

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392087



The
Haemophilia
Society

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

held on Thursday 10 November 1988, at
123 Westminster Bridge Road

Present: Revd Alan Tanner, Mr K Milne, Mr K Colthorpe, Mr T Fitton, Mrs C Haslewood,
Mrs J Hodgson, Mr G Kirman, Mr C Knight and Mr J Miller.

AGENDA

- 88.53 Apologies for absence
- 88.54 Minutes of the meeting held on 8 September 1988
- 88.55 Matters arising
- 88.56 Formal report of Executive Committee Conference
- 88.57 Reports from Working Parties
- 88.58 World Federation of Hemophilia
- 88.59 General Secretary's Report
- 88.60 Any other business
- 88.61 Date and place of next meeting

88.53 **Apologies for absence** were received from Dr L Kuttner, Mr A Cowe and Mr J Prothero.

88.54 **Minutes of the meeting held on 8 September 1988**, having been circulated in advance, were proposed for adoption as an accurate record of proceedings at that meeting by George Kirman, seconded by Ken Milne, and agreed unanimously.

88.55 **Matters arising:** All such matters were covered elsewhere on the agenda.

88.56 **Formal Report of the Executive Committee Conference:** The Chairman expressed thanks to the General Secretary for arranging the event and for producing the fully documented report which members had received earlier in the week. All members spoke warmly of the potential that they felt the Society had and the helpfulness in the outcome of the Seminar towards harnessing that potential. It was emphasised that the goals which were determined at the close of the conference should be constantly kept before all members of the Executive Committee and the Working Parties of the Society. Terry Fitton was anxious that Working Party members should study the entire report most especially and realise the implications in their own Working Party and in the full Executive Committee.

88.57 **REPORTS FROM WORKING PARTIES:**

- (a) **Finance and General Purposes Report:** A report had been circulated in advance dealing with the fund-raising needs of the Society and other matters as follows:-
 - (i) **Cheque signatories:** It was proposed by the Chairman that the General Secretary and the Administrative Secretary be empowered to sign cheques of up to £2,000. This was agreed unanimously. It was also agreed that cheques for a sum larger than £2,000 should bear the signature of one member of the Executive Committee and at least the General Secretary.

Those matters had been discussed in detail with the Auditors prior to discussion within the Finance and General Purposes Working Party.

- (ii) **Budgets:** The General Secretary was asked to implement the formalisation of budgetting procedures as soon as possible.
 - (iii) **The International Airlines Charity Ball:** The General Secretary reported that the Haemophilia Society would, in all probability, benefit from the International Airlines Charity Ball for a further three years.
- (b) **Treatment and Care:** Mr Milne reported on a number of items being dealt with by the Treatment and Care Working Party: Those included the Employment Survey, Centre Reports, Children and HIV Infection Seminar for Health Care Professionals, a proposed Seminar for Social Workers and other Health Care Professionals, meetings with the Medical Advisory Panel, Safer Sex Counselling Guidelines for Health Care Professionals, a Wellness Programme - Holistic Health, a report on the Haemophilia Centre Directors' Annual meeting in Dublin, and a CCETSW matter. The topics that received more detailed consideration were as follows:-
- (i) **Children and HIV Infection Seminar for Health Care Professionals:** This matter had been discussed, and approved in principle at the September meeting of the Executive Committee. The details of the programme were discussed and it was resolved that the Haemophilia Society would underwrite the costs on the understanding that the cost in real terms would be negligible. This was proposed by Ken Milne, seconded by George Kirman and agreed unanimously.
 - (ii) **Safer Sex Counselling Guidelines for Health Care Professionals:** This was discussed in detail and it was agreed that it should be subjected to revision in view of comments from Counsellors in the field and from a number of additional experts. It was felt that further rewriting was necessary to translate it to the English language as spoken in the United Kingdom. The Guidelines are to be returned to the January 1989 Executive Committee meeting for further consideration. It was also felt that a new Haemofact should be prepared on the facts relating to safer sexual behaviour, looking in particular at current prevalence of HIV positivity in the wives and partners of those with haemophilia who are HIV positive.
 - (iii) **A Wellness Programme - Holistic Health:** Ken Milne explained that the Canadian Government were providing the funding to produce a book and tape for home use on the subject of holistic medicine - that is an approach to the wellbeing of the whole body (mind and spirit) working alongside traditional medicine. The aim is to heighten awareness and improve the quality of life. It was becoming obvious that the person to prepare the Canadian package was based in the UK and meetings had been held with the lady in question - Shirin Naidoo - who is a leading UK practitioner in holistic health. The Executive Committee welcomed the exercise to the point it had reached and felt it warranted further exploration. It also noted that Dr Mark Winter, Director of Margate Haemophilia Centre and a member of the Treatment and Care Working Party, was interested in running a pilot project with a number of his patients.
 - (iv) **Centre Directors' Meeting:** Ken Milne reported briefly on the content of this meeting, mentioning in particular the fact that the Centre Directors had now asked the Haemophilia Society to produce a new UK Centre Guide. This would cover Centres in the United Kingdom and some discussion took place about the format in which it should appear and the gradings which would be applied to Centres to make it clear that not all Centres provided identical levels of treatment.
- (c) **Case Committee:** The General Secretary reported that at the September meeting the Case Committee awarded one grant of £200 and at the October meeting twenty applications were considered and grants totalling £2,195 were made. The General Secretary also reported that at the November meeting, held

immediately prior to the Executive Committee meeting, nine applications were considered resulting in grants of £721. Four applications were refused or referred back for further information.

It was also felt, after discussion, that there needed to be an interaction between the Allocations Committee of the Macfarlane Trust and the Case Committee of the Haemophilia Society.

- (d) Overseas: The General Secretary discussed a letter he had received from a medical student in Warsaw who had haemophilia. It was agreed that this matter should be referred to the Secretary of the IHTC, Dr Peter Kernoff, for further consideration by that body. George Kirman felt that the history of our association with haemophilia care in India needed to be re-explained to the Council of the Society. It was agreed that such a re-presentation would take place.
- (e) Publications and External Relations: A report had been circulated from Andy Cowe in which he dealt with the Bulletin and Update - both publications having successfully met their publication schedule for 1988. A new 'Introduction to Haemophilia' is being costed at the present time. A slide presentation is also at the costing stage: this is likely to be expensive but important for the future of the Society. The Annual Membership Application Form is also undergoing minor amendment and comments would be invited in the near future. In his report Mr Cowe also dealt with a briefing to Parliamentarians who had supported the Campaign which led to the formation of the Macfarlane Trust. The Executive Committee noted Mr Cowe's report.
- (f) Group Liaison/Training:
- (i) Groups: Mr Kirman reported that he and Mr Fitton would be visiting Groups in Nottingham, the North West, Northampton, Birmingham and Cornwall in the coming weeks. In addition the General Secretary was attending the AGM of Grampian Group.
- (ii) Training: Discussion took place regarding the South West Regional Seminar Training Weekend. It was proposed by Ken Milne, seconded by Terry Fitton, and agreed unanimously, that this event proceed. Outline plans for the weekend were presented and the provisionally arranged date of April 14/16 1989 was confirmed.
- (iii) North Wales Adventure Holiday: The Executive Committee discussed the future of the North Wales Adventure Holiday in some detail. They were unanimous in their support for this annual event which many described as one of the most important aspects of our work. It was agreed that the administration should, at the request of the North Wales Group, be taken on board by the Haemophilia Society, with the North Wales Group as the sub-Committee dealing with the practical arrangements. Funding will become a matter for Groups and the national office. It was noted that further discussion was needed on this aspect of fund-raising. That the matter be agreed in principle was proposed by George Kirman, seconded by Terry Fitton and agreed unanimously. It was also agreed that if there was a shortfall in income from the 1988 North Wales Adventure Holiday this would be examined by the Executive Committee.
- In connection with the Group Liaison/Training Working Party discussion also took place on the payment of expenses for those who represented the Society. This matter was referred to the Finance and General Purposes Working Party for further consideration.
- (g) Sales: Keith Colthorpe reported that the 1988 Christmas activities were now in profit. Discussion also took place on the absorption of the work connected with the Annual Sales activity into the central administration of the national office. A paper setting out sales objectives and policy was tabled. Any detailed discussion of those to be dealt with at the January meeting of the Executive Committee.

(h) Grant Applications: There were none due for consideration.

88.58 **World Federation of Hemophilia**: The Chairman reported that the office had moved - details had been circulated to all members of the Executive Committee. It was hoped that the appointment of the Executive Director of WFH would now proceed, a final shortlist of three candidates having been prepared.

88.59 **GENERAL SECRETARY'S REPORT**

- (a) Section 64 Grant Applications: An application had been tendered with the Department of Health for the post of Resource Health Adviser, plus deficit funding for 1988. This application exceeded £100,000 and copies were made available to all members of the Executive Committee.
- (b) Job Titles: Job titles for Linda Matthews and Jonathan Cooper had still not been finalised and it was agreed that present job titles would remain until after the CERT review, subject to approval by Council.
- (c) Education: The General Secretary introduced this subject by highlighting changes that had taken place in state education and legislation governing that over the past few years. He felt that education policy for people with haemophilia was no longer a simple matter of attending local schools on the same basis as the non-haemophilic counterpart; too many changes had taken place to allow that vague policy to continue. The General Secretary's suggestion was that an Education Working Party be established, as an off-shoot of Treatment and Care, to harness much of the expert advice and input available from teachers involved in the work of Society. It was agreed that this matter should be explored further with T&C.
- (d) Relationships with the Macfarlane Trust: The General Secretary reported that Tudor Williams, the Trust's new Social Worker, was receiving induction training at the Society's offices. It was also anticipated having a combined Christmas get-together which members of the Executive Committee and Trustees would, as available, be able to attend.
- (e) Compensation: The General Secretary drew attention to the letter which had been circulated to all members of the Executive Committee and Council regarding the award of \$1.6m against Miles Laboratories in the United States. It was emphasised that this award held out no hope for compensation awards in the United Kingdom.
- (f) Payments for dietary requirements via income support: The General Secretary reported a sense of optimism in claims being settled quickly, and backdated, at least, until May 1985, the date on which the Society first advised people who were HIV positive to follow a high quality diet. A number of such cases were now succeeding with ease.
- (g) Staffing - extra secretarial support: The Executive Committee agreed to the appointment of additional secretarial support for the two additional working days when Heather Maynard was not in the office. This would give additional secretarial assistance to Jonathan Cooper.
- (h) Birmingham AIDS Help-line: The Birmingham Group had requested authority to provide the necessary funding for the installation of an extra telephone line in the offices of the Birmingham and West Midlands AIDS helpline. This would deal exclusively with HIV/AIDS calls for people with haemophilia. In discussing this the Executive Committee were mindful of the Newcastle experience, although appreciating the difference between that service and the one proposed by the Birmingham Group. It was also noted that the National AIDS (Freephone) Line only received enquires from negligible numbers of people with haemophilia. Note was taken of the fact that the persons manning the telephone would

receive specialist training input for haemophilia and issues surrounding HIV infection in haemophilia. Before making a final decision the Executive Committee required further information regarding numbers of calls being dealt with at the present time by the existing helpline services in Birmingham and the West Midlands. The Committee recognised the minimal costs involved in this exercise but wanted to be sure that the service would be well targeted.

- (i) AIDS Conference - Montreal June 1989: It was agreed unanimously that the Haemophilia Society should fund one place at the AIDS Conference at Montreal in June 1989, the General Secretary and the AIDS Co-ordinator to establish who attended.
 - (j) St Thomas' Hospital Christmas Party: It was agreed unanimously that £250 be donated to the Children's Christmas Party at St Thomas' Hospital.
 - (k) Brendan Foster/Catherine Cookson Awards: It was noted that a number of nominations had now been received and these would be considered in due course.
- 88.60 **Any other business**: Julian Miller stated that the Prison Art Show materials would be viewed by himself and an art expert within the next two weeks.
- 88.61 **Date and place of next meeting**: Tuesday 10 January 1989 at 6 pm for 6.30 pm at 123 Westminster Bridge Road, London SE1.

APPROVED as an accurate record of proceedings at the meeting on
10 November 1988

Signed: _____

GRO-C

10 January 1989

The Revd Alan J Tanner MA
Chairman