Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

#### **INFECTED BLOOD INQUIRY**

#### WITN6392028



# ANNUAL REPORT 1984

P.O. Box 9 16 Trinity Street London SE1 1DE



The Society's Patron: H.R.H. The Duchess of Kent Portrait Study by Norman Parkinson, Camera Press

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Dr. B. Colvin, MRCP., MRCPath.

Dr. C. D. Forbes, MD., FRCP (Glasgow)
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Dr. P. Jones, MD., MRCP., DCH. Dr. E. E. Mayne, MD., MRCPath.

Dr. C. R. Rizza, MD., FRCP.

Dr. E. G. D. Tuddenham, MRCP., MRCPath.

Co-ordinator:

David G. Watters, J.P.

Auditors:

Taylor, Viney & Marlow, Upminster.

Solicitors:

Paisner & Co., London,

Bankers:

National Westminster Bank PLC

# WHAT IS HAEMOPHILIA?

ut simply, haemophilia is a hereditary bleeding disorder. The blood of a erson with haemophilia does not 'clot' in the same way as other people's. Iost especially, bleeding is into muscles and joints causing pain and ermanent damage. Today, modern treatment is reducing the damage hich arises from prolonged bleeding but there is still some way to go until he CURE is found.

#### INTRODUCTION

he Haemophilia Society was established in 1950 and was Incorporated as Company Limited by guarantee on 21st October 1983.

he aims of the Society are:

- (a) To promote research into and the study of the causes diagnosis and treatment of haemophilia and all related blood disorders, including (but without prejudice nevertheless to the generality of the foregoing) research into and the development of processes, techniques and drugs for the cure, prevention and/or control of all such disorders, and publish the useful results of such research, and
- (b) To provide or assist in the provision of medical, surgical and pharmaceutical care and treatment together with advice and aid (both financial and in kind) for sufferers from haemophilia and all related disorders who are in need.

practice the Society operates at two levels — first of all that of providing apport, friendship, advice and information to people with haemophilia — hd those involved in their care. This is achieved through various ablications, including The Bulletin, and by encouraging, for example, the rmation of professional groups for nurses and social workers as well as cal groups of members. Secondly, the Society seeks to encourage and apport research into the condition; since the Society was formed more than 450,000 has been collected for research and this has contributed greatly to be advances in treatment and care which benefit so many today.

recent years, we have recorded the steady growth which has taken place the Society's activites and membership and the way in which the Iministration has been improved to deal more efficiently with the creasing requests for information and practical support.

# ANNUAL REPORT

One subject dominated all others in the Society's work during 1984 when we became increasingly aware of the serious problems arising from the transmission of the acquired immune deficiency syndrome, known as AIDS. In the United States of America the total number of cases increased very substantially and, among people with haemophilia, there was growing

It became clear that definite action was required to eliminate this contamination caused by a virus transmitted by affected blood donors and the Society's Officers made strong representations to the Government and those responsible for the Blood Transfusion Service.

concern about the contamination of blood products used in their treatment;

An important meeting took place at the Department of Health and Social Security when the officers discussed with Lord Glenarthur the action to be taken by the Government with regard to AIDS, particularly his plans for providing heat-treated blood products which would reduce the risks

At the same time, the Officers sought from Lord Glenarthur an assurance that there would be no change in the programme for the National Health Service to be self-sufficient in the supply of blood products for people with haemophilia.

Distress was caused by the way in which some newspapers reported cases of

AIDS which occurred in the United Kingdom, so a good deal of attention was given to Public Relations and the release of information to the Press. Radio and Television. HAEMOFACT proved to be a most effective means of passing accurate information to all members of the Society immediately it became available. In this way much unnecessary anxiety was alleviated. We continue to be grateful to Mr Clive Knight, the Editor of the The

Bulletin, for using his special gifts in preparing the material for HAEMOFACT.
AIDS continues to be a worrying matter for us all, but there are indications

that the doctors and scientists involved are now more informed about its

cause and the ways in which its progress might be arrested.

The Society has kept in close touch with other organisations concerned with AIDS, especially with the World Hemophilia Aids Centre in Los Angeles,

which is the international centre co-ordinating information for people with

haemophilia.

involved in their use.

The Executive Committee has seen its main responsibilities as being in keeping members informed about developments and in emphasising its policy that:

"the benefits arising from the continued use of blood products far outweigh any risk involved with regard to AIDS"

#### THE ANNUAL SEMINAR

The fourth residential seminar was held at the Duriston Court Hotel, Bournemouth, in March 1984 where, at a Civic Reception, we were welcomed by the Deputy Mayor of Bournemouth, Mrs. Jean Curtis.

The facilities were well suited for the concentrated programme of the weekend which, as on previous occasions, was oversubscribed. The seminar is now well established as a most effective means of communicating information to members of the Society.

The Inaugural Haemophilia Society Lecture was given by Dr. Peter Kernoff, MD., MRCP., a Director of the Haemophilia Centre at the Royal Free Hospital in London. He chose as his subject "Blood Products and Their Problems". The Society Lecture provides the opportunity to pay tribute to a doctor or scientist who has made a significant contribution to work in haemophilia and great care is taken in thoosing the person to be invited to deliver the lecture.

#### THE SUPPLY OF BLOOD PRODUCTS

During 1984 evidence became available that the virus thought to be responsible for AIDS could be inactivated by heat treatment. With the Society's encouragement, nost Haemophilia Centres adopted an immediate policy of using only heat-treated Factor VIII. It appeared that there might be a consequent shortage of heat-treated naterial, but adequate supplies of heat-treated Factor VIII were imported to insure that people with haemophilia could be treated with the safest available naterials. The Blood Products Laboratory (BPL) at Elstree also announced that all Factor VIII produced there would be heat-treated from April 1985.

Building work on the new plasma fractionation facility at Elstree began early in 984, and is on target for completion in January 1986. The new factory is intended o give the United Kingdom the capacity for self-sufficiency in blood products, but thas become increasingly evident that there will be great difficulty in obtaining nough donated plasma for processing. The Society continues to press the DHSS to llocated sufficient resources to the Blood Transfusion Service to allow the eccessary plasma to be collected.

n the longer term, the supply of sufficient blood-clotting factors throughout the vorld may depend on the development of processes for their synthetic production.

#### PROFESSIONAL ASSOCIATIONS

Ve record our gratitude for the support and advice given by members of our fedical Advisory Panel. We look to them for guidance in dealing with applications or grants for research projects and we have been especially grateful for their help egarding the information published about AIDS.

our relationship with the Social Workers at the Centres has been most valuable nd we appreciate being involved with the Special Interest Group in Haemophilia, ponsored jointly by the British Association of Social Workers and the Society. We re represented at the regular meetings of the Group and are grateful for the rofessional advice we receive from them.

The link with the Haemophilia Nurses' Association is now well established ar gives an opportunity for us to express our own views about the facilities available; the Centres and the treatment provided. The Nurses' Association is concerned with the standard of training and other aspects of the work of nursing staff in the Centres.

The Society enjoys the privilege of being represented at the Haemophilia Cent. Directors' Meetings. We are indebted to the Centre Directors for the welcon extended at these discussions and, in particular, for inviting the Society nominate two members for their working party concerned with the classification Haemophilia Centres.

#### THE R G MACFARLANE AWARD

The R G Macfarlane Award is the highest tribute in the gift of the Society are perpetuates the name of Professor Macfarlane, our President and a pioneer in wor in haemophilia.

The Award in 1984 was made to Dr E G D Tuddenham MD, RCPath, a Director the Haemophilia Centre at The Royal Free Hospital, London. The citation on the inscribed parchment records the work for which he received this honour:

# Presented to EDWARD G D TUDDENHAM

by the Haemophilia Society in recognition of his original work in the purification of human Factor VIII and particularly for his leadership of the team which first produced a sufficient quantity for chemical characterisation, of the gene and the biosynthesis of Factor VIII.

The occasion of the Award was memorable as Professor Macfarlane himse presented the medal and the citation to Dr. Tuddenham at the Royal Free Hospit on 17 October 1984.



Dr. Tuddenham receives the Award from Professor Macfarlane.

#### AWARDS

The Society is indebted to Catherine Cookson and Brendan Foster for their continued generosity in making those Awards available. They are awarded for achievement in education in the case of the Catherine Cookson Awards and for achievement in any field of sport, indoor or outdoor, in the case of the Brendan Foster Awards. The 1984 Awards were presented at the Annual General Meeting as follows:—

The Catherine Cookson Awards for Achievement in Education:

JUNIOR AWARD — GRO-A

SENIOR AWARD — GRO-A

The Brendan Foster Awards for Achievement in Sport

JUNIOR AWARD — GRO-A

SENIOR AWARD — GRO-A

#### The Chairman with the 1984 Award Winners

After presenting those Awards the Chairman also expressed the thanks of the Society to Dr. Peter Jones for his valuable help with the Awards each year.

#### THE CASE COMMITTEE

During 1984 the Committee, which again met regularly each month, received 66 request for help — 9 more than in the previous year. In accordance with the principle that, where properly and fully presented, assistance should be given wherever possible, 61 grants were approved — ie only 5 were declined. The average payment was £69, compared to £48 in 1983.

The Case Committee feel that financial assistance is one of the Society's most important functions in providing a lifeline for those unfortunate members who are in distress and in this connection are heartened to note that well over 200 people were helped by the Society to obtain Mobility or Attendance Allowance in 1984—adding an annual income of more than £200,000 to our members.

#### **OVERSEAS**

Our plans to support the work of the newly formed Indian Federation of Haemophilia have been welcomed by members of the Society. Following his visit to New Delhi as Chairman of the World Federation of Haemophilia, in November 1983, the Chairman has maintained close relationships with the Officers of the Indian Society as they develop the plans for their first Haemophilia Centre to be opened in New Delhi.

Dr Dinesh Jain, an Indian haematologist has been studying with Professor Mannucci in Milan and on his way home at the end of his work at the International Haemophilia Training Centre there, visited London to discuss the Society's involvement with the project.

#### PERSONALIA

Pressure of his own professional work led to Mr. Howard Abrahams, FCA, FCCA, not seeking re-election to the office of Treasurer. We record our gratitude for the time which he gave to this demanding task and are pleased that he agreed to stay as a member of the Executive Committee.

His place as Treasurer was filled by Mr. John Prothero who applied himself with great industry to this new responsibility. Mr. Ken Milne was elected to take Mr. Prothero's place as a Vice-Chairman.

Mrs. Irene Watson retired from her work in the office as Assistant Secretary after almost twenty years. Her retirement was marked by the presentation at the Seminar of a cheque, to which contributions had been made by members and the Groups. The Officers and other members of the Executive Committee expressed personally their gratitude for Mrs. Watson's work for the Society by arranging a small dinner party for her and Mr. Watson.

We record the death in the course of the year of Mr. Frank Smith, Founder and pas President of The International Haemophilia Society. Older members of the Society will recall that Mr. Smith took the initiative in convening the first meetings of people with haemophilia which lead on to the formation of the Haemophilia Society.

#### THE WORLD FEDERATION OF HEMOPHILIA

We have continued to support strongly the work of the World Federation of Hemophilia and have valued particularly the formation of the World Federation AIDS Centre, under the direction of Dr. Shelby Dietrich.

The Society was represented at the XVI World Congress in Rio de Janeiro, Brazil in August 1984.

The Federation celebrated its twentieth anniversary in 1983 and now, under the guidance of the President, Mr. Frank Schnabel, and the Executive Secretary, Mrs Marthe Schnabel, continues its special working parties; co-ordination of the activities of the National Societies and promotion of activity in the developing countries.

#### THE FUTURE

In many ways, this has been a difficult year with the shadow of AIDS lurking over us, stretching our limited resources to the ultimate. Without the unstinting efforts of the office staff and the professional skill and dedication of the Co-ordinator, Mr. David Watters, we could not have provided such outstanding service to members of the Society.

We are well aware that AIDS is only one problem to be solved. Efforts must still be directed, for example, towards the elimination of hepatitis from blood products and we have to continue our efforts to see that blood products are available in sufficient quantities to meet our needs.

However, the year was also marked by Dr. Tuddenham's publishing the work for which he received the R G Macfarlane Award. So we can look to the future expectantly knowing that when synthesised materials become available some of the present anxieties will no longer arise.

People with haemophilia are accustomed to living with uncertainties, difficulties and calculated risks. It is our hope that we shall find the future more secure as we reap the benefit of discoveries which will be available to all.

As we move forward, we can report with confidence that the Society has never been more efficiently organised than now, nor more readily poised to meet the needs of its members in the days to come.

# GIFTS, GRANTS AND LEGACIES The Society wish to express grateful thanks to the following organisations.

churches, possible:-	schools, -	trust	and	individuals	whose	generosity	has	made	our	work
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GRO-D Aldwyns Trust; IV Askew Charitable Trust; Harold Amelan Charitable Trust; Benham Charitable Settlement; Gerald Bentall Charitable Trust; Sir Arthur Black Charities; Sydney Black Charitable Trust; The Boeke Charitable Trust; Boots Charitable Trust; R. M. Burton 1958 Charitable

Settlement; Catholic Newspapers Charitable Trust; Courage Charitable Trust; C. & A. Charitable Trust; Denise Cohen Charitable Trust; Drapers Charitable Trust; Robert Fleming & Co. Charitable Trust; Forum Lodge; Grove Charity Management; Good Neighbours Trust; Headley Foundation; Hogg Robinson Charitable Trust; Inchcape Charitable Trust; Low & Bonar Charitable Trust; Lodge of Perservance; Bryan Lancaster Trust; Joseph Lucas Charitable Trust; The Marsh Christian Trust Fund; The Miss March Charitable Trust; Mercer's Company; Moorgate Trust Fund; Musical Chairs for Charity; Murphy Neuman Charitable Trust; Patients' Aid Association; The Podde Trust; Tollemache Buckminster Charitable Trust; I.G. Uridge Charitable Trust; Walter Raleigh Lodge; Smith's Charity; Winchester Lions; Wogan Anniversary Trust; Kilmarnock Academy; Liverpool City Mission; Melbourne Methodist Fellowship; St. Phillip's Young Phoenix Club; Strood High School; Theydon Bois Baptist Church; B.R. Southern Region; Bally Yoga Club; Bolton Business & Professional Women's Club; Cabin Inn, Bowness; Curl Service Sports Club; Grape Vaults; Heathrow Jets AFC; Norfolk Women's Club; Smiths Industries (Basingstoke); L.E.B. Poplar; Seiko Time; 2nd Wakefield Scout Group; R.A.F. Wildenrath; Wentworth Arms; Worthing & District Bowling Association; Yiewsley & W. Drayton Rotary Club; 124 High Street Club; AID 1976 Fund; Armour Pharmaceutical; Austin Rover: Barclays Bank; B.P. Group of Companies; Coats UK Ltd; Cutter Laboratories; Coutts & Co: Halifax Building Society; Hanover Insurance; Hunter Group Management Ltd; Immuno Ltd; Imperial Life Assurance Co. Ltd; Japan International Bank; E. Jones & Son (Eltham); Kleinwort Benson; Landrover UK: Leyton Fasteners; Liberty & Co; Lloyds Bank; Members of Lloyds & Brokers at Lloyds; London Association of Funeral Directors; Maison Jeanne; Mercantile Credit; Midland Bank; Stanley P. Morrison Ltd; National Westminster Bank; N.G.B.; Nice Irmas Floating Carpet Co; Pearl Assurance Co; Prudential Assurance Co; Thomas Reed Ltd; Royal Bank of Canada; Scotch Meat Shop (Bexley); Speywood Laboratories; Stagers Ltd; T.V.S.; Talent & Production Services; Thomas Tunnock Ltd; Vacu-Lug Traction Tyres Ltd; Whitecroft Ltd; White Gate Windows; Birmingham Group; Cambridge & District Group; Colchester Group; East Kent Group; Jersey Group; Lewisham Group; Lincoln & District Group; Merseyside & District Group; Norfolk & Norwich Group; Northampton & District Group; North Eastern Group; Northern Group; Northern Ireland Group; North Wales Group; North West Group; Oxford & District Group; Scottish Group; Sheffield Group; Southern Group; South Essex Group; South Wales Group; Sussex Group; Tayside Group

egacies	
GRO-A	

#### RESEARCH FUND

During 1984 the following grants were approved from the Research Fund:

Royal Victoria Hospital, Belfast: A top-up grant of £370 to meet additional salary costs of a part-time physiotherapist.

Royal Liverpool Hospital £5,000 to enable major improvements in patient treatment facilities. An equal sum to

be donated by the Leukaemia Society.

University Hospital of Wales: £595 for funding connected with work on gene

analyses of haemophilia B

Royal Free Hospital, London: £224 being top-up grants to meet increased

equipment costs.

The Children's Hospital. £6,800 being salary costs for one year in Birmingham

respect of a research social worker.

#### TREASURER'S REPORT

It is a matter of great pleasure to note that 1984 has restored the financial side of the Society's work to a more satisfactory level. That this has been achieved without any decrease in the range of services we are able to offer to members, and at a time of great activity in connection with the development of AIDS, etc., is especially noteworthy.

Not only have we received a substantial sum from legacies but donations have increased substantially and the Annual Draw broke all records indeed the surplus from the one event was responsible for over forty per cent of the whole surplus for the years.

During the year it was decided, as the Research Appeal had reached its target, that the Appeal should be discontinued. It was felt that not having funds specifically committed to formal research projects only would result in a more flexible approach to other matters of concern to members and would permit a swifter and easier response to those needs. The Society's commitment to the support of research projects, of course, continues as strongly as ever and it is hoped that the improvement in the Society's financial affairs this year will enable this to continue.

31st December 1984

Statement of Accounts

#### Report of the Auditors to the Members of The Haemophilia Society

We have audited the financial statements annexed in accordance with approved auditing standards having regard to the matters referred to in the following paragraph.

In common with many businesses of a similar size and organisation the Company's system of control is dependent upon the close involvement of the Officers who are guarantors. Where independent confirmation of the completeness of the accounting records was therefore not available we have accepted assurances from the Officers that all the Company's transactions have been reflected in the records.

Subject to the foregoing in our opinion the financial statements which have been prepared under the Historical Cost Convention give a true and fair view of the state of the Company's affairs as at 31st December 1984 and of its profit and source application of funds for the year then ended and comply with the Companies Acts 1948 to 1981.

TAYLOR, VINEY & MARLOW Chartered Accountants, 60a, Station Road, Upminster, Essex.

17th May 1985



#### Income and Expenditure Account year ended 31st December 1984

	Notes	1984
Income	2	91180
Administrative Expenses		72055
Surplus of Income		19125
Transfer to Benefit Fund		4500
	•	14625
Accumulated General Fund transferred from		
Haemophilia Society		(15257)
Accumulated General Fund carried forward	5	(632)

The notes on pages 15 to 18 form part of these accounts.

#### Balance Sheet — as at — 31st December 1984

	Notes	1984
Fixed Assets		
Tangible Assets:	5	
Office Equipment and Furniture		1655
Current Assets		
Stocks	1	3665
Debtors		363
Cas at Bank and in Hand		127219
		131247
Creditors		
Amounts falling due within one year		28858
Net current assets		102389
Total assets less current liabilities		104044
Creditors		
Amounts falling due after more than one year		
	!	104044
Reserves		
General Accumulated Fund		(632)
Research Fund		104248
Social Worker Fund		51
Benefit Fund		377
	!	104044

The notes on pages 15 to 18 form part of these accounts.

#### Notes to the Accounts year ended 31st December 1984

#### 1. Accounting Policies

#### **Accounting Convention**

The accounts are prepared under the historical cost convention on a going concern basis.

#### Depreciation

Depreciation is provided on all tangible fixed assets at rates calculated to write the assets down to their residual value at the end of their anticipated useful life as follows:—

Office Equipment and Furniture — 15% p.a. on written down value Stocks

Stocks are stated at the lower of cost and net realisable value.

#### 2. Income

Income represents the total amount of subscriptions, donations, legacies and other income received during the period.

3. Excess Of Income	1984
This is after charging:	
Audit and Accountancy Fees	345
Depreciation	292
	£ 637

#### Notes to the Accounts year ended 31st December 1984

	1984
4. Staff Costs	•
Wages and Salaries	20438
Social Security Costs	2044

The average weekly number of employees during the year was 2 made up as follows:—

Office and Management — 2

#### 5. Fixed Tangible Assets

	Office Equipment & Furniture	Total
Cost or valuation:		
Transferred from Haemophilia Society	1947	1947
Additions	=	
As at 31st December 1984	1947	1947
Depreciation:		
Depreciation for period	292	292
As at 31st December 1984	292	292
NET BOOK VALUE	£ 1655	1655

#### Notes to the Accounts year ended 31st December 1984

		1984
6. Research Fund		
Balance as at 1st January 1984		87773
Add: Donations and sums received		31990
		119763
Deduct		
Grants Paid and Payable:		
Birmingham Childrens Hospital	6800	
Liverpool Royal Hospital	5000	
Royal Victoria Hospital Belfast	370	
Welsh National School of Medicine	345	
Bradford Health Authority	3000	
		15515
Balance as at 31st December 1984		£ 104248
7. Social Worker Fund		
Balance as at 1st January 1984		51
Balance as at 31st December 1984		£ 51
8. Benefit Fund		
Balance as at 1st Jaunary 1984		100
Add: Transfer from General Fund		4500
		4600
Deduct — Grants to Members		4222
Balance as at 31st December 1984		£ 378

#### Notes to the Accounts year ended 31st December 1984

		1984
9. Debtors		
Sundry Debtors and Prepaid Expenses	£	363
	=	
10. Creditors		
Amounts falling due within one year:		
Sundry Creditors and Accrued Expenses		2573
Research Fund Grants Payable		23587
Other Taxes and Social Security Costs	_	2698
	£_	28858

#### 11. Company Incorporation

The Haemophilia Society was incorporated on the 21st October 1983 as a company limited by guarantee. With effect from the 1st January 1984 all the assets and liabilities of the old Society were transferred at cost to the new Company.



## Source and Application of Funds Statement year ended 31st December 1984

Source of Funds Surplus of Income on ordinary activities		<b>1984</b> 19125
Adjustment for items not involving the		19125
and the second s		
Depreciation	:	292
Total generated from operations		19417
Funds from other Sources	٠.	
Transfer of Assets from Haemophilia Society		.: . :
upon incorporation		72667
Total Funds Obtained		92084
Application of Funds		•
Funds Distributed		12252
Funds Applied	 	12252
Working Capital — increase/(decrease)	£	104336
Change in Working Capital		
Funds introduced from Haemophilia Society		•
upon incorporation		
		(147)
Debtors — (decrease)		(1439)
Creditors — decrease		
		81831
Increase in Net Liquid Funds		22505
Working Capital — increase	£	104336

#### Income and Expenditure Account year ended 31st December 1984

Income		1984
Subscriptions		1053
Donations		58196
Legacies Received		13171
Annual Draw		9439
Interest Received		8357
Sale of Badges, Books etc.		964
		91180
Deduct		91100
Expenditure		
Office Rent	3300	
Rates and Water	1439	
Light and Heat	546	
Lease of Office Equipment	2387	
General Office Expenses	4017	
Salaries and National Insurance	22482	
Travelling	6910	
Cost of Attendances at World Federation of Haemophilia Congress	1343	
Appeal Expenses	958	
Postage and Telephone	5611	
Printing and Stationery	13416	
Subscription and Donations to Affiliated		
Organisations	1271	
Auditors Remuneration	345	
Publications	1146	
Seminar Weekends	1673	
Meeting Expenses and Hall Hire	3638	
Book-keeping Expenses	281	
North Wales Group Holiday Project	1000	
Depreciation	292	
		72055
Excess of Income over Expenditure		19125
Transfer to Benefit Fund		4500
		£ 14625