

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392065



**The
Haemophilia
Society**

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

**held on Saturday 14 March 1987, at the
Hawkstone Hall, Kennington Road, London SE1**

Those present: Revd A J Tanner, Mr K Milne, Dr L Kuttner, Mr J L Prothero,
Mrs M I Britten, Mr K Colthorpe, Mr A Cowe, Mrs D Daniel, Mr G Kirman,
Mr S Taylor, representatives from the following Groups: Birmingham, Cambridge,
Derby, East Kent, Leicester, Lewisham, Lincoln, Merseyside, Norfolk, North
East, North Wales, North West, Northampton, Northern, Northern Ireland,
Oxford, Scottish, Sheffield, South Wales, Tayside and Cornwall.
In attendance: Mr and Mrs McAughey (Perth Charity Shop)
Mr D Watters, (General Secretary) and
Miss L Matthews (PA to Mr Watters)

AGENDA

- 87.01 Apologies for absence
 - 87.02 Minutes of the meeting held on 15 November 1986
 - 87.03 Matters arising
 - 87.04 Reports of the Working Parties
 - 87.05 World Federation of Hemophilia
 - 87.06 Any other business
 - 87.07 Date and place of next meeting
- 87.01 APOLOGIES for absence were received from Hampshire, South Essex, Jersey
and Southern Groups, and Mr Abrahams.
- 87.02 MINUTES of the meeting held on 15 November, which had been circulated in
advance, were unanimously agreed as an accurate record of proceedings at that
meeting having been proposed by Mr Colthorpe, seconded by Mr Kirman.
- 87.03 MATTERS ARISING
- (a) AIDS: The Chairman reported on various aspects of AIDS and HIV infection,
including the forthcoming HAEMOFACT 12, dealing with issues relating to
compensation; a Counselling Day which he had attended the previous day in
Oxford; evidence to the House of Commons Select Committee on AIDS, and
proposals for co-ordinating the various members of the House of Commons
who have shown an interest in the subject as it affects people with
haemophilia.
- (b) Airlines Ball: Mr Prothero reported that a total of £10,000 had been
received as a result of the Ball, plus £2,429 from GRO-D's sponsored
slim. We had also received formal notification that we would benefit from
the Ball, in 1987 and 1988. Gratitude was expressed to Nicholas Lawson
of Lawson International Travel Services for the vital role he had played in
securing the benefit of the Ball for the Society. It was also announced
that the winter meeting of the Council would now be held on Saturday 28
November at 2 pm (ie afternoon meeting only), following the Ball on 27
November. This would make it possible for members of the Council to
attend the Ball without incurring extra travel costs.

- (c) Office Premises: During the lunch period a large number of Council members had been taken on tours of the new offices. The Chairman expressed his gratitude to the staff for working under very difficult circumstances during the move and to the General Secretary for planning the smooth transition from Trinity Street to the new offices.
- (d) Group Caravans:
- (i) Northern Ireland: Mrs [GRO-A] reported that the Northern Ireland Group had now taken delivery of their caravan and that, with the help of the loan from Society funds, it had been paid for. It was expected that it would be fully booked in the summer - bookings were due to begin in April.
- (ii) Birmingham: Mr [GRO-A] reported that the Group had paid a deposit on its new caravan which would be sited at Christchurch. Enquiries for bookings continued to be received. It was expected that the advance from the Society, agreed at the November meeting, would be requested in the near future.

87.04

REPORTS FROM WORKING GROUPS

This session had occupied the entire morning session but is formally reported here.

- (a) Finance and General Purposes: Mr Prothero reported that the computerisation of the Society's accounts was about to begin. This would, in time, lead to more useful reporting and improved presentation of accounts.

The present state of Society finances was:-

Special Deposit Account	£120,000
Ordinary Deposit Account	£ 3,000
Current Account	£ 200

Mr Prothero anticipated a small deficit overall for the financial year 1986 but it was agreed that this was a good result bearing in mind the Society's workload.

- (b) Blood Products: Mr Milne reported on the projected date for the opening of the Blood Products Laboratory (BPL) - late in 1987 - and on questions arising from the stockpile for non-donor tested plasma at BPL. Mr Milne also reported on Armour products, mentioning in particular Monoclate, the new chemically cleaned product which would be available in due course.
- (c) Treatment and Care: Mr Milne also reported on this Working Group mentioning, in particular, new Welfare Benefits Notes which were being prepared by Mr Pegram. The Working Group had rejected using anyone other than the General Secretary to represent people with haemophilia at Tribunals, etc, in view of the degree of knowledge of haemophilia required. The Working Party was also planning a survey of employment status in people with haemophilia. Representation had also been made to the sub-committee of the Haemophilia Centre Directors' Organisation dealing with the re-organisation of haemophilia care in the UK.

The General Secretary also amplified the possible benefit of the outcome of a Court of Appeal ruling on Attendance Allowance (the case of Moran), announced the previous day. It was noted that the finding of the Court of Appeal could be subject to appeal to the House of Lords by the Department of Health and Social Security.

Questions were also raised concerning confidentiality of HIV test results and the reactions of some doctors (GPs) and dentists to patients with positive antibody test results. It was STRESSED that all instances of questionable practice by health care professionals should be reported directly and urgently, in writing, to the General Secretary.

- (d) **Case Committee:** Dr Kuttner reported that since the last meeting in November the Case Committee had received between thirty and forty applications for grants and that grants totalling £3,500 had been made. In 1985 the total of grants paid was £5,000 (approximately); in 1986 this figure rose to £9,800. Dr Kuttner explained that the Executive Committee had empowered the Case Committee to make grants of up to £300, without reference to the Executive Committee. The question of increasing the current limit on Groups (£50) was discussed but it was agreed that £50 was adequate to cope with emergency situations as they arose. Mr Prothero and the General Secretary stressed that grants could reach people in need within 48 hours of a request being received. Mrs Daniel (formerly Mrs Lewis) stated that she made many grant applications in the course of her work: she knew of no organisation which could match the Haemophilia Society on the speed with which decisions were made.
- (e) **Overseas:** Mrs Britten reported that correspondence was being maintained with India and that further consignments of needles would be sent from April onwards. Relevant sections of a letter from Mr. GRO-D were read and noted. Mrs Britten agreed to write to Dr Wensley and Dr Evans to thank them for donating their spare butterfly and other needles for use in India.
- (f) **Publications and External Relations:** Mr Cowe reported on the work of this group since the last meeting of the Council. The subjects covered included:
- (i) The Society's submission to the House of Commons Select Committee on AIDS and,
 - (ii) related to that, issues arising from potential claims for compensation, HAEMOFACT 12, and a campaign aimed at achieving recompense for people with haemophilia who had come into contact with HIV
 - (iii) 'The Bulletin' and the new interim publication, UPDATE, which would appear half-way in the interval between Bulletins
 - (iv) A review of Society publications - eg new Membership Forms and Deed of Covenant forms; a replacement for 'He Has Haemophilia' entitled 'What is Haemophilia?'; 'What the Society Can Do For You' and, in the future, a new 'Introduction to Haemophilia' and 'Notes for Parents', etc.
 - (iv) An application to the Reader's Digest Association for a grant to enable the Society to employ an 'AIDS Co-ordinator'. The importance of this post was readily appreciated by all concerned.

Mrs GRO-D had been approached by Hull Health Authority regarding a leaflet they were preparing. She had agreed to her name and address appearing on the leaflet which was for health care professionals. The General Secretary counselled those present against doing this, since a number of very nasty phone calls had been received at the national office, along with some 'hate mail' - anonymous, of course.

- (g) **Seminar:** Mrs Daniel confirmed that the Seminar - two weeks away - was on target. Mrs GRO-A (Northern Group) felt that the national office should have notified all members in the Newcastle area, individually, about the Seminar. The General Secretary explained that everyone had been notified, in the last two Bulletins.

- (h) Group Liaison Officer: Mr Kirman reported on his work and asked Mr [GRO-A], secretary of the Brimingham Group, to outline some of the work recently carried out by his Group. Mr [GRO-A] outlined how, in the face of further possible cutbacks in haemophilia care in the West Midlands, the Group had 'taken on' MPs, health authorities, etc, and achieved funding for two additional sisters and a senior psychologist. In addition, special funds had been made available from central government sources for counselling (£16,000) - the only such allocation made to a Centre which was not a designated Reference Centre. The General Secretary paid tribute to the very excellent work of the Group and commended the model to other Groups in a similar position.
- (i) Sales: Mr Colthorpe outlined various items and their usefulness in fundraising. Sample Christmas cards would be available around mid-1987 and the personalisation available for a minimum order of 50 cards. Mr Colthorpe hoped that the Society's first catalogue of saleable items would be available within a week.
- (j) Research Grants: The Chairman introduced this session and drew attention to the separate paper circulated earlier in the day.
- (i) Professor Preston, Sheffield: This application, for a two year grant of £9,594 in the first year and £10,381 in the second year. The object of the proposed study was to identify early indicators of dementia in people with haemophilia who had developed antibodies to HIV, since this could have potential value when considering treatment. The study group would comprise 40 patients - 20 who were HIV ab+ and 20 who showed no sign of reaction to the virus. The tests to be employed were "paper and pen" exercises, supervised by a clinical psychologist.

The application had been referred to the Medical Advisory Panel (MAP) who were not of one mind about the application, most members observing that, since there was a high degree of psychology involved, they did not necessarily feel best qualified to comment.

In considering the application the Executive Committee had been mindful of the following points:-

- (a) The stressful nature of the tests
- (b) The usefulness of the end product

In connection with (a) it was known that there are much more sensitive, computer based, tests available to test neurological function when "failure" would be less obvious and not subject to personal supervision. Equally, it was not known if dementia could be taken as an early indicator of AIDS: the only paper on the subject indicated 4.5 months life expectation after detection. Additionally, this kind of study was already being carried out on a much larger scale at other institutions.

Bearing these points in mind, and in the absence of a protocol, which had not been submitted, the Executive Committee recommended that NO GRANT be paid to Professor Preston in response to this application.

Mr [GRO-A] spoke, on behalf of the Sheffield Group, in support of Professor Preston's application. It was proposed by Mr Kirman that the application should be referred to a neuro-psychologist for further expert opinion. After discussion this was seconded by Mr [GRO-D]. Put to the vote this motion failed, having attracted 11 votes in favour, 14 against, with two abstentions. It was then proposed from the Chair that no grant be paid. This was carried with 21 votes in favour, 4 against and 2 abstentions.

- (ii) Dr I W Delamore, Manchester: This application sought funding for three years - £6,000 in year one, £3,000 in years two and three - to develop a rapid technique for the detection of HIV rather than antibody to the virus. The MAP were supportive of the application and on their recommendation it was referred to Dr Richard Tedder, a virologist at the Middlesex. Dr Tedder was fully supportive of the project - so long as an agreed amount of time is devoted exclusively to haemophilia patients. Accordingly the Executive Committee recommended that the application succeed for the first year and that, in order for the application to succeed for the second and final year, the normal reports and evidence of other applications be submitted before 1 January 1988. This was proposed by the Chairman and approved, 27 votes being in favour, one against and one abstention.
- (iii) Dr G L Scott, Bristol: Dr Scott sought a grant of £7,500 (+ VAT) for the purchase of a platelet aggregometer. The Executive Committee were of the view that such equipment was standard and ought to be properly provided through health service resources. On this basis it was recommended that no grant be paid. This was proposed by the Chairman and agreed nem con.
- (iv) Dr S J Machin, London (Middlesex): Dr Machin sought a grant of £5,168 for a study of the decrease in the peripheral blood lymphocyte count (white cells) in people with haemophilia at different stages in the development of HIV infection. The MAP gave the application a low priority, and the Executive Committee recommended that no grant be made. This was proposed by the Chairman and agreed nem con.
- (v) Dr L Parapia, Bradford: In November 1985 the Council approved a grant to Dr Parapia for a study of psychosocial factors in HIV ab+ patients with haemophilia. The Executive Committee had received a report from Dr Parapia and Dr Dobson of the first year's work and were happy to recommend a grant of £3,500 for a further year. The study was of three year total duration, and Dr Parapia should submit a full report and details of other support sought, by 1 January 1988, if such further funding was sought. This was proposed by the Chairman and agreed nem con.

At this stage the Chairman asked Mr Kirman to introduce those representing the Cornwall area, who were present to seek recognition of the Cornwall Group of the Haemophilia Society. Mr Kirman introduced Mr [GRO-A] and Mr [GRO-A]. Mr [GRO-A] outlined his work over the past three years and thereafter it was proposed by the Chairman that the Group be formally accepted into the Society. This was agreed unanimously and with acclamation.

87.05

WORLD FEDERATION OF HEMOPHILIA: The Chairman reported that the Executive Committee of the World Federation of Hemophilia was due to meet in Brussels later in the year, although there was some current doubt about the actual venue.

87.06

ANY OTHER BUSINESS: None had been notified in advance, but Mrs [GRO-A] raised a point regarding the new membership application forms and putting members in touch with their local Groups. In response to the reply from the General Secretary, she doubted if members were always aware that they had been put in touch with their Groups.

The Chairman proceeded to accept cheques as follows:

Sheffield Group	£ 750
Northern Group	£ 320 (London Marathon 198 5 ⁶)
South Wales Group	£1,000
Northern Ireland group	£1,000
North East Group	£ 500
Derby Group	£ 600 (earmarked for North Wales Adventure Holiday)
Lincoln Group	£1,500
Perth Chairty Shop	£1,000

Charity

In accepting these cheques the Chairman stressed how deeply appreciative he, and all the members of the Executive Committee, were at the enthusiasm, energy, commitment and time devoted to the hard work of fundraising. He wished those present to take back with them, to their Groups, the warm thanks of the whole Society in appreciation of this excellent support.

87.07

DATE AND PLACE OF THE NEXT MEETING: Saturday May 30 (venue to be announced).

Approved as an accurate record of the proceedings.

Signed

GRO-C

The Chairman

On 30 May 1987