Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

# INFECTED BLOOD INQUIRY

# WITN6392038

## **CHARITY NUMBER: 288260 COMPANY NUMBER: 1763614**

THE HAEMOPHILIA SOCIETY (A COMPANY LIMITED BY GUARANTEE) **REPORT AND FINANCIAL STATEMENTS** FOR THE YEAR ENDED **31 DECEMBER 2001** 



28/08/02

# HORWATH **CLARK WHITEHILL**

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Chartered Accountants A member of Horwath International

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# THE HAEMOPHILIA SOCIETY INDEX TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2001

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# GENERAL INFORMATION

# FOR THE YEAR ENDED 31 DECEMBER 2001

PATRON	HRH Duchess of Kent
PRESIDENT	The Rt. Hon. The Lord Morris of Manchester PC AO QSO
VICE PRESIDENTS	Rt. Hon Frank Field MP Rt. Hon Sir Geoffrey Johnson Smith DL MP Professor G I C Ingram MD FRCP The Reverend Alan Tanner OBE Dr Peter Jones Professor the Lord Winston Baroness Masham of Ilton DL
	Karin Pappenheim
TRUSTEES	Chris Hodgson (Chairman)
	Philip Dolan (Vice Chairman to 23 June 2001, elected 23 June 2001) Keith Colthorpe (Vice Chairman to 23 June 2001) Simon Taylor (Treasurer) GRO-A Ian Hayes (co-opted 29 November 2001) George Levvy (co-opted 23 June 2001) Rona Macdonald (elected 23 June 2001) Pat McAughey (retired 23 June 2001) Carolyn McGimpsey Alex Susman-Shaw (appointed Vice Chair 23 June 2001) Roderick Morrison (elected 23 June 2001)
SUB COMMITTEES	
Resources Sub Committee	Simon Taylor (Chair) Chris Hodgson Keith Colthorpe Roderick Morrison
Health Sub Committee	Alex Susman-Shaw (Chair) GRO-A Philip Dolan Nigel Hamilton Chris Harrington (co-opted) Dr Ian Hann (co-opted) Dr Has Dasani/Dr Peter Collins (co-opted) Dr Paul Giangrande (co-opted) Dr Brian Colvin (co-opted)
Information and communication	s Sub Committee
	Rona Macdonald (Chair) GRO-A Keith Colthorpe

Keith Colthorpe Nigel Hamilton Carolyn McGimpsey

## GENERAL INFORMATION

## FOR THE YEAR ENDED 31 DECEMBER 2001

## MEDICAL ADVISORY PANEL

## Haemophilia:

- Dr Brian Colvin, MRCP FRCPath, Senior Lecturer in haematology, The London Hospital
- Dr Mark Smith, , MB ChB FRACP FRCPA, Consultant Haematologist, St Thomas' Hospital
- Prof. Christine Lee, MA MD FRCP DRc (Med) FRCPath, Consultant Haematologist/Haemophilia Centre Director Royal Free Hospital NHS Trust
- Dr Mark Winter, FRCP FRCPath, Haemophilia Centre Director, Kent and Canterbury Hospital
- Dr Mike Makris, , MA MBBS MD MRCP MRCPath, Consultant Haematologist, Sheffield
- Dr Peter Collins, MRCP MD MRCPath, Consultant Haematologist, Cardiff
- Dr Isabel Walker, MD FRCP FRCPath, Consultant Haematologist & co-director of Haemophilia Department, Glasgow Royal Infirmary
- Dr Paul Giangrande, BSc MD FRCP FRCPath FRCPCH , Consultant Haematologist, Oxford

#### Nursing:

• Kate Khair, MSC, SRN RSCN, Clinical Nurse Specialist for Haemophilia, Great Ormond Street

#### Orthopaedics:

- Professor Learmonth MBCHB, FRCS (ED) FRCS (ENG) FRCS (SA) Orth, Head of Department of Orthopaedics, Bristol
- Christopher Dodd, FRCS, Consultant Orthopaedic Surgeon, Nuffield Orthopaedic Centre

## Hepatology:

- Dr G Alexander, Consultant Hepatologist (Addenbrooke's Hospital, Cambridge)
- Dr G Foster, PhD FRCP, Consultant Hepatologist and Reader in Hepatology (St Mary's Hospital, London)

## Physiotherapy:

 Brenda Buzzard, SRP MSc Post Grad Dip MCSP, Superintendent Physiotherapist, Newcastle Royal Infirmary

# **GENERAL INFORMATION**

# FOR THE YEAR ENDED 31 DECEMBER 2001

SECRETARY	Karin Pappenheim
REGISTERED OFFICE	Chesterfield House 385 Euston Road London NW1 3AU
COMPANY REGISTRATION NUMBER	1763614
CHARITY REGISTRATION NUMBER	288260
BANKERS	The Co-operative Bank Plc Olympic House 6 Olympic Court Montford Street Salford M5 2QP
SOLICITORS	Farrer and Co 66 Lincoln's Inn Fields London

AUDITORS

Horwath Clark Whitehill 25 New Street Square London EC4A 3LN

WC2A 3LH

## TRUSTEES' REPORT

#### FOR THE YEAR ENDED 31 DECEMBER 2001

The Trustees present their report and financial statements of the charity for the year ending 31 December 2001. The financial statements have been prepared in accordance with the accounting policies set out on pages 15 and 16 and comply with the charity's trust deed and applicable law.

## CONSTITUTION AND OBJECTIVES

The Haemophilia Society is constituted as a company limited by guarantee, number 1763614, under Memorandum and Articles of Association dated 21 October 1983, and registered as a charity on 30 November 1983, charity number 288260.

Among the primary objects of the charity are to provide information and advice on haemophilia and related disorders, to provide assistance and represent the interest of families with haemophilia and to advance knowledge and awareness of haemophilia.

The mission as currently defined by the Trustees is to ensure that people with haemophilia and related disorders and their families receive the best possible treatment, care and support. This is achieved through the provision of information, advice, support and advocacy services by the Society and through seeking to promote best practice in health and social care for people with bleeding disorders.

## ORGANISATION AND DECISION MAKING STRUCTURE

The Society is governed by a board of 12 Trustees, ten of whom are directly elected by the members, and two of whom are co-opted by the board itself to meet particular skills requirements. The board appoints from within its members a treasurer and up to two vice chairmen. The chairman is elected for a three year term of office; all other elected Trustees retire by rotation with a third either retiring or standing for re-election each year. After six years continuous service Trustees are required to retire. Those Trustees who have served during the year are listed on page 1.

Trustees meet at least six times a year as a board, in addition to which there are three sub committees of the board to consider resources, health and information/communications. Sub committees meet between board meetings and report back.

The Society has also formed a Medical Advisory Panel, whose members are listed on page 2, to advise Trustees and staff on important medical issues.

Day to day management of the Society is delegated to the Chief Executive who manages the staff team of 12, reporting regularly to Trustees. The Chief Executive also serves as company secretary.

The Society is a membership organisation with current membership standing at 2702. In certain localities members are organised into local branches of the Society. There are currently 21 local groups (branches) of the Society. Groups are kept in regular contact with Trustees and staff of the national charity by means of twice yearly meetings and quarterly information mailings.

#### PRINCIPLE ACTIVITIES AND BUSINESS REVIEW

2001 was a very eventful year for the Society in achieving our goals of raising the profile of haemophilia and related bleeding disorders and reaching out to every one of the 13,500 affected people and their families in the UK. Thanks to increased publicity and marketing, and the high profile GMTV fundraising effort, we saw a 46% increase in requests for information and advice and rising numbers of members. In a year dominated by shortages of recombinant and worries about vCJD and product safety, there was much demand for the Society's information, advice and support services.

## TRUSTEES' REPORT

## FOR THE YEAR ENDED 31 DECEMBER 2001

## NEW PROJECTS AND SERVICE DEVELOPMENTS

The Society's services and activities include:

- Publications, website and a resources centre, including a quarterly information newsletter distributed to over 4,000 people
- Specialist advice and support through a freephone telephone helpline, receiving over 5000 calls in 2001
- Pager scheme for approximately 800 parents with children affected by haemophilia
- Events throughout the UK to provide opportunities for people to share their experiences in 2001 12 events were held, varying from a weekend event for young people affected by haemophilia and HIV to small local information events around the country
- 21 local self-help groups and support groups for parents, people with HIV and hepatitis C
- Holiday schemes and other activities for over 60 children and young people annually
- An active campaigning, advocacy and public education role

Throughout the year the Society's 0800 helpline continued to provide information and advice on all aspects of living with haemophilia. This was particularly necessary during the recombinant shortage and following the news that some plasma products had been manufactured from plasma donated by a person with vCJD. Calls to the helpline are carefully monitored; and over the year steps were taken to improve quality standards with a view to securing accreditation from the Telephone Helplines Association in 2002.

Information and education for the patient group was also provided throughout the year at a series of events held in different parts of the UK. Evening meetings on haemophilia were held in Hull, Cambridge and Bristol, each addressed by an expert medical speaker and representatives of the Society, with audiences of between 20 to 40 people. The Society's national conference and AGM in Solihull on the theme of achieving best quality care was highly successful, attended by 170 adults and 57 children.

Meeting the special needs of those affected by HIV and hepatitis was a priority in 2001. Thanks to funding from the Department of Health, and a number of trust and corporate supporters, the Society was able to undertake pioneering work to address the particular treatment challenge posed by HIV/HCV co-infection and the psycho-social support needs of those with hepatitis.

In May, the Society organised the first national seminar for professionals on HIV/HCV co-infection attended by 122 delegates. A particular success was the involvement throughout the planning of this event of affected people, a number of whom attended and spoke at the seminar. Some 800 copies of the conference report were distributed later in the year. This initiative will be followed up in 2002 with a series of local co-infection information evenings around the country.

With support from the Elton John AIDS Foundation and Pilgrim Trust, the Society continued work to support young people with haemophilia who are co-infected with HIV/HCV. Following the successful youth weekend in 2000, a similar event was held in Manchester in 2001.

The Society also organised hepatitis information evenings in Exeter, Shrewsbury and Belfast (funded by the Northern Ireland Department of Health and Social Services) in 2001 providing an opportunity for affected people to hear expert speakers on the latest treatment.

A first in 2001 was the weekend event Living with Hepatitis held in Hothorpe Hall in September and attended by 70. This was especially designed to address psycho-social issues, and involved a large input from the Society's self management tutors. The event also formed part of the Department of Health funded project to address the counselling needs of people with HCV.

With support from the Roald Dahl Foundation, the self management programme developed still further over the year with the addition of a fourth specially trained tutor. The Society's pioneering work in self management in partnership with the LMCA and other patient groups has been recognised by

## TRUSTEES' REPORT

#### FOR THE YEAR ENDED 31 DECEMBER 2001

government within its expert patient programme, and this approach is now to be delivered in primary health care.

In 2002 the Society's self management tutors will continue to offer courses in eight locations around the country, again in collaboration with MS Society and other patient groups.

Another significant development in 2001 was the establishment of a Scottish base for the Society in Glasgow and appointment of a development officer for Scotland. With funding from the Community Fund (Scotland) and Scottish Executive, the development worker will lead a three year project to meet the needs of people with haemophilia in Scotland.

## PUBLICATIONS

A key role of the Society is to produce information and education publications for affected people and their families. Our aim throughout the year was to continue to improve the quality and accessibility of our publications. The achievements for 2001 were:

- Redesign of the Society's popular quarterly newsletter which is distributed to subscribers on our database, through haemophilia centres and via the website. In 2002 the publication will be relaunched with a new name, HQ (Haemophilia Quarterly) and it is planned to produce a separate supplement for young people.
- Fact sheets on orthopaedics, issues for carriers of haemophilia, travel and insurance, employment and benefits were prepared and made available via the website as well as directly in response to inquiries. Other fact sheets on hepatitis and HIV/HCV co-infection topics were also prepared.
- Introduction to Haemophilia, a general booklet explaining diagnosis, inheritance patterns, treatment and other key issues was produced with expert medical advisors and input from affected people. It is available both in hard copy and as a PDF file on the website.
- A guide for women living with von Willebrands was published in March as the first initiative in the Society's programme of work for women affected by bleeding disorder.
- Meeting the Challenge, a general information booklet for those affected by hepatitis C was
  published in February and some 3000 have been distributed during the year.

#### **ORGANISATION DEVELOPMENTS**

#### Goals for 2001

- To increase the involvement and participation of people with haemophilia and von Willebrand's both as individual members and groups
- To increase awareness of haemophilia amongst politicians, the health service, general public and funders
- To sustain, diversify and increase our funding base
- To continue to improve and develop our range of services for people with haemophilia and von Willebrand's
- To play a full role in the international haemophilia community through the European Haemophilia Consortium and World Federation of Hemophilia
- To be a powerful voice and influence to advocate on behalf of people with haemophilia and related bleeding disorders

Staff development continues to be an important priority of the Society, and in addition to providing a range of training opportunities for the staff team, Trustees carried out a salary policy review with the advice of external personnel consultant John Burnell. This involved a benchmarking exercise comparing the Society's salaries with other similar charities; and the development of a new salary grades structure for implementation in 2002. The Society's long-term aim is to retain and reward a skilled, expert staff team.

## TRUSTEES' REPORT

## FOR THE YEAR ENDED 31 DECEMBER 2001

## **BOARD/GOVERNANCE**

The trustee board continued in 2001 to review its own effectiveness and to seek to involve individuals with suitable skills and talents as Trustees from within the haemophilia community. This led to renewed efforts to reach out to Society members with finance, strategic and fundraising/marketing expertise who might join the board. Trustees also conducted a skills audit and adopted conflict of interest and code of conduct policies in 2001.

Throughout the year the Trustees kept under review the conduct of the campaign on behalf of those affected by contaminated blood products. After a major review of the campaign's aims and potential for success in year 2000, Trustees decided in early 2001 to employ a specialist public affairs firm to carry forward the campaign and to allocate significant sums from reserves to this purpose. Following a competitive tender exercise, Weber Shandwick Public Affairs were retained in March to pursue the goals of recombinant for all, a public inquiry into contaminated blood products, and financial recompense for those with hepatitis C (in addition to that already provided by government for those who suffered HIV infection from contaminated blood products).

#### RESEARCH

The Society's Trustees decided in 2000 to designate a modest fund for the support of research. It is hoped in time to add to this particularly through the Jeans for Genes fundraising initiative, which the Society will join as a guest charity in 2002.

In 2001 two studies were undertaken, the first by Dr Linda Garvican into the treatment of people with HIV/HCV co-infection and the second looking at the social and economic impact of HCV on people with haemophilia. In 2002 it is planned to launch the research funding programme supported by an expert advisory group.

#### INTERNATIONAL

The UK Society took on the secretariat of the European Haemophilia Consortium (EHC) at the end of 1999. This involves a number of staff and Trustees in work to coordinate a network of 42 member organisations for people with haemophilia in Eastern and Western Europe. A high point of the year was the 14<sup>th</sup> annual EHC members conference jointly organised by the UK and Swedish Haemophilia Society in Malmo, Sweden in September.

The UK Society continued to play an active part in the World Federation of Hemophilia, with representatives attending the Second Global Forum on Safety and Supply of Treatment in Montreal in February. During the year the twinning programme with Russia also involved sharing of ideas and expertise and a successful joint application to the WFH for a grant to support the twinning activities in 2002.

## ADVOCACY/CAMPAIGNING

The Society's campaigning throughout the year focused on the goal of achieving access to recombinant as the treatment of choice for all in the UK. Through press/media and parliamentary activities the Society drew attention to the inequity of current provision in the UK. Patients in Scotland and Wales, whatever their age, can be treated with recombinant, whilst in England and Northern Ireland it is available only for children and youth under 20 years. Society representatives, joined by the UK Haemophilia Doctors Organisation and Haemophilia Nurses Association, met with health minister Lord Hunt of Kings Heath in January 2001 to urge government to fund recombinant for all. In early 2002 a further meeting with health minister Yvette Cooper MP followed up this approach. As yet an answer from government is still awaited.

During 2001 considerable effort also went into the campaign for those infected by contaminated blood products. Parliamentary activity was concentrated in a Carpet of Lilies campaign, in which MPs were urged to wear a white lily in support of the Society's campaign, culminating in a day of action on 13

## TRUSTEES' REPORT

## FOR THE YEAR ENDED 31 DECEMBER 2001

November and a question to the Prime Minister on 14 November. A notable success in the year was the establishment of an All Party Group on Haemophilia chaired by Michael Connarty MP.

The other significant development in 2001 was the completion of the national service specification for haemophilia by the Haemophilia Alliance, co-chaired by the Society and the UK Haemophilia Doctors Organisation. The new specification was endorsed by health minister John Hutton MP and launched at the House of Commons in December. A national conference is planned in February 2002 for NHS commissioners and managers to discuss the implementation of the specification.

## FINANCIAL REVIEW

Overall, the Society ended 2001 in a strong financial position, largely due to the extra income generated through the GMTV appeal in July. These funds will be spent on service developments in 2002.

#### RESERVES

Given the difficulties of fundraising for haemophilia and uncertainties around government and other funding sources, Trustees have maintained the policy of holding at least six months running costs as free reserves. This enables use of reserves to support areas of work as necessary.

The level of free reserves available to the charity at 31 December 2001 was £282,342. This approximates seven months running costs and the trustees are therefore satisfied that this level of reserves is sufficient to fulfil this policy.

In 2001, following the Trustees review of the campaign for people affected by contaminated blood products, it was decided to use £120,000 from reserves to step up the effort significantly. Those funds were used primarily to retain the major public affairs firm, Weber Shandwick, and to cover the additional costs of new campaign materials during the year.

#### FUNDRAISING

Trustees took the decision in 2001 to invest significantly more in fundraising as the charity is finding it difficult to raise sufficient money to cover planned activities each year. This led to the recruitment of a fundraising and marketing assistant and the use of a freelance trusts fundraiser for six months. These steps were necessary given the insecurity of existing government and trust fund income and the increasingly competitive fundraising environment, especially for medium sized charities such as the Society. The relatively small number of people affected by haemophilia in the population is another obstacle in fundraising, and somewhat restricts the Society's appeal for funders.

The key fundraising strategy in 2001 has been to sustain our existing funding base of government and trusts; diversify our sources of funding to find new trusts and corporate supporters and secure more funding from the Community Fund; and increase our funding base through planned fundraising and marketing strategies.

The biggest fundraising achievement of the year was to be selected as one of the five charities to be featured on the GMTV Get Up and Give appeal. Not only did this provide the Society with the opportunity to raise awareness of haemophilia among the general public, it also raised approximately £155,000. The vast majority of the funds raised will be carried forward into 2002 to develop new and existing services.

Trust income has been weaker than anticipated. Final instalments of many project grants have been received, and the Society entered the new financial year with little trust funding committed. Key achievements this year included securing further funding for the HIV Youth Project from the Elton John AIDS Foundation, and securing smaller amounts from the Baring Foundation and Lloyds TSB Foundation. The annual appeal was extended to include many new trusts and it is hoped that these applications will secure and diversify the trust funding base in the coming years.

## TRUSTEES' REPORT

## FOR THE YEAR ENDED 31 DECEMBER 2001

Corporate income exceeded its budgeted target in 2001 thanks to continued funding by pharmaceuticals and changes in the gift aid legislation allowing companies to make their donations gross. Additional effort has been put into sending ad-hoc mailing to companies with corporate involvement schemes to secure smaller amounts of unrestricted funding. We are continuing to build our relationship with members to ensure that more in-roads are made into larger companies.

Over the year the Society received £158,000 (18% of income) in the form of government grants. This included a Section 64 grant of £100,000 per annum and project grant for the hepatitis C counselling project. The Northern Ireland DHSS committed a one-off payment of £8,000 towards the provision of information, advice and support for people with haemophilia in Northern Ireland. The Scottish Executive continued their support of £10,000 towards the Scottish Development Project. Whether this level of government funding is sustainable in future is uncertain, and Trustees have considered the risk that core funding in particular may be vulnerable.

#### **Risk analysis**

The Trustees undertook a risk analysis in 2001 of the major risks facing the charity and are satisfied that sufficient controls are in place to mitigate those risks. This analysis will be kept under review by the board in the coming year.

#### Adequacy of funds

The Trustees believe there will be adequate funds available to complete all ongoing projects.

#### Investment policy

Under the memorandum and articles of Association the trustees may invest surplus funds in any investment they consider appropriate.

To this end the trustees have invested surplus funds in COIF Investment Funds as they consider the flexibility and returns of this investment suitable for the charity.

## AUDITORS

A resolution re-appointing Horwath Clark Whitehill as auditors to the charity will be put to the Annual General Meeting.

## TRUSTEE RESPONSIBILITIES

Company law requires the Trustees, who are directors for Companies Act 1985 purposes, to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those financial statement, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements, and
- prepare the financial statements on the going concern basis unless it is inappropriate to assume that the charity will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial

## TRUSTEES' REPORT

# FOR THE YEAR ENDED 31 DECEMBER 2001

statements comply with the Companies Act 1985. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud or other irregularities.

By Order of the Board of Trustees

		GRO-C	
Chris Chair	Hodgsor	GRO-C	
	8 Ap-1	2002	

## **AUDITORS' REPORT**

## TO THE MEMBERS OF

## THE HAEMOPHILIA SOCIETY

We have audited the financial statements of The Hemophilia Society for the year ended 31 December 2001 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes set out on pages 12 to 14. These financial statements have been prepared under the historical cost convention as modified by the revaluation of investment assets to market value and the accounting policies set out therein.

## Respective responsibilities of the directors and auditors

The responsibilities of the Trustees, who are also the directors under company law, for preparing the Trustees Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards are set out in the Statement of Trustees Responsibilities on pages 9 to 10.

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and United Kingdom Auditing Standards.

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Companies Act 1985. We also report to you if, in our opinion, the Trustees Report is not consistent with the financial statements, if the charitable company has not kept proper accounting records, if we have not received all the information and explanations we require for our audit, or if information specified by law regarding directors' remuneration and transactions with the charitable company is not disclosed.

We are not required to consider whether the statement by the Trustees in the Trustees Report concerning the major risks to which the charitable company is exposed covers all existing risks and controls, or to form an opinion on the effectiveness of the charitable company's risk management and control procedures.

We read other information contained in the Trustees Report and consider whether it is consistent with the audited financial statements. We consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the financial statements. Our responsibilities do not extend to any other information.

#### Basis of opinion

We conducted our audit in accordance with United Kingdom Auditing Standards issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgments made by the Trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charitable company's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance as to whether the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

#### Unqualified opinion

In our opinion the financial statements give a true and fair view of the state of affairs of the charitable company as at 31 December 2001 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended and have been properly prepared in accordance with the Companies Act. 76-an Cal Wheall Horwath Clark Whitehill

Chartered Accountants and Registered Auditors Date

8 Apr 1 2002



25 New Street Square London EC4A 3LN

# STATEMENT OF FINANCIAL ACTIVITIES

# FOR THE YEAR ENDED 31 DECEMBER 2001

# INCOME AND EXPENDITURE

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	Notes	Unrestricted Funds	Restricted Funds	Endowed Funds	Total Funds 2001	Total Funds 2000
Incoming Resources Voluntary income		£	£	£	£	£
Subscriptions		16,896	-	-	16,896	24,173
Covenants and Donations		46,758	1,355	4,500	52,613	33,015
Legacies		42,500	.,	-	42,500	20,628
Trust Income		35,774	106,968	-	142,742	147,224
Government Grants	2	100,000	58,000	-	158,000	137,451
GMTV grant	-	136,833	-	-	136,833	-
Community Fund		-	33,951	-	33,951	-
Corporate Funding		43,523	107,500	-	151,023	128,299
Activities for generating funds						,
Annual Draw and Events		49,903		-	49,903	49,004
Local Groups Income	3	35,045	3,100	-	38,145	116,078
Other Income		6,285		• -	6,285	17,840
Interest receivable		27,945	738	-	28,683	34,223
Total incoming resources		541,462	311,612	4,500	857,574	707,935
Resources expended Cost of generating funds - Fundraising						
Annual Draw and Events	4	12,221	738	` 🗕	12,959	11,186
Fundraisers costs	4	66,974	-	-	66,974	53,113
Investment managers fees		421	-	-	421	475
		79,616	738	-	80,354	64,774
Net incoming resources available for						
charitable application		461,846	310,874	4,500	777,220	643,161
Charitable expenditure Core membership and						
Information services		121,763	91,899	*	213,662	171,172
Children and family activities		-	61,259	-	61,259	71,320
HCV activities		23,852	63,739	-	87,591	75,060
HIV activities		-	73,432	-	73,432	53,442
Advocacy		122,185	-	-	122,185	39,418
International activities		18,907	-	-	18,907	32,939
Groups activities		31,163	9,775	-	40,938	117,088
Support of groups	_	48,285	3,100	-	51,385	48,524
Support costs	5	58,234	-	-	58,234	67,258
Management and administration	5	14,422			14,422	12,970
		438,811	303,204	-	742,015	689,191
Total resources expended		518,427	303,942		822,369	753,965

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## STATEMENT OF FINANCIAL ACTIVITIES

## FOR THE YEAR ENDED 31 DECEMBER 2001

Net incoming/(outgoing) resources	23,035	7,670	4,500	35,205	(46,030)
Unrealised (Loss)/Gain	(23,007)	-	-	(23,007)	2,885
Net movement in funds	28	7,670	4,500	12,198	(43,145)
Fund balance brought forward at 1 January 2001	606,658	31,629	13,500	651,787	694,932
Fund balance carried forward at 31 December 2001	606,686	39,299	18,000	663,985	651,787

The Statement of Financial Activities includes all gains and losses recognised in the current and preceding year.

The notes on pages 15 to 21 form part of these financial statements.

# BALANCE SHEET

## AS AT 31 DECEMBER 2001

	Notes		2001	2000			
		£	£	£			
FIXED ASSETS Tangible fixed assets Investments	7 8		30,079 179,878	24,863 202,885			
			209,957	227,748			
CURRENT ASSETS Debtors Cash at bank and in hand	9	94,475 <u>438,357</u> 532,832	-	57,223 421,282 478,505			
CREDITORS: amounts falling due within one year:	10	78,804	-	54,466			
NET CURRENT ASSETS			454,028	424,039			
			663,985	651,787			
FUNDS							
Unrestricted funds Designated funds Local Group funds Restricted funds Endowed funds	11 11 11 12 13		312,422 225,000 69,264 39,299 18,000	419,428 100,000 87,230 31,629 13,500			
			663,985	651,787			
Approved by the Board of Trustees on & April 2002 and signed on its behalf by							
GRO-C Chris Hodgsor Chairman	8~ 1	PAIL Zo	. <b>5</b> 2				

The notes on pages 15 to 21 form part of these financial statements.

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GRO-C

Chairman

## FOR THE YEAR ENDED 31 DECEMBER 2001

## 1. ACCOUNTING POLICIES

#### a) Basis of preparation of accounts

The accounts are prepared under the historical cost convention and in accordance with applicable accounting standards and the Statement of Recommended Practice, Accounting and Reporting by Charities; (SORP 2000)

## b) Grants

Grant income is recognised in accordance with the terms of the grant and when the conditions of receipt have been complied with. When donors specify that grants given to the charity must be used in future accounting periods, the income is deferred until those periods.

## c) Donations, legacies and similar incoming resources

Donations, legacies and similar incoming resources are included in the year in which they are receivable, which is when the charity becomes entitled to the resource.

#### d) Resources expended

All expenses are accounted for on an accruals basis. Expenditure incurred in connection with the specific objects of the charity is included under the heading charitable expenditure together with an apportionment of the general overheads of the charity. The apportionment has been established by analysing staff time spent between charitable activities and those relating to the support of the charity.

#### e) Cost of generating funds

The costs of generating funds are accounted for on an accruals basis. These costs are split between those direct costs to the annual draw and events and the salary and other costs of the fundraiser.

#### f) Tangible fixed assets and depreciation

Tangible fixed assets for use by the charity are stated at cost less depreciation.

Depreciation is provided at rates calculated to write off the cost or valuation of fixed assets, less their estimated residual value, over their expected useful lives on the following bases:

Freehold buildings Office Equipment & furniture Leasehold Property 2% per annum, straight line 25% per annum, written down value over life of lease

#### g) Pension Costs

Pensions in respect of qualifying employees are provided by individual money purchase schemes. The Society's contributions to these schemes are charged to the Statement of Financial Activities in the year in which they arise.

# THE HAEMOPHILIA SOCIETY NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2001

## 1. ACCOUNTING POLICIES (continued)

#### h) Value added tax

Value added tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

## i) Group funds

The Society is represented throughout the country by Local Groups. Group funds are incorporated within the Society's financial statements.

## j) Management and Administration expenditure

Management and administration comprises the costs of maintaining the organisation's status as a charitable company. These include Trustees expenses, audit fees and costs attributable to compliance with constitutional and statutory requirements.

# k) Support costs

Support costs are costs incurred in the general running the charity. These include an apportionment of rent, salaries and office overheads.

### I) Investment gains and losses

The investment gains and losses represent the difference between the opening market value and closing market value or proceeds of sale, and are recognised in the financial statements in the period to which they relate.

#### m) Operating Leases

Rentals payable under operating leases are taken to the Statement of Financial Activities in the period in which they arise.

## 2. GOVERNMENT GRANTS RECEIVED

£158,000 was received in respect of Section 64 Charitable Grant for the following:

	2001 £	2000 £
Core Grant Hepatitis C Counselling Project HIV/HCV Co-infection Seminar Scottish Executive Northern Ireland Office Deferred government grants	100,000 40,000 - 10,000 8,000	100,000 20,950 10,000 6,501
	158,000	137,451

## 3. LOCAL GROUP FUNDS

The branches incurred a deficit of  $(\pounds 10, 140)$  (2000 deficit  $\pounds 1, 010$ ). From this deficit, an amount of  $\pounds 4,727$  (2000:  $\pounds 7,072$ ) was paid as a donation to National Office.

4.	FUNDRAISING COSTS	2001 £	2000 £
	Fundraising worker's salary and NIC costs Annual draw Merchandise	49,778 1,439 10,782	23,172 1,447 9,739
	Other fundraising costs (including 50 <sup>th</sup> Anniversary expenses) COIF investment management costs	17,934 421	29,941 475
		80,354	64,774
5.	MANAGEMENT, ADMINISTRATION AND SUPPORT COSTS	2001 £	2000 £
	Office overheads	15,662	26,158
	Charity administration	20,164	14,060
	Professional and legal fees	14,422	12,970
	Salary core costs	22,408	27,040
		72,656	80,228

Auditors remuneration during the year was £4,000 (2000 : £4,054). Fees for other services were £1,000 (2000: £ nil).

During the year, ten Trustees (2000: ten) received £6,950 (2000: £13,244) as reimbursement of travel expenses incurred.

## 6. STAFF COSTS

The number of full time equivalent staff employed by the Society during the year was:

	2001 No.	2000 No.
Direct charitable expenditure Fundraising Management and administration	9 2 1	9 1 1
	12	11
The aggregate staff costs were:	2001 £	2000 £
Wages and Salaries Social Security Employers pension contribution	242,655 22,650 7,752	230,105 21,495 10,336
	273,057	261,936

# NOTES TO THE ACCOUNTS (CONTINUED)

# FOR THE YEAR ENDED 31 DECEMBER 2001

The number of employees whose emoluments were greater than £50,000 in the year were as follows:

	£50,001 - £60,000			Nil	Nil
7.	TANGIBLE FIXED ASSETS	Land And Building £	Computer and Office equipment £	Caravans £	Total £
	<b>Cost</b> At 1 January 2001 Additions Disposals	8,790 - -	95,364 12,757 	27,179 - -	131,333 12,757 
	At 31 December 2001	8,790	108,121	27,179	144,090
	Depreciation At 1 January 2001 Charge for year On disposals	798 133 	78,493 7,408	27,179	106,470 7,541
	At 31 December 2001	931	85,901	27,179	114,011
	Net book value 31 December 2001	7,859	22,220	<u> </u>	30,079
	31 December 2000	7,992	16,871		24,863
	The net book value of land and buildings	comprises:-		2001 £	2000 £
	Long Leasehold property (Hemsby Chale	t)		7,859	7,992
8.	INVESTMENTS Cash invested with COIF These funds are subject to a 0.22% annu	al managemer	ot charge.	179,878	202,885
9.	DEBTORS Prepayments Other debtors Accrued Income			11,901 31,187 51,387 94,475	12,431 44,792 
10.	CREDITORS: amounts falling due within	one year			
	Trade creditors Other taxes and social security costs Other creditors Deferred income Accruals Membership fees received in advance			15,718 7,390 4,852 30,000 16,672 4,172 78,804	33,695 7,798 4,547 7,778 648 54,466

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## 11. UNRESTRICTED FUNDS

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Designated funds:	Balance 1 January 2001 £	Incoming Resources £	Outgoing Resources £	Unrealised Gains £	Transfer Between Funds £	Balance 31 December 2001 £
Dilapidation Fund Research Fund GMTV Fund	50,000 50,000 -	- - 125,000	-	- -	- -	50,000 50,000 125,000
	100,000	125,000	-	-		225,000
Local Groups General Funds	87,230 419,428	35,045 381,417	(48,285) (470,142)	(23,007)	(4,726)	69,264 312,422
	606,658	541,462	(518,427)	(23,007)		606,686

The dilapidation fund is intended for dilapidation charges and necessary refurbishment of office accommodation.

The research fund is to be used to contribute to the advancement of scientific research in the field of Haemophilia.

The GMTV fund is to be applied to the development of the Society's information, advice and support services in 2002.

12.	RESTRICTED FUNDS	Balance 1 January 2001 £	Incoming Resources £	Outgoing Resources £	Balance 31 December 2001 £
	Core membership and				
	Information Services	-	55,140	55,140	-
	Children and family activities	3,871	67,409	61,259	10,021
	HCV activities	-	58,980	58,980	-
	HIV activities	14,380	64,519	73,432	5,467
	Local groups	-	9,775	9,775	-
	Scottish Development Project	7,944	43,951	28,759	23,136
	Northern Ireland Project	-	8,000	8,000	-
	Local Group Funds	-	3,100	3,100	•
	Research	675	-	-	675
	Other restricted funds	4,759	-	4,759	-
	Philip Morris Award	-	410	410	-
	Howard Abraham	*	328	328	*
	_	31,629	311,612	303,942	39,299

# THE HAEMOPHILIA SOCIETY NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2001

#### Membership and Information Fund

This fund is made up of restricted funds donated by pharmaceutical companies, including, Baxter Bioscience, Bayer Plc, Novo Nordisk, Roche, Schering Plough and Wyeth Pharmaceuticals. Funds have also been contributed by the Lloyds TSB Foundation and five of our local groups. This fund is used for our membership and information services which include our telephone helpline and publications.

#### Children and Families Fund

This fund is made up of restricted funds donated from West London Synagogue and BBC Children in Need. Pharmaceutical funds are from Baxter Bioscience, Bayer Plc, Novo Nordisk and Wyeth Pharmaceuticals. This fund is used for all our children and families activities including childcare at events and adventure.

#### **HCV Activities**

This fund is made up of restricted funds donated by two pharmaceutical companies – Roche and Schering Plough. The Pilgrim Trust and a local group have donated funds. This fund is used for funding our HCV worker and related HCV events.

## **HIV Activities**

This fund is made up of restricted funds donated by two Pharmaceutical Companies – Roche and Schering Plough, Elton John AIDS Foundation, John Ellerman Foundation, The Pilgrim Trust and a local group have donated funds. This fund is used for funding our HIV worker, co-infection evenings and other events.

#### International

No new funds received during 2001.

#### Local Groups

Restricted income received from the Baring Foundation. This has been used in the development of our local group packs and local group forum.

#### Scottish Development Project

Funds received from the Community Fund (£33,951) and a grant from the Scottish Executive of £10,000. During 2001 a Scottish Office has been set up as the start of a three year project.

#### Northern Ireland Project

Grant received from the Northern Ireland DHSS. This has been used to improve the range of information available and relevant to people in Northern Ireland.

## Research

No new funds received during 2001.

## Other restricted funds

No new funds received.

## GRO-A Memorial Award Fund

This is a bursary awarded to an individual with haemophilia or related blood disorder in pursuit of one of the professions, or studying which is in relation to the professions. This award has been made possible by the **GRO-A** family in memory of their son. The sum available in any one year will be interest earned on the initial investment of £6,000.

#### GRO-A

O-A Art Award Fund

This award is open to students with Haemophilia or related bleeding disorder studying the arts. Preference will be given to a student studying music, as a reflection of **GRO-A** love of music developed in later life. The sum available in any one year will be the interest earned on an initial investment of £12,000.

# THE HAEMOPHILIA SOCIETY NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 DECEMBER 2001

## 13. ENDOWMENT FUND

The endowment fund consists of the **GRO-A** Art Award Fund and **GRO-A** Memorial Award Fund. The income generated from these funds is the interest earned on the initial investment and is released in the financial statements in the period it is received.

## 14. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Fixed Assets	Net Current Assets	Total
Endowed funds	-	18,000	18,000
Restricted funds	-	39,299	39,299
Unrestricted funds	209,957	102,465	312,422
Designated funds	· -	225,000	225,000
Local group funds		69,264	69,264
	209,957	454,028	663,985

## 15. LIMITED BY GUARANTEE

The society has no share capital and is limited by guarantee. The Liability of each of the twelve members is a maximum of  $\pounds 1$ .

#### 16. FINANCIAL COMMITMENTS

At 31 December 2001 the company had annual commitments under operating leases as set out below:

	2001		2000	
	Land and Buildings £	Other £	Land and Buildings £	Other £
Operating leases that expire:				
Within one year In the second to fifth years Over five years	23,030	6,622	23,030	3,786
	23,030	6,622	23,030	3,786