Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392030

The Haemophilia Society

ANNUAL REPORT
1986

123 Westminster Bridge Road London SE1 7HR

ANNUAL REPORT
1986

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

General Secretary: David G. Watters, J.P.

Auditors: Taylor, Viney & Marlow, Leigh-on-Sea.

Solicitors: Paisner & Co., London

Bankers: National Westminster Bank PLC

What is Haemophilia?

Put simply, haemophilia is a heriditary 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 to 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 £500,000 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' was the dominant theme of the last Annual Report and it would be comforting if we were able to give priority to some other subject this year. Alas, that cannot be so. The work of the Society has been increasingly concerned with the way in which acquired immune deficiency syndrome has affected our members. Many are known to have been in contact with the human immunodeficiency virus (HIV) and are anxious about the long term implications of this side effect of their treatment for haemophilia. Others have developed AIDS itself and some have suffered the full, dire consequence of infection by the virus.

Much attention has been given to AIDS by national newspapers (sometimes sensationally) and the coverage on radio and television has been considerable. We have become accustomed to hearing startling news about AIDS regarding the number of people affected and its rapid spread in such areas as the United States of America and parts of Africa. A main responsibility of the Society has been in seeing that errors of fact are corrected and accurate information made available speedily to our members.

At the same time, we have been careful to preserve our own identity as a group among all others affected by AIDS, for people with haemophilia have special concerns. For instance, we have particular representations to make to those who are responsible for the supply and purity of the blood products which are essential for the well-being of our members. Again, there have been occasions when children at school have been treated adversely when it became known that they might have been in contact with the virus and we know that some employers have reacted against members of their staff in similar circumstances. We have acted in all such cases which have been brought to our attention and have sought opportunities to keep the Government informed about these distressing acts of discrimination, so that appropriate action might be taken to prevent their repetition.

Compensation

We have taken legal advice about the position of people with haemophilia who are known to be 'HIV antibody positive', an indication that they have been in contact with the virus. Many of those in this category experience serious disadvantages regarding employment, life insurance and mortgages, as well as in their general social relationships.

It is clear from the advice we have received from Counsel that there is no case that the Society can pursue on behalf of our members, either corporately or individually. As each individual's circumstances are different it would be necessary for them to discuss their particular position with a solicitor before it can be established whether it is worth pursuing such an action through the Courts. While we sought this advice generally, and not based on any particular set of personal circumstances, we have to say that, on present known facts and upon our judgment of the advice we have received, the prospect of the majority of claims succeeding is remote. There are two important reasons for this: the difficulty of proving negligence and the difficulty of identifying the proper body or person from whom compensation might be sought.

Meanwhile, we are continuing to present to the Government the very special needs of people with haemophilia with regard to such matters as life insurance and mortgages. We shall press for some special recompense for the benefit of our members who have been diagnosed as 'HIV positive'.

Communication

The HAEMOFACT leaflets are now well established as an effective means of providing accurate information as soon as it becomes available and THE BULLETIN, which is produced regularly, continues to be the other main publication. A high standard of presentation has been maintained and we record our appreciation of the work done by the editor, Mr Clive Knight, and all others associated with its production.

The sixth Annual Seminar was held in March 1986 and once again we returned to Bournemouth for this important event in our calendar. The number attending was restricted to 130 so that people were able to meet each other and share their interests and concerns, informally as well as in the small groups which were a central feature of the programmes. The theme of the Seminar was "Haemophilia and AIDS", and the Haemophilia Society lecture was given by Dr R S Lane, Director of the Blood Products Laboratory in Elstree, on the subject of self-sufficiency in blood products.

The financial support given by some of the Pharmaceutical Companies reduced the net cost of the Seminar. We are most grateful to them for their help and to Mrs Diane Daniel for arranging such an informative weekend.

The Executive Committee

The pressures on the Executive Committee increased very considerably indeed in the course of the year as we established the Society's policy on matters arising from the AIDS situation and sought to protect the interests of our members.

We saw the importance of our taking counsel together to determine the most effective way of using the time and resources available to us in fulfilling our responsibilities. This led to our withdrawing to a centre at St Ives, Cambridgeshire, for a short residential consultation, in which we fashioned our plans for the future work of the Executive Committee. Working parties were formed to concentrate on particular aspects of our work and the benefit of that historic weekend retreat is already evident in our improved efficiency in managing the Society's affairs.

The Groups

New members joining the Society are invited to make contact with the local Group near their homes. Those who take advantage of this opportunity to meet other members often find new friends, sharing common interests and offering mutual support in difficult times. The Groups have an essential part in the structure of the Society and their representatives attend meetings of the Council at which expenditure is discussed and policy decisions are confirmed. Many Groups promote fund-raising activities as part of their programme and so make substantial contributions to the Society's work. In 1986, in excess of £30,000 was raised by the Groups, which represents considerable time and effort invested by those members involved in these fund-raising projects.

Mr George Kirman was appointed as Group Liaison Officer during the year and brought to this new responsibility his characteristic vigour, commitment and forthright style.

The Office

For some time it had been recognised that the Society's office accommodation at Trinity Street was no longer adequate. After a prolonged search, new premises were found at 123 Westminster Bridge Road which, after some adaptation, proved to be suitable for our present purposes, providing sufficient space for the staff with a modest degree of comfort.

The Case Committee

Dr Ludwig Kuttner led the Case Committee in considering the increased number of applications for financial assistance made during the year. 107 applications were received of which 99 were considered to be cases qualifying for grants. All applications were considered with care and sympathy and help was given whenever possible. £10,351 were allocated in grants, compared with £5,143 for the previous year, indicating the substantial increase in the cases of need brought to the Society.

Blood Products

Mr Ken Milne continued to monitor the position regarding the supply of blood products, which remained similar to that in 1985. The main proportion of factor VIII concentrate was provided by imported materials and it seems that the situation is not likely to change until the new production facility at the Blood Products Laboratory, Elstree, is opened. This has been delayed but we now hope it will be during 1987.

A major concern during 1986 was to ensure that blood products used to treat people with haemophilia were now not only heat-treated but also derived from plasma donations individually screened, to exclude any containing the human immunodeficiency virus. All products now used in the United Kingdom are both screened and heat-treated.

Sales

The sale of fund-raising items has proved to be a profitable development, which has the added advantage of giving some publicity to the Society's name.

Mr Keith Colthorpe has been responsible for managing this department and his declared intention has been to "keep the quality high and the price low"! He has been successful in both respects.

The total sales have grown to a level where it seems feasible to produce a catalogue of the items available and this possibility is being studied carefully.

The Society also produced its own Christmas cards for the first time for several years, the local groups providing the main channel for their distribution. The profit from this venture was £1,000 and members appreciated this way of associating their Christmas greetings with a reference to the Society's work. Some of the Christmas cards were used by business houses and this potential market will be explored further in 1987.

The World Federation of Hemophilia

We have maintained our enthusiastic support for the World Federation of Hemophilia, which co-ordinates the activities of over sixty national organisations and acts as the centre of communication and inspiration for all concerned with haemophilia throughout the world.

The World Hemophilia AIDS Centre (WHAC) in Los Angeles, under the direction of Dr Shelby Dietrich, provides an immensely valuable service in collecting information and keeping all concerned informed about developments in research and treatment.

The Society was well represented at the WFH Congress in Milan, in June 1986, which was generally regarded as being of an exceptionally high medical and scientific standard, under the direction of Professor Pier Mannucci.

The International Hemophilia Training Centres Committee awarded a number of fellowships when it met in Milan. These fellowships allow doctors and scientists from developing countries to spend some time at one of the IHTC Centres to broaden their experience and develop their own understanding of haemophilia treatment and care.

Dr Kevin Rickard of Australia was appointed as the new Chairman of the IHTC Committee with Dr Peter Kernoff, from the Royal Free Hospital, London, as Secretary.

We record our gratitude to Mr Frank Schnabel, the Founder and President of the World Federation, for his unique contribution to the welfare of people with haemophilia throughout the world.

The Indian Hemophilia Federation

The first Haemophilia Centre in India was opened at the Lions' Hospital, New Delhi, after several delays, and its first patients were registered and treated. We receive regular news of the progress of the Indian Federation and we have fulfilled our intention of giving practical support by providing two essential items of equipment for the new Centre.

The Indian Federation is subsidising treatment for its members, some of whom are now receiving appropriate treatment for the first time in their lives. We also have good news of a second Centre, in Calcutta, which is now developing facilities for its patients. A regular news sheet is produced by the Calcutta Chapter of the Indian Hemophilia Federation.

Mrs Peggy Britten has been responsible for the collection and delivery of two consignments of medical supplies, at greatly reduced freight charges, the carriage being undertaken by a British Airways pilot who is the father of a boy with haemophilia. The first package contained filter and butterfly needles, supplied to us free by two Centres, and the second disposable syringes, bought by the Society. These supplies were shared between the new national Centre in New Delhi and the Centre in Calcutta.

We were also able to provide the living expenses of a doctor who spent a year in the United Kingdom in preparation for his work at a new centre in Trivandrum, Kerala. Dr N Krishnand Pai, from Trivandrum, worked for this period in the Haemophilia Centre of the Royal Free Hospital, London, the Edgware Blood Transfusion Centre and the Oxford Haemophilia Centre. He greatly enjoyed his time in the United Kingdom and we look forward to continuing our association when he returns to work in his own Centre.

The Co-ordinator

The Co-ordinator experienced a re-incarnation and emerged as the General Secretary, a title which describes more accurately his present position in the Society and the functions he performs.

He is responsible for the day-to-day administration of the Society's office and its staff, as well as for general communication with the Society's members by correspondence and telephone. In addition, he has special responsibilities in connection with Mobility and Attendance Allowances, often supporting members personally when they attend Appeal Tribunals.

With the particular pressures experienced by the Society at the present time, our debt to David Watters in incalculable and we record our gratitude to him for his deligence in managing the Society's affairs with such efficiency and good humour.

The Future

The future for people with haemophilia is not so clear as it has been in recent years when we were encouraged by successive developments in treatment and care. Now the shadow of AIDS hovers around us and we move forward into a future which is uncertain because unknown.

However, as we do so, we rely on that resilience and courage with which people with haemophilia generally confront adversity as it comes to them. The Society is a fellowship of all affected by haemophilia, so we renew our commitment to encourage and support each other as we look to the future with confidence and with hope.

THANK YOU

The Society wishes to thank the following donors for their generous support throughout 1986.

Corporate Donors

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Individuals who gave £50 or more

GRO-D

(Our thanks also go to all those who gave us donations of less than £50 – too many to name! – and to those who wish to remain anonymous.)

In Memoriam

We are grateful to the friends and relatives of those whose names appear below for remembering their friends through a donation to our work.

GRO-A

Bequests were received from the following estates:

GRO-A

Lastly, but by no means least, our own LOCAL GROUPS:

Birmingham · Cambridge · Colchester · Derby · East Kent · Hampshire · Jersey · Leicester Lewisham · Lincoln · Merseyside · Norfolk & Norwich · North Eastern · North Wales · North West · Northampton · Northern · Northern Ireland · Oxford · Scottish · Sheffield · South Essex · South Wales · Southern · Tayside and our Perth Charity Shop.

TREASURER'S REPORT

It is satisfying to note that the Society's income for the year passed the £200,000 mark for the first time. This, coupled with our financial policy in recent years, means that we were able to meet the extra expenditure involved in the move to our new offices and the inevitable higher costs involved in the running of the Society, without restricting in any way the help and support we were able to give directly to people with haemophilia.

The level of grants made for the purpose of various types of research was again at a high level and it was gratifying to be able to assist those projects without having any adverse effects on the increasing levels of other services we were able to provide for those with haemophilia and for those involved with all aspects of their welfare.

New systems of financial management were introduced at the end of the year and it is hoped that these will further improve the way our funds are handled and applied.

31st December 1986
Statement of Accounts

Report to 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 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 1986 and of its profit and source application of funds for the year then ended and comply with the Companies Act 1985.

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

16th April 1987

The Haemophilia Society

Income & Expenditure Account year ended 31st December 1986

	Notes	1986	1985
Income	2	205128	170894
Total Expenditure		175029	110543
Surplus of Income		30099	60351
Transfer to Benefit Fund		9800	5000
		20299	55351
Accumulated General Fund Brought Forward		54719	(632)
Accumulated General Fund Carried Forward		£75018	£54719

The notes on pages 19 to 22 form part of these accounts.

The Haemophilia Society

Balance Sheet — as at — 31st December 1986

	Notes	1986	1985
Fixed Assets			
Tangible Assets:	5		
Leasehold Property		5296	—
Improvements to Leasehold Property		8457	—
Office Equipment and Furniture		15235	7536
		28988	7536
Current Assets			
Stocks	1	6076	1500
Debtors		17600	2763
Cash at Bank and in Hand		121813	163791
		145489	168054
Creditors			
Amounts falling due within one year		75957	49838
Net Current Assets		69532	118216
Total assets less current liabilities		98520	125752
Creditors			
Amounts falling due after more than one year		—	—
		£98520	£125752
Reserves			
General Accumulated Fund		75018	54719
Research Fund		23299	70747
Social Worker Fund		51	51
Benefit Fund		152	235
		£98520	£125752

The notes on pages 19 to 22 form part of these accounts.

The Haemophilia Society

Notes to the Accounts year ended 31st December 1986

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:—

Leasehold Property	– over the term of the lease
Improvements to Leasehold Property	– over the term of the lease
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**	**1986**	**1985**
This is after charging:		
Audit and Accountancy Fees	750	575
Depreciation	9567	1330
	£10317	£1905

The Haemophilia Society

Notes to the Accounts year ended 31st December 1986

4. Staff Costs

	1986	1985
Wages and Salaries	38061	31908
Social Security Costs	3122	2792

The average weekly number of employees during the year was 4 made up as follows:

Office and Management — 4

5. Fixed Tangible Assets

	Leasehold Property	Improvements to Leasehold Property	Office Equipment & Furniture
Cost or valuation as at 1st January 1986	—	—	9158
Additions	7944	12687	10388
As at 31st December 1986	7944	12687	19546
Depreciation brought forward	—	—	1622
Depreciation for period	2648	4230	2689
As at 31st December 1986	2648	4230	4311
NET BOOK VALUE	5296	8457	15235

The Haemophilia Society

Notes to the Accounts year ended 31st December 1986

		1986		1985
6. **Research Fund**				
Balance as at 1st January 1986		70747		104248
Add: Donations and sums received		4447		3576
		75194		107824
Deduct				
Grants Paid and Payable:				
Royal Victoria Infirmary Newcastle	23877			
St. Thomas Hospital	14477			
Glasgow Royal Infirmary	8122			
Thanet District Hospital	3549			
Royal Victoria Hospital Belfast	1870			
		51895		
Middlesex Hospital Public Health Laboratories Services			25725	
Royal Victoria Hospital Belfast			1170	
Royal Free Hospital London			357	
Glasgow Royal Infirmary			1999	
Bradford Royal Infirmary			3500	
Birmingham Children's Hospital			4326	37077
Balance as at 31st December 1986		£23299		£70747
7. **Social Worker Fund**				
Balance as at 1st January 1986		51		51
Balance as at 31st December 1986		£51		£51

The Haemophilia Society

Notes to the Accounts year ended 31st December 1986

	1986	1985
8. **Benefit Fund**		
Balance as at 1st January 1986	235	378
Add: Transfer from General Fund	9800	5000
	10035	5378
Deduct		
Grants to Members	9883	5143
Balance as at 31st December 1986	£152	£235
9. **Debtors**		
Sundry Debtors and Prepaid Expenses	£17600	£2763
10.. **Creditors**		
Amounts falling due within one year:		
Sundry Creditors and Accrued Expenses	3484	3227
Research Fund Grants Payable	72473	44951
Other Taxes and Social Security Costs	—	1660
	£75957	£49838

The Haemophilia Society

Source and Application of Funds Statement year ended 31st December 1986

	1986	1985
Source of Funds		
Surplus of Income on Ordinary Activities	30099	60351
Adjustment for items not involving the movement of funds:		
Depreciation	9567	1330
Total generated from operations	39666	61681
Application of Funds		
Additions to Fixed Assets	31019	7211
Funds Distributed	57331	38643
Funds Applied	88350	45854
Working Capital – (decrease)/increase	£(48684)	£15827
Change in Working Capital		
Stock – increase/(decrease)	4576	(2165)
Debtors – increase	14837	2400
Creditors – (increase)	(26119)	(20980)
	(6706)	(20745)
(Decrease)/Increase in Net Liquid Funds	(41978)	36572
Working Capital – (decrease)/increase	£(48684)	£15827

The Haemophilia Society

Income and Expenditure Account year ended 31st December 1986

Income		**1986**		**1985**
Subscriptions		6838		7173
Donations		155963		121408
Legacies Received		7146		5287
Annual Draw		12933		13008
Interest Received		16866		15250
Sale of Badges, Books, etc.		5382		8768
Deduct		205128		170894
Expenditure				
Office Rent	6417		3862	
Rates and Water	3241		1465	
Light and Heat	856		682	
Lease of Office Equipment	9583		4216	
General Office Expenses	4575		3029	
Salaries and National Insurance	41183		34700	
Travelling	21430		8285	
Cost of Attendances at World Federation of Hemophilia Congress	456		—	
Appeal Expenses	21966		6050	
Insurance	756		439	
Postage and Telephone	13119		11449	
Printing and Stationery	15994		24109	
Subscriptions and Donations to Affiliated Organisations	1676		2115	
Audit and Accountancy Charges	750		575	
Publications	2924		2903	
Seminar Weekends	2423		(528)	
Meeting Expenses and Hall Hire	8381		3562	
Company Incorporation Costs	—		2300	
Indian Haemophilia Society Grant	8512		—	
Costs re. training grant	1220		—	
Depreciation	9567		1330	
		175029		110543
Excess of Income over Expenditure		30099		60351
Transfer to Benefit Fund		9800		5000
		£20299		£55351