

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

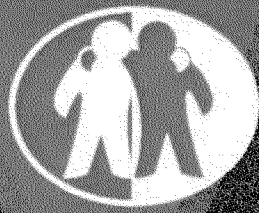
Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392058**

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THE  
HAEMOPHILIA  
SOCIETY

GRO-A

Statements. 2020/21

Registered charity no. 288260 (Scotland SC039732) Company limited by guarantee reg. no. 01763614

WITN6392058\_0002



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THE  
HAEMOPHILIA  
SOCIETY

**The Haemophilia Society**  
**Charity reference and administrative details**  
**Year ended 31 March 2021**

**President** Baroness Meacher  
**Chief Executive** Kate Burt

**Board of Trustees**

Lisa Bagley

Gordon Dixon

GRO-A

Kate Khair

Conan McIlwrath

GRO-A

Paul Sartain

GRO-A

Chair

Jo Traunter

Anna Geffert

**Subcommittees**

**Finance & Risk Committee**

Lisa Bagley

GRO-A

GRO-A

Kate Khair

Gordon Dixon - Chair

**Nominations Committee**

GRO-A

GRO-A

**Public Inquiry Committee**

GRO-A

GRO-A

Paul Sartain

Conan McIlwrath

GRO-A

- Chair





THE  
HAEMOPHILIA  
SOCIETY

**The Haemophilia Society**  
**Charity reference and administrative details**  
**Year ended 31 March 2021**

**Clinical Advisory Group**

Dr Rezan Abdul-Kadir  
Dr. Susie Shapiro  
Tom Burke  
Robert James  
Dr Kate Khair  
Prof Mike Laffan  
Prof Mike Makris  
Andrew Martin  
Debra Pollard  
David Stephenson  
Musrat Pinnu

**Company Secretary**

Paul Sartain

**Bankers**

NatWest Bank  
London Bridge  
PO Box 35  
10 Southwark Street  
London  
SE1 1TJ

**Solicitors**

Eversheds Southernland  
1 Wood Street  
London  
EC2V 7WS

**Auditors**

Azets Audit Services  
2nd Floor, Regis House  
45 King William Street  
London EC4R 9AN

**Registered Office**

52b Borough High Street  
London  
SE1 1XN

**Company registration number**

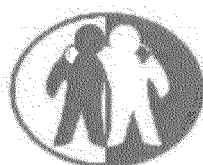
01763614

**Charity registration number**

288260

**Scottish charity registration number**

SC039732



## Chair's statement

Year ended 31 March 2021

2020 provided a global challenge like no other. Some small charities faced a threat to their very existence. Whilst The Haemophilia Society never found itself quite in that position, at times it felt like we were almost on a war footing. Staff were furloughed, tough financial decisions had to be made and we had to completely reassess our strategy and what we could deliver under the constraints on everyone's freedom.

It is only right, that this year I start by saying a huge thank you to our staff team. Our appreciation, thanks and gratitude is immeasurable. The team, who took on the daunting role of running the organisation during a time of external and internal challenge, showed enormous stamina, spirit and resilience which is testament to their professionalism and commitment to our community. As well as the staff team, I have to mention my fellow trustees. Hundreds of hours have been voluntarily given to assist with the running of the charity, along with the exhaustive search for a new CEO. As chair, I couldn't ask for a better team of staff and trustees to work with. This year has been exceptional and it is a true privilege to be your chair.

Which leads me onto our new CEO, Kate Burt. With nearly 70 applicants for the role, Kate stood out amongst a crowded field. Completely undaunted by our IT failures on the morning of interview, Kate has settled into her new role incredibly well. Not being able to travel and meet people face to face, Kate has spent much time listening to our community and getting to understand the challenges of where we have been, where we are and where we are going. I know Kate is looking forward to getting out and about and meeting people in person. On behalf of us all, a very warm welcome and we wish you every success.

With every challenge comes opportunity. Not being able to organise events has allowed us to reflect internally on work that needs to be done to ensure we are fit for the future. Over the last 12 months we have been working on our database and membership. Alongside this, work commenced on a new website to integrate it better with our systems, providing a better experience for visitors. This work continues and you will continue to see some changes later into 2021 and beyond.

One issue that came to a head in 2021 was members experience of treatment delivery by Healthcare at Home (HaH, now Sciensus). HaH undertook an IT upgrade towards the end of 2020 which had terrible consequences for our community. Home deliveries to our members were hugely disrupted at a time when many wanted to avoid having to go to hospital for obvious reasons. Myself, Kate and the staff team met with HaH in early 2021 to explain the distress and disruption this had caused. As a result of this, we have now set up a Patient Forum Group which meets regularly with HaH to assist them with trying to improve the patient experience. We will continue our work on this to ensure everyone receives the same high standard of service.

We endeavoured to stay connected with our community via virtual events. We ran a series of *Bleeding Matters Live!* webinars on a variety of topics such as virtual consultations, school and bleeding disorders and the Clinical Reference Group (CRG) to name a few. All remain on our website available to view.

We saw a return to the 'new normal' in October and December with the holding of the Service of Thanksgiving and Carol Service at St Botolph's Church at Liverpool Street, London. Both services were live-streamed and I know people tuned in from as far afield as Canada and Australia to the Carol Service.



## Chair's statement

### Year ended 31 March 2021

In February of this year, time was allocated to The Haemophilia Society to give evidence at the Infected Blood Inquiry. Our former General Secretary from the 1980s, David Watters, gave evidence over several days to the Inquiry. Other witnesses were expected to give evidence on The Society's behalf in February, but that was delayed until later in the year. The Society has campaigned for many years for a public inquiry. We welcome the scrutiny of our role in what happened in the past and we are already reflecting on how we can learn from the evidence given to the Inquiry.

On 25 March 2021, the Paymaster General, Penny Mordaunt MP, announced that Government would be setting up a review into a compensation framework for those impacted by contaminated blood. In addition, Penny Mordaunt MP announced there would be parity of financial support to beneficiaries of the infected blood support schemes and enhancements to psychological support schemes for those infected. As I said at the time, this is the closest any government has come to acknowledging liability for the contaminated blood disaster. For those that are no longer with us, this will come too late. But I hope it will provide some peace to those left behind. As and when Sir Brian Langstaff publishes his report, any recommendation for compensation that might be made must be honoured as quickly as possible. The announcement of the compensation framework, in parallel with the Inquiry, will hopefully achieve this. It has been an incredibly long battle, but it finally feels like we are moving towards the final chapter of this dark tragedy.

In last year's report I mentioned our Women's Committee. Despite not being able to launch this new Committee at an event in York because of the pandemic, the Committee and Steering Group are up and running. In January 2021, the first international guidelines for the treatment of Von Willebrand Disease (VWD) were published. We hope this will be a platform for many women (and men) with VWD to demand the care they deserve. This will provide a focus for the Committee and will inform its work in the future.

Last year created significant hurdles in our efforts to get our local group network up and running. Work on this has been going well and as of April 2021, we have 3 groups in existence, with 3 additional groups in the pipeline. Honourable mention has to go to the West Yorkshire Local Group who came up with the idea of the "Race Around the World". Commencing in March 2021, the aim was for participants to run, swim, cycle, and walk enough miles to cover the distance around the world. The aim was to arrive back in Yorkshire in time for World Haemophilia Day, on 17 April 2021. Being God's County, the Yorkshire group delivered ahead of schedule and made it a significant way around again! The Race Around the World raised £5,000 to go towards point of care ultrasound equipment and events for the West Yorkshire Local Group. With many people being more sedentary during lockdown, we intend to run this event again next year and have even bigger plans to get others involved.

Our Ambassadors, in particular our Youth Ambassadors, continue to show their commitment to the community. At the start of 2021, Haemnet provided training for our Youth Ambassadors to help them develop their skills. With lockdown lifting, I'm sure they will be out and about demonstrating what is possible whilst living with a bleeding disorder. We have also worked alongside Haemnet on a number of projects over the last year. The Cinderella Study sought to understand the lived experience of women with bleeding disorders.



## Chair's statement

Year ended 31 March 2021

And we are currently working with Haemnet on Project Phoenix, a project to improve standards of care in bleeding disorders across the UK. We hope to continue to build our relationship with Haemnet and have developed a memorandum of understanding on how we hope to work together.

The World Federation of Hemophilia (WFH) Congress was scheduled to take place in Malaysia in 2020. This became a virtual event with around 7,000 people attending online. The WFH held its annual meeting of the General Assembly virtually in October 2020. I was privileged to be elected to the Board of Directors of the World Federation. The European Haemophilia Consortium held its conference virtually. It had been scheduled to be held in Copenhagen. We hope to be able to get back to face to face conferences in the near future, certainly within Europe.

Due to COVID-19 our finances have been heavily impacted, which had a knock on consequences in terms of delivering events and services, leading to the postponement of activities into the next financial year. Overall income has dropped by 12%. However, with a tight control over expenditure, a reduction in costs associated with events and services, and a solid investment return, we have ended the year with a net gain of £155,046. This was partly due to a forecasting of our income, but mainly due to exercising tight fiscal control throughout the year. This was truly a team effort and means The Society retains a strong base of reserves and enters 2021 in a solid financial position.

There is only one place to end this year's report and that is by mentioning our outgoing trustees. Lisa Bagley and **GRO-A** (my predecessor as chair have reached a point in their tenure when they must take a year off. Having served for 6 years, they are both eligible for re-election in a year's time for another 3 year period. In the meantime, we thank them for their dedicated service to the Society and hope to see them back soon.

Dr Kate Khair however, has reached the end of her 9 year's service. It is impossible to articulate my own personal thanks to Kate, let alone the thanks we owe her on behalf of the community. Kate was my haemophilia nurse at Great Ormond Street Hospital and is very much the reason I am here on the board. Kate is the reason I am in such good health despite my bleeding disorder. Kate is the reason so many people with bleeding disorders in London, Africa and around the world have access to the best quality care. Kate's idea of a holiday is going to Africa to look after people with bleeding disorders (as well as see the elephants!).

I can say without fear of contradiction that Kate is the greatest haemophilia nurse in the world. We cannot replace Kate and the void she will leave is immeasurable. How lucky we are to have had her on our board. As a token of our appreciation, we will make Kate an Honorary Vice-President of the Society. On behalf of a community, thank you.

**GRO-A**

**GRO-A**

Chair of the Board of Trustees  
The Haemophilia Society

**GRO-A**



## Trustees' Annual Report Year ended 31 March 2021

The trustees present their report and the audited financial statements of the charity for the year ended 31 March 2021. 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 Companies Act 2006, 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 (resigned 14/11/20)

Gordon Dixon

GRO-A

Kate Khair

Conan McIlwrath

GRO-A

Paul Sartain

GRO-A

Anna Geffert (appointed 14/11/20)

Jo Traunter



## Trustees' Annual Report Year ended 31 March 2021

### 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 over 4,000 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 2021

### 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.



## Trustees' Annual Report Year ended 31 March 2021

### 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 36,000 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 the vital funds needed to give those affected the services they deserve and need to live the best life they can.

GRO-A





## Trustees' Annual Report Year ended 31 March 2021

### Activities

#### Member's Conference

This year due to COVID-19 restrictions we held our Members Conference virtually for the first time and over just one day. We had over 100 people join us online to hear from and ask questions of a variety of speakers covering topics such as gene therapy, women and bleeding disorders and the importance of keeping mobile during the national lockdowns.

In a time where it has been a challenge to stay connected with the community it was a wonderful opportunity to engage virtually with some familiar and fresh faces. We have learnt that the online format also allows greater access to those who are not able to travel, and we will be looking to use this type of platform again in the future.

We can't thank our amazing volunteers and colleagues enough for the incredible energy and vitality they brought to the Member's Conference this year.

#### Newly Diagnosed Family Weekends

Our weekends for parents of recently diagnosed children are free to attend and enable new parents to learn more about what to expect when raising a child with a bleeding disorder. It is a chance to meet others who are experiencing the same emotions and spend time hearing from and talking to experts, helping parents build a foundation of knowledge and support as they start their journey as a family.

Specialist bleeding disorder physiotherapists, nurses, doctors, psychologists and play specialists facilitate sessions, alongside our trustees and Youth Ambassadors.

This year we were not able to hold these events as usual due to pandemic restrictions so instead we trialled a virtual version, which was then recorded and made available on our website as a helpful resource for families.

However, on review, the virtual weekend could not replicate the value of a face-to-face weekend, especially the dedicated creche which allows parents ring-fenced time away from their children to learn and share experiences. As a result, a decision was taken to suspend the Newly Diagnosed Weekend programme until such times as they could be reinstated as usual.



**Trustees' Annual Report**  
**Year ended 31 March 2021**

GRO-A

**Webinars**

As a reaction to changing circumstances we introduced a series of virtual meetings covering a range of topics under the heading of *Bleeding Matters Live!*

These sessions included updates about the peer review report on the audit of centres, sharing experiences on changing treatments and virtual consultations, back to school and mindfulness training.

These sessions were well attended at first but declined over time, which could be attributed to 'zoom fatigue' affecting our audience's appetite for online content. However, it is a format which in the right circumstances and for select topics, we feel is well worth using again in the future.

***Bleeding  
Matters  
Live!***



THE  
HAEMOPHILIA  
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**Trustees' Annual Report**  
**Year ended 31 March 2021**



**Youth Activities**

Unfortunately, we were unable to run Youth Camp during this financial year, but rest assured it will return.

**Youth Ambassador engagement**

Our Youth Ambassadors have been active this year helping us to run webinars, producing content, informing the community through Instagram takeovers and blogs, and attending virtual conferences and events advocating for the community. This year the Youth Ambassadors have also been key in helping us to shape our future plans, and despite COVID-19 restrictions we now have two more ambassadors; representing Haemophilia B and Northern Ireland.



## Trustees' Annual Report Year ended 31 March 2021

### Talking Red Programme

Unfortunately, due to the pandemic we had to cancel our Talking Red conference for the second year running, however the Women's Sub-Committee and staff have been busy in the background.

We published the results of the women's survey, and now have a women's working group up and running. This group is helping to steer the work of the Talking Red programme, with exciting plans for late 2021 and the re-booked Talking Red Conference scheduled for March 2022.



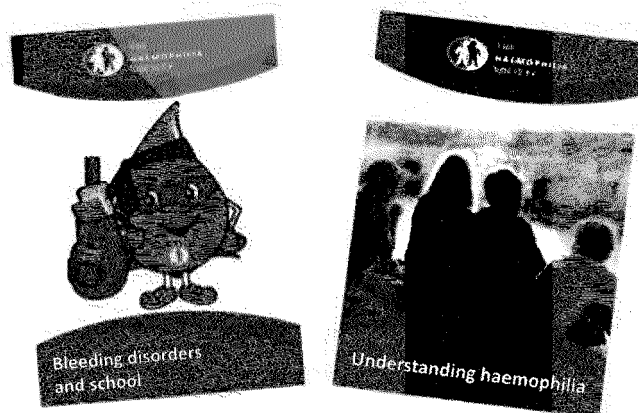
### Service of Thanksgiving and Remembrance

The lifting of some pandemic restrictions in October allowed a Service of Remembrance to take place, albeit with limited in-person attendees. For the first time the event was live-streamed, and over 450 people joined the service virtually to reflect on lives tragically lost through contaminated blood. The success of the live-streaming demonstrated that people unable to travel to London to attend the service in person appreciated the opportunity to be able to join the event online, and still take part. We plan to make live-streaming available for future Services of Remembrance.

### Publications

As the pandemic made some of our usual activity impossible, we took the opportunity to work on our publications; producing an updated *Bleeding disorders and school* booklet and an *Understanding haemophilia* booklet, and also completing work on our Rare Disease series of fact sheets.

Work also began on two new publications for release in late in 2021. Additionally, we undertook to translate our publications into several other languages, improving access to information to a wider proportion of our community.





## Trustees' Annual Report Year ended 31 March 2021

### Local Groups

Our community told us that we needed to do more with local groups, and so work has been progressing to re-write our engagement policy for local groups as well as secure funding for this project so that once COVID-19 restrictions allow, we can be more proactive in developing our local group network.

### Advocacy

We have been able to continue the work to advocate for access to new treatments for people with bleeding disorders, responding to NICE consultations, NHSE consultations on new treatments 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.

We have set up a forum to look at home care delivery with a patient led work group feeding directly to a main provider because of serious issues arising in autumn last year. We hope to build on the work of this group to see how we can develop this model to better influence more aspects of service delivery in time.

We have worked with EIBSS, who have attended our webinars (and the associated devolved nations support organisations) and the APPG on Haemophilia and Contaminated Blood to challenge decisions on support for those affected by contaminated blood and continued to call on governments to end the disparity between nations.

We have worked with the APPG to investigate the challenges people living with bleeding disorders face whether access to improved treatment, access to quality service or disparity of services across the UK and a dedicated APPG report was launched in March 2021 with a list of recommendations which will inform our advocacy goals in the future.

### Surveys and Research

We conducted a comprehensive survey into the impact of COVID-19 on the services received by our community from their centres during lockdown, and the wider impact on their health. The results were accepted for publication and were presented virtually at the EAHAD clinical conference in February. We plan to repeat the survey in late 2021 to compare two separate years of data, providing insight into the impact of COVID-19 and changes to working practice and service provision.

We continue to be involved in a variety of projects looking at shared decision making and the development of services and working practice.



## Trustees' Annual Report Year ended 31 March 2021

### Database and Processes

We have been steadfastly moving forward to improve our technology, to reflect the changing needs of the charity sector and how we interact with people with bleeding disorders, the community, suppliers and our wider public.

We secured valuable advice from PwC; a leading consultancy company who undertook a thorough audit and strategic review of our processes and technology on a pro bono basis. We are now moving into agreeing final specifications before the implementation of new technology and systems.

### Public Inquiry into infected blood

This year the scheduled start of the hearings with clinicians and haemophilia centres was delayed from June to mid-September when most of the evidence was given by video link. However, we were able to continue to give daily updates on social media to our members interested parties as well as provide weekly summaries, webinars, dedicated newsletters and updates on our website.

In early 2020 former trustees and staff of the Haemophilia Society were called to give evidence to the inquiry followed by evidence about trusts and schemes and Treloar School.



We continue to support the work of the inquiry and hope that we will be able to engage with people again at the hearings once restrictions are lifted.

In February we made the difficult decision to change legal firm 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.



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## Trustees' Annual Report Year ended 31 March 2021

### Fundraising

Our fundraisers have been active throughout the year organising sports days, baking, knitting, hosting brunches and initiating a range of fun activities. We welcome feedback about different activities and stories of success, especially with the ongoing challenges of COVID-19.

We are very grateful that people are still running, walking, cycling and swimming to raise money for the Haemophilia Society, and we want to thank all our supporters for their commitment, personal sacrifices, and hours of training.

We have launched a virtual shop to allow supporters to buy merchandise from us, including Christmas cards, and we plan to expand this in the future to include publications. Thank you to everyone who has contributed to our campaigns; this means that we can continue to provide information and support to our members free of charge.

This year we successfully held our Big Red Bridge Walk Glasgow but unfortunately had to cancel our Big Red Bridge Walk London due to COVID-19 lockdown restrictions. We hope to reinstate this event next year as it was so well-attended and supported previously.

GRO-A



## Trustees' Annual Report Year ended 31 March 2021

### What we are proud of

- Developing our Youth Ambassadors and the work they have done
- Our work on the Public Inquiry into infected blood
- Developing our communications via our website and social media
- Our Services to youth and families
- Our work with the public inquiry

### What we could do better

- Engagement with local groups
- Improve relationships with haemophilia centres to engage more people affected with bleeding disorders
- Develop a more structured volunteering process
- Increase the diversity of fundraising

### We remember

We remember our members, friends and volunteers who have died during the year and cherish their memories. For those who have lost loved ones from contaminated blood, it may have become increasingly hard and brought back difficult and traumatic memories as the Inquiry has begun to hear the personal testimony of individuals and families affected.

For the sake of the brave people who are reliving this tragedy, and those who have given evidence, we hope that the Inquiry finds the truth and their loss can be remembered knowing that justice has been done by them.

### Future plans

In 2020-21 we completely reviewed our strategy in order to adapt to economic uncertainty and build a strong and effective Society, that meets the future needs of all people suffering bleeding disorders.

We will continue to support the Infected Blood Inquiry and through listening to personal testimonies and engaging more closely with what our community needs, are committed to developing services which inspire our members and the wider community.

We are focusing energy in building our profile and reputation to appeal to both the wider community and increase the total and diversity of our revenue streams.

We will continue to evolve our Talking Red programme and are committed to ensuring women's issues are integrated into all of our events and programmes.





## Trustees' Annual Report Year ended 31 March 2021

We are looking to increase our range of publications to include publications on gene therapy and women & girls with bleeding disorders booklet as well as updating our Understanding VWD booklet. To increase our accessibility we have also had our booklets translated into Arabic, Polish and Urdu.

As we move into a second year of adapting to COVID-19, we are refining ways of engaging with our community with more local groups, improved centre engagement, increased online activities, virtual events and stronger social media engagement. We are continuing to improve our background process and technology to improve efficiency and engagement with our members.

### Financial review - Income and expenditure overview

This financial year was the first year in The Societies history, where we operated under different levels of COVID-19 related conditions, throughout the entire year, impacting both our activities and expenditure as well as our fundraising.

The infected blood Inquiry continued this year and in order to be able to support the proceedings and service our community we incurred costs of £107,359. This is significantly lower than the previous year and we expect expenditure to continue at this level or below until the estimated end of the Inquiry in Autumn 2022. In 2018-19 the Board agreed to designate £600,000 from reserves, which we expect to be sufficient to cover the entire period of the Inquiry. Funds not used in this respect, will be freely re-designated to general reserves.

Overall, we have generated a gain of the year of £43,437 (before the impact of gain on investments, which results in The Society continuing to be well capitalised.

Income (including legacies) for FY21 was down by 12% from £924,744 in FY20 to £814,955 in FY21. We experienced 37% fall in community income which reduced from £115,159 in YE20 to £72,165 in YE21. Our legacy Income also decreased by £130,932 (37% when compared with YE20.)

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 or 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.

Due to restrictions imposed by COVID-19 we have postponed some events, which resulted in deferring some of our expenditure to next financial year, mostly this relates to restricted income received from companies. Therefore, expenditure on charitable activities went down from £850,830 in FY20 to £656,298 in FY21.



## Trustees' Annual Report Year ended 31 March 2021

### Fundraising and volunteers

The Society's members have participated in a number of fundraising activities this year, which have in the main been undertaken online. We have benefited from members participating in a wide range of events alongside individual giving. They have made significant combined donations of £176,460 with additional Gift Aid receipts of £11,985. For this 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 unpaid volunteers who are 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 and their selfless giving of time.

We are also grateful for the extensive pro-bona support from professionals that The Society received during the year including important strategic work undertaken by PWC in planning a new CRM system.

### Grant and trust income

Although we submitted applications to the value of £472,000, we only received £6,700 income from trust applications this year (FY20: £21,390). The revenue stream was severely impacted by circumstances which presented minimal non-core funding requirements, much greater demand for sector funding, and given our sporadic grant and trust income over recent years likely limited our opportunities as funders focused resources on charities with which they had an existing relationship. This area of income is still under development, and we continue work on our strategy to focus on more targeted applications.

### Corporate income

Corporate funding has increased to £318,330 in FY21 (up from £274,086 in FY20)

This remains a key area of focus for the team and our corporate supporters have continued to provide us with substantial backing

### Legacies

Legacy income received of £220,294 FY21 was down by £130,932 compared with the previous year (£351,226 in FY20). Given the nature of legacies, there will always be a large variance on a yearly basis. We encourage any members, without immediate families to consider helping The Society in this manner.

### Costs

Overall costs in FY20 were £771,518. This is against a total income of £814,955, representing a surplus of £43,437 before net (losses)/gains on investments.



## Trustees' Annual Report Year ended 31 March 2021

### Reserves

The board of trustees reviewed and updated the reserves policy in March 2021. As COVID-19 may have longer term economic effects which could have a significant impact on our future income streams, the board of trustees made the decision to keep the liquidation fund at the same level of £337,465 to cover at least 6 months of running costs.

Recognising the significant financial and general resource impact of the current public inquiry into infected blood in 2019 the board designated £600,000 of reserves to fund the charity's work on the Inquiry. We 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 annum until Autumn 2022. The combined years to date we have spent £305,440 of the designated funds. Designated funds are reviewed annually to ensure the appropriate use of reserves.

As of 31 March 2021, unrestricted general reserves (excluding local group funds) stood at £1,347,827. 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 and unpredictable 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 on our behalf, based on a diversified and prudent investment strategy directly into assets to mitigate concentration of risks. As at the end of FY21 our funds had a market value of £1,395,552.

### 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. This will increase this year as the actions of The Society will be heard by the Inquiry and witnesses called to give evidence.

We will continue to monitor the risks and refer to the board to ensure they are aware of issues arising.

### COVID-19

The need to follow government procedure and lockdown guidance which began in March 2021 had significantly impacted the way we work and our ability to deliver face to face service events and fundraising activities. This could have a long term effect on the workings of The Society and our ability to engage with the community and we must remain agile and adapt to a changed environment.



## Trustees' Annual Report Year ended 31 March 2021

### Structure, governance and management

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 trustee board has

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

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  
HAEMOPHILIA  
SOCIETY

## Trustees' Annual Report Year ended 31 March 2021

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.

### 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.

GRO-A

GRO-A, Chair

Date: 29 September 2021

**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 2021 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and the notes to the financial statements, including 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 2021 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**

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

**Other information**

The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. 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. 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 course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine

## **The Haemophilia Society**

**Year ended 31 March 2021**

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

whether this gives rise to a material misstatement in the financial statements themselves. 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.

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 for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report included within the trustees' report has 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 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; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemptions in preparing the directors' report included within the trustees' report and from the requirement to prepare a strategic report.

### **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

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

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 is available on the Financial Reporting Council's website at [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

**Extent to which the audit was considered capable of detecting irregularities, including fraud**

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the company through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of noncompliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

**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



**The Haemophilia Society**

**Year ended 31 March 2021**

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

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.

**GRO-C**

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

Date: 14 October 2021

# The Haemophilia Society

## Statement of financial activities (including income and expenditure account)

Year ended 31 March 2021

		2021			2020
		Unrestricted funds	Restricted funds	Endowment funds	Total
Note		£	£	£	£
<b>Income and endowments from:</b>					
Donations and legacies	2	382,318	274,380	625	657,323
Charitable activities	3	72,941	3,750	-	76,691
Investments	4	40,643	934	-	41,577
Other		39,364	-	-	39,364
<b>Total income and endowments</b>		<b>535,266</b>	<b>279,064</b>	<b>625</b>	<b>814,955</b>
<b>Expenditure on:</b>					
Raising funds	5	86,352	28,868	-	115,220
Charitable activities	6	534,474	121,824	-	656,298
<b>Total expenditure</b>		<b>620,826</b>	<b>150,692</b>	<b>-</b>	<b>771,518</b>
Net (losses) / gains on investments		111,609	-	-	111,609
<b>Net income / (expenditure)</b>	9	<b>26,049</b>	<b>128,372</b>	<b>625</b>	<b>155,046</b>
<b>Transfers between funds</b>		<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Net movement in funds</b>		<b>26,049</b>	<b>128,372</b>	<b>625</b>	<b>155,046</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward		1,379,544	22,635	14,125	1,416,304
<b>Total funds carried forward</b>		<b>1,405,593</b>	<b>151,007</b>	<b>14,750</b>	<b>1,571,350</b>

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 2021

	Note	2021 £	2020 £
<b>Fixed assets</b>			
Tangible assets	13	11,084	15,609
Investments	14	1,395,552	1,183,943
		<u>1,406,636</u>	<u>1,199,552</u>
<b>Current assets</b>			
Debtors	15	181,251	84,605
Cash at bank and in hand		56,016	201,892
		<u>237,267</u>	<u>286,497</u>
<b>Creditors: amounts falling due within one year</b>	16	(72,553)	(69,745)
<b>Net current assets</b>		<u>164,714</u>	<u>216,752</u>
<b>Net assets</b>		<u>1,571,350</u>	<u>1,416,304</u>
<b>Charity funds</b>			
Endowment funds	17	14,750	14,125
Restricted funds	17	151,007	22,635
Unrestricted general funds	17	715,802	586,773
Local group funds	17	57,766	53,387
Designated funds	17	632,025	739,384
<b>Total charity funds</b>	18	<u>1,571,350</u>	<u>1,416,304</u>

The financial statements were approved and authorised for issue by the board on

Signed on behalf of the board of trustees

**GRO-A** Chair

**GRO-A**

The notes on pages 31 to 44 form part of these financial statements.

Company registration number: 01763614

**The Haemophilia Society**

**Statement of cash flows**

**Year ended 31 March 2021**

	Note	2021 £	2020 £
<b>Net cash flow from operating activities</b>	19	<u>(84,448)</u>	<u>89,888</u>
<b>Cash flow from investing activities</b>			
Payments to acquire tangible fixed assets		(3,005)	(13,382)
Net cash flow from sale and purchase of fixed asset investments		(100,000)	(50,000)
Interest received		41,577	39,620
<b>Net cash flow from investing activities</b>		<u>(61,428)</u>	<u>(23,762)</u>
<b>Net increase / (decrease) in cash and cash equivalents</b>		(145,876)	66,126
<b>Cash and cash equivalents at 1 April 2020</b>		201,892	135,766
<b>Cash and cash equivalents at 31 March 2021</b>		<u>56,016</u>	<u>201,892</u>
<b>Cash and cash equivalents consists of:</b>			
Cash at bank and in hand		56,016	201,892
<b>Cash and cash equivalents at 31 March 2021</b>		<u>56,016</u>	<u>201,892</u>

**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 3 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 Howard Abraham 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.

**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.

**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
--------------------------------	------------------------------

**(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 2021**

**1 Summary of significant accounting policies (continued)**

**(m) Government grants**

Government grants are recognised at the fair value of the asset received or receivable when there is reasonable assurance that the grant conditions will be met and the grants will be received.

A grant that specifies performance conditions is recognised in income when the performance conditions are met. Where a grant does not specify performance conditions it is recognised in income when the proceeds are received or receivable. A grant received before the recognition criteria are satisfied is recognised as a liability.

**(n) 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.

**(o) Going concern**

Trustees have considered the continuing impact of the COVID-19 virus on the future viability of The Society, 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 resources for the charitable company to be able to continue as a going concern.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charitable company has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

**2 Income from donations and legacies**

	2021 £	2020 £
Donations from individuals	100,365	93,274
Legacies	220,294	351,226
Grants and trust income	6,700	21,390
Corporate income	318,330	274,086
Gift Aid	11,634	16,496
	<hr/> 657,323	<hr/> 756,472

Income from donations and legacies includes £274,380 (2020: £242,783) attributable to restricted funds, £382,318 (2020: £513,689) attributable to unrestricted funds, and £625 (2020: £nil) attributable to endowment funds.



Notes to the financial statements

Year ended 31 March 2021

**3 Income from charitable activities**

	2021 £	2020 £
Local group activities	4,526	2,051
Community fundraising and events	72,165	115,159
	<u>76,691</u>	<u>117,210</u>

Income from charitable activities includes £3,750 (2020: £77) attributable to restricted funds, and £72,941 (2020: £117,133) attributable to unrestricted funds.

**4 Income from investments**

	2021 £	2020 £
Interest - fixed interest securities	41,577	39,619
Interest - deposits	-	1
	<u>41,577</u>	<u>39,620</u>

Income from investments includes £934 (2020: £966) attributable to restricted funds, and £40,643 (2020: £38,654) attributable to unrestricted funds.

**5 Analysis of expenditure on raising funds**

	2021 £	2020 £
Direct costs	32,337	31,366
Support costs	82,883	67,675
	<u>115,220</u>	<u>99,041</u>

£28,868 (2020: £13,334) of the above costs were attributable to restricted funds. £86,352 (2020: £85,707) of the above costs were attributable to unrestricted funds.

**6 Analysis of expenditure on charitable activities**

	Activities undertaken directly £	Grant funding of activities £	Support costs £	Total £
Communications	50,744	-	73,417	124,161
Membership	12,688	-	18,037	30,725
Services	56,047	-	266,588	322,635
Advocacy and influencing	17,554	-	32,785	50,339
Corner stone project	20,079	-	-	20,079
Public inquiry	7,606	-	99,753	107,359
Tanner Fund grants	-	1,000	-	1,000
	<b>164,718</b>	<b>1,000</b>	<b>490,580</b>	<b>656,298</b>

£121,824 (2020: £262,694) of the above costs were attributable to restricted funds. £534,474 (2020: £588,136) of the above costs were attributable to unrestricted funds.

**7 Allocation of support costs**

Support cost 2021	Basis of allocation £	Raising funds £	Charitable activities £	Total £
Governance	% of direct costs	1,439	7,411	8,850
Travel, postage and carriage	% of direct costs	1,345	1,750	3,095
Information technology	% of direct costs	3,092	15,931	19,023
Salary costs	% of staff time	63,452	395,658	459,110
Depreciation	% of direct costs	1,224	6,306	7,530
Office costs (incl. rental)	% of direct costs	6,792	34,990	41,782
Recruitment, training and temp staff	% of direct costs	1,769	9,116	10,885
Other expenses	% of direct costs	3,770	19,418	23,188
<b>Total</b>		<b>82,883</b>	<b>490,580</b>	<b>573,463</b>

Notes to the financial statements

Year ended 31 March 2021

**7 Allocation of support costs (continued)**

Support cost 2020	Basis of allocation	Raising funds	Charitable activities	Total
	£	£	£	£
Governance	% of direct costs	1,186	11,063	12,249
Travel, postage and carriage	% of direct costs	1,976	9,807	11,783
Information technology	% of direct costs	1,906	17,785	19,691
Salary costs	% of staff time	51,765	418,318	470,083
Depreciation	% of direct costs	829	7,739	8,568
Office costs (incl. rental)	% of direct costs	4,789	44,687	49,476
Recruitment, training and temp staff	% of direct costs	2,603	24,291	26,894
Other expenses	% of direct costs	2,621	24,455	27,076
Total		67,675	558,145	625,820

**8 Governance costs**

	2021	2020
	£	£
Trustee expenses	110	2,536
Auditors' remuneration - current year	8,460	8,100
Auditors' remuneration - prior year	-	-
Other expenses	280	1,613
	8,850	12,249

**9 Net income / (expenditure) for the year**

Net income / (expenditure) is stated after charging:

	2021	2020
	£	£
Government grants	14,090	-
Depreciation of tangible fixed assets	7,530	8,568
Operating lease rentals	39,453	42,110
Auditors' remuneration	8,460	8,100

Government grants of £14,090 (2020: £nil) relates to amounts received from the job retention scheme claimed by the charitable company for staff that were furloughed due to COVID-19. Under the scheme employers can claim 80% of a furloughed employee's wages up to £2,500 plus associated employer's costs. The government grants has been included within other income.

Notes to the financial statements

Year ended 31 March 2021

**10 Auditors' remuneration**

	2021 £	2020 £
Fees payable to the charitable company's auditor for the audit of the charitable company's annual accounts	8,460	8,100

**11 Trustees' and key management personnel remuneration and expenses**

The trustees neither received nor waived any remuneration during the year (2020: £nil).

The Charity considers its key management personnel to be the board of trustees and the Chief Executive. The aggregate benefits of key management personnel amounted to £98,053 (2020: £89,306).

The reimbursement of trustees' expenses was as follows:

	2021 Number	2020 Number	2021 £	2020 £
Travel, subsistence and accommodation	2	7	138	2,536

Included in trustees' expenses was £43 (2020: £1,387) paid directly to third parties.

**12 Staff costs and employee benefits**

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

	2021 Number	2020 Number
	9	11

The total staff costs and employee benefits was as follows:

	2021 £	2020 £
Wages and salaries	400,174	409,019
Social security	34,703	34,971
Defined contribution pension costs	24,233	26,092
Interim staff	-	13,956
Recruitment and training	5,326	5,935
	464,436	489,973

# The Haemophilia Society

## Notes to the financial statements

### Year ended 31 March 2021

#### 12 Staff costs and employee benefits (continued)

One employee received emoluments of more than £60,000 during the year ended 31st March 2021 (2020: two) and within the following bands:

	2021	2020
£60,000 - £70,000	1	1
£70,001 - £80,000	-	1

#### 13 Tangible fixed assets

	Computers and Office Equipment £
Cost:	
At 1 April 2020	90,289
Additions	3,005
At 31 March 2021	93,294
Depreciation:	
At 1 April 2020	74,680
Charge for the year	7,530
At 31 March 2021	82,210
Net book value:	
At 31 March 2021	11,084
At 31 March 2020	15,609

#### 14 Fixed asset investments

	COIF Investment £	Other investments £	Total £
Cost or valuation			
At 1 April 2020	1,182,994	949	1,183,943
Additions	100,000	-	100,000
Disposals	-	-	-
Revaluation	111,609	-	111,609
At 31 March 2021	1,394,603	949	1,395,552

# The Haemophilia Society

## Notes to the financial statements

Year ended 31 March 2021

### 14 Fixed asset investments (continued)

Investments at fair value comprise:

	2021 £	2020 £
Equities	949	949
Securities	1,394,603	1,182,994
	<u>1,395,552</u>	<u>1,183,943</u>

The fair value of listed investments is determined by reference to the fund price.

### 15 Debtors

	2021 £	2020 £
Prepayments and accrued income	151,044	26,719
Other debtors	30,207	57,886
	<u>181,251</u>	<u>84,605</u>

### 16 Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	21,722	11,733
Accruals and deferred income	35,739	47,499
Other creditors	15,092	10,513
	<u>72,553</u>	<u>69,745</u>

Notes to the financial statements

Year ended 31 March 2021

17 Fund reconciliation

Unrestricted funds

	Balance at 1st April 2020 £	Income £	Expenditure £	Gains / (losses) £	Transfers £	Balance at 31st March 2021 £
Local groups	53,387	4,526	(147)	-	-	57,766
General funds	586,773	530,740	(513,320)	111,609	-	715,802
Designated funds – Public inquiry	401,919	-	(107,359)	-	-	294,560
Designated funds – Liquidation fund	337,465	-	-	-	-	337,465
	1,379,544	535,266	(620,826)	111,609	-	1,405,593

Restricted funds

	Balance at 1st April 2020 £	Income £	Expenditure £	Transfers £	Balance at 31st March 2021 £
Talking Red	-	15,000	(8,524)	-	6,476
Tanner Fund	2,514	-	(1,000)	-	1,514
Memorial Service	2,528	-	(1,585)	-	943
Newly Diagnosed	-	34,080	(17,699)	-	16,381
AGM	-	25,000	(25,000)	-	-
Ambassadors	-	22,000	(7,267)	-	14,733
APPG Project	4,239	-	(4,239)	-	-
Overseas Research	2,995	-	(2,995)	-	-
Booklets	-	45,500	(28,997)	-	16,503
Factsheets	-	1,500	-	-	1,500
9 Survey	-	30,000	(14,489)	-	15,511
Youth Camps	-	30,000	(3,647)	-	26,353
Hour Record	-	53,958	(20,671)	-	33,287
Journal Subscription	-	1,092	(1,092)	-	-
Checklist	-	3,000	(2,413)	-	587
Website	-	12,000	(9,588)	-	2,412
Centre Engagement	-	5,000	(1,486)	-	3,514
Philip Morris Art Award	6,251	487	-	-	6,738
Howard Abrahams Memorial Award	4,108	447	-	-	4,555
	22,635	279,064	(150,692)	-	151,007

17 Fund reconciliation (continued)

Endowment Funds

	Balance at 1st April 2020 £	Income £	Expenditure £	Transfers £	Balance at 31st March 2021 £
Philip Morris Art Award	7,500	-	-	-	7,500
Howard Abrahams Memorial Award	6,625	625	-	-	7,250
	14,125	625	-	-	14,750

Fund descriptions

a) Unrestricted funds

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

Designated funds – Public inquiry: Recognising the significant financial and general resource impact of the current public inquiry into infected blood, in 2019 the board designated £600,000 of reserves to fund the charity's work on the Inquiry over four years. We participate in the Inquiry, support and inform members of the community affected by the Inquiry. 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.

Designated funds – Liquidation fund: Recognising the impact of COVID-19 on charity income, the board has designated funds to provide sufficient cover for at least 6 months of running costs.

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.

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



## The Haemophilia Society

### Notes to the financial statements

#### Year ended 31 March 2021

##### 17 Fund reconciliation (continued)

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

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.

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.

Booklets: Funding for productions of information booklets and translation to other languages

Factsheets: Funding for translation of Rare Disease Factsheets

COVID-19 Survey: Funding to carry out pre & post COVID-19 survey

Youth Camps – Funding to organise youth camps to help children and young people to develop independence, by taking part in new experiences and challenges where they will also participate in sessions which focus on learning to self-treat.

Hour Record: Sponsorship in support professional cyclist and haemophiliac Alex Dowsett as he attempts to regain the world hour record by covering the longest distance on a cycling track in 60 minutes. The event is steeped in history and regarded as one of the most recognised challenges for physical endurance.

Journal subscription: Funding for Haemophilia Journal annual subscription

Checklist: Funding to develop a diagnosis checklist for women with Bleeding disorders

Website: Funding to support renewal of website (<https://haemophilia.org.uk/>), to deliver a better user experience.

Centre Engagement: Funding to help with reengagement with Haemophilia Centres

##### 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.

Howard Abrahams 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.

# The Haemophilia Society

## Notes to the financial statements

### Year ended 31 March 2021

#### 18 Analysis of net assets between funds

	Unrestricted funds	Local group funds	Restricted funds	Endowment funds	Total
	£	£	£	£	£
Fixed assets	1,391,886	-	-	14,750	1,406,636
Net current assets	(44,059)	57,766	151,007	-	164,714
<b>Total</b>	<b>1,347,827</b>	<b>57,766</b>	<b>151,007</b>	<b>14,750</b>	<b>1,571,350</b>

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

	2021 £	2020 £
Net (expenditure) / income for year	155,046	(41,272)
Interest receivable	(41,577)	(39,620)
Depreciation of tangible fixed assets	7,530	8,568
Losses / (gains) on investments	(111,609)	16,145
Decrease / (increase) in debtors	(96,646)	181,292
Decrease in creditors	2,808	(35,225)
<b>Net cash flow from operating activities</b>	<b>(84,448)</b>	<b>89,888</b>

#### 20 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 £24,233 (2020: £26,092).

#### 21 Financial commitments

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

	2021 Within 1 year £	2021 Within 1-5 years £	2020 Within 1 year £	2020 Within 1-5 years £
Land and buildings	36,300	24,200	36,300	60,500
Other	5,151	12,020	4,100	6,874
<b>Total</b>	<b>41,451</b>	<b>36,220</b>	<b>40,400</b>	<b>67,374</b>

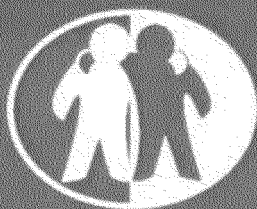
**The Haemophilia Society**

**Notes to the financial statements**

**Year ended 31 March 2021**

**22 Related party transactions**

The charity received donations from two trustees during the period totalling £3,967 (2020: £625).



# THE HAEMOPHILIA SOCIETY

Find the information you need on our website at [haemophilia.org.uk](http://haemophilia.org.uk), email us at [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk), or give us a call on 020 7939 0780.

Your Society: getting in touch

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Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

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HaemophiliaSocietyUK



HaemoSocUK



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Registered charity no. 288260 (Scotland SC039732)

Company limited by guarantee reg. no. 01763614

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

Chair: **GRO-A**

President: Baroness Meacher

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