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

# INFECTED BLOOD INQUIRY

## WITN6392186



# HAEMOPHILIA SOCIETY

THE

P.O. BOX 9 · 16 TRINITY STREET · LONDON, SEI 1DE

Telephone : 01-407 1010

THE SECONIND MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY was held on Saturdalay, 25th November, 1972 at 2.30 p.m. at the Society's Offices, 16 Trinityty Street, London, SE1 1DE.

Those pressent:

Mr. Hunter (in the Chair) Dr. Dormandy, Mrs. Britten, Mrs. **GRO-A**, Mrs. **GRO-A**, Dr. Kuttner, Rev. A. Tanner, Messrs. Biggs, Polton, Prothero, Rosenblatt, Turner

Dr. P. Jones, Royal Victoria Infirmary, Newcastle.

Also pressent:

Apologies::

Dr. Biggs, Miss Atkin, Mrs. Hunter, Miss Spooner, Drs. Davies and Forty, Profs. Hardisty and Wilkinson, Mr. Neil Marten MP, Lord Willis, Messrs. Caine, Leven and Owen

#### AGENDA

- 1. Minutes of the previous Council Meeting
- 2. Matters arising
- 3. Reports from Groups
- 4. Infusion Materials
- 5. Any other business
- 1. Minuttes of the previous Council Meeting

Correction: Item 4. paragraph 4 was deleted and the following was substituted:

"Mr. King proposed and Dr. Kuttner seconded that £1,000 should be given to the Oxford Haemophilia Centre. £500 of this was being held by Oxford and District Group, being the proceeds of the Oxford premier of 'Nicholas and Alexandra'. The Group intended to raise £500 a year to support the research into immunological problems being carried out at the Blood Coagulation Research Unit at Oxford." This was agreed.

The Minutes were then signed as a correct record.

### 2. <u>Matteers</u> arising

The Niorway Society's report and booklets on the hostel in Oslo are now being translated. It was noted that summer visitors to Norway were recommended to spend a day or two at the hostel at the beginning of their stay to meet the staff and become acquainted with the system of treatment.

# Matters arising continued

The Chairman noted how few Groups were represented, welcomed the representatives from the Great Ormond Street, Manchester and Oxford Groups and expressed the hope that Groups would endeavour to send representatives to all Council meetings, not only to those preceded by the special meetings of Group representatives.

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3. <u>Reports from Groups</u> - will be included in the News Bulletin

# Birmingham and Midland

Group membership was increasing and future activities included a showing of the film "Home Infusion", a children's party and gathering of members at which the prize winning raffle tickets, sold throughout December, will be drawn, and on 4th February, 1973, 20 members will be seeing the ATV programme "Golden Shot".

### Cardiff

Dr. Kuttner is to present the £500 cheque for the Welsh National School of Medicine, agreed by the Council at its first meeting, at a meeting of the Group on 2nd December 1972 in Cardiff Castle Banqueting Hall.

#### East Kent

The Group AGM will be on 16th December, 1972 at Canterbury Hospital.

## GreatnOrmond.Street

Mr. Biggs reported on the last two meetings when representatives of the North London Blood Transfusion Centre and the Society's Honorary Secretary spoke. He reported the difficulty the Group had sometimes in getting members to attend meetings and the reasons for this. The Council advanced suggestions for the Group's consideration in meeting the problem.

A wine and cheese party and a dance were projected for the future.

#### Leeds

Dr. Swinbourne will be the guest speaker at the Group's AGM on 2nd December.

### Lewisham

The Group benefited from a charity concert given by the Metropolitan Police Male Voice Choir to the extent of £110 which was being generously donated by the Group to the Society's Benefit Fund.  $\pounds 65$  was raised for Group Funds at the Group's stall at the Mayor of Lewisham's Michaelmas Market.

### Manchester

Mrs. **GRO-A** and Mrs. **GRO-A** reported on the Group. The AGM was held on 24th September and the offices elected were:-

Chairman: Mr.	GRO-A		<b>a</b> .			
Secretary: Mrs.		<u> </u>	Chairman	: Mr.	GRO-A	
	GRU-A	Trea	surer:	Mr.	GRO-A	

A Charity Concert and a "Good as New" shop had raised £263 between them. Informal meetings at members' homes were continuing with three coming in the next few months.

# Newcaastle - No report.

#### Oxford

Mr. Trurner reported that the grant to the Oxford Centre had been presented to Dr. Biggs on 24th October by our President, Sir Weldon Dalrymmple-Champneys. The Group Christmas party was being held on 3rd Deecember 1972 and a party of about 30 boys from Lord Mayor Treloar Collegge were expected at it. The hostel committee had given help and addvice to the Cheshire Foundation who are setting up a hostel for disabled students to enable them to attend Oxford University or Polyteechnic.

#### Scotlaand

Dr. Kuittner addressed a meeting in Edinburgh and spoke on "The Running of a Giroup". The meeting was followed by a buffet tea and provided an opportunity for members to discuss mutual problems in an informal and happy atmosphere.

#### Southern

Dr. Kuittner apologised for the absence of a Group representative. He report ed on the successful 'Brains Trust' which had been held and on the other events, including a Fireworks Party and a Bazaar. Forthcoming activitties included a Jumble Sale, Christmas Party and St. Valentine's Dance.

A letteer had been received from a member in Derby who wished to form a Group iin that area. Dr. Kuttner had replied and it was hoped that something fruitful might come out of the enquiry.

### 4. Infusioon Materials

In the absence of Mr. Morris, this item was postponed.

## 5. Any other business

The Chairman welcomed Dr. Peter Jones, Consultant Paediatrician at the Royal Victoria Infirmary, Newcastle-upon-Tyne, who described the proposed further development of the Newcastle Regional Haemophilia Service, to cover Northumberland, Durham, North Yorkshire, Cumberland and Westtmorland. A central Haemophilia Centre at the Infirmary and a new C(oagulation Laboratory should open in the new year. This would act as the central diagnostic and treatment clinic which it was hoped would provide for the optimum care of patients near their own homes. In orderr to be able to do this efficiently and to the maximum benefit of haemcophiliacs, it was necessary to build up a central data bank containing complete records of all patients. As the records were scattereed not only between hospitals in the group, but also between departmeents in some hospitals, some patients are not registered and their dilagnosis unconfirmed. Dr. Jones described the project for standardiization of regional records in support of his application for a grant of £1,800 for the purpose. This had been considered by the Executive Committee who recommended approval. Dr. Jones answered the

Council's questions on the running of the project and the availability of statistics from the computer which would process the data. Mr. Polton proposed, and Mr. Rosenblatt seconded that a grant of £1,800 be made to the Newcastle Haemophilia Centre for their project for standardization of Regional records on patients with Hereditary Coagulation disorders and it was unanimously approved.

Two requests for grants from Dr. I. Delamore at the Royal Infirmary, Manchester were discussed.

The first was for money to meet the salary necessary to obtain secretarial assistance necessitated by the expansion of the Manchester Centre, and the second, for £285 to purchase a new deep freeze for storing cryoprecipitate.

Mrs. **GRO-A** and Mrs. **GRO-A** described the circumstances leading to the requests and the Council felt that these were items of expenditure which should properly be met by the Department of Health and Social Security or the Hospital Board. It was understood that the secretarial assistance would not be needed until next year and it was agreed that Dr. Kutner should see Dr. Delamore during his forthcoming visit to Manchester to discuss the matter with him. The Council were disturbed to learn of the need for a new deep freeze and felt that the condition of the old one reflected badly on the Hospital Board and the Department of Health. It was agreed that Mr. **GRO-A** be asked to see Dr. Delamore on the matter, but Mr. Polton proposed and Dr. Kutner deep freeze was not otherwise available, a grant of £285 be made. The Manchester Group has raised money which it would like to use for this purpose if necessary and this was agreed unanimously.

Dr. D.I. Evans of the Royal Manchester Children's Hospital had asked for assistance in purchasing two books, costing £12.50 for use in the Centre. It was proposed by Mrs. **GRO-A** and seconded by Mr. Prothero that a grant be made for this purpose and this was unanimously agreed.

Dr. Dormandy reported briefly on the meeting of Centre Directors at Oxford and on the Society's report on Infusion Materials. She summed up the basic decisions of the meeting and the likely outcome and it was understood that a letter would be sent to the Society concerning its report.

At Dr. Kuttner's suggestion the Council agreed that a request be made to Dr. Biggs for the Society to be allowed to send one or two observers to any future Centre Directors' meetings.

The Council were delighted to learn that Dr. G.I.C. Ingram, a member of our Medical Panel, had been appointed Professor and the Chairman reported that he had written and congratulated Prof, Ingram and had received a typically modest reply.

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Mr. . Polton proposed and Dr. Kuttner seconded the proposal that the Counnell recommended to the Executive Committee, that they consider exteending the scope of the present Social Worker Fund and renaming it. This was unanimously agreed.

The ) next Council Meeting was fixed for 17th March 1973 at 2.30 p.m. and  $\iota$  would be preceded by a meeting of Group representatives in the mornming. It was hoped that all Groups would make every effort to send a representative to the meetings.

The . A.G.M. and preceding Council meeting was to be held on 29th April 19733. As it had been held at Lewisham this year, Council felt it adviisable to hold it further from London next year and it was agreed thatt the Honorary Officers should investigate the possibilities.

GRO-C 3 17.3.