Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392042

THE HAEMOPHILIA SOCIETY

(A COMPANY LIMITED BY GUARANTEE)

CHARITY NUMBER: 288260

COMPANY NUMBER: 1763614

REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31ST DECEMBER 2005

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CHARTERED
ACCOUNTANTS

16 New Bridge Street London EC4V 6AX

THE HAEMOPHILIA SOCIETY

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31ST DECEMBER 2005

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THE HAEMOPHILIA SOCIETY

REFERENCE AND ADMINISTRATIVE INFORMATION

FOR THE YEAR ENDED 31ST DECEMBER 2005

PRESIDENT	The Rt. Hon. The Lord Morris of Manchester PC AO QSO
VICE PRESIDENTS	Rt. Hon Frank Field MP
	Dr Peter Jones
	Baroness Masham of Ilton DL
	The Reverend Alan Tanner OBE
	Professor the Lord Winston
CHIEF EXECUTIVE	Graham Whitehead (to 28th July 2005)
	Margaret Unwin (from 3rd October 2005)
TRUSTEES	Roddy Morrison (Chairman)
	Paul Bullen (from 17 September 2005)
	Philip Dolan
	Keith England (co-opted 12 January 2005)
	Ian Hayes (to 17 September 2005)
	Ann Hithersay
	Gareth Lewis (from 17 September 2005)
	Rona Macdonald (to 17 September 2005)
	William Payne
	Debra Pollard (from 17 September 2005)
	Dawn Prideaux de Lacy (co-opted 12 January 2005)
	Elizabeth Rizzuto
	GRO-A
	Alex Susman-Shaw (to 17 September 2005)
	Stephen Wratten (Treasurer)
SUB COMMITTEES	
Resources Sub Committee	Stephen Wratten (Chair)
	Ann Hithersay
	Roddy Morrison
	Dawn Prideaux de Lacy
Health Sub Committee	William Payne (Chair)
	Dr Brian Colvin (co-opted)
	Dr Has Dasani/Dr Peter Collins (co-opted)
	Dr Paul Giangrande (co-opted)
	Dr Ian Hann (co-opted)
	Chris Harrington (co-opted)
	Paul Bullen
	Philip Dolan
	Debra Pollard
	Elizabeth Rizzuto
	GRO-A
Information/Communications	The sub committee meets on an ad hoc basis, as needed.

THE HAEMOPHILIA SOCIETY

REFERENCE AND ADMINISTRATIVE INFORMATION (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

MEDICAL ADVISORS

The following is a list of medical advisors who provide periodic advice:

Haemophilia:

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

Nursing:

- Kate Khair, MSc, SRN RSCN, Clinical Nurse Specialist for Haemophilia, Great Ormond Street
- Chris Harrington, RGN Cert Ed, Nurse Consultant, Royal Free Hospital

Orthopaedics:

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

Hepatology:

- Dr G Alexander, Consultant Hepatologist (Addenbrooke's Hospital, Cambridge)
- Professor G Foster, PhD FRCP (Royal London Hospital)

Physiotherapy:

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

WOMEN BLEED TOO PROJECT BOARD

- Dr Rezan Kadir, MBChB MRCOG MD FRCSFRCOG - Chair, Consultant Obstetrician & Gynaecologist, Royal Free Hospital
- Dr Paul Giangrande, BSc MD FRCP FRCPath FRCPCH, Consultant Haematologist, Oxford
- GRO-A – patient representative
- Dr Ann Harper - MD, FRCOG, Consultant Obstetrician & Gynaecologist, Royal Jubilee Maternity Service (RJMS), Belfast
- GRO-A – patient representative
- Professor John Pasi, MBChB,FRCP,FRCPath,PhD,FRCPCH – Professor haemostasis and thrombosis, Barts and the London Hospital
- Angela Whitton, RGN – Gynaecology Nurse
- Debra Pollard, RGN – Haemophilia Nurse Practitioner, Royal Free Hospital
- GRO-A – patient representative
- Professor Christine Lee, MA MD FRCP DRc (Med) FRCPath, Consultant Haematologist/Haemophilia Centre Director, Royal Free Hospital NHS Trust
- Elizabeth Hammersley – Haematology Specialist Midwife, Saint Mary's Clinic, Manchester

THE HAEMOPHILIA SOCIETY

REFERENCE AND ADMINISTRATIVE INFORMATION (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

RESEARCH ADVISORS

- Professor Edward G.D.Tuddenham Chair, MBBS MD FRCP FRCPath FRPCE FMedSci
- Dr Michael Makris MA, MB BS, MD, FRCP, FRCPath, Vice-chair, Reader in Haemostasis and Thrombosis, Sheffield
- Dr Paul Giangrande, BSc MD FRCP FRCPath FRCPCH, Consultant Haematologist, Oxford
- Kate Khair SRN RSCN MSc MCGI, Nurse Consultant - Haemophilia, Great Ormond Street
- GRO-A, patient representative
- Christopher Hodgson, patient representative
- GRO-A patient representative

THE HAEMOPHILIA SOCIETY

REFERENCE AND ADMINISTRATIVE INFORMATION (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

SECRETARY	Stephen Wratten
REGISTERED OFFICE	Petersham House 57a Hatton Garden London EC1N 8JG
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 WC2A 3LH
AUDITORS	Knox Cropper 16 New Bridge Street London EC4V 6AX

THE HAEMOPHILIA SOCIETY

TRUSTEES REPORT

FOR THE YEAR ENDED 31ST DECEMBER 2005

The Trustees present their report and financial statements of the charity for the year ending 31 December 2006. The financial statements have been prepared in accordance with the accounting policies set out on pages 18 and 19 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.

The Charity's objects are:

(1) The relief of people suffering from Haemophilia, and
(2) The advancement of public education into the nature and causes of Haemophilia

The Society's Mission is:
To secure the best possible care, treatment and support for all people with haemophilia and related bleeding disorders.

The charity works to assist people with haemophilia and related disorders by providing information and support, by representing the interests of people with haemophilia and related disorders and their families and by raising awareness of bleeding disorders amongst the public and with health professionals.

The Trustee Board governs the Society and has responsibility for the overall strategic and policy direction of the organisation. Trustees who have served during the year are listed on page 1.

ORGANISATION AND DECISION MAKING STRUCTURE

There are currently 12 Trustees; 10 are directly elected by the membership and two are co-opted by the Board to meet particular skills requirements. The Board appoints, from within the Trustees, a Treasurer and up to two Vice Chairs. The Chair is elected for a three-year term of office; other elected Trustees retire by rotation, with a third of Trustees either retiring or standing for re-election each year. Trustees are required to retire entirely after six years continuous service.

Trustees appoint the Chief Executive and day to day management of the Society is delegated to this postholder. The Chief Executive reports regularly to the Board and is directly accountable through the Chair.

Trustees meet up to six times a year. There are three standing sub-committees that report to and advise the Board of Trustees. These are:

- The Resources Committee (meets up to six times per year) – for details of membership see page 1
- The Health Sub-Committee meets one or two times a year – for details of membership see page 1
- The Information and Communications Committee (meets on an ad hoc basis, as needed)

In addition the Society has established three advisory panels to advise Trustees and staff on important aspects of the Society's work:

- Medical Advisors – for details see page 2
- Women Bleed Too Project Board – for details of membership see page 2
- Research Advisors – for details see page 3

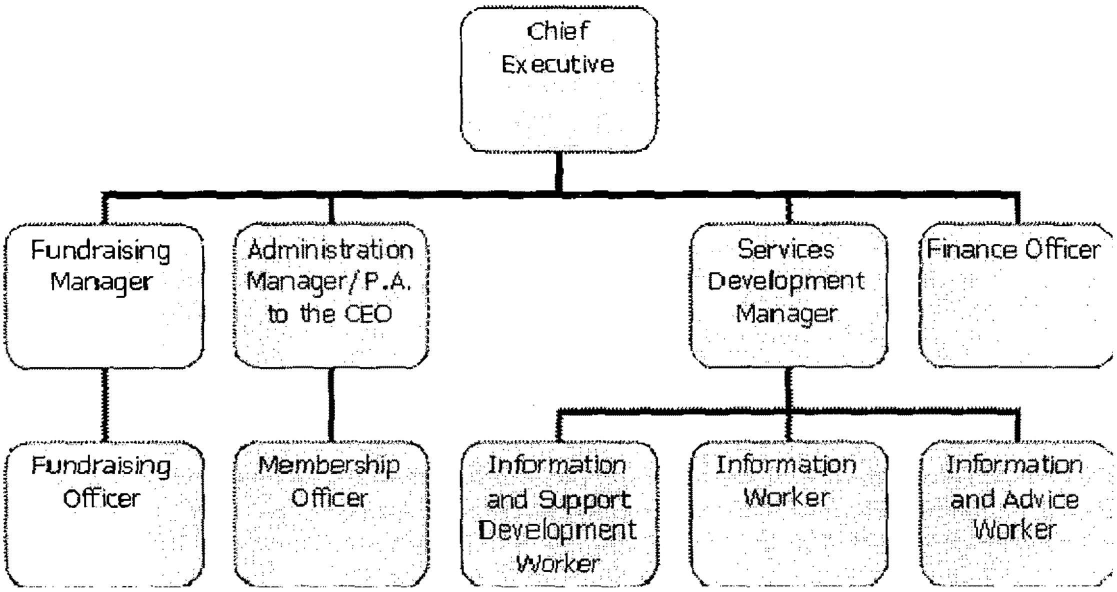
THE HAEMOPHILIA SOCIETY

TRUSTEES REPORT (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

ORGANISATION AND DECISION MAKING STRUCTURE (CONTINUED)

The organisational structure of the Society is set out below:



The Society is a membership organisation with 4300 individual members and registrants on its database. These members are kept in touch with the Society's work through regular mailings, the website and the annual general meeting.

The Society has a network of 17 local groups, official branches of the Society. Groups are financially and operationally accountable to Head Office. Groups are kept in regular contact with the Society by means of regular information mailings and annual general meetings.

Recruitment, Induction and Training of Trustees
Trustees are elected by the membership and have personal experience of bleeding disorders. In addition two Trustees are co-opted to bring specific skills to the Board, for example business skills and public relations skills.

New Trustees undergo an induction covering:
- Roles and responsibilities of Trustees
- Their legal obligations under charity law
- The content of the Memorandum and Articles of Association
- The Board and decision-making processes
- The current strategic plan
- Financial matters associated with the charity
- Meeting key members of staff and fellow Trustees

There is an annual Board planning day and Trustees are encouraged to attend appropriate external training on an ongoing basis to enhance their skills and support their role. Bespoke Trustee training is planned for 2006.

Financial Decision Making & Internal Controls

Management accounts are prepared monthly by the Finance Officer and the Board of Trustees reviews the management accounts at their meeting. The Society has a set of written financial procedures that lays down the internal controls necessary to ensure that the risk of fraudulent or inappropriate use of funds is minimised as much as possible.

Detailed annual budgets are prepared each year by the chief executive and senior managers and approved by the Board of Trustees. At each Trustee Meeting the Board reviews financial statements showing actual against budget.

The Resources sub Committee has delegated authority to review all financial matters in detail before bringing recommendations to the full trustee Board. The Committee receive management accounts monthly.

Risk Statement

Trustees regularly review the major risks facing the charity and this process was completed in 2005. Trustees have put in place a risk management plan to mitigate the identified risks. The chief executive is responsible for the appropriate management of this plan and for reporting to Trustees at each Board meeting any significant changes or events that impact on the Society's exposure to risk.

OBJECTIVES AND ACTIVITIES

Aims

The Society identified 6 organisational goals and principles in its operational plans 2005-2007. These have been reviewed and revised during 2006 to the following 5 long term aims:

1. To advocate effectively to government and service providers on behalf of all people with bleeding disorders and their families throughout the UK in order to secure the best possible care, treatment and support
2. To provide a range of information, advice and support services to people with bleeding disorders and their families to ensure they are fully informed about their condition(s) and current treatments and are able to access welfare benefits
3. To raise awareness of bleeding disorders amongst the wider medical profession and the general public in order to secure more accurate diagnosis and better treatment for those affected
4. To ensure there is a network of local groups and active individuals across the UK that are well resourced to provide mutual support to people affected by bleeding disorders in their area
5. To play an active role in the international bleeding disorders community in order to share good practice and improve treatment in other parts of the world

Key Objectives 2004-2007

The Society has identified 12 key objectives that it wants to achieve by 2007. These objectives are reviewed annually and will be updated again in 2006.

The 12 objectives are:

1. To increase the number of women referred to haemophilia centres for testing by 40%
2. To develop tailored membership packs for women and young people
3. To distribute information on women's bleeding disorders to GP surgeries
4. To achieve 50% of the Society's membership being affected women
5. To increase youth membership (16-21 years) by 100%
6. To develop a twinning partnership with one developing country
7. To increase campaigning activity overall
8. To increase hardship grants made by the Society to individuals, via the Tanner Fund, to £25k in total
9. To ensure 90% of the UK has a local haemophilia group or representative
10. To develop a five year fundraising strategy in order to increase fundraising growth in line with organisational growth
11. To target research projects that address people's psychosocial needs
12. To maintain the current level of information and advice the Society provides to individuals

Progress Towards the 12 Objectives in 2005

Referrals of women for testing
- The Society commissioned research to devise a training tool for primary healthcare professionals
- The Society created a new post to provide additional helpline support for women who suspect they may have a bleeding disorder
- Funding and medical approval for a bleeding disorders checklist was secured

Tailored membership packs for women and young people
- Introductory information was developed for women (and also for other discrete groups: men and people living with HIV/HepatitisC)
- A new publication "Female Factors" was developed for women with bleeding disorders

Information to GPs
- Funding was secured for the 'Bleeding disorders checklist' and the content agreed with the Women Bleed Too advisory board
- During early 2006 posters and leaflets were sent to a pilot group of GP surgeries in the South West

Affected women in membership
- An information worker with a specific brief to support women living with a bleeding disorder was appointed in April 2005
- A pilot edition of *Female Factors* was distributed to 5000 members and registrants in September
- A communication drive through all channels (website, newsletters and haemophilia centres) was initiated in order to increase awareness and encourage membership of women

Membership of 16-21 year olds
- A new free membership scheme was introduced to encourage membership within this age group
- A first 14-17 age group activity weekend was held
- 'Role-models' aged 18+ were identified and recruited to assist support and information services

Twinning partnership
- In early 2006 the Society visited the Armenian Haemophilia Association in Yerevan
- The UK Society provided a day's training for trustees
- Further contact with the Russian Haemophilia Society brought the previous twinning to a conclusion

Campaigning activity
- Work on the campaign for a public inquiry continued during 2005
- Extensive media coverage about the campaign was secured around World Haemophilia Day in 2006
- A partnership with Red Door Communications resulted in effective media coverage during 2005/06

Hardship grants
- Individuals experiencing hardship received a total of £8,000 during 2005
- The fund was renamed the "Tanner Fund" (to reduce stigma)
- A new committee was established and the awards criteria were revised to make them more focused
- Additional publicity about the Tanner Fund resulted in a slight increase in numbers of applications

Local groups and representatives
- 17 local groups continued to operate in 2005
- Local groups mailings were improved and regularised during the year
- Individual activists posted a total of 1344 discussion forum postings during the year

Research projects

- Awards for 2005 projects and commitment for 2006 awards made in 2005 totalled £74,000
- An appropriate balance of medical/scientific, psychosocial and commissioned research was broadly achieved, as per the target in 2004
- Additional funding was sourced for a regional needs assessment (initially in the SW of England)

Information and advice

- The Society maintained its Helpline service, from 10am – 4pm daily, dealing with a range of inquiries including issues around new diagnosis, insurance queries and questions about benefits
- A total of 1436 telephone and email enquiries were responded to during the year
- Additional von Willebrands support was provided by the new Information worker, resulting in an enhanced service on the previous year

Role and contribution of volunteers

Volunteers are involved in many aspects of the charity's work including as Trustees, as part of local groups, assisting at Society events and working in the Society's office.

The Society has a volunteer policy that was updated in 2005. Induction training is provided for new volunteers and appropriate training and support is offered to enable them to carry out their roles.

Grants

The charity makes a small number of hardship grants to individuals via the Tanner Fund. Applications are sponsored by a health or social care professional who knows the applicant. The Grants Committee, comprising the Chief Executive, Treasurer and Fundraising Manager meets bi-monthly to consider and approve applications. Grants expenditure in 2005 was £8,000.

In addition the society makes grants for research, including particularly for research into the psychosocial needs of people with bleeding disorders. The Society is increasingly taking a commissioning approach to identifying research projects that should be funded.

Objectives for 2006

National development

The key objective is to ensure the Society is able to support people with bleeding disorders across the UK.

1. Secure additional funding to recruit a national development worker, to supplement funding already received for London, Scotland and the South West of England
2. Carry out a South West needs assessment survey and use findings to inform the national development officer's work plan
3. Put in place a plan to build capacity in the existing network of groups and in addition develop 5 new groups in 2006, including in London

Women Bleed Too

The key objective of the work is to increase public and professional awareness of women's bleeding disorders and ensure women receive appropriate diagnosis and support.

4. Conduct awareness-raising and training activities to enhance knowledge amongst primary care professionals
5. Improve awareness of bleeding disorders affecting women amongst the general public through continuing media publicity and other routes
6. Develop a focused plan to enhance support services for affected women

Children & youth
The key objective of the work is to ensure the Society is able to provide an appropriate, targeted service for and with the input of young people.

7. Investigate options for improving the support currently available, including the option to recruit a young people's worker to work with young people to develop appropriate activities and support

Information and support services
The key objective of this work is to provide targeted, up to date information for people with bleeding disorders and ensure they are able to access support around claiming benefits, new diagnosis, treatment options and other key areas.

8. Continue to improve the website to meet changing needs throughout the year, including development of the travel section, improved campaigns page and development of the youth website
9. Review the Helpline to ensure it has the resources it needs to provide the appropriate level of service
10. Develop new fact sheets and resources in response to identified need, including for people with inhibitors
11. Promote the Tanner Fund to increase uptake up to a budget of £25,000 in 2007
12. Conduct a review of membership and implement recommendations

Research
The key objective of this work is to develop partnerships with academic researchers to enhance the understanding of bleeding disorders, of the science and of appropriate models of support.

13. Finalise the pain management tool and roll this out across the UK
14. Develop and pilot the Women Bleed Too education tool
15. Finalise the South West needs assessment project and use the data gathered to inform the Society's work

Administration/support
The key objective of the work is to ensure the Society has the appropriate administrative and office resources to enable it to carry out its work effectively.

16. Ensure the Society's office is utilised in the most appropriate way and all staff are adequately resourced with IT and other equipment
17. Review the use of IT and develop an IT policy to enhance usage
18. Review the Society's policies and start a programme to update and revise all policies
19. Update the current appraisal system for all staff taking account of current best practice
20. Review the Society's database and make appropriate modifications to ensure it is utilised in the most effective and efficient way to enhance support to members and supporters

Communications/Campaigns
The objective of this work is to ensure the Society has a profile and is a respected organisation and the issues of importance to people who have bleeding disorders are highlighted to key audiences.

21. Recruit and induct a new communications manager and develop a communications strategy to take the work forward
22. Continue to seek a public inquiry into why people with haemophilia became infected with HIV and Hepatitis C
23. Conduct a review of communications and implement recommendations
24. Conduct preliminary work to establish potential timetable to rebranding and seek views of key stakeholders

Fundraising

The purpose of the work is to ensure the Society has adequate funding from appropriate sources to enable it to carry out its objectives.

25. Implement the fundraising strategy developed in early 2006 to ensure income targets are met in 2006 and beyond
26. Ensure the level of trust funding is increased, in line with targets
27. Develop an appropriate donor development plan and implement it to ensure increased funding is secured from existing and new donors
28. Review and enhance, as appropriate, the involvement of patrons in fundraising
29. Develop a consortium of funders and implement payroll giving through this group

Major activities planned for 2006

- Annual conference and AGM at Gatwick Airport for up to 250 delegates, incorporating consultation with membership
- Support for partner organisations' events, including *Something for the Weekend*, bereavement training and family days
- Strong representation at the World Federation of Haemophilia Congress in Vancouver 2006, including oral and poster presentations
- Media awareness campaign for Women Bleed Too project to be launched in March
- Women Bleed Too professional awareness initiatives to be launched, including devising professional awareness tool, attendance at primary care conferences and producing articles and guidelines for publication
- New websites for Women Bleed Too (professional awareness and public information and support) planned
- New annual programme of weekends for whole families to be launched to enhance 8-13 year old and 14-17 year old activity weekends
- Appointment of communications manager and national development officer and decide appropriate model to support young people
- Facilitation of national Inhibitors Support Group and development of new resources for people who have inhibitors
- First regional needs assessment to be conducted in the South West of England
- Two training visits to twinning partner in Armenia
- Continue European activities including exchange visit with French school children (2006), attendance at EHC meeting in Sofia and further contact with the European Advocacy Initiative
- Review of policies, membership and communications
- Training and development for trustees

Key performance indicators

The charity will develop key performance indicators during 2006 to enable Trustees and staff to assess the impact of the Society's work.

Key fundraising activities

Fundraising performance overall in 2005 was higher than projected. This was mainly due to a large one off legacy. Whilst income from special appeals decreased as expected due to reduced income from Jeans for Genes, the Society managed to replace this income with increased funding from the community and events fundraising. The Society also ran further fundraising activities including World Haemophilia Day in April, and a Global Feast event in September.

Projected income over the next five years will expand as the Society increases its number of income streams. During 2006 the Society has established a new strategy and has further increased its events and community fundraising work. During 2006 there will be a concerted effort to target trusts and there will be less reliance on increasing funding from pharmaceutical companies.

This strategy includes setting up a new fundraising consortium to raise funds from Corporates, Payroll Giving, Events and Direct Mail. In addition to this the Society has new In Memoriam, Legacy and Online fundraising strategies. This will provide the Society with a much more stable and secure funding base.

Investment performance

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 funds in COIF Investment Funds as they consider the flexibility and returns of this investment suitable for the charity. Given that those funds were not immediately needed to finance service provision, trustees took the decision four years ago to establish this long term investment fund of £200,000 with COIF. The COIF investments have begun to recover in value despite being in overall deficit, and in 2005 there was an unrealised gain of £21,449 (£7,986– 2004). Trustees will be seeking advice in 2006 about future investment policy.

Internal and external factors impacting on the Society's work

Senior managers completed an exercise to identify key external and internal factors during 2005. This will be updated as necessary. Key factors identified include:

External factors

Factor	Implications/comments
Insecure funding for recombinant products	Rationing of factor
Proposed national procurement contracts for recombinant	Reduced choice of products
Retirement of a number of key haemophilia doctors	Opportunities for service reconfiguration that could reduce the number of haemophilia centres and thus less access to care
Plans to reconfigure services in London and reduce the number of centres from 8 to 1 or 2	Could reduce the number of haemophilia centres and thus less access to care
Pharmaceutical companies increasingly offering direct services and support to patients, including websites, activities, IT packages	Funding not available to the Society for these initiatives. Great potential for replication of services and confusion for people with bleeding disorders. The Society not seen as the key agency for this support
Macfarlane Trust much more significantly involved in meeting the psychosocial needs of registrants than it was initially. Business Case predicated on increasing rather than decreasing this type of support	Funding not available to the Society for these initiatives. Potential for replication of services and confusion for people with bleeding disorders. The Society not seen as the key agency for this support
Threats to incapacity benefit may hit people who have bleeding disorders particularly hard as their condition is not well understood	Need for the Society to increase its support to people on benefits and have a targeted campaign, but currently resources for this work are limited
Potential deterioration in the relationships with Department of Health and clinicians in haemophilia centres as the campaign for a public inquiry gathers momentum	This could impact on funding and general levels of support for the organisation's work, with a detrimental effect on people with bleeding disorders

Internal factors

Factor	**Implications/comments**
Limited resources for campaigning and a huge agenda	New communications manager will be recruited to manage the strategy
Limited capacity to support local groups and no capacity to develop work in the regions	New national development officer will be recruited to develop this work. Funding needs to be secured for further outreach work.
Fundraising down in 2005 due to insufficient funding achieved from charitable trusts	Deficit position will be faced in 2006 if funding is not secured
Membership is not increasing at the levels hoped. Current numbers in July 2006 – 4300. Needs of members are not clearly understood	Insufficient membership base makes the Society weaker. Need to review membership and increase numbers in 2006 and beyond
Raisers Edge database is expensive and inadequately used	Donors not supported as well as they could be. Need a donor development plan. Need to review use of Raisers Edge
The Society needs to review its policies covering employment, etc as some are out of date	This represents a risk to the Society at present and the work must be completed quickly
Chairman standing down in 2007.	A succession plan will be put in place during 2006 to address finding a replacement for the current Chairman. A skills audit will be conducted during 2006 to ensure the Board has the appropriate balance of skills needed to enable it to carry out its role. Training for Trustees in roles and responsibilities is being planned for 2006.

FINANCIAL REVIEW

In 2005, the Society started a three year initiative to utilise some reserves on a planned basis. This was intended to facilitate the development of regional outreach. Funding bids were not successful in 2005 and the project has been delayed.

Income generated in 2005 was 14% greater than that in 2004, due mainly to a single unexpected legacy. This enabled the Society to achieve a much smaller deficit than was predicted. Other principal sources of income come from the Department of health, grant giving bodies and trusts, cooperates, sponsors and community fundraising. The restricted funds column in the Statement of Financial Activities shows £179k of income was for particular projects and the Society holds a further £106k which will be used as these projects progress.

Designated Funds

The trustees discussed and agreed funds to be designated for the following purposes:

- Dilapidation Fund intended for the restoration charges and refurbishment of current office accommodation.
- Equipment Fund to contribute towards annual replacement of computer and office equipment.
- Research Fund to be used to contribute to the advancement of scientific and psychosocial research in the field of haemophilia. This is ongoing.
- Scottish Legal Case. The Society's trustees agreed to set aside a portion of funds towards a legal case taking place in Scotland that is expected to bear significantly on the work towards a public inquiry. The sum set aside is £52.3k. The Society will only become liable if the action is unsuccessful and costs are awarded against the plaintiff.

THE HAEMOPHILIA SOCIETY

TRUSTEES REPORT (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

Reserves

The Board has a policy of maintaining six months running costs as free reserves. This is to ensure that the Society has enough resources to fund projects and to meet its financial responsibilities to staff in the event the organisation has to wind up.

The amount of free reserves (including designated reserves but excluding local group funds) held at the end of 2005 was £395,953 which is broadly in line with the plan and is expected to remain so for the foreseeable future.

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 statements, 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 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.

GRO-C

By Order of the Board of Trustees GRO-C
Roddy Morrison, Chairman

9/8/2006

INDEPENDENT AUDITORS' REPORT TO THE

MEMBERS OF

THE HAEMOPHILIA SOCIETY

We have audited the financial statements of The Haemophilia Society for the year ended 31st December 2005 set out on pages 16 to 25. These financial statements have been prepared under the historical cost convention, as modified by the revaluation of investments, and the accounting policies set out on page 18 and 19.

This report is made solely to the company's members, as a body, in accordance with Section 235 of the Companies Act 1985. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report or for the opinion we have formed.

RESPECTIVE RESPONSIBILITIES OF THE BOARD OF DIRECTORS AND AUDITORS

The trustees' responsibilities for preparing the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) are set out in the Statement of Trustees' Responsibilities.

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland).

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 Directors' Report is not consistent with the financial statements, if the 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 company is not disclosed.

We read other information contained in the financial statements, and consider whether it is consistent with the audited financial statements. This other information comprises only the Trustees' Report. 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 AUDIT OPINION

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) 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 judgements made by the trustees' in the preparation of the financial statements, and of whether the accounting policies are appropriate to the Charity's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that 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.

OPINION

In our opinion the financial statements give a true and fair view of the state of the Charity's affairs as at 31st December 2005 and of its incoming resources and resources expended, including its income and expenditure for the year then ended and have been properly prepared in accordance with the Companies Act 1985.

GRO-C

Knox Cropper
Chartered Accountants
Registered Auditors

16 New Bridge Street
London EC4V 6AX

9th August 2006

THE HAEMOPHILIA SOCIETY
STATEMENT OF FINANCIAL ACTIVITIES THE YEAR ENDED 31ST DECEMBER 2005

	Notes	Un-restricted funds	Restricted funds	Endowed funds	Total funds 2005	Total funds 2004
INCOMING RESOURCES		£	£	£	£	£
Voluntary income						
Subscriptions		26,566	-	-	26,566	29,563
Regular giving & donations		44,746	5,149	-	49,895	62,368
Legacies		128,492	-	-	128,492	14,920
Trust Income		34,415	73,226	-	107,641	103,906
Government Grants	2	100,000	10,000	-	110,000	110,000
Special Appeals	3	100	13,722	-	13,822	44,866
Corporate funding		57,409	63,724	-	121,132	134,566
Activities for generating funds						
Annual draw & events		87,716	8,095	-	95,811	54,979
Local groups	4	39,615	-	-	39,615	50,047
Other income	5	12,337	-	-	12,337	13,416
Interest Receivable/Return on Investments		20,253	5,725	-	25,977	22,855
Gain on sale of assets		-	-	-	-	-
TOTAL INCOMING RESOURCES		551,649	179,640	-	731,289	641,486
RESOURCES EXPENDED						
Cost of generating funds						
Fundraising						
Annual draw & events		26,909	-	-	26,909	9,715
Fundraising costs		150,315	-	-	150,315	119,600
	6	177,224	-	-	177,224	129,315
Charitable expenditure						
Research Grants		3,315	29,674	-	32,989	31,871
Costs of activities in furtherance of charity's objects :						
Core membership & Information services		261,466	89,610	-	351,076	284,495
Children & Family Activities		23,439	37,224	-	60,663	37,929
HCV Activities		-	-	-	-	21,107
HIV Activities		-	-	-	-	20,257
International activities		13,308	5,134	-	18,442	16,468
Group activities		60,467	-	-	60,467	40,063
Support of Groups		21,168	-	-	21,168	29,810
Support costs	7	46,206	-	-	46,206	42,593
Management & Administration	8	8,405	-	-	8,405	4,648
		437,774	161,642	-	599,416	529,241
TOTAL RESOURCES EXPENDED		614,998	161,642	-	776,640	658,556
NET INCOMING/(OUTGOING) RESOURCES		(63,349)	17,998	-	(45,351)	(17,070)
Unrealised gains on investments		21,449	-	-	21,449	7,986
Net movement in Funds		(41,900)	17,998	-	(23,902)	(9,084)
Fund balance brought forward at 1st January 2005		495,150	88,327	19,344	602,821	611,905
Fund balance carried forward at 31st December 2005		£453,250	£106,325	£19,344	£578,919	£602,821

THE HAEMOPHILIA SOCIETY

BALANCE SHEET

AS AT 31ST DECEMBER 2005

	Notes	2005		2004	
		£	£	£	£
FIXED ASSETS					
Tangible assets	10		36,228		12,630
Investments	11		192,068		170,619
			228,296		183,249
CURRENT ASSETS					
Debtors	12	42,488		32,536	
Cash at Bank and in hand		386,671		523,883	
		429,159		556,419	
CREDITORS: Amounts falling due *within one year*					
Creditors	13	(78,536)		(136,847)	
NET CURRENT ASSETS			350,623		419,572
			£578,919		£602,821
FUNDS					
Unrestricted General Funds	14		273,703		311,079
Designated funds	14		122,250		100,000
Local Group funds	14		57,297		84,071
Restricted funds	15		106,325		88,327
Endowed funds	16		19,344		19,344
			£578,919		£602,821

Approved by the Board of Trustees on *and signed on its behalf by:*

GRO-C

Roddy Morrison, Chairman

9/8/2006

The notes on pages 18-25 form part of these accounts.

THE HAEMOPHILIA SOCIETY

NOTES FORMING PART OF THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31ST DECEMBER 2005

1. ACCOUNTING POLICIES

a) **Basis of Preparation of Accounts**
The accounts are prepared under the historical cost convention with the exception of investments which are disclosed at market value and in accordance with the applicable accounting standards and the Statement of Recommended Practice 2000, Accounting and Reporting by Charities.

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 cost 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 basis:

Freehold Buildings	2% per annum, straight line
Office Equipment and Furniture	25% per annum, straight line
Leasehold Property	Over life of lease
Leasehold Improvements	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 income and expenditure account in the year in which they arise.

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.

1. ACCOUNTING POLICIES (Continued)

i) **Group Funds**
The Society is represented throughout the country by Local Groups. Group funds are incorporated into the Society's financial statements.

j) **Management and Administrative 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.

l) **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

£100,000 was received under section 64 Charitable grants from The Department of Health as core grant.

	2005	2004
	£	£
Core Grant	100,000	100,000
Scottish Executive	10,000	10,000
	£110,000	£110,000

THE HAEMOPHILIA SOCIETY

NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

3. SPECIAL APPEALS

	2005 £	2004 £
Jeans for Genes	13,822	44,866
	13,822	£44,866

4. LOCAL GROUP FUNDS

Net Expenditure of the Branches amounted to £20,852 excluding transfers to Haemophilia Society (Net Income of £9,984 in 2004). Local group transfers (donations to the Society totalled £5,922 (£7,922 in 2004) and were allocated for the following purposes:

	2005 £	2004 £
Children & Family Activities	-	1,020
Women & Bleeding Disorders	-	1,200
Research	-	200
Unrestricted	5,922	5,502
	£5,922	£7,922

5. OTHER INCOME

	2005 £	2004 £
Gift Aid	12,230	12,618
Other Income	107	798
	£12,337	£13,416

6. FUNDRAISING COSTS

	2005 £	2004 £
Fundraising Salary Costs (inc Pension & NIC)	48,941	55,142
Merchandise	25,784	8,805
Annual Draw	1,125	910
Public Relations	35,056	-
Other Fundraising costs	66,318	64,458
	£177,224	£129,315

THE HAEMOPHILIA SOCIETY

NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

7. SUPPORT COSTS

	2005 £	2004 £
Office Overheads	5,471	5,043
Charity Administration	16,753	15,443
Salary Core Costs	23,982	22,107
	£46,206	£42,593

8. MANAGEMENT & ADMINISTRATION

	2005 £	2004 £
Audit Fee	4,618	3,995
Accountancy	1,645	204
Professional Legal Fees	2,142	450
	£8,405	£4,648

9. STAFF COSTS

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

	2005 No.	2004 No.
Direct Charitable Expenditure	6	6
Fundraising	2	2
Management and Administration	1	1
	9	9

The aggregate staff costs were:

	£	£
Wages and Salaries	252,797	227,282
Social Security	26,458	23,344
Employers Pension Contribution	8,635	9,224
	£287,890	£259,850

During the year, 12 trustees (2004: 12) received £3,337 (2004: £1,985) reimbursements for travel expenses incurred.

No employees received emoluments greater than £50,000 during 2005.

THE HAEMOPHILIA SOCIETY

NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

10. TANGIBLE FIXED ASSETS

	Leasehold Improvements £	Computers and Office Equipment £	Total £
Cost			
At 1st January 2005	-	123,423	123,423
Additions	9,606	21,455	31,061
Scrapped	-	(103,889)	(103,889)
At 31st December 2005	£9,606	£40,989	£50,595
Accumulated Depreciation			
At 1st January 2005	-	110,793	110,793
Charge for the Year	864	6,599	7,463
Eliminated on scrapping	-	(103,889)	(103,889)
At 31st December 2005	£864	£13,503	£14,367
Net Book Values			
At 31st December 2005	£8,742	£27,486	£36,228
At 31st December 2004	£ -	£12,630	£12,630

11. INVESTMENTS

	2005 £	2004 £
COIF Investments		
At 31st January 2005	170,619	162,633
Unrealised gain on Investments	21,449	7,986
Carried Forward at 31st December 2005	£192,068	£170,619

12. DEBTORS

Debtors	11,942	11,243
Prepayments	19,222	11,096
Accrued Income	11,020	10,062
Pensions	304	135
	£42,488	£32,536

13. CREDITORS

Trade Creditors	16,969	16,835
Other Creditors	30	23,000
Deferred Income (including membership fees in advance)	8,414	71,112
Accruals	46,006	17,292
Other Tax & Social Security	7,117	8,608
	£78,536	£136,847

THE HAEMOPHILIA SOCIETY

NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

14. UNRESTRICTED FUNDS

	Balance 01.01.05	Incoming	(Outgoing)	Gains/ Losses	Transfer Between Funds	Balance 31.12.05
Designated Funds:	£	£	£	£	£	£
Dilapidation Fund	50,000	-	(15,000)	-	(20,000)	15,000
Research Fund	50,000	-	-	-	-	50,000
Equipment Fund	-	-	-	-	5,000	5,000
Legal Case Fund	-	-	-	-	52,250	52,250
	100,000	-	(15,000)	-	37,250	122,250
Local Groups	84,071	39,615	(66,389)	-	-	57,297
General Funds	311,079	512,034	(533,609)	21,449	(37,250)	273,703
	£495,150	£551,649	£(614,998)	£21,449	£ -	£453,250

The Dilapidation Fund is intended for dilapidation charges and necessary refurbishment of the Hatton Garden office accommodation, upon vacation, to restore the premises to the condition they were in when initially occupied by the Society. The **Designated Research Fund** is to be used to contribute to the advancement of scientific research in the field of Haemophilia. The **Equipment Fund** is for the renewal of computer and office equipment. The **Legal Case Fund** is to fund potential costs in connection with a legal case in Scotland (See Note 20).

15. RESTRICTED FUNDS

	Balance 01.01.05	Incoming	(Outgoing)	Balance 31.12.05
	£	£	£	£
Research	33,580	6,421	(29,674)	10,327
Scottish Development Project	18,728	10,990	(5,569)	24,149
Twinning Project	5,243	247	(34)	5,456
Women and Bleeding Disorders	4,571	20,581	(5,152)	20,000
Children & Families	25,404	32,807	(37,224)	20,987
Core Membership and Info Services	-	77,475	(77,475)	-
South West Project	-	24,567	-	24,567
Awards	-	1,414	(1,414)	-
Indian Child Appeal	801	5,138	(5,100)	839
	£88,327	£179,640	£(161,642)	£106,325

15. RESTRICTED FUNDS (Continued)

Research
The Research fund is to be used to contribute towards the advancement of scientific research in the field of Haemophilia and related bleeding disorder.

Scottish Development Project
This fund is used to finance outreach work in Scotland.

Twinning Project
The UK Society has been twinned with the Russian Haemophilia Society for over five years. Through the arrangement the UK supports the development of the Russian Society through exchange of know-how, information and training.

Women and Bleeding Disorders Project
The Society has been raising funds for an education project which aims to raise awareness of the particular needs of women and girls who may be affected by a bleeding disorder as a carrier of the haemophilia gene, through having von Willebrands disorder, or as a parent, partner or carer of someone with a bleeding disorder.

Children and Families Fund
This fund is used for all our children and families activities including childcare at events and adventure holidays.

Membership and Information Fund
This fund is used for our membership and information services which include our telephone helpline and publications. It is also used to give hardship grants to individuals needing financial assistance.

South West Project
This project is part of a plan of programme of regional outreach and is designed to reach out to people living with Bleeding Disorder in the South West and their families.

Philip Morris 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 Philip's 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.

GRO-A ***Memorial Award Fund***
This is a bursary awarded to an individual with Haemophilia or related bleeding 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.

Indian Child Appeal
The Indian Child Appeal was set up in 2003, in collaboration with Haemophilia Federation in India. This fund is used to sponsor children with Haemophilia to enable them access to treatment so that they could live a full and an active life.

THE HAEMOPHILIA SOCIETY

NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

FOR THE YEAR ENDED 31ST DECEMBER 2005

16. ENDOWED FUNDS

The endowed funds include Philip Morris Art Award Fund and GRO-A Memorial Award Fund. The interest earned on these funds is credited to the relevant restricted fund to fund awards.

17. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Fixed Assets	Net Current Assets	Total
	£	£	£
Endowed Funds	-	19,344	19,344
Restricted Funds	-	106,325	106,325
Unrestricted Funds	228,296	45,407	273,703
Designated Funds	-	122,250	122,250
Local Group Funds	-	57,297	57,297
	£228,296	£350,623	£578,919

18. LIMITED BY GUARANTEE

The Society has no share capital and is limited by guarantee. The liability of each of the twelve trustee members is a maximum of £1.

19. LEASE COMMITMENTS

At 31st December 2005 the company had annual commitments under operating leases as set out below. The figures stated are the amounts payable in the following year.

	2005		2004	
	Land and Building	Other	Land and Building	Other
	£	£	£	£
Operating Leases that expire:				
Within one year	-	-	-	-
In the second to fifth years	-	-	-	-
Over five years	51,718	11,895	25,859	6,622
	£51,718	£11,895	£25,859	£6,622

In January 2005 the society entered into a new lease for premises in Hatton Garden. Under the terms of the lease there is a rent free period for six months following which period the annual rent is £51,718 inclusive of VAT.

20. OTHER COMMITMENTS

The trustees have agreed to fund the legal costs up to a maximum of £52,250, of a case being brought against the Scottish Parliament calling for a judicial review by the families of 4 individuals who died of Hepatitis C. The case is due to take place in August 2006 and legal costs will arise should the case be unsuccessful. A designated fund has been set up for this purpose. (See Note 14).