Witness Name: Katherine Victoria Burt Statement No: WITN6392001 Exhibits: WITN6392002 - WITN6392267

# INFECTED BLOOD INQUIRY

# WITN6392052

THE HAEMOPHILIA SOCIETY (A COMPANY LIMITED BY GUARANTEE) CHARITY REGISTRATION NUMBER: 288260 SCOTTISH CHARITY REGISTRATION NUMBER SC039732 COMPANY REGISTRATION NUMBER: 01763614

> REPORT AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

# FINANCIAL STATEMENTS

# FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

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# **REFERENCE AND ADMINISTRATIVE INFORMATION**

# FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

PRESIDENT	Baroness Molly Meacher
VICE PRESIDENT	Rt. Hon Frank Field MP Dr Peter Jones Baroness Masham of Ilton DL The Reverend Alan Tanner OBE Professor the Lord Winston
CHIEF EXECUTIVE	Liz Carroll
BOARD OF TRUSTEES	Richard Brook Alan Burgess (from November 2014) Helen Campbell (from November 2014) Adam Fleming (to September 2014) Lynne Kelly (to June 2014) Kate Khair Bernard Manson – Chair Andrew Martin Simon Mower GRO-A Bill Payne Barbara Scott Jeremy Young

**SUB COMMITTEES** 

Resources & Audit Sub Committee

Bernard Manson Simon Mower – Chair Barbara Scott Jeremy Young

Nominations Committee

Helen Campbell Liz Carroll Bernard Manson Barbara Scott Jeremy Young

## **REFERENCE AND ADMINISTRATIVE INFORMATION (Continued)**

### FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

## **CLINICAL ADVISORY GROUP**

Dr Rezan Abdul-Kadir Dr Gary Benson Dr Andrew Brewer Susan Hook Robert James Dr Kate Khair Dr Mike Laffan Dr Mike Makris Andrew Martin Debra Pollard Mark Simmons David Stephenson

COMPANY SECRETARY

Liz Carroll

**REGISTERED OFFICE** 

Ground Floor Willcox House 140 – 148 Borough High Street London SE1 1LB

COMPANY REGISTRATION NUMBER 1763614

CHARITY REGISTRATION NUMBER 288260

SCOTTISH CHARITY REGISTRATION NUMBER SC039732

BANKERS

The Co-operative Bank Plc Relationship Accountant Support Service Team PO Box 250 Skelmsdale WN6 6WT

SOLICITORS

Stone King LLP 13 Queen Square Bath BA1 2HJ

AUDITORS Knox Cropper 8/9 Well Court London EC4M 9DN

# **Chair's Statement**

We are the only UK-wide charity for everyone affected by an inherited bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For 65 years we have campaigned for better treatment, been a source of practical information and support, and enabled people living with long-term conditions to:

- lead fulfilling lives
- make informed choices about their treatment and care
- support and inspire others to do the same.

We also continue to advocate for a fair settlement and access to the best possible health and social care for those members of our community affected by the contaminated blood disaster. Membership of The Haemophilia Society is free and open to all.

Almost 26,000 men, women and children in the UK have a diagnosed inherited bleeding disorder. Of these, around 10,200 have von Willebrand disease and around 6,800 have haemophilia. There are also around 1,800 carriers of haemophilia who are recorded in the National Haemophilia Database as having low levels of factor; they may experience bleeding themselves. The balance is made up of people with rarer bleeding disorders.

This has been a year of substantial progress for the charity, building on the changes started last year. The new management team under our CEO Liz Carroll is now fully in place, and we have agreed a strategy developed after consultation with members and begun work on a three-year plan. The Trustees' Report details services we have delivered during the year, and demonstrates our increase in activity since 2013/2014.

In recent years the charity has had an excess of expense over sustainable income, but as reported in the Financial Review we have diversified and increased sustainable funding despite the ending of our annual government grant, while at the same time the move to new premises along with a review and renewal of all of our supply contracts has substantially reduced our fixed cost base. We have professionalised our measurement of the impact of our service provision, and this has already had a positive effect on the willingness of funders to support our projects. In the current financial climate, fundraising continues to be a core issue for the charity, but we are confident that we are on a path to increase income to fully cover expense by 2016/2017; meanwhile we have adequate reserves to cover the budgeted shortfall for next year.

A disappointing feature of the year has been the late delivery of the Penrose Report into Contaminated Blood and its unsatisfactory conclusion contradicting the detailed evidence the report itself presents.

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This has contributed to delay in the Government acting on the Prime Minister's promise to review the settlement for those suffering the impact of contaminated blood.

The Society continues to advocate for a speedy review and revision of the settlement, based firmly on independent analysis of the needs of those affected.

An important initiative this year has been our initiation of a Burden of Illness study into the cumulative impact of severe haemophilia across all aspects of life. This will be by far the largest study of its type and will become an important resource for economic analysis of treatments when it reports in the third quarter of 2015.

As Chair, I have had the opportunity to see how many people, paid and unpaid, have contributed to the work of the Society. I would like to thank all of them, including our staff, who work far beyond what we could reasonably expect, our trustees, member volunteers in many areas, clinicians who support events, review articles or provide advice, MPs who support the work of the APPG, our President Baroness Meacher, those who are helping plan the Glasgow WFH Congress, those who have raised funds for the charity and those who have donated, and our many commercial sponsors. Without the contribution of all of these people we simply could not function.

I have been honoured to be Chair of the Society and am proud of what we have achieved over the last few years. As announced last year, I am stepping down as Chair soon; this is so that my successor, to be appointed in September 2015, has a full handover and is equipped to lead the charity in the two-year run-up to our welcoming the world to the WFH Congress in Glasgow in 2018. With the new strategy in place under our superb CEO Liz and the growing engagement of our members, I am confident that the Society will continue to go from strength to strength.



Bernard Manson

GRO-C

Chair of the Board of Trustees, The Haemophilia Society

# **Our Vision, Mission and Values**

Our vision: Wellbeing for everyone with a bleeding disorder.

**Our mission:** For all those affected by bleeding disorders, we will provide information and services; build community and mutual support; influence government health and welfare policies, including advocating for those impacted by contaminated blood; and involve people in making decisions about their own care.

**Our values:** We relate everything we do to the needs of everyone affected by bleeding disorders; act with integrity, honesty and transparency; make the best use of our resources; and are inclusive and independent.

# **Trustees' Report**

# **Public benefit statement**

The Haemophilia Society's services are available to everybody affected by inherited bleeding disorders in the UK. We have almost 5,000 members; membership is open to all, with no charge, and services are open to members and non-members alike. We provide social, psychological, and practical support, complementing the care given by the NHS and bringing people together to reduce the isolation many of our community experience. We advocate to ensure levels of NHS service are maintained and improved, and encourage patients to become involved in decision making about their own treatment. We are recognised by the government as a key patients' representative promoting informed patient involvement in monitoring and developing services.

The trustees have paid due regard to the Charity Commission guidance on public benefit when reviewing the charity's objectives and activities.

# Specific activities providing public benefit include:

- Providing information, services and support on all aspects of inherited bleeding disorders, enabling people to live well and make informed decisions about their own treatment and care. Information is provided at service events, by phone and email, and through a website, very active Facebook pages, leaflets on specific aspects of bleeding disorders, a network of local groups, and publications.
- Running day and residential events for different groups of people with bleeding disorders in order to provide social support and education. For example, during the year we ran two weekends for parents with children newly diagnosed with bleeding disorders and weekends for children and teenagers with bleeding disorders, and held our first public awareness campaign for women with bleeding disorders. We also held an information day for people infected with Hepatitis C by contaminated blood products in the 1970s in 1980s.

- Ensuring that the patients' viewpoint is heard in key NHS and Department of Health forums, for example on the Clinical Reference Group for Haemophilia.
- Escalating issues of provision of care to the NHS government health teams.
- Advocating for fair treatment and support for those impacted by the contamination of blood products supplied by the NHS in the 1970s and 1980s.
- Commissioning research with the intention of benefiting those with bleeding disorders, for example the Burden of Illness study on the impact of haemophilia which was initiated during the year.

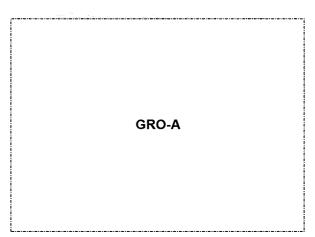
# **Services and Activities**

## Newly diagnosed weekends

This year we were able to build on the learning from our pilot services in 2013 to improve our weekends for newly diagnosed families. We held two weekends, bringing together 32 families comprising 62 adults and 64 children.

The weekends enabled families to learn from each other and from haemophilia experts. Each weekend gave the opportunity to hear from a haemophilia consultant, a physiotherapist, and a specialist paediatric haemophilia nurse. Topics included what a diagnosis means, living with a bleeding disorder, treatments and the importance of physiotherapy. There were also opportunities for mums and dads to separate and have a facilitated discussion about their feelings, coping strategies and the issues they face following the diagnosis of their child. Common themes emerged: for mums, feelings of guilt for passing on an affected gene or not spending enough time with the rest of the family, or frustration over having to stop working and always be on call. There were also discussions about being constantly on guard and fearful of anyone else looking after their child. Dads discussed feelings of isolation and uncertainty about the future, as well as sadness about how their relationship with their son or daughter may be affected by their diagnosis. The weekends were held at Center Parcs to take the event away from a hospital setting; families could feel part of normal life, children could be cared for and parents could relax.

For many families the weekend was the first time they had dared to stay away home following their child's diagnosis and for almost every mum, the first time someone else had looked after their child. The highlight of the weekend for many was the involvement of our new Youth Ambassadors. The Youth Ambassadors all have a bleeding disorder themselves and were able to talk about the ups and downs in their life, as well as showing parents how they gave themselves clotting factor treatment.



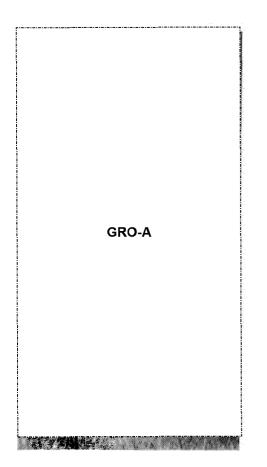
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'The weekend at Sherwood Forest really exceeded our expectations and more. I just feel like a massive weight has been lifted, which I never knew was actually there. I think as a parent with a child of any condition you get fixated on them as they are your world and you then forget about yourself and how it's actually affecting you. It was a very emotional weekend, but in a positive way.'

'Our present experience of haemophilia is a very positive one, which I have to say is mostly down to The Haemophilia Society and the support and direction you have provided, most of all during the weekend.'

### **Activity weekends**

Some children with a bleeding disorder experience isolation, and parents can struggle to have the confidence to let their children be active and participate in certain school activities. Some children and parents find it difficult to cope with learning to self-treat. We ran two activity weekends this year, one for children aged 8–13 and another for teenagers. Twenty-six young people attended our weekends; this included siblings as well as those with a bleeding disorder. A diagnosis has just as big an impact on brothers and sisters and we know it is important to invite them too. The first weekend for the younger children was in Preston where the children took part in abseiling, archery, and go-karting, and got thoroughly soaked during a raft building and sailing finale to the weekend.



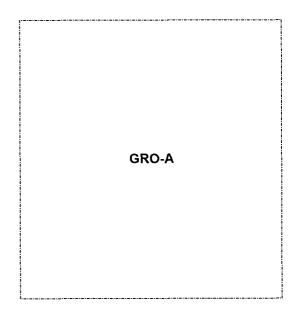
However, the biggest impact came in the quieter moments. At the campfire session the children were encouraged to talk about what it feels like to have a bleeding disorder and to ask any question they wanted. The session was facilitated by specialist nurses and the conversations ranged widely, from 'how do you describe it to your friends?' to 'who do you tell?' and 'why do I bleed differently to you?' There was an interesting discussion about the difference in clotting between haemophilia and von Willebrand Disease.

We also encouraged the children who didn't already treat themselves to have a go. Everyone had treatment together, sharing tips, discussing techniques and learning from each other. We also asked the children a few questions before and after the weekend which showed that the event clearly had a positive impact. **GRO-A** (8) summed up the weekend as "*My best holiday ever*!!"

At the beginning of the weekend 40% of the children didn't know what bleeding disorder they had compared to 28% at the end of the weekend.

Before the weekend 84% would tell someone if they had a bleed (those that didn't said it was so they could keep playing or do sport). Afterwards 99% said they would tell someone as they understood why early treatment was important.

The 'Big Teen weekend' had a similar impact. For example, GRO-A (15) commented: 'it was so much better than sitting at home watching Netflix'. During the weekend the teenagers worked together as a team, gaining new skills, supporting each other physically and emotionally and growing in confidence, joined and encouraged by a Youth Ambassador.



'I thought you might like to know that the big weekend continues to help here. Our son is happy about treating himself again. He got far more out of the weekend than just having a great time doing the activities. It's hard to explain exactly, but he is now confident at expressing what he needs to look after himself and is much more self-assured generally about having haemophilia.'

### **Global family get together**

GRO-A

During the summer our 'Global family' met. Global family is our service for families who feel particularly isolated due to their bleeding disorder. This may be due to belonging to a community where any ill health is seen as unacceptable, or where someone lives far from their relatives or is a single parent. The (indoor) picnic to bring people together in a safe environment was a riot of food, colour, fun and games. For many of the children attending this was the first time they had been able to speak with anyone else about their bleeding disorder, and for parents a first opportunity to share their concerns and feelings.

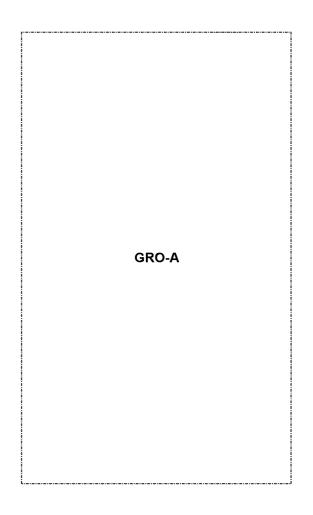
## World Haemophilia Day

GRO-A

We celebrated World Haemophilia Day with a radio campaign to raise awareness of bleeding disorders and with The Buddy Awards. The Buddy Awards enable young people to nominate someone who has helped and supported them through tricky times with a bleeding disorder. Brothers and sisters, teachers, nurses and friends were all nominated. Two hundred guests attended and celebrity children's entertainers Dick and Dom presented the awards. The Buddy Awards are a fantastic opportunity to recognise and thank the people who support our community.

## **Talking Red**

We know that hundreds of thousands of women in the UK may be living with a bleeding disorder and not know. Symptoms can include easy bruising, heavy menstrual bleeding or frequent nose bleeds. In June we launched our first Talking Red Campaign, where we encouraged women with a bleeding disorder to talk about it with family and friends, and launched an awareness media campaign. Women across the UK shared their stories on social media, painting their nails red and joining in our awareness-raising Red Knicker night. Our press coverage for the campaign reached people across the UK with lots of stories in local papers and The Daily Mail. The campaign had a direct impact, as evidenced by women who contacted the Society having seen the stories, took the information we had shared to their GP and were referred to a haemophilia centre after many years of being told their symptoms were normal. Some were subsequently diagnosed with a bleeding disorder.



## **Contaminated blood**

Many of our older members were infected with multiple viruses including Hepatitis C and HIV through their NHS treatment in the 1970s and 1980s. We continue to work with the community affected to support them in living with complex multiple conditions. We continue to advocate on their behalf to government, the Department of Health and the NHS to ensure they receive the support and care they deserve and need. This year we held our first Hepatitis C information days in partnership with the Hepatitis C Trust. For many of those infected, the stigma of infection and fear of others' reaction leads to isolation and lack of support. Our information days enabled the participants to meet in a safe environment and learn more about living well with hepatitis C and haemophilia. The day included information on nutrition and maintaining your health, with excellent evaluations. The participants had often not spoken about their infection to others and built relationships over the events that have since continued.

The Society is also the secretariat for the APPG (All Party Parliamentary Group) on Haemophilia and Contaminated Blood and we work closely with them to ensure the voice of those affected by contaminated blood is strongly heard in parliament. The Society and MPs frequently hear from people who have struggled to negotiate the complex and often distressing system of Trusts set up to provide financial support to the people affected. This year we encouraged and supported the APPG to undertake an inquiry into the current support for those affected by the contaminated blood scandal in the UK. The Society funded the survey and report publication and has used the findings to advocate to government. We worked closely with Diana Johnson MP and Jason McCartney MP, then co-chairs of the APPG, and with the Rt Hon Alistair Burt MP who has been particularly supportive and influential in bringing about positive steps towards a new and improved package of support for the community. The report was launched in parliament in January, followed by a three-hour backbench debate, where MPs from across the House showed their support and commitment to the community. The report is available on our website.

### The Society online

During the year we launched our new website, which we continue to develop and update. The website has information on living with a bleeding disorder, including benefits, travel insurance, personal stories and information about our events and activities. It also provides information approved by our clinical advisory group on medical aspects of the different bleeding disorders. www.haemophilia.org.uk

Our social media presence continues to grow, with over 6,000 participants on our three Facebook pages and groups. The pages are very active, with members sharing experiences, seeking and giving support and sharing thoughts on the work of the charity.

### Worldwide connections

We continue to work with government and with the NHS, particularly with the UK Haemophilia Centre Doctors' Association (UKHCDO) and the Haemophilia Nurses Association. As members of the NHS Clinical Reference Group, NHS Tender procurement groups and Department of Health Blood Safety Consultative Committee, we are able to influence decision making about quality and safety of care as well as to ensure the patient voice is represented.

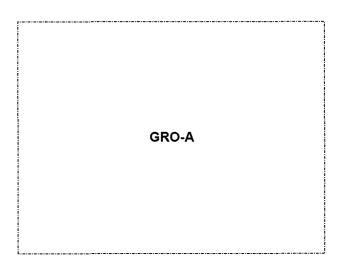
We are also active members of the European Haemophilia Consortium (EHC) and The World Federation of Hemophilia (WFH). During the year, staff and trustees attended WHF events, including the WFH Congress 2014, where we heard from experts about developments in treatment, care and support across the world; feeding into our activities on behalf of our members. These events also provided opportunities to build relationships with other Societies across the world and learn from others' experiences, for example in relation to our Talking Red Campaign and new Youth Ambassador Programme. EHC training events have enabled staff and trustees to learn about particular issues such as von Willebrand Disease, inhibitors and economics of health technology. In October we were fortunate to host the EHC annual conference in Belfast, thanks to the hard work of Gordon Clarke, a leading member of EHC and WFH over many years. Gordon's dedication to the community enabled us to sponsor two members from mainland UK to attend as well as sponsoring places for 50 members from Northern Ireland. The conference was a huge success and provided inspiration for our strategy development at our AGM in November.

### **Burden of Illness study**

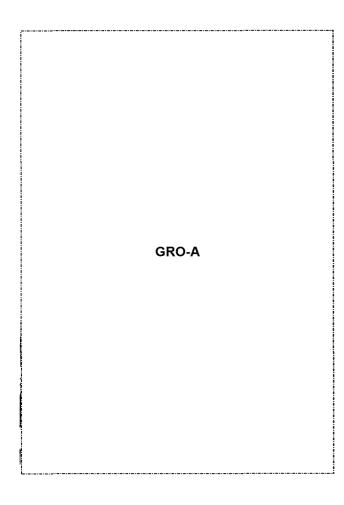
In 2013 we started work on the Burden of Illness study on haemophilia. In 2014 we reached agreement with an academic partner and the study was named CHESS: The 'Cost of Haemophilia across Europe: a Socioeconomic Survey' and will be by far the largest study of its type. Liz Carroll chaired the steering group for the study, which included colleagues from the Societies in the other EU countries where the study was undertaken (France, Spain, Germany, Italy). Chester University led the study and employed Health Care Decisions (HCD) Ltd. to undertake the research. This was not the Society's first choice of partner, as trustee **GRO-A** is a Director of HCD; however the Charity Commission approved the decision to partner with Chester University and agreed the Society had acted appropriately and had not provided any personal benefit to our trustee. Recruitment of patients was well underway as the year ended in March 2014. Our thanks go to **GRO-A** for driving this study forward including sourcing the funding and enabling the Society to initiate such an important research study for our community. Results are expected to be published in summer 2015 and we hope to use these to influence key decisions on health and social care, as well as contributing to the world's understanding of the true impact of severe haemophilia.

# **Local Groups**

Our Local Groups continue to grow and develop with many holding social, fundraising and educational activities during the year. These ranged from the 'Nippy Dipper' in Grampian – an annual Boxing Day fancy dress dash into the North Sea – to a family fun day to bring families with bleeding disorders together for support in Bournemouth. Our thanks go to the volunteers who run our local groups; the support and encouragement they give to members in their local communities is invaluable.

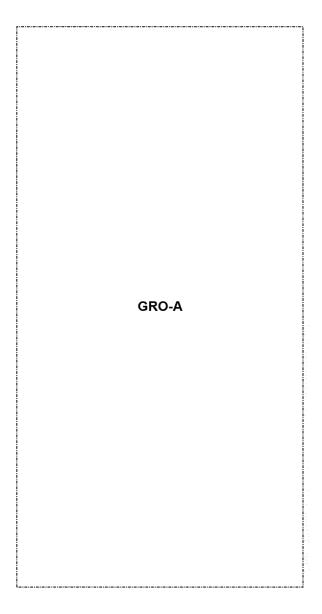


# **AGM and Conference**



The 2014 AGM and Conference was our largest for many years, with over 100 members of all ages attending. The AGM dealt with the formal business of the Society and was followed by our 'Fit for the Future' conference. Members heard from our new celebrity ambassador, Paralympic swimmer Jack Bridge, and our Celebrity Supporter gold-medallist cyclist, Alex Dowsett. Both Alex and Jack have severe haemophilia and are role models for many members of the bleeding disorder community. The conference enabled members to attend workshops on ageing and haemophilia, Talking Red - women and bleeding disorders, sticking with treatment even when you don't want to, learning to selftreat and singing for your soul. There was also a chance to swim with Jack and cycle with Alex. During the day we asked members to help us prioritise the services they felt we should focus on in the next three years; this helped shape the long-term plan we finalised later in the year.

# Fundraising



With no government funding and an increasingly challenging fundraising environment, the Board of Trustees approved increased spending on fundraising staff and activities; this is already enabling us to diversify our funding streams and to increase our income in a sustainable way. This year we extended the range of fundraising activities for our supporters to take part in with our very first Challenge event - Trek Iceland where 11 trekkers braved high winds and freezing temperatures to raise £37,000 for the Society. We also had a significant increase in the number of people running marathons, cycling and holding community fundraising events; these included an exceptionally wet Ride London 100-mile cycle ride and a very chilly Santa Run. Investing in fundraising has been an important decision this year, which we believe will improve our financial sustainability. Thank you to everyone who has pushed themselves to their limits, raised funds, organised events and sponsored our activities. Without your support we would not be able to provide the much needed information and support we do.

# We remember

We remember our members, friends and volunteers who have died during the year; they have left us with hope and determination: hope that we can provide information and support for our members to lead positive lives and determination to ensure that the tragedies of the past are resolved and will never happen again.

# **Financial Review**

The charity had net outgoing resources on general unrestricted funds, a deficit, of £42,444, for the year.

Together with the accumulated surplus brought forward from previous years, the charity now has an accumulated surplus on general unrestricted funds of £746,887 (2014: £791,145) together with designated funds of £57,925 (2014: £56,111).

Restricted funds carried forward at 31 March 2015 amounted to £62,203 (2014: £81,358) and Endowed funds carried forward amounted to £19,344 (2014: £19,344). This is sufficient for the activities for which the funds were provided.

# **Reserves policy**

Our aim is to maintain reserves at six months' worth of costs to ensure that the Society has a prudent level of resources to fund projects and to meet its financial responsibilities during periods of uncertain or fluctuating income streams. Free reserves, general reserves less fixed assets, currently stand at £706,221.

Under the Memorandum and Articles of Association the Trustees may invest surplus funds in any investment they consider appropriate. To this end we have invested in COIF Investment Funds, which invest based on a diversified and prudent investment strategy to mitigate concentration of risk. The total investments of the Charity at 31 March 2015, including deposits, totalled £802,916 (2014: £782,233).

### **Risk Management**

The Trustees have assessed the major risks to which the charity is exposed, in particular those related to the operations and finances of the charity, and are satisfied that systems and procedures are in place to mitigate our exposure to the major risks.

# **Statement of Trustees' responsibilities**

The Board of Trustees are responsible for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable UK 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 presume that the charitable company will continue in business.

The Board of Trustees, who are also directors of the Company for the purposes of the Companies Act, and trustees for charity law purposes, confirms that the annual report and financial statements of the charity comply with current statutory requirements, the requirements of the charity's governing document and the provisions of the Statement of Recommended Practice "Accounting and Reporting by Charities" issued in March 2005.

The Haemophilia Society is a registered charity in England (number 288260) and Scotland (number SC039732) and company limited by guarantee (number 01763614). The Haemophilia Society's governing document is its Memorandum and Articles of Association.

The Board of Trustees have overall responsibility for ensuring that the Charity has an appropriate system of controls, financial and otherwise. They are also responsible for keeping adequate 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 2006, the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the governing document. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the detection and prevention of fraud and other irregularities.

The Board of Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

In so far as the Trustees are aware

- there is no relevant audit information of which the charitable company's auditor is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information

This report was approved and authorised for issue by the Board of Trustees on  $10 \frac{10 \text{ Sec. 2015}}{\text{Sec. 2015}}$  and signed on its behalf by:

GRO-C	

Bernard Manson

Chair

### 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 March 2015 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. 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 auditor's 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 opinions we have formed.

#### Respective responsibilities of trustees and auditor

As explained more fully in the Trustees' Responsibilities Statement the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors.

#### Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements.

In addition, we read all the financial and non-financial information in the Trustees' Report to identify material inconsistencies with the audited financial statements. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

#### **Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31st March 2015 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

#### Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' Annual Report for the financial year for which the financial statements are prepared is consistent with the financial statements.

### INDEPENDENT AUDITORS' REPORT TO THE

### MEMBERS OF

### THE HAEMOPHILIA SOCIETY (CONTINUED)

#### Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the charitable company has not kept proper and adequate accounting records; or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

**GRO-C** 

Kevin Lally (Senior Statutory Auditor) For and on behalf of Knox Cropper Chartered Accountants Statutory Auditors

8/9 Well Court London EC4M 9DN

Date: 10" September 2015

Knox Cropper Chartered Accountants is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

# THE HAEMOPHILIA SOCIETY STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015 (INCORPORATING THE INCOME AND EXPENDITURE ACCOUNT)

INCOMING RESOURCES FROM GENERATED	Notes	Un- restricted Funds	Restricted Funds	Endowed Funds	Total Funds 2015	Total Funds 2014
FUNDS		£	£	£	£	£
Voluntary income		-	-	-	-	-
Government Grants	2		2	-	-	100,000
Other Grants and Donations	3	378,436	162,185	-	540,621	229,374
Legacies	-	16,129	*	-	16,129	321,051
Activities for generating funds						
Local Group Activities		16,513	*	-	16,513	14,724
Community Fundraising and Events		54,351	2	ian i	54,351	92,783
Investment Income		27,864	#8		27,864	18,934
Other Income						
Other		13,299	**		13,299	9,247
TOTAL INCOMING RESOURCES		506,592	162,185	e e se este 😤	668,777	786,113
RESOURCES EXPENDED Cost of Generating Funds						
Costs of Generating Voluntary Income	4	210,155	48).	-aer	210,155	71,892
Fundraising Trading Costs		1. ju 1. juli	<u>.</u>		<u></u>	4,622
		210,155	*.	***	210,155	76,514
Charitable Activities	5					
Communications	-	126,674	47,672	a.	174,346	137,593
Membership		30,215	 ني	شد	30,215	76,061
Cultivation		51,013	2,186	<u></u>	53,199	- ***
Services		4,685	130,416	÷.	135,101	181,365
International Activities			1884° -	wr,	-	26,302
Advocacy & Influencing		62,734	2,000	*	64,734	10,415
Tanner Fund Grants			838	. ÷	838	12,567
	•	275,321	183,112		458,433	444,304
Governance Costs	7	122,471		. <u></u> .	122,471	117,404
TOTAL RESOURCES EXPENDED	,	607,947	183,122	·	791,059	638,220
NET INCOME/ (EXPENDITURE)		(101,355)	(20,927)		(122,282)	147,892
Transfers between Funds		(101,333)	1,772	-	(122,202)	200, 172 -
Net Movement in Funds		(103,127)	(19,155)	-	(122,282)	147,892
Gain/(Loss) on investments	10	60,683	(10,100)	-	(122,282) 60,683	(2,792)
Net movement in Funds	10	(42,444)	(19,155)	 	(61,599)	145,100
		\~2, <del>~~</del> *;	(13,133)	-	(01,333)	173,100
Fund balance brought forward at 1st April 2014		847,256	81,358	19,344	947, <del>9</del> 58	802,858
Fund balance carried forward at 31st March 2015	*	£804,812	£62,203	£19,344	£886,359	£947,958

The statement of financial activities includes all gains and losses in the year.

 $\label{eq:allincoming} \mbox{ and resources expended arise from continuing activities.}$ 

### **BALANCE SHEET**

# AS AT 31<sup>ST</sup> MARCH 2015

	Notes		March 015	31	<sup>st</sup> March 2014
		£	£	£	£
FIXED ASSETS					
Tangibleassets	9		40,666		40,664
Investments	10		802,916		782,233
			843,582		822,897
CURRENT ASSETS					
Debtors	11	33,505		46,302	
Cash at Bank and in hand	<u></u>	72,240	_	125,495	
		105,745	-	171,797	
CREDITORS: Amounts falling due within one year					
Creditors	12	(62,968)	<b>-</b> ^	(46,736)	
NET CURRENT ASSETS			42,777		<b>125,06</b> 1
			£886,359		£947,958
FUNDS					
Unrestricted General Funds	13		746,887		<b>791,14</b> 5
Local Group funds	13		57,925		56,111
Restricted funds	14		62,203		81,358
Endowed funds	15		19,344		19,344
			£886,359		£947,958

Approved by the Board of Trustees on 10 Spp115 and signed on its behalf by:

GRO-C

Bernard Manson, Chair

The notes on pages 20-28 form part of these accounts.

Company Registration Number 01763614

### **NOTES FORMING PART OF THE FINANCIAL STATEMENTS**

## FOR THE YEAR ENDED 31<sup>st</sup> MARCH 2015

### 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 2005, 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 (support costs) of the charity.

#### e) Cost of Generating Funds

The cost of generating funds is accounted for on an accruals basis. These costs are split between the direct costs of the annual draw and events, and the salaries and other costs of the fundraisers.

### 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:

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.

### NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

# FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

### 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) Governance Costs

Governance 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 together with an apportionment of the general overheads based on an analysis of staff time spent.

#### k) Support Costs

Support costs are costs incurred in the general running of the charity. These costs have been allocated to charitable activities, fundraising and governance based on an analysis of staff time spent.

#### 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

In 2014 The Society received £100,000, the fifth of five yearly capacity building grants, from the Department of Health.

	2015	2014
	£	£
Capacity Building Grant	•	100,000
	£	£100,000

# THE HAEMOPHILIA SOCIETY NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued) FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

### 3. OTHER GRANTS AND DONATIONS

	2015	2014
	£	£
Trust Income	6,150	19,200
Corporate Income	205,077	66,659
Donations from Individuals	314,498	112,818
Gift Aid	14,896	30,697
	£540,621	£229,374

### 4. COSTS OF GENERATING VOLUNTARY INCOME

2015	2014
£	£
41,046	31,320
<b>#</b> .	4,622
110,390	13,927
58,719	26,645
£210,155	£76,514
	£ 41,046 - 110,390 58,719

The Direct Costs in 2015 comprised expenditure in respect of Swim Around Britain (£46,282), Iceland Trek (£21,483), Local Group Fundraising Expenditure (£14,699) and Other Fundraising Activities (£27,926).

## 5. CHARITABLE ACTIVITIES

	Undertaken Directly £	Grant Activities £	Support Costs £	<b>2015</b> £	2014 £
Communications	121,895		52,451	174,346	137,593
Membership	8,120	÷.	22,095	30,215	76,061
Cultivation	31,557	\$- *	21,642	53,199	÷
Services	78,572	÷.	56,529	135,101	181,365
International Activities		-	÷0	-	26,302
Advocacy & Influencing	37,655	**	27,079	64,734	10,415
Tanner Fund Grants		838		838	12,567
	£277,799	£838	£179,796	£458,433	£444,302

Cultivation reflects expenditure on Local Group Activities and developing working relationships with Haemophilia Centres, UKHCDO and haemophilia specialist nurses and physios.

Advocacy & Influencing reflects expenditure on areas such as the All Party Parliamentary Group on Haemophilia and Contaminated Blood, World Federation of Haemophilia and the European Haemophilia Consortium together with legal fees in respect of influencing.

# NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

# FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

### 6. SUPPORT COSTS

	2015 £	2014 £
Office Overheads	206,640	103,127
Charity Administration	31,604	17,669
Salary Core Costs	31,875	71,948
	£270,119	£192,744
Governance Costs	31,604	8,390
Cost of generating voluntary income	58,719	26,645
Cost of charitable activities	179,796	157,710
	£270,119	£192,745
<b>GOVERNANCE COSTS</b>		
	2015	2014
	£	£
Trustee Board	11,107	12,385
Staff çosts	22,750	÷
Audit Fee	5,130	4,665
Exceptional Costs	51,880	91,964
Support Costs	31,604	8,390
	£122,471	£117,404

### 8. STAFF COSTS

7.

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

	2015	2014
	No.	No.
	5.4	7
The aggregate staff costs were:		
	£	£
Salaries	187,278	200,194
National Insurance	20,457	19,551
Employers Pension Contribution	6,498	8,033
Redundancy Costs	18,004	27,078
Interim Chief Executive	-	62,640
Other Interim Staff	67,210	26,793
	£299,447	£344,289

During the year 7 (2014: 11) trustees received £1,514 (2014: £4,780) reimbursements for expenses incurred.

One employee received emoluments of more than £60,000 during the year ended 31 st March 2015 (2014: Nil).

# **NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)**

# FOR THE YEAR ENDED 31<sup>st</sup> MARCH 2015

# 9. TANGIBLE FIXED ASSETS

	Leasehold Improvements £	Computers and Office Equipment £	Total £
Cost			
At 1st April 2014	9,606	64,167	73,773
Additions	-	14,869	14,869
Disposals	(9,606)	(24,239)	(33,845)
At 31stMarch 2015	-	54,797	54,797
Accumulated Depreciation			
At 1 <sup>st</sup> April 2014	8,789	24,320	33,109
Charge for the Year	817	14,050	14,867
Eliminated on Disposal	(9,606)	(24,239)	(33,845)
At 31stMarch 2015		14,131	14,131
Net Book Values			
At 31st March 2015		40,666	40,666
At 31st March 2014	817	39,847	40,664

### 10. INVESTMENTS

	COIF Investment S	Virgin Charity Deposit	Other Equities	31 <sup>st</sup> March 2015	<b>31<sup>st</sup> M</b> arch <b>20</b> 14
	£	£	£	£	£
COIFInvestments					
At 1st April 2014	695,491	85,700	1,042	782,233	573 <i>,</i> 325
Additions		.*	÷	*	211,700
Disposals	(40,000)	, sin,	*	(40,000)	-
Gain/(Loss) on Investments	60,683	in .		60,683	(2,792)
Carried Forward at 31st March 2015	716,174	85,700	1,042	802,916	782,233

# 11. **DEBTORS**

	31 <sup>st</sup> March	31 <sup>st</sup> March
	2015	2014
	£	£
Debtors	22,000	34,446
Prepayments	11,505	11,856
	£33,505	£46,302

### 12. CREDITORS

	31 <sup>st</sup> March	31 <sup>st</sup> March
	2015	2014
	£	£
Trade Creditors	39,837	21,543
Deferred Income	-	8,000
Accruais	23,131	13,525
Other Tax & National Insurance	<b>*</b> 1-	3,668
	£62,968	£46,736

# NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

# FOR THE YEAR ENDED 31<sup>st</sup> MARCH 2015

# 13. UNRESTRICTED FUNDS

	Balance			Gains/		Balance
	01.04.14	Incoming	(Outgoing)	(Losses)	Transfers	31.03.15
	£	£	£	£	£	£
Local Groups	56,111	16,513	(14,699)	<b>.</b>	-	57,925
General Funds	791,145	490,079	(593,248)	60,683	(1,772)	746,887
	£847,256	£506,592	£(607,947)	£60,683	£(1,772)	£804,812

# 14. RESTRICTED FUNDS

	Balance 01.04.14	Incoming	(Outgoing)	Transfers	Balance 31.03.15
	£	£	f f	£	£
Women & Bleeding Disorders	10,546	25,128	(35,674)		
Inhibitors	8,784		(8,784)	2	<b></b>
Ageing, Health & Independence	1,612		(1,612)	2	- <u>-</u>
Rare Bleeding Disorders	7,870		(7,870)	¥	*
Von Willebrand Projects	15,000	<i>2</i>	~	ü	15,000
Tanner Fund	3,927	520	(838)		3,609
Memorial Service	4,977	11,273	(691)	<u>ش</u>	15,559
Cornwall and Devon	46	÷.	(46)		#1
Local Group Forum Event	5,148	5,000		÷	10,148
South Central Activities Fund	1,135	*.	(1,135)	Ψ.	æ?-
London & South Group	1,005		(1,005)		
WFH Close the Gap	1,000	1,000	(2,000)	-	<b>.</b>
Belfast Event	2,219	- 1999 -	(2,219)	-	Ť
Thrombosis & Haemophilia					
Conference	689	-	-	-	689
Newly Diagnosed	17,400	15,000	(34,172)	1,772	-
Youth Activity & Teen					
Weekends	-	31,420	(14,222)	-	17,198
Website	-	10,500	(10,500)	-	-
Reader Panel	*	5,000	(5,000)	-	-
Swim Around Britain	-	54,344	(54,344)	-	-
World Haemophilia Day		3,000	(3,000)	-	-
	£81,358	£162,185	£(183,112)	£1,772	£62,203

#### NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)

### FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

# These Restricted Funds are:

#### Women and bleeding disorders

Funding to support women with bleeding disorders, including carriers via our Talking Red campaign.

#### Inhibitors

Funding to support to begin development on services and needs for those with inhibitors

#### Ageing, Health & Independence

Funding to support a project addressing issues faced by older people affected by bleeding disorders

#### Rare Bleeding Disorders

Funding to begin the development of information for people with rare bleeding disorders

#### Von Willebrand Projects

Funding to develop a new publication for people with von Willebrand disease.

Tanner Fund

A hardship fund providing grants of up to £200.

#### **Memorial** Service

Funds held for the administration of an annual service of thanks giving and remembrance in London for those who died as a result of the contamination of blood products in the 1970s and 1980s

#### Cornwall and Devon

Funds held by the Society for use by the Cornwall and Devon Group

#### Local Group Forum Event

Funding to provide a training and development event for members of our local groups

#### South Central Activities Fund

Funds to support the South Central Group

### London & South Group Funds to support the London and South Group

#### WFH Close the Gap Grant made to the Warld Enderstion of Hasmanhilia to support the Close the Gap Cap

Grant made to the World Federation of Haemophilia to support the Close the Gap Campaign

#### Belfast Event

Funds to support a specific event for members in Belfast area

#### Thrombosis & Haemophilia Conference

Funds for the conference

### Newly Diagnosed

Funds to support services for families with a newly diagnosed child

#### Youth Activity & Teen Weekends

Funds to support services for young people and teenagers with a bleeding disorder

### **NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)**

### FOR THE YEAR ENDED 31<sup>ST</sup> MARCH 2015

#### Website

Funding to develop the website

### **Reader** Panel

Funding to develop and support a new members reader panel to review our publications

### Swim Around Britain

Funding to for a new project to encourage members to become more active and swim.

#### World Haemophilia Day

Funding for a radio campaign on World Haemophilia Day

### 15. ENDOWED FUNDS

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

## 16. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Fixed	Net Current	
	Assets	Assets	Total
	£	£	£
Endowed Funds	19,344		19,344
Restricted Funds	tái-	62,203	62,203
Unrestricted Funds	824,238	(77,351)	746,887
Local Group Funds		57,925	57,925
	£843,582	£42,777	£886,359

### 17. 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.

# **NOTES FORMING PART OF THE FINANCIAL STATEMENTS (Continued)**

# FOR THE YEAR ENDED 31<sup>5T</sup> MARCH 2015

# 18. LEASE COMMITMENTS

At 31st March 2015 the Society had annual commitments under operating leases as set out below. The figures stated are the amounts payable in the following year.

	31 <sup>st</sup> March 2015		31 <sup>st</sup> March 2014	
	Land and Building		Land and Building	ţ.
		Other		Other
	£	£	£	£
Operating Leases that expire: Within one year			69,906	
In the second to fifth years Over five years	28,665	3,768	006,60	3,768
,	£28,665	£3,768	£69,906	£3,768

The 2015 Land and Buildings commitment represents the lease on the Willcox House premises.