

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392089



**The
Haemophilia
Society**

123 Westminster Bridge Road
London SE1 7HR
Telephone: 01-928 2020
Fax: 01-620 1416

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

held on Sunday 29 October 1989 at the Crest Hotel, Newcastle

Present: Revd Alan Tanner, Mr K Milne, Mr J Lander, Mr K Colthorpe, Mr A Cowe, Mr T Fitton, Mrs C Hazlewood, Mrs J Hodgson, Mr G Kirman, Mr C Knight and Mr J Miller and representatives from the following Groups: Birmingham, Cambridge, Cornwall, Derby, East Kent, Grampian, Hampshire, Leicester, Lewisham, Lincoln, Merseyside, Norfolk & Norwich, North East, North West, Northampton, Northern, Northern Ireland, Sheffield, South East Scotland, South Essex, South Wales, Southern, Tayside and West of Scotland.
In attendance: Mr D Watters, Miss L Matthews, Mr J Cooper, Mrs H Maynard, Mr P Burba, and representatives from the Irish Haemophilia Society.

AGENDA

- 89.30 Apologies for absence
- 89.31 Minutes of the meeting held on Saturday 23 September 1989
- 89.32 Matters arising
- 89.33 Working Party Reports
- 89.34 World Federation of Hemophilia
- 89.35 General Secretary's Report
- 89.36 Date and place of next meeting

89.30 **APOLOGIES FOR ABSENCE** were received from the following Groups: Jersey, North Wales, Nottingham, Oxford, North Wales, Perth and Swansea.

89.31 **MINUTES OF THE MEETING** held on Saturday 23 September 1989, having been circulated in advance, were proposed for adoption as an accurate record of proceedings at that meeting by Mrs [GRO-D], seconded by Mrs [GRO-D], and agreed unanimously.

At this stage the Chairman referred to the death of our Vice-Chairman, John Prothero, whose memory had been honoured at the beginning of the Chairman's Conference of which this Council meeting was a part. In view of the great amount of activity taking place the Chairman went on to explain that it was desirable that there was a 'full team' leading the work of the Society and, accordingly, he invited Mr Cowe to accept the position of acting Vice-Chairman pending the next annual meeting of the Society. This was greeted with acclamation. In addition, the Chairman announced that the Executive Committee would co-opt a member from the Council to fill the vacancy now created by Mr Cowe's promotion.

89.32 **MATTERS ARISING**

- (i) **CERT:** The Council had spent the weekend discussing the CERT report, along with the Executive Committee recommendations, in some detail. Those proposals had all been received with much enthusiasm and it was therefore put by the Chairman that the Council receive the CERT report

and approve the recommendations for action and implementation by the Executive Committee. This was agreed unanimously. The Chairman stressed his delight at the willingness of Council to accept this change in the structure and management of the Society and hailed it as the beginning of a new era in the life of the Haemophilia Society.

- (ii) Centralised Banking: Mr Lander spoke of the simplified system which would be introduced to enable Groups to embark on centralised banking, stressing that twelve Groups had already joined this scheme.
- (iii) Compensation: The General Secretary outlined the present situation affecting the campaign for an out-of-court settlement and the litigation taking place in the High Court. It was clear from the hearing in the High Court on Monday 23 October that the earliest possible date for the full trial to begin would be the early part of 1991. In the meantime there were various issues to be tried on a preliminary basis each with its own right of appeal. In addition, the judge had indicated that people embarking on actions would be responsible for costs from 29 June 1989.

The Parliamentary Campaign was proceeding well with many warm responses from Members of all Parties in the House. Early Day Motions had been tabled and questions to Ministers were appearing with great regularity. The General Secretary outlined a letter which he had finalised immediately before the Council meeting for distribution to all members of the Society, inviting them to write to their Members of Parliament in the coming week. In response to questions, the position of those who did not qualify for Legal Aid, but nonetheless could not afford to fund private litigation, was discussed. It was agreed to defer this matter until the final outcome of the Parliamentary Campaign was known.

- (iv) The USA - Visas and Waivers: The Council, once again, gave their whole-hearted approval to the steps taken so far in dealing with this issue. The General Secretary reported that, since taking the original stand, the UK had been joined by Canada, the Federal Republic of West Germany, Greece, Austria and Chile.

89.33

WORKING PARTY REPORTS

- (a) Finance and General Purposes: Mr Lander reported that 'Sales' had now been incorporated within F&GP. He also mentioned that simplified notes for Treasurers, including standardised accounting procedures, were in the latter stages of preparation and would be circulated in the near future.
- (b) Treatment and Care: Mr Milne introduced further details about the Women's Weekend which would be held during the Spring. It was hoped that this conference could achieve full sponsorship and that places would be available at no cost. In addition, it was projected that a Family Weekend would be held during 1990, relating to haemophilia itself.
- (c) Case Committee: The General Secretary reported that this Committee had exceeded its budget for the year but was continuing to spend in the interests of people with haemophilia. (It should be noted that this Committee is now replaced by the authorisation given to the General Secretary, under the terms of the CERT report, whereby grants of up to £500 can be approved immediately.)
- (d) Overseas: There was no report.
- (e) Publications and External Relations: There was no report.

(f) Group Liaison and Training:

- (i) Grampian Group: The Group sought authority to continue with the Highland Adventure Holiday at Newtonmore for people with haemophilia aged ten to eighteen years and to continue to raise funds in order to provide the necessary resources to enable this to happen. The Group also sought authority to continue to fundraise to furnish the Haemophilia Centre at Aberdeen Royal Infirmary and, in particular, to fundraise for an ice-making machine which was likely to cost £1,000. That both those matters be approved was proposed by Mrs [GRO-D] seconded by Mr [GRO-D], and agreed unanimously.
- (ii) North West Group Caravan: The General Secretary reported that a letter had been received from Mr [GRO-A] Secretary of the North West Group, in connection with a new caravan. An application had been made to the Children in Need Appeal and a grant of £7,000 had been forthcoming. An additional grant of up to £3,000 would be necessary in order to finance the purchase of the caravan. That those funds be made available from the national Society was proposed by Mr Milne, seconded by Mrs [GRO-D], and agreed unanimously.

The General Secretary asked that North West Group forward the £7,000 to the national Society so that the full amount could be paid from central funds and thereby reflect this major piece of expenditure on behalf of the Society.

(g) Grant Applications: There were none.

89.34 WORLD FEDERATION OF HEMOPHILIA: There was nothing to report.

89.35 GENERAL SECRETARY'S REPORT: The General Secretary expressed his delight at the steps taken at the Council meeting in adopting the recommendations, as amended by the Executive Committee, of the CERT report. In addition he expressed thanks to the staff of the Society for the work they had done throughout the year and, in particular, in connection with the Chairman's Conference itself.

Mrs [GRO-D] of the Irish Haemophilia Society, attending as an observer, spoke of the appreciation of the Irish Society for everything which the General Secretary had done to help them achieve a fund to look after the welfare interests of people with haemophilia and HIV in Ireland. He had been helpful in encouraging and persuading the authorities in Ireland to follow the UK example.

89.36 DATE AND PLACE OF NEXT MEETING: This was announced, provisionally, as Saturday 25 March 1990 although, in view of the wish of Council that meetings should be less frequent but for longer periods of time, this could be subject to change.

Approved as an accurate record of the proceedings of the meeting

Revd Alan Tanner (Chairman)

GRO-C

17 March 1990