Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392143

THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society
123 Westminster Bridge Road, London SE1 7HR
Telephone: 071-928 2020
Facsimile: 071-620 1416
Registered Charity No: 288260. A company registered in England and limited by guarantee. Registered Company No: 1763614

THE HAEMOPHILIA SOCIETY

ANNUAL REPORT AND ACCOUNTS 1992

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The Rev Prebendary A J Tanner, MA

VICE CHAIRMEN
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Mr R A Cowe MBA

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Mr N S Lawson F Inst D

ACTING TREASURER (from November 1992)
Mr G Clarke (from June 1992)

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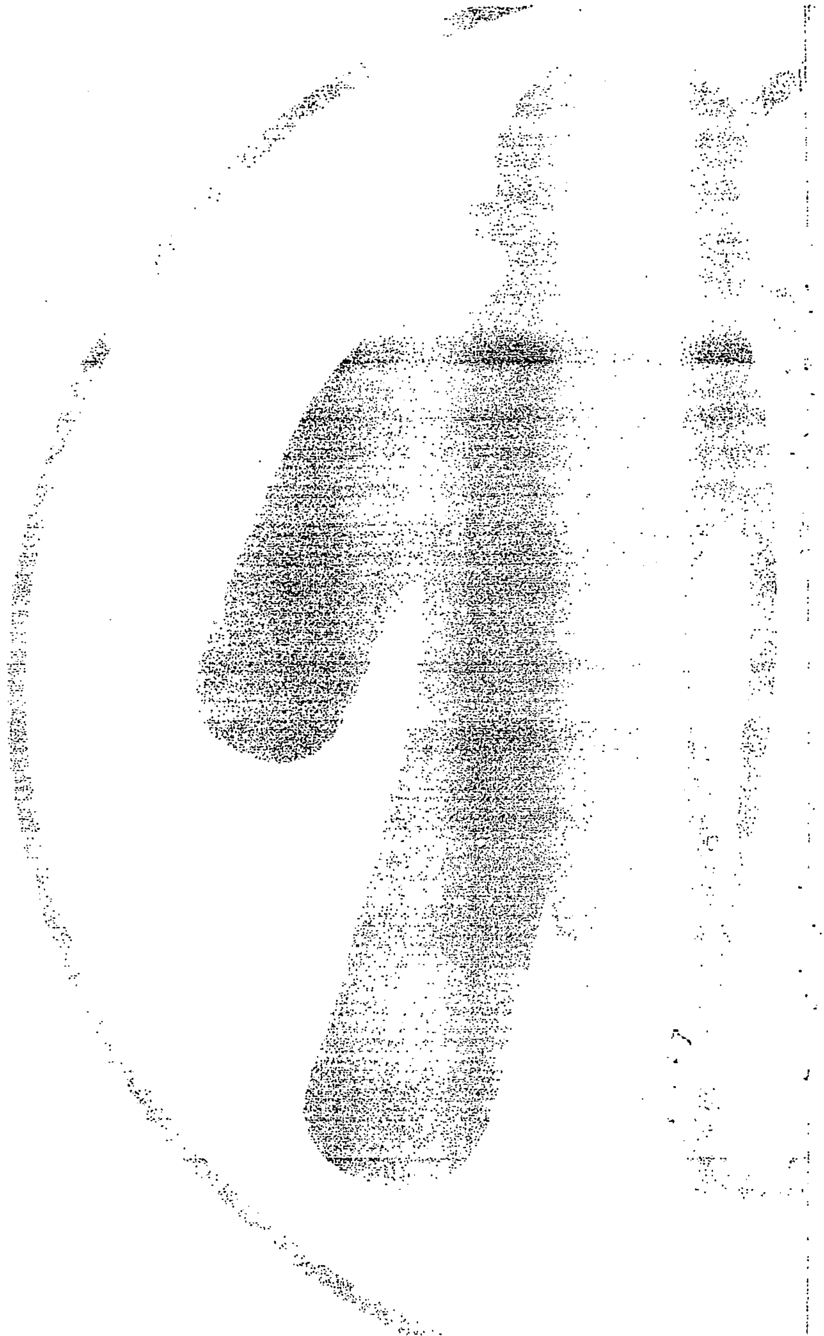
Mr R Dickason
Professor L F Evans (from June 1992)
Mrs N Guy
Mrs C Hazlewood (until April 1992)
Mrs J Hodgson
Mr J Lander
Mr S Taylor
Dr [redacted] (until June 1992)

GENERAL SECRETARY
Mr D G Watters JP



DONORS DURING 1992

Agfa Gavaert Ltd
Air Canada
Air Seychelles
Alfred Dunhill Ltd
Allied Distillers Ltd
Argos
Arjo Wiggins Appleton
Bentalls
C & J Clark Ltd
Chef & Brewer Group
Coats Viyella
Del Monte Foods International
Fortnum & Mason Plc
Harrods
John Lewis Partnership
John Menzies
Johnson Wax Ltd
Marks & Spencer
Martini & Rossi
McDonald's
Metro Goldwyn Mayer
Michael Butler Leather Goods
Olau-Line (UK) Ltd
Parfums Christian Dior UK Ltd
Pearson
Pentax
Pizza Hut (UK) Ltd
Reader's Digest Trust
Sainsbury's
Schweppes Great Britain
Taunton Cider Company
Tesco Charity Trust
Thorn EMI
Thorntons plc
Time-Life International Ltd
Virgin Atlantic
Wedgwood & Sons Ltd
Wella Great Britain
Whitbread plc
Yardley Lentheric Group
29th May 1961 Charity
Abbey Life
AIB Bank
Alchemy Foundation
Aldwyns Trust
Andrew Anderson Trust
APV plc
John M Archer Charitable Trust
Associated British Ports
Andrew Balint Charitable Trust
Bank of Scotland
Barclays Bank plc
Paul Bassham Charitable Trust
Benfield Motors Charitable Trust
Benham Charitable Settlement
Gerald Bentall Charitable Trust
Birkin Group
Sydney Black Charitable Trust
Sir Arthur Black Trust
Lady Blakenham's Charity Trust
Blankstone Sington Ltd
Celia Bonham Christie
Boots Charitable Trust
C T Bowring (Charities Fund)
Brand Trust
Jan Branford Charitable Trust
Bridon Group Charitable Trust
British Steel plc
British Tissues
Britvic Soft Drinks
Brixton Estate plc
Edward Cadbury Charitable Trust
Calor Group Plc
Cape plc
Capel-Cure Myers
Sir Andrew Carnwath's Charitable Trust
Carroll-Marx Charitable Foundation
Chaircraft (Wholesale) Ltd
Chandris Foundation
George Henry Collins Charity
Colonial Mutual Group
Commercial Union plc
Compaq Computer Group Ltd
Courage
Coutts Charitable Trust
Credit Suisse Asset Management Ltd
Dalgety plc
J Davies Charities Ltd
De Clermont Charitable Company Ltd
Helen and Geoffrey De Freitas Charitable Trust
Emma De Yong Charitable Trust
Delta plc
Digital Equipment Co Ltd
Dominion Insurance Company Ltd
Dowager Countess Eleanor Peel Trust
Druck Ltd
Eagle Star
Gilbert & Eileen Edgar Foundation
Electolux Ltd
Electra Kingsway Ltd
Emilienne Charitable Trust
Emmandjay Trust
Esselte Letraset Ltd
Douglas Heath Eves Charitable Trust
Express Newspapers plc
Fenwick Ltd
Fisco Products Ltd
Fitton Trust
Freemasons' Grand Charity
General Accident
Mrs M M Gill's Charitable Trust
Girobank plc
Gleeson
Glynwed Charitable Trust
Godinton Charitable Trust
D. W. Greenwood Charitable
Guardian Royal Exchange Charitable Trust
Guinness plc
Alfred Haines Charitable Trust
Harris & Sheldon Group Ltd
Henderson Administration Group plc
Antony Hornby Charitable Trust
Hospital Saturday Fund Charitable Trust
Howard Charitable Trust
Hunting Group Charitable Trust
IMI plc
Inchcape Charitable Trust Fund
Inverforth Charitable Trust
J Bibby & Sons plc
James Beattie plc
Johnson & Firth Brown plc
Johnston Group plc
JTH Charitable Trust
A R & J S Julius Charitable Trust
Kleinwort Benson Charitable Trust
Christopher Laing Foundation
Beatrice Laing Trust
R & J Lass Charities Ltd
Lawson International
Edgar Lee Foundation
LEP International
Lewis Family Charitiable Trust
Lloyds Bank Charitable Trust
Lloyd's Charities Trust
London & Manchester Group plc
Longley Trust
Low & Bonar Charitable Fund
Joseph Lucas Charitable Trust Ltd
M N A
Marsh Christian Trust
Matthews Wrightson Charity Trust
MEPC plc
MG Owners' Club
Michelin Tyre plc
Millichope Foundation
Minaar Imports Ltd
Misselbrook & Weston Ltd
Morrison Bowmore Distillers
Morton Charitable Trust
Multitone Electronics plc
Murphy-Neumann Charity Co Ltd
Newage International Ltd
News International plc
NFC Plc
Nicholas Charitable Trust
Norton Abrasives
Norwich Union Insurance Group
Onneley Trust
Ormonde Charitable Trust
P & E Leboff Charitable Trust
P F Charitable Trust
Paravicini-Dyer Charitable Trust
Pearl Assurance plc
Pfizer
A M Pilkington's Charitable Trust
F C Pollard Charitable Trust
Portrack Charitable Trust
Provident Life
Prudential Corporation
Rainford Trust
Christopher H R Reeves Charitable Trust
Refuge Assurance plc
Robert Fleming Holdings Ltd
Rover Group Ltd
Royal London Insurance
Sanford Charitable Trust
Silentnight Holdings plc
Simon's Charity
Wm. Sinclair & Sons (Stationers) Ltd
N. Smith Charitable Settlement
Smiths Industries plc
Smith's Charity
Sobell Foundation
Sovereign Health Care
St Katherine's Fund
Stapylton Charitable Trust
Mrs Gabrielle M Sugden-Wilson's
Sun Alliance Group
Swiss Pioneer Life plc
Charles & Elsie Sykes Trust
Thomas French & Sons plc
Thomas Tunnock Ltd
Sir Jules Thorn Charitable Trust
Travis Perkins
Douglas Turner Trust
University of Surrey
Vandervell Foundation
W A Handley Charity Trust
W.E.D. Trust
Peter Wakefield Charitable Trust
Weinstock Fund
James Weir Foundation
Welconstruct Trust
Wesleyan
Lois West-Russell Charitable Trust
Simon Whitbread Charitable
Whitbread plc
Willis Corroon Group plc
Maurice Wohl Charitable Trust
G M Wolfe Family Charit. Trust
Wolseley plc
Worshipful Company of Carmen
Worshipful Company of Carpenters
Worshipful Company of Coopers
Worshipful Company of Drapers
Worshipful Company of Fan Makers
Worshipful Company of Haberdashers

BALANCE SHEET AT 31st DECEMBER 1992

		1992	
		£	£
FIXED ASSETS			39,160
CURRENT ASSETS	Debtors	18,560	
	Cash at bank & in hand	99,312	
		117,872	
CREDITORS Amounts falling due within one year		(72,078)	
NET CURRENT ASSETS			45,794
			84,954
FUNDS	General Accumulated Fund		67,792
	Group Funds		17,162
			84,954

INCOME AND EXPENDITURE ACCOUNT FOR YEAR ENDED 31st DECEMBER 1992

		1992	
		£	£
INCOME	Donations		302,864
	Legacies		174,622
	Voluntary Income		**477,486**
	Services and Goods		12,570
	Grants Receivable		23,000
	Interest Receivable		8,713
			521,769
EXPENDITURE	Member Services	214,000	
	Policy and Development	86,674	
	Organisation and Resources	196,469	
			(497,143)
INCOME LESS EXPENDITURE			**24,626**

Accounts audited by Dodson Lifford Hall, Greengate House, 87 Pickwick Road, Corsham, Wiltshire SN13 9BY. A full set of accounts is available upon application to the Haemophilia Society

Alan Tanner *Chairman*

GRO-C

CHAIRMAN'S STATEMENT

In this report we record new developments in the work of the Society and are particularly pleased to give the good news that the financial position has been stabilised

We entered 1992 realising that we were carrying a financial deficit due largely to the effects of the recession, an experience shared by the majority of voluntary organisations. We were aware of the need to restrict our expenditure and consolidate the organisation so that we could "weather the storm" without allowing the support we provide for our members to be at risk. In that endeavour, the Society has been markedly successful and, at the end of the year, we were able to report that the tide had turned. We finished the year showing a small surplus in the accounts.

That significant achievement was a sign of the strength of the Society not least because, during those critical days, the established service provided for our members was maintained.

At the same time the work of the Strategic planning process was developed and we monitored carefully the way in which changes in the provision of the National Health Service might affect people with haemophilia. Our discussions with the Government Ministers concerned have borne fruit. We expect the present facilities for haemophilia care to be preserved, although we shall be vigilant and take appropriate action if the wellbeing of people with haemophilia seems to be threatened.

I take this opportunity to express our gratitude to all who have supported our work during the year. We are indebted to our generous supporters and to all who are involved professionally in the treatment and care of haemophilia.

I add a special word of appreciation for the support of my peers, the officers and other members of the Executive Committee, who bring to their work a wide variety of skills and experience and a commitment to our cause which has enabled the Society to emerge from the difficulties we have experienced. At the same time I recognise the dedication and efficiency of the General Secretary and the members of his staff who continue to provide such outstanding services to us all.

The Society is poised to meet the challenges of the years ahead and I am proud to be associated with an organisation which is so resilient and effective in helping to meet the needs of our members.

A REVIEW OF THE YEAR

In 1992 the Society faced the greatest of challenges - that of survival. Our 1991 financial outcome was disheartening. Transforming a huge deficit into a surplus, while retaining our services to people with haemophilia, was central to our thinking during the year. We were able to reduce our expenditure by making stringent economies. In addition our income rose significantly, largely as a result of an increase in legacy income but also due to the sterling efforts of many of our members and friends.

Our Members

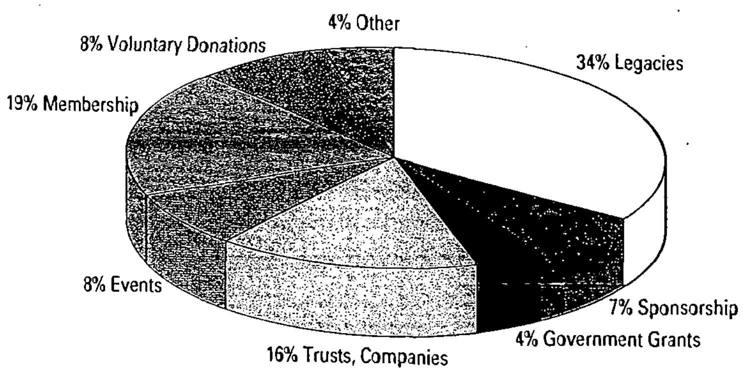
The prime purpose of the Society is to care for people with haemophilia and their families. At the time of writing membership has just reached 4,500, the highest ever, and our services are needed as never before. The introduction of the Disability Living Allowance has not eased access to Social Security benefits – indeed there are more demands than ever on our limited resources to assist members with financial applications and appeals. We help directly wherever we can and continue to administer the Armourpage scheme making pagers available to the parents of children under 16 years who have haemophilia.

As our Strategic Plan begins to unfold we hope to be able to launch new services in future years - services which have been researched and requested by our members in response to their own needs. Those developments will require major funding and we rely very much on our friends, members and supporters to help get them on the road.

Local Groups have an increasingly important role to play in helping the national office identify and respond to needs and we are actively recruiting volunteers to help identify local problems in haemophilia health care in areas not covered by Groups. Our publications - The Bulletin and Update - continue to be widely distributed to our members, overseas and to Haemophilia Centres and during the year we have worked hard to improve their image and make them more reader friendly and accessible.

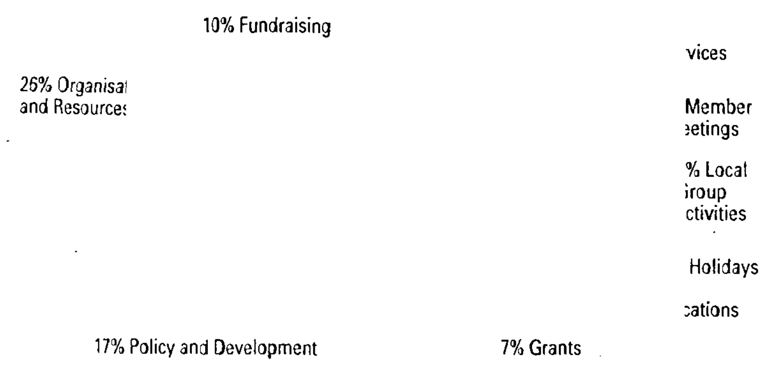
Strategic Planning

In 1992 work on Strategic planning, which began in Autumn 1991, progressed to the stage where we were able to produce a Strategic plan for the next two years. This identified four specific areas of work:-
* Identifying the needs of members
* Monitoring and influencing local care for people with haemophilia
* Developing new services to meet the identified needs, and
* Developing the membership of the Society.



1992 INCOME

Legacies	34%	174,622
Sponsorship	7%	34,304
Government Grants	4%	23,000
Trusts, Companies	16%	83,027
Events	8%	42,740
Membership	19%	101,470
Voluntary Donations	8%	42,279
Other	4%	20,327
TOTAL		**521,769**
Other income		
Interest	8,713	
Fees	4,504	
Sales	2,085	
Philip Morris Award	5,025	
TOTAL	**20,327**	



1992 EXPENDITURE

Member Services	16%	81,975
Member Meetings	7%	35,967
Local Group activities	5%	22,417
Adventure holidays	5%	24,525
Publications	7%	35,409
Grants	7%	32,601
Policy and Development	17%	84,206
Organisation and Resources	26%	128,471
Fundraising	10%	51,572
TOTAL		**497,143**

TREASURER'S STATEMENT

It was my pleasure to assume the role of Acting Treasurer during the year when, because of family illness, it was no longer possible for Nicholas Lawson to give the necessary degree of attention to the task of Treasurer.

It is gratifying to record that a sizeable deficit in 1991 was transformed into a modest surplus in 1992. However the Society lacks investments and investment income and it remains a long term goal to be able to establish this base of financial security from which we can operate as responsible Trustees and employers.

On behalf of my fellow Trustees I express gratitude to our auditors and to Susan Archer, our Resources Manager, who looks after our day by day detail with care and diligence.

Gordon Clarke *Acting Treasurer* GRO-C

We were assisted by the Compass Partnership and a small but effective and committed group of Executive Committee, council and staff. During 1993 we will be carrying out the work identified in the four headings through contact with members and local Groups.

Strategic planning holds the key to the future of the Society, our understanding of the problems faced by members and the development of services to find solutions. It is of the very greatest importance that we dedicate ourselves to pursuing these goals so we can secure a better future by caring for people with haemophilia.

Local Groups

Our Groups continued to play an important part during the year. Some help us raise large sums of money for local and national purposes and others offer support to individuals and monitor local services. In 1992 we spent more time than usual with them through local and regional seminars. These enabled us to learn from local experiences and encouraged local Groups to gather strength from others working locally and nationally.

Haemophilia Days

An important concept developed throughout the country in 1992 was Local Haemophilia Days. The pilot events in Huddersfield in 1991 and in Newcastle, Waltham Abbey and Doncaster in 1992 allowed us to bring together around 80 people on each occasion to share the latest knowledge of haemophilia and on haemophilia and HIV. Experts and small groups discussed topics including treatments, life with HIV, children and HIV, physiotherapy and welfare benefits.

These days were richly worthwhile; many friendships were formed and it was good to provide an environment in which people could meet with others and share problems, often for the first time. The future of Haemophilia Days and local Group training events is dependent on continued sponsorship.

Hepatitis

As we reported in our Review of 1991 the large numbers of hepatitis infections in the past was a source of major concern. There have been no new infections since 1986/7 but it remains important to ensure that blood products used in the UK are safe from hepatitis in all its forms.

Important work is being carried out on treatment with Interferon and the future could be brighter for some of those infected, although unfortunately some have already died. Our role continues to be keeping everyone up to date with developments surrounding hepatitis.

The Health Service Changes

We have continued to monitor the influence of National Health Service changes on the treatment and care of people with haemophilia. It has become increasingly clear that in a cash-led health care structure, cost becomes the governing factor with safety, purity and adequacy of supply left in the margins. This is clearly worrying and we face the future with a degree of uncertainty. We are however firmly committed to securing an adequate supply of safe, pure products from a variety of sources in the United Kingdom.

During the year the UK Haemophilia Centre Directors' Organisation published their Recommendations on Therapeutic Products and we were delighted with their endorsement of high purity products. We are pleased that liaison between the Directors' Organisation and the Society has continued to improve throughout the year.

The restriction on the use of earmarked AIDS funds to pay for high purity factor VIII for HIV positive members was a great concern for us in 1992. In the light of scientific evidence it was clear that this was detrimental to the health of our people. After an intensive campaign, in which we were joined by the Haemophilia Centre Directors, the Chief Medical Officer accepted the evidence was there to support this. This was a significant victory in the face of growing opposition from those concerned with health finance.

We have worked closely with the Department of Health throughout the year and as a result the Health Circular governing the treatment and care of haemophilia is being revised. This document will give guidance on the standards of care required at Centres and on aspects of contracts which form the groundwork of the new-look Health Service. We draw great encouragement from our participation in these important developments which will maintain standards of care by specifying in contracts the exact nature of the service to be provided.

European Haemophilia Consortium

The UK Society continued to provide the Secretariat for the European Haemophilia Consortium (EHC) and during 1992 meetings were held in Dublin and Athens. Our concerns remained the safety and purity of blood products within the community coupled with an adequate supply to ensure people with the condition enjoy a markedly improved quality of life.

Self sufficiency as a long term goal is desirable for any community but within the European Community there is a reliance of 50 per cent on imported blood products. That shortfall cannot be met overnight and there are still low levels of treatment in some member states. Some self-sufficient countries within the Community are experiencing problems with HIV and hepatitis from home-sourced plasma.

The EHC has continued to achieve new frontiers in the treatment and care of people with haemophilia in countries such as Poland, Slovakia, the Czech Republic, Hungary and the states of former Jugoslavia. As a member of the Consortium we have been pleased to offer support to people with haemophilia infected with HIV in Denmark, Belgium, Portugal and the Netherlands who had not achieved appropriate levels of compensation. The situation in Denmark has been resolved but we are anxious to see fair recognition for those people with haemophilia infected with HIV in the other EC states.

World Federation of Hemophilia

The UK Society continued to play a major role in the World Federation of Hemophilia in 1992 with our chairman, Revd Prebendary Alan Tanner, unanimously elected as Federation Chairman at the XX Congress in Athens in October. The General Secretary, David Watters, was also elected to the Council of the Federation for four years and members of the Executive Committee are developing the Federation's Decade Plan - their Strategic Planning process.

THE FUTURE

People with haemophilia have never needed a Society more than today. The changes in the Health Service require a constant vigilance which cannot only come from doctors or those receiving care. The onward sweep of scientific advances in developing new, purer products, the realisation of the dream of synthetic (recombinant) products and with the prospect of gene therapy around the corner it might be thought that our days are numbered.

Nothing could be further from the truth. Life for people with haemophilia is fraught with problems and the pathway is strewn with obstacles which demand the presence of an active and healthy organisation geared to representing the interests of people with haemophilia on a daily basis.

Our high profile days in campaigning to secure compensation for those infected with HIV may be over, but the need for our services by the haemophilia population has never been greater. We look forward to your continued support so we can continue to meet the unique and particular needs of people with haemophilia, securing for them an improved quality of life.

GRO-C

David G Watters *General Secretary*