

Witness Name: Katherine Victoria Burt

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WITN6392082



From May 6 1990 our '01' telephone numbers shown will become '071'

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MINUTES OF A MEETING OF THE COUNCIL OF THE

HAEMOPHILIA SOCIETY

held on Saturday 17 March 1990 at The Kennedy Hotel, London NW1

Present: Revd Alan Tanner, Mr K Milne, Mr K Colthorpe, Mr A Cowe, GRO-A,
GRO-A, GRO-A, Mrs J Hodgson, Mr GRO-A and Mr C Knight.
Representatives from the following Groups: Birmingham, Cambridge,
Cornwall, Derby, Grampian, Hampshire, Jersey, Leicester, Lincoln,
Merseyside, Norfolk & Norwich, North East, North Wales, North West,
Northampton, Northern, Northern Ireland, Nottingham, Oxford,
Sheffield, South Essex, South Wales, Southern, Swansea and West of
Scotland.
In attendance: Mr D Watters, GRO-A, Mr J Cooper, Mrs H
Maynard (Staff) and Mrs GRO-A

A G E N D A

- 90.01 Apologies for absence
- 90.02 Chairman's opening remarks
- 90.03 CERT: Implementation
- 90.04 Reports from Working Parties
- 90.05 Report of Group donations and acceptance of cheques
- 90.06 Consultation on Compensation issues
- 90.07 Any other business
- 90.08 Date of next meeting

90.01 **APOLOGIES FOR ABSENCE:** were received from GRO-A, Julian Lander, Julian Miller and representatives from the following Groups: Lewisham, Perth, South East of Scotland and Tayside.

90.02 **MINUTES OF THE MEETING** held on Sunday 29 October 1989, having been circulated in advance, were proposed for adoption as an accurate record of proceedings at that meeting by Mr Kirman, seconded by Mrs GRO-A, and agreed unanimously.

In welcoming everyone to this meeting of Council the Chairman stressed that, following the highly successful Chairman's Conference held in Newcastle in October, this meeting was following a new format with much greater facilities for personal involvement and participation. He hoped that everyone present would feel free to participate fully in the meeting.

90.03 **CERT: Implementation**

The Chairman reported that since the meeting held in Newcastle in late October, the new Committee structure had been established and membership of the Committees defined as follows:-

RESOURCES COMMITTEE

Chairman: Alan Tanner
Members: [GRO-A]
Jane Hodgson
Julian Lander

POLICY COMMITTEE

Chairman: Andy Cowe
Members: Keith Colthorpe
[GRO-A]
Clive Knight

MEMBER SERVICES COMMITTEE

Chairman: Ken Milne
Members: [GRO-A]
[GRO-A]
Julian Miller

GRANTS COMMITTEE

Chairman: Alan Tanner
Members: Ken Milne
Andy Cowe
Julian Lander

In addition the Resources Committee was serviced by [GRO-A], Policy Committee by Jonathan Cooper; Member Services Committee by [GRO-A]. The Grants Committee would be serviced by the General Secretary who also attended all the Committees of the Executive Committee. Those changes were subject to gradual introduction and all the Committees mentioned above had, in fact, already met, apart from the Grants Committee.

90.04 **REPORTS FROM WORKING PARTIES:**

In introducing this part of the agenda the Chairman pointed out that when the agenda was originally planned it was not thought that the new Committees would have met. It had therefore been projected on the basis of the old Working Party system rather than the new Committee structure. This would, therefore, be the last occasion on which reports from Working Parties would be received at a meeting of the Council of the Society.

- (a) **Finance and General Purposes:** The Chairman reported that the work of this Committee, along with new duties, had already been absorbed within the new Resources Committee of the Society. The Annual Audited Accounts were in the final stages of preparation and would be included within the 1989 Annual Report. The Chairman reminded the Council of the indebtedness of this Committee to the Work of [GRO-A] who had transformed the work of the financial accounting of the Society from that of a small organisation to one with growing income and needs. Issues which the new Resources Committee would be exploring over the coming months included staff conditions of employment and levels of staffing of the Society. Decisions had already been made regarding salaries with effect from 1 January 1990.

- (b) Treatment and Care: In introducing Mr Milne, who reported on the workings of the old Treatment and Care Working Party, the Chairman pointed out that the work of this Working Party was now included within the remit of the Member Services Committee. Mr Milne reported on the forthcoming Women's Weekend which was heavily oversubscribed. Consideration was being given to further meetings to meet the needs of women involved in the care of people with haemophilia and HIV. Costs were likely to prohibit further residential meetings. Consideration was also being given to meetings dealing with other subjects and a Family Weekend was receiving active consideration. It had been a disappointment to the Haemophilia Society that funding for the Women's Weekend had not been forthcoming from the National AIDS Trust. Mr Milne also drew people's attention to the forthcoming Families and Carers Day to be held at the University of Manchester in conjunction with London Lighthouse and the Terrence Higgins Trust.

Among other matters being considered by the Committee were the National Health Service Review, the Human Fertility and Embryology Bill and treatment issues such as inhibitors and liver disease. The availability, quality and price of blood products remained a concern. BPL now produced 70% of the requirement for England and Wales. Scotland and Northern Ireland were virtually self-sufficient through the product made available from the Libberton Plant in Edinburgh. Mr Milne also mentioned European legislation whereby blood products would become a commodity, like toothpaste, with a preference for unpaid, voluntary, donors.

In discussion points raised included the future availability of high technology products since BPL was, currently, only geared to the production of products which were unlicensed. The General Secretary asked members of Council to discuss the level of satisfaction felt at being recipients of unlicensed blood products. It was generally agreed that self-sufficiency, of itself, was inadequate and that, implicit in the call for self-sufficiency, lay the requirement for the product to be of the best possible quality. Discussion also centred on those who had developed hepatitis as a result of the receipt of blood products and now faced severe problems with their livers. The General Secretary drew attention to the fact that this matter was under consideration and asked Groups to give the matter further deliberation in their own Committees since it appeared that there could be problems in achieving good levels of co-operation with Centres on account of the current litigation involving HIV.

- (c) Publications and External Relations: In introducing this subject the Chairman, once again, made it clear that this Working Party's tasks were now included within the remit of a new Committee - namely the Policy Committee of the Society.

Mr Cowe drew attention to new publications - THE CHILDREN'S HAEMOPHILIA BOOK, INTRODUCTION TO HAEMOPHILIA (3rd Edition), THE DIRECTORY OF LOCAL GROUPS and THE BULLETIN. In connection with THE DIRECTORY OF LOCAL GROUPS he made a plea for Groups to keep this information up to date by always advising the office of changes, using the correct pro-forma for the procedure. In connection with THE BULLETIN Mr Cowe drew attention to the fact that the Armour Pharmaceutical Company was now sponsoring this publication for the remainder of this year. This had been made possible through a single grant of £10,000. One member voiced concern that the Society should be seen to use money from Armour Pharmaceutical Company since they could be seen as one of those who introduced HIV to the UK. This view was not accepted by the meeting and it was felt to be important that the Society used any opportunity to further its work providing that the sponsoring body could not, in any way, influence, or be seen to influence, the policy and direction of the Society. All parents, known to the Society's computer, had been sent a copy of THE CHILDREN'S HAEMOPHILIA BOOK provided their children were aged 12 or under. Additional copies were available to Centres and a donation of £1.50 per copy was sought. Copies were available, at no cost, to Groups and parents themselves.

Among forthcoming publications were the Annual Report, the next edition of UPDATE and the booklet "SAFER SEX - THE CHOICE IS HERE". The last publication is being financed with a Grant of £20,000 from the Health Education Authority.

Mr Cowe reported that Jonathan Cooper had recently spent six weeks in Montreal giving further service to the WFH publication "A GUIDE TO LIVING WITH HIV".

The Press Service was explained in detail by Mr Cowe. He reported that the Society was one of the very few organisations which gave a 24hr, 7 days a week, cover to the media by way of Message Master machines. Those were sophisticated Radio Pagers. The Service had, time and again, proved its value and this was only achievable by virtue of people being prepared to carry pagers 24hrs a day and be on call on a rota basis.

The General Secretary was conducting a series of Parliamentary lunches in conjunction with the Chairman and the staff of GJW. Those were proving most useful and were, of course, concerned largely with deliberations concerning a future Campaign for an out of court settlement.

Finally Mr Cowe reported on a new facility which was being made available by the Armour Pharmaceutical Company. This involved the provision of free Pagers - including both initial and quarterly costs - to the parents of people with haemophilia aged 16 and under. This was being made available under a scheme promoted by Armour and British Telecom. A full announcement would be made in due course.

- (d) Group Liaison and Training In introducing this subject the Chairman paid tribute to the work of [GROA] and Mr Fitton. The tasks of this Working Party were now included within the remit of Member Services. [GROA] reported that, following the October meeting in Newcastle and the commitment of the Executive Committee to nurture and foster Groups, a detailed proposal was being prepared by the General Secretary in this connection which would be considered by the Member Services Committee at its next meeting.
- (e) Case Committee Grants: The General Secretary reported that the work formally undertaken by the Case Committee was now, in view of the recommendations in CERT, dealt with by the General Secretary on a daily basis. If applications fell within established policy guidelines the application could be dealt with within 8 hours, i.e. on the same day. Otherwise the matter was referred by the General Secretary to a member of the Member Services Committee.
- (f) Overseas: The Chairman reported that Ashok Verma, Secretary of the Indian Federation Haemophilia had visited London during January and had done so as the guest of the Society. In addition, the Chairman reported that he was hoping to take part in a WFH workshop in India later in the year, in the company of Professor Mannucci and Dr Peter Kernoff from the Royal Free Hospital.
- (g) Grant Applications: The General Secretary reported that the Executive Committee had made grants of £2,500 to the Royal Hospital, Truro in connection with their maintenance of patient records. In addition a grant of £200 had been made to Dr P C Winter at the Royal Victoria Hospital, Belfast for the purchase of an electrophoresis gel tank to be used in connection with DNA/Carrier Detection Techniques in the Province. This formed part of a grant package totalling £450 which had included attendance at a Seminar by Dr Winter. An application from the University of Bradford for a computer based project to assess the amount of factor VIII to be administered to each patient in each set of circumstances had been rejected by the Executive Committee and an application from Dr Paula Bolton-Maggs at Liverpool for a grant of £3,000 for work on factor XI deficient patients had been deferred, pending further consideration. There was also an application pending from the Nuffield Department of Orthopaedic surgery which sought an annual grant in the region of £40,000 for the establishment of a National Orthopaedic Service for people with haemophilia. This had been referred back, in September 1989, and had not been heard of since.
- (h) Macfarlane Trust: The Chairman reported that the Trust had succeeded in making the vast majority of payments to those entitled to the £20,000 per person granted by the Secretary of State for Health in November. He also stressed that the payment of this money would, subject to ratification of Trustees at their meeting to be held the following week, not be borne in mind when considering applications for items of particular need.

- (1) World Federation of Hemophilia: The General Secretary reported that the World Federation of Hemophilia were continuing with their Congress in Washington in August 1990. This was regretted by many of those present. The General Secretary also outlined the Countries supporting a boycott of the United States, in particular Canada, France, West Germany, Austria, Belgium, Greece and Panama. In addition Norway, Sweden, Denmark and South Africa would not attend the meeting of the General Assembly.

The meeting adjourned for lunch.

The meeting reconvened at 2:00pm and continued as follows:-

90.05 REPORT ON GROUP DONATIONS

The General Secretary reported that donations from Groups had been received as follows:-

	£
South Wales	1,300
Cornwall	800
Northampton	4,000
North Wales	300
West of Scotland	973
Lincoln	500

and the following donations had been received through the Centralised Banking scheme:-

	£
North East	861.28
South Essex	55.78
Hampshire	1,671.80
Merseyside	1,242.04
South Wales	169.30
Sheffield	762 48
Derby	64.37
Southern	3,163.14

In addition it had not been possible to allocate three donations of £34, £100.60 and £646.75 from the records provided by the bank. This would, however, be detailed at a future date.

The General Secretary reported that there were now eleven Groups within the Centralised Banking scheme and one more Group had made further enquiries earlier that day.

The above donations were equal to £16,644.54 received between 1 November 1989 and 28 February 1990. The appreciation of the Council was expressed with acclamation.

CONSULTATION ON COMPENSATION ISSUES:

The Chairman introduced this session and identified it as the main business of the day. He outlined the process whereby in 1987, following a high profile campaign conducted through the media, the Government had given £10m with which the Macfarlane Trust had been established. Throughout it had been acknowledged that a Charitable Trust was not, by any means, the ideal solution to the situation in which people with haemophilia and HIV found themselves. There had been a constant desire to give people charge over their own financial affairs. This led, in 1989, to a more concerted, and perhaps more professional Campaign, which led to a Government award of £24m in November of that year. This money was made available on the basis of £20,000 per person with haemophilia infected with HIV or per family of those who had already died. The purpose of the consultation was to establish feelings from around the Country on how we should proceed. The Chairman outlined, for instance, that the average life assurance payout was in the region of £23,000 and the average mortgage protection plan was in the region of £48,000. The £20,000 granted by the Government clearly fell far short of this amount.

The General Secretary reported, on the litigation front, that prior to the award of the most recent Government ex-gratia payment there had been 600 cases before the courts from the entire United Kingdom. It now appeared that that number could exceed 900 and possibly be as many as 1,200. The next court hearing was on 10 April 1990 when the numbers involved would become clearer. While the foregoing referred to England and Wales, the General Secretary also outlined the fact that at the present time the situation in Scotland and Northern Ireland was not bound by any limitation date established by the High Court in London. Mr Dolan raised the question of delays in the granting of Legal Aid in Scotland.

Everyone present was anxious to know how the Secretary of State, Kenneth Clarke, had worked out the figure of £20,000 per capita. No-one knew the answer to this question and it was generally regarded as the price which the Cabinet felt would satisfy the Tory backbenchers who were supportive of our cause, along with the other appeals running at the same time.

Many people commented that there was a shortage of information from the Macfarlane Trust concerning items for which help might be available.

While many people felt a sense of short-term gratitude for what had been given, none regarded it as compensation, but they were, at the same time, deeply conscious of the need not to appear "greedy" in the process of representing the case.

The General Secretary advised everyone present that, at one stage in the process of the Campaign, civil servants had enquired about the level of settlement which might enable the lawyers to recommend discontinuance of the legal cases. This yielded an average figure of £80,000.

Clive Knight commented on the fact that privately funded legal actions were getting more costly and, in addition, the fact that many people were discouraged by virtue of the fact that the process itself was humiliating.

The General Secretary commented on the usefulness of the lunch-time meetings with small groups of Members of Parliament. All had fresh insights to give as to the best course to pursue. The General Secretary also urged those present, and their Groups, not to expect the next campaign to be in the same vein as the last one. He also pointed out that for every one week of high media profile there were approximately 6 months of very careful background planning. Drawing up a campaign to commence before the trial of all the issues in the High Court - estimated for January 1991 - would mean that sufficient time was not available. Among the models proposed by Members of Parliament was that of inviting MPs to visit local Haemophilia Centres and meet patients there. This would identify them very closely, at a home base level, with the people intimately concerned.

At the end of the consultation session, which lasted for well over an hour, it was agreed that the matter should proceed further. The General Secretary undertook to keep all parties informed through UPDATE and THE BULLETIN. The Chairman thanked everyone for their close attention and preparation for this helpful discussion.

90.07 ANY OTHER BUSINESS:

- (a) The General Secretary reported that [GRO-A], from the Northampton Group, was currently unwell and in hospital. It was agreed that a message of goodwill from the Council meeting should be sent to him, wishing him a speedy recovery to full health.
- (b) The question had arisen regarding the provision of creche facilities to enable those with young children to attend meetings of Council. While the idea of providing such facilities attracted support, it was generally felt that the place for provision, in the form of alternative care, could be at home within the local Group. Problems could arise if, say, a person with five or more children wished to attend. Who would be responsible for the fares? The General Secretary was invited to look more closely into the matter and local Groups were invited to report to him.

90.08 DATE OF NEXT MEETING:

The next meeting will be held at 10:45am on Saturday 2 June 1990, immediately preceeding the Extraordinary General Meeting and Annual General Meeting to be held in Sheffield on that day.

APPROVED as an accurate record of proceedings of the meeting of 17 March 1990

Signed

GRO-C

2 June 1990

The Revd Alan J Tanner, Chairman