposes: A written report had been circulated in advance. This sought formal approval for the purchase of the various items necessary for the computerisation of the Society's accounts and the provision of a portable typewriter for the General Secretary to enable him to draft items to photocopying stage when away from the office. Approval for both sets of items was unanimous, the computer items having been proposed by Dr Kuttner, seconded by Mr Colthorpe and the portable typewriter having been proposed by Mrs Daniel, seconded by Mr GRO-A.
- (b) Blood Products: While Mr Milne had not circulated a written report, there were two items on which he wished to comment. The first concerned an answer given in the House of Commons on 18 December by Baroness Trumpington which indicated that Blood Products Laboratory (BPL) had now processed the stock pile of factor VIII derived from non-donor screened plasma. The reply also stated that a controlled evaluation was being carried out to ascertain the quality of the product. It was agreed that this should be explored further. Mr Milne also raised the question of Monoclate, the new chemically cleaned Armour product. It was agreed that an invitation should be given to Armour to come and explain this new product to the Executive Committee at a mutually convenient time.
- (c) Treatment and Care: A report had been circulated in advance. This report dealt with a number of matters relating to welfare benefits, in conjunction with Mr GRO-D. The report also sought the approval of the Executive Committee for a survey of the employment status of people with haemophilia. This was formally agreed and the Working Party was asked to bring a draft to a future meeting of the Executive Committee. The Working Party had also addressed itself to a number of matters relating to **confidentiality**. It was agreed that, as a matter of priority, a meeting should be arranged with the Medical Advisory Panel (MAP) to consider this in some depth. The General Secretary highlighted a number of difficulties which had arisen through meetings of Health Authorities and, in some cases, Haemophilia Centre Directors who had not kept up to date with Guidelines such as those issued by the Department of Education and Science. It was noted that Mr Milne and the General Secretary would be attending a meeting of the newly constituted subcommittee of the Haemophilia Centre Directors' Organisation to consider the matter of the organisation of haemophilia care in the UK.

WORKING PARTY REPORTS:

- (c) The meeting also gave some consideration to a survey of safer sexual practices which had been mentioned by a number of Centre Directors. It was decided that the Centres were the most appropriate agency to investigate this question.

- (d) Case Committee: A detailed report had been circulated in advance which showed that in November 1986 the Committee considered seven applications for financial assistance and approved grants in all cases, totalling £915. The December meeting considered eleven applications and approved grants of up to £770 in response to nine of those applications.

In addition, the Case Committee brought two recommendations to the Executive Committee for grants in excess of the £250 limit agreed at the Executive Conference:-

- (i) It was recommended that a grant of £350 be made to a member for an item of essential equipment for him, his wife and his family.
(ii) It was recommended that a grant of up to £400 be made available to a family who had to face a very large essential payment with no notice that this was likely to arise.

Both matters were agreed without dissent in view of all the circumstances which were fully explained by the General Secretary.

It was also formally resolved that the Case Committee should be empowered to spend up to £300 without reference to the full Executive Committee.

- (e) Overseas: Mrs Britten reported that, as a result of the letter received from the High Commission in London, the duty payable to the recently despatched filter needles had been considerably reduced. It was noted that Mr GRO-A had used up his cargo allocation until March 1987.
- (f) Publications and External Relations: A report had been circulated in advance. The report dealt with regular scheduling of THE BULLETIN and a new interim publication - name to be decided in due course - all designed to give a higher profile to the work of the Society. The 'Press Rota' and the new system for handling press enquiries was also described in the report. The Working Party had also requested items for the Database from a number of members of the Executive Committee and others. The Database would be 'the Bible' for those handling press enquiries, covering a variety of topics. Mr Cowe had circulated a draft proposal for a fund-raising leaflet which had been discussed: a draft would be presented to the Executive Committee in due course. The Working Party had also discussed the content of a submission to the House of Commons Select Committee on AIDS and a report had been drawn up and submitted within the time limits required by the Committee.

It was proposed by Dr ^{Knutner}~~Knutner~~, seconded by Mr Prothero that the report of the Publications and External Relations Working Party be noted and that the proposal relating to the interim publication be approved. This was agreed unanimously.

WORKING PARTY REPORTS:

- (g) Seminar: Mrs GRO-A outlined progress to date in connection with the Seminar and the practical arrangements surrounding it. The fact that a decision had not yet been made on a subject and speaker for the HAEMOPHILIA SOCIETY LECTURE was noted and in view of the absence of any other proposals it was agreed that the Chairman should resolve the matter on a basis of some urgency.
- (h) Sales: Mr Colthorpe had circulated a report in which he highlighted the possibility of the Society having to register for Value Added Tax if the Sales Programme took off as predicted in his paper. After discussion it was agreed that Mr Colthorpe should confer with Mr Prothero and the General Secretary about this.
- (i) Group Liaison: Mr GRO-A had circulated a report which dealt with his visits to Local Groups in Manchester, Belfast and Derby. It was reported that the Local Group referred to several times in recent months had still to produce their accounts, etc. The Group in question was now to be regarded as closed and further steps would continue to formally wind up the affairs of the Group.

It was also noted that any Group wishing to make arrangements for a member of the Executive Committee, etc, to visit should make the arrangement through the General Secretary's office in London rather than direct or through other members of the Executive Committee.

- (j) Research Grants: The Chairman reported that applications on the current 'round' were now being received and would, as appropriate, be circulated to the Executive Committee in due course.

87.05

TREASURER'S REPORT:

Mr Prothero reported that income for the year to 31 December 1986 appeared to be in the region of £200,000 (without taking the Airlines Ball into account). Balances held were expected to show approximately £20,000 on ordinary deposit while there was till £120,000 on special deposit with the Money Market.

It had been agreed some long time ago that when the Society moved to new offices, the bank account would also be transferred to the nearest branch of the National Westminster Bank, with whose Baker Street Station Branch the Society had transacted its business since 1950, at least. While there was much to be said for dealing with a local branch, one of the principle benefits was that deposits would reach the account (and accrue interest) from the date of paying-in, rather than some four days later as was the practice now. Since the Bank had failed to take the necessary steps at the time of our Incorporation it was also necessary to approve the following more detailed proposal.

Having been proposed by Mrs GRO-A seconded by Mr Colthorpe, it was agreed unanimously that:-

- (a) The bank accounts of the Haemophilia Society be transferred from the Baker Street Station Branch of the National Westminster Bank plc to their Lambeth North Branch.

TREASURER'S REPORT:

- (b) 1 That **National Westminster Bank PLC** (the Bank) as bankers to the Company be and are hereby authorised to honour all cheques or other orders for payment drawn on behalf of the Company including bills and promissory notes accepted or made on behalf of the Company and payable at the Bank notwithstanding that any such payment may cause any account or accounts of the Company to be overdrawn or increase any existing overdraft provided such documents are signed by*

2 That as regards the special transactions referred to in the Schedule to these Resolutions the Bank be and are hereby authorised to accept on behalf of the Company only the signatures of the respective officials therein mentioned.

3 That the Company give the Bank a list of the names of the Directors, Secretary and other officers of the Company and advise the Bank in writing of any changes that may take place and the Bank shall be entitled to act upon the information so given.

4 That these Resolutions be communicated to the Bank and shall constitute the Company's Mandate to the Bank to remain in force until revoked by notice in writing to the Bank signed by the Chairman or any Director or the Secretary acting or purporting to act on behalf of the Company and for this purpose any instruction varying or purporting to vary the Mandate contained in these Resolutions shall be deemed a revocation.

87.06

WORLD FEDERATION OF HEMOPHILIA:

The General Secretary reported that our 1987 Assessment from the World Federation had been received and that we were due to pay US\$2,077 (net). That his be paid was proposed by Mrs Britten, seconded by Mr GRO-A, and agreed unanimously.

87.07

GENERAL SECRETARY'S REPORT:

- (a) Collecting Stockings: It was formally agreed that we should not produce a further stock of collecting stockings. The present ones (with the Trinity Street address) were six years old at least and still in abundant supply.
- (b) Executive Committee Conference: Following a number of difficulties about the date, it was agreed that the Conference be deferred until later in the year - overnight Friday 25 September being the date.
- (c) Archy Kirkwood's 'Access to Personal Files' Bill: The General Secretary gave a brief outline to this Bill which we had been asked to support. The object of the Bill was to give the same right of access to 'paper' records as would be the case with computerised records from November 1987. Of particular relevance was the matter of medical notes: patients would have right of access unless the doctor ruled that they contained information which would be detrimental to the health, mental or physical, of the patient concerned. There was a right of appeal against a refusal to allow access. After careful consideration it was proposed by Mrs Britten, seconded by Mr Prothero, that we should support this Bill. The General Secretary was asked to take the appropriate steps.

87.08

ANY OTHER BUSINESS:

There was no other business.

87.09

DATE AND PLACE OF THE NEXT MEETING:

Thursday 5 March 1987 at 6 pm for 6.30 pm at 123 Westminster Bridge Road, London SE1 7HR. (NB First Thursday in the month.)