Witness Name: Katherine Victoria Burt Statement No: WITN6392001 Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392226



THE HAEMOPHILIA SOCIETY

PATRON: H. R. H. THE DUCHESS OF KENT

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MINUTES OF THE MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY held on Sunday 10 March 1985 at the Heathlands Hotel, Grove Road, Bournemouth.

Those present:

The Revd. A J Tanner, Mr D Rosenblatt, Mr K Milne, Mr J Prothero, Mrs M I Britten, Mr K Colthorpe, Mr C Knight, Dr L Kuttner, Mrs D Lewis, and representatives of the following Groups:-Birmingham, Bristol, Cambridge, Colchester, East Kent, Jersey, Leicester & Rutland, Lewisham, Lincoln & District, Merseyside, Norfolk & Norwich, Northern, Northampton, North Eastern, Northern Ireland, North Wales, North Western, Oxford & District, Scottish, Sh effield, Southern, South Essex, South Wales, Tayside In attendance: D G Watters (Co-ordinator)

Miss I Hawkins (Personal Assistant)

AGENDA

| | 85.01 Apologies for absence | | | | |
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| | 85.02 Minutes of the meeting held on 24 November 1984 | | | | |
| | 85.03 Matters arising | | | | |
| | 85.04 Centralised Funding | | | | |
| | 85.05 Treasurer's Report | | | | |
| | 85.06 Research Grant Applications | | | | |
| | 85.07 World Federation of Hemophilia 85.08 Society Representatives | | | | |
| | 85.08 Society Representatives 85.09 Matters from the Seminar | | | | |
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| | 85.10 Any other business 85.11 Date and place of next meeting | | | | |
| 85.01 | APOLOGIES FOR ABSENCE: were received from Mrs Holliday, Mr Abrahams and Mr Wetherell. | | | | |
| 85.02 | MINUTES of the meeting held on 24 November, which had been circulated in advance, were unanimously approved as an <u>accurate</u> record of proceedings at that meeting having been proposed by MrsiGRO-A and seconded by Mr Colthorpe after the following amendments had been made at 84.34 (c) after Panel insert a coma and "since it was recognised that this application was fundamentally different in its methodology from that of Dr Ian Peak". | | | | |
| 85.03 | MATTERS ARISING:- (a) <u>AIDS</u> : The Chairman thanked all those who had written to their MP's and the Minister of Health about AIDS. This had been of great assistance in drawing attention to the position. The Chairman also reported that we had been awarded a grant of $\pounds15,000$ under Section 64 of the Social Security Act to assist us with our extra workload relating to AIDS. | | | | |
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Matters arising continued.

Special tribute was also paid to Dr Peter Jones for his support of the Society and its staff; his excellent book "AIDS AND THE BLOOD"

and his lecture to the Seminar on the previous day. Finally the Chairman thanked Clive Knight for his excellent work on HAEMOFACT.

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(b)Blood Products Sub-Committee: Mr Milne drew attention to the fact that while the developments at the Blood Products Laboratory, Histree, were on target no progress had apparently been made

regarding the procurement of the supplies of plasma to ensure selfsufficiency. The Co-ordinator drew attention to the fact that the

discussion of this had been brought into the open by Dr Contreras of the North London Transfusion Centre and that Kenneth Clarke had admitted on television that plasma procurement was "a problem".

(c)Date and location of the 1985 Annual Draw: The Chairman mentioned the outstanding success of the 1984 Annual Draw, gross takings being slightly in excess of £10,000, a considerable improvement of the previous "best" of just over £4,000 gross. Mrs **GRO-**, who had sold 341 books in the 1984 Draw suggested that in future there be 5 tickets per book and that the cost be 20p per ticket. Groups were asked to consider playing a wider role in the national draw with its improved prizes and the Co-ordinator explained the "credit" which could be given to Groups for their part. Groups were also asked to consider offering an event to host the 1985 Draw. Offers should be made to the Co-ordinator. Mrs GRO-Araised the question of the date of the Draw and suggested it should be held earlier in the year. The Chairman asked that she write to the Co-ordinator in detail concerning this.

CENTRALISED FUNDING: The Treasurer explained that this item could not proceed at this meeting since the Finance Sub-Committee had not yet considered Mr Lander's paper on the subject. Note would be taken of the strong representations received from a number of Groups against

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TREASURER'S REPORT: The treasurer reported that the financial position had improved very greatly during 1984 and that the Ceneral Fund had shown a surplus of some £18,000. While the 1985 budget had been completed it was not available for distribution but this would take place before the Annual General Meeting. MriGRO-Alasked about progress on the acquisition of a computer and was assured by Mr Rosenblatt and the Treasurer that this had been agreed and would proceed. It was reported that all Groups apart from Bristol* Birmingham, Cambridge Colchester, Leicester & Rutland*, Lewisham, Northern and Scottish had submitted their accounts up to 31 December 1984. Those marked

RESEARCH GRANT APPLICATIONS:

(a) The Chairman reported that the officers had recently met with the members of the Medical Advisory Panel and finalised the new strategy to be applied to all grant applications. Under this system applications would be considered only twice in each year and at those times the Treasurer would advise how much funding was available for distribution.

Research Grant applications continued:

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The Panel members would then "score" applications and recommendations would be formulated as a result of that. It was hoped that this would prove a more satisfactory method of handling applications.

(ii) <u>Applications</u>: By way of a preamble the Chairman drew the attention of the Council members to the fact that the Reference Centre Directors had made unanimous overtures to the Executive Committee requesting that absolute priority be given to applications from Dr Richard Tedder and Dr Philip Mortimer (see below). This recommendation featured largely in the mind of the Executive Committee in drawing up their recommendations to the Council on the following applications:-

(a) <u>Dr C A Ludlam, Edinburgh</u>: Dr Ludlam's application had been considered by the November meeting of the Council and subsequently referred to the Medical Advisory Panel. This had now been done and the results scrutinised. No Panel member recognised the work as original in any way and while the work was "supported" it was also recognised as fairly "run of the mill" and the facilities were becoming widely available. The Executive Committee therefore continued to recommend that no grant be made and this was agreed with two votes against the recommendation and one abstention.

(b) <u>Dr Richard Tedder, Middlesex Hospital:</u> <u>Dr Philip Mortimer, Public Health Laboratory Service</u>: This combined application, which had received the whole-hearted support of the Reference Centre Directors, was concerned with work on the HTLV-III positivity tests in all United Kingdom haemophiliacs. The study was crucial in evaluating the newly introduced heat-treated materials and would provide a picture of the likely pattern of AIDS in people with haemophilia. Each doctor sought funding of up to £10,000 for the employment of a basic grade scientist and Dr Tedder further sought £3,225 to purchase a computer for analysis of the findings. That a grant of up to £23,225 be awarded was agreed with one abstention.

(c) <u>Ms Campbell, PHLS Coventry:</u> Ms Campbell sought a grant to enable her to attend a forthcoming conference at CDC in Atlanta in furtherance of her degree work on AIDS. The Executive Committee recommended no grant and this was approved nem con.

(d) Dr E E Mayne, Belfast; The Chairman explained that in 1982 the Council had approved funding to Dr Mayne to enable her to appoint a part-time physiotherapist. Because of problems with her hospital structure the person appointed had not taken up the post until January 1984. Dr Mayne had been unable to secure hospital funding to continue the post and required funding for another year. The Northern Ireland Group supported the application unanimously on account of the benefit members had derived from this important facility. Accordingly it was unanimously agreed to grant $\mathfrak{L}_{1,170}$ for a further year.

(e) Dr E G D Tuddenham, London: Dr Tuddenham sought a grant of f_{2298} to purchase a column synchropak for his work on the synthesis of factor VIII. There was f_{200} available in the Research Fund from the Tayside Group, earmarked for this purpose. That this application be granted was agreed nem con.

(f) <u>Dr R T Wensley, Manchester</u>: The Chairman indicated that an application had been received from Dr Wensley in connection with studies on the collection of plasma. This would be referred to the Medical Advisory Panel and finalised at the June meeting of the Council.

WORLD FEDERATION OF HEMOPHILIA: (a) The Chairman commented upon the value of the World Hemophilia AIDS Centre mailings. It was noted that they were a little out of date by the time received and that their recording did not appear to be particularly accurate.

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(b) The Chairman also reported that the newly appointed haematologist at the New Delhi Centre had visited the office in London and although AIDS had detracted from progress on assistance to the Indian Society, there were still very good intentions of pursuing that further.

85.08 SOCIETY REPRESENTATIVES: The Co-ordinator reported that Mr GRO-A had been appointed Representative for Cornwall and that Mi GRO-had been appointed for Sussex.

85.09 MATTERS FROM THE SEMINAR: The Chairman reiterated his thanks to all those who had worked so hard to make the 1985 Seminar "the best ever". He expressed particular thanks to Dr Aronstam and Dr Jones for their excellent lectures and to all those who had led workshops: to Mrs Lewis and Mr Knight for their planning and the Co-ordinator, David Watters, and Miss Hawkins for their part in ensuring that all went well and to Mri. <u>GROD</u> for the transportation of the Society's equipment. Mrs Britten felt that a major factor in the success of the weekend had been the welcome large number of new faces, especially the younger participants, both parents and haemophiliacs.

85.10 ANY OTHER BUSINESS: NEW GROUPS: The Chairman welcomed Mrs GRO-A and Mrs GRO-A who represented an informal group of parents and patients based in Portsmouth. He was delighted, on the recommendation of the Co -ordinator, to ask the Council to welcome them formally and institute the new Hampshire Group. That this be so was proposed by MigRO-A, seconded by Mr Colthorpe and agreed unanimously.

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| 85.11 DATE AND PLACE OF THE NEXT MEETING: Prior to the AGM in the Post Graduate Centre at St Thomas' Hospital, London, SE1, on Saturday 1 June 1985. | | | | | |
| pproved on | 1 June 1985. | a | s an accurate | | |
| ecord of proceedings. | GRO-C | CHAIRMAN | | | |
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