

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392228**

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# THE HAEMOPHILIA SOCIETY

P.O. BOX 9 · 16 TRINITY STREET · LONDON, SE1 1DE

Telephone: 01-407 1010

## NEWS BULLETIN

OCTOBER 1976

### RESEARCH APPEAL

Yet another landmark in the history of The Haemophilia Society was reached in 1976 when our Research Appeal passed the figure of £100,000. For a comparatively small organisation, still almost entirely voluntary, this is an achievement of which we can all feel proud. Our success is due to all those members who have raised money in a variety of ways. Individually they have organised jumble sales, darts matches, sponsored walks, dances, wine and cheese parties, tripe and onion parties, sponsored swims, sold ball point pens, made collections in clubs and pubs. They have sent cheques ranging from a few pounds to many hundreds of pounds. As Groups (now 23 in number) they have given wonderful support. During the past few months we have received: £1,000 from Northampton; £1,000 from South Wales; £1,000 from Manchester; £200 from Norwich/Norfolk; £500 from Nottingham/Derby. The North Wales Group has, in the few months since it was formed, raised almost £1,000 which is to be given to two hospitals in the area.

Our Ball Committee, a group of ladies who organise annual events in aid of the Society, have recently sent a further donation of £1,400. Many charitable trusts and commercial companies have responded to our appeal letters by sending substantial donations and last, but obviously by no means least, we have received a second donation of £25,000 from a charitable trust wishing to remain anonymous. For this last gift we are particularly grateful to the member who recommended to the trust committee our work and the projects we are supporting.

We extend our thanks to all these good and generous people. Their support has made it possible for us to make grants totalling approximately £95,000 to 20 different hospitals during the past five years. We have provided money for many differing projects. For medical equipment to help with diagnosis and treatment; for the salary of a researcher investigating the Factor VIII molecule; to cover the cost of an investigation into the prevalence of hepatitis B antigen and its antibody; to pay the salary of a nursing sister at the haemophilia unit of a children's hospital; to pay the cost of a researcher engaged in tracing, treating and organising a home treatment programme for patients with bleeding disorders in a particular area; and for helping generally with the development and organisation of a number of Haemophilia Centres.

It is sometimes said that we may be providing money for projects which should be paid for by the National Health Service but we usually reach the point where, unless we give support, a particular project may founder. Also, it is a fact that Haemophilia Society money has initiated projects or appointments and when, after one or two years their success and usefulness is seen, the responsibility is taken over by the local Health Authority.

Present economic trends mean that we are receiving more requests for financial help from Haemophilia Centres and other hospitals than ever before. For some the cutbacks in their allocations of money have reached crisis proportions. It is therefore essential that we continue to give help when and where we can. We hope all within the Society will carry on playing their part and giving their support in raising another £100,000. All money raised will be well spent and could make the difference between many haemophiliacs receiving good treatment, inadequate treatment or even no treatment. We all know what this can mean in terms of pain and crippling. It may even bring a little nearer the day when the long hoped for and long sought after cure is found.

Why not support our Research Appeal by displaying the enclosed sticker? You never know, one of these days your car may be followed by a friendly, philanthropic millionaire!

We still have ball point pens available and now is a particularly good time of the year to sell them. Inscribed "Haemophilia Research" they are 8p each or in a display drum of 50 for £4.

#### CHRISTMAS DISEASE PLASMA

We have received a request from Dr. Ethel Bidwell who is responsible for the production of Factor IX concentrate at the Plasma Fractionation Laboratory, Churchill Hospital, Headington, Oxford. In order to assay the batches of Factor IX concentrate prior to issue for the treatment of patients with Christmas Disease, supplies of plasma are required which are totally deficient in Factor IX. As availability of treatment becomes more widespread, to obtain such plasma becomes more difficult.

If any patient feels he can help and is willing to give a little of his blood will he please tell the Director of the Haemophilia Centre he attends, and he will make the necessary arrangements. It is those who have 0% of Factor IX and who have not received any concentrate for several weeks, whose blood will probably be of most use.

#### CHRISTMAS PARTY

This will again take place at the Warwick Row Centre, London SW1 on Sunday, 12th December 1976, 3 p.m. to 6 p.m.

#### ANNUAL DRAW

We are sorry that you will only have 3 or 4 weeks to sell Draw Tickets this year but we nevertheless hope you will do your best to make the Annual Draw a success. In addition to the First Prize of £50 there are many other excellent prizes including a Kodak camera, a Ronson lighter, an electric iron, etc.

A book of tickets is enclosed, please send for more today.

The Draw will take place at the Christmas Party on 12th December, 1976.

3rd EUROPEAN REGIONAL CONGRESS - WORLD FEDERATION OF HEMOPHILIA

An ambition of many people was realised when our Society was privileged to host the first Congress held in the country in the name of the World Federation of Hemophilia.

During the 27th/28th/29th April 1976 over 300 doctors, scientists, social workers, nurses, technicians, haemophiliacs and their families, from 17 different countries, gathered together in London, to listen to the distinguished speakers and to participate in general discussion.

We were most fortunate that Professor R.G. Macfarlane, former Director of the Medical Research Council's Blood Coagulation Research Unit at Oxford, renowned throughout the world as the man who for many years led the way in haemophilia research and treatment, was present to perform the opening ceremony. This was followed by Professor G.I.C. Ingram who spoke on "The History of Haemophilia", covering the period from the earliest descriptions in ancient writings to the present time, and the development of modern treatment. The paper was to be published by the British Journal of Clinical Pathology and an advance copy was presented to each delegate.

The entire afternoon session of the first day was chaired by Dr. Peter Jones and covered "The organisation and role of the Haemophilia Centre in the comprehensive care of the Haemophiliac". Members of the staff of the Newcastle Haemophilia Centre including a laboratory technician, social workers, a nursing sister, a physiotherapist, a psychiatrist, a dentist, and a surgeon presented papers on the various aspects of their work. Dr. Peter Jones was presented with a special award by Mr. Henri Chaigneau, President of the French Haemophilia Association, for his work on haemophilia.

On the second day the morning session was on "The preparation and optimum use of blood products" and in the afternoon we heard of "Behavioural problems and those of relationships, education, rehabilitation and genetics". During the latter session we were honoured by the presence of our Patron, H.R.H. The Duchess of Kent, accompanied by her Lady in Waiting, Miss Jane Pugh. Her Royal Highness was introduced to many of the delegates and was obviously most interested in talking to the mothers of haemophiliacs.

On the third day we had sessions on "Social Work" and "The future - a realistic look at the possibilities for the care of haemophiliacs in the next few years". At the close of this session, Dr. David Owen, M.P., Minister of State at the Department of Health, congratulated the Society on organising the Congress and gave an assurance that it was the policy of his Department to see that the United Kingdom would eventually be self-supporting in the production of blood products for the treatment of haemophilia.

Since the close of the Congress we have received many letters congratulating us on its organisation, commenting upon the many interesting and varied papers, and the happy and encouraging atmosphere. Our intention to devote the majority of the time available to social problems and subjects more readily understood by lay delegates, was obviously successful.

We are most grateful to all those doctors who gave their support and among the many others to whom thanks are due we particularly mention the ladies who staffed the reception desks, the nurses who staffed the emergency treatment room, the volunteers who provided an emergency 24-hour car service, the members who acted as interpreters and stewards and of course, the Organising Committee who gave so much of their spare time to arrange what proved to be such a worthwhile and memorable event.

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The proceedings of the Congress are being published at a price of £10.50 and an order form is enclosed.

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We have purchased a quantity of the interesting and informative paper presented by Professor G.I.C. Ingram, "The History of Haemophilia". These have been specially produced for us and anyone requiring a copy (free of charge) need only send their request accompanied by a 6p stamp.

A specially printed News Bulletin, giving more precise information about the Congress, will be sent to all members in the New Year.

#### FAMILY FUND

The Family Fund has been publicised in our previous News Bulletins and we know of many members who have made successful applications.

Since the Fund was set up in 1972, by the Government, to assist parents in their care of severely handicapped children, a total of £6.8 million has been disbursed to about 23,500 families (out of 32,000 applications) the average grant being £291.

4789 families have been given cars; 1621 helped with fares; 2643 have had driving lessons; 766 have had car hire paid; 346 vehicle repairs; 3544 running costs and 1138 general transport needs. Grants for clothing, 5043; and bedding 4260 have been made, 8491 families have been given washing machines and 4661 tumble dryers.

If you think the Fund could help you, write to:-

The Secretary, The Family Fund,  
P.O. Box 50, YORK, YO3 6RB.

#### HAVE YOU ANY BOOKS?

Mrs. Cynthia Morris, wife of one of our Executive Committee members, is a dealer in second-hand and antiquarian books. She is willing to try and sell any books donated, all proceeds to go to the Society.

If you have any books (not paperbacks) that might be suitable please write to Mrs. Morris at: Deacon's Croft, Barnet Lane, Elstree, Herts WD6 3QZ.

Where possible books will be collected.

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\* We apologise for the long period of time since the last News  
\* Bulletin was sent to members. During the past few months  
\* we have had to contend with a number of difficulties which  
\* we hope are now resolved.  
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## GROUP NEWS

Groups all over the country have been very active this year, especially in the field of fund-raising, and 17 groups made donations of £100 each towards the cost of the 3rd European Congress.

During the past year new groups have been formed in Belfast, Sussex, North Wales and Liverpool (Merseyside & District).

Group secretaries as follows:-

Northern Ireland:

Mr. Gordon Clarke,

GRO-C

Sussex:

Mr. Richard Cuffley,

GRO-C

North Wales:

Mrs. Joan Butler,

GRO-C

Merseyside &  
District:

Mr. Leslie Dodd,

GRO-C

To relate all the activities of all groups would need a 30-page News Bulletin, but we would particularly mention the following items reported at a recent meeting attended by representatives of 17 of our 23 groups, and chaired by our Group Liaison Officer, Dr. L. Kuttner, as enthusiastic as ever!

BIRMINGHAM & MIDLAND - have had stalls at various markets, sponsored swims, and have given talks to Round Tables and Soroptomist Clubs, etc. Much of their time has been spent on replacing the holiday caravan which was wrecked in last year's winter gales. Thanks to a great deal of hard work they were able to fulfil bookings from the beginning of July through to late September.

BRISTOL & SOUTH WEST - are running a weekly bingo ticket game which they hope will raise about £60 per week. In November they have a Wine and Cheese Party where they will have displays depicting home treatment, job prospects, etc. Among those invited are G.P.'s., local Councillors, Social Workers, Magistrates etc.

JERSEY - presented the General Hospital with a platelet aggregator meter, the event being well publicised by the local press and television. Future plans include an Autumn Draw, a barbeque, and the sale of specially printed Christmas cards.

MERSEYSIDE & DISTRICT - held their inaugural meeting in May when an interim committee was formed. Dr. F.E. Boulton, Director of the local Haemophilia Centre, very kindly agreed to act as Chairman for the first year. In the first 3 months almost £400 has been raised for group funds. It is hoped to hold a half-day seminar early in 1977 to which members of other groups will be invited.

NORFOLK & NORWICH - participated in an Art Exhibition, and a "mini-fete" organised by four children aged between 4 and 8 years raised £8.10p. The group has invested in an "Air-Call" radio bleep for the use of the two haematologists in the area who can now be contacted when on call, even if not at home.

NORTHAMPTON & DISTRICT - raised £510 at their Garden Fete held in June and have organised other events such as disco's, dancing displays, etc. The Social Committee has constructed a "Toy Town Train" (with carriage) from an old Triumph Herald - this splendid vehicle has won First Prize at several local carnivals and fetes. At the group's A.G.M. the guest speaker was Dr. Charles Rizza, from the Oxford Haemophilia Centre, and a large contingent from the Nottingham/Derby Group attended.

NORTH EASTERN (LEEDS) - had a stall at the Lord Mayor of Bradford's Gala and raised over £100 with a bottle tombola and gift stall and have organised two outings. Christmas Party on 11th December in Leeds.

NORTHERN IRELAND - managed to persuade Ulster Television to produce a 30-minute film on haemophilia. It was made in Belfast with the help of several local families and Dr. E. Mayne, Consultant Haematologist at the Royal Victoria Hospital. The group has formed a Swimming Club and from the results of various fund-raising activities is to purchase an electric wheelchair for the Haematology Ward at the Royal Victoria Hospital.

NORTH WEST (MANCHESTER) - have purchased a 6-berth caravan sited at Crook of Lune Caravan Park, near Caton, Lancashire, to be used by members for holidays. Fund-raising very active, a tombola stall at Westhoughton Summer Show raised over £200, a sponsored walk round a cricket field raised £235 and a member who shaved off half his beard and moustache was sponsored for each day he remained half shaven - he raised £245!!

SOLENT - held their Annual Charity Dance in Southampton and raised £200. A donation has been made to Lord Mayor Treloar College to purchase an alarm system.

SOUTHERN (BOURNEMOUTH) - The beach hut has been well used this summer and is available for any member staying in the area. A member of the group has had both his knee joints replaced surgically with apparent success. We hope to have a more detailed report on this considerable achievement by the Haemophilia Centre at Boscombe Hospital and this will be published in a future Bulletin.

SOUTH WALES - Fund-raising events have again been well supported and the group's float in the Lord Mayor of Cardiff's Parade was judged the best entry out of 75. At the A.G.M. it was announced that Dr. A.L. Bloom, Director of the Cardiff Haemophilia Centre, has been awarded a Chair for his work on haemophilia. Congratulations go from us all to Professor Bloom.

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More news from other groups in our next Bulletin. It should be mentioned however that some groups are experiencing apathy amongst members. As an example our Great Ormond Street Group recently sent out 25 invitations to a combined meeting and children's party. Of these only four replies were received, two to accept and two to decline. The event was therefore cancelled.

This is extremely discouraging for those group committees who work so hard for the benefit of their members and the Society. Whilst appreciating that many are not in a position to participate actively in the affairs of their group, we hope they will support and attend the meetings and other functions held from time to time.

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