Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392029

The
Haemophilia
Society

ANNUAL REPORT
1985

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

PATRON
HRH The Duchess of Kent

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Executive Committee:
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Mrs. M. I. Britten, BSc.
K. Colthorpe
Mrs. C. Holliday
G. Kirman
C. Knight, BA.
L. Kuttner, LLD.
Mrs. D. Lewis

Medical Advisory Panel:
Professor A. L. Bloom, MD., MRCP., FRCPath.
Dr. B. Colvin, MRCP., MRCPath.
Dr. C. D. Forbes, MD., FRCP (Glasgow)
Professor R. M. Hardisty, MD., MRCP., FRCP., FRCPath.
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?

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

Acquired immune deficiency syndrome (AIDS) is a serious complication of treatment which faces the Society at the present time.

INTRODUCTION

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

The 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.

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

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

ANNUAL REPORT

of the Executive Committee

"AIDS" has become a household word for people with haemophilia. The acquired immune deficiency syndrome was recognised as a serious threat during 1983 but it has now come to dominate the work of the Society to such an extent that an increasing proportion of our resources, in terms of time and money, is devoted to the problems associated with its apparently rapid transmission by the use of blood products.

Our main concern has been in seeing that accurate information is made available to people with haemophilia and members of the general public. AIDS has a mysterious quality; there is an incubation period possibly extending into several years, there is, at the moment, no known cure, nor any method of immunisation.

However, in all this uncertainty there are now clear guidelines about ways in which AIDS may be transmitted from one person to another. Our efforts have been directed towards informing people of the facts about this transmission, particularly regarding sexual intercourse. We have been grateful for the financial support given by the Government for this educational part of our work; a grant of £15,000 for 1984/85 with another £20,000 in 1985/86.

The demands made upon the officers and members of the staff have been almost overwhelming. Members of the Society have sought advice to allay their anxieties, the general public have sought information and a substantial amount of time has been given to the media. We have featured in several television programmes and many radio broadcasts, generally to take the opportunity to redress errors of fact which have been circulated about AIDS and haemophilia.

We have also made representations to the Government about such matters as the supply of heat-treated concentrates, the provision of counselling facilities and the development of the Blood Products Laboratory at Elstree.

We are glad to report that the supply of heat-treated materials (by which process the AIDS virus is destroyed) is now sufficient to avoid the use of non-treated concentrates so newly diagnosed patients are no longer at risk from AIDS by means of their treatment. Another encouraging development is in the work at the Blood Products Laboratory at Elstree being on target so that it will be operational in 1986 and providing concentrates in such quantity as to lead to England and Wales being self-sufficient quite soon after that.

COUNSELLING

It has become clear that there is a pressing need for more facilities to be available for counselling. For instance, those who have been exposed to the AIDS virus need careful explanation about the implications of their condition and members of their families and their friends are often in a need of support. It is also evident that such facilities should be available locally and we have made representations to the Government for funding for professionally qualified people to be appointed for this work.

AIDS is still with us as a worrying feature in the lives of all people with haemophilia but, already, there is greater understanding about its nature, and a more positive attitude about the way in which we may support each other as we work through this new problem.

COMMUNICATION

We have continued the publication of the HAEMOFACT leaflets which are designed to produce immediate, accurate information regarding haemophilia in general and now AIDS in particular. HAEMOFACT is distributed widely and is appreciated by our members as a valuable way of keeping them informed.

We are grateful to Mr Clive Knight who edits HAEMOFACT, as well as THE BULLETIN, which is widely regarded as one of the most informative publications issued by any National Haemophilia Society.

THE SEMINAR

The fourth Residential Seminar was held in Bournemouth in March 1985. Once again, the places were in great demand as the numbers were limited to 120 to preserve the principle that those attending should have the opportunity to meet others in the small groups. The emphasis in the groups and the plenary sessions was on AIDS and the whole weekend provided an immensely valuable occasion for sharing information and experiences. We acknowledge the financial support given by the Pharmaceutical Companies which has led to the net cost of the Seminars being reduced each year since 1981. We are indebted to Mrs Diane Lewis, Mr Clive Knight and others who helped them in the arrangements for the Seminars.

PROFESSIONAL ASSOCIATIONS

We are in close contact with several other groups who are involved in the care of people with haemophilia. First, with the Special Interest Group of the British Association of Social Workers, concerned with haemophilia and related disorders. The Group invites representatives of the Society to join in its meetings and we derive much benefit from this association.

Secondly, we note with pleasure the progress made by the Haemophilia Nurses' Association which now meets regularly and is well established in its concern to maintain high standards in the training given to nurses appointed to Haemophilia Centres and in the quality of care provided to them.

We are also privileged to attend some meetings of the Haemophilia Centre Directors and we welcome the appointment of Dr Charles Forbes as the new Chairman of the Haemophilia Centre Directors Organisation. He takes the place of Professor Arthur Bloom who has been a good friend and counsellor of the Society throughout his period in office.

CASE COMMITTEE

The Case Committee met regularly during the year under the Chairmanship of Mr David Rosenblatt. The Committee received a total of 79 applications for financial assistance – 13 more than in 1984. 75 of those applications were successful and well over £5,000 was paid in grants: an average of £69, as was the case in 1984.

The Case Committee continue to recognise the importance of financial assistance to people with haemophilia who are in distress and operate very much on the principle of helping wherever possible.

THE WORLD FEDERATION OF HAEMOPHILIA

The benefit we derive from our membership of the World Federation is immeasurable. Its membership is continuing to increase so that now over sixty national organisations are joined together in this fellowship of communication and mutual support. We record our appreciation of the efforts of Mr Frank Schnabel, the President and Founder of the WFH, who continues his work for people with haemophilia throughout the World.

Two of the most important branches of its work are of particular interest to us all. The World Federation Haemophilia AIDS Centre (WHAC) is now well established in Los Angeles under the direction of Dr Shelby Dietrich. WHAC is well equipped to collect and collate information about AIDS and distribute it widely to all National Societies and others concerned.

The work of the International Haemophilia Training Centres also continues as one of the most valuable activities of the World Federation particularly with its work in the developing countries. Professor Pier Mannucci set a high standard for the IHTC projects during his long period as Chairman and he has now handed over to Dr Louis Aledort of Mount Sinai Hospital, New York.

THE INDIAN FEDERATION OF HAEMOPHILIA

Our link with the Indian Federation has been developed in the course of the year and we are delighted that the first Haemophilia Centre in the country is to be opened, after many difficulties. It is to be at the Lions Hospital in New Delhi where the Indian Federation was formed in November 1983. The Council of the Society has decided to help in providing the basic equipment required at the Centre and members are encouraged to provide financial support for this fund-raising project.

We also have news that treatment facilities are being developed in Calcutta where the first, limited supplies of concentrates are being made available.

At times, the problems associated with haemophilia here in the United Kingdom seem formidable but they are seen in different perspectives when compared with other places, such as India, where the facilities are so limited at present. A number of our members have expressed their commitment to helping those less fortunate than ourselves by providing the facilities for treatment and care which are so essential, but in such short supply, in India.

THE CO-ORDINATOR

We record our gratitude for the work of the Co-ordinator to whom this has been a particularly busy year. He is responsible for the supervision and general business of the office but he also undertakes special work such as that concerned with Mobility and Attendance Allowances; particularly in supporting members involved in Appeals. The pressure associated with public relations arising from AIDS and the heavy load of telephone calls from members at moments of crisis have increased substantially in the course of this year. He has helped to steer the Society through these very difficult days affecting the welfare of our members.

THE FUTURE

Some see an element of irony in the fact that the concentrates, which have done so much to transform the lives of people with haemophilia, should now be revealed as the very means by which AIDS is transmitted to them. So, for the moment, a shadow has been cast over the well-being of our members and their families.

However, people with haemophilia are used to living with adversity and are familar with the uncertainties and disappointments which come to them.

Our experience is that, quite often, people with haemophilia, as a result of reflecting on their conditions and coming to terms with adversity, are led on to a much deeper quality of life. Their lives have been enriched with experiences and their ability to cope with them.

But that is not so far all – we are aware that some live lonely, isolated lives and are in need of help. We recognise our responsibility to support them.

This has been a difficult year for the Society but we have never been in a better position to meet the demands being made upon us.

We are aware that many doctors, scientists, nurses and counsellors have our interests at heart and are working for us. We share in a strong fellowship of all concerned with haemophilia.

We are here to support each other, and that is the source of our confidence and our hope as we look to the future together.

TREATMENT SURVEY

During the year the Society conducted a survey of members to try and establish what sort of treatment services are available.

The survey came about after the Society had been invited to join a working party set up by the Heamophilia Centre Directors' Organisation to make recommendations about the organisation of the UK Haemophilia Centres.

It has been the Society's view that the wide-spread introduction of home therapy had prompted a need to make comprehensive care more widely available and some organisational changes are needed.

BLOOD PRODUCTS SUB-COMMITTEE

Throughout 1985 we maintained a close liaison with the Blood Products Laboratory at Elstree, and the committee visited the site to study progress with the new building.

All being well Elstree's new facility will start production this year (1986), with the capacity to produce a range of blood products – including at least 100 million units of Factor VIII and ample supplies of Factor 1X.

Despite the problems caused by the re-building programme the BPL was able to convert its Factor VIII production to heat-treated material, and later in the year introduced an improved Factor VIII (product VIII Y). A heat-treated Factor IX was also introduced.

The Society also kept in close contact with the pharmaceutical companies which supplied the UK with Factor VIII to meet the shortfall between our needs and NHS production. The companies were able to import large amounts of heat-treated Factor VIII at short notice after the decision was made to use only heat treated material.

After a fall in the amount of Factor VIII used in 1983, volume started to rise again . . . as it had done in every year for the past 15 years.

TREASURER'S REPORT

It is again reassuring to note the continued improvement in the Society's financial position, helped by a change in the way in which our main funds are now managed. This has resulted in an increase in our investment income.

We have been able to respond more easily to the increasing demands on our resources, not so much in the requests for direct financial help to members, but in the levels of service, etc, we have been able to supply to members and others.

It was most satisfying to be able to respond immediately to a request for a large grant to help fund AIDS research and the importance of our work in the dissemination of information on AIDS was recognised by a grant from the Department of Health & Social Security towards the additional costs we have incurred in that respect.

It is hoped that further improvements in our financial management, to be introduced during 1986, will enable us to maintain the increase in funding needed to meet our greatly increased work.

The Haemophilia Society

31st December 1985

Statement of Accounts

Report of the Auditors to the Guarantors 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 dependant 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 statments 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 1985 and of its profit and source application of funds for the year then ended and comply with the Companies Acts 1985.

TAYLOR, VINEY & MARLOW
Chartered Accountants,
1422 London Road,
Leigh-on-Sea,
Essex.

28th March 1985

The Haemophilia Society

Income and Expenditure Account year ended 31st December 1985

	Notes	1985	1984
Income	2	170894	91180
Administrative Expenses		110543	72055
Surplus of Income		60351	19125
Transfer to Benefit Fund		5000	4500
		55351	14625
Accumulated General Fund Brought Forward		(632)	15257
Accumulated General Fund carried forward		£547719	£(632)

The notes on pages 4 to 8 form part of these accounts.

The Haemophilia Society

Balance Sheet — as at — 31st December 1985

	Notes	1985	1984
Fixed Assets			
Tangible Assets:	5		
Office Equipment and Furniture		7536	1655
Current Assets			
Stocks	1	1500	3665
Debtors		2763	363
Cash at Bank and in Hand		163791	127219
		168054	131247
Creditors			
Amounts falling due within one year		49838	28858
Net current assets		118216	102389
Total assets less current liabilities		125752	104044
Creditors			
Amounts falling due after more than one year		—	—
		£125752	£104044
Reserves			
General Accumulated Fund		54719	(632)
Research Fund		70747	104248
Social Worker Fund		51	51
Benefit Fund		235	377
		£125752	£104044

The notes on pages 4 to 8 form part of these accounts.

The Haemophilia Society

Notes to the Accounts year ended 31st December 1985

1. Accounting Policies

Accounting Convention

The accounts are prepared under the historical cost convention on a going conern 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

This is after charging:	1985	1984
Audit and Accountancy Fees	575	345
Depreciation	1330	292
	£1905	£637

The Haemophilia Society

Notes to the Accounts year ended 31st December 1985

	1985	1984
4. **Staff Costs**		
Wages and Salaries	31908	20438
Social Security Costs	2792	2044

The average weekly number of employees during the year was 3 made up as follows:—

Office and Management — 3

5. Fixed Tangible Assets

	Office Equipment & Furniture
Cost or valuation as at 1st January 1985	1497
Additions	7211
As at 31st December 1985	9158
Depreciation brought forward	292
Depreciation for period	1330
As at 31st December 1985	1622
NET BOOK VALUE	£7536

The Haemophilia Society

Notes to the Accounts year ended 31st December 1985

		1985		1984
6. **Research Fund**				
Balance as at 1st January 1985		104248		87773
Add: Donations and sums received		3576		31990
		107824		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
Middlesex Hospital)	25725			
Public Health Laboratories Services)				
Royal Victoria Hospital Belfast	1170			
Royal Free Hospital London	357			
Glasgow Royal Infirmary	1999			
Bradford Royal Infirmary	3500			
Birmingham Childrens Hospital	4326			
		37077		
Balance as at 31st December 1985		£70747		£104248
7. **Social Worker Fund**				
Balance as at 1st January 1985		51		51
Balance as at 31st December 1985		£51		£51

Notes to the Accounts year ended 31st December 1985

	1985	1984
8. **Benefit Fund**		
Balance as at 1st January 1985	378	100
Add: Transfer from General Fund	5000	4500
	5378	4600
Deduct – Grants to Members	5143	4222
Balance as at 31st December 1985	£235	£378
9. **Debtors**		
Sundry Debtors and Prepaid Expenses	£2763	£363
10. **Creditors**		
Amounts falling due within one year:		
Sundry Creditors and Accrued Expenses	3227	2573
Research Fund Grants Payable	44951	23587
Other Taxes and Social Security Costs	1660	2698
	£49838	£28858

The Haemophilia Society

Source and Application of Funds Statement year ended 31st December 1985

	1985	1984
Source of Funds		
Surplus of Income on ordinary activities	60351	19125
Adjustment of items not involving the movement of funds:		
Depreciation	1330	292
Total generated from operations	61681	19417
Funds from other Sources		
Transfer of Assets from Haemophilia Society upon incorporation	—	72667
Total Funds Obtained	61681	92084
Applications of Funds		
Additions to Fixed Assets	7211	—
Funds Distributed	38643	12252
Funds Applied	45854	12252
Working Capital – increase/(decrease)	£15827	£104336
Change in Working Capital		
Funds introduced from Haemophilia Society upon incorporation	—	72667
Stock – (decrease)	(2165)	(147)
Debtors – increase/(decrease)	2400	(1439)
Creditors – (increase)/decrease	(20980)	10750
	(20745)	81831
Increase in Net Liquid Funds	36572	22505
Working Capital – increase	£15827	£104336

The Haemophilia Society
Income and Expenditure Account year ended 31st December 1985

Income		1985		1984
Subscriptions		7173		1053
Donations		121408		58196
Legacies Recived		5287		13171
Annual Draw		13008		9439
Interest Received		15250		8357
Sale of Badges, Books etc.		8768		964
		170894		91180
Deduct				
Expenditure				
Office Rent	3862		3300	
Rates and Water	1465		1439	
Light and Heat	682		546	
Lease of Office Equipment	4216		2387	
General Office Expenses	3029		4017	
Salaries and National Insurance	34700		22482	
Travelling	8285		6910	
Cost of Attendance at World Federartion of Haemophilia Congress	—		1343	
Appeal Expenses	6050		958	
Insurance	439		—	
Postage and Telephone	11449		5611	
Printing and Stationery	24109		13416	
Subscriptions and Donations to Affiliated Organisations	2115		1271	
Auditors Remuneration	575		345	
Publications	2903		1146	
Seminar Weekend	(528)		1673	
Meeting Expenses and Hall Hire	3562		3638	
Company Incorporation Costs	2300		—	
Book-keeping Expenses	—		281	
North Wales Group Holiday Project	—		1000	
Depreciation	1330		292	
		110543		72055
Excess of Income over Expenditure		60351		19125
Transfer to Benefit Fund		5000		4500
		£55351		£14625