

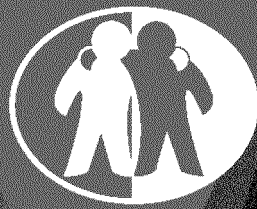
Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392056



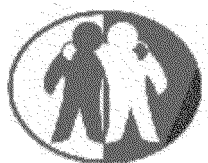
THE
HAEMOPHILIA
SOCIETY

GRO-A

Annual report and financial statements: 2018/19

Registered charity no. 288260 (Scotland SC039732) Company limited by guarantee reg. no. 1763614

WITN6392056_0002



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THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society
Charity reference and administrative details
Year ended 31 March 2019

President Baroness Meacher
Chief Executive Liz Carroll

Board of Trustees

Lisa Bagley
Catherine Benfield

GRO-A

Kate Khair

GRO-A

Simon Mower

GRO-A

GRO-A

Paul Sartain

GRO-A – Chair

Subcommittees

Resources & Audit Committee

Liz Carroll
Lisa Bagley

GRO-A

GRO-A

Simon Mower – Chair

Nominations Committee

Liz Carroll

GRO-A

Public Inquiry Committee

GRO-A

GRO-A

Paul Sartain

GRO-A – Chair



THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society

Charity reference and administrative details

Year ended 31 March 2019

Clinical Advisory Group

Dr Rezan Abdul-Kadir

Dr Gary Benson

Tom Burke

Robert James

Dr Kate Khair

Dr Mike Laffan

Dr Mike Makris

GRO-A

Debra Pollard

David Stephenson

Company Secretary

GRO-A

Bankers

NatWest Bank

London Bridge

PO Box 35

10 Southwark Street

London

SE1 1TJ

Solicitors

Eversheds Southernland

1 Wood Street

London

EC2V 7WS

Auditors

Wilkins Kennedy Audit Services

2nd Floor

Regis House

45 King William Street

London EC4R 9AN

Registered Office

Ground Floor

Willcox House

140-148 Borough High Street London

SE1 1LB

Company registration number

01763614

Charity registration number 288260

Scottish charity registration number

SCO39732



Chair's statement

Year ended 31 March 2019

"May you live in interesting times" said Robert F Kennedy in 1966. He could easily have been talking about the haemophilia community in 2019 when speaking those words. No sooner had we delivered arguably the most successful World Congress of the World Federation of Hemophilia in Glasgow in 2018, it was time to shift our focus to the Infected Blood Inquiry and the many other challenges the community faces in 2019.

The hosting of the World Congress and a public inquiry are usually a once in a generation occurrence for any charity. To have them overlap as they have is probably unique within the world haemophilia community. Robert F Kennedy went on to say "but they are also the most creative of any time in the history of mankind." While life currently for our community is often very much a challenge, we must also see it as an opportunity. Never will we have this moment in time again to shape the future care of our community and ensure everyone is able to access the very best treatment and support. Individual, personalised care must be the aim for all.

One of the significant items on our 2019 'To-Do List' has been to look at our strategy as a Society for the next three years. It is a sign of the times that we usually look at this every five years, but have instead decided to revisit it in only three. Changes in treatment in the next handful of years is likely to surmount anything we have seen in the last 30 years. The development of gene therapy continues unabated. Meanwhile, extended half-life (EHL) treatments and interruptive therapies with alternative methods of administration are revolutionising care.

Since becoming a trustee four years ago now, the biggest insight I have had into The Society is how much the team delivers with a relatively small number of staff. We currently have 10 members of staff, five of whom are part time. Many are surprised not to see a team of 30 or more beavering away in the office when they stop by for the first time. That is testament to Liz, the senior management team and all the staff who dedicate themselves to the community on a daily basis. All those unseen phone conversations, support behind the scenes and providing information to our members to ensure they get what they need in order to live their best life. My thanks to you all.

However, we can always do more. And in some areas, we can undoubtedly do better. Following our review of our strategy, we feel very much that we need to engage you, the community, more. So much of our work goes on behind the scenes; much of it you may not know about. That is partly our fault and we have been working on trying to inform you more about what we do and what we can do for you. As I've said elsewhere, it's never been more important to be a well-informed patient, knowing what you as a patient are entitled to demand from your haemophilia centre. Our website has changed radically and is a fertile resource for members looking for answers. We are always here for our members and to that end we will be looking to launch a helpline for people to call to get up-to date information and support.

Our core work continues too: Newly Diagnosed Family Weekends, inhibitors, von Willebrand's and women with bleeding disorders to name just a few areas. This year has also seen a new intake of fantastic Youth Ambassadors. Their training has already begun, and we look forward to you meeting them at our events in the very near future.



Chair's statement

Year ended 31 March 2019

We continue as the secretariat to the All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood. With the Inquiry now up and running, its focus has been able to shift to the haemophilia community at large and it is currently undertaking a review into the way in which treatment and care is commissioned in the UK. The current treatment tender model is ill-equipped to deal with novel therapies such as gene therapy. As one commentator said, patients will not accept new treatments becoming available and gathering dust on the shelf simply because government is unwilling to pay for it. The parliamentary cycle is not our friend, with government looking only a few years into the future in terms of budget and funding. This model needs to change if everybody is to gain access to the treatment and care they desire.

Alongside all of this, we continue to diversify our income. Less than 50% of our funding now comes from pharmaceutical companies. In this regard we compare very favourably to other societies around the world who are heavily dependent on this income stream. We do much good work for the community alongside pharmaceutical companies and they fund many of our important projects. But we must never be beholden to them. By having a varied funding stream, we are able to continue to work for you safe in the knowledge that we will always be here to support you without charging for our services.

Which brings me lastly to you. Our members. We have had almost 700 new members over the last 12 months, which is fantastic. It demonstrates that we continue to be relevant in this ever-changing world. Since becoming Chair, I hope I have been visible to many of you in the community. Many of you have spoken to me or got in contact to discuss matters, which I greatly appreciate. If there are areas in which you feel we are falling short, please let us know. Nearly all of us on the board have or are affected by a bleeding disorder, so we hope we have a good knowledge and understanding of our community. However, everyone's experience is different. If there is anything you feel we could do to help you, then please do get in touch.

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Chair of the Board of Trustees
The Haemophilia Society



Trustees' Annual Report Year ended 31 March 2019

The trustees present their report and the audited financial statements of the charity for the year ended 31 March 2019. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) Accounting and Reporting by Charities (FRS 102) in preparing the annual report and financial statements of the charity. The Trustees' annual report incorporates the Directors' report and Strategic report.

The financial statements have been prepared in accordance with the accounting policies set out in notes to the accounts and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland published on 16 July 2014.

Trustees of the charity

The directors of the charitable company are its trustees for the purposes of charity law. The trustees who have served during the year and since the year end were as follows:

Lisa Bagley

Catherine Benfield (from April 2018)

Liz de Freitas (to November 2018)

GROA

Kate Khair (from November 2018)

GRO-A

Simon Mower

GROA

to November 2018)

GRO-A

Collette Pigden (to April 2018)

GRO-A

Paul Sartain (from November 2018)

GROA



Trustees' Annual Report Year ended 31 March 2019

Our Vision, Mission, Aims & Values

Our vision:

Anyone affected by a genetic bleeding disorder has the opportunity to live a fulfilled life.

Our mission:

- Inform
- Advocate
- Empower

Our aims:

- Everyone affected by a bleeding disorder has equality of opportunity
- Everyone affected by a bleeding disorder has the opportunity to connect with others in the community
- Everyone affected by a bleeding disorder has the knowledge to feel empowered

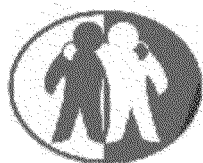
Our values:

- Transparent
- Professional
- Pioneering
- Supportive

Public benefit statement

The Haemophilia Society's services are available to everybody affected by genetic bleeding disorders in the UK. We have almost 5,500 members: membership is open to all who support our vision and values, with no charge. 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 members to become involved in decision making about their own treatment.

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



Trustees' Annual Report Year ended 31 March 2019

Objectives and activities

Specific objectives and activities providing public benefit include:

Providing information, services and support on all aspects of genetic bleeding disorders, enabling people to live a fulfilled life and be empowered to make informed decisions about their own treatment and care. Information is provided at service events, by phone, email and through a website, active social media pages, publications on specific aspects of bleeding disorders and a network of local groups providing peer support throughout the UK. Running day and residential events and services for members led by expert health professionals and member volunteers in order to provide social support and information.

Ensuring that the patients' viewpoint is heard in key NHS and Department of Health forums, for example on the Clinical Reference Group for Haemophilia, and supporting the work of the APPG on Haemophilia and Contaminated Blood as secretariat. Escalating issues of inequalities in care and concerns over access to care to the NHS and 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 and cooperating with the public inquiry into infected blood.

Fundraising regulation

We are signed up to the Fundraising Regulator's 'Fundraising Promise' which summarises our commitment to individuals who support our work. The promise includes a commitment to make our supporters' experience as positive and rewarding as we can. We are committed to being honest and transparent about where our supporters' donations go and why we need funding. The safety of our supporters' data is very important to us.

We are determined to take all obligations very seriously and we will:

- never sell or share our supporters' data with any third-party fundraising organisations;
- be both respectful and accountable to our supporters;
- continue to be sensitive when engaging with vulnerable people and our practices will reflect this; and
- continue to ensure our supporters feel valued and in control of their relationship with us.

As reported to the Fundraising Regulator we had no complaints during the year around fundraising. We do not, and have not, engaged with any third party to fundraise on our behalf.



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Strategic report

Introduction

We are the **only** UK-wide charity for all those affected by a genetic bleeding disorder: a community of individuals and families, healthcare professionals and supporters.

For almost 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

We:

- Raise awareness about bleeding disorders
- Provide support throughout members lives
- Influence and advocate for the community on health and social care policy and access to treatment

More than 30,000 men, women and children in the UK have a diagnosed bleeding disorder and the number rises every year. Membership of The Haemophilia Society is free and open to all.

Our peer support – through local groups around the UK and our online community – offers friendship and a listening ear when needed, as well as enabling people to share their views and experiences. By bringing people together for information and support at events tailored to all life stages, we amplify their voices to reduce isolation and influence government, welfare and health care policy.

Our community is at the heart of everything we do – we work collaboratively with members and health professionals to ensure we make decisions influenced by their valued input and direction.

As bleeding disorders are rare, many people will never encounter The Haemophilia Society; we are largely invisible beyond the communities we serve. So, we must work doubly hard to raise both awareness and understanding of bleeding disorders and vital funds needed to give those affected the services they deserve and need to live the best life they can.



Trustees' Annual Report Year ended 31 March 2019

Activities

WFH Congress 2018

The year began by hosting the World Federation of Hemophilia (WFH) Congress in Glasgow from 20-24 May 2018. Congress was a huge success, with 5,110 delegates from 132 nations attending. Delegates included people with a bleeding disorder, healthcare professionals, allied health professionals, pharmaceutical industry staff and charity staff from across the world.

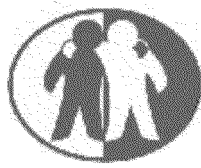
Our role included shaping the programme, recommending speakers, promoting the event, training Glasgow city tourism representatives and recruiting almost 100 volunteers to support Congress activity over seven days, including hosting a treatment room for those who didn't have access to treatment in their own county. This was a huge piece of work collaborating closely with WFH, Haemnet, People Make Glasgow Welcome and SECC.

This was a unique event for our members, giving them the opportunity to meet friends and colleagues from across the world, hear about advances in treatment and support, and share experiences and make memories that last a lifetime. We were able to share examples of our services and publications as well as introduce our mascot Buddy, who proved to be very popular.

Following Congress, we have maintained strong relationships with our colleagues in areas of the world where access to treatment is limited. We are now working with WFH to look at how we can formally support their work in developing countries as part of the legacy of Congress.

We can't thank our amazing volunteers and colleagues enough for the incredible energy and vitality they brought to the event.

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Trustees' Annual Report Year ended 31 March 2019

Newly Diagnosed Family Weekends

Hearing that your child has a bleeding disorder brings with it a huge range of emotions. For those who know they have a family history it often brings guilt for passing on the gene, or fear that your child will go through some of the devastating consequences you, your father or brothers experienced. For others the news is totally unexpected and comes along with questions about unexplained bruising, social services involvement and fear for your baby and your family life.

Our free weekends enable new parents to learn more about what to expect, meet others who are experiencing the same emotions and spend time hearing from and talking to experts, helping them build a foundation of knowledge and support as they start their journey as a family.

Specialist bleeding disorder physios, nurses, doctors, psychologists and social workers facilitate sessions alongside our local group representatives and Youth Ambassadors.

This year we held four weekends for families with a newly diagnosed child, with one focusing specifically on mild and moderate bleeding disorders, while the others focused on children with a severe bleeding disorder. This year, following feedback from members, weekends have developed to include psychological support for parents and distraction techniques for children while having their treatment.

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Trustees' Annual Report Year ended 31 March 2019

Youth Activities

This year we focused our youth activities for younger children at summer camp in the Lake District that reduced the isolation of living with a bleeding disorder, recognised the impact on siblings and raised confidence levels in our younger members. From learning to give your treatment for the first time and understanding what your condition really means for you, to understanding how teamwork and determination can help you make huge leaps (literally in some cases), the campers loved every moment.

During the year our Youth Ambassadors had been working on developing events for young adults. This culminated in Lads and Dads and Mums and Daughters weekends in the Brecon Beacons over very wet weekends in March, where parents were pitted against their children in archery, quad biking, canyoning and more. The final activity for both groups was an invigorating – for that read very cold water – morning canyoning at the National Park's waterfalls, with a breathtaking white water and rapids ride. This concluded brilliantly with a seven-metre jump into a waterfall!

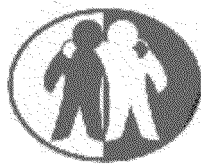
Youth Ambassador engagement

Our Youth Ambassadors are fundamental to our work. They attend many of our events and services, sharing their experiences, demonstrating treatment and offering a role model to younger members as well as reassurance to parents that a severe bleeding disorder won't hold you back in life.

This year two of our Youth Ambassadors decided it was time to move on, but before they stepped down helped us shape a new development programme that has led to the recruitment of seven new Youth Ambassadors.

We have also sponsored two young people to attend the EHC youth leadership programme and another to attend their leadership weekend. Our thanks go to Rob Barnard and Luke Pembroke for their passion and commitment to our community.

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Trustees' Annual Report Year ended 31 March 2019

Talking Red Programme

Talking Red this year focused on raising awareness of bleeding disorders with women in universities and our conference events that enable women to come together, talk about the challenges of living with a bleeding disorder and find support from others in similar situations.

It can be incredibly isolating when you don't meet others who understand the daily challenges you face, be that not being able to leave the house due to heavy periods, waking up with a nosebleed, or having to manage daily life where bruises are questioned and pregnancy planning becomes a complex multi-agency conversation.

Ageing

Following our member surveys and conferences, in the last few years we have been developing our 'living well' resource pack for members as they get older. Many are concerned about social care as they become less able to care for themselves and live with multiple complex diagnoses. This new resource pack aims to guide people through the issues they may face and ensure they can access the support they need.

At the ageing information day this year members fed back on the draft pack, enabling us to ensure it provides the essential information and support they require.

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Trustees' Annual Report Year ended 31 March 2019

Inhibitor Project

Living with an inhibitor long term or hearing that your child has been diagnosed with an inhibitor is often a highly stressful and emotional time. Knowing that the treatment usually given to treat your condition won't work and that you need to embark on intensive treatment that may require multiple treatments a day for several years is daunting.

We know that the care people receive in the NHS is excellent, but the emotional support and day-to-day tips that come from others who are currently living with or have successfully achieved treatment tolerization is invaluable. We are able to bring families together, ensuring they have support and up-to-date information on treatments and know they are not alone.

This year we have focused on developing an inhibitor resource pack, working with members who live with an inhibitor, as well as hosting an information day looking at what care and support people can expect when coping with the huge challenges of life with an inhibitor.

Volunteering

We couldn't function without our incredible volunteers. Throughout the year over 30 healthcare professionals supported us at our events, volunteering either for a day or an entire weekend.

This is in addition to the hundreds of members who run our local groups and helped organise events across the country, while Youth Ambassadors and Talking Red Ambassadors have also volunteered at our events and education days.

Across the UK we have some incredible volunteers who run our local groups, arranging events and raising funds to support members in their local community.

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We have been working with our local group volunteers to better understand their support needs and are working on developing better support for them.



Trustees' Annual Report Year ended 31 March 2019

Advocacy

This year we have continued to advocate for access to new treatments for people with bleeding disorders, responding to NICE consultations and as part of the NHS Tender Boards for treatment and home delivery.

As members of the Clinical Reference Group in England (which is attended by Welsh and Scottish clinicians' representatives too) we bring the collective patient voice, along with two patients, to provide advice to the decision makers in the NHS on what matters to our members about treatment, care and support. This included access to innovative new treatments, access to specialist nursing and physio care, and sharing people's experiences of their haemophilia centres.

We have also represented patients' views on the Welsh Inherited bleeding disorder project board, which is redesigning care for people in Wales with a bleeding disorder. We also worked closely with the DWP to highlight concerns over benefits, particularly for those with a bleeding disorder who are routinely being refused PIP but are successful on appeal.

Our work has identified gaps in assessors' knowledge and recommended expert advisers to support a fairer system. We have also worked closely with EIBSS and the APPG on Haemophilia and Contaminated Blood to challenge decisions on support for those affected by contaminated blood, and called on government to end the disparity between nations.

Throughout the year we have been patient advocates on numerous working groups including the haemophilia centre peer review audit development facilitated by the West Midlands Quality Review Service as well as the James Lynd Alliance research questions development project (Stop the Bleeding).

Public inquiry into infected blood

Following the previous year's announcement of a statutory public inquiry into infected blood we employed two staff to work full time on the Inquiry to support our members and prepare for evidence. This included a communications expert to ensure the community was informed of the activities of the Inquiry and had access to information in a consistent and balanced way.

We welcomed Sir Brian Langstaff's consultation on the Terms of Reference. Using a range of channels, including a new social media group, we gathered opinions to inform our response to this consultation. The opening of the Inquiry hearings in late September was both welcome and emotional for everyone affected.

In November we were required to provide some documentation to the Inquiry and found ourselves in the difficult position where, for reasons beyond our control, we were not able to do so. This led to the Inquiry threatening action against The Society and us reporting the incident to the Charity Commission as a serious reputational risk.



Trustees' Annual Report Year ended 31 March 2019

In February we made the difficult decision to change our legal representatives, but felt this was the right thing for The Society and our members. We have delivered over 40,000 documents to the Inquiry from The Society archive and have been working with members to support those who wish to be represented by our legal team.

Fundraising

Our fundraisers continue to amaze us with their imagination, time and energy. From running marathons to cake sales, or hosting one of our new 'Buddies Who Brunch' events, we couldn't do it without you.

We have also seen increased support from community groups such as rotary clubs and schools. We know how busy our members and friends are and appreciate every event you do to help support our work.

In the coming years, we will need to significantly increase our community fundraising activity so we can continue to provide information and support to our members free of charge, so are working on new ways to engage with our community and the wider public.

This year we held our biggest Big Red London Bridge Walk to date, with over 100 walkers dressed in our fabulous red T-shirts. This was an amazing event that not only raised important funds, but also built new friendships and shared experiences participants will remember for years to come.

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Trustees' Annual Report Year ended 31 March 2019

What we are proud of

- Delivering Congress in Glasgow
- Our work on the Public Inquiry into infected blood
- Our youth work, building on previous years' feedback and recruiting new youth ambassadors
- Engaging members in fundraising for The Society through new events like the Big Red London Bridge Walk

What we could do better

- Working with local groups volunteers, supporting them to meet members' needs in their local area
- Delivering services closer to people's home so they don't need to travel long distances to meet others affected by a bleeding disorder.
- Communicating better with members so they know what support and information is available to them

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 support our members to live fulfilled and positive lives and determination to ensure the public inquiry into infected blood continues to seek the truth and highlight the injustice the community has experienced for over 30 years.

We know that those who received contaminated blood are dying at a rate of one every four days, and for each person who dies many more are devastated by their loss.

Future plans

In 2019-20 we will review our strategy, working with our members and stakeholders to ensure we are relevant to our community and are a trusted and sustainable organisation.

We will continue to develop our publications and services, while increasing our advocacy and work with the APPG to broaden its focus from just contaminated blood to understanding the wider challenges of access to treatment people with bleeding disorders may face in the era of treatment advances such as gene therapy.



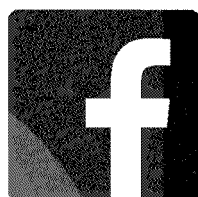
THE
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SOCIETY

Trustees' Annual Report
Year ended 31 March 2019

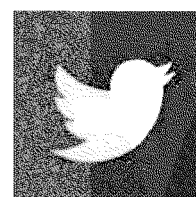
The Haemophilia Society in numbers



4,262
TOTAL
FOLLOWERS



3,376
TOTAL
FOLLOWERS





Trustees' Annual Report Year ended 31 March 2019

Financial review - Income and expenditure overview

The results for this financial year demonstrate the level of continued activity being undertaken by The Society. This financial year contained two significant changes to our activities when compared to prior years. Firstly, the UK hosted the WFH Conference in Glasgow in May 2018, which from a financial perspective generated a net surplus of £419,687. This was a hugely important event for our community and we anticipate, in line with general practice, that an element (to be determined) of this surplus will be reinvested in the global community over future years.

Secondly, the infected blood inquiry commenced during the year. In order to be able to support the proceedings and service our community we have incurred costs of £311,267 in this financial year. An amount of these costs relates to setting up the architecture and platform for optimising our support to the Inquiry and we would note that we expect expenditure in future years to be at a lower level. The Board has agreed to designate £600,000 from reserves, which we expect to sufficiently cover the period of the Inquiry. Funds not used in this respect can be freely redesignated to general reserves.

Overall, we have generated a surplus for the year of £192,177 (before the impact of gains and losses on investments), which results in The Society continuing to be well capitalised. This surplus was distorted by the net WFH Congress receipts noted above and offset by the Inquiry expenditure. Excluding the impact of these individual items, our outcome for the year would have been a surplus of £125,058. Nonetheless, and given the planned expenditure from reserves over the coming years, fundraising remains a critical challenge for The Society. We continue to see reduced income year on year from donations and community fundraising.

Income (including legacies) for FY19 was £1,264,750, as compared to £682,389 in FY18. This included corporate funding of £325,956 in FY19 (up from £294,795 in FY18) and a reduction in individual donations and community fundraising (combined) from £203,315 in FY18 to £177,960 in FY19.

We very gratefully benefited from legacy income of £34,846 during the year (FY18: £109,417).

Expenditure for FY19 increased by £294,440 to £1,072,573 from £778,133 in FY18. Excluding the expenses relating to the WFH Congress and the Inquiry, expenditure for the year was £548,467.

The Society retains a strong base of reserves and a solid financial position, which has further strengthened this year. The board of trustees continues to consider selective investment opportunities for the deployment of reserves into charitable activities where it is deemed that there could be significant benefit to the community from undertaking them. Balanced against this, we remain mindful of the volatility of fundraising and so we will continue to act prudently in this respect.



Trustees' Annual Report Year ended 31 March 2019

Fundraising and volunteers

The Society's members have participated in many fundraising activities this year and have made significant donations of £177,960, with additional Gift Aid receipts of £26,259. We have benefited from members participating in a wide range of events alongside individual giving, for all of which we are very grateful.

We are focused on continuing to support and promote any fundraising undertaken by our members and friends as a most important and valued source of unrestricted income and a way to highlight our services to the widest community.

The charity also benefits from a number of volunteers involved in many aspects of our work including as trustees, as part of local groups, assisting at events and helping in the office. We very much appreciate the important contribution of all these volunteers to our work.

We are also grateful for the extensive pro-bono support from professionals The Society received during the year.

Grant and trust income

We have sought to reinvigorate our focus on applications for grant and trust donations. In FY19 we have invested in this area, and while it hasn't delivered the immediate expected growth in fundraising, we believe that we have put in place strong foundations for future years. We have received income from trust applications of £21,010 this year (FY18: £26,500). Broadening our sources of income is an area we continue to focus on.

Corporate income

Corporate income increased from £294,795 in FY18 to £325,956 in FY19. This remains a key area of focus for the team and our corporate supporters have continued to provide us with substantial backing.

Legacies

We have been very fortunate to receive legacy income during FY19 of £34,846 (£109,417 in FY18).

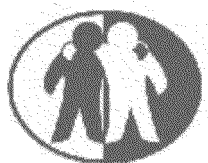
Costs

Costs in FY19 were £1,072,573. Against a total income of £1,264,750, this represents a surplus of £192,177 before net gains/(losses) on investments.

Reserves

The board of trustees reviewed and updated the reserves policy in January 2019. The board of trustees aims to maintain unrestricted reserves at a minimum of 12 months' running cost to ensure we can fund our ongoing projects for members and meet our financial responsibility during periods of uncertainty or fluctuating income streams.

Recognising the significant financial and general resource impact of the current public inquiry into infected blood, the board has designated £600,000 of reserves to fund the charity's work on the Inquiry in the next four years.



Trustees' Annual Report Year ended 31 March 2019

It is anticipated that our work to participate in the Inquiry, and support and inform members of the community affected by the Inquiry may cost up to £150,000 per year until 2023. Designated funds will be reviewed annually to ensure appropriate use of reserves.

As at 31 March 2019, unrestricted general reserves stood at £1,334,713. As noted, the board of trustees continually reviews potential opportunities to invest for the good of The Society, while prudently managing reserves in an uncertain environment.

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 directly into assets to mitigate concentration of risk. As at the end of FY19 our funds had a market value of £1,150,088.

Key risks and uncertainties

Key risks to the charity fell into three distinct areas and were identified as:

Financial

Significant reliance on charitable contributions from pharmaceutical companies and a challenging financial environment brings a lack of certainty over the sustainability and security of these sources of funds.

Reputation

The reputation of The Society, staff and trustees is at risk due to the Inquiry, as The Society's actions over the past 30+ years are scrutinised. In March we reported a serious reputational risk to the Charity Commission following a media report in connection with the Inquiry. The Charity Commission reviewed the risk and accepted the board of trustees had acted responsibly and appropriately. No further action was required.

Each risk was carefully monitored, and mitigation procedures put in place to reduce the likelihood and impact of the risk. The board of trustees reviewed the risks and mitigation quarterly.

Structure, governance and management

The Haemophilia Society is a registered charity in England (number 288260) and Scotland (number SCO39732) and company limited by guarantee (number 01763614). The Haemophilia Society's governing document is its Memorandum and Articles of Association.

The trustee board has

- seven ordinary trustees (elected by members of The Society)
- one honorary chairman
- up to four co-opted trustees



Trustees' Annual Report Year ended 31 March 2019

Elections take place prior to the AGM in November each year and trustees are elected for a three-year term. They may stand again for election for a further three-year term and then must take at least one year's break. One further three-year term as a trustee is permitted but having served nine years an individual may not stand for election or be co-opted to the board again.

A call for nominations is sent to every member in September requesting trustees' nominations signed by another member. Information on the roles and responsibilities of a trustee and details of current trustees are available on our website.

The Chair is appointed to the board following an interview process.

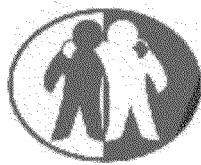
Statement of accounting and reporting responsibilities

The trustees (who are also the directors of The Haemophilia Society for the purposes of company law) are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the directors to prepare financial statements for each financial year. Under that law the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing these financial statements, the directors are required to:

- select the most suitable accounting policies and then to apply them consistently
- observe the methods and principles in the Charities SORP
- make judgements and accounting 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 charity will continue in operation.

The directors are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions, 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 and the provisions of the charity's constitution. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.



THE
HAEMOPHILIA
SOCIETY

Trustees' Annual Report Year ended 31 March 2019

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Relevant audit Information

We, the directors of the company who held office at the date of approval of these financial statements as set out above each confirm, so far as we are aware, that:

- there is no relevant audit information of which the company's auditors are unaware, and
- we have taken all the steps that we ought to have taken as directors in order to make ourselves aware of any relevant audit information and to establish that the company's auditors are aware of that information.

In approving the trustees' annual report, we also approve the strategic report included therein, in our capacity as company directors.

On behalf of the board

GROA

GROC

GROA, Chair

Simon Mower, Treasurer

Date: 26 September 2019

The Haemophilia Society

Year ended 31 March 2019

Independent auditor's report to the members of The Haemophilia Society

Opinion

We have audited the financial statements of The Haemophilia Society (the 'charitable company') for the year ended 31 March 2019 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2019 and of its incoming resources and application of resources, 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 requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least 12 months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information we are required to report that fact.

The Haemophilia Society

Year ended 31 March 2019

Independent auditor's report to the members of The Haemophilia Society

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report, which includes the directors' report and strategic report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the directors' report included within the trustees' report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the strategic report or the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, 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.

Responsibilities of trustees

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, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

The Haemophilia Society

Year ended 31 March 2019

Independent auditor's report to the members of The Haemophilia Society

Use of our report

This report is made solely to the charitable 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 charitable 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 charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

GROC *Audit Service*

John Howard (Senior Statutory Auditor)
for and on behalf of Wilkins Kennedy Audit Services
Statutory Auditor
2nd Floor, Regis House
45 King William Street
London EC4R 9AN

Date: 17 October 2019

The Haemophilia Society

Statement of financial activities (including income and expenditure account)

Year ended 31 March 2019

		2019				2018
	Note	Unrestricted funds £	Restricted funds £	Endowment funds £	Total £	Total £
Income and endowments from:						
Donations and legacies	2	196,107	282,387	-	478,494	512,551
Charitable activities	3	746,395	-	-	746,395	126,403
Investments	4	33,502	1,620	-	35,122	28,067
Other		4,739	-	-	4,739	15,368
Total income and endowments		980,743	284,007	-	1,264,750	682,389
Expenditure on:						
Raising funds	5	132,054	-	-	132,054	103,197
Charitable activities	6	688,501	252,018	-	940,519	674,936
Total expenditure		820,555	252,018	-	1,072,573	778,133
Net gains / (losses) on investments		41,301	-	-	41,301	(20,842)
Net income / (expenditure)	9	201,489	31,989	-	233,478	(116,586)
Transfers between funds		-	-	-	-	-
Net movement in funds		201,489	31,989	-	233,478	(116,586)
Reconciliation of funds:						
Total funds brought forward		1,187,125	17,629	19,344	1,224,098	1,340,684
Total funds carried forward		1,388,614	49,618	19,344	1,457,576	1,224,098

All income and expenditure derive from continuing activities.

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

The Haemophilia Society

Balance sheet

Year ended 31 March 2019

	Note	2019 £	2018 £
Fixed assets			
Tangible assets	12	10,795	8,478
Investments	13	1,150,088	1,103,787
		<hr/>	<hr/>
		1,160,883	1,112,265
Current assets			
Debtors	14	265,897	85,707
Cash at bank and in hand		135,766	145,677
		<hr/>	<hr/>
		401,663	231,384
Creditors: amounts falling due within one year	15	(104,970)	(119,551)
		<hr/>	<hr/>
Net current assets		296,693	111,833
		<hr/>	<hr/>
Net assets		1,457,576	1,224,098
		<hr/>	<hr/>
Charity funds			
Endowment funds	16	19,344	19,344
Restricted funds	16	49,618	17,629
Unrestricted general funds	16	734,713	1,128,970
Local group funds	16	53,901	58,155
Designated funds	16	600,000	-
		<hr/>	<hr/>
Total charity funds	17	1,457,576	1,224,098

The financial statements were approved and authorised for issue by the board on **26 September 2019**

Signed on behalf of the board of trustees

GROA

GRO-A, Chair

The notes on pages 30 to 41 form part of these financial statements.

Company registration number: 01763614

The Haemophilia Society

Statement of cash flows

Year ended 31 March 2019

	Note	2019 £	2018 £
Net cash flow from operating activities	18	<u>(31,478)</u>	<u>(87,059)</u>
Cash flow from investing activities			
Payments to acquire tangible fixed assets		(8,555)	(5,179)
Purchase of fixed asset investments		(5,000)	(557,071)
Interest received		35,122	28,067
Net cash flow from investing activities		<u>21,567</u>	<u>(534,183)</u>
Net decrease in cash and cash equivalents		(9,911)	(621,242)
Cash and cash equivalents at 1 April 2018		145,677	766,919
Cash and cash equivalents at 31 March 2019		<u>135,766</u>	<u>145,677</u>
Cash and cash equivalents consists of:			
Cash at bank and in hand		135,766	145,677
Cash and cash equivalents at 31 March 2019		<u>135,766</u>	<u>145,677</u>

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

1 Summary of significant accounting policies

(a) General information and basis of preparation

The Haemophilia Society is a company limited by guarantee in the United Kingdom. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 2 of these financial statements. The nature of the charity's operations and principal activities are to provide support and services to everybody affected by inherited bleeding disorders in the UK.

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with *Accounting and Reporting by Charities: Statement of Recommended Practice* applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011, the Companies Act 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention, with the exception of investments which are disclosed at fair value. The financial statements are prepared in sterling which is the functional currency of the charity.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

(b) Funds

Unrestricted general funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

The Society is represented throughout the country by local groups. Local group funds are incorporated into The Society's financial statements.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The cost of raising and administering such funds is charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

Endowment funds represent those assets which must be held permanently by the charity, principally the Philip Morris Art Award Fund and the GROA Memorial Award Fund. The interest earned on these funds is credited to the relevant restricted fund to fund awards.

(c) Income recognition

All incoming resources are included in the Statement of financial activities (SoFA) when the charity is legally entitled to the income after any performance conditions have been met, the amount can be measured reliably and it is probable that the income will be received.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

1 Summary of significant accounting policies (continued)

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.

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.

Income from charitable activities includes income earned from community fundraising and events and local group activities to raise funds for the charity. Income is received in exchange for supplying goods and services in order to raise funds and is recognised when entitlement has occurred.

Investment income is earned through holding assets for investment purposes. It includes interest income, which is included when the amount can be measured reliably and the charity's right to receive payment is established.

No amount is included in the financial statements for volunteer time in line with the SORP (FRS 102).

(d) Expenditure recognition

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Expenditure is recognised where there is a legal or constructive obligation to make payments to third parties, it is probable that the settlement will be required and the amount of the obligation can be measured reliably. It is categorised under the following headings:

- costs of raising funds includes fundraising salary and trading costs, direct and support costs
- expenditure on charitable activities includes communications, membership, cultivation, services and advocacy and influencing costs, and
- other expenditure represents those items not falling into the categories above.

VAT is charged as an expense against the activity for which expenditure arose.

(e) Support costs allocation

Support costs are those that assist the work of the charity but do not directly represent charitable activities and include office overheads, governance costs, charity administration and salary core costs. They are incurred directly in support of expenditure on the objects of the charity and include project management carried out at headquarters. Where support costs cannot be directly attributed to particular headings they have been allocated to cost of raising funds and expenditure on charitable activities in proportion to direct costs incurred. Salary costs are allocated based on an analysis of staff time spent.

The analysis of these costs is included in note 7.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

1 Summary of significant accounting policies (continued)

(f) Tangible fixed assets

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

Depreciation is provided on all tangible fixed assets, at rates calculated to write off the cost, less estimated residual value, of each asset on a systematic basis over its expected useful life as follows:

Office equipment and furniture	25% per annum, straight line
Leasehold property	Over life of lease
Leasehold improvements	Over life of lease

(g) Investments

Investments are recognised initially at fair value. Subsequent gains and losses, which represent the difference between the opening market value and closing market value or proceeds of sale, are recognised in the financial statements in the period to which they relate.

(h) Debtors and creditors receivable / payable within one year

Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure.

(i) Impairment

Assets not measured at fair value are reviewed for any indication that the asset may be impaired at each balance sheet date. If such indication exists, the recoverable amount of the asset, or the asset's cash generating unit, is estimated and compared to the carrying amount. Where the carrying amount exceeds its recoverable amount, an impairment loss is recognised in profit or loss unless the asset is carried at a revalued amount where the impairment loss is a revaluation decrease.

(j) Provisions

Provisions are recognised when the charity has an obligation at the balance sheet date as a result of a past event, it is probable that an outflow of economic benefits will be required in settlement and the amount can be reliably estimated.

(k) Leases

Rentals payable and receivable under operating leases are charged to the SoFA on a straight line basis over the period of the lease.

(l) Employee benefits

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

Notes to the financial statements

Year ended 31 March 2019

1 Summary of significant accounting policies (continued)

(m) Tax

The charity is an exempt charity within the meaning of schedule 3 of the Charities Act 2011 and is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes.

(n) Going concern

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern.

2 Income from donations and legacies

	2019 £	2018 £
Donations from individuals	70,423	81,619
Legacies	34,846	109,417
Grants and trust income	21,010	26,500
Corporate income	325,956	294,795
Gift Aid	26,259	220
	<hr/> 478,494	<hr/> 512,551

Income from donations and legacies includes £282,387 (2018: £153,018) attributable to restricted funds, and £196,107 (2018: £359,533) attributable to unrestricted funds.

3 Income from charitable activities

	2019 £	2018 £
Local group activities	6,332	4,707
Exceptional income from the WFH	632,526	-
Community fundraising and events	107,537	121,696
	<hr/> 746,395	<hr/> 126,403

Exceptional income and expenditure was recognised in the financial year relating to the WFH conference held in Glasgow in May 2018. This generated significant exceptional activity from both an income and expenditure perspective and both note 3 and note 6 should be consulted to understand the net impact.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

4 Income from investments

	2019 £	2018 £
Interest - fixed interest securities	35,122	27,553
Interest - deposits	-	514
	<u>35,122</u>	<u>28,067</u>

Income from investments includes £1,620 (2018: £1,142) attributable to restricted funds, and £33,502 (2018: £26,925) attributable to unrestricted funds.

5 Analysis of expenditure on raising funds

	2019 £	2018 £
Direct costs	45,899	24,098
Support costs	86,155	79,099
	<u>132,054</u>	<u>103,197</u>

£9,041 (2018: £nil) of the above direct costs relates to grant application agency costs.

6 Analysis of expenditure on charitable activities

	Activities undertaken directly £	Grant funding of activities £	Support costs £	Total £
Communications	22,882	-	38,411	61,293
Membership	25,762	-	43,245	69,007
Services	96,356	-	161,747	258,103
Advocacy and influencing	10,083	-	16,927	27,010
Exceptional expenditure from the WFH	79,458	-	133,381	212,839
Public inquiry	116,203	-	195,064	311,267
Tanner Fund grants	-	1,000	-	1,000
	<u>350,744</u>	<u>1,000</u>	<u>588,775</u>	<u>940,519</u>

Exceptional income and expenditure was recognised in the financial year relating to the WFH conference held in Glasgow in May 2018. This generated significant exceptional activity from both an income and expenditure perspective and both note 3 and note 6 should be consulted to understand the net impact.

£252,018 (2018: £154,435) of the above costs were attributable to restricted funds. £688,501 (2018: £520,501) of the above costs were attributable to unrestricted funds.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

7 Allocation of support costs

Support cost	Basis of allocation £	Raising funds £	Charitable activities £	Total £
Governance	% of direct costs	3,781	28,972	32,753
Travel, postage and carriage	% of direct costs	3,043	7,218	10,261
Information technology	% of direct costs	3,768	28,875	32,643
Salary costs	% of staff time	64,176	436,445	500,621
Depreciation	% of direct costs	720	5,518	6,238
Office costs (incl. rental)	% of direct costs	5,382	41,241	46,623
Recruitment, training and temp staff	% of direct costs	2,373	18,183	20,556
Other expenses	% of direct costs	2,912	22,323	25,235
Total		86,155	588,775	674,930

8 Governance costs

	2019 £	2018 £
Trustee expenses	3,950	9,114
Auditors' remuneration - current year	6,750	6,500
Auditors' remuneration - prior year	1,050	3,050
Other expenses	21,003	8,743
	32,753	27,407

9 Net income / (expenditure) for the year

Net income / (expenditure) is stated after charging:

	2019 £	2018 £
Depreciation of tangible fixed assets	6,238	15,946
Operating lease rentals	47,838	29,216
Auditors' remuneration	6,750	6,500

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

10 Trustees' and key management personnel remuneration and expenses

The trustees neither received nor waived any remuneration during the year (2018: £nil).

The Charity considers its key management personnel to be the board of trustees and the Chief Executive, Liz Carroll. The aggregate benefits of key management personnel amounted to £93,222 (2018: £88,749).

The reimbursement of trustees' expenses was as follows:

	2019 Number	2018 Number	2019 £	2018 £
Travel, subsistence and accommodation	7	3	3,950	9,114

11 Staff costs and employee benefits

The average monthly number of full-time equivalent employees during the year was as follows:

	2019 Number	2018 Number
	12	10

Senior level staff numbers have increased to support our work on the public inquiry including members support and expertise in providing communications to members.

The total staff costs and employee benefits was as follows:

	2019 £	2018 £
Wages and salaries	436,905	306,102
Social security	37,998	27,050
Defined contribution pension costs	25,718	20,690
Interim staff	14,487	19,554
Recruitment and training	1,049	9,047
	<u>516,157</u>	<u>382,443</u>

Two employees received emoluments of more than £60,000 during the year ended 31st March 2019 (2018: one) and within the following bands:

	2019	2018
£70,001 - £80,000	1	-
£80,001 - £90,000	-	1
£90,001 - £100,000	1	-

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

12 Tangible fixed assets

	Computers and Office Equipment £
Cost:	
At 1 April 2018	68,352
Additions	8,555
At 31 March 2019	<u>76,907</u>
Depreciation:	
At 1 April 2018	59,874
Charge for the year	6,238
At 31 March 2019	<u>66,112</u>
Net book value:	
At 31 March 2019	<u>10,795</u>
At 31 March 2018	<u>8,478</u>

13 Fixed asset investments

	COIF Investment £	Other investments £	Total £
Cost or valuation			
At 1 April 2018	1,102,838	949	1,103,787
Additions	400,000	-	400,000
Disposals	(395,000)	-	(395,000)
Revaluation	41,301	-	41,301
At 31 March 2019	<u>1,149,139</u>	<u>949</u>	<u>1,150,088</u>

14 Debtors

	2019 £	2018 £
Prepayments and accrued income	199,122	59,385
Other debtors	66,775	26,322
	<u>265,897</u>	<u>85,707</u>

Accrued income includes a final payment from the WFH for The Society share in the surplus income of Congress held in May 2018 following the WFH audited accounts confirmation that was received in June 2019.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

15 Creditors: amounts falling due within one year

	2019 £	2018 £
Trade creditors	36,807	39,389
Accruals and deferred income	58,361	68,462
Other creditors	9,802	11,700
	<u>104,970</u>	<u>119,551</u>

16 Fund reconciliation

Unrestricted funds

	Balance at 1st April 2018 £	Income £	Expenditure £	Gains / (losses) £	Transfers £	Balance at 31st March 2019 £
Local groups	58,155	6,333	(10,587)	-	-	53,901
General funds	1,128,970	974,410	(809,968)	41,301	(600,000)	734,713
Designated funds	-	-	-	-	600,000	600,000
	<u>1,187,125</u>	<u>980,743</u>	<u>(820,555)</u>	<u>41,301</u>	<u>-</u>	<u>1,388,614</u>

Restricted funds

	Balance at 1st April 2018 £	Income £	Expenditure £	Balance at 31st March 2019 £
Talking Red	-	15,025	(15,025)	-
Tanner Fund	4,894	40	(1,000)	3,934
Memorial Service	10,181	610	(4,781)	6,010
Local Group Forum Event	-	5,000	(5,000)	-
Ageing	-	25,000	(25,000)	-
Inhibitors	-	33,568	(33,568)	-
Newly Diagnosed	-	75,250	(75,250)	-
AGM	-	25,000	(25,000)	-
Ambassadors	-	50,350	(50,350)	-
Core Patient Advocacy	-	6,544	(6,544)	-
APPG Project	-	34,000	(4,000)	30,000
Overseas Research	-	6,000	(500)	5,500
Trinidad Collaboration	-	6,000	(6,000)	-
Philip Morris Art Award	1,348	1,117	-	2,465
GROA Memorial Award	1,206	503	-	1,709
	<u>17,629</u>	<u>284,007</u>	<u>(252,018)</u>	<u>49,618</u>

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

16 Fund reconciliation (continued)

	Balance at 1st April 2018 £	Income £	Expenditure £	Balance at 31st March 2019 £
Endowment Funds				
Philip Morris Art Award	13,344	-	-	13,344
<div>GROA</div> Memorial Award	6,000	-	-	6,000
	19,344	-	-	19,344

Fund descriptions

a) Unrestricted funds

Local groups: The Society is represented throughout the country by local groups. Group funds are incorporated into the Society's financial statements.

Designated funds: Recognising the significant financial and general resource impact of the current public inquiry into infected blood, the board has designated £600,000 of reserves to fund the charity's work on the Inquiry in the next four years. It is anticipated our work to participate in the Inquiry, support and inform members of the community affected by the Inquiry may cost up to £150,000 per year until 2023. Designated funds will be reviewed annually and where the duration of the Inquiry is shortened or such amounts of expenditure are not required we will release relevant Designated Funds back into General Funds.

b) Restricted funds

Talking Red: Talking Red includes all our work for women with bleeding disorders including an awareness campaign and services for those with a diagnosis.

Tanner Fund: A hardship fund providing grants of up to £200.

Memorial Service: Funds held for the administration of an annual service of thanksgiving and remembrance in London for those who died as a result of contamination of blood products in the 1970s and 1980s.

Local Group Forum Event: Funding to provide a training and development event for members of our local groups.

Ageing: Fund to support our services and events for our ageing community.

Inhibitors: Fund to support our services and events for people with an inhibitor.

Newly Diagnosed: Fund to support our services and events for families with a newly diagnosed child with a bleeding disorder.

AGM: Funding for the annual general meeting and conference of The Society.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

16 Fund reconciliation (continued)

Ambassadors: Fund to support six Youth Ambassadors, who are volunteer advocates for the charity, to receive training, attend events and services and support the development of The Society's work and strategy.

Core Patient Advocacy - Funding to support our policy and advocacy activity across the UK, in particular supporting projects and reports to improve quality of care, such as our Early Diagnosis report.

APPG Project: A project with the APPG on Haemophilia and Contaminated Blood to investigate access to treatment in the UK.

Overseas Research: Exploring British Overseas Territories and our role as the UK Society to help empower and advocate.

Trinidad Collaboration: Developing an understanding of other national member organisations with hard-to-reach could community and to develop and share ideas around engagement.

c) Endowment funds

Philip Morris Art Award: This award is open to students with haemophilia or related bleeding disorders 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.

GROA Memorial Award: This is a bursary awarded to an individual with haemophilia or related bleeding disorders in pursuit of one of the professions or study relating to a profession. This award has been made possible by the Abrahams family in memory of their son.

Donations and interest earned on these funds are credited to the relevant restricted fund.

17 Analysis of net assets between funds

	Unrestricted funds	Local group funds	Restricted funds	Endowment funds	Total
	£	£	£	£	£
Fixed assets	1,141,539	-	-	19,344	1,160,883
Net current assets	193,174	53,901	49,618	-	296,693
Total	1,334,713	53,901	49,618	19,344	1,457,576

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2019

18 Reconciliation of net income / (expenditure) to net cash flow from operating activities

	2019 £	2018 £
Net income / (expenditure) for year	233,478	(116,586)
Interest receivable	(35,122)	(28,067)
Depreciation of tangible fixed assets	6,238	15,946
(Gains) / losses on investments	(41,301)	20,842
Increase in debtors	(180,190)	(3,260)
(Decrease) / increase in creditors	(14,581)	24,066
Net cash flow from operating activities	<u>(31,478)</u>	<u>(87,059)</u>

19 Pensions and other post-retirement benefits

The charity operates a defined contribution pension plan for its employees. The amount recognised as an expense in the period was £25,718 (2018: £20,690).

20 Financial commitments

The total of future minimum lease payments under non-cancellable operating leases for each of the following periods are:

	2019 Within 1 year £	2019 Within 1-5 years £	2018 Within 1 year £	2018 Within 1-5 years £
Land and buildings	52,285	7,525	4,778	-
Other	1,494	-	1,868	1,269
	<u>53,779</u>	<u>7,525</u>	<u>6,646</u>	<u>1,269</u>

21 Related party transactions

There are no related party transactions during the period (2018: £nil).



THE HAEMOPHILIA SOCIETY

Find the information you need on our website at www.haemophilia.org.uk, email us at info@haemophilia.org.uk, or give us a call on 020 7939 0780.

Your Society: getting in touch

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HaemophiliaSocietyUK



HaemoSocUK



thehaemophiliasociety

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Company limited by guarantee reg. no. 1763614

Members of the European Haemophilia Consortium and the World Federation of Hemophilia

Chair: **GRO-A**

President: Baroness Meacher

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