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INFECTED BLOOD INQUIRY

WITN6392217



The Haemophilia Society

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MINUTES OF A MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY

held on Saturday 28 November at the Hawkstone Hall,
Kennington Road, London SE1, at 2 pm

Present: Reverend A J Tanner, Mr K Milne, Dr L Kuttner, Mr K Colthorpe, Mr A Cowe, Mrs D Daniel, Mr T Fitton, Mr G Kirman, Mr C Knight and Mr S Taylor.
Representatives from the following Groups: Birmingham, Derby, East Kent, Lewisham, Lincoln, Merseyside, Norfolk, North Eastern, North West, North Wales, Northampton, Oxford, Sheffield, Southern and Tayside.
In attendance: Mr D Watters (General Secretary), Mr J Cooper (AIDS Co-ordinator), Miss L Matthews (Administrative Secretary), Mrs C Robertson, Mrs I Cruickshank (Grampian area) and Mrs M I Britten.

AGENDA

- 87.26 Apologies for absence
 - 87.27 Minutes of the meeting held on 3 October 1987
 - 87.28 Matters arising
 - 87.29 Reports from Working Parties
 - 87.30 World Federation of Hemophilia
 - 87.31 Any other business
 - 87.32 Date and place of next meeting
- 87.26 **APOLOGIES FOR ABSENCE** were received from Mr J Prothero, Mr P Stevens and the following Groups: Jersey, Northern, Northern Ireland, Perth, Scottish and South Wales.
- 87.27 **MINUTES OF THE MEETING** held on 3 October 1987 had been circulated in advance. That they be adopted as an accurate record of proceedings at that meeting was proposed by Mr Colthorpe, seconded by Mr Kirman, and agreed unanimously.
- 87.28 **MATTERS ARISING**
- (a) **International Airlines Charity Ball:** Mrs Guy enthused about the Ball which she had attended on the previous evening. She felt that the warmest thanks of the Council were due to the Committee of the International Airlines Charity Ball for organising a wonderful event on behalf of the Society. She also felt that those who had not attended had missed a superb evening in aid of the Haemophilia Society and she urged people to attend in 1988. The Chairman also expressed his thanks to Nicholas Lawson for his part in obtaining the benefit of the Ball for the Haemophilia Society.
 - (b) **Haemophilia Society Award:** The Chairman reported that, following the last meeting of the Council, the North West Group had made a certain suggestion regarding the first recipient of this award. This had been endorsed by the Executive Committee and the presentation would be made at the 1988 AGM at Birmingham on Saturday 11 June. The name of the recipient would not be made known in advance of that time.
 - (c) **Brendan Foster and Catherine Cookson Awards:** The Chairman reported that an appeal for nominations for those awards would appear in the New Year edition of the Bulletin. It was felt that the matter would get lost in the Christmas edition which would be going out in the near future.

87.29 REPORTS FROM WORKING PARTIES

- (a) Finance and General Purposes: In the absence of John Prothero, the Chairman reported that, had he been present, he would have reported that income for the year was likely to top £250,000 for the first time in the history of the Society.
- (b) Blood Products: Ken Milne reported on problems facing self-sufficiency and that the latest date for achieving this was now 1989. It was noted that there were problems in relation to the shortfall in factor VIII supply and questions were asked as to whether this was an equally distributed problem. The General Secretary remarked that he was aware that the problem was affecting Birmingham in particular. Mr Milne undertook to look further into this.
- (c) Treatment and Care: Ken Milne reported that it was hoped, at an early date, to involve Jonathan Cooper in the work of the Treatment and Care Working Party. This would relate, in particular, to evaluation and tabulation of facilities provided at Reference and other Haemophilia Centres throughout the United Kingdom.
- (d) Case Committee: Dr Kuttner reported that grants totalling £2,753 were made in September and October 1987 and that the level of grants continued to remain high.
- (e) Overseas: The Chairman reported on his recent visit to India, as part of an International Haemophilia Training Committee. He had visited Calcutta and Trivandrum and had been impressed by the progress made since his last visit to India some three years ago. Professor Mannucci had also taken part in the visit, conducting clinics in both cities.
- (f) Publications and External Relations: In introducing this item the Chairman stressed, that despite the award of a grant of £10m by the Government, the Campaign still continued; if anything, its work had been enhanced by the recognition given by the Government to the special needs and circumstances of people with haemophilia who had come into contact with HIV through their NHS-prescribed material.

The Chairman outlined the history of the Campaign, concentrating, in particular, on the political aspects. On 3 November 1987 a delegation from the Haemophilia Society had met with the Secretary of State, John Moore, and the Minister of Health, Tony Newton. The delegation had been received with warmth, concern and compassion. On Thursday 5 November 1987 a similar delegation had met with Parliamentarians at a special meeting in the House of Commons, hosted by Frank Field and Robert Key. This meeting had been very well attended by an excess of sixty people. The Chairman paid particular tribute to those who had assisted with the Campaign, especially those who had been prepared to identify themselves publicly as having haemophilia and HIV infection. In addition, gratitude was expressed to the many members of the Haemophilia Society who had written to Members of Parliament and thereby ensured that they not only received correspondence from the Haemophilia Society but, more importantly, that they received it from their constituents.

As a result of all this action, the Government had responded very quickly with the establishment of a Fund to which they had promised to contribute £10m. Since that time the most frequently asked question had been, "Is it enough ... ?", to which the Chairman felt the only sensible answer was, "What is enough ... ?". It was important that first of all the Fund be seen as 'a start'. The Chairman remained confident that, if there were a need to return to the Secretary of State in the future, he would be prepared to listen to a clearly put and strong case, as he had in the past. Meantime, it was not in the least helpful simply to declare "It is not enough . . . !". Government would, however, only be persuaded by a well constructed and strongly made case.

The Executive Committee had now had an opportunity to explore this matter in some detail and it felt that three measures were essential:

- (i) Money Management: The administration of a £10m fund was no small matter and it was hoped that Government help would be given with this. Tony Newton, Minister of Health, deputising for the Secretary of State, had indicated that Section 64 funding would be available to cover all administrative costs relating to the Fund. Various options were being explored but it was, at that moment, too early to make definitive statements.
- (ii) There was a need to establish the criteria by which grants would be made. It was important that the Haemophilia Society remained in close control of this policy-committee which would look at the various degrees of need being faced by people with haemophilia who had developed AIDS, the dependants of those who had already died and those whose lives were being affected by HIV infection.
- (iii) Lastly, the Chairman saw a need for an allocation committee which would be quite independent of the Haemophilia Society. This committee would decide which cases constituted need and the extent and eligibility for grants from the Fund.

In concluding his presentation, the Chairman stressed that the £10m made no difference to the ongoing work of the Society, which had to continue to serve the interests of people with haemophilia, regardless of HIV status. In addition, it was stressed again that the Campaign went on, it was a continuing campaign to secure benefits for people with haemophilia who have become HIV antibody positive. The Chairman emphasised that the matters which concerned him most of all were the underwriting of life insurance and mortgage protection schemes. The Secretary of State had assured him that provision for this had been made within the allocation of £10m. These problems had been given back to the Government and their expert advisers for further exploration earlier in the week and it was anticipated that, as a result, Government would be forced to realise that the grant of £10m was far from adequate.

Mr Lander (Merseyside Group) outlined events at a meeting of his Group, held earlier in the week, which had been attended by the General Secretary. He felt that what had been achieved so far deserved the warmest praise of all members of the Haemophilia Society and, further, felt that it was vital at a time such as this to maintain the highest possible standards of communication to ensure that everyone with haemophilia, regardless of whether or not a Society member, was fully apprised of all the facts. The General Secretary commented that leaflet-dispensers should be in all Haemophilia Centres and serviced by local Groups. Copies of all publications, apart from Update, are sent to Centres on a regular basis. It was noted that Haemofact 17 was due for publication at an early date.

Various points were raised by Ted Ryan (Birmingham) and Peter Evans (North Wales).

There were fears in many peoples' minds that decisions had already been taken about the allocation of the Fund and that the opinions of those concerned would not be sought. The suggestion was made that each Group should be consulted about the criteria of distribution of the Fund. Others felt that the opinion of all 1,200 HIV antibody positive people with haemophilia be sought. It was recognised that speed was of the essence in the allocation of this Fund and many opinions regarding allocation had been expressed to the Society already in writing. It was important to note that the Society wished to retain control, by direct representation of people with haemophilia on the committee, which would establish the criteria for the allocation of funds.

The question of confidentiality was mentioned by many people and it was acknowledged that this was a problem being considered by the Executive Committee.

Simon Taylor summarised the importance of members keeping in touch with their Members of Parliament. Without a doubt the Campaign so far had been greatly helped by the numbers of people who had been prepared to write to their MPs and to follow up correspondence with them. Mr Taylor stressed that the Campaign was still alive and had a very real job to do and urged all to play their full part, both as individuals and local Groups. This received the approbation of those present. In conclusion of this part of the meeting it was proposed by Irene Clinton, seconded by Margaret Brierly and agreed unanimously, that it be placed on record that the Council of the Haemophilia Society welcomed the progress made by the representatives of the Society in their negotiations with the Government, leading to the granting of £10m to people with haemophilia who were HIV antibody positive, and that the Council expressed its warmest congratulation to everyone concerned.

- (g) Seminar: Diane Daniel reported that there were two 'strands' emerging for the 1988 Seminar; firstly the subject relating to 'The Society' and secondly the subject of 'Keeping Healthy' - the latter subject relating particularly to those with HIV infection. Julian Lander warmly welcomed the fact that the Seminar would be coming to Merseyside and reported that Dr Charles Hay, the local Haemophilia Centre Director, had mentioned his intention to be present, with an appropriate staff team, throughout the Seminar weekend.
- (h) Sales: Keith Colthorpe reported that Christmas card sales were going well and that he had nothing further to report at this stage.
- (i) Group Liaison: George Kirman reported that no objections had been received to the proposed Grampian Group so the formation of this Group was due to be ratified at this meeting. That a new Grampian Group be established was proposed by Norma Guy, seconded by Jim Holliday, and agreed unanimously.

Mr Kirman went on to report on his Scottish tour and, in particular, thanked Andy Cowe for driving him around.

Mr Kirman also mentioned the 'needs identification exercise' conducted at the last Council meeting, the results of which are now available for circulation - this would form the basis of the future Group Management Training Course.

- (j) Research Grants: There were no applications outstanding, the next closing date being 1 January 1988.

87.30 **WORLD FEDERATION OF HEMOPHILIA**: The Chairman announced that the following delegates had been offered places on the 1988 WFH Congress in Madrid:-

- (1) Representing Local Groups: Andrew Whittaker, Carol Holliday and Alan Weir.
- (2) Representing the Executive Committee: Ken Milne, Keith Colthorpe and John Prothero.

87.31 **ANY OTHER BUSINESS**

- (a) Jim Holliday (North Wales) advised that a video of the 1987 North Wales Adventure Holiday would be available on loan from the North Wales Group in the near future.

(b) The Chairman proceeded to receive cheques as follows:-

Oxford Group	£ 500
Southern Group	£1,000
Tayside Group	£ 400
North Wales Group	£ 250

The Chairman expressed the thanks of the Executive Committee and Council to those Groups for their thoughtful and generous donations, which were so very warmly welcomed by the Society.

(c) There being no other business the Chairman thanked all those present for their hard work and endeavour during 1987 and wished everyone a Happy Christmas and a peaceful and prosperous New Year.

87.32 DATE AND PLACE of the next meeting: Saturday 16 April 1987 in the Hawkstone Hall, Kennington Road, London SE1.

Approved as an accurate record of the proceedings

GRO-C

The Revd Alan Tanner (Chairman)

16 April 1988