

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392255



THE HAEMOPHILIA SOCIETY

P.O. BOX 9 . 16 TRINITY STREET . LONDON, S.E.1

Telephone: 01-407 1010

THE FIFTH MEETING OF THE EXECUTIVE COMMITTEE was held on Thursday, 28th August, 1969, at 7 p.m. at the Society's Offices, 16 Trinity Street, London, S.E.1.

Those present: Mr. Prothero (in the Chair)
Messrs. Elliott, Leven, Morris, Polton, Rogers, Mrs. Britten,
Mr. Rosenblatt.
Apologies: Mr. & Mrs. Hunter, Miss Brodie, Mr. Crawley.

A G E N D A

1. Minutes of the meeting held on 7.8.69.
2. Matters arising from the Minutes.
3. Report of Appeals Sub-Committee.
4. World Federation Congress Report and Overseas matters.
5. Honorary Treasurer's Report.
6. Honorary Secretary's Report.
7. Any other business.

Minutes of the meeting held on 7.8.69.

The following alterations were made:

P.3. World Federation & Overseas Matters line 17 to read:
"International Centre which would benefit overseas haemophiliacs as well
as those in Britain"

P.5. Any other business please add the following:

It was proposed and agreed that all educational problems should be reported to Dr. M. Scott Stevenson at the Department of Education & Science.

It was agreed that each year's first bulletin should advise members to ensure that they could get treatment in their holiday resorts before going.

The Minutes were then signed as a correct record.

Matters arising from the Minutes.

Dr. Rusalem will arrive in London on 19th September and leave 21st September, 1969. It is hoped that some members of the Committee may be able to meet him with the nominees to the Behavioural Sciences Committee.

Mrs. GRO-D has now sent in £110 the proceeds of a Charity Walk and hopes to forward £30-£40 more in due course.

Bank charges had now been refunded, and the Manager had written to say that he would personally supervise the account and contact the Society if any changes are contemplated in handling it.

The Greater London Association for the Disabled had written to say that their Committee had great pleasure in accepting our affiliation and looked forward to working with us in the future.

As a result of the Press Conference called on Invalid Tricycles, reports had appeared in four national newspapers and several provincial papers. It was hoped that the Lancet would be publishing an article on Tricycles by Charles Pocock, General Secretary of the Disabled Drivers Association, and that the B.M.J. would publish an article specifically on the haemophiliac's case. The Spastics Society had offered to put their public relations set-up at the disposal of the organizers of the mass lobbying of M.P.'s. by tricycle drivers originally planned for June, 1970, but now to be brought forward, it was hoped to November, 1969, as a result of all the publicity. Other organisations had also offered their help.

Prof. Hardisty and Dr. Ingram had promised copies of their talks, and it was agreed to send a letter to "WHICH" on tricycles.

The Irish Haemophilia Society had not realised lay people could go to the World Federation Meeting in Moscow and therefore Mr. Carey, the Chairman, did not attend. Dr. O'Riordan, who represented Eire at the Congress, informed them that the Eire Government had agreed to establish a National Treatment Centre in Dublin, under a Dr. Temperley. Initially this would be the main centre for diagnosis and assessment and all surgery would be done there. Cryo. would be sent from there to other hospitals which it is hoped will later become more specialised.

50 copies of Miss [GRO-D] article had been sent out for the World Federation and one had been sent to all Centres, including those abroad.

'Petticoat' had replied to the Honorary Secretary's letter and agreed to draw their reader's attention to the error. They had now been asked to let us know when as we would like a copy for the files.

Mme. [GRO-D] will be letting us know whether or not treatment costs will be free for boys in France on exchange visits.

The Committee was glad to hear that [GRO-A] of [GRO-A] is not now to go to the "rough" and unsuitable school but to a much more suitable one, following a letter written by Dr. Dormandy after Mrs. [GRO-A] had appealed to the Society for help.

Appeals Sub-Committee

The Sub-Committee Minutes were received. At its meeting on 20th August, 1969, the Sub-Committee had decided to sell Christmas Cards again this year. Some of the cards will be overprinted with details of the Society with the emphasis on research, and will be on sale at 6 for 3/-, giving the Society 25% profit. Two other packs will also be sold without the overprinting. The manufacturers also sell Christmas gifts etc. and catalogues will go to selected members. Any goods ordered through them will earn a commission for the Society. The Committee agreed these proposals.

Mr. Rosenblatt announced that he had arranged for the proceeds of a Bridge Tournament for the Arthur Gilbert Cup to go to the Society, and he also hoped to raise further funds at the tournament by the sale of pens, etc.

World Federation of Haemophilia Congress Report.

Mrs. Britten and Mr. Rosenblatt reported on the Congress. Compared with the Montreal Congress last year, the World Federation has now established itself as the means of bringing more and more human help to each and every haemophiliac throughout the world. The three main ways, which will of necessity take time to progress, will be through affiliation with the World Health Organisation, the establishing of International Centres, and the increase in quantity and improvement in distribution of concentrates on a commercial basis.

Mr. Frank Schnabel, Chairman of the World Federation, and Dr. Tony Britten had attended the 22nd World General Assembly of W.H.O. in Boston in July, 1969, when W.F.H. had become affiliated to W.H.O. Many useful contacts had been made and Dr. Britten informed Congress of the nature of W.H.O. and the benefits and liabilities which would accrue to W.F.H. as a result of affiliation, although there would not be any fiscal commitment by either side. The W.F.H. Executive were authorised by Congress to make appointments for contacts with W.H.O.

Dr. A.F.H. Britten had proposed the formal setting up of International Treatment Centres to provide not only rehabilitation, evaluation and treatment to those referred internationally, but acute care for travelling haemophiliacs, training for foreign doctors and technologists, and, eventually, to provide an expert to go abroad to help set up new treatment centres in underdeveloped countries. He had added that he believed the establishment of such centres would accelerate the effectiveness of many more and would generate financial support. After discussion the proposal was carried unanimously, as was the proposal that the selection of the first international centres be left to a sub-committee.

Frank Schnabel had already had preliminary discussions with commercial producers of concentrates with the idea that the firms should produce concentrates in more countries, reduce the prices of factor VIII and IX concentrates and make their profits primarily from the remaining blood constituent^s. Congress unanimously agreed that the Executive should

press hard with this scheme, and that transfusion services should be encouraged to make ^{direct} cryoprecipitate concentrate wherever possible.

Four new countries were admitted to the World Federation - Eire, Poland, Spain, U.S.S.R.

As a result of Mrs. Britten's report as Regional Secretary responsible for the Commonwealth and the rest of Africa, two South African doctors asked for the Society's literature and decided to start a Haemophilia Society in their own country, as did doctors from India and Iran. Mrs. Britten was also given names and addresses of doctors and patients in Pakistan and there seems to be a chance of a Society being formed there. Literature etc. was also requested by other countries.

A Credentials Committee, consisting of France, Sweden and Great Britain, was formed to consider the position with regard to the U.S.A. which had sent \$1,000 of their assessed \$2,400 fees just before the Congress. At the Credentials Committee meeting it was felt that the action ~~taken~~ by W.H.O., that of withdrawing the countries voting power if they had not paid their dues for two years, was not appropriate in the case of the USA, as it would penalise the individual members in the USA by divorcing them from the rest of the world. It was finally agreed that Frank Schnabel would approach each of the Chapters making up the National Hemophilia Foundation in the USA individually and put the position to them and ask them to pay their dues to the World Federation direct as it was felt they may be dissatisfied with the N.H.F. Whereas countries such as France and Great Britain are paying a large part of their income each year to the World Federation the USA has to pay a much smaller part of their income and even this is not received. **GRO-D** would be seen in Paris by Monsieur H. Chaigneau, Chairman of the French Society and Monsieur Andes, Treasurer of the World Federation, who would put the W.F.H.'s opinion on this matter to him and the Honorary Secretary was asked to do the same in Dublin.

Next Year's Congress would be in Munich on 2nd - 8th August, and in 1971 the Congress would be in Iran.

Our delegates informed the Committee that the World Federation holds Great Britain in very high regard and emphasised the importance of keeping that regard.

The Committee expressed their unanimous vote of thanks to Mrs. Britten and Mr. Rosenblatt for their report and the extremely hard work they had done in connection with the Congress.

Honorary Treasurer's Report

The balances were given as: Deposit A/c £1,500. 0. 0.
Current A/c £3,010. 14. 3.

The figures for the half year showed a surplus on General account of £200. However, in the second half of the year a lot more payments would need to be made and unless some more money is received the General account at the end of the year could show a deficit of anything up to £1,500. It was hoped however that more funds would be obtained.

permitted
but never yet
taken

M. E. Audan
H

Mr. Polton proposed and Mr. Morris seconded a proposal that £600 be paid to the Royal Free Hospital on account of the Royal Free Hospital Appeal Fund, and this was agreed.

Mr. GRO-D had sent in the Oxford Hostel Accounts and a report which showed the Hostel to be running smoothly. A letter about the Hostel was to be sent to all Centres by the Honorary Secretary.

Mr. GRO-A of GRO-A had written to say that he had been in Hospital for some time and although he was now out he wondered if the Society could provide him with a rug making set in order to fill in his convalescence. The Committee agreed to order one for him.

The Committee agreed to meet the expenses incurred by the Honorary Secretary in attending the Regional Meeting of the World Federation in Dublin in September.

Mrs. Britten and Mr. Rosenblatt had refunded £16/they had not needed for their visit to Moscow. Their affiliates fees had to be sent from London and they recommended that only half be paid to the I.S.B.T. as they were only there for part of the time. It was therefore agreed to send £25 now for each of them and the other £25 each if asked for later.

GRO-A of GRO-A. A Medical Social Worker from the London Borough of Ealing had written to say that he had to wear specially built-up shoes and could only afford one pair which made repairs difficult, and asked if the Society would give £3.10.0. to pay for a second pair and also grant him £5 towards the cost of a holiday. It was agreed to send the £5 and to suggest that the shoes might be obtainable through Hammersmith Hospital, which he attended, but if not it was agreed to pay the £3.10.0.

Honorary Secretary's Report.

Mr. Robertson of South Africa had written again about Invalid Tricycles.

An enquiry had been received from Miss A. Voak, Fashion Director of the magazine 'Vanity Fair' requesting details of various aspects of haemophilia for an article she was writing. This had been given and some literature sent, and Miss Voak had agreed to let the Honorary Secretary see the draft article in case of mistakes.

An enquiry had been received from the Disablement Income Group concerning disabled haemophilic Civil Servants, but none were known. The Honorary Secretary had replied mentioning the problems confronting haemophilic Civil Servants from his personal knowledge.

Mr. GRO-A of GRO-A had written enquiring about the Oxford Boarding School project as he hoped his son might go there in view of the time he is missing at his present school. He had been informed of the position and told about Treloars.

Mrs. GRO-A of GRO-A had written asking exactly what haemophilia was. Although she had two haemophilic boys and her father also suffered from it no one had ever explained it to her. She would be sent some literature and the Honorary Secretary was writing to her about it and also mentioning Treatment Centres.

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Mr. **GRO-A** of **GRO-A**. A telephone call had been received from a Social Worker asking if a visit could be made to Mr. **GRO-A**, 20, who was depressed at not being able to get a job in a bank as he had hoped. Mr. Leven agreed to visit him.

The date of the next meeting was fixed for 18th September, 1969.

GRO-C

18.9.69