THE HAEMOPHILIA SOCIETY

England & Wales · Charity number 288260

Details

Status	Registered
Legal form	Charitable company
Company number	01763614
Registered	1983-11-30
Register	View on the Charity Commission register

Contact

Address	52B Borough High Street London SE1 1XN
Phone	02079390780
Email	info@haemophilia.org.uk
Website	www.haemophilia.org.uk

Activities

Objects: 1) THE RELIEF OF PEOPLE SUFFERING FROM HAEMOPHILIA AND RELATED OR ASSOCIATED BLEEDING DISORDERS2) THE ADVANCEMENT OF PUBLIC EDUCATION INTO THE NATURE AND CAUSES OF HAEMOPHILIA AND RELATED OR ASSOCIATED BLEEDING DISORDERS.

Activities: The Society represents, offers support, and provides information for all people affected by bleeding disorders.

Classification

- **How:** Provides Human Resources, Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, People With Disabilities, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£590,276	£862,721	£185,717	10
2024-03-31	£562,789	£940,418	£462,976	11
2023-03-31	£795,226	£1,073,201	£843,995	15
2022-03-31	£749,428	£1,183,010	£1,168,607	13
2021-03-31	£814,955	£771,518	£1,571,350	9

Trustees

Name	Role	Appointed
Conan McIlwrath		2019-11-16
Gordon Dixon		2019-11-16
Helen Tate		2024-11-17
Joanne Traunter		2019-11-16
Lisa Bagley		2023-11-18
Natalie Lawson		2021-11-20
Paul Sartain		2018-12-01
Peta Dixon		2024-11-17
Rayaz Ali Chel		2021-11-20
Simon Blackwell		2025-01-07
Stacey McGeown		2023-11-18

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Accounts

The Haemophilia Society
Annual Report
2024/25

The Haemophilia Society

About the Haemophilia Society

We are the only UK-wide charity for everyone affected by a genetic and acquired bleeding disorder, and our charity is here for you.

At the Haemophilia Society (THS) we want to empower everyone affected by a bleeding disorder to live life to the full, whatever your stage in life.

One in 2,000 men, women and children in the UK have a diagnosed bleeding disorder, which are a group of conditions, including haemophilia and von Willebrand disorder, that result when the blood cannot clot properly.

As many as a third of bleeding disorder diagnoses have no known family history and can be the result of a random gene mutation. This means a bleeding disorder diagnosis can come completely out of the blue.

THS brings together people with bleeding disorders and their families to share experiences and understand more about how to live well with a bleeding disorder. Together, we can all make a difference.

Contents

Chair's welcome


Conan McIlwrath, THS Chair

I will start this, my first annual report, on a personal note which I hope captures the pride I have at being the new chair of the Haemophilia Society (THS). I've been a member of this wonderful organisation since I was a young boy, thanks to my parents who were heavily involved in THS's work in Northern Ireland. Had someone told me 10 years ago that today I would be putting my thoughts on a page as chair I would have laughed in disbelief. However, life is full of surprises, struggles, joy and opportunities, and when this chance came around I wanted to grab it. It is an honour to serve as your chair. Whatever your bleeding disorder and wherever you live in the UK, we are here for you and your family.

The publication of the Infected Blood Inquiry's landmark report in May 2024 represented the culmination of decades of support and advocacy from THS on behalf of our members who were infected and affected by the contaminated blood scandal. The result of its six-year investigation was a vindication of the worst fears of the infected blood community and resulted in an apology from the Prime Minister on behalf of the nation. Our work does not stop, in fact it has increased dramatically as we support our members and their families through a complex compensation process.

We continue to offer highly valued in-person events to support our entire community, whether it's families with a child recently diagnosed with a bleeding disorder, young people having a first taste of independence at our summer Youth Camp or our annual Big-Get Together conference which connects and empowers our members, young and old.

I'm proud of the work we're doing to ensure that everyone with a bleeding disorder is supported by THS. We have working groups which focus on rare bleeding disorders and von Willebrand disorder (VWD) to make sure our charity is inclusive and reflects the needs of our whole membership.

Funding our small charity is a serious and increasing challenge and we are so grateful to everyone who has donated, organised a fundraiser or remembered us in their will. We hope the government will honour a recommendation from the Infected Blood Inquiry that our charity should receive statutory funding for our advocacy work. We continue to look for new funding sources and opportunities.

I look forward to five positive and busy years as chair as we restructure, regroup and focus on delivering what is important for you all.

Conan McIlwrath
THS Chair

Our year in numbers

2,153
items bought from the shop

8
Stronger together grants

5430
members
6.8% increase

444
event attendees

14
London marathon runners
£35,577 raised

£284,415
raised through individual giving

152,573
website visitors

13,806
social media followers

13,446
video views

Who we are

Resilient

Empowering

Compassionate

We exist to support you, and everybody affected by a genetic bleeding disorder in the UK, to enable you to live life well. We are both a charity and a member organisation, founded 75 years ago.

The Haemophilia Society supports the bleeding disorders community by:

- Organising events which share expert knowledge and bring together people with similar experiences
- Providing free in-depth and unique publications. From starting school to the challenges of ageing with a bleeding disorder, we publish 12 different booklets offering support and information, many of which are offered in other languages including Arabic, Polish, Urdu, Welsh and Bengali. We've also produced 19 free, downloadable factsheets on everything from applying for benefits to how to prepare for a virtual doctor's consultation.
- Sharing the latest news about developments in treatment, our work or anything else relevant to our community via social media, email and in our Community Matters twice-yearly members' magazine.
- Campaigning. Together with you, our members, we raise awareness about bleeding disorders and lobby government, the NHS and clinicians for the best possible care and equal access to effective treatment. We also campaign in support of our many members who were infected and affected by the contaminated blood scandal.
- Listening to what you, our members, need. We regularly invite feedback and survey our membership to find out what is most important to our community. We also invite members to join working groups to steer our strategy and activity.

Today we have 5,430 members, and a very active community on our social media channels. Our posts have a reach of more than 13,000 people.

Our vision

'Our new three-year strategy is an ambitious but achievable roadmap which will keep us focused on our key priorities, ensuring that we're working efficiently and effectively for our members.'

Kate Burt, Chief Executive of the Haemophilia Society

Kate Burt, Chief Executive

This year we've launched a three-year strategy which gives us a clear direction for our future work. We have created a shared mission which we believe will support and empower our members whilst ensuring the ongoing financial viability of our small charity.

Our four strategic pillars are:

- Connecting and empowering our community through shared knowledge, engagement and leadership
- Improving standards of treatment and access to care
- Empowering and connecting people infected and affected by contaminated blood products to access compensation and support
- Improving the efficiency, security and stability of THS

Making sure that our charity has a sustainable financial footing is a key objective. In the current challenging economic climate it is crucial that THS has firm foundations so that our members can be confident of our ongoing support. We have a new fundraising plan to achieve this by diversifying our major donor sources and encouraging more members to commit to regular giving. We are also calling on government to honour the Infected Blood Inquiry's recommendation that our charity should receive statutory funding for our advocacy work.

We will continue to use our insight and knowledge to inform health policy, and inform care commissioners. Our aim is always to improve standards of treatment and help to ensure equal access to excellent care for everyone with a bleeding disorder.

We recognise the importance of bringing together our community both online and in-person to share experiences and to reduce isolation and anxiety. Although the cost of hosting events is an increasing challenge, we understand how much our members value the chance to get together and we will do all we can to maintain this service.

Shared stories, knowledge and informed support give people with bleeding disorders and their families the power and confidence to advocate for the best treatment and care.

Our new strategy helps us focus on this all-important goal.

What we do

Youth support

Ryan Reynolds, Young Ambassaador

> **‘I became a Young Ambassador because I know first-hand what a struggle it can be as a young person growing up with a bleeding disorder and I wanted to help. I loved volunteering at Youth Camp and seeing a change in mindset in the children who left the event believing they could do so much more than when they arrived.’**
>
> Young Ambassador Ryan Reynolds, who has severe haemophilia A

Ensuring that our young members are welcomed, supported and empowered to manage their bleeding disorder independently is an important part of our work.

We have a strong Young Ambassador programme, dating back to 2015, which is open to members aged 18-30. Our Young Ambassadors act as mentors to our younger members, offering advice and reassurance about the reality of living with a bleeding disorder. They also attend our events to talk about their lived experience. Many people, particularly parents of newly diagnosed children, find it very reassuring to hear about the full lives these approachable and positive young people lead.

Our Young Ambassadors also regularly attend global conferences to share their experiences, helping them to build their skills to become advocates for themselves and our community.

Young Ambassador training weekend

This year we welcomed three new Young Ambassadors and said farewell to three of our more senior members, who have been wonderful role models for our charity. We held a specialist training session in London in September to boost all our Young Ambassadors’ storytelling skills and to discuss our new strategy to ensure their views were incorporated.

It’s been a year of challenges, with four experienced Young Ambassadors, who all live with bleeding disorders, taking part in tough physical tests. The team tackled the gruelling Fan Dance walk in the Brecon Beacons and, as part of our on-going twinning project, took part in a 6km open water swim between Gozo and Malta. With careful planning in consultation with their medical teams, they completed both events. Two videos will be released in 2025 as a record of their achievements which we hope will inspire other young people with bleeding disorders to take on challenging projects of their own.

Young Ambassador training weekend

Team THS at the Gozo-Malta swim

> **‘The Malta Swim Challenge summarised why we all do what we do – it proved to others, and more importantly to ourselves, that our bleeding disorders aren’t barriers, and that overcoming the physical and mental challenges often takes a village, which is exactly what we had around us. Completing the challenge alongside friends and family without bleeding disorders also highlighted the importance of a supportive community.’**
>
> Young Ambassador Peta Dixon who has a bleeding disorder of unknown cause (BDUC)

Peta Dixon, Young Ambassador

Youth Camp

Our annual Youth Camp, which is free to members, took place in Staffordshire in July and was attended by 42 young people aged nine to 15 who either have a bleeding disorder or have a sibling with a bleeding disorder. Supporting the families of people with a bleeding disorder is an essential part of our work, and a recognition of the impact that living with a bleeding disorder has on parents, grandparents and siblings.

The camps, which could not be run without the support of our volunteers, including clinicians such as specialist paediatric nurses and physiotherapists, allow our young people freedom and independence in a safe environment. Here they can try activities such as climbing and a high ropes course which builds their confidence.

Imaan, aged nine

My daughter loved Youth Camp, she gained a lot of confidence and felt great doing all the activities knowing she is safe and under great guidance. She made lovely friends who she is still in contact with – they are hoping to meet at the next camp.'

Sidra, mum of Imaan, who has Glanzmann thrombasthenia

'Youth Camp gave my son more confidence in understanding his condition and he enjoyed meeting other children who are managing the same feelings and emotions as him. He and his brother loved the opportunity of trying new activities and conquering some fears too. Thank you!'

Bernadette, mum of Ayden and Lucca, who has severe haemophilia A

They also meet others who have been through similar experiences, often resulting in long-lasting friendships. For many of our campers this is the first opportunity they've had to stay away from home independently , and gives parents a rare break too.

We were delighted to be joined by a family from Malta, as part of our twinning project with the Malta Bleeding Disorders Society. We hope to support our friends and colleagues in Malta to organise a similar event for young people in the future.

As always, our feedback was excellent from Youth Camp 2024, from both the young people themselves and their parents or carers.

Community support

Bringing people together to share experiences and find out about the latest care and treatment available is one of the most rewarding aspects of our work. Genetic bleeding disorders are rare, and it can be isolating to be the only person with this condition in a workplace, village, school or sports team. By connecting our members through in-person events and our supportive social media community, people can be reassured that they are not alone in whatever challenges they are facing. Sharing experiences also empowers people to think again about their care as they learn about the treatment of others and find out more about the options open to them.

This year, 444 adults and children registered to attend one of five in-person events held in four locations in England.

Big Get-Together annual conference and AGM

'I have an extremely rare bleeding disorder. At the Big Get-Together I was able to meet with other people with different rare bleeding disorders, this gave me a safe place to talk about our shared experiences without being judged or dismissed. I feel that I have gained a voice to be able to advocate for myself, my daughter and others. Most importantly, for the first time in my life I have gained a group of friends who understand the issues of living with a rare bleeding disorder as a woman and are now my support network.'

Chris

Our one-day Big Get-Together (BGT) conference and AGM was packed with informative talks, workshops and discussions featuring contributions from some of the UK's leading experts in bleeding disorder care as well as people who live with a bleeding disorder. Held in Leicester, the event attracted 191 people. Our younger members joined a dedicated teen session run by a specialist paediatric nurse to discuss the issues around living with a bleeding disorder that mattered to them.

In addition to sessions on mental and physical health, we were joined by the interim Chief Executive of the Infected Blood Compensation Authority who offered one-to-one conversations with members of the contaminated blood community. There was also plenty of time to network informally and share experiences.

Newly diagnosed families weekend

What parents said about the event:

'I enjoyed meeting other families and the childcare was fantastic. The session content was brilliant. I felt cared for and supported by the Haemophilia Society team.'

'The weekend showed me that I am not alone, there are other families in the same situation as us. Thanks to the Haemophilia Society, we now have a support network, which is life-changing.'

'I enjoyed meeting other families and the childcare was fantastic. The session content was brilliant. I felt cared for and supported by the Haemophilia Society team.'

Our Newly Diagnosed Weekends (NDWs) provide families with expert advice, invaluable peer support and a safe space to ask questions in the very early stages of diagnosis. THS Young Ambassadors also attend these events, sharing their experiences and bringing positivity to families who may feel uncertain about their child's future. Specialist clinicians also support us at NDWs, answering a range of questions about treatment and care.

This weekend is free to our members and offers a creche facility. For many parents, this is the first time they've left their child with anyone other than another family member. The experience can be a valuable stepping stone in supporting parents with the transition to nursery.

We held our NDW in Milton Keynes this year where we welcomed 21 adults and 20 children. There were discussions about the benefit of physiotherapy for children and a presentation about the role of specialist haemophilia nurses as well as a chance to talk to young adults living with a bleeding disorder.

Feedback from the event was extremely positive, with 100% of parents telling us that attending the weekend had positively affected their view of living with a child with a bleeding disorder. They also felt more empowered to make decisions about their child's treatment and wellbeing.

Future of bleeding disorder care seminar at the Royal School of Medicine

We were honoured to be invited by Royal School of Medicine to host an afternoon of discussion and shared experiences focussing on the future of bleeding disorder care at its prestigious headquarters in London.

The free event gave us an invaluable opportunity to engage a new audience of healthcare professionals and people interested in rare conditions as well as involving our members and supporters in top level debate.

Thanks to the support of leading bleeding disorder clinicians and people with lived experience of a bleeding disorder, the event offered a stimulating window into what the future of bleeding disorder care might look like.

A total of 110 people attended the event, including resident doctors and trainee physiotherapists who had an interest in pursuing haematology as a specialism as well as clinicians from different areas who wanted to understand more about haemophilia and other bleeding disorders.

Von Willebrand Awareness Day

More than 30 adults with von Willebrand disorder (VWD) got together to share experiences and discover more about treatment and care at an event organised by the Royal London Hospital's Haemophilia Centre team, which we were pleased to support.

The aim of the day was to bring people with VWD together to discuss their experiences of living with the bleeding disorder as well as to involve healthcare professionals who gave updates on treatment, barriers to diagnosis,physiotherapy and the benefits of counselling.

Community support event for the contaminated blood community

More than 60 people attended a support event in London for those infected and affected by the contaminated blood scandal of the 1970s and 80s. The event took place on the eve of the publication of the Infected Blood Inquiry's report and was designed to offer solidarity and friendship as the infected blood community prepared for one of the most important days in the history of this scandal.

Service of Remembrance and Thanksgiving

We are proud to host this important event every October to remember all those people with inherited bleeding disorders who have died due to their treatment with contaminated blood products. The service is held at St Botolph without Bishopsgate, London, where the Book of Remembrance is kept. This year's service had an exceptionally high attendance, with some families represented by three generations touched by the contaminated blood scandal. As well as remembering loved ones who have died, the event is also a safe and supportive space to talk to others who have been bereaved and are grieving.

Carol Service

Our annual Carol Service held at St Botolph without Bishopsgate is gaining in popularity due in part to the wonderful singing of the church choir and its location in the heart of the City of London. This paid-for event is increasingly being attended by non-members who work locally, giving us an opportunity to increase awareness about our work to a different audience.

Ambassadors

We have three dedicated ambassadors to support our members. These are: THS staff member Scott McLean, our Mental Health Ambassador, William McKeown, our Access and Service Improvement Ambassador and Mark Ward, our LGBTQ Ambassador. All our ambassadors attend conferences on our behalf to highlight and support our work as well as provide us with invaluable insights into the needs of the communities they work with.

> **‘I’m incredibly proud to be the Haemophilia Society’s LGBTQ Ambassador. It’s important to me that we have an inclusive and compassionate bleeding disorders community and I’m here as a friend and support to anyone who needs me. I also advocate for the community at conferences, to politicians and a variety of organisations across the UK, because education and understanding about bleeding disorders and the history of our community is essential.’**
>
> Mark Ward, THS LGBTQ Ambassador


Mark Ward, THS LGBTQ Ambassador

Working Groups

The Haemophilia Society is committed to supporting all genetic bleeding disorders. We want all our members to have access to services, support and events that match their specific needs and challenges. One way we ensure the needs of those with different disorders are heard and understood is through our working groups. These groups, made up of a diverse group of volunteers, are dedicated to representing, advocating for and serving the needs of a specific community within our membership. This helps us shape what we do to ensure these needs are properly met.

Women’s Working Group

We have 18 members of the Women’s Working Group who represent women with a range of genetic bleeding disorders or who care for a female with a bleeding disorder. The group takes the lead in setting the agenda for our annual Talking Red Live conference which is a day dedicated to women and girls with a bleeding disorder. Through regular online meetings, the group also helps to shape our priorities for this section of our membership. Members have provided valuable contributions to the SACRed project, our latest major research initiative into the treatment and care of women and girls (see Advocacy). The group was formed in 2020.

Rare and Bleeding Disorder of Unknown Cause (BDUC) Working Group

Launched in 2024, the Rare and BDUC Working Group has attracted members representing more than eight extremely rare conditions, such as Glanzmann thrombasthenia, factor V deficiency and factor VII deficiency. Although every condition is different, common themes have emerged, such as challenges with diagnosis, treatment, and psychological support. From this, the group has set goals which include identifying educational gaps for healthcare professionals, improving information online and for treating clinicians. The group meets monthly online and has created a much-needed space for individuals to share experiences, promote understanding and create ideas on how to improve knowledge about their conditions.

> **‘I’m the only person in my family with a bleeding disorder and I didn’t know anyone with a bleeding disorder, so it has been great to get to know the other members of the group and follow their journeys. It’s nice to have that community inside the Haemophilia Society. I attended my first conference about rare bleeding disorders thanks to the group, which was really informative. I learnt a lot about what treatment is – and sometimes isn’t – available for rares and it gave me more confidence to advocate for better care.’**
>
> Lucy, who has a factor VII deficiency and is a member of the Rare and BDUC Working Group

Von Willebrand Disorder (VWD) Working Group

Established in 2023, the VWD Working Group was set up to raise the profile of this condition within the bleeding disorder community, healthcare profession and the general public.

There are about 11,500 people in the UK with a VWD diagnosis, which makes it the most common genetic bleeding disorder. Despite this, it is a condition that can take years to diagnose and one about which most people know very little. Our VWD Working Group aims to change this.

Publications

This year we produced 12 booklets and 19 downloadable factsheets. We sent out 1,501 publications, some of which are available in five languages, including Welsh, Urdu and Arabic. The booklets are used in haemophilia centres as well as by individual members to help them and their friends and relatives to understand their condition.

This year we offered the following free publications:

- Understanding Haemophilia
- Understanding VWD
- Ageing with a bleeding disorder – social care and support
- Ageing with a bleeding disorder: Managing trips, falls and mobility
- Rare bleeding disorders
- Bleeding Disorders and School
- Women living with bleeding disorders
- Girls with living with bleeding disorders
- Dental care for adults with a bleeding disorder
- Sex and bleeding disorders
- A-Z guide to sport and physical activity for children with a bleeding disorder
- Understanding gene therapy for haemophilia

We offered the following downloadable factsheets:

- Disability Living Allowance (DLA) for children with bleeding disorders
- Personal Independence Payment (PIP) Making a claim
- PIP Assessment process
- Emicizumab (for people without an inhibitor)
- Emicizumab (for people with an inhibitor)
- Extended half-life (EHL) factor VIII
- Top tips for parents
- Patient checklist to prepare for virtual consultations
- Factor V, factor VIII combined deficiency
- Factor XIII deficiency
- Factor XI deficiency
- Factor X deficiency
- Factor VII deficiency
- Factor V deficiency
- Prothrombin (factor II) deficiency
- Fibrinogen (factor 1) deficiency
- Bernard Soulier syndrome
- Glanzmann thrombasthenia
- A-Z guide to sport and physical activity for children with a bleeding disorder

Video projects

'Chris Clotter's Sports Day' animation series

This year we launched a video project to encourage children with bleeding disorders to get involved in sport, featuring Chris Clotter, our mascot and young person's champion.

The series of four short videos offer practical advice and support to parents, emphasising the benefits of getting and keeping their children fit and healthy by finding a sport they love.

We're excited that the project is endorsed by two elite athletes who have reached the top of their sports while living with haemophilia. Alex Dowsett, a former professional cyclist and Ed Fuller, who won gold as a rower in the Paralympic Games in Paris in 2024, both feature in the videos as animated characters.

The Sports Day concept is now being taken toward as a UK-wide community event, planned for Autumn 2025.

We will also be releasing videos of the Young Ambassador's long-distance swimming and walking challenges in the UK and Malta later in 2025 to inspire others to believe that, with the right clinical support, most physical activities are possible.

Infected Blood Inquiry

> **‘This is a day of shame for the British state...the result of this inquiry should shake our nation to its core.’**
>
> Prime Minister, Rishi Sunak

> **‘I’m grateful for the incredible support I had from the Haemophilia Society who have put so much energy into helping our community through the compensation process. Communication has been helpful and staff have gone out of their way to give me support when I had nowhere else to turn.’**
>
> Meg

The contaminated blood scandal has been a central part of our campaigning and support work for the last five decades. In 2017 there was a great leap forward when the government set up the Infected Blood Inquiry to investigate how and why people were infected with viruses including hepatitis C and HIV through contaminated NHS blood and blood products in the 1970s and 80s. More than 3,000 people who were infected have died following their infections, and thousands more lives have been ruined as a result of this scandal.

In May 2024 the Infected Blood Inquiry, after six years of analysing evidence, published its report which concluded that the scandal could have largely been avoided and was a result of multiple failings across institutions including government and the NHS. Repeatedly, patient safety was not prioritised. The Prime Minister apologised on behalf of the nation and accepted that compensation should be paid. The inquiry’s conclusions attracted global interest and our charity’s representatives were interviewed by national and international media, helping to highlight significance of the issue.

The inquiry’s Recommendations nine and 10 are focussed specifically on bleeding disorder care and advocacy. Recommendation nine outlines measures for protecting the safety of haemophilia care and Recommendation 10 focuses on giving patients a voice. We are active members of various working groups tasked with providing the expertise to enable government to implement the inquiry’s recommendations. (See Advocacy section).

After decades of campaigning by THS and many other groups, it was a major milestone to hear the government commit to setting aside £11.8 billion for a compensation settlement.

Much of our work since this announcement has been lobbying government to produce a fair compensation scheme and to implement the report’s other recommendations. We also received a huge number of calls and emails following the publication of the government’s compensation scheme and have devoted significant staff time to supporting our members through the process.

While progress this year has been significant, it has also been a period of great uncertainty as the infected blood community tried to make sense of what the proposed compensation scheme meant for them. Many fear dying before justice is seen to be done.

We have also been continuing to press for a bespoke psychological support service for England. As well as campaigning for this service we have also provided advice and insight about how the new service should look. Northern Ireland, Wales and Scotland already have this service, but England lags behind. While progress has been made, the new service is not due to be operational until Summer 2025.

Our Public Inquiry Team continues to support those infected and affected by the scandal and keep our members up to date with the work of the Infected Blood Inquiry and any political developments. We hold webinars on key topics and run a dedicated Facebook support page as well as a Twitter/X account for news updates.

We are pleased to be working with the Wellcome Trust on an archiving project which will ensure all the documents stored by THS for use by the inquiry will be preserved. We expect most of this information to be publicly available, although some documents will need to be redacted to ensure personal data is not compromised.

Advocacy and influencing

A vital part of our charity’s work is advocating for higher standards of treatment and care and greater awareness of bleeding disorders. We represent our members across the UK through engagement at all levels from parliament and central government, through health and NHS bodies, clinician groups and other stakeholders all the way down to individual centres, hospitals and trusts.


All Party Parliamentary Group on Haemophilia and Contaminated Blood

Standards of Care and Access to Treatment

We founded the Haemophilia and Bleeding Disorder Alliance, a group that brings together patient groups from across the UK and clinician groups to speak as one voice on issues affecting people with a bleeding disorder and to push for higher standards and better access to treatment and care. With the UK-wide audit of haemophilia centres now complete, the alliance is preparing to consider its finding when they are published later in 2025 and to push for gaps in care to be addressed by the relevant trusts and Integrated Care Boards (ICBs). The alliance is also focused on ensuring that the Infected Blood Inquiry’s recommendations relating to improvements in bleeding disorder care are implemented.

We continue to be a member of the specialised blood disorders Clinical Reference Group (CRG) as one of the two patient representatives on the group. The CRG works with NHS England to coordinate specialist care for people with bleeding disorders and leads on the development of new treatment and care guidelines, policies and service specifications.

A new draft service specification was finalised which will establish an important baseline in bleeding disorder care. It focusses on access to full multidisciplinary care, improving people’s rights to physiotherapy, providing better care to women and girls with bleeding disorders and providing more psycho-social support. This will be consulted on in 2025 and come into force in 2026.

Influencing the political agenda

In response to the Infected Blood Inquiry's Recommendation nine, NHS England worked with us and other stakeholders to ascertain the size of resource gaps across haemophilia centres. A proposal we worked on to improve funding for centres is now under consideration by the Department of Health and Social Care (DHSC).

We also developed, with NHS England, a proposal to strengthen networks for haemophilia centres so they work more collaboratively to support people with bleeding disorders. We were involved in developing new clinical commissioning policies for recombinant von Willebrand factor and expanded use of the subcutaneous haemophilia A treatment emicizumab.

We continue to work with NICE, a government body which evaluates new treatments for use in the NHS. We support the process by advocating for the needs of patients and demonstrating the need for new treatments. This year we made written and oral submissions to the NICE review of marstacimab a new subcutaneous treatment for haemophilia A and B. In addition, our advocates, including President of the Haemophilia Society, Clive Smith, gave evidence to committees considering a new long-acting factor product for haemophilia A, efanesoctocog alfa. Our previous work on access to gene therapy for haemophilia B paid off, with a positive recommendation for funding for Hemgenix through the Innovative Medicines Fund, which was announced in June 2024. This announcement means that gene therapy is now available on the NHS for people with severe haemophilia B, which is a major treatment breakthrough.

We are members of NHS England's Specialised Commissioning Stakeholder Forum and the Specialised Health Care Alliance (SHCA) which allows us to raise wider issues about how NHS treatment and care is commissioned and delivered across England. We also work with the Haemophilia Nurses Association (HNA), the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) and the Haemophilia Chartered Physiotherapists' Association (HCPS) to ensure patient's views are taken into account in all aspects of haemophilia and bleeding disorder care.

We were part of the DHSC's Homecare Medicines Services Patient and Professional Advisory group to improve monitoring and outcomes for people who rely on home delivery of treatment.

The SACRed Project, a multiyear investigation into the experiences of women and girls with bleeding disorders was completed this year. The final report, Underserved/Overlooked: How our health systems are failing women and girls with a bleeding disorder will be published in Summer 2025.

We supported Genomics England's Generations Study, a project to provide genetic testing for rare diseases to newborns, in development of patient information for people with suspected bleeding disorders.

Through our work in parliament, we seek to ensure that the treatment and care needs of people with genetic bleeding disorders is understood by political decision-makers of all parties. After the general election in July 2024 we worked with Clive Efford MP to reestablish the All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood. We were reappointed as secretariat of the APPG with responsibility for facilitating meetings, coordinating parliamentary campaigns, updating MPs on developments in bleeding disorder care and treatment, briefing MPs on the campaign for justice for people infected and affected by contaminated blood products and maintaining the webpage, social media and membership information of the APPG.

We attended the Labour Party conference in Liverpool, and had useful conversations with delegates about the future of the NHS and how to ensure that a fair compensation scheme is delivered to people impacted by contaminated blood products.

Debra Morgan and Laurence Woollard at the 2024 Labour Party Conference

Global connections

THS values and seeks to strengthen our links with fellow haemophilia and bleeding disorder associations around the world. We believe that our attendance at bleeding disorder conferences is essential in giving us the knowledge and contacts to advocate effectively for our members. These events also offer our Young Ambassadors and our members the chance to find out more about their condition and how to advocate more effectively for better treatment and care.

We attended major global conferences including the European Haemophilia Consortium (EHC) conference in Sofia, Bulgaria and the World Federation of Hemophilia's (WFH) conference in Madrid, Spain. Amy Owen-Wyard, a THS trustee and our nominee, was elected to join the EHC's steering committee.

Amy Owen-Wyard at 2024 EHC conference in Sofia, Bulgaria

We also had a representative at the EHC's New Technologies conference in Helsinki in Finland where the latest treatment and research is unveiled and discussed. We also sent two staff members to the European Association for Haemophilia and Associated Disorders (EAHAD) conference in Milan, Italy. Members of our Rare and Bleeding Disorder of Unknown Cause Working Group attended the EHC's European Rare and Inhibitor Network Summit in Zagreb, Croatia and we sent representatives to the EHC's Leadership Development Conference in Brussels.

We were also pleased to be invited to attend the National Institute for Health and Care Excellence (NICE) in Manchester, England. Our Chief Executive, Kate Burt, addressed the annual conference of the haemophilia doctors' organisation, the UKHCDO in London, England.

In addition, we have individual members who are active on the international stage. Our member, Bonnie Taylor, who has severe haemophilia A, is the EHC's Ambassador for Women with a Bleeding Disorder. Our trustee Jo Traunter is a member of the EHC's von Willebrand disorder (VWD) Working Group and Amy Owen-Wyard is chair of the EHC's European Rare and Inhibitor Network (ERIN).

Malta twinning project

Our four-year twinning project with the Malta Bleeding Disorders Society (MBDS), funded by grants from the World Federation of Hemophilia is now in its second year. We are working with the MBDS board to improve their governance, increase their fundraising capacity, strengthen their advocacy and get better access to care and treatment in Malta.

This year, we welcomed a family from Malta to the UK attend our Youth Camp, which we hope will inspire a similar event in the future. A delegation of staff, Young Ambassadors and trustees travelled to Malta in September 2024 for a weekend of workshops and advocacy, culminating in some of the team undertaking the Gozo to Malta open water swim to raise money for a youth support event in the country. We really value the strengthening ties that are developing between our two organisations.


THS staff and ambassadors at a workshop with the Malta Bleeding Disorders Society


Amy Owen-Wyard and Mark Ward visiting haemophilia centra at Mater Dei in Malta

Working together across the UK

National haemophilia centres

We are grateful for the productive relationships we have with the national haemophilia charities in Wales, Scotland and Northern Ireland. We liaise with both all organisations to maximise advocacy, particularly in relation to issues arising from the Infected Blood Inquiry's work.

Little Bleeders

We continue to work closely with Little Bleeders, the charity established by former professional cyclist Alex Dowsett, which encourages young people with bleeding disorders to get involved in sport and stay active

Our volunteers

> **'I find it rewarding to be able to provide lived experience as a trustee. Ensuring that THS's priorities are shaped by the day-to-day experiences of people living with a bleeding disorder is very important to me.'**
>
> Rayaz Chel, THS trustee


THS trustee Rayaz Chel (right) with Dr Gary Benson

THS trustees at a board meeting

THS staff member, Julia Collins, and Young Ambassador, Ryan Reynolds volunteering at Youth Camp

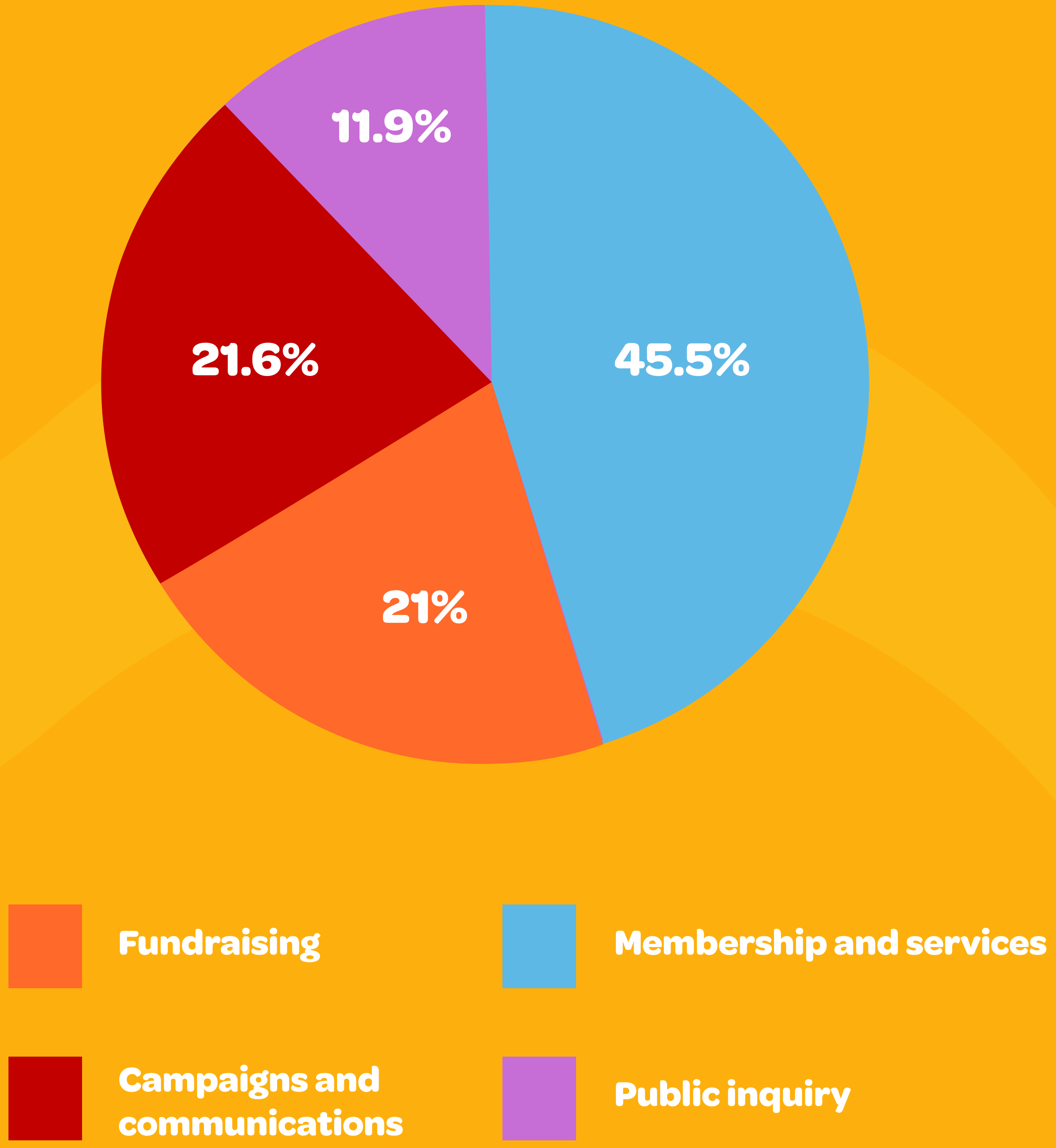
THS staff member, Rosie Devlin volunteering at Youth Camp

Without our volunteers, we would be unable to host the events which we know our members find so valuable, nor could we run our charity, which is governed by unpaid volunteers who are elected to serve on our Board of Trustees. We'd like to thank our trustees, who give their time so generously to ensure our organisation is run as efficiently and productively as possible for the benefit of our members.

We are very grateful to our clinical volunteers, such as haemophilia nurses, consultants and physiotherapists, who give up their time to attend events, such as Youth Camp and Newly Diagnosed Weekends, or to speak at our conferences or information days. We also could not manage events such as Youth Camp without an army of volunteers to oversee the welfare of those attending, as they climbi walls, canoe, zip-wire and other fun activities that make this event so special for our younger members. We appreciate the contribution of every single volunteer.

THS trustee, Natalie Lawson and Micheal Warwick volunteering at Youth Camp

How we use your money



Fundraising and Partnerships

We are grateful to have such dedicated partners who help us to support our members and the wider bleeding disorders community. The generosity of charitable trusts, corporate partners and volunteers helps us to continue to deliver our core services for our members.

Corporate partners

We receive ongoing support from partners in the pharmaceutical and private sectors, which includes sponsorship of member events, charitable grants and travel expenses to educational events.

Without this funding, it would be impossible for us to run many of our events which offer essential support to our members. We would like to emphasise that there are strict guidelines relating to donations from pharmaceutical companies to health organisations which we adhere to at all times.

Companies must respect the independence of the project and organisation to which they have donated and are not allowed to influence any of its written material. As per clause 29 of the 2021 ABPI code, all pharmaceutical companies must declare their sponsorship of 'patient organisations', which is how THS is classed under the code.

This year we are grateful for support from our corporate partners in the following areas of our work:

Events

Young Ambassador's training day, London, September 2024 - SOBI

Youth Camp, Whitemoor Lakes, Staffordshire July 2024 - Takeda, Roche-Chugai, EHC

Big Get-Together annual conference, Leicester, Nov 2024 - SOBI, Takeda, LFB, Pfizer

Newly Diagnosed Weekend, Milton Keynes, May 2024 - SOBI, Novo Nordisk, Roche-Chugai, Pfizer, LFB

Digital projects

Young Ambassador's Fan Dance Walk and video project - SOBI, CSL Behring

Young Ambassador's Malta to Gozo swim and video project - Pfizer

Development of Chris Clotter videos - SOBI, Roche-Chugai

Policy programmes

Sacred Project on-going research - SOBI, Roche-Chugai, LFB, Octapharma, Takeda

Dental Survey Publication of Findings - Nordic

Publications

Development of Ageing booklets - Octapharma

Development of Paediatric Dental Booklets - Nordic

Review of Understanding Haemophilia and Schools Booklets - SOBI

Attendance at conferences

WFH Madrid, April 2024 - SOBI, Roche- Chugai

EAHAD, Milan, Feb 25 - LFB

Royal Society of Medicine supported:

Medicines and Me event, London, February 2025

European Haemophilia Consortium supported :

Attendance at Conference:

New Technologies in Bleeding Disorders, Helsinki, Nov 24

EHC Leadership Development Conference June 24

ERIN Conference December 2024

Events:

Youth Camp 2024

Came from core funding:

EHC conference in Sofia, October 24

Labour conference in Liverpool, September 24

Service of Remembrance and Thanksgiving October 2024

Trusts and Foundations

We continue to strengthen our relationships and grow support from trusts and foundations to fund our ongoing project delivery. We have built robust sources of funding and are committed to further strengthening our partnership with our funders to support continued growth.

Thank you to the following trusts and foundations for your support this year:

Adint Charitable Trust, The Astor Foundation, Harris Charitable Trust, Douglas Heath Eve Charitable Trust, Sir Samuel Scott of Yews Trust and Hospital Saturday Fund.

A big thank you

Thank you to everyone who walked, ran, cycled, swam, sky dived, played golf, baked, organised raffles and undertook many other challenges to raise funds for THS. We appreciate all that you do for our charity.

We have some of the most loyal and generous supporters any charity could wish for. The individual donations and legacies that we receive and the contributions from our partners, large or small, makes everything that we do possible.

Together, we continue to work to improve the lives of everyone with a genetic bleeding disorder and their families in the UK.


Ross running the 2024 London Marathon


Georgia, and Reggie, after completing the Colchester Zoo run


Emily and Heather after finishing the London - Essex bike ride


Barry doing a wing walk in memory of his wife

Our staff


Kate Burt
Chief Executive


Fiona Donoghue
HR and Office Manager


Debra Morgan
Head of Policy and Campaigns


Nicola Sugg
Events and Membership Manager


Julia Collins
Events and Content Officer
(until August 24)

Jessica Bomford
Communications Manager

Rosie Devlin
Trusts and Data Officer

Jefferson Courtney
Policy and Public Affairs Manager

Sam Wilson
Digital Marketing and Content Manager

Scott McLean
Fundraiser and Member Advocate

Paula McCabe
Finance Officer
(until December 24)

Our governance

We work hard to set the highest standards as an organisation. Our policies and procedures reflect our values and we designed them to help us keep to those standards. We communicate them to our employees and volunteers and give everyone the training they need to uphold them. We also record our decisions and incidents, monitor our performance, and gather feedback to help us learn and improve.

This year we updated our Articles of Association, the document which defines our governance and purpose, to better reflect our work as a modern charity. The changes were approved at an Emergency General Meeting in October 2024.

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 seriously and we will:

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

Administration and legal details

President	Baroness Meacher (until November 24), Clive Smith (from November 24)
Patrons	Baroness Meacher, Dame Diana Johnson MP and Kate Khair (from November 24)
Chief Executive	Kate Burt
Board of Trustees	Clive Smith - Chair (until November 2024) Conan McIlwrath - Chair (from November 2024) Susan Stretch - Vice Chair (resigned January 2025) Gordon Dixon - Treasurer Simon Blackwell (co-opted January 2025) Paul Sartain Joanne Traunter Natalie Lawson Helen Tate (elected November 2024) Amy Owen-Wyard - Vice Chair (from December 2024) Rayaz Chel - Vice Chair (from December 2024) Lisa Bagley Stacey McGeown Peta Dixon (co-opted November 2024)

Subcommittees

Finance and Risk Committee	Gordon Dixon - Chair Clive Smith Conan McIlwrath Susan Stretch (until January 2025) Rayaz Chel
Nominations Committee	Gordon Dixon Clive Smith (until November 2024)
Public inquiry Committee	Clive Smith - Chair (until November 2024) Conan McIlwrath (from November 2024) Susan Stretch (until January 2025) Paul Sartain Eileen Ross Barry Flynn

Medical and Scientific Advisory Group	Dr Rezan Abdul-Kadir Dr Susie Shapiro Anna Wells Cathy Harrison Dr Gary Benson Dr Lochana Nanayakkara Dr Mary Mathias Dr Suthesh Sivapalaratnam Natalie Lawson
Company Secretary	Paul Sartain
Bankers	Natwest Bank London Bridge PO Box 35 10 Southwark Street London, SE1 1TJ
Solicitors	Eversheds Sutherland 1 Wood Street London, EC2V 7WS
Auditors	Ellacotts Audit Service Limited Countrywide House 23 West Bar Banbury, OX16 9SA
Company registration number	01763614
Charity registration number	288260
Scottish charity registration number	288260

Trustees' report

The Trustees present their annual report and financial statements for the year ended 31 March 2025.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "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)".

Objectives and activities

Public benefit

The Trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

Achievements and performance

Significant activities and achievements against objectives

Financial review

The unpredictable and challenging times the charity and voluntary sector has experienced in recent years continued in the financial year 2024-2025. For THS, as for many organisations, the 'perfect storm' created by funding falling, costs increasing, and demand for our support climbing remains.
These challenges make it more important than ever that we focus on efficiency and ensuring that we offer our members a relevant and useful service with an increased effort on achieving diverse and reliable funding sources.

Income for FY25 grew by 7.2% compared to FY24 to £590,300. However, corporate and events income fell short of forecast and has still not returned as we had projected to pre-pandemic levels. Costs were reduced by 8.5% for FY25 with total expenditure of £862,700. Overall, we have generated a loss for the year of £277k, which resulted in a significant reduction of reserves.

Legacy income received of £85,680 FY25 decreased by 53% compared with the previous year and by 89% from FY23. Given the nature of legacies, there will always be a large variance on a yearly basis. We are grateful to all our members who remember THS in their will.

Reserves

THS held investments at 31/03/2025 of £351,614 .

In recognition of the significant financial and general resource impact of the ongoing Infected Blood Inquiry, THS has invested £1,033,000 of the charity's reserves on our work supporting the inquiry and the infected blood community since 2017. Even with this level of investment we have not been able to keep up with demand for our support, particularly over the last 12 months as our supporters have tried to work out what the Infected Blood Compensation Scheme means for them.

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.

Reserves policy

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's expenditure. The Trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Key risks and uncertainties

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

Financial

As described above, we are operating in a challenging financial environment and planning to focus our income generating strategy on building trust and foundation relationships as well as increasing and diversifying our corporate partnerships. The Infected Blood Inquiry report published in May 2024 including a recommendation that THS receives statutory funding to support our advocacy work and giving patients a voice. Negotiations are ongoing with government on this recommendation.

Reputational

As part of its Terms of Reference, the inquiry examined the work of THS over a 40-year period. As expected this was set out in its final report.

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

Structure, governance and management

The charity is a company limited by guarantee

The Trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

Paul Sartain	
Rayaz Chel	
Gordon Dixon	
Natalie Lawson	
Conan McIlwrath	
Amy Owen-Wyard	(Resigned September 2025)
Clive Smith	(Resigned November 2024)
Susan Stretch	(Resigned January 2025)
Jo Traunter	
Lisa Bagley	
Stacey McGeown	
Helen Tate	(Appointed November 2024)
Peta Dixon	(Appointed November 2024)
Simon Blackwell	(Appointed 7 January 2025)

None of the Trustees has any beneficial interest in the company. All of the Trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

Auditor

In accordance with the company's articles, a resolution proposing that Ellacotts Audit Services Limited be reappointed as auditor of the company will be put at a General Meeting.

Disclosure of information to auditor

Each of the Trustees has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditor is aware of such information.

The Trustees' report was approved by the Board of Trustees.

....

Conan McIlwrath
Trustee

Date: 19 December 2025

Statement of trustee's responsibility

The Trustees, who are also the directors of The Haemophilia Society for the purpose of company law, are responsible for preparing the Trustees' 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 Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that year.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping adequate accounting records that 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. 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.

Independent auditor’s report to the members of the Haemophilia Society

Opinion

We have audited the financial statements of The Haemophilia Society (the ‘charity’) for the year ended 31 March 2025 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and 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 2025 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the 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 charity 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 charity'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 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 our audit:

- the information given in the Trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, 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 charity 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 Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of Trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose 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 charity'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.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

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

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 non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also performed the following procedures:

- Enquiry of management and those charged with governance around actual and potential litigation and claims.
- Enquiry of entity staff in compliance functions to identify any instances of non-compliance with laws and regulations.
- Reviewing minutes of meetings of those charged with governance.
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations.
- Reviewed income and expenditure to ensure classified to the appropriate fund.
- Reviewed minutes of board meetings for matters relevant to the audit.
- Auditing the risk of management override of controls, including thorough testing of journal entries and other adjustments for appropriateness, and evaluating the rationale of significant transactions outside the normal course of business for the charity.

A further description of our responsibilities is available on the Financial Reporting Council's website at: https:// www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

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.

Leigh Dudley

Leigh Dudley FCCA (Senior Statutory Auditor)
For and on behalf of Ellacotts Audit Services Limited, Statutory Auditor
Chartered Accountants
Countrywide House 23 West Bar Banbury Oxfordshire
OX16 9SA
England

Date: 22 December 2025

Statement of financial activities (including income and expenditure account)

Current financial year

	Notes	Unrestricted funds 2025 £	Restricted funds 2025 £	Endowment funds 2025 £	Total 2025 £	Total 2024 as restated £
Income and endowments from:						
Donations and legacies	**2**	278,194	142,344	-	420,538	416,247
Charitable activities	**3**	140,904	5,835	-	146,739	106,390
Investments	**4**	19,128	-	-	19,128	23,473
Other income	**5**	3,871	-	-	3,871	4,543
Total income		442,097	148,179	-	590,276	550,653
Expenditure on:						
Raising funds	**6**	182,318	2,886	-	185,204	198,337
Charitable activities	**7**	537,205	140,312	-	677,517	744,360
Total expenditure		719,523	143,198	-	862,721	942,697
Net gains/(losses) on investments	**12**	(4,814)	-	-	(4,814)	39,212
Net income/(expenditure)		(282,240)	4,981	-	(277,259)	(352,832)
Transfers between funds		55,767	(55,767)	-	-	-
Net movement in funds	9	(226,473)	(50,786)	-	(277,259)	(352,832)
Reconciliation of funds:						
Fund balances at 1 April 2024		278,010	169,666	15,300	462,976	815,808
Fund balances at 31 March 2025		51,537	118,880	15,300	185,717	462,976

All income and expenditure derive from continuing activities.
The statement of financial activities includes all gains and losses recognised in the year.

Prior financial year

	Notes	Unrestricted funds 2024	Restricted funds 2024	Endowment funds 2024	Total 2024
		£	£	£	£
Income and endowments from:					
Donations and legacies	2	319,950	96,297	-	416,247
Charitable activities	3	95,319	11,071	-	106,390
Investments	4	23,473	-	-	23,473
Other income	5	4,324	219	-	4,543
Total income		443,066	107,587	-	550,653
Expenditure on:					
Raising funds	6	184,243	14,094	-	198,337
Charitable activities	7	662,133	82,227	-	744,360
Total expenditure		846,376	96,321	-	942,697
Net gains/(losses) on investments	12	39,212	-	-	39,212
Net income/(expenditure)		(364,098)	11,266	-	(352,832)
Transfer between funds		(40,328)	40,328	-	-
Net movement in funds	9	(404,426)	51,594		(352,832)
Reconciliation of funds:					
Fund balances at 1 April 2023		682,436	118,072	15,300	815,808
Fund balances at 31 March 2024		278,010	169,666	15,300	462,976

Balance sheet

As at 31 March 2025

	Notes	2025 £	2025 £	2024 £	2024 £
Fixed assets					
Tangible assets	14		44		634
Investments	15		109,202		404,966
			109,246		405,600
Current assets					
Debtors	16	49,959		69,694	
Cash at bank and in hand		264,993		263,591	
		314,952		333,285	
Creditors: amounts falling due within one year	17	(238,481)		(275,909)	
Net current assets			76,471		57,376
Total assets less current liabilities			185,717		462,976
The funds of the charity					
Endowment funds	19		15,300		15,300
Restricted income funds	20		118,880		169,666
Unrestricted funds	21		51,537		278,010
			185,717		462,976

The financial statements were approved by the Trustees on Friday 19 December 2025.

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Conan McIlwrath
Trustee

Company registration number 01763614 (England and Wales)

Statement of cash flows

Year ended 31 March 2024

	Notes	2025		2024	
		£	£	£	£
Cash flows from operating activities					
Cash absorbed by operations	**25**		(308,676)		(264,678)
Investing activities					
Proceeds from disposal of investments		290,950		364,000	
Investment income received		19,128		24,473	
Net cash generated from investing activities			310,078		387,473
Net cash generated from financing activities			-		-
Net increase in cash and cash equivalents			1,402		122,795
Cash and cash equivalents at beginning of year			263,591		140,796
Cash and cash equivalents at end of year			264,993		263,591

At the year end £168,581 (2024 - £157,530) of the total cash and cash equivalents is held on behalf of third parties. An equal and opposite amount is also showing within the other creditor at the year end.

The notes on pages 47 to 62 form part of these financial statements.

Notes to the financial statements for the year ended 31 March 2025

1 Accounting policies

Charity information

The Haemophilia Society ("THS") 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 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.

1.1 Basis of preparation

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 Companies Act 2006, the Charities Act 2011 and the provisions of the Charities Act 2022 in force at the time of preparing these accounts, and UK Generally Accepted Practice.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared on a going concern basis under the historical cost convention, modified to include the revaluation of investments at market value. The principal accounting policies adopted are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

1.2 Going concern

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. Based on the projected cash flow information for 12 months from the date of approval of these financial statements, taking into consideration the estimation of the continued impact of Covid and resources available, 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.

1.3 Charitable funds

Unrestricted 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.

THS is represented throughout the country by local groups. Local group funds are incorporated into THS'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 Phillip 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.

1.4 Income

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.

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).

1.5 Expenditure

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, services, advocacy and influencing, corner stone project, public inquiry and tanner fund grant 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.

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.

1.6 Tangible fixed assets

Tangible fixed assets for use by the charity are are initially measured at cost and subsequently measured at cost, less accumulated depreciation.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% per annum, straight line
Office equipment and furniture	25% per annum, straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Fixed asset 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.

1.8 Impairment of fixed assets

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.

1.9 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.10 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

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.

1.11 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

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

1.12 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

1.13 Leases

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

1.14 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.

1.15 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.

1.16 Taxation

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.

2. Income from donations and legacies

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2023 £	Total 2023 £
Donations and gifts	162,330	188	162,518	79,732	18,551	98,283
Legacies	69,691	-	69,691	181,082	-	181,082
Grants and trust income	10,500	12,906	23,406	13,387	16,746	30,133
Corporate income	35,673	129,250	164,923	45,703	61,000	106,703
Other	-	-	-	46	-	46
	278,194	142,344	420,538	319,950	96,297	416,247

3. Income from charitable activities

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Local group activities						
Events	-	1,852	1,852	-	794	794
Community fundraising and events						
Events	140,904	3,983	144,887	95,319	10,277	105,596
	140,904	5,835	146,739	95,319	11,071	106,390

4. Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest	19,128	23,473

5. Other incomes

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Other income	3,871	-	3,871	2,688	219	2,907
Insurance claim	-	-	-	1,636	-	1,636
	3,871	-	3,871	4,324	219	4,543

6. Expenditure on raising funds

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Fundraising and publicity						
Seeking donations, grants and legacies	49,314	2,886	52,200	38,757	14,094	52,851
Support costs	133,004	-	133,004	145,486	-	145,486
	182,318	2,886	185,204	184,243	14,094	198,337

7. Expenditure on charitable activities

	Communications 2025 £	Membership funds 2025 £	Services 2025 £	Advocacy and influencing 2025 £	Cornestone project 2025 £	Public inquiry 2025 £	Tanner fund grants 2025 £	Total 2025 £
Direct costs								
Activities undertaken directly	32,822	6,141	67,346	26,645	6,060	(4,997)	-	134,017
Grant funding of activities	-	-	-	-	-	-	44,354	44,345
	32,822	6,141	67,346	26,645	6,060	(4,997)	44,354	178,371
Share of support and governance costs (see note 8)								
Support	100,369	14,469	273,104	35,842	-	75,362	-	499,146
	133,191	20,610	340,450	62,487	6,060	70,365	44,354	677,517
Analysis by fund								
Unrestricted funds	133,191	20,610	250,552	62,487	-	70,365	-	537,205
Restricted funds	-	-	89,898	-	6,060	-	44,354	140,312
	133,191	20,610	340,450	62,487	6,060	70,365	44,354	677,517

7. Expenditure on charitable activities (previous year)

	Communications 2024 £	Membership funds 2024 £	Services 2024 £	Advocacy and influencing 2024 £	Cornestone project 2024 £	Public inquiry 2024 £	Tanner fund grants 2024 £	Total 2024 £
Direct costs								
Activities undertaken directly	47,351	20,447	97,258	21,160	8,365	2,391	-	196,972
Grant funding of activities	-	-	-	-	-	-	1,400	1,400
	47,351	20,447	97,258	21,160	8,365	2,391	1,400	198,372
Share of support and governance costs (see note 8)								
Support	109,788	15,827	298,733	39,206	-	82,434	-	545,988
	157,139	36,274	395,991	60,366	8,365	84,825	1,400	744,360
Analysis by fund								
Unrestricted funds	157,139	35,975	315,463	60,366	8,365	84,825	-	662,133
Restricted funds	-	299	80,528	-	-	-	1,400	82,227
	157,139	36,274	395,991	60,366	8,365	84,825	1,400	744,360

8. Support costs allocated to activities

	2025	2024
	£	£
Staff costs	473,044	511,746
Depreciation	590	4,537
Governance	24,438	17,592
Travel, postage and carriage	9,105	25,862
Information technology	30,266	17,718
Office costs	21,638	11,504
Recruitment, training and temporary staff	10,571	11,424
Other expenses	13,644	60,745
Governance costs	48,854	30,346
	632,150	691,474
Analysed between:		
Fundraising	133,004	145,486
Communications	100,369	109,788
Membership	14,469	15,827
Services	273,104	298,733
Advocacy and influencing	35,842	39,206
Public inquiry	75,362	82,434
	632,150	691,474

9. Net movement in funds

	2025	2024
	£	£
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	10,500	10,500
Depreciation of owned tangible fixed assets	590	2,035
Loss on disposal of tangible fixed assets	-	2,502
Operating lease charges	48,854	30,346

10. Trustees

None of the Trustees (or any persons connected with them) received or waived any remuneration or benefits from the charity during the year.

£9,327 (2024 - £7,417) was reimbursed to seven (2024 - eleven) trustees during the year for travel, subsistence and accommodation expenses. Included within trustee expenses was £2,587 (2024 - £2,992) paid directly to third parties.

11. Employees

The average number of employees during the year was:

	2025	2024
	Number	Number
Employees	10	11

	2025	2024
Employment costs	£	£
Wages and salaries	408,984	443,630
Social security costs	35,415	38,517
Other pension costs	28,645	29,599
	473,044	511,746

	2025	2024
The number of employees whose annual remuneration was more than £60,000 is as follows:	Number	Number
£90,001-£100,000	1	1

Remuneration of key management personnel

The charity considers its key management personnel to be the board of trustees and the Chief Executive. The remuneration of key management personnel was as follows:

	2025	2024
	£	£
Aggregate compensation	103,119	103,973

12. Gains and losses on investments

	Unrestricted funds 2025	Unrestricted funds 2024
Gains/(losses) arising on:	£	£
Revaluations of investments	(4,814)	39,212

13. Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

14. Tangible fixed assets

	Fixtures and fittings	Office equipment and furniture	Total
Cost	£	£	£
At 1 April 2024	20,169	3,176	23,345
At 31 March 2025	20,169	3,176	23,345
Depreciation and impairment			
At 1 April 2024	19,624	3,087	22,711
Depreciation charged in the year	545	45	590
At 31 March 2025	20,169	3,132	23,301
Carrying amount			
At 31 March 2025	-	44	44
At 31 March 2024	545	89	634

15. Fixed asset investments

	LIsted Investments
Cost or valuation	£
At 1 April 2024	404,966
Valuation changes	(4,814)
Disposals	(290,950)
At 31 March 2025	109,202
Carrying amount	
At 31 March 2025	109,202
At 31 March 2024	404,966

16. Debtors

	2025	2024
Amounts falling due within one year:	£	£
Other debtors	27,250	32,098
Prepayments and accrued income	22,709	37,596
	49,959	69,694

17. Creditors: amounts falling due within one year

	2025	2024
	£	£
Other taxation and social security	9,514	10,562
Trade creditors	30.087	30,885
Other creditors	185,625	169,270
Accruals and deferred income	13,255	65,192
	238,481	275,909

The Haemophilia Society has formal partnerships with two organisations that match our mission to support people with bleeding disorders in the UK:

The Haemophilia Nurses' Association (HNA) represents specialist nurses who care for people with bleeding disorders in the UK through direct clinical practice and research.

Little Bleeders is a registered charity that supports young people with bleeding disorders by providing grants to participate in sport and physical activities.
The Haemophilia Society acts as custodians for both organisations' funds and provides finance and governance expertise. A breakdown of these balances is set out within note 24.

18. Retirement benefit schemes

	2025	2024
Defined contribution schemes	£	£
Charge to profit or loss in respect of defined contribution schemes	28,645	29,599

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

19. Endowment funds

Endowment funds represent assets which must be held permanently by the charity. Income arising on the endowment funds can be used in accordance with the objects of the charity and is included as unrestricted income. Any capital gains or losses arising on the assets form part of the fund.

	At 1 April 2024	At 31 March 2025
	£	£
Permanent endowments		
	15,300	15,300

Previous year	At 1 April 2023	At 31 March 2024
	£	£
Permanent endowments		
Philip Morris Art Award	7,500	7,500
Howard Abrahams Memorial Award	7,800	7,800
	15,300	15,300

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.

20. Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2024	Incoming resources	Resources expended	Transfers	At 31 March 2025
	£	£	£	£	£
Talking Red	43,392	10,231	(21,458)	(23,000)	9,165
Tanner Fund	64	-	-	-	64
Newly Diagnosed	-	31,055	(29,140)	(1,915)	-
Ambassadors	16,577	10,906	(13,410)	-	14,073
Booklets	35,886	4,075	(18,118)	(7,000)	14,843
Covid Survey	950	-	-	(950)	-
Youth Camps	-	21,103	(29,526)	8,423	-
Centre Engagement	16,705	-	(679)	-	16,026

20. Restricted funds (continued

	At 1 April 2024	Incoming resources	Resources expended	Transfers	At 31 March 2025
	£	£	£	£	£
Patient Experience Survey	-	6,325	-	(6,325)	-
Local Groups	8,859	1,852	(2,858)	-	7,853
Mental Health Training	1,562	-	-	-	1,562
EAHAD	-	4,000	(523)	-	3,477
Haemfest	-	5,000	-	-	5,000
Chris Clotter Project	-	12,500	(6,315)	-	6,185
Information Days	1,903	150	-	-	2,053
WFH Congress	31,705	10,000	(6,060)	(25,000)	10,645
Conference / AGM	-	20,795	(15,111)	-	5,684
Philip Morris Art Award	7,971	-	-	-	7,971
Howard Abrahams Memorial Award	3,792	187	-	-	3,979
VWD Event	30	10,000	-	-	10,300
	169,666	148,179	(143,198)	(55,767)	118,880

Previous Year	At 1 April 2023	Incoming resources	Resources expended	Transfers	At 31 March 2024
	£	£	£	£	£
Talking Red	19,218	30,300	(5,828)	-	43,690
Tanner Fund	64	-	-	-	64
Newly Diagnosed	-	15,000	(22,257)	7,257	-
Ambassadors	21,000	10,000	(14,423)	-	16,577
Booklets	29,886	6,000	-	-	35,886
Covid Survey	950	-	-	-	950
Youth Camps	-	4,596	(18,141)	13,545	-
Centre Engagement	16,706	-	-	-	16,706
Local Groups	9,482	794	(1,417)	-	8,859
Mental Health Training	1,562	-	-	-	1,562
Haemfest	-	5,140	(11,690)	6,550	-
Community Matters Magazine	-	-	(12,976)	12,976	-
Information Days	3,128	-	(1,225)	-	1,903
WFH Congress	4,313	35,757	(8,365)	-	31,705
Philip Morris Art Award	7,971	-	-	-	7,971
Howard Abrahams Memorial Award	3,792	-	-	-	3,792
	118,072	107,587	96,321	40,328	169,666

A transfer of £40,328 has been made to reflect costs funded from unrestricted reserves

20. Restricted funds (continued

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.

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

Booklets: Funding for productions of information booklets and transition to other languages. Covid Survey: Funding to carry out pre & post Covid 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.

Centre Engagement: Funding to help with reengagement with Haemophilia Centres.

Patient Experience: Funding to develop and carry out survey to investigate patient experiences of rare bleeding disorders with the aim of identifying areas in which patients can receive greater support.

Local Groups: Funding to support development and launch of local groups around the UK to support the activities of THS and haemophilia Centres.

Mental Health Training: Funding for mental health staff training.

Emergency Fund (Ukraine): Help to provide crucial support to those in need during ongoing conflict and humanitarian crisis in Ukraine.

Haemfest: A camping weekend for families with bleeding disorders.

Community Matters Magazine: formerly titled HQ, the biennial magazine for our members.

Information Days: a series of educational days for Talking Red, Von Willebrand's Disorder, Rare and bleeding Disorders of Unknown Cause and Haemophilia Live.

WFH (World Federation of Haemophilia) Congress: participation at the biennial international congress which in 2022 took place in Montreal, Canada.

Cut the Cap: a restricted grant from CSL Behring to create a digital awareness campaign.

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.

21. Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2024	Incoming resources	Resources expended	Transfers	Gains and losses	At 31 March 2025
	£	£	£	£	£	£
Local groups	54,345	-	-	-	-	54,345
Designated funds - Public inquiry	78,249	-	-	-	-	78,249
Designated funds - Liquidation fund	168,733	-	-	-	-	168,733
General funds	(23,317)	442,097	(719,523)	55,767	(4,814)	(249,790)
	278,010	442,097	(719,523)	55,767	(4,814)	51,537
Previous year	**At 1 April 2023**	**Incoming resources**	**Resources expended**	**Transfers**	**Gains and losses**	**At 31 March 2024**
	£	£	£	£	£	£
Local groups	54,345	-	-	-	-	54,345
Designated funds - Public inquiry	78,249	-	-	-	-	78,249
Designated funds - Liquidation fund	168,733	-	-	(168,732)	-	168,733
General funds	381,109	443,066	(846,376)	(40,328)	39,212	(23,317)
	682,436	443,066	(846,376)	(40,328)	39,212	278,010

THS is represented throughout the country by local groups. Group funds are incorporated into THS'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. We participate in the Inquiry and support and inform members of the communicated affected by the Inquiry. Designated funds are 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 in to General Unrestricted Funds.

Designated funds - Liquidation fund: Recognising the impact of Covid on charity income the board has designated funds to provide sufficient cover for approximately months of running costs.

22. Analysis of net assets between funds

	Unrestricted funds 2025	Restricted funds 2025	Endowment funds 2025	Total 2025
	£	£	£	£
At 31 March 2025:				
Tangible assets	44	-	-	44
Investments	93,902	-	15,300	109,202
Current assets/(liabilities)	(42,409)	118,880	-	76,471
	51,537	118,880	15,300	185,717
	Unrestricted funds 2024	**Restricted funds 2024 as restated**	**Endowment funds 2024**	**Total 2024 as restated**
	£	£	£	£
At 31 March 2024:				
Tangible assets	634	-	-	634
Investments	389,666	-	15,300	404,966
Current assets/(liabilities)	(112,290)	169,666	-	57,376
	278,010	169,666	15,300	462,976

23. Operating lease commitments

Lessee

At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2025	2024
	£	£
Within one year	44,220	24,649
Between two and five years	190,682	3,145
	234,902	27,794

24. Related party transactions

The charity received no donations from trustees during the period (2024: none).

At the year end the charity has the following balances due to other Charities with common trustees:
Haemophilia Nurses Association: £101,999 (2024: £88,237)
Little Bleeders: £66,581 (2024: £69,293)

25. Cash generated from operations

	2025	2024
	£	£
Deficit for the year	(277,259)	(352,832)
Adjustments for:		
Investment income recognised in statement of financial activities	(19,128)	(23,473)
(Gain)/loss on disposal of tangible fixed assets	-	2,502
Fair value gains and losses on investments	4,814	(39,212)
Depreciation and impairment of tangible fixed assets	590	2,035
Movements in working capital:		
Decrease in debtors	19,735	2,036
Increase in creditors	(37,428)	144,266
Cash absorbed by operations	(308,676)	(264,678)

26. Analysis of changes in net funds

The charity had no material debt during the year.

For more information, please visit our website **haemophilia.org.uk** or contact us on **020 7939 0780** or email **info@haemophilia.org.uk**

If you would like this information in a different format, such as audio tape, braille or large print, or in another league , please speak to our team on **020 7939 0708**.

Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia
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Accounts

Annual Report

and financial statement 2023/24

Registered charity no. 288260 (Scotland SC039732)

About the Haemophilia Society

We are the only UK-wide charity for everyone affected by a genetic bleeding disorder, and our charity is here for you.

At the Haemophilia Society (THS) we want to empower everyone affected by a genetic bleeding disorder to live life to the full, whatever your stage in life.

One in 2,000 men, women and children in the UK have a diagnosed bleeding disorder, which are a group of conditions, including haemophilia and von Willebrand disorder, that result when the blood cannot clot properly.

As many as a third of bleeding disorder diagnoses have no known family history and can be the result of a random gene mutation. This means a bleeding disorder diagnosis can come completely out of the blue.

THS brings together people with bleeding disorders and their families to share experiences and understand more about how to live well with a bleeding disorder. Together, we can all make a difference.

Contents

Welcome

Like every small charity, the need to find diverse and sustainable funding sources has been a top priority this year in our quest to maintain and expand the vital services we provide for everyone with a bleeding disorder in the UK.

While our focus must be on the needs of our members, we have had to address the increasingly difficult fundraising landscape that is significantly impacting the charity sector. We continue to be agile and resourceful in looking at new ways of working to ensure efficiency and maximise the effectiveness of our small team.

The bleeding disorders community has evolved significantly in recent years with far more awareness about less well-known conditions. I'm proud to say that we have been inspired by our trustees to do more to ensure that the diverse needs of everyone with a bleeding disorder are represented by our charity. This year we've set up new von Willebrand disorder (VWD) and Rare and Bleeding Disorder of Unknown Cause Working Groups. These groups will guide our work and ensure that we are hearing directly from the people we are trusted to support.

Our popular regular events continued this year with our Newly Diagnosed Weekend in Bolton, our Haemfest camping weekend in Derbyshire and Talking Red Live in Leicester, which focuses on the needs of women and girls with a bleeding disorder. Our annual Youth Camp for children aged nine to 15 with a bleeding disorder and their siblings was an incredible week of learning and growth. I know many adults still talk about their own experiences at Youth Camp, particularly learning how to administer factor treatment and the independence they gained. It truly is a life-changing experience.

We have spent a huge amount of time and energy this year thumping on the door of government, urging it to honour the recommendations of the Infected Blood Inquiry's Second Interim Report which called for compensation to be paid as soon as possible to everyone infected and affected by the contaminated blood scandal. Our community has suffered enough and this on-going delay, as we wait for the inquiry for publish its final recommendations, has been extremely damaging.

For those of you who have not been directly impacted by the inquiry, I would like to say that our work has also been for you. Our dedication to the inquiry has been to ensure that our community never endures such a scandal again. Hopefully the inquiry's greatest legacy will be to provide a safe treatment landscape for us all for the future.

Finally, a personal note if I may. After nine years on the board and six years as chair, this will be my last annual report before I step down as your volunteer-in-chief in November 2024. It has been the greatest privilege of my life to lead such an incredible, passionate and inspiring organisation. Whilst I appreciate that much my time will be remembered for the Infected Blood Inquiry, an incredible amount of progress has been made in advancing treatment and care for all bleeding disorders. That is down to the selflessness of the staff, trustees and our wider community. I couldn't have wished to be supported by a more incredible team who have challenged and inspired me to lead us to be the best we can be.

C. Smith

Clive Smith
Chair

Impact Statistics

Our membership

5,085 members

Our online community

15,000
followers on social media

150,708 visits to our website

12,439
video views

5.7%
increase in new followers on social media

Our team

SIX new youth ambassadors recruited

Our fundraisers

over
£83,000
raised by individual fundraisers

Our resources

3,033 booklets sent out

Our merch

3,624
items bought from our online shop

Our events

363
people supported through our face-to-face events

FIVE in-person events held in four locations across the UK

Who we are

We exist to support you, and everybody affected by a genetic bleeding disorder in the UK, to enable you to live life well. We are both a charity and a member organisation, founded over 70 years ago.

> **‘Exceptional care for haemophilia and bleeding disorders hinges on empowered patient voices and active advocacy. With monumental changes upon us, there’s no better moment than now for a strong haemophilia society to champion the patient’s voice and perspective.’**
>
> Professor Pratima Chowdary, Chair of the UKHCDO, the haemophilia doctors’ organisation.

How we give support

The Haemophilia Society supports the bleeding disorder community by:

- **Organising events** which share expert knowledge and bring together people with similar experiences.
- Providing free in-depth and **unique publications**. From starting school to the challenges of ageing with a bleeding disorder, we publish nine different booklets offering support and information, many of which are offered in other languages including Arabic, Polish, Urdu, Welsh and Bengali. We also produce eight free, **downloadable factsheets** on everything from applying for benefits to how to prepare for a virtual doctor’s consultation.
- **Sharing** the latest news about developments in treatment, our work or anything else relevant to our community via social media, email and in our Community Matters members’ magazine.
- **Campaigning.** Together with you, our members, we raise awareness about bleeding disorders and lobby government, the NHS and clinicians for the best possible care and equal access to effective treatment. We also campaign in support of our many members who were infected and affected by the contaminated blood scandal.
- **Listening** to what you, our members, need. We regularly invite feedback and survey our membership to find out what is most important to our community. We also invite members to join working groups to steer our strategy and activity.

Members are at the heart of our work at the Haemophilia Society. Everyone’s experiences are different; sometimes the complexity and severity of the bleeding disorder means having to adapt to the day-to-day challenges. But with access to the right education and support, everyone can have the opportunity to better manage and take control of their lives – making it the best it can be.

Today we have 5,098 members, and a very active community on our social media channels. Our posts have a reach of more than 700,000 people.

Membership of the Haemophilia Society is free, and so are all the events and services that we provide for our members. This is only possible thanks to the generosity of all our amazing supporters. Thank you!

What we do

Youth Support

Ensuring that our young members are welcomed, supported and empowered to manage their bleeding disorder is a central part of our work.

'I'm now part of a community where my bleeding disorder is seen as normal. It's great to chat about these topics and connect with others who can relate to my story or whose stories I can relate to.'
Emily, new THS Youth Ambassador


Emily, Youth Ambassador

We have a strong Youth Ambassador programme, dating back to 2015, which is open to members aged 18-30. Our Youth Ambassadors act as mentors to our younger members, offering advice and reassurance about the reality of living with a bleeding disorder. They also attend our events to talk about their lived experience. Many people, particularly parents of newly diagnosed children, find it very reassuring to hear about the full lives these approachable and positive young people lead.

Our Youth Ambassadors also regularly attend global conferences to share their experiences, helping them to build their skills to become advocates for themselves and our community.

We also have a Youth Board, made up of six senior Youth Ambassadors, all with a bleeding disorder, which provides an opportunity to take more responsibility within the charity. The board ensures that our strategies and initiatives are relevant, inclusive and responsive to the needs of young people within our community. Board members will also continue to mentor younger Youth Ambassadors as well as our youth community.

'Attending Youth Camp as a child helped me realise that I could have a normal life as well as lots of fun. It's great to be back as an adult volunteer, helping the next generation of kids with a bleeding disorder to get involved and enjoy themselves.'
Sam, Youth Camp volunteer who has moderate haemophilia A


Sam, volunteer


Alex (blue coat), Ross and Josh Youth Ambassadors

This year we had two recruitment events for Youth Ambassadors which offered our younger members the chance to meet the team and find out more about what's involved in the role. As a result of the events we have welcomed six new Youth Ambassadors

Three senior members of the Youth Board, Ross Bennett and brothers Alex and Josh Taylor-Rose, who all have severe haemophilia, took part in a video project showing their successful completion of the Yorkshire Three Peaks challenge. The video, which was supported by Sobi and CSL Behring, highlighted the mental and physical challenges of taking on the trek and was designed to encourage others with a bleeding disorder to set themselves an activity outside their comfort zone.

Our annual Youth Camp, which is free to members, took place in Derbyshire in July 2023 and was attended by 50 young people aged nine to 15 who either have a bleeding disorder or have a sibling with a bleeding disorder. Supporting the families of people with a bleeding disorder is an essential part of our work, and a recognition of the impact that living with a bleeding disorder has on parents, grandparents and siblings.

The camps, which could not be run without the support of our volunteers, including clinicians such as specialist paediatric nurses and physiotherapists, allow our young people freedom and independence in a safe environment. Here they can try activities such as climbing and a high ropes course which builds their confidence. They also meet others who have been through similar experiences, often resulting in long-lasting friendships. For many of our campers this is the first opportunity they've had to stay away from home independently, and for parents this gives them a rare break.

As always, our feedback was excellent from Youth Camp 2023, from both the young people themselves and their parents or guardians.

Community Support

Bringing people together to share experiences and find out about the latest care and treatment available is one of the most rewarding aspects of our work.

Genetic bleeding disorders are rare, and it can be isolating to be the only person with this condition in a workplace, village, school or sports team. By connecting our members through in-person events and our supportive social media community, people can be reassured that they are not alone in whatever challenges they are facing. Sharing experiences also empowers people to think again about their care as they learn about the treatment of others and find out more about the options open to them.

This year, 363 adults and children registered to attend one of five in-person events held in four locations in England.

Big Get-Together annual conference

We were held our first in-person conference since 2019, which took place in Leeds and attracted 129 attendees. The one-day Big Get-Together (BGT) was packed with informative talks, workshops and discussions featuring input from some of the UK's leading experts in bleeding disorder care as well as people who live with a genetic bleeding disorder. There was also plenty of time to network informally and share experiences.

Talking Red Live

‘I’ve never felt part of something until I was surrounded by a range of young girls and women that have been through the things I am scared to face. I feel empowered and included because of the Haemophilia Society and I am eternally grateful.’

Phoebe, who attended Talking Red in March 2024

Talking Red is our focus on women and girls with a bleeding disorder. This takes the form of an annual dedicated event but is also a year-round campaign to raise awareness that women and girls live with genetic bleeding disorders. Although women and girls now make up the majority of people in the UK with a diagnosed bleeding disorder, women often do not get the quality of care and treatment they need. Women are more likely to be diagnosed as adults and studies show that on average women with bleeding disorders are diagnosed 10 years later than men.

Talking Red Live took place this year in Leicester and featured a talk on iron deficiency and anaemia as well as a discussion about the standards of care in the UK for women and girls with a bleeding disorder. There was also a special breakout session for teenagers. We have an active Women’s Working Group which helps us set the agenda for this event to ensure that the issues discussed are what matters most to our community.

Haemfest

‘My family thoroughly enjoyed HaemFest. I’d recommend it for all ages to meet others in a much more relaxed way and connect with affected people, families and health care professionals. My children have exchanged numbers with other kids and are already asking about next year.’


Cathy (right) at Haemfest

Cathy Harrison, Advanced Nurse Practitioner who volunteered at the event

In June 2023 we held our second HaemFest, a camping event, free to members, in Derbyshire which was attended by 118 people. This family event allows us to bring together our members in an informal, cost-effective way, allowing new friendships to be formed and experiences shared. As well as workshops, there were also activities such as stage combat fighting, circus skills and a popular arts and crafts tent. Our specialist haemophilia nurse volunteers ran a workshop for parents and children which encouraged them to think about treating themselves using a prosthetic arm to practice infusions. On Saturday evening we came together to enjoy some lively Irish dancing.

‘HaemFest is more than just an event, it’s a community. The chance to connect with other families, network, and share experiences in a supportive environment is truly invaluable.’

Parent, who attended Haemfest

Newly Diagnosed Weekends

‘The key lesson I learnt from the Newly Diagnosed Weekend was that my child can live a normal life and treatment can be well managed. There is a lot of support available.’

Our Newly Diagnosed Weekends (NDWs) provide families with expert advice, invaluable peer support and a safe space to ask questions in the very early stages of diagnosis. THS Youth Ambassadors also attend these events, sharing their experiences and bringing positivity to families who may feel uncertain about their child’s future. Specialist clinicians also support us at NDWs, answering a range of questions about treatment and care.

We held one NDW this year in Bolton where we welcomed 16 parents and 12 children. There were discussions about the benefit of physiotherapy for children and a presentation about the role of specialist haemophilia nurses as well as a chance to talk to young adults living with a bleeding disorder.

Feedback from the event was fantastic, with 100% of parents telling us that they felt more informed about their child’s bleeding disorder and empowered to make decisions about their child’s care.

‘I liked that it was a relaxed event with plenty of great information and amazing people sharing family experiences.’

Parent, who attended Newly Diagnosed Families Weekend

Awareness Days

More than 50 adults with von Willebrand disorder (VWD) got together for a day of sharing experiences and discovering more about treatment and care at an event hosted in Sheffield.

The awareness day, which was jointly organised by the Haemophilia Society's VWD Working Group and Sheffield Teaching Hospitals NHS Foundation Trust, was open to people who use Sheffield Haemophilia Centre.

The aim of the day, which was themed, 'We all have a voice', was to bring people with VWD together to discuss their experiences of living with the bleeding disorder as well as to involve healthcare professionals who gave updates

Service of Remembrance & Thanksgiving

We are honoured to host this important annual event to remember all those people with inherited bleeding disorders who have died due to their treatment with contaminated blood products. The service is held at St Botolph without Bishopsgate, London, where the book of remembrance and icon is kept. With the Infected Blood Inquiry nearing its end, there is a greater need than ever for this service, which offers a safe and welcoming space for everyone infected and affected by the contaminated blood scandal of the 1970s and 80s.

World AIDS Day gathering

World AIDS Day in December is an important date for our community. About 1,250 people with haemophilia and other bleeding disorders were infected with HIV through treatment with contaminated blood products in the 1980s. Less than 250 are still alive. We held a small gathering in London for anyone who was infected or wanted to remember someone who had died.

Carol Service

Our annual Carol Service held at St Botolph without Bishopsgate, London, is gaining in popularity due in part to the wonderful singing of the church choir. This paid-for event is increasingly being attended by non-members who work locally, giving us an opportunity to increase awareness about our work to a new audience. We are proud of our long-standing connection with St Botolph's, which dates back to the 1990s when our Chair, Rev Alan Tanner served at the church.

Ambassadors

We have four dedicated Ambassadors to support our members. Mark Ward is our LGBTQ Ambassador, Sunny Maini is our VWD Ambassador, THS staff member Scott McLean is our Mental Health Ambassador and Dr William McKeown is our Access and Service Improvement Ambassador. Mark, Sunny and William kindly volunteer their time to provide this service, and all four travel to conferences to highlight these issues as well as talking directly to our members to offer support and advice.

Working Groups

The Haemophilia Society is committed to supporting all genetic bleeding disorders. We want all our members to have access to services, support and events that match their specific needs and challenges. One way we ensure the needs of those with different disorders are heard and understood is through our working groups. These groups, made up of a diverse group of volunteers, are dedicated to representing, advocating for and serving the needs of a specific community within our membership. This helps us shape what we do to ensure these

Women's Working Group

We have 18 members of the Women's Working Group who represent women with a range of genetic bleeding disorders or who care for a female with a bleeding disorder. The group takes the lead in setting the agenda for our annual Talking Red Live conference which is a day dedicated to women and girls with a bleeding disorder. Through regular online meetings, the group also helps to shape our priorities for this section of our membership. Members have provided valuable contributions to the SACRED project (see Advocacy), our latest major research initiative. The group was formed in 2020.


Hannah Yarnall, VWD working group member

Rare and Bleeding Disorder of Unknown Cause (BDUC) Working Group

Launched in 2024, the Rare and BDUC Working Group has attracted members representing more than eight extremely rare conditions, such as Glanzmann Thrombasthenia, factor V deficiency and factor VII deficiency. Although every condition is different, common themes have emerged, such as challenges with diagnosis, treatment, and psychological support. From this, the group has set goals which include identifying educational gaps for healthcare professionals, improving information online and for treating clinicians. The group meets monthly online and has created a much-needed space for individuals to share experiences, promote understanding and create ideas on how to improve knowledge about their conditions.

'The Rare and BDUC Working Group has brought together people with extremely rare bleeding disorders that are often poorly understood and lacking effective treatment options. Together, we want to foster better awareness among healthcare professionals as well as the wider bleeding disorders community about

Amy Owen-Wyard, Chair, Rare and BDUC Working Group


Amy and her son, Logan

Von Willebrand disorder (VWD) Working Group

Established in 2023, the VWD Working Group was set up to raise the profile of this condition within the bleeding disorder community, healthcare profession and the general public.

The group was instrumental in organising the VWD Awareness Day in Sheffield (See Community Support) and hopes to hold similar events in other parts of the UK. There are about 11,500 people in the UK with a VWD diagnosis, which makes it the most common genetic bleeding disorder. Despite this, it is a condition that can take years to diagnose and one about which most people know very little. Our VWD Working Group aims to change this.

'We are in an exciting phase of von Willebrand disorder awareness, education and treatment. Our working group contains invaluable advocates who will use their personal experiences and wider knowledge to continue to push for excellent, accessible and equitable care for everyone with VWD.'

Hannah, VWD Working Group Member

Publications and educational materials

This year we produced 10 booklets and 19 downloadable factsheets. We sent out 3,033 publications, some of which are available in five languages, including Welsh, Urdu and Arabic. The booklets are used in haemophilia centres as well as by individual members to help them and their friends and relatives to understand their condition. A total of 2,860 factsheets or booklets were downloaded from our website this year.

This year we offered the following free publications:

- Understanding Haemophilia
- Understanding VWD
- Ageing with a bleeding disorder – social care and support
- Rare bleeding disorders
- Bleeding Disorders and School
- Women living with bleeding disorders
- Girls with living with bleeding disorders
- Dental care for adults with a bleeding disorder
- Sex and bleeding disorders
- A-Z guide to sport and physical activity for children with a bleeding disorder

We offered the following downloadable factsheets:

- Disability Living Allowance (DLA) for children with bleeding disorders
- Personal Independence Payment (PIP) Making a claim
- PIP Assessment process
- Emicizumab (for people without an inhibitor)
- Emicizumab (for people with an inhibitor)
- Extended half-life (EHL) factor VIII
- Top tips for parents
- Patient checklist to prepare for virtual consultations
- Factor V, factor VIII combined deficiency
- Factor XIII deficiency
- Factor XI deficiency
- Factor X deficiency
- Factor VII deficiency
- Factor V deficiency
- Prothrombin (factor II) deficiency
- Fibrinogen (factor 1) deficiency
- Bernard Soulier syndrome
- Glanzmann Thrombasthenia
- A-Z guide to sport and physical activity for children with a bleeding disorder

Advocacy

From advocating for higher standards of care and equal access to effective treatment, to campaigning on local issues, THS is here to raise awareness about bleeding disorders. We work to influence decision-makers on behalf of people affected by bleeding disorders. Our advocacy is a vital part of our role, although it is often less visible than other aspects of our charity's work.

Standards of Care and Access to

We were a member of the specialised blood disorders Clinical Reference Group (CRG) as one of the two patient representatives on the group. The CRG works with NHS England to coordinate specialist care for people with bleeding disorders and leads on the development of new treatment policies and service specifications. This year we worked to review the Service Specification, which had not been updated since 2013, which details the care that should be delivered by haemophilia centres. This was an opportunity to make sure people with bleeding disorders can expect all aspects of care they need in all centres across the country, and we can ensure people can live their best life with a bleeding disorder.

The new draft service specification focusses on access to full multidisciplinary care, improving people's rights to physiotherapy and seeks to strengthen networks for haemophilia centres so they work more collaboratively to support people with bleeding disorders. The new standards also form part of the peer review of haemophilia centres, taking place in 2024.

We continue to work with NICE, a government body which provides evidence-based guidelines for treatment and care in the NHS. We support the process by advocating for the needs of patients and access to new treatments. This year we made submissions to the NICE review of Pfizer's gene therapy for Haemophilia B and Sobi's long-acting factor VIII product efanesoctocog alfa. Our ambassador Ross was the patient expert on the NICE committee considering CSL Behring's Haemophilia B gene therapy Hemgenix.

We worked closely with NHS England in the creation of new gene therapy hubs in preparation for the routine commissioning of Hemgenix and other future gene therapies for haemophilia.

Our work on the consenting process for gene therapy in haemophilia and the pathway of care was accepted for presentation and publication at the WFH Annual Congress in Madrid.

We are members of NHS England's Specialised Commissioning Stakeholder Forum which allows use to raise wider issues with how NHS treatment and care is commissioned and delivered across England. We also work with the Haemophilia Nurses Association (HNA), the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) and the Haemophilia Chartered Physiotherapists' Association (HCPS) to ensure we are across all aspects of haemophilia and bleeding disorder care.

The SACRed Project, a multiyear investigation into the experiences of women and girls with bleeding disorders that will make recommendations for improving standards of care and access to treatment continued with a series of focus groups at our Big Get-together and Talking Red Live. The final report will be published in Spring 2025. We are grateful to Octapharma, LFB, Sobi, Takeda and Roche who are sponsoring this project.

In partnership with Nordic Pharma we launched a survey to find out more about dental care for people with a bleeding disorder.

Infected Blood Inquiry

'Thank you so much for the support and attention to detail throughout the whole inquiry.'

Comment from our dedicated public inquiry Facebook page

In April 2023 the Infected Blood Inquiry published its Second Interim Report which recommended that compensation should be paid to those infected and affected by contaminated blood products. Much of our work this year has been lobbying government to implement these recommendations.

Our Chief Executive, Kate Burt and Chair, Clive Smith were interviewed extensively for national and regional print and broadcast media when the report was published and throughout the year as we attempted to keep the pressure on government to deliver compensation.

Members of the government, including the Prime Minister, were called to give evidence to the Infected Blood Inquiry in July, which reconvened for a week to press the politicians about the pace of progress towards paying compensation.

We organised a protest and march to the inquiry building to draw attention to the anxiety and anger the government was causing by refusing to commit to paying full compensation. In February, we jointly organised a mass lobby of Parliament to highlight the issue once more. We were grateful to MPs from all parties for their support.

We have also been involved in pressing for a bespoke psychological support service for England. As well as demanding this service we have also provided advice about how the new service should look. Northern Ireland, Wales and Scotland already have this service, but England lags behind. While progress has been made, the new service is not due to be operational until autumn 2024.

Our Public Inquiry Team continues to support those infected and affected by the scandal and kept our members up to date with the work of the Infected Blood Inquiry and any political developments. We run a dedicated Facebook support page as well as a Twitter account for news updates.

Influencing the political agenda

We seek to ensure that the treatment and care needs of people with genetic bleeding disorders is understood by political decision-makers of all parties.

This year we attended the Labour and Conservative party conferences with our Chair, Clive Smith, invited to speak at Labour fringe events on the challenges facing the NHS and what they mean for people with bleeding disorders and a meeting on justice for people affected by political scandals. He met with shadow Labour ministers to discuss compensation and justice for people infected and affected by the contaminated blood scandal.

In February, we organised a mass lobby of parliament where over a hundred people gathered in Westminster Hall to meet their MPs. demand transparency from the government and seek a commitment that compensation to people infected and affected by contaminated blood products will be paid. The lobby was addressed by Labour Leader Keir Starmer.

In addition, the Haemophilia Society continued to provide the secretariat to the All Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood. In this role we facilitate meetings to coordinate parliamentary campaigns, update MPs on developments in bleeding disorder care and treatment, further the campaign for justice for people infected and affected by contaminated blood products and maintain the webpage, social media and membership information of the APPG.

Global Connections

'Being part of an international conference is a great way to learn more about the experiences of others with a bleeding disorder from around the world. There's lots to learn from the treatment and care offered by other countries.'

Ross, Bennett, Youth Ambassador and Chair of Youth Board

THS values and constantly seeks to strengthen our links with fellow haemophilia and bleeding disorder associations around the world

We attended major global conferences including the European Haemophilia Consortium (EHC) conference in Zagreb, Croatia where our Youth Ambassadors Ross Bennett and Hannah Yarnall gave speeches, as did our Chair, Clive Smith.

We also had representatives at the EHC's New Technologies conference in Lisbon, Portugal where the latest treatment and research is unveiled and discussed. We also sent two staff members to the European Association for Haemophilia and Associated Disorders (EAHAD) conference in Frankfurt, Germany.

Our trustee, Amy Owen-Wyard and staff member Scott McLean, attended the first ever conference dedicated to Glanzmann Thrombasthenia which took place in Boston in the US. Amy spoke about her experiences as the mother of a young boy with Glanzmann Thrombasthenia and led a series of workshops.

We were also pleased to be invited to attend the National Institute for Health and Care Excellence (NICE) in Manchester, England. Our Chief Executive, Kate Burt, addressed the annual conference of the haemophilia doctors' organisation, the UKHCDO in London, England.

In addition, we have individual members who are active on the international stage. Our member, Bonne Taylor, who has severe haemophilia A, became the EHC's Ambassador for Women with a Bleeding Disorder. Our trustee Jo Traunter and VWD Ambassador Sunny Maini are both members of the EHC's VWD Working Group and Amy Owen-Wyard is part of the EHC's European Rare and Inhibitor Network (ERIN).

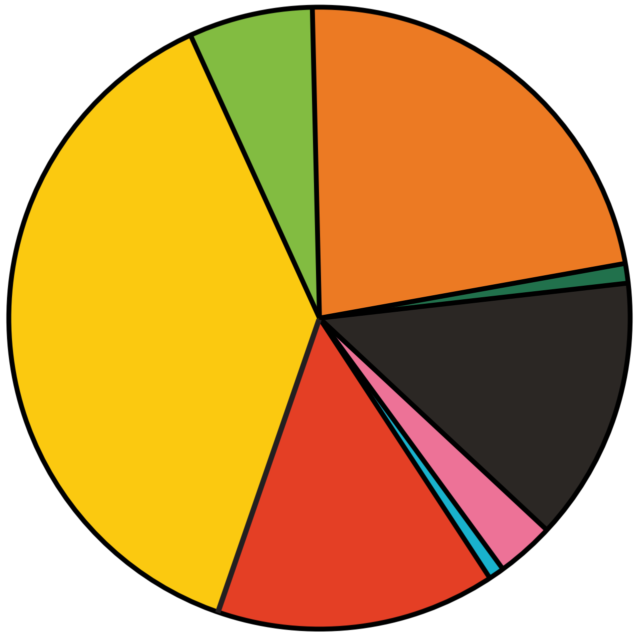
conference. A number of our Youth Ambassadors addressed conference sessions, as well as our Chair, Clive Smith. We were pleased to share our knowledge on these global stages and to learn more about other countries' experiences.

This year the International Society of Thrombosis and Haemostasis (ISTH) and the European Association for Haemophilia and Allied Disorders (EAHAD) held their conferences in London and Manchester, respectively, giving us the opportunity to send more representatives to learn about new treatments and advancements in care. Equally importantly, it was another chance to forge links with many UK health professionals and organisations within the bleeding disorders community.

Global Connections

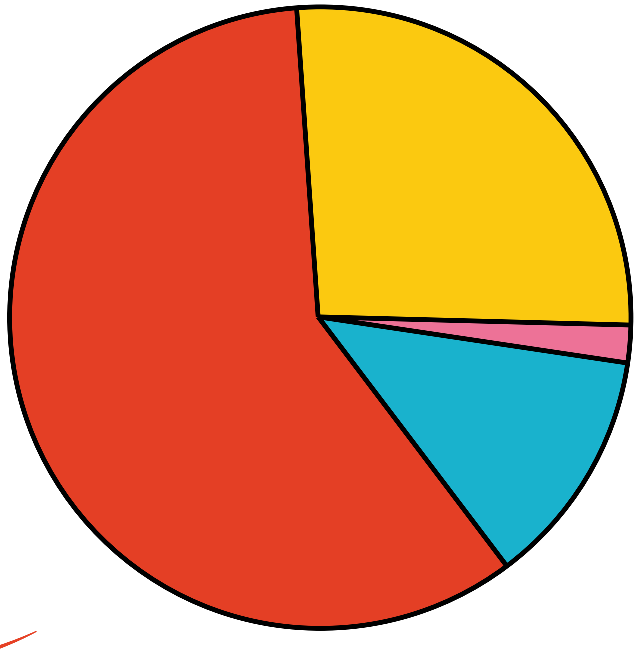
This year we started a three-year twinning project with the Malta Bleeding Disorders Society (MBDS), funded by grants from the World Federation of Hemophilia. During this project we will work with the MBDS board to improve their governance, increase their fundraising capacity, strengthen their advocacy and get better access to care and treatment in Malta.

How we manage your money



Income Composition 2023-24

🟥	Donations from individuals	17%
🟨	Legacies	32%
🟩	Grants & trusts	5%
🟧	Corporates	21%
🟩	Gift aid	>1%
⬛	Community fundraising & events	19%
🟪	Investments	4%
🟦	Other	>1%



Charitable activities & Expenditure 2023-24

🟥	Events & member services	58%
🟨	Campaigns & communications	30%
🟪	Grants awarded	>1%
🟦	Public inquiry	11%

Fundraising and partnerships

We are grateful to have such dedicated partners who help us to support our members and the wider bleeding disorders community. The generosity of charitable trusts, corporate partners and volunteers helps us to continue to deliver our core services for our members.

Events

Thank you to everyone who walked, ran, cycled, swam, sky dived, played golf, baked, organised raffles and undertook many other challenges to raise funds for THS. We are very grateful for all that you do.

Val, who is part of our Lincolnshire and East Midlands Local Group, raising vital funds

Trusts and Foundations

We continue to strengthen our relationships and grow support from trusts and foundations to fund our ongoing project delivery. We have built robust sources of funding and are committed to further strengthening our partnership with our funders to support continued growth.

Andrea, who raised £12,000 of the £40,000 made by our amazing London Marathon team

Corporate Partners

We receive ongoing support from partners in the pharmaceutical and private sectors, which includes sponsorship of member events, charitable grants and gifts of pro bono support.

Thank you to CSL Behring, LFB, Nordic Pharma, Octapharma, Pfizer, Roche-Chugai, SOBI and Takeda for their support in 2023 to 2024 and beyond.

Without this funding, it would be impossible for us to run many of our events which offer essential support to our members. We would like to emphasise that here are strict guidelines relating to donations from pharmaceutical companies to health organisations which we adhere to at all times.

Companies must respect the independence of the project and organisation to which they have donated and are not allowed to influence any of its written material. As per clause 29 of the 2021 ABPI code, all pharmaceutical companies must declare their sponsorship of 'patient organisations', which is how THS is classed under the code.

National haemophilia charities

We are grateful for the productive relationships we have with the national haemophilia charities in Scotland and Northern Ireland. We liaise with both organisations to maximise advocacy, particularly in relation to issues arising from the Infected Blood Inquiry's work.

Volunteers

Without our volunteers, we would be unable to host the events which we know our members find so valuable, nor could we run our charity, which is governed by unpaid volunteers who are elected to serve on our Board of Trustees.

We are very grateful to our clinical volunteers, such as haemophilia nurses, consultants and physiotherapists, who give up their time to supervise events, such as Youth Camp and HaemFest or to speak at our conferences or information days. We also could not manage events such as Youth Camp without an army of volunteers to supervise climbing walls, canoeing, fire building and other fun activities that make this event so special for our younger members. We appreciate the contribution of every single volunteer.

Natalie, trustee, volunteering at Youth Camp 2023

Little Bleeders

We continue to work closely with Little Bleeders, the charity established by former professional cyclist Alex Dowsett, which encourages young people with bleeding disorders to get involved in sport and stay active.

> **‘Becoming a THS trustee has given me the opportunity to develop my knowledge and understanding of bleeding disorders and how these affect our population. I am privileged to use this experience to help advocate for better education and treatment for all bleeding disorders. Most importantly, I have made friends and connections who I know will be a support to me for life.’**
>
> Stacey, THS Trustee

Trustees at board meeting in Belfast

Stacey, THS Trustee

A big thank you

Together, we continue to work to improve the lives of everyone with a genetic bleeding disorder and their families.

We have some of the most loyal and generous supporters any charity could wish for. The individual donations and legacies that we receive and the contributions from our partners, large or small, makes everything that we do possible.

We’d also like to thank our trustees, who give their time so generously to ensure our organisation is run as efficiently and productively as possible for the benefit of our members.

Matt, whose uncle had haemophilia and died as a result of the contaminated blood scandal, spent a year fundraising for THS and made more than £3,000 for our charity

The Hearne family ran the Westminster Mile after young Amelia was diagnosed with von Willebrand disorder

Tegan held a ‘wear red’ day at her school to raise awareness about haemophilia on behalf of her younger brother Jago who has the condition.

Reya and Jayden, whose mother has a factor VII deficiency, fundraising for THS

Jacob, who has severe haemophilia A, and his pal Joshua on a sponsored walk

Craig Wheeler, pictured with Scott McLean from THS, raised more than £11,000 for THS by nominating us as his Charity of the Year when he became Mayor of Thrapston. Craig’s son Arthur has severe haemophilia B.

Our Staff

We are an extremely busy charity and rely on our staff to offer an efficient, knowledgeable and compassionate service to our members and our stakeholders. We currently have 11 members of staff, four of whom work part-time.

Kate Burt,
Chief
Executive

Fiona Donoghue,
HR and
Office Manager

Debra Morgan,
Head of Policy and
Public Affairs

Nicola Sugg,
Events and
Membership Manager

Julia Collins,
Events and
Content Officer

Rosie Devlin,
Events and
Office Coordinator
(from September 2023)

Jessica Bomford,
Communications
Manager

Jefferson Courtney,
Policy and
Public Affairs Manager

Sam Wilson,
Digital Marketing and
Content Manager
(from September 2023)

Paula McCabe,
Finance
Officer

Scott McClean,
Fundraiser and
Member Advocate

Lina Gorenscek,
Community Fundraiser
(until September 2023)

Our governance

We work hard to set the highest standards as an organisation. Our policies and procedures reflect our values and we designed them to help us keep to those standards. We communicate them to our employees and volunteers and give everyone the training they need to uphold them. We also record our decisions and incidents, monitor our performance, and gather feedback to help us learn and improve.

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 seriously and we will:

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

Administration and legal details

Who we are

President	Baroness Meacher
Chief Executive	Kate Burt
Board of Trustees	Clive Smith – Chair Conan McIlwrath – Vice Chair Susan Stretch – Vice Chair Gordon Dixon – Treasurer Sonia O'Hara (until November 2023) Paul Sartain Joanne Traunter Anna Geffert (until November 2023) Amy Owen-Wyard Rayaz Ali Chel Natalie Lawson Lisa Bagley (from November 2023) Stacey McGeown (from November 2023)

Subcomittees

Finance and Risk Committee	Gordon Dixon – Chair Clive Smith Conan McIlwrath Susan Stretch Rayaz Ali Chel
Nominations Committee	Gordon Dixon Clive Smith
Public Inquiry Committee	Clive Smith – Chair Conan McIlwrath Susan Stretch Paul Sartain Eileen Ross Barry Flynn
Clinical Advisory Group	Dr Rezan Abdul-Kadir Dr Susie Shapiro Dr Kate Khair Prof Mike Laffan 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 Sutherland 1 Wood Street London EC2V 7WS
Auditors	Ellacotts, Countrywide House, 23 West Bar Street, Banbury, OX16 9SA
Company registration number	01763614
Charity registration number	288260
Scottish charity registration number	SC039732

Trustees' report

The trustees present their report and the audited financial statements of the charity for the year ended 31 March 2024. 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 (effective 1 January 2019).

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:

Financial review

The charitable sector continues to be hit hard rising demand for services and falling income. THS, like many others, has felt the impact of this as our members feel the squeeze on their own budgets.

These challenges make it more important than ever that we focus on efficiency and ensuring that we offer our members a relevant and useful service while doubling down on achieving diverse and reliable funding sources.

We expect to reap the benefits of a long-term investment in a new platform to record data and organise information in the 2024/25 financial year. Much of this year has been spent sorting through data and putting in place systems which mean we will be able to communicate more effectively and efficiently with our members and stakeholders.

Overall, we have generated a loss for the year of £377k, which resulted in a significant reduction of reserves. This figure includes the planned investment in the data management systems, as described above.

Income (including legacies) for FY24 has fallen by26% compared to FY23 to £562,769 in FY24. Corporate and events income has still not returned as we had forecasted to pre-pandemic levels. Costs were reduced by 12% for FY24 with total expenditure of £940,418

Legacy income received of £181,082 FY24 has decreased by 36% compared with the previous year (£282,147 in FY23). Given the nature of legacies, there will always be a large variance on a yearly basis. We are grateful to all our members who remember THS in their will.

Reserves

THS reserves on 31/03/24 stood at £634,986.

In recognition of the significant financial and general resource impact of the ongoing Infected Blood Inquiry, the board in 2019 designated £600,000 of reserves to fund the charity's work in this area. In the combined years to date we have invested £813,054 to our work on the inquiry. Designated funds are reviewed annually to ensure the appropriate use of reserves.

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.

Key risks and uncertainties

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

Financial

As described above, we are operating in a challenging financial environment and planning to focus our income generating strategy on building trust and foundation relationships as well as increasing and diversifying our corporate partnerships.

Reputational

The Infected Blood Inquiry's final report and recommendations are expected in 2024. As part of its Terms of Reference, the inquiry has examined the work of THS over a 40-year period and we would expect this to be set out in its final report.

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

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 THS)
- one honorary chair
- up to four co-opted trustees.

Elections take place prior to the AGM in November each year and trustees are elected for a five-year term. They may stand again for election for a further five-year term.

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
- 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.

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

C. Smith

Clive Smith
Chair, the Haemophilia Society
Date: 13 December 2024

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

Opinion

We have audited the financial statements of The Haemophilia Society (the 'charity') for the year ended 31 March 2024 which comprise the statement of financial activities, the summary income and expenditure account, the balance sheet, the statement of cash flows and 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 2024 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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 charity 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 charity'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 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 the matters prescribed by the Companies Act 2006

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

- the information given in the Trustees' report for the financial year for which the financial statements are prepared, which includes the directors' report prepared for the purposes of company law, 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 charity 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 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate and proper 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 Trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees

As explained more fully in the statement of Trustees' responsibilities, the Trustees, who are also the directors of the charity for the purpose 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 charity'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

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

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.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

The extent to which our procedures are capable of detecting irregularities, including fraud, is detailed below.

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

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 non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

As part of an audit in accordance with ISAs (UK), We exercise professional judgment and maintain professional scepticism throughout the audit. We also performed the following procedures:

- Enquiry of management and those charged with governance around actual and potential litigation and claims.
- Enquiry of entity staff in compliance functions to identify any instances of non-compliance with laws and regulations.
- Reviewing minutes of meetings of those charged with governance.
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations.
- Reviewed income and expenditure to ensure classified to the appropriate fund.
- Reviewed minutes of board meetings for matters relevant to the audit.
- Auditing the risk of management override of controls, including thorough testing of journal entries and other adjustments for appropriateness, and evaluating the rationale of significant transactions outside the normal course of business for the charity.

A further description of our responsibilities is available on the Financial Reporting Council's website at: https:// www.frc.org.uk/ auditorsresponsibilities. This description forms part of our auditor's report.

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 and to the regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and trustees 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, the charitable company's members as a body,and the charitable company's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

....
Leigh Dudley FCCA (Senior Statutory Auditor)
for and on behalf of Ellacotts Audit Services Limited

Chartered Accountants Statutory Auditor Countrywide House
23 West Bar Banbury Oxfordshire England OX16 9SA

Date.........................

Statement of financial activities (including income and expenditure account)

Current financial year

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Endowment funds 2024 £	Total 2024 £	Total 2023 as restated £
Income and endowments from:						
Donations and legacies	**2**	319,950	96,297	-	416,247	659,016
Charitable activities	**3**	95,319	11,071	-	106,390	96,331
Investments	**4**	23,473	-	-	23,473	24,891
Other income	**5**	4,324	219	-	4,543	13,551
Total income and endowments		443,066	107,587	-	550,653	793,789
Expenditure on:						
Raising funds	**6**	184,243	14,094	-	198,337	183,151
Charitable activities	**7**	662,133	82,227	-	744,360	885,862
Total expenditure		846,376	96,321	-	942,697	1,069,013
Net gains/(losses) on investments	**12**	39,212	-	-	39,212	(46,637)
Net income/(expenditure)		(364,098)	11,266	-	(352,832)	(321,861)
Transfers between funds		(40,328)	40,328	-	-	-
Net movement in funds	9	(404,426)	51,594	-	(352,832)	(321,861)
Reconciliation of funds:						
Fund balances at 1 April 2023		682,436	118,072	15,300	815,808	1,137,669
Fund balances at 31 March 2024		278,010	169,666	15,300	462,976	815,808

All income and expenditure derive from continuing activities.
The statement of financial activities includes all gains and losses recognised in the year.

Previous financial year

	Notes	Unrestricted funds 2023 as restated £	Restricted funds 2023 as restated £	Endowment funds 2023 as restated £	Total 2023 as restated £
Income and endowments from:					
Donations and legacies	**2**	475,589	183,127	300	659,016
Charitable activities	**3**	87,261	9,070	-	96,331
Investments	**4**	23,492	1,399	-	24,891
Other income	**5**	13,131	420	-	13,551
Total income and endowments		599,473	194,016	300	793,789
Expenditure on:					
Raising funds	**6**	171,930	11,221	-	183,151
Charitable activities	**7**	746,283	139,579	-	885,862
Total expenditure		918,213	150,800	-	1,069,013
Net gains/(losses) on investments	**12**	(46,637)	-	-	(46,637)
Net expenditure and movement in funds		(365,377)	43,216	300	(321,861)
Reconciliation of funds:					
Fund balances at 1 April 2022		1,047,813	74,856	15,000	1,137,669
Fund balances at 31 March 2023		682,436	118,072	15,300	815,808

Summary income and expenditire account

All income funds

	2024	2023
		as restated
	£	£
Gross income	550,653	793,489
Gains/(losses) on investments	39,212	(46,637)
Total income in the reporting period	589,865	746,852
Total expenditure from income funds	942,697	1,069,013
Net expenditure for the year	(352,832)	(322,161)

Balance sheet

As at 31 March 2024

		2024		2023	
				as restated	
	Notes	£	£	£	£
Fixed assets					
Tangible assets	14		634		5,172
Investments	15		404,966		729,754
			405,600		734,926
Current assets					
Debtors	16	69,694		71,730	
Cash at bank and in hand		263,591		140,796	
		333,285		212,526	
Creditors: amounts falling due within one year	17	(275,909)		(131,644)	
Net current assets			57,376		80,882
Total assets less current liabilities			462,976		815,808
The funds of the charity					
Endowment funds	19		15,300		15,300
Restricted income funds	20		169,666		118,072
Unrestricted funds	21		278,010		682,436
			462,976		815,808

The financial statements were approved by the Trustees on Friday 13 December 2024.

C. Smith

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Clive Smith

Trustee

Company registration number 01763614 (England and Wales)

Statement of cash flows

Year ended 31 March 2024

	Notes	2024 £	£	2023 £	£
Cash flows from operating activities					
Cash absorbed by operations	**25**		(264,678)		(263,056)
Investing activities					
Purchase of tangible fixed assets		-		(2,036)	
Proceeds from disposal of investments		364,000		250,000	
Investment income received		23,473		24,891	
Net cash generated from investing activities			387,473		272,855
Net cash used in financing activities			-		-
Net increase in cash and cash equivalents			122,795		9,799
Cash and cash equivalents at beginning of year			140,796		130,997
Cash and cash equivalents at end of year			263,591		140,796

At the year end £157,530 (2023 - £28,187) of the total cash and cash equivalents is held on behalf of third parties. An equal and opposite amount is also showing within the other creditor at the year end.

The notes on pages 37 to 51 form part of these financial statements.

Notes to the financial statements for the year ended 31 March 2024

1 Accounting policies

Charity information

The Haemophilia Society ("THS") 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 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.

1.1 Accounting convention

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 Companies Act 2006, the Charities Act 2011 and the provisions of the Charities Act 2022 in force at the time of preparing these accounts, and UK Generally Accepted Practice.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared on a going concern basis under the historical cost convention, modified to include the revaluation of investments at market value. The principal accounting policies adopted are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

1.2 Prior period error

During the audit, it was noted that income and expenditure relating to two third party organisations had previously been recognised in the statement of financial activities of The Haemophilia Society. This was subsequently corrected for the year to 31 March 2024 however it also resulted in a restatement of the comparative figures.

The impact on the comparative figures was a reduction to income of £1,437, a reduction to expenses of £4,188 and an improvement to the result of £2,751. Amounts due to the third party organisations of £28,187 have been restated from restricted reserves to liabilities.

1.3 Going concern

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. Based on the projected cash flow information for 12 months from the date of approval of these financial statements, taking into consideration the estimation of the continued impact of Covid and resources available, 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.

1. Summary of significant accounting (continued)

1.4 Charitable funds

Unrestricted 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.
THS is represented throughout the country by local groups. Local group funds are incorporated into THS'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 Phillip 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.

1.5 Income

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.

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).

1.6 Expenditure

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, services, advocacy and influencing, corner stone project, public inquiry and tanner fund grant costs, and
- other expenditure represents those items not falling into the categories above

1. Summary of significant accounting (continued)

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

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.

1.7 Tangible fixed assets

Tangible fixed assets for use by the charity are are initially measured at cost and subsequently measured at cost, less accumulated depreciation.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% per annum, straight line
Office equipment and furniture	25% per annum, straight line

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.8 Fixed asset investment

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

1.9 Impairment of fixed assets

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

1.10 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.11 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

1. Summary of significant accounting (continued)

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.

1.12 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

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

1.13 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

1.14 Leases

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

1.15 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.

1.16 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.

1.17 Taxation

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.

2. Income from donations and legacies

	Unrestricted funds 2024	Restricted funds 2024	Endowment funds 2024	Total 2024	Unrestricted funds 2023		Endowment funds 2023	Total 2023
	£	£	£	£	£	£	£	£
Donations	79,732	18,551	-	98,283	(54,074)	183,127	300	129,353
Legacies	181,082	-	-	181,082	282,147	-	-	282,147
Grants and trust income	13.387	16,746	-	30,133	50,500	-	-	50,500
Corporate income	45,703	61,000	-	106,703	176,751	-	-	176,751
Gift Aid	46	-	-	46	20,265	-	-	20,265
	319,950	96,297	-	416,247	475,589	183,127	300	659,016

3. Income from charitable activities

	Unrestricted funds 2024	Restricted funds 2024	Total 2024	Unrestricted funds 2023	Restricted funds 2023	Total 2023
	£	£	£	£	£	£
Local group activities						
Events	-	794	794	114	-	114
Community fundraising and events						
Events	95,319	10,277	105,596	87,147	9,070	96,217
	95,319	11,071	106,390	87,261	9,070	96,331

4. Income from investments

	Unrestricted funds 2024	Restricted funds 2024	Total 2024	Unrestricted funds 2023	Restricted funds 2023	Total 2023
	£	£	£	£	£	£
Interest	23,473	-	23,473	23,492	1,399	24,891

5. Other incomes

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Other income	2,688	219	2,907	13,131	420	13,551
Insurance claim	1,636	-	1,636	-	-	-
	4,324	219	4,543	13,131	420	13,551

6. Expenditure on raising funds

	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Fundraising and publicity						
Seeking donations, grants and legacies	38,757	14,094	52,851	25,479	11,221	36,700
Support costs	145,486	-	145,486	146,451	-	146,451
	184,243	14,094	198,337	171,930	11,221	183,151

7. Expenditure on charitable activities

	Communications 2024 £	Membership funds 2024 £	Services 2024 £	Advocacy and influencing 2024 £	Cornestone project 2024 £	Public inquiry 2024 £	Tanner fund grants 2024 £	Total 2024 £
Direct costs								
Activities undertaken directly	47,350	20,447	97,258	21,160	8,365	2,391	-	196,971
Grant funding of activities	-	-	-	-	-	-	1,400	1,400
	47,350	20,477	97,258	21,160	8,365	2,391	1,400	198,371
Share of support and governance costs (see note 8)								
Support	109,788	15,827	298,733	39,206	-	82,434	-	545,988
	157,138	36,274	395,991	60,366	8,365	84,825	-	744,359
Analysis by fund								
Unrestricted funds	157,138	35,975	315,463	60,366	8,365	84,825	-	662,132
Restricted funds	-	299	80,528	-	-	-	1,400	82,227
	157,138	36,274	395,991	60,366	8,365	84,825	1,400	744,359

7. Expenditure on charitable activities (previous year)

	Communications 2023 £	Membership funds 2023 £	Services 2023 £	Advocacy and influencing 2023 £	Cornestone project 2023 £	Public inquiry 2023 £	Tanner fund grants 2023 £	Total 2023 £
Direct costs								
Activities undertaken directly	13,663	7,809	142,836	9,272	14,778	2,956	-	191,314
Grant funding of activities	-	-	-	-	-	-	1,450	1,450
	13,663	7,809	142,836	9,272	14,778	2,956	1,450	192,764
Share of support and governance costs (see note 8)								
Support	139,369	20,092	379,223	49,769	-	104,645	-	693,098
	153,032	27,901	522,059	59,041	14,778	107,601	1,450	885,862
Analysis by fund								
Unrestricted funds	150,118	27,422	393,822	62,247	5,073	107,601	-	746,283
Restricted funds	2,914	479	128,237	(3,206)	9,705	-	1,450	139,579
	153,032	27,901	522,059	59,041	14,778	107,601	1,450	885,862

8. Support costs allocated to activities

	2024 £	2023 £
Staff costs	511,746	675,805
Depreciation and loss on disposals	4,537	6,053
Governance	17,592	14,173
Travel, postage and carriage	25,862	13,376
Information technology	17,718	19,492
Office costs	11,504	7,273
Recruitment, training and temporary staff	11,424	11,842
Other expenses	60,745	49,421
Governance costs	30,346	42,114
	691,474	839,549
Analysed between:		
Fundraising	145,486	146,451
Communications	109,788	139,369
Membership	15,827	20,092
Services	298,733	379,223
Advocacy and influencing	39,206	49,769
Public inquiry	82,434	104,645
	691,474	839,549

9. Net movement in funds

	2024	2023
	£	£
The net movement in funds is stated after charging/(crediting):		
Fees payable for the audit of the charity's financial statements	10,500	11,100
Depreciation of owned tangible fixed assets	2,035	6,053
Loss on disposal of tangible fixed assets	2,502	-
Operating lease charges	30,346	42,114

10. Trustees

None of the Trustees (or any persons connected with them) received or waived any remuneration or benefits from the charity during the year.

£7,417 (2023 - £6,426) was reimbursed to eleven (2023 - nine) trustees during the year for travel, subsistence and accommodation expenses. Included within trustee expenses was £2,992 (2023 - £3,398) paid directly to third parties.

11. Employees

The average number of employees during the year was:

	2024	2023
	Number	Number
Employees	11	15

	2024	2023
Employment costs	£	£
Wages and salaries	443,630	582,919
Social security costs	38,517	54,827
Other pension costs	29,599	38,059
	511,746	675,805

	2024	2023
The number of employees whose annual remuneration was more than £60,000 is as follows:	Number	Number
£60,000-£70,000	-	2
£80,001-£90,000	-	1
£90,001-£100,000	1	-

Remuneration of key management personnel

The charity considers its key management personnel to be the board of trustees and the Chief Executive. The remuneration of key management personnel was as follows:

	2024	2023
	£	£
Aggregate compensation	103,973	102,758

12. Gains and losses on investments

	Unrestricted funds 2024	Unrestricted funds 2023
Gains/(losses) arising on:	£	£
Revaluations of investments	39,212	(46,637)

13. Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

14. Tangible fixed assets

	Fixtures and fittings	Office equipment and furniture	Total
Cost	£	£	£
At 1 April 2023	20,169	80,949	101,118
Disposals	-	(77,773)	(77,773)
At 31 March 2024	20,169	3,176	23,345
Depreciation and impairment			
At 1 April 2023	18,964	76,983	95,947
Depreciation charged in the year	660	1,375	2,035
Eliminated in respect of disposals	-	(75,271)	(75,271)
At 31 March 2024	19,624	3,087	22,711
Carrying amount			
At 31 March 2024	545	89	634
At 31 March 2023	1,205	3,967	5,172

15. Fixed asset investments

	LIsted Investments
Cost or valuation	£
At 1 April 2023	729,754
Valuation changes	39,212
Disposals	(364,000)
At 31 March 2024	404,966
Carrying amount	
At 31 March 2024	404,966
At 31 March 2023	729,754

16. Debtors

	2024	2023
Amounts falling due within one year:	£	£
Other debtors	32,451	41,942
Prepayments and accrued income	37,596	29,788
	70,047	71,730

17. Creditors: amounts falling due within one year

	2024	2023
	£	£
Other taxation and social security	10,562	27,523
Trade creditors	30,885	31,193
Other creditors	169,270	61,828
Accruals and deferred income	65,192	11,100
	275,909	131,644

18. Retirement benefit schemes

	2024	2023
Defined contribution schemes	£	£
Charge to profit or loss in respect of defined contribution schemes	29,599	38,059

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

19. Endowment funds

Endowment funds represent assets which must be held permanently by the charity. Income arising on the endowment funds can be used in accordance with the objects of the charity and is included as unrestricted income. Any capital gains or losses arising on the assets form part of the fund.

	At 1 April 2023	Incoming resources	At 31 March 2024
	£	£	£
Permanent endowments			
Philip Morris Art Award	7,500	-	7,500
Howard Abrahams Memorial Award	7,800	-	7,800
	15,300	-	15,300
Previous year	**At 1 April 2022**	**Incoming resources**	**At 31 March 2023**
	£	£	£
Permanent endowments			
Philip Morris Art Award	7,500	-	7,500
Howard Abrahams Memorial Award	7,500	300	7,800
	15,000	300	15,300

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.

20. Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2023	Incoming resources	Resources expended	Transfers	At 31 March 2024
	£	£	£	£	£
Talking Red	19,218	30,000	(5,828)	-	43,390
Tanner Fund	64	-	-	-	64
Newly Diagnosed	-	15,000	(22,257)	7,257	-
Ambassadors	21,000	10,000	(14,423)	-	16,577

20. Restricted funds (continued

	At 1 April 2023	Incoming resources	Resources expended	Transfers	At 31 March 2024
	£	£	£	£	£
Booklets	29,886	6,000	-	-	35,886
Covid Survey	950	-	-	-	950
Centre Engagement	16,706	-	-	-	16,706
Local Groups	9,482	794	(1,417)	-	8,859
Mental Health Training	1,562	-	-	-	1,562
Haemfest	-	5,140	(11,690)	6,550	-
Community Matters Magazine	-	-	(12,976)	12,976	-
Information Days	3,128	-	(1,225)	-	1,903
WFH Congress	4,313	35,757	(8,365)	-	31,705
Philip Morris Art Award	7,971	-	-	-	7,971
Howard Abrahams Memorial Award	3,792	-	-	-	3,792
VWD Event	-	300	-	-	300
	118,072	107,587	(96,321)	40,328	169,666

Previous Year	At 1 April 2022	Incoming resources	Resources expended	Transfers	At 31 March 2023
	£	£	£	£	£
Talking Red	-	22,357	(388)	-	21,969
Tanner Fund	514	-	(1,450)	1,000	64
Memorial Service	-	644	(644)	-	-
Newly Diagnosed	2,106	34,000	(36,106)	-	-
Ambassadors	-	21,000	-	-	21,000
Booklets	2,266	34,000	(6,380)	-	29,886
Covid Survey	950	-	-	-	950
Youth Camps	21,932	16,588	(25,520)	(13,000)	-
Centre Engagement	16,960	-	(254)	-	16,706
Patient Experience Survey	5,000	-	(5,000)	-	-
Local Groups	9,961	-	(479)	-	9,482
Mental Health Training	1,562	-	-	-	1,562
Emergency Fund (Ukraine)	2,241	1,171	(3,412)	-	-
Haemfest	-	420	(13,420)	13,000	-
Community Matters Magazine	-	6,000	(6,000)	-	-
Information Days	-	15,000	(11,872)	-	3,128
WFH Congress	-	15,000	(10,687)	-	4,313
Cut the Cap	-	25,000	(25,000)	-	-
Philip Morris Art award	7,278	693	-	-	7,971
Howard Abrahams Memorial Award	4,086	706	-	(1,000)	3,792
	74,856	194,016	150,800	-	118,072

A transfer of £40,328 has been made to reflect costs funded from unrestricted reserves

20. Restricted funds (continued

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.

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

Booklets: Funding for productions of information booklets and transition to other languages. Covid Survey: Funding to carry out pre & post Covid 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.

Centre Engagement: Funding to help with reengagement with Haemophilia Centres.

Patient Experience: Funding to develop and carry out survey to investigate patient experiences of rare bleeding disorders with the aim of identifying areas in which patients can receive greater support.

Local Groups: Funding to support development and launch of local groups around the UK to support the activities of THS and haemophilia Centres.

Mental health training for staff: funding for mental health staff training.

Emergency Fund (Ukraine): help to provide crucial support to those in need during ongoing conflict and humanitarian crisis in Ukraine.

Haemfest: A camping weekend for families with bleeding disorders.

Community Matters Magazine: formerly titled HQ, the biennial magazine for our members.

Information Days: a series of educational days for Talking Red, Von Willebrand's Disorder, Rare and bleeding Disorders of Unknown Cause and Haemophilia Live.

WFH (World Federation of Haemophilia) Congress: participation at the biennial international congress which in 2022 took place in Montreal, Canada.

Cut the Cap: a restricted grant from CSL Behring to create a digital awareness campaign.

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.

21. Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2023	Incoming resources	Resources expended	Transfers	Gains and losses	At 31 March 2024
	£	£	£	£	£	£
Local groups	54,345	-	-	-	-	54,345
Designated funds - Public inquiry	78,249	-	-	-	-	78,249
Designated funds - Liquidation fund	168,733	-	-	-	-	168,733
General funds	381,109	443,066	(846,375)	(40,328)	39,212	(23,317)
	682,436	443,066	(846,375)	(40,328)	39,212	278,010

Previous year	At 1 April 2022	Incoming resources	Resources expended	Transfers	Gains and losses	At 31 March 2023
	£	£	£	£	£	£
Local groups	58,660	114	(4,429)	-	-	54,345
Designated funds - Public inquiry	185,850	-	(107,601)	-	-	78,249
Designated funds - Liquidation fund	337,465	-	-	(168,732)	-	168,733
General funds	465,838	599,359	(806,183)	168,732	(46,637)	381,109
	1,047,813	599,473	918,213	-	(46,637)	682,436

21. Unrestricted funds (continued)

THS is represented throughout the country by local groups. Group funds are incorporated into THS'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. We participate in the Inquiry and support and inform members of the communicated affected by the Inquiry. Designated funds are 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 in to General Unrestricted Funds.

Designated funds - Liquidation fund: Recognising the impact of Covid on charity income the board has designated funds to provide sufficient cover for at least 3 months of running costs.

22. Analysis of net assets between funds

	Unrestricted funds 2024	Restricted funds 2024	Endowment funds 2024	Total 2024
		£	£	£
At 31 March 2024:				
Tangible assets	634	-	-	634
Investments	389,666	-	15,300	404,966
Current assets/(liabilities)	(112,290)	169,666	-	57,376
	278,010	169,666	15,300	462,976

	Unrestricted funds 2024	Restricted funds 2024 as restated	Endowment funds 2024	Total 2024 as restated
	£	£	£	£
At 31 March 2023:				
Tangible assets	5,172	-	-	5,172
Investments	714,454	-	15,300	729,754
Current assets/(liabilities)	(37,190)	118,072	-	80,882
	682,436	118,072	15,300	815,808

23. Operating lease commitments

Lessee
At the reporting end date the charity had outstanding commitments for future minimum lease payments under non-cancellable operating leases, which fall due as follows:

	2024	2023
	£	£
Within one year	24,649	42,771
Between two and five years	3,145	26,798
	27,794	69,569

24. Related party transactions

The charity received no donations from trustees during the period (2023 - one trustee £652). There were no further disclosable related party transactions during the year (2023 - none).

25. Cash generated from operations

	2024	2023 as restated
	£	£
Deficit for the year	(338,437)	(321,861)
Adjustments for:		
Investment income recognised in statement of financial activities	(23,473)	(24,891)
Prior period adjustment	-	(30,938)
Loss on disposal of tangible fixed assets	2,502	-
Fair value gains and losses on investments	(39,212)	46,637
Depreciation and impairment of tangible fixed assets	2,035	6,053
Movements in working capital:		
Decrease in debtors	1,683	19,206
Increase in creditors	130,224	42,738
Cash absorbed by operations	(264,678)	(263,056)

26. Analysis of changes in net funds

The charity had no material debt during the year.

For more information, please visit our website **haemophilia.org.uk** or contact us on **020 7939 0780** or email **info@haemophilia.org.uk**

If you would like this information in a different format, such as audio tape, braille or large print, or in another league , please speak to our team on **020 7939 0708**.

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HaemophilaSocietyUK
HaemoSocUK
thehaemophiliasociety

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

Members of the European Haemophilia Consortium and the World Federation of Hemophilia
Chair: Clive Smith
Clive@haemophilia.org.uk
President: Baroness Meacher

Together for life

The Haemophilia Society

Accounts

The Haemophilia Society

Annual Report

and financial statement 2022/23

Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1766314

About the Haemophilia Society

We are the only UK-wide charity for everyone affected by a genetic bleeding disorder, and our charity is here for you.

At the Haemophilia Society (THS) we want to empower everyone affected by a genetic bleeding disorder to live life to the full, whatever your stage in life.

One in 2,000 men, women and children in the UK have a diagnosed bleeding disorder, which are a group of conditions, including haemophilia and von Willebrand disorder, that result when the blood cannot clot properly.

As many as a third of bleeding disorder diagnoses have no known family history and can be the result of a random gene mutation. This means a bleeding disorder diagnosis can come completely out of the blue.

THS brings together people with bleeding disorders and their families to share experiences and understand more about how to live well with a bleeding disorder. Together, we can all make a difference.

Contents

Welcome

The last financial year was one in which the charity sector continued to feel the after-effects of the pandemic combined with the cost-of-living crisis impacting income, and inflation adding to costs.

In spite of these challenges the Haemophilia Society (THS) continued to deliver free services to members including new events focused on von Willebrand disorder (VWD) and rare bleeding disorders, Haemophilia Live and HaemFest, a weekend of camping in Derbyshire. We were also pleased to offer free to members our annual women and girl-focused Talking Red Live event, Newly Diagnosed Weekends and Youth Camp, all of which were over-subscribed.

We represented the UK bleeding disorder community on the global stage at the World Federation of Hemophilia's Congress in Canada, the first in-person congress since the UK hosted the WFH in Glasgow in 2018. The UK has representatives on the European Haemophilia Consortium's (EHC) VWD disorder and Youth committees and we attended the EHC annual conference in Denmark. The war in Ukraine has touched so many of us, and we were proud to provide financial support to the Duisburg Haemophilia Centre in Germany, which was supporting a large number of displaced families with bleeding disorders in desperate need of treatment.

Nationally we represented the community's interests as part of the working party that has started the process to review the NHS national service specification, which aims to improve the standards of care for all people living with bleeding disorders.

We have developed a major new campaign to assess the provision of service and care for women and girls across the UK.

We're encouraged by progress in bringing gene therapy in both haemophilia A and B to the market, with significant steps being made globally. We, alongside many of our members who have been involved in research, will continue to work with the organisations involved in supplying, commissioning and delivery of gene therapy to ensure it will be available as a treatment option in the UK in the near future.

Six years after the Infected Blood Inquiry was announced, an important milestone was reached when the hearings came to an end in February 2023. The payment of interim compensation in October 2022 to those registered on UK support schemes was an important step forward, but there is much to do in ensuring full compensation is paid to everyone infected and affected by the contaminated blood scandal. THS continues to offer its full support to those impacted until justice is delivered, and beyond.

As we look forward to 2024, the 60th anniversary of THS being granted charitable status, we do not take for granted your support and that of the staff team and our board of trustees, without whom none of our work goes on.

Thank you.

Clive Smith Chair	Kate Burt Chief Executive
C. Smith	

Impact Statistics

Our membership

8% increase in membership

Our online community

12,000 followers on social media

120,360 visits to our website

6000 video views

7.2% increase in new followers on social media

Our fundraisers

over **£130,000** raised by individual fundraisers

Our resources

3600 booklets sent out

1,079 factsheets downloaded

Our events

640 people supported through our face-to-face events

95% of parents attending our Newly Diagnosed Weekends feel more confident and empowered about making decisions related to their child's treatment and well-being.

11 in-person events held in nine locations across the UK

Who we are

We exist to support you, and everybody affected by a genetic bleeding disorder in the UK, to enable you to live life well. We are both a charity and a member organisation, founded over 70 years ago.

How we give support

The Haemophilia Society supports the bleeding disorder community by:

- **Organising events** which share expert knowledge and bring together people with similar experiences.
- Providing free in-depth and **unique publications**. From starting school to the challenges of ageing with a bleeding disorder, we publish nine different booklets offering support and information, many of which are offered in other languages including Arabic, Polish, Urdu, Welsh and Bengali. We also produce eight free, **downloadable factsheets** on everything from applying for benefits to how to prepare for a virtual doctor's consultation.
- **Sharing** the latest news about developments in treatment, our work or anything else relevant to our community via social media, email and in our Community Matters members' magazine.
- **Campaigning.** Together with you, our members, we raise awareness about bleeding disorders and lobby government, the NHS and clinicians for the best possible care and equal access to effective treatment. We also campaign in support of our many members who were infected and affected by the contaminated blood scandal.
- **Listening** to what you, our members, need. We regularly invite feedback and survey our membership to find out what is most important to our community. We also invite members to join working groups to steer our strategy and activity.

Members are at the heart of our work at the Haemophilia Society. Everyone's experiences are different; sometimes the complexity and severity of the bleeding disorder means having to adapt to the day-to-day challenges. But with access to the right education and support, everyone can have the opportunity to better manage and take control of their lives – making it the best it can be.

Today we have 5,098 members, and a very active community on our social media channels. Our posts have a reach of more than 700,000 people.

Membership of the Haemophilia Society is free, and so are all the events and services that we provide for our members. This is only possible thanks to the generosity of all our amazing supporters. Thank you!

Matthew at Youth Camp 2022

> **'THS's conference in November 2019 was where I met one of my best friends, who also has haemophilia. We've been at Youth Camp together since and now keep in touch online and we enjoy sleepovers.'**

What we do

Youth Support

Ensuring that our young members are welcomed, supported and empowered to manage their bleeding disorder is a central part of our work.

'All the Youth Ambassadors, but especially Jess, spoke beautifully and passionately about how the condition brought something to their lives instead of taking something away.'
A parent who attended our Newly Diagnosed Weekend in Essex, September 2022


Jess, Youth Ambassador

We have a strong Youth Ambassador programme, dating back to 2015, which is open to members aged 18-30. Our Youth Ambassadors act as mentors to our younger members, offering advice and reassurance about the reality of living with a bleeding disorder. They also attend our events to talk about their lived experience. Many people, particularly parents of newly diagnosed children, find it very reassuring to hear about the full lives these approachable and positive young people lead.

Our Youth Ambassadors also regularly attend global conferences, such as this year's World Federation of Hemophilia's Congress in Montreal, to share their experiences, helping them to build their skills to become advocates for themselves and our community.

This year we've been thinking about how to ensure the voices and experiences of young people are reflected in the work of our charity, while also working with younger members on developing the next generation of Youth Ambassadors.

We were pleased to announce the formation of our Youth Board, made up of six senior Youth Ambassadors, all with a bleeding disorder, who will ensure that our strategies and initiatives are relevant, inclusive and responsive to the needs of young people within our community. The board is chaired by Ross Bennett, who has severe haemophilia B. They will also continue to mentor younger Youth Ambassadors as well as our youth community.

Meanwhile, our annual Youth Camp, which is free to members, took place in Surrey in July 2022 and was attended by 44 young people aged nine to 15 who either have a bleeding disorder or have a sibling with a bleeding disorder. Supporting the families of people with a bleeding disorder is an essential part of our work, and a recognition of the impact that living with a bleeding disorder has on parents, grandparents and siblings.

The camps, which could not be run without the support of our volunteers, including clinicians such as specialist paediatric nurses and physiotherapists, allow our young people freedom and independence in a safe environment. Here they can try activities such as climbing and a high ropes course which builds their confidence. They also meet others who have been through similar experiences, often resulting in long-lasting friendships.

As always, our feedback was excellent from Youth Camp 2022, from both the young people themselves and their parents or guardians.

'Both girls agreed that camp was amazing! They had lots of fun making memories and being with lots of people who are living with haemophilia which helped them see that there are others in this world living with the same condition as their brother.'
Kirsty, mum of Phoebe and Scarlett, pictured right.


Ross, Youth Ambassador and Chair of the Youth Board

'Youth Ambassador Ross helped me realise that my son can live a fun and normal life and do stuff that other boys can, just with a little more planning.'
A parent who attended our Newly Diagnosed Weekend in Essex, September 2022

Community Support

Bringing people together to share experiences and find out about the latest care and treatment available is one of the most rewarding aspects of our work.

Genetic bleeding disorders are rare, and it can be isolating to be the only person with this condition in a workplace, village, school or sports team. By connecting our members through in-person events and our supportive social media community, people can be reassured that they are not alone in whatever challenges they are facing. Sharing experiences also empowers people to think again about their care as they learn about the treatment of others and find out more about the options open to them.

This year, 640 adults and children registered to attend one of 11 in-person events held in nine locations across the UK. This is a 42% increase on last year, reflecting our focus on trying to attract a greater range of people to our events by holding them in locations around the UK.

Information Days

'I felt like my voice was heard and nothing was judged or dismissed. It was very helpful to just 'vent', almost, to express this new side of my life.'

Feedback from our Rare and BDUC information day

'The separate conference made me feel VWD is important. I was pleased with all the information we got during the day and enjoyed the opportunity to meet other people with VWD.'

Feedback from an attendee of our VWD Information Day in Southampton

HaemFest 2022

Rare and BDUC information day 2023

Following feedback from our members, in 2022-23 we held a series of information days dedicated to a specific bleeding disorder and rarer conditions.

The first information day focused on von Willebrand disorder (VWD) and was held in Southampton. Participants told us that they enjoyed the chance to talk about the specific issues relating to VWD and a clinician's presentation on dental care was particularly well received.

We held our second information day on rare bleeding disorders and bleeding disorders of unknown cause (BDUC) in London. Over 15,000 people have a rare bleeding disorder or a BDUC. This was the first event of its kind in the UK to bring this community together to discuss treatment, care and personal experiences. We were pleased to welcome a representative from the European Haemophilia Consortium (EHC) who told us about the organisation's work in this area.

Our third dedicated event, Haemophilia Live in Nottingham, focused on haemophilia and featured sessions on shared decision making as well as treatment updates and a chance to swap experiences.

Talking Red Live

Talking Red is our focus on women and girls with a bleeding disorder. This takes the form of an annual dedicated event but is also a year-round campaign to raise awareness that women and girls live with genetic bleeding disorders. Although women and girls now make up the majority of people in the UK with a diagnosed bleeding disorder, women often do not get the quality of care and treatment they need. Women are more likely to be diagnosed as adults and studies show that on average women with bleeding disorders are diagnosed 10 years later than men.

Talking Red Live took place this year in Oxford, and featured updates on pregnancy and childbirth and gave members the chance to share their journey living as a woman with bleeding disorders in workshops. We have an active Women's Working Group which helps us set the agenda for this event to ensure that the issues discussed are what matters most to our community. We also used this event to launch our SACRed project, a major new project which focuses on women's treatment and care. You can read more about this in the advocacy section of this report.


Talking Red Live 2023

Growing up, the idea of a woman with a severe bleeding disorder was considered a novelty by people I met and even some doctors, and that was often isolating. Talking Red Live is a unique opportunity for women to come together and share our lived experiences and challenges; something I had never done before in 40 years of having von Willebrand disorder!"

Anna, pictured above, THS trustee and attendee of Talking Red Live

Haemfest

In June 2022 we held our first HaemFest, a camping event, free to members, in Derbyshire. We wanted to offer an event to bring together our members in an informal way, allowing new friendships to be formed and experiences shared. As well as workshops, there were also activities such as stage combat fighting, circus skills, yoga, belly-dancing and a popular arts and crafts tent. On Saturday evening we came together to enjoy some lively Irish dancing.


Jacob at HaemFest 2022

‘Jacob’s inspiration for fundraising for THS came from attending HaemFest and wanting to make sure that all children with bleeding disorders could have access to such fun events.’

Nicola, Jacob’s mum.

Newly Diagnosed Weekends

‘We attended the NDW in July 2022 with some hesitation and fear around it bringing back up all our emotions when we first learnt our son had haemophilia. However, it turned out to be exactly what we needed! Being surrounded by other families who understood what we had been through and sharing our stories really made us not feel alone. It gave us a real sense of togetherness. THS put on such a professional and informative event while creating a relaxed environment where you felt you could be open and honest. It is a weekend we are truly thankful for and one we didn’t know we needed as a family!’

Ian, who attended NDW with his partner Danielle and son Ryan.

Our Newly Diagnosed Weekends (NDWs) provide families with expert advice, invaluable peer support and a safe space to ask questions in the very early stages of diagnosis. THS Youth Ambassadors also attend these events, sharing their experiences and bringing positivity to families who may feel uncertain about their child’s future. Specialist clinicians also support us at NDWs, answering a range of questions about treatment and care.

We held three NDWs this year, reaching 29 families. We were pleased to join up with Haemophilia NI to host one event in Limavady, and the other two took place in Bolton, Greater Manchester and Brentwood, Essex.

Feedback from the events shows that 95% of parents attending our NDWs feel more confident and empowered about making decisions related to their child’s treatment and well-being.


Ian, Danielle and Ryan at our NDW

Service of Remembrance & Thanksgiving

We are honoured to host this important annual event for all those people with inherited bleeding disorders who have died due to their treatment with contaminated blood products. The service is held at St Botolph without Bishopsgate, London, where the book of remembrance and icon is kept. With the Infected Blood Inquiry reaching the end of its hearings, there is a greater need than ever for this service, which offers a safe and welcoming space for everyone infected and affected by the contaminated blood scandal of the 1970s and 80s.

Carol Service

Our annual Carol Service held at St Botolph without Bishopsgate, London, is gaining in popularity due in part to the wonderful singing of the church choir. This paid-for event is increasingly being attended by non-members who work locally, giving us an opportunity to increase awareness about our work to a new audience. We are proud of our long-standing connection with St Botolph's, which dates back to the 1990s when our Chair, Rev Alan Tanner served at the church.

Ambassadors

We have four dedicated Ambassadors to support our members. Mark Ward is our LGBTQ Ambassador, Sunny Maini is our VWD Ambassador, THS staff member Scott McLean is our Mental Health Ambassador and Dr William McKeown is our Access and Service Improvement Ambassador. Mark, Sunny and William kindly volunteer their time to provide this service, and all four travel to conferences to highlight these issues as well as talking directly to our members to offer support and advice.

This year we offered the following free publications:

- Understanding Haemophilia
- Understanding VWD
- Ageing with a bleeding disorder – social care and support
- Rare bleeding disorders
- Bleeding Disorders and School
- Women living with bleeding disorders
- Girls with living with bleeding disorders
- Dental care for adults with a bleeding disorder
- Sex and bleeding disorders

We offered the following downloadable factsheets:

- DLA
- PIP Making a claim (Disability Living Allowance)
- PIP Assessment process
- Emicizumab (for people without an inhibitor)
- Emicizumab (for people with an inhibitor)
- Extended half-life (EHL) factor VIII
- Top tips for parents
- Patient checklist to prepare for virtual consultations

Publications and educational materials

This year we produced nine booklets and eight downloadable factsheets. We sent out 3,600 publications, some of which are available in five languages, including Welsh, Urdu and Arabic. The booklets are used in haemophilia centres as well as by individual members to help them and their friends and relatives to understand their condition. Last year 1,079 factsheets or booklets were downloaded from our website.

We have also collaborated with companies Cor 2 Ed and AKT to help produce videos about the reality of living with a bleeding disorder. One video focused on three generations of women living with a bleeding disorder and the other looked at the impact of growing up with haemophilia. We are grateful to our members who took part in these videos which do so much to raise awareness about living with a bleeding disorder.

Adam filming an AKT awareness video.

Standards of Care

The specialised blood disorders Clinical Reference Group (CRG) was reconstituted this year and THS was successful in our application to be one of the two patient representatives on the group. The CRG works with NHS England to coordinate specialist care for people with bleeding disorders and leads on the development of new treatment policies and service specifications.

It was announced that next year we will have the opportunity to review the Service Specification, which has not been updated since 2013, which details the care that should be delivered by haemophilia centres. This is an opportunity to make sure people with bleeding disorders can expect all aspects of care they need in all centres across the country and we can ensure people can live their best life with a bleeding disorder.

We continue to work with NICE, a government body which provides evidence-based guidelines for treatment and care in the NHS. We support the process by advocating for the needs of patients and access to new treatments. This year we made submissions to the NICE review of Hemgenix which is a proposed gene therapy treatment option for haemophilia B. We also bring the voice of people with a bleeding disorder to the changes to tender frameworks for current treatments and any license extensions, this ensures that other factors beyond price, such as ease of use, are considered when choosing products for supply to haemophilia centres.

This year NHS England began the tender process to select sites across the country to deliver gene therapies if and when they are recommended by NICE for routine commissioning. We are part of the review group that will consider applications and choose which centres are best placed to lead on delivering these innovative new treatments.

We are members of NHS England's Specialised Commissioning Stakeholder Forum which allows use to raise wider issues with how NHS treatment and care is commissioned and delivered across England.

We also work with the Haemophilia Nurses Association (HNA), the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) and the Haemophilia Chartered Physiotherapists' Association (HCPS) to ensure we are across all aspects of haemophilia and bleeding disorder care.

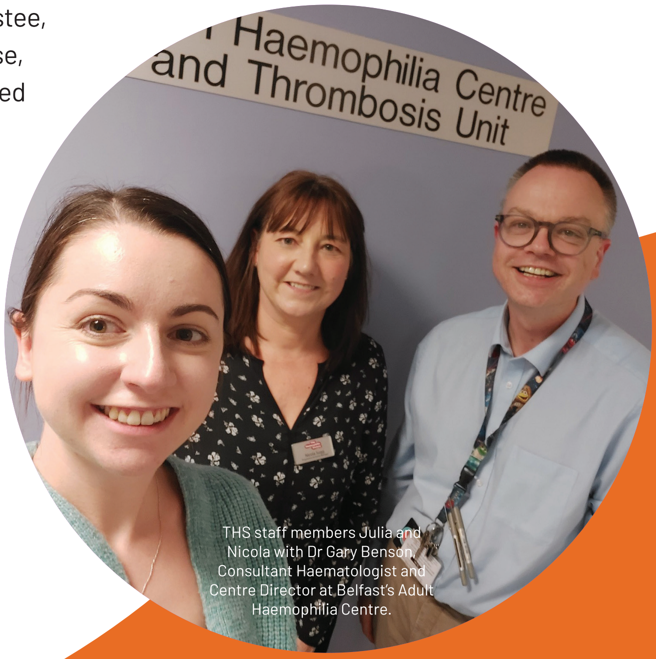
This year we launched the SACRed Project, a multi-year investigation into the experiences of women and girls with bleeding disorders that will make recommendations for improving standards of care and access to treatment. The report will be published in November 2024. We are grateful to Octapharma, LFB, Sobi, Takeda and Roche who are sponsoring this project.

Raising Awareness

An important part of our role is to ensure that people outside our community understand accurately the reality of living with a bleeding disorder. We answer a large number of media inquiries, many relating to the Infected Blood Inquiry, but also about the latest treatments and issues relating to quality of care. In January 2023 the BBC's popular Call the Midwife series ran an episode about a baby born with haemophilia. Our medical trustee, Natalie Lawson, who is a paediatric haemophilia nurse, acted as consultant for the programme, which resulted in a huge spike in google searches for 'haemophilia' during the episode and doubled our website traffic. Exposure to such a mainstream programme was a very effective way of raising awareness about haemophilia and we're grateful for the sensitive and thorough way the issue was handled.

Advocacy

From advocating for higher standards of care and equal access to effective treatment, to campaigning on local issues, THS is here to raise awareness about bleeding disorders. We work to influence decision-makers on behalf of people affected by bleeding disorders. Our advocacy is a vital part of our role, although it is often less visible than other aspects of our charity's work.



THS staff members Julia and Nicola with Dr Gary Benson, Consultant Haematologist and Centre Director at Belfast's Adult Haemophilia Centre.

Infected Blood Inquiry

'Huge thanks to the Haemophilia Society for providing a summary of evidence throughout the statutory public inquiry. I, for one, have greatly appreciated your summarised, unbiased reporting.'

Comment from our dedicated public inquiry Facebook page

Clive Smith, THS Chair, delivers a letter to the Prime Minister

Our Public Inquiry Team has continued to support those infected and affected by the contaminated blood scandal and kept our members up to date with the work of the Infected Blood Inquiry. We have a dedicated public inquiry Facebook page where we update members about the inquiry's evidence or any other related developments.

This marked an important year for the inquiry, which concluded its oral hearings in February 2023 and published its first interim report on compensation in August 2022. This was implemented by the government and resulted in interim payments of £100,000 to people registered on Infected Blood Support Schemes in England, Scotland, Northern Ireland and Wales in October 2022.

As a result of the interim compensation scheme, a number of people have come forward with queries about their eligibility for the UK's support schemes. Our Public Inquiry Team has supported many members, particularly bereaved partners, who did not realise they could apply for the scheme and have since been accepted.

We continued to press for compensation to be extended to bereaved parents and children. Our Chair, Clive Smith was part of a delegation to 10 Downing Street in the Summer of 2022 calling for the compensation criteria to be widened. We, along with other campaigners, protested outside Parliament in November 2022 in advance of a debate in Westminster Hall on the issue of compensation.

Our Chief Executive, Kate Burt and Clive Smith were interviewed extensively for national and regional print and broadcast media on the issues of interim compensation and the end of the inquiry's hearings.

Influencing the political agenda

We seek to ensure that the treatment and care needs of people with genetic bleeding disorders is understood by political decision-makers of all parties. This year we attended the Labour and Conservative party conferences with our Chair, Clive Smith, invited to speak at two fringe events on the challenges facing the NHS and what they mean for people with rare diseases.

There was also an opportunity for Jeff Courtney, our Policy and Public Affairs Manager, to discuss key issues, such as compensation for people infected and affected by the contaminated blood scandal and inequalities in health provision.

In Parliament, our Chief Executive, Kate Burt addressed a meeting on novel treatments and future gene therapy and we were pleased to host in a roundtable event which discussed how we deal with the major problems faced by people with bleeding disorders in accessing full multidisciplinary care, particularly physiotherapy. We continue to campaign for full multi-disciplinary care for people with bleeding disorders at all haemophilia centres across the UK.

In addition, the Haemophilia Society provides a secretariat service to the All Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood. In this role we maintain the membership information of the APPG and facilitate meetings of the group in conjunction with the chairs.

Members of the THS and guests at the parliamentary round table event we hosted to highlight the need for access to full multidisciplinary care.

Global Connections

THS values and constantly seeks to strengthen our links with fellow haemophilia and bleeding disorder associations around the world. It is truly saddening how stark the disparities are in treatment provision between nations. We recognise how fortunate we are to live in a country where we can expect to receive the latest treatment and acknowledge our responsibility to support our colleagues and people with bleeding disorders around the world who do not have the choices we enjoy.

We are proud to continue to support WFH's Cornerstone Project which aims to close the gap in treatment by providing support, expertise and training to countries with minimal levels of care.

The war in Ukraine sparked a crisis in Europe, which has also had an impact on our bleeding disorders community. This year we were proud to support a major haemophilia treatment centre in Duisberg, Germany, with a grant of £10,000 to help it accommodate Ukrainian children and adults with a bleeding disorder displaced by the war who were in urgent need of treatment and care.

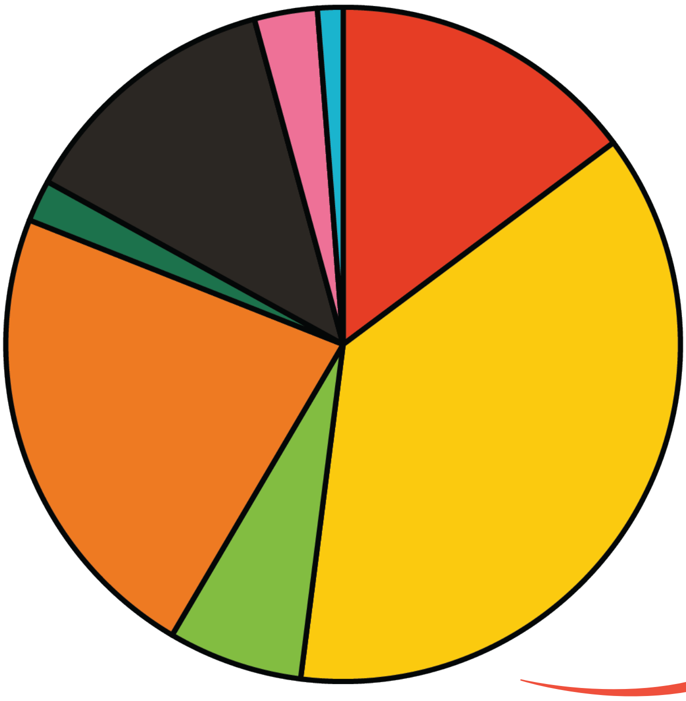
We attended major global conferences including the WFH's Congress in Montreal and the European Haemophilia Consortium's (EHC) new technologies conference. A number of our Youth Ambassadors addressed conference sessions, as well as our Chair, Clive Smith. We were pleased to share our knowledge on these global stages and to learn more about other countries' experiences.

This year the International Society of Thrombosis and Haemostasis (ISTH) and the European Association for Haemophilia and Allied Disorders (EAHAD) held their conferences in London and Manchester, respectively, giving us the opportunity to send more representatives to learn about new treatments and advancements in care. Equally importantly, it was another chance to forge links with many UK health professionals and organisations within the bleeding disorders community.

THS at the International Society of Thrombosis and Haemostasis (ISTH) in London.

THS represented at the European Association for Haemophilia and Allied Disorders (EAHAD) in Manchester.

How we manage your money

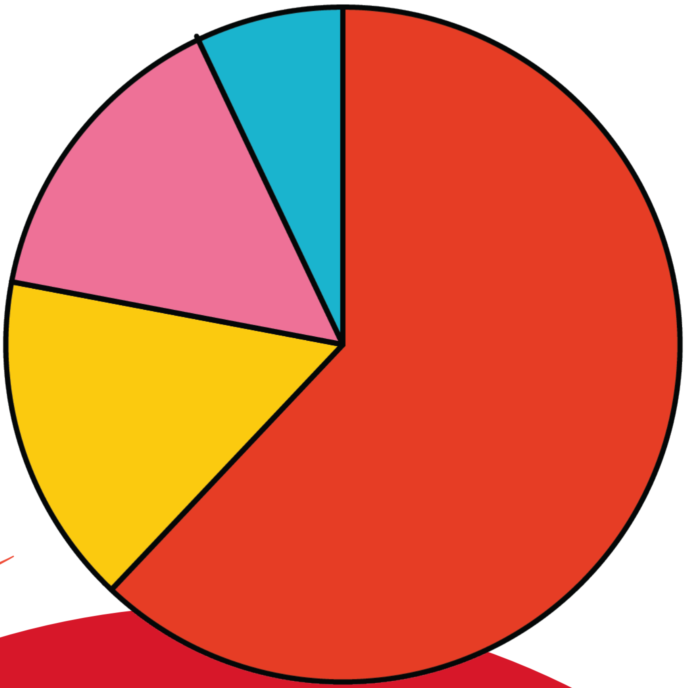


Income Composition 2022-23

🟥	Donations from individuals	16%
🟨	Legacies	36%
🟩	Grants & trusts	6%
🟧	Corporates	22%
🟩	Gift aid	3%
⬛	Community fundraising & events	12%
🟪	Investments	3%
🟦	Other	2%

Charitable activities & Expenditure 2022-23

🟥	Events & member services	62%
🟨	Campaigns & communications	16%
🟪	Grants awarded	15%
🟦	Public inquiry	7%



Fundraising and partnerships

We are grateful to have such dedicated partners who help us to support our members and the wider bleeding disorders community. The generosity of charitable trusts, corporate partners and volunteers helps us to continue to deliver our core services for our members.

Events

Thank you to everyone who walked, ran, cycled, swam, sky dived, played golf, baked and undertook many other challenges to raise funds for THS. We are very grateful for all that you do.


The Big Red Bridge Walk, Glasgow

National haemophilia charities

We are grateful for the productive relationships we have with the national haemophilia charities in Scotland and Northern Ireland. This year we collaborated with Haemophilia NI to hold a Newly Diagnosed Weekend in Limavady and joined Haemophilia Scotland on its Big Red Bridge Walk. We also liaise with both organisations to maximise advocacy, particularly in relation to issues arising from the Infected Blood Inquiry's work.

Corporate Partners

We receive ongoing support from partners in the pharmaceutical and private sectors, which includes sponsorship of member events, charitable grants and gifts of pro bono support.

Thank you to CSL Behring, Novo Nordisk, Roche-Chugai, Sanofi, SOBI, Pfizer, LFB and Takeda for their support in 2022 – 2023 and beyond.

Without this funding, it would be impossible for us to run many of our events which offer essential support to our members. We would like to emphasise that there are strict guidelines relating to donations from pharmaceutical companies to health organisations which we adhere to at all times.

Companies must respect the independence of the project and organisation to which they have donated and are not allowed to influence any of its written material. As per clause 27 of the 2019 ABPI code, all pharmaceutical companies must declare their sponsorship of 'patient organisations', which is how THS is classed under the code.

Trusts and Foundations

We continue to strengthen our relationships and grow support from trusts and foundations to fund our ongoing project delivery. We have built robust sources of funding and are committed to further strengthening our partnership with our funders to support continued growth.

Volunteers

'Volunteering for the Haemophilia Society was a truly enriching experience, allowing me to make a meaningful difference in the lives of individuals affected by this condition. The connections I forged and the positive impact I witnessed made it a rewarding journey that I will always cherish.'

Ravi, Youth Camp volunteer

Without our volunteers, we would be unable to host the events which we know our members find so valuable, nor could we run our charity, which is governed by unpaid volunteers who are elected to serve on our Board of Trustees.

We are very grateful to our clinical volunteers, such as haemophilia nurses, consultants and physiotherapists, who give up their time to supervise events, such as Youth Camp and HaemFest or to speak at our conferences or information days. We also could not manage events such as Youth Camp without an army of volunteers to supervise climbing walls, canoeing, fire building and other fun activities that make this event so special for our younger members. We appreciate the contribution of every single volunteer.


Ravi volunteering at Youth Camp 2022

'Being a THS trustee has given me a world of experience outside of my normal background. Coming from Northern Ireland I wanted to give the regions a voice and have been able to work with both local and UK governments on a range of issues. Most important are the community connections I've made and friends I now value and can always rely on.'

Conan, THS Trustee

Little Bleeders

We continue to work closely with Little Bleeders, the charity established by former professional cyclist Alex Dowsett, which encourages young people with bleeding disorders to get involved in sport and stay active.


Youth Camp 2022


THS trustee Conan

A big thank you

Together, we continue to work to improve the lives of everyone with a genetic bleeding disorder and their families.

We have some of the most loyal and generous supporters any charity could wish for. The individual donations and legacies that we receive and the contribution from our partners, large or small, makes everything that we do possible.

We'd also like to thank our trustees, who give their time so generously to ensure our organisation is run as efficiently and productively as possible for the benefit of our members.

Newly Diagnosed Weekend, Bolton, July 2022

HaemFest 2022

HaemFest 2022

Youth Camp 2022

HaemFest 2022

Our governance

We work hard to set the highest standards as an organisation. Our policies and procedures reflect our values and we designed them to help us keep to those standards. We communicate them to our employees and volunteers and give everyone the training they need to uphold them. We also record our decisions and incidents, monitor our performance, and gather feedback to help us learn and improve.

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 seriously and we will:

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

Administration and legal details

Who we are

President	Baroness Meacher
Honorary Vice President	Dr Kate Khair
Chief Executive	Kate Burt
Board of Trustees	Clive Smith – Chair Conan McIlwrath – Vice Chair Susan Stretch – Vice Chair Gordon Dixon – Treasurer Sonia O'Hara (resigned 19 November 2023) Paul Sartain Joanne Traunter Anna Geffert (resigned 19 November 2023) Amy Owen-Wyard Rayaz Ali Chel Natalie Lawson Lisa Bagley (appointed 19 November 2023) Stacey McGeown (appointed 19 November 2023)

Subcomittees

Finance and Risk Committee	Gordon Dixon – Chair Clive Smith Conan McIlwrath Susan Stretch Rayaz Ali Chei
Nominations Committee	Gordon Dixon Clive Smith
Public Inquiry Committee	Clive Smith – Chair Conan McIlwrath Susan Stretch Paul Sartain Eileen Ross Barry Flynn
Clinical Advisory Group	Dr Rezan Abdul-Kadir Dr Susie Shapiro Dr Kate Khair Prof Mike Laffan 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 Sutherland 1 Wood Street London EC2V 7WS
Auditors	Azets Audit Services 2nd Floor, Regis House 45 King William Street London EC4R 9AN
Company registration number	01763614
Charity registration number	288260
Scottish charity registration number	SC039732

Trustees' report

The trustees present their report and the audited financial statements of the charity for the year ended 31 March 2023. 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, provisions of the Charities Act 2022 in force at the time of preparing these accounts 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 (effective 1 January 2019).

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:

Clive Smith
Conan McIlwrath
Susan Stretch
Gordon Dixon
Sonia O'Hara (resigned 19 November 2023)
Paul Sartain
Joanne Traunter
Anna Geffert (resigned 19 November 2023)
Amy Owen-Wyard
Rayaz Ali Chel
Natalie Lawson
Lisa Bagley (appointed 19 November 2023)
Stacey McGeown (appointed 19 November 2023)

Financial review

The charitable sector continues to be hit hard by the cost-of-living crisis and fall-out from changes in the way in which people fundraise following the Covid pandemic. THS, like many others, has felt the impact of this as our members feel the squeeze on their own budgets.

These challenges make it more important than ever that we focus on efficiency and ensuring that we offer our members a relevant and useful service while doubling down on achieving diverse and reliable funding sources. To this end, we had to take some difficult decisions, making three staff posts redundant in March 2023 and not filling a vacancy left by a departing staff member.

We expect to reap the benefits of a long-term investment in a new platform to record data and organise information in the 2023/24 financial year. Much of this year has been spent sorting through data and putting in place systems which mean we will be able to communicate more effectively and efficiently with our members and stakeholders.

Overall, we have generated a loss for the year of £277,975 (before the impact of the loss on investments), which resulted in a reduction of reserves.

Income (including legacies) for FY22-23 was £795,226 compared to £749,428 in the previous financial year. Legacy income received of £282,147 for FY22-23 has increased by 24% compared with the previous year (£227,459 in FY22). Given the unpredictable nature of legacies, there will always be a large variance on a yearly basis. We are grateful to all our members who remember THS in their will. Grants from Trusts & Foundations grew strongly in 2022-23 to £50,500 up from £14,050 in 2021-22. Corporate income has not recovered to pre pandemic levels, but still represented 22.2% of total income for the year.

The Infected Blood Inquiry continued this year and therefore so did our work to support our members and keep them up to date with inquiry evidence and related issues. This incurred costs of £107,601.

Through the European Haemophilia Consortium we supported the Duisburg Haemophilia Centre in Germany with a grant of £10,000 who are supporting a large number of families with bleeding disorders displaced through the conflict in Ukraine.

Overall costs in FY22-23 were £1,073,201. This is against a total income of £795,226, representing a deficit of £277,975 before net losses on investments.

Reserves

THS reserves on 31/03/23 stood at £843,995, a decrease of £324,612 from the prior year, due to draw downs from investments.

The board of trustees made the decision to designate £168,733 to create a liquidation fund to cover three months of running costs. Previously the trustees designated the liquidation fund to be 6 months running costs but considered it prudent to amend this to be 3 months to mitigate the difficult economic environment.

The Haemophilia Society is currently developing a new three-year strategy to be published in early 2024.

In recognition of the significant financial and general resource impact of the ongoing Infected Blood Inquiry, the board in 2019 designated £600,000 of reserves to fund the charity's work in this area. In the combined years to date we have spent £521,751 leaving a balance of £78,249 to cover costs until the end of the inquiry. Designated funds are reviewed annually to ensure the appropriate use of reserves.

As of 31 March 2023, unrestricted general reserves (excluding local group funds) stood at £628,091. As noted, the board of trustees continually reviews potential opportunities to invest for the good of THS, 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 FY22-23 our funds had a market value of £729,754.

Key risks and uncertainties

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

Financial

As described above, we are operating in a challenging financial environment and planning to focus our income generating strategy on building trust and foundation relationships as well as increasing and diversifying our corporate partnerships.

Reputational

The Infected Blood Inquiry's final report and recommendations are expected in 2024. As part of its Terms of Reference, the inquiry has examined the work of THS over a 40-year period and we would expect this to be set out in its final report.

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

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 THS)
- one honorary chair
- 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
- 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.

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

C. Smith

Clive Smith
Chair, the Haemophilia Society
Date: 20 December 2023

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 2023 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 2023 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 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 the 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 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. This description forms part of our auditor's report.

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

IIrregularities, 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 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.

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

Date: 20 December 2023

Statement of financial activities (including income and expenditure account)

Year ended 31 March 2023

	Note	2023 Unrestricted funds £	2023 Restricted funds £	2023 Endowment funds £	2023 Total £	2022 Total £
Income and endowments from:						
Donations and legacies	2	475,589	184,564	300	660,453	584,641
Charitable activities	3	87,261	9,070	-	96,331	120,259
Investments	4	23,492	1,399	-	24,891	35,538
Other		13,131	420	-	13,551	8,990
Total income and endowments		599,473	195,453	300	795,226	749,428
Expenditure on:						
Raising funds	5	171,932	11,221	-	183,153	287,175
Charitable activities	6	746,281	143,767	-	890,048	895,835
Total expenditure		918,213	154,988	-	1,073,201	1,183,010
Net (losses) / gains on investments		(46,637)	-	-	(46,637)	30,839
Net (expenditure) / income	9	(365,377)	40,465	300	(324,612)	(402,743)
Transfers between funds		-	-	-	-	-
Net movement in funds		(365,377)	40,465	300	(324,612)	(402,743)
Reconciliation of funds:						
Total funds brought forward		1,047,813	105,794	15,000	1,168,607	1,571,350
Total funds carried forward		682,436	146,259	15,300	843,995	1,168,607

All income and expenditure derive from continuing activities.

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

Balance sheet

Year ended 31 March 2023

	Note	2023 £	2022 £
Fixed assets			
Tangible assets	13	5,172	9,189
Investments	14	729,754	1,026,391
		734,926	1,035,580
Current assets			
Debtors	15	71,730	90,936
Cash at bank and in hand		140,796	130,997
		212,526	221,933
Creditors: amounts falling due within one year	16	(103,457)	(88,906)
Net current assets		109,069	133,027
Net assets		843,995	1,168,607
Charity funds			
Endowment funds	17	15,300	15,000
Restricted funds	17	146,259	105,794
Unrestricted general funds	17	381,109	465,838
Local group funds	17	54,345	58,660
Designated funds	17	246,982	523,315
Total charity funds	18	843,995	1,168,607

The financial statements were approved and authorised for issue by the board on 19 December 2023

Signed on behalf of the board of trustees

C. Smith

Clive Smith, Chair

Company registration number: 01763614

Statement of cash flows

Year ended 31 March 2023

	Note	2023 £	2022 £
Net cash flow from operating activities	19	(263,056)	(354,770)
Cash flow from investing activities			
Payments to acquire tangible fixed assets		(2,036)	(5,787)
Net cash flow from sale and purchase of fixed asset investments		250,000	400,000
Interest received		24,891	35,538
Net cash flow from investing activities		272,855	429,751
Net increase in cash and cash equivalents		9,799	74,981
Cash and cash equivalents at 1 April 2022		130,997	56,016
Cash and cash equivalents at 31 March 2023		140,796	130,997

Cash and cash equivalents consists of:			
Cash at bank and in hand		140,796	130,997
Cash and cash equivalents at 31 March 2023		140,796	130,997

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 47 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 Companies Act 2006, the Charities Act 2011, provisions of the Charities Act 2022 in force at the time of preparing these accounts, 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.

THS is represented throughout the country by local groups. Local group funds are incorporated into THS'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.

1. Summary of significant accounting (continued)

(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.

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, services, advocacy and influencing, corner stone project, public inquiry and tanner fund grant 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 below.

(d) 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.

1. Summary of significant accounting (continued)

The analysis of these costs is included in note 7 (page 36)

(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. THS's contributions to these schemes are charged to the SoFA in year in which they arise.

(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.

1. Summary of significant accounting (continued)

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

The Trustees recognise that in the current economic climate, expenditure cannot continue as originally projected based on the income growth. In November 2022 a review commenced of our operating model. The cost base was restructured, removing £380,000 from expenditure from 1 April 2023. The Trustees have considered the level of funds held and the expected level of income and expenditure, together with execution of the mitigation plan for 12 months from authorising these financial statements. Based on the projected cash flow information for 12 months from the date of approval of these financial statements, taking into consideration the estimation of the continued impact of Covid and resources available, 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

	2023	2022
	£	£
Donations from individuals	130,790	97,096
Legacies	282,147	227,459
Grants and trust income	50,500	14,050
Corporate income	176,751	230,414
Gift Aid	20,265	15,622
	660,453	584,641

Income from donations and legacies includes £184,564 (2022: £192,791) attributable to restricted funds, £475,589 (2022: £391,600) attributable to unrestricted funds, and £300 (2022: £250) attributable to endowment funds.

3. Income from charitable activities

	2023 £	2022 £
Local group activities	114	2,384
Community fundraising and events	96,217	117,875
	96,331	120,259

Income from charitable activities includes £9,070 (2022: £66,121) attributable to restricted funds, and £87,261 (2022: £54,138) attributable to unrestricted funds.

4. Income from investments

	2023 £	2022 £
Interest - fixed interest securities	24,891	35,538
	24,891	35,538

Income from investments includes £1,399 (2022: £1,071) attributable to restricted funds, and £23,492 (2022: £34,467) attributable to unrestricted funds.

5. Analysis of expenditure on raising funds

	2023 £	2022 £
Direct costs	36,702	120,921
Support costs	146,451	166,254
	183,153	287,175

£11,221 (2022: £85,471) of the above costs were attributable to restricted funds. £171,932 (2022: £201,704) 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 2023 £
Communications	13,661	-	139,369	153,030
Membership	7,809	-	20,092	27,901
Services	142,837	-	379,223	522,060
Advocacy and influencing	13,459	-	49,769	63,228
Corner stone project	14,778	-	-	14,778
Public inquiry	2,956	-	104,645	107,601
Tanner Fund grants	-	1,450	-	1,450
	195,500	1,450	693,098	890,048

£143,767 (2022: £219,925) of the above costs were attributable to restricted funds. £746,281 (2022: £675,910) of the above costs were attributable to unrestricted funds.

	Activities undertaken directly £	Grant funding of activities £	Support costs £	Total 2022 £
Communications	88,369	-	92,708	181,077
Membership	14,208	-	20,068	34,276
Services	171,971	-	343,091	515,062
Advocacy and influencing	2,467	-	37,243	39,710
Corner stone project	16,000	-	-	16,000
Public inquiry	4,451	-	104,259	108,710
Tanner Fund grants	-	1,000	-	1,000
	297,466	1,000	597,369	895,835

£219,925 (2021: £121,824) of the above costs were attributable to restricted funds. £675,910 (2021: £534,474) of the above costs were attributable to unrestricted funds.

7. Allocation of support costs

Support cost 2023	Basis of allocation £	Raising funds £	Charitable activities £	Total 2023 £
Governance	% of direct costs	2,226	11,947	14,173
Travel, postage and carriage	% of direct costs	2,534	10,842	13,376
Information technology	% of direct costs	3,062	16,430	19,492
Salary costs	% of staff time	120,298	555,507	675,805
Depreciation	% of direct costs	951	5,102	6,053
Office costs (incl. rental)	% of direct costs	7,758	41,629	49,387
Recruitment, training and temp staff	% of direct costs	1,860	9,982	11,842
Other expenses	% of direct costs	7,762	41,659	49,421
Total		146,451	693,098	839,549

7. Allocation of support costs (continued)

Support cost 2022	Basis of allocation £	Raising funds £	Charitable activities £	Total 2022 £
Governance	% of direct costs	3,758	9,275	13,033
Travel, postage and carriage	% of direct costs	1,113	3,581	4,694
Information technology	% of direct costs	5,255	12,971	18,226
Salary costs	% of staff time	120,298	483,103	603,401
Depreciation	% of direct costs	2,215	5,467	7,682
Office costs (incl. rental)	% of direct costs	12,511	30,881	43,392
Recruitment, training and temp staff	% of direct costs	8,084	19,954	28,038
Other expenses	% of direct costs	13,020	32,137	45,157
Total		166,254	597,369	763,623

8. Governance costs

	2023 £	2022 £
Trustee expenses	3,073	4,153
Auditors' remuneration - current year	11,100	8,880
	14,173	13,033

9. Net income/ (expenditure) for the year

Net income / (expenditure) is stated after charging:

	2023 £	2022 £
Depreciation of tangible fixed assets	6,053	7,682
Operating lease rentals	42,080	39,272
Auditors' remuneration	11,100	8,880

10. Auditor's remuneration

	2023 £	2022 £
Fees payable to the charitable company's auditor for the audit of the charitable company's annual accounts	11,100	8,880

11. Trustees and key management personnel remuneration and expenses

The trustees neither received nor waived any remuneration during the year (2022: £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 £102,758 (2022: £101,106).

The reimbursement of trustees' expenses was as follows:

	2023 Number	2022 Number	2023 £	2022 £
Travel, subsistence and accommodation	9	9	6,426	2,299

Included in trustees' expenses was £3,398 (2022: £861) 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:

2023 Number	2022 Number
15	13

12. Staff costs and employee benefits (continued)

The total staff costs and employee benefits was as follows:

	2023 £	2022 £
Wages and salaries	582,919	520,482
Social security	54,827	48,231
Defined contribution pension costs	38,059	34,688
	675,805	603,401
Recruitment and training	4,840	20,495
	680,645	623,896

Three employees received emoluments of more than £60,000 during the year ended 31st March 2023 (2022: two) and within the following bands:

	2023	2022
£60,000 - £70,000	2	1
£70,001 - £80,000	-	-
£80,001 - £90,000	1	1

13. Tangible fixed assets

	Computers and Office Equipment £
Cost:	
At 1 April 2022	99,081
Additions	2,036
At 31 March 2023	101,117
Depreciation:	
At 1 April 2022	89,892
Charge for the year	6,053
At 31 March 2023	95,945

13. Tangible fixed assets (continued)

Net book value:	
At 31 March 2023	5,172
At 31 March 2022	9,189

14. Fixed asset investments

	COIF Investment	Other investments	Total
	£	£	£
Cost or valuation			
At 1 April 2022	1,025,442	949	1,026,391
Additions	-	-	-
Disposals	(250,000)	-	(250,000)
Revaluation	(46,637)	-	(46,637)
At 31 March 2023	728,805	949	729,754

Investments at fair value compromise:

	2023	2022
	£	£
Equities	949	949
Securities	728,805	1,025,442
	729,754	1,026,391

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

15. Debtors

	2023	2022
	£	£
Prepayments and accrued income	29,788	60,440
Other debtors	41,942	30,496
	71,730	90,936

16. Creditors: amounts falling within one year

	2023 £	2022 £
Trade creditors	31,193	18,657
Accruals and deferred income	11,100	33,708
Taxation and social security	27,523	1,031
Other creditors	33,641	35,510
	103,457	88,906

17. Fund reconciliation

Unrestricted funds

	Balance at 1st April 2022	Income	Expenditure	Gains / (losses)	Transfers	Balance at 31st March 2023
	£	£	£	£	£	£
Local groups	58,660	114	(4,429)	-	-	54,345
General funds	465,838	599,359	(806,183)	(46,637)	168,732	381,109
Designated funds – Public inquiry	185,850	-	(107,601)	-	-	78,249
Designated funds – Liquidation fund	337,465	-	-	-	(168,732)	168,733
	1,047,813	599,473	(918,213)	(46,637)	-	682,436

17. Fund reconciliation (continued)

Restricted funds

	Balance at 1st April 2022	Income	Expenditure	Transfers	Balance at 31st March 2023
	£	£	£	£	£
Talking Red	-	23,794	(4,576)	-	19,218
Tanner Fund	514	-	(1,450)	1,000	64
Memorial Service	-	644	(644)	-	-
Newly Diagnosed	2,106	34,000	(36,106)	-	-
Ambassadors	-	21,000	-	-	21,000
Booklets	2,266	34,000	(6,380)	-	29,886
Covid Survey	950	-	-	-	950
Youth Camps	21,932	16,588	(25,520)	(13,000)	-
Centre Engagement	16,960	-	(254)	-	16,706
Patient Experience Survey	5,000	-	(5,000)	-	-
Local Groups	9,961	-	(479)	-	9,482
Mental health training for staff	1,562	-	-	-	1,562
Emergency Fund (Ukraine)	2,241	1,171	(3,412)	-	-
Little Bleeders	30,938	1,437	(4,188)	-	28,187
Heamfest	-	420	(13,420)	13,000	-
Community Matters Magazine	-	6,000	(6,000)	-	-
Information Days	-	15,000	(11,872)	-	3,128
WFH Congress	-	15,000	(10,687)	-	4,313
Cut the Cap	-	25,000	(25,000)	-	-
Philip Morris Art Award	7,278	693	-	-	7,971
Howard Abrahams Memorial Award	4,086	706	-	(1,000)	3,792
	105,794	195,453	(154,988)	-	146,259

Endowment Funds

	Balance at 1st April 2022	Income	Expenditure	Transfers	Balance at 31st March 2023
	£	£	£	£	£
Philip Morris Art Award	7,500	-	-	-	7,500
Howard Abrahams Memorial Award	7,500	300	-	-	7,800
	15,000	300	-	-	15,300

Fund descriptions

a) Unrestricted funds

THS is represented throughout the country by local groups. Group funds are incorporated into THS'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. 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 on charity income, the board has designated funds to provide sufficient cover for at least 3 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.

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

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

Covid Survey: Funding to carry out pre & post Covid 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.

Centre Engagement: Funding to help with reengagement with Haemophilia Centres.

Fund descriptions (continued)

Patient Experience: funding to develop and carry out survey to investigate patient experiences of rare bleeding disorders with the aim of identifying areas in which patients can receive greater support.

Local Groups: funding to support development and launch of local groups around the UK to support the activities of THS and Haemophilia Centres.

Mental health training for staff: funding for mental health staff training.

Emergency Fund (Ukraine): help to provide crucial support to those in need during ongoing conflict and humanitarian crisis in Ukraine.

The Haemophilia Society has a partnership with Little Bleeders charity to administer their income and expenditure.

Haemfest: a camping weekend for families with bleeding disorders.

Community Matters: formerly titled HQ, the bi annual magazine for our members.

Information Days: a series of educational days for Talking Red, Von Willebrand's Disorder, Rare and Bleeding Disorders of Unknown Cause and Haemophilia Live.

World Federation of Hemophilia Congress: participation at the biennial international congress which in 2022 took place in Montreal, Canada.

Cut the Cap: a restricted grant from CSL Behring to create a digital awareness campaign

c) Endownment 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.

18. Analysis of net assets between funds

	Unrestricted funds £	Local group funds £	Restricted funds £	Endowment funds £	Total £
Fixed assets	719,626	-	-	15,300	734 ,926
Net current assets	(91,535)	54,345	146,259	-	109,069
Total	628,091	54,345	146,259	15,300	843,995

19. Reconciliation of net expenditure to net cash flow

	2023 £	2022 £
Net expenditure for year	(324,612)	(402,743)
Interest receivable	(24,891)	(35,538)
Depreciation of tangible fixed assets	6,053	7,682
Losses / (gains) on investments	46,637	(30,839)
Decrease in debtors	19,206	90,315
Increase in creditors	14,551	16,353
Net cash flow from operating activities	(263,056)	(354,770)

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 £38,059 (2022: £34,688).

21. Financial commitments

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

	2023 Within 1 year £	2023 Within 1-5 years £	2022 Within 1 year £	2022 Within 1-5 years £
Land and buildings	37,620	25,080	24,200	-
Other	5,151	1,718	5,151	6,869
	42,771	26,798	29,351	6,869

22. Related party transactions

The charity received donations from one trustee during the period totalling £652 (2022: three trustees £1,208).

For more information, please visit our website **haemophilia.org.uk** or contact us on **020 7939 0780** or email **info@haemophilia.org.uk**

If you would like this information in a different format, such as audio tape, braille or large print, or in another league , please speak to our team on **020 7939 0708**.

The Haemophilia Society
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HaemophilaSocietyUK
HaemoSocUK
thehaemophiliasociety

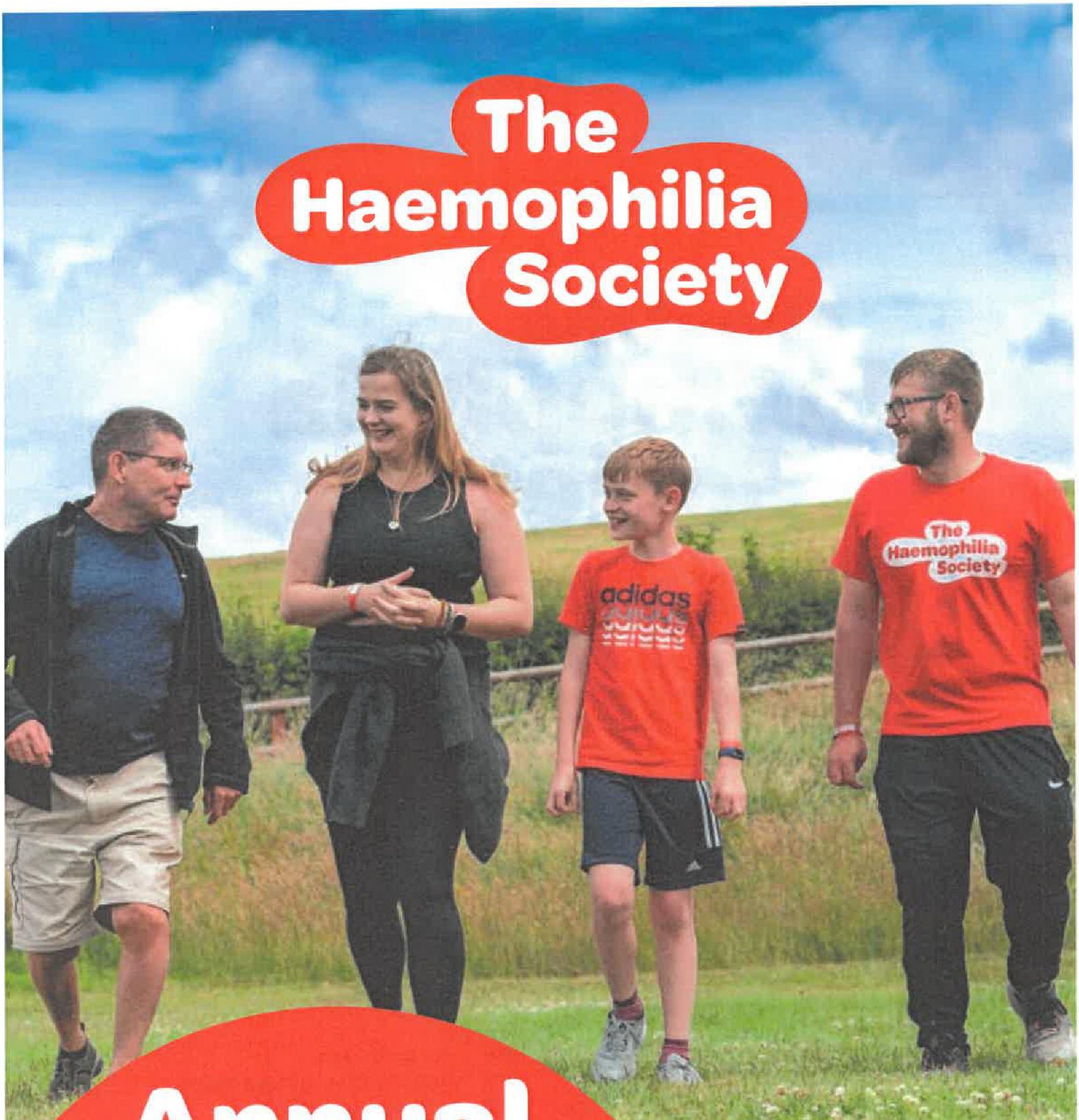
Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia
Chair: Clive Smith
Clive@haemophilia.org.uk
President: Baroness Meacher

Together for life

The Haemophilia Society

Accounts

The Haemophilia Society



Annual report and financial statement 2021/22

Charity registration number: 288260. Scottish charity registration number: SC039732. Company registration number: 01763614

About the Haemophilia Society

We are the only UK-wide charity for everyone affected by a genetic bleeding disorder, and our community is here for you.

At the Haemophilia Society (THS) we want to empower everyone affected by a genetic bleeding disorder to live life to the full, whatever your stage in life.

One in 2,000 men, women and children in the UK have a diagnosed bleeding disorder, which are a group of conditions, including haemophilia and von Willebrand disorder, that result when the blood cannot clot properly. As many as a third of bleeding disorder diagnoses have no known family history and can be the result of a random gene mutation. This means a bleeding disorder diagnosis can come completely out of the blue.

Life after diagnosis may start out hard, but we learn by doing, making mistakes, asking questions and surrounding ourselves with people who understand. Then, slowly, with the right support, it just becomes life again.

Contents

The Haemophilia Society

Welcome from Clive Smith

Chair of our board of trustees

The last financial year has seen a year of change and progress. Building on our previous internal work, the Haemophilia Society went through an important re-branding exercise - the first in over 70 years. This enables us to market ourselves in a more modern way to our community and beyond. We remain very much your organisation and believe this is encapsulated in our new mantra 'together for life'.

Alongside this, more and more face-to-face events have taken place. The first event we had to cancel due to the Covid pandemic was Talking Red Live, for women with bleeding disorders, so it was wonderful to see this return in March 2022 in York. Our regular events such as Youth Camp, Newly Diagnosed Weekends and our carol service have returned. We've also created new events such as Haemfest, a weekend of camping in Derbyshire with activities for all ages.

Our work on treatment and diagnosis continues. We have launched a unique symptom checker, designed to help women and girls get to know the symptoms of a bleeding disorder and encourage them to seek specialist medical advice if needed. The symptom checker received national media coverage and we hope has supported women and girls with bleeding disorders obtaining a diagnosis. We move ever closer to the licensing of gene therapy within both haemophilia A and B. We continue to monitor the safety of such products and are working alongside the NHS to ensure payment models are in place for when these products come to market.

Five years after the Infected Blood Inquiry was announced, the end of its hearings is almost in sight. It is expected to finish taking evidence in 2022 and report in the middle of 2023. It has undoubtedly taken longer than expected and this has taken a great toll on many people involved. At the time of writing, government has announced that interim compensation of £100,000 will be paid to all those currently registered on support schemes. For many, this money is long overdue and much needed. For others, the fact that we are talking about 'compensation' and an acknowledgment of responsibility by government is significant. For those who are not included in this announcement, we will continue to fight until justice is delivered for all our community.

Finally, as ever, my thanks to the staff team and board. I hope that doesn't sound like I take them for granted. I don't. They are the most incredibly hard-working team and a pleasure to work with.

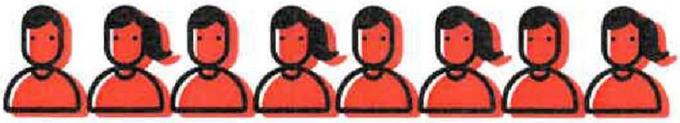
C. Smith

Impact Statistics

April 2021 to March 2022

Our membership

8.7% increase in membership



367 individuals were supported through our events face-to-face

17% of our members support us with a cash donation

Our online community

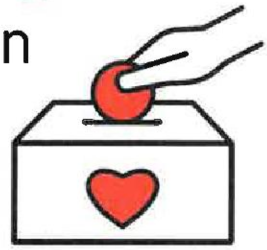
Over 90,000 unique users on our website

23,083 social media engagements

10% increase in new followers on social media

Our fundraisers

4,045 kilometres run and walked



Over £97,000 raised by individual fundraisers


Haemfest 2022 was attended by 140 people

Our supporters

18 ambassadors from the bleeding disorders community

£584,641
raised from fundraisers, members, corporate partners and grant income

Over 2,200
hours given by our volunteers

Our campaigns

Talking Red

Over 111,000
individuals reached as part of our Talking Red awareness campaign

57 meetings with NHS England and NICE, civil servants, ministers, shadow ministers, MPs and peers

Our impact

Over 18,800
people reached

£108,710
investment in advocating for and reporting on the Infected Blood Inquiry

850
women completed our symptom checker to help them seek a diagnosis

Who we are

We exist to support you, and everyone affected by a genetic bleeding disorder in the UK, to enable you to live life well. We are both a charity and a member organisation, founded over 70 years ago.

How we give support

The Haemophilia Society supports the bleeding disorders community by:

- Creating events which share expert knowledge and the chance to meet other people with challenges in common
- Providing in-depth and unique resources. From school days to retirement or factsheets on how to apply for benefits, we offer free access to unparalleled booklets, factsheets and online resources
- Sharing the latest news, whether on gene therapy or the Infected Blood Inquiry, online, via social media, email and in our Community Matters members' magazine
- Campaigning. Together with you, our members, we raise awareness about bleeding disorders and lobby government, the NHS and clinicians for the best possible care and equal access to effective treatment
- Listening to what you, our members, need. We regularly invite feedback and survey our membership to find out their priorities. We also invite members to join working groups to steer our strategy and activity.

Members are at the heart of our work at the Haemophilia Society. Everyone's experiences are different; sometimes the complexity and severity of the bleeding disorders mean having to adapt to the day-to-day challenges. But with access to the right education and support, everyone can have the opportunity to better manage and take control of their lives – making it the best it can be.

Today we have 4,927 members, and a very active community on our social media channels with a combined reach of over one million people. Membership to the Haemophilia Society is entirely free, and so are all the events and services that we provide. This is only possible thanks to the generosity of all our amazing supporters, thank you.

"Henry is now a member of a local archery club and regularly goes shooting at the weekend. I'd say it was thanks to haemophilia! And events from the Haemophilia Society." Carreen.

Our promise

Our aim is to 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 Haemophilia Society's trustees have paid due regard to the Charity Commission guidance on public benefit when reviewing the charity's objectives and activities.

In addition, as part of our work in 2021 to revitalise THS's 70-year-old brand, which involved consultation with member focus groups, trustees and staff, a new vision, mission and values were agreed for the organisation:

- Our **vision** is that anyone affected by a bleeding disorder has the opportunity to live a fulfilled life
- Our **mission** is to support each other, raise awareness and advocate on what matters to our community
- Everything we do is underpinned by our three **values**; we always strive to be empowering, compassionate and resilient.

> **"Can't thank you enough for having us, it's been great to meet so many other families in the same position. Very informative, supportive, and the youth ambassadors are a credit to the society.**
>
> **If anybody is considering joining a future event, you won't regret it!"**
>
> **Simone, Newly Diagnosed Weekend attendee.**

In 2022 we have also set out themes to underpin THS's three-year strategy and enable us to better evaluate and report back on our progress. We identified five key themes for our ambitions: youth support, Talking Red – our focus on women with bleeding disorders, health and wellbeing, community support and advocacy.

In the next section you can see how our work is delivering on each of these key themes.

What we do

Youth support

THS is here for everyone, for whatever stage of life you are at. This could mean giving parents somewhere to turn in the first few months after their child's diagnosis or giving young people the rare chance to meet in person and gain support from their peers. Our youth support programme encompasses this and more.

> **"Had the best time this weekend. Thank you so much for providing such a fabulous event! It has been amazing to meet so many other lovely families going through the same as us as well as the youth ambassadors too.**
>
> **"All the information has really helped us understand our son's condition more and really reassured us that we have so much support around us healthcare wise and also through the Haemophilia Society."**
>
> **Danielle, NDW attendee.**

Our Newly Diagnosed Weekends (NDWs) provide families with expert advice, invaluable peer support, and a safe space to ask questions in the very early stages of diagnosis. THS Youth Ambassadors also attend these events, sharing their experiences and bringing positivity to families who may feel uncertain about their child's future.

We have held three NDWs in various locations across the country this past year, all free to members and reaching 35 families. NDWs are always fully subscribed and have waiting lists. We are proud of the overwhelmingly good feedback that we receive for these events, which demonstrates that our work is making a difference. 100% of parents who completed post-event evaluation forms say they now understand their child's condition much better.

Meanwhile, our annual Youth Camp, which is free to members, took place in July 2021 and as usual booked up very quickly with over 40 participants. The camps allow children and young people affected by bleeding disorders and their siblings the freedom to be themselves in a safe environment, surrounded by people who understand their challenges. They also learn a host of new activities and outdoor skills, and make friends with other young people who know what it's like to be affected by bleeding disorders.

We are proud that we consistently receive excellent feedback on our Youth Camps from both the young people taking part, and their parents or guardians.

> **"My boys had a brilliant time and came home with lots of stories of all the fun they had. Thank you to everyone volunteering or behind the scenes that made this happen."**
>
> **Sarah, talking about Youth Camp**

Youth Ambassadors are also part of our youth support programme. We are very grateful to the 12 young men and women who have volunteered to be Youth Ambassadors for THS in the last year, supporting the community and helping to raise awareness more widely. They are amazing mentors and role models who have a presence at all our events and provide a reassuring and inspiring voice on social media. Feedback also regularly reveals how much parents appreciate their advice.

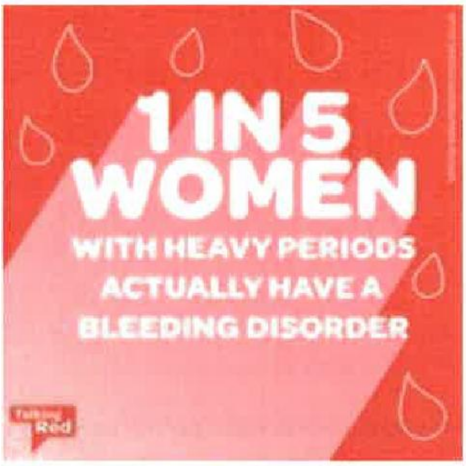
As the next generation who will be pushing for better care for people with bleeding disorders, we are proud to empower our Youth Ambassadors to advocate on a wider stage. Conferences and platforms that some have attended this year include the World Federation of Hemophilia Congress in Canada, the European Haemophilia Consortium (EHC) Youth Leadership Board and EHC's conference on Women and Bleeding Disorders.

Several Youth Ambassadors also received professional training this year to allow them to make the most of social media for THS, such as how to create films and stories. In addition, we worked with two of our Youth Ambassadors and were supported by pharmaceutical companies Roche and Chugai to launch two videos with online platform LADbible. The videos took a very creative approach to help bust myths around living with haemophilia, hitting 9.7 million impressions across the campaign and with over 71,000 people engaged with the content across Facebook and Instagram.

"It's great to be here and make new friends. Apart from my mum and baby brother, I don't know anyone else with haemophilia, so it's a been really good because now I know loads!" Olivia, at Youth Camp, third from left.

Talking Red

Talking Red is THS's campaign to raise awareness about women and girls with bleeding disorders, who often struggle to be diagnosed and properly supported. It is estimated that 35,000 women in the UK today are living with an undiagnosed bleeding disorder and therefore not receiving the care that they need and deserve. Talking Red also brings together women and girls to share knowledge and their experiences.



Bespoke, impactful graphics were designed for the social media campaign.

In November 2021 we ran a campaign to promote our new Talking Red Symptom Checker to encourage women and girls with heavy menstrual bleeding to consider whether this and other symptoms might be caused by an underlying bleeding disorder. Through national newspapers and social media, we encouraged women to complete a simple online symptom checker; a tool designed and created by THS in conjunction with our sponsors and reviewed by our Medical and Scientific Advisory Group . The symptom checker guides users through the most common indicators and offers further information, empowering women and girls to have the confidence to seek specialised medical advice.

"I'd never met another woman with haemophilia until last month, and I'm 26! I'm really looking forward to the Talking Red Live event to get more involved and meet more women like me." Catherine.

During the campaign we reached over 125,000 people on social media, and hundreds of thousands more by persuading major news sites to feature our case studies and story, including the Mail on Sunday and The Sun Online. Since the launch our symptom checker web pages have been used by over 3,000 people.

We also held our Talking Red Live event once again, this time in York. Over 40 people joined us in person for the day-long event. As well as expert talks, we held several focus groups to understand which issues our attendees considered important, such as managing heavy bleeding in the workplace and the psychological impact of having a bleeding disorder. Once again at this event, attendees warmly welcomed the opportunity to talk to others with similar issues and feedback was very positive.

Meanwhile our 15-person Women's Working Group which comprises members and trustees met four times, and helped shape our symptom checker campaign and future plans for Talking Red.

Health & Wellbeing

We want everyone with a bleeding disorder to feel empowered to live life to the full, and of course, good health and wellbeing is key. As the only UK-wide charity for everyone affected by a genetic bleeding disorder, we have a vital role in producing the kinds of detailed, independent, specialist resources that are very hard to find elsewhere, to give people the confidence and understanding that they need to manage their condition well.

A remarkable 6,000+ booklets providing specialist health information and reassuring advice were given out by THS this year. As well as our versions in English we also have translations in Arabic, Urdu, Welsh and Polish. Booklets were sent to schools, hospitals, centres, shared at conferences and other relevant events, and crucially, sent directly to you, our members, and people affected by bleeding disorders. There were also 1,710 downloads of our publications and factsheets this year.

New booklets written and produced by THS this year included 'Girls Living with Bleeding Disorders' and 'Women Living with Bleeding Disorders', which have been very well received. Several booklets were also updated, including 'Understanding VWD', and our booklet written for families with school age children which is also ideal for sharing with schools. A new booklet about gene therapy is also soon being published. All our publications are reviewed by our 11-person strong Clinical Advisory Group, comprising many renowned clinicians.

In addition, many more people visit our site for information and advice than are members of THS. This year we had 90,398 visitors to our new-look website with 233,100 page views.

Scott, our newly appointed Mental Health Ambassador.

We have also revamped our members magazine to make it more engaging, and health and wellbeing articles now form a key part of the magazine's mix, making it another useful source of advice.

To enable our staff to better support members, four staff and all our youth ambassadors were this year trained in mental health first aid. We also appointed one of our former Youth Ambassadors as a fully-trained Mental Health Ambassador, so that he is able to offer support and advice. He has also been able to give talks at our events this year about the importance of good mental health. Two members of staff were also trained in first aid, to support our events.

Community Support

From diagnosis to treatment, to acceptance and normality, living with a bleeding disorder can be a roller coaster. It impacts on every aspect of your life; personal, professional, and social. That's why THS strives to bring together people affected by bleeding disorders as a community so that they can support each other, and works to support and drive a more engaged and healthy bleeding disorders community in the UK.

This year we have made our membership services more efficient, including investing in a new data system that will mean that we can give members, with all their varied interests and experiences, more tailored information. We have also launched membership cards and improved the welcome journey for new members.

We are also keen to support members and affiliated members such as nurses and physios to start forming support networks in their area. To make this easier, this year we have produced a step-by-step guide with all the information that you need to get started. We hope to send out many more of these packs in the coming year. As we have started to visit centres in person again, we are planning joint events to engage local communities.

> **"Thank you so much for a truly amazing weekend. Was very informative and lots of fun."**
>
> **Hollie, talking about Haemfest.**

"Being a member, I've made friendships with people who I might never normally meet, people who are facing some of the same challenges as me." Val, right, with members of the Lincolnshire and East Midlands Local Group.

It has also been fantastic to be able to bring our community back together in person once again, especially as lockdown prompted us to think what we could do differently to make events more appealing and useful for you. Our 2021 AGM was a hybrid event which could be watched from home or attended in person.

Haemfest, in June 2022, was a brand-new event with lots of fun activities for all ages, conceived to appeal to a sector of our community that might not usually come to events. This camping weekend in Derbyshire was enjoyed by 140 people, and we received very positive feedback. The event was also designed to appeal to non-members, but it is still proving challenging to promote our activities beyond our usual audience, which is very much a key aim for THS in the coming year.

We also held our Christmas Carol Service and our Service of Thanksgiving and Remembrance in 2021. Despite concerns over the prevalence of Covid these events were very well-attended in person, especially our Service of Thanksgiving and Remembrance where we are able to spend time reflecting those lives that were tragically lost through contaminated blood products.

Visit to Royal London Hospital for World Haemophilia Day 2022.

Advocacy

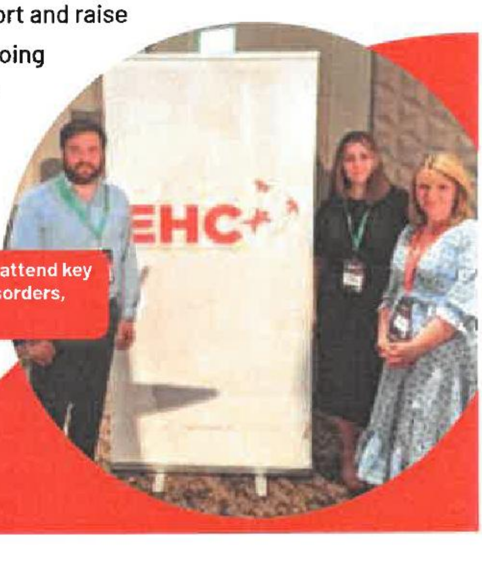
From advocating for higher standards of care and equal access to effective treatment, to campaigning for local issues, THS is here to raise awareness about bleeding disorders and seek to influence decision makers on behalf of people affected by bleeding disorders. Our advocacy work is always ongoing in the background, looking for opportunities to raise issues that matter to you.

The National Institute for Health and Care Excellence (NICE) and NHS England began their consideration of whether to approve the use of gene therapies for haemophilia. We have served on NHS England's Clinical Reference Group and were involved with the scoping exercise for the first gene therapy coming to market. We also represented our members on the tender processes for blood products, factor and the new home delivery provider, ensuring new products became available and people have greater choice of treatment and treatment delivery.

We continue to be the secretariat to the All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood through which we've worked with 41 MPs and members of the House of Lords. In the last year we have had six meetings of the APPG where we have been able to campaign for compensation and raise issues with the contaminated blood support schemes. In addition to our ongoing work with the infected blood support schemes we have had two meetings with Labour shadow ministers in Westminster, attended party-political conferences and met with Department of Health and Social Care officials. This work has seen big changes to the support people receive and the first compensation payments now set to be made before the end of 2022.

> **"Thank you for your commitment to providing daily updates on evidence at the Infected Blood Inquiry. They allow me to follow what's happening which I find invaluable."**
>
> **Colin, whose father died as a result of the contaminated blood scandal.**

The enormous importance of the Infected Blood Inquiry for our community is reflected in the work of our Public Inquiry Team which is dedicated to providing support, information and advice about its hearings and issues arising from it. We offer daily updates on inquiry evidence, manage a supportive and private Facebook group for those infected and affected and are always available to give advice on accessing financial and psychological support as well as how to participate in the inquiry process. On the wider political stage, we campaign on issues such as improving financial support and raise awareness about the ongoing and significant impact of this treatment disaster today.

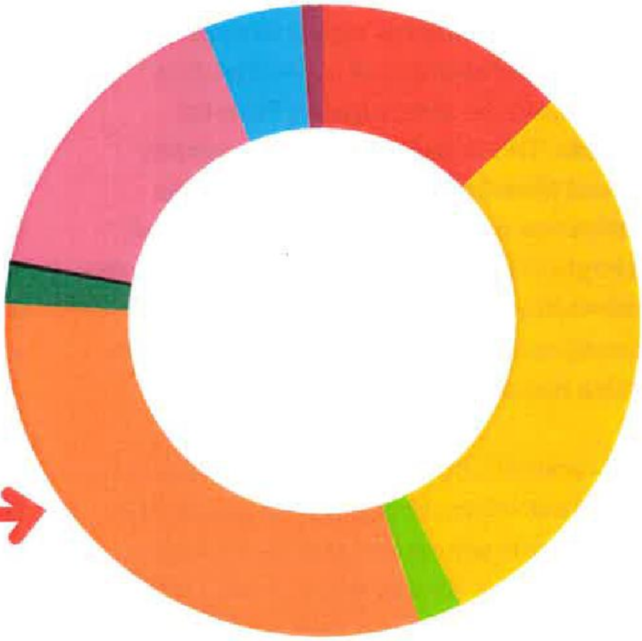


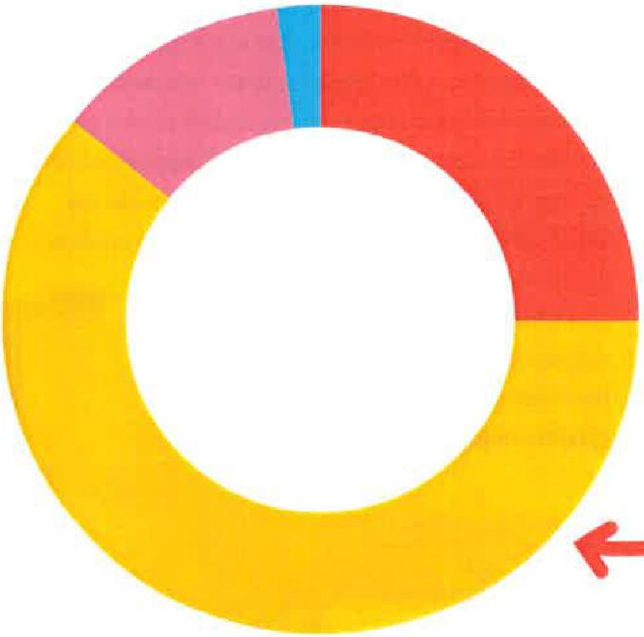
Staff, trustees and members attend key events related to bleeding disorders, representing THS members.

How we manage your money

Income Composition 2021-2022

🟥	Donations from individuals	13%
🟨	Legacies	30%
🟩	Grants and trust income	2%
🟧	Corporate income	31%
🟩	Gift Aid	2%
⬛	Local group activities	0.3%
🟪	Community fundraising and events	15.7%
🟦	Interest - fixed interest securities	5%
🟫	Other	1%





Charitable Activities Expenditure 2021-22

🟥	Campaigning & Communications	25%
🟨	Events & Membership Services	61%
🟪	Public Inquiry	12%
🟦	Grants Awarded	2%

Fundraising and partnerships

We are grateful to have such dedicated partners who help us to support our members and the wider bleeding disorders community. From charitable trusts, corporate partners, volunteers, and professional cyclists, their generosity helps us to continue to deliver our core services for our members.

Trusts and Foundations

We continue to strengthen our relationships and grow support from trusts and foundations to fund our ongoing project delivery. We have built a robust pipeline of funding opportunities and are committed to further strengthening our partnership with our funders to support continued growth.

Corporate Partners

We receive ongoing support from partners in the pharmaceutical and private sectors, which ranges from sponsorship of member events, charitable grants, and gifts of pro bono support.

Thank you to CSL Behring, Novo Nordisk, Roche-Chugai, Sanofi, SOBI and Takeda for their support in 2021-2022 and beyond.

We would also like to thank PwC and HCD Economics for their technical expertise, and Bird & Blend Tea Co for supporting our Bloody Good Brew fundraiser.

Volunteers

We also benefit 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.

Alex Dowsett and Little Bleeders

We were incredibly excited when professional cyclist and THS member Alex Dowsett jointly raised money for us and his own Little Bleeders charity through his attempt to break the world record for longest ever distance covered on a cycling track in 60 minutes. Alex is the only known elite sportsperson with haemophilia A to compete in an able-bodied field, and his exceptional performance made a huge impact in supporting the work we do with young people with bleeding disorders.

"This is my small way of trying to bring awareness to the haemophilia community, as well as hopefully inspiring a generation of people with haemophilia to reconsider their limitations and what's possible with what was once a very debilitating condition." Alex Dowsett, founder of Little Bleeders.

What we'll do next from Kate Burt

Chief Executive

The financial year 2021-22 was a challenging one for the charity sector as we emerged into a post-pandemic world. Looking forward, we must be ever more resourceful and agile to ensure that we continue to survive and thrive in this difficult financial climate.

I am extremely grateful to our members and supporters who give so generously in recognition of the support and advocacy provided by THS. In tough times it is crucial to strengthen our community and to work hard to ensure that the choices and voices of people living with a bleeding disorder are heard.

It has been a joy to see our community together again, and the success of our first Haemfest event in June 2022, which brought together members from around the UK for a weekend of outdoor activities and workshops, shows the importance of companionship and shared experience. Our popular Newly Diagnosed Weekends, Youth Camp and Talking Red Live, our focus on women with bleeding disorders, will also help to forge lasting connections and friendships.

This year we are introducing three new one-day events dedicated respectively to von Willebrand disorder (VWD), rare and unclassified disorders and haemophilia as we adapt to stay relevant and useful. These will replace the format of a one-day annual conference.

Behind the scenes, we are working to influence and improve the quality of care and treatment for our community and continue to support the All-Party Parliamentary Group for Haemophilia and Contaminated Blood, a crucial platform for our advocacy at Westminster. We are also improving our engagement with haemophilia centres to ensure there's a constructive flow of information between us.

Mindful of connecting with all our members, young and old, we are improving communication through our social media channels and are looking to produce more information in video format.

The year ahead will see the conclusion of the Infected Blood Inquiry which we hope will finally deliver truth and justice to those who have suffered for so long. Thanks to sustained pressure, the government has finally accepted the case for interim compensation, but we need to ensure that all those infected and affected receive full and fair compensation. Our campaign and support work for the contaminated blood community will continue long into the future.

We are living in uncertain and volatile times. The demand for our services has never been higher but we face some of the most challenging fundraising conditions in our history. I am determined to ensure that THS is there to support the next generation of the bleeding disorder community. With your help, we are together for life.

Kate Burt

A big thank you

Everything we do is because of you.

The individual donations and legacies that we receive from the public and our enthusiastic fundraisers, and the contributions from our partners, large and small, makes everything that we do possible.

We'd also like to extend a massive thank you to our trustees, volunteers and members for their commitment to THS and the work we do to reach everyone in the UK with a genetic bleeding disorder.

Thanks to your donations, all our events are free to our members.

Our governance

We work hard to set the highest standards as an organisation. Our policies and procedures reflect our values and we designed them to help us keep to those standards. We communicate them to our employees and volunteers and give everyone the training they need to uphold them. We also record our decisions and incidents, monitor our performance, and gather feedback to help us learn and improve.

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.

Administration and legal details

Who we are

President	Baroness Meacher
Chief Executive	Kate Burt
Board of Trustees	Clive Smith - Chair Conan McIlwrath - Vice Chair Susan Stretch - Vice Chair Gordon Dixon Sonia O'Hara Paul Sartain Joanne Traunter Anna Geffert Natalie Lawson Amy Owen-Wyard Rayaz Ali Chel

Subcommittees	
Finance & Risk Committee	Gordon Dixon - Chair
	Clive Smith
	Conan McIlwrath
	Susan Stretch
	Rayaz Ali Chel
Nominations Committee	Gordon Dixon
	Clive Smith
Public Inquiry Committee	Clive Smith – Chair
	Barry Flynn
	Eileen Ross
	Paul Sartain
	Conan McIlwrath
	Susan Stretch
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 Sutherland 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

Trustees' report

The trustees present their report and the audited financial statements of the charity for the year ended 31 March 2022. 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 (effective 1 January 2019).

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:

Financial review

Income and expenditure overview

The charitable sector was hit hard by the double whammy of continuing Covid restrictions for the first half of this financial year and the emerging cost-of-living crisis. The Haemophilia Society, like many others, has felt the impact of this in loss of income from events and a drop in individual giving, as our members feel the squeeze on their own budgets.

These challenges make it more important than ever that we focus on efficiency and ensuring that we offer our members a relevant and useful service while doubling down on achieving diverse and reliable funding sources.

We look to the future with optimism and have chosen this year to invest in two projects which are essential in placing us at the forefront of an increasingly competitive charitable sector. Firstly, we have completed an impactful rebrand for the first time in our 70-year history, and secondly, we invested in a new platform to record data and organise information to help us communicate more efficiently with members and healthcare professionals. We've also expanded our fundraising team.

Overall, we have generated a loss for the year of £433,582 (before the impact of gain on investments), which resulted in a significant reduction of reserves. This figure includes the planned investment in the brand and data management systems, as described above.

Income (including legacies) for FY22 has dropped by 8% from £814,955 in FY21 to £749,428 in FY22, which resulted in £65,527 loss of income. The most significantly affected area was our corporate income which reduced by 28%, resulting in a loss of £87,916 corporate income. This remains a key area of focus for the team and our corporate supporters have continued to provide us with substantial backing however Covid has impacted the level of income we received in FY 22.

Legacy income received of £227,459 FY22 has increased by 3% compared with the previous year (£220,294 in FY21). Given the nature of legacies, there will always be a large variance on a yearly basis. We are grateful to all our members who remember THS in their will.

We could no longer apply for government grants, which were available in the previous year through the Job Retention scheme, where we claimed £14,090. However, we were very fortunate to benefit from a joint event run with Alex Dowsett and his Little Bleeders charity, which has raised £61,875 in total to be shared between both charities. Of the £61,875 raised, £30,938 has been included in a restricted fund as this is to be shared with the Little Bleeders charity and will be transferred to them in FY23.

Due to restrictions imposed by Covid in 2020-21, we postponed some events, which resulted in deferring some of our income and expenditure to this financial year, mostly this relates to restricted income received from companies. Expenditure on charitable activities went up from £656,298 in FY21 to £895,835 in FY22.

The Infected Blood Inquiry continued this year and therefore so did our work to support our members and keep them up to date with inquiry evidence and related issues. This incurred costs of £108,710.

We continued our support of the World Federation of Hemophilia's Cornerstone initiative to ensure all people with inherited bleeding disorders have access to care, regardless of their type of disorder, their gender, or where they live. In total we paid £45,000 over three years towards this project.

Overall costs in FY22 were £1,183,010. This is against a total income of £749,428, representing a deficit of £433,582 before net (losses)/gains on investments.

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

Reserves

Covid 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 designate £337,465 to create a liquidation fund to cover at least six months of running costs.

THS reserves on 31/03/22 stood at £1,168,607, a decrease of £402,743 from the prior year, due to decrease in income due to continued Covid impacts and challenging economic environment and significant investment made in re-branding costs and new CRM database system implementation.

In recognition of the significant financial and general resource impact of the ongoing Infected Blood Inquiry, the board in 2019 designated £600,000 of reserves to fund the charity's work in this area. In the combined years to date we have spent £414,150 of the designated funds leaving a balance of £185,850 to cover costs until the end of the inquiry. Designated funds are reviewed annually to ensure the appropriate use of reserves.

As of 31 March 2022, unrestricted general reserves (including designated funds but excluding local group funds) stood at £989,153. As noted, the board of trustees continually reviews potential opportunities to invest for the good of THS, 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 FY22 our funds had a market value of £1,026,391.

Key risks and uncertainties

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

Financial

As described above we are operating in a challenging financial environment and planning to focus our income generating strategy on building trust and foundation relationships as well as increasing and diversifying our corporate partnerships.

Reputation

The Infected Blood Inquiry's final report and recommendations are expected in 2023. As part of its Terms of Reference, the inquiry has examined the work of THS over a 40-year period and we would expect this to be set out in its final report.

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

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 Haemophilia Society)
- one honorary chair
- 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 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.

On behalf of the board

C. Smith

Clive Smith, Chair

Date:.....07/12/2022............................

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 2022 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 2022 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 auditors 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 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 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. 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 non-compliance. 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 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.

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

Date: 08 December 2022

Statement of financial activities

(including income and expenditure account)

Year ended 31 March 2022

		2022				2021
	Note	Unrestricted funds £	Restricted funds £	Endowment funds £	Total £	Total £
Income and endowments from:						
Donations and legacies	2	391,600	192,791	250	584,641	657,323
Charitable activities	3	54,138	66,121	-	120,259	76,691
Investments	4	34,467	1,071	-	35,538	41,577
Other		8,790	200	-	8,990	39,364
Total income and endowments		488,995	260,183	250	749,428	814,955
Expenditure on:						
Raising funds	5	201,704	85,471	-	287,175	115,220
Charitable activities	6	675,910	219,925	-	895,835	656,298
Total expenditure		877,614	305,396	-	1,183,010	771,518
Net (losses) / gains on investments		30,839	-	-	30,839	111,609
Net income / (expenditure)	9	(357,780)	(45,213)	250	(402,743)	155,046
Transfers between funds		-	-	-	-	-
Net movement in funds		(357,780)	(45,213)	250	(402,743)	155,046
Reconciliation of funds:						
Total funds brought forward		1,405,593	151,007	14,750	1,571,350	1,416,304
Total funds carried forward		1,047,813	105,794	15,000	1,168,607	1,571,350

All income and expenditure derive from continuing activities.

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

Balance Sheet

Year ended 31 March 2022

	Note	2022 £	2021 £
Fixed assets			
Tangible assets	13	9,189	11,084
Investments	14	1,026,391	1,395,552
		1,035,580	1,406,636
Current assets			
Debtors	15	90,936	181,251
Cash at bank and in hand		130,997	56,016
		221,933	237,267
Creditors: amounts falling due within one year	16	(88,906)	(72,553)
Net current assets		133,027	164,714
Net assets		1,168,607	1,571,350
Charity funds			
Endowment funds	17	15,000	14,750
Restricted funds	17	105,794	151,007
Unrestricted general funds	17	465,838	715,802
Local group funds	17	58,660	57,766
Designated funds	17	523,315	632,025
Total charity funds	18	1,168,607	1,571,350

The financial statements were approved and authorised for issue by the board on 07/12/2022
Signed on behalf of the board of trustees

C. Smith

Clive Smith, Chair

The notes on pages 34 to 49 form part of these financial statements.
Company registration number: 01763614

Statement of cash flows

Year ended 31 March 2022

	Note	2022 £	2021 £
Net cash flow from operating activities	19	(354,770)	(84,448)
Cash flow from investing activities			
Payments to acquire tangible fixed assets		(5,787)	(3,005)
Net cash flow from sale and purchase of fixed asset investments		400,000	(100,000)
Interest received		35,538	41,577
Net cash flow from investing activities		429,751	(61,428)
Net increase / (decrease) in cash and cash equivalents		74,981	(145,876)
Cash and cash equivalents at 1 April 2021		56,016	201,892
Cash and cash equivalents at 31 March 2022		130,997	56,016

	2022 £	2021 £
Cash and cash equivalents consists of:		
Cash at bank and in hand	130,997	56,016
Cash and cash equivalents at 31 March 2022	130,997	56,016

Notes to the financial statements

Year ended 31 March 2022

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 20 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.

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

1 Summary of significant accounting policies (continued)

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.

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:

1 Summary of significant accounting policies (continued)

- 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 (page 40).

(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.

1 Summary of significant accounting policies (continued)

(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. THS's contributions to these schemes are charged to the SoFA in year in which they arise.

(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.

1 Summary of significant accounting policies (continued)

(o) Going concern

The Trustees recognise that in the current economic climate, income has declined, and expenditure cannot continue as originally projected based on the income growth. We have put in place a three-stage mitigation plan to cut overheads cost by 20%, 15% and 8% each stage. The Trustees have considered the level of funds held and the expected level of income and expenditure, together with execution of the mitigation plan for 12 months from authorising these financial statements. Based on the projected cash flow information for 12 months from the date of approval of these financial statements, taking into consideration the estimation of the continued impact of Covid resources available, 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. The Trustees' decision was supported by incorporating the three-stage mitigation plan with a future cost cutting plan if the charity was faced with further income shortfall.

2 Income from donations and legacies

	2022 £	2021 £
Donations from individuals	97,096	100,365
Legacies	227,459	220,294
Grants and trust income	14,050	6,700
Corporate income	230,414	318,330
Gift Aid	15,622	11,634
	584,641	657,323

Income from donations and legacies includes £192,791 (2021: £274,380) attributable to restricted funds, £391,600 (2021: £382,318) attributable to unrestricted funds, and £250 (2021: £625) attributable to endowment funds.

3 Income from charitable activities

	2022 £	2021 £
Local group activities	2,384	4,526
Community fundraising and events	117,875	72,165
	120,259	76,691

Income from charitable activities includes £66,121 (2021: £3,750) attributable to restricted funds, and £54,138 (2021: £72,941) attributable to unrestricted funds.

4 Income from investments

	2022 £	2021 £
Interest - fixed interest securities	35,538	41,577
Interest - deposits	-	-
	35,538	41,577

Income from investments includes £1,071 (2021: £934) attributable to restricted funds, and £34,467 (2021: £40,643) attributable to unrestricted funds.

5 Analysis of expenditure on raising funds

	2022 £	2021 £
Direct costs	120,921	32,337
Support costs	166,254	82,883
	287,175	115,220

£85,471 (2021: £28,868) of the above costs were attributable to restricted funds. £201,704 (2021: £86,352) 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	88,369	-	92,708	181,077
Membership	14,208	-	20,068	34,276
Services	171,971	-	343,091	515,062
Advocacy and influencing	2,467	-	37,243	39,710
Corner stone project	16,000	-	-	16,000
Public inquiry	4,451	-	104,259	108,710
Tanner Fund grants	-	1,000	-	1,000
	297,466	1,000	597,369	895,835

£219,925 (2021: £121,824) of the above costs were attributable to restricted funds. £675,910 (2021: £534,474) of the above costs were attributable to unrestricted funds.

7 Allocation of support costs

Support cost 2022	Basis of allocation	Raising funds	Charitable activities	Total
	£	£	£	£
Governance	% of direct costs	3,758	9,275	13,033
Travel, postage and carriage	% of direct costs	1,113	3,581	4,694
Information technology	% of direct costs	5,255	12,971	18,226
Salary costs	% of staff time	120,298	483,103	603,401
Depreciation	% of direct costs	2,215	5,467	7,682
Office costs (incl. rental)	% of direct costs	12,511	30,881	43,392
Recruitment, training and temp staff	% of direct costs	8,084	19,954	28,038
Other expenses	% of direct costs	13,020	32,137	45,157
Total		166,254	597,369	763,623

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
Total		82,883	490,580	573,463

8 Governance costs

	2022 £	2021 £
Trustee expenses	4,153	110
Auditors' remuneration - current year	8,880	8,460
Auditors' remuneration - prior year	-	-
Other expenses	-	280
	13,033	8,850

9 Net income / (expenditure) for the year

Net income / (expenditure) is stated after charging:

	2022 £	2021 £
Government grants	-	14,090
Depreciation of tangible fixed assets	7,682	7,530
Operating lease rentals	39,272	39,453
Auditors' remuneration	8,880	8,460

Government grants of £nil (2021: £14,090) relates to amounts received from the job retention scheme claimed by the charitable company for staff that were furloughed due to Covid. 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.

10 Auditor's remuneration

	2022 £	2021 £
Fees payable to the charitable company's auditor's for the audit of the charitable company's annual accounts	8,880	8,460

11 Trustees' and key management personnel remuneration and expenses

The trustees neither received nor waived any remuneration during the year (2021: £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 £101,106 (2021: £98,053).

The reimbursement of trustees' expenses was as follows:

	2022 Number	2021 Number	2022 £	2021 £
Travel, subsistence and accommodation	9	2	2,299	138

Included in trustees' expenses was £861 (2021: £43) 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:

	2022 Number	2021 Number
	13	9

The total staff costs and employee benefits was as follows:

	2022 £	2021 £
Wages and salaries	520,482	400,174
Social security	48,231	34,703
Defined contribution pension costs	34,688	24,233
	603,401	459,110
Recruitment and training	20,495	5,326
	623,896	464,436

12 Staff costs and employee benefits (continued)

Two employees received emoluments of more than £60,000 during the year ended 31st March 2022 (2021: one) and within the following bands:

	2022	2021
£60,000 - £70,000	1	1
£70,001 - £80,000	-	-
£80,001 - £90,000	1	-

13 Tangible fixed assets

	Computers and Office Equipment 2022 £
Cost:	
At 1 April 2021	93,294
Additions	5,787
At 31 March 2022	99,081
Depreciation:	
At 1 April 2021	82,210
Charge for the year	7,682
At 31 March 2022	89,892
Net book value:	
At 31 March 2022	9,189
At 31 March 2021	11,084

14 Fixed asset investments

	COIF Investment £	Other Investment £	Total £
Cost or valuation			
At 1 April 2021	1,394,603	949	1,395,552
Additions	-	-	-
Disposals	(400,000)	-	(400,000)
Revaluation	30,839	-	30,839
At 31 March 2022	1,025,442	949	1,026,391

14 Fixed asset investments (continued)

Investments at fair value compromise:

	2022 £	2021 £
Equities	949	949
Securities	1,025,442	1,394,603
	1,026,391	1,395,552

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

15 Debtors

	2022 £	2021 £
Prepayments and accrued income	60,440	151,044
Other debtors	30,496	30,207
	90,936	181,251

16 Creditors: amounts falling due within one year

	2022 £	2021 £
Trade creditors	18,657	21,722
Accruals and deferred income	33,708	24,110
Taxation and social security	1,031	15,092
Other creditors	35,510	11,629
	88,906	72,553

17 Fund reconciliation

Unrestricted funds

	Balance at 1st April 2021 £	Income £	Expenditure £	Gains / (losses) £	Transfers £	Balance at 31st March 2022 £
Local groups	57,766	2,384	(1,490)	-	-	58,660
General funds	715,802	486,611	(767,414)	30,839	-	465,838
Designated funds - Public inquiry	294,560	-	(108,710)	-	-	185,850
Designated funds - Liquidation fund	337,465	-	-	-	-	337,465
	1,405,593	488,995	(877,614)	30,839	-	1,047,813

Restricted funds

	Balance at 1st April 2021 £	Income £	Expenditure £	Transfers £	Balance at 31st March 2022 £
Talking Red	6,476	10,000	(12,419)	(4,057)	-
Tanner Fund	1,514	-	(1,000)	-	514
Memorial Service	943	505	(1,448)	-	-
Newly Diagnosed	16,381	33,073	(47,348)	-	2,106
AGM	-	15,000	(15,000)	-	-
Ambassadors	14,733	-	(14,733)	-	-
Booklets	16,503	2,588	(16,825)	-	2,266
Factsheets	1,500	-	(1,500)	-	-
Covid Survey	15,511	-	(14,561)	-	950
Youth Camps	26,353	32,291	(36,712)	-	21,932
Hour Record	33,287	43,171	(76,458)	-	-
Journal Subscription	-	1,125	(1,125)	-	-
Checklist	587	-	(4,644)	4,057	-
Website	2,412	10,000	(12,412)	-	-
Centre Engagement	3,514	15,000	(1,554)	-	16,960
Patient Experience Survey	-	20,000	(15,000)	-	5,000
Local Groups	-	20,000	(10,039)	-	9,961
CRM	-	20,000	(20,000)	-	-
Mental health training for staff	-	2,000	(438)	-	1,562
Emergency Fund (Ukraine)	-	2,268	(27)	-	2,241
Little Bleeders	-	32,091	(1,153)	-	30,938
Philip Morris Art Award	6,738	540	-	-	7,278
Howard Abrahams Memorial Award	4,555	531	(1,000)	-	4,086
	151,007	260,183	(305,396)	-	105,794

17 Fund reconciliation (continued)

Endowment Funds

	Balance at 1st April 2021 £	Income £	Expenditure £	Transfers £	Balance at 31st March 2022 £
Philip Morris Art Award	7,500	-	-	-	7,500
Howard Abrahams Memorial Award	7,250	250	-	-	7,500
	14,750	250	-	-	15,000

Fund descriptions

a) Unrestricted funds

THS is represented throughout the country by local groups. Group funds are incorporated into THS 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 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.

17 Fund reconciliation (continued)

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

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

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

Factsheets: Funding for translation of Rare Disease Factsheets.

Covid Survey: Funding to carry out pre & post Covid 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 of Alex Dowsett, a professional cyclist who has haemophilia, 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.

Patient Experience: Funding to develop and carry out survey to investigate patient experiences of rare bleeding disorders with the aim of identifying areas in which patients can receive greater support.

Local Groups: Funding to support development and launch of local groups around the UK to support the activities of THS and Haemophilia Centres.

CRM: To support delivery of a new CRM system and internal infrastructure.

Mental health training for staff: Funding for mental health staff training.

17 Fund reconciliation (continued)

Emergency Fund (Ukraine): Help to provide crucial support to those in need during ongoing conflict and humanitarian crisis in Ukraine.

Little Bleeders: 50% of funding collected in joint event with Little Bleeders Charity. This should be distributed to Little Bleeders Charity in 2022/23.

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.

18 Analysis of net assets between funds

	Unrestricted funds	Local group funds	Restricted funds	Endowment funds	Total
	£	£	£	£	£
Fixed assets	1,020,580	-	-	15,000	1,035,580
Net current assets	(31,427)	58,660	105,794	-	133,027
Total	989,153	58,660	105,794	15,000	1,168,607

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

	2022 £	2021 £
Net (expenditure) / income for year	(402,743)	155,046
Interest receivable	(35,538)	(41,577)
Depreciation of tangible fixed assets	7,682	7,530
Losses / (gains) on investments	(30,839)	(111,609)
Decrease / (increase) in debtors	90,315	(96,646)
Increase in creditors	16,353	2,808
Net cash flow from operating activities	(354,770)	(84,448)

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 £34,688 (2021: £24,233).

21 Financial commitments

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

	2022 Within 1 year £	2022 Within 1-5 years £	2021 Within 1 year £	2021 Within 1-5 years £
Land and buildings	24,200	-	36,300	24,200
Other	5,151	6,869	5,151	12,020
	29,351	6,869	41,451	36,220

22 Related party transactions

The charity received donations from three trustees during the period totalling £1,208 (2021: £3,967).

The Haemophilia Society

Annual report and financial statement 2021/22

Find the information you need on our website at **haemophilia.org.uk** or contact us on **020 7939 0780** or email **info@haemophilia.org.uk**

If you would like this information in a different format, such as audio tape, braille or large print, or in another language, please speak to our team on **020 7939 0708.**

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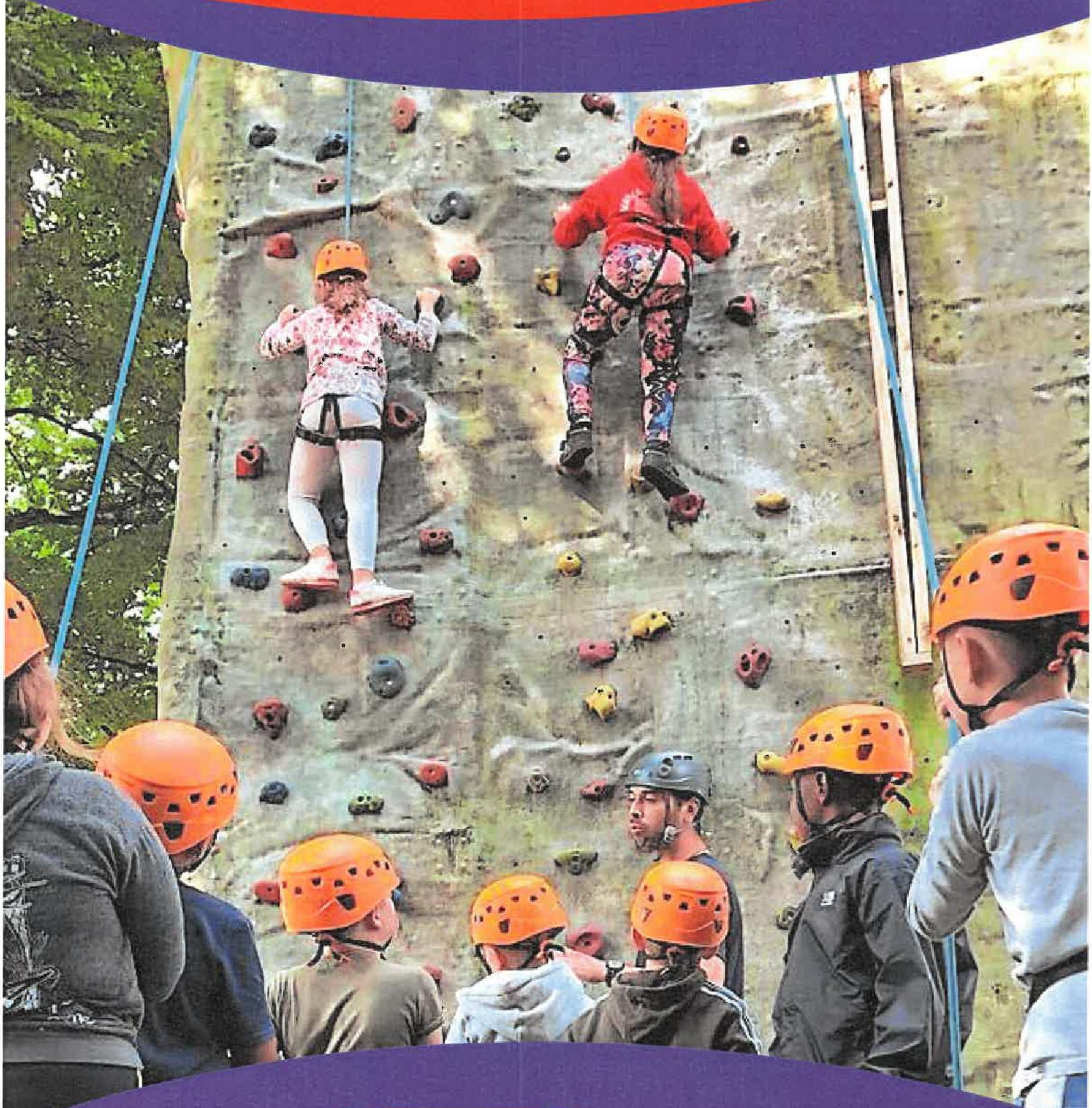
HaemophiliaSocietyUK
HaemoSocUK
thehaemophiliasociety

Registered charity no. 288260 (Scotland SC039732)
Company limited by guarantee reg. no. 1763614
Members of the European Haemophilia Consortium and the World Federation of Hemophilia
Chair: Clive Smith
Clive@haemophilia.org.uk
President: Baroness Meacher

Accounts

THE
HAEMOPHILIA
SOCIETY



Annual report and financial statements: 2020/21

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

THE
HAEMOPHILIA
SOCIETY

Contents

THE
HAEMOPHILIA
SOCIETY

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

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

Clinical Advisory Group
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Dr. Susie Shapiro
Tom Burke
Robert James
Dr Kate Khair
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Prof Mike Makris
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Charity registration number
288260

Scottish charity registration number
SCO39732

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. Wehope 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 Barry Flynn (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.

C. Smith

Clive Smith
Chair of the Board of Trustees
The Haemophilia Society

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
Barry Flynn
Kate Khair
Conan McIlwrath
Sonia O'Hara
Paul Sartain
Clive Smith
Anna Geffert (appointed 14/11/20)
Jo Traunter

THE
HAEMOPHILIA
SOCIETY

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.

THE
HAEMOPHILIA
SOCIETY

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.

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.

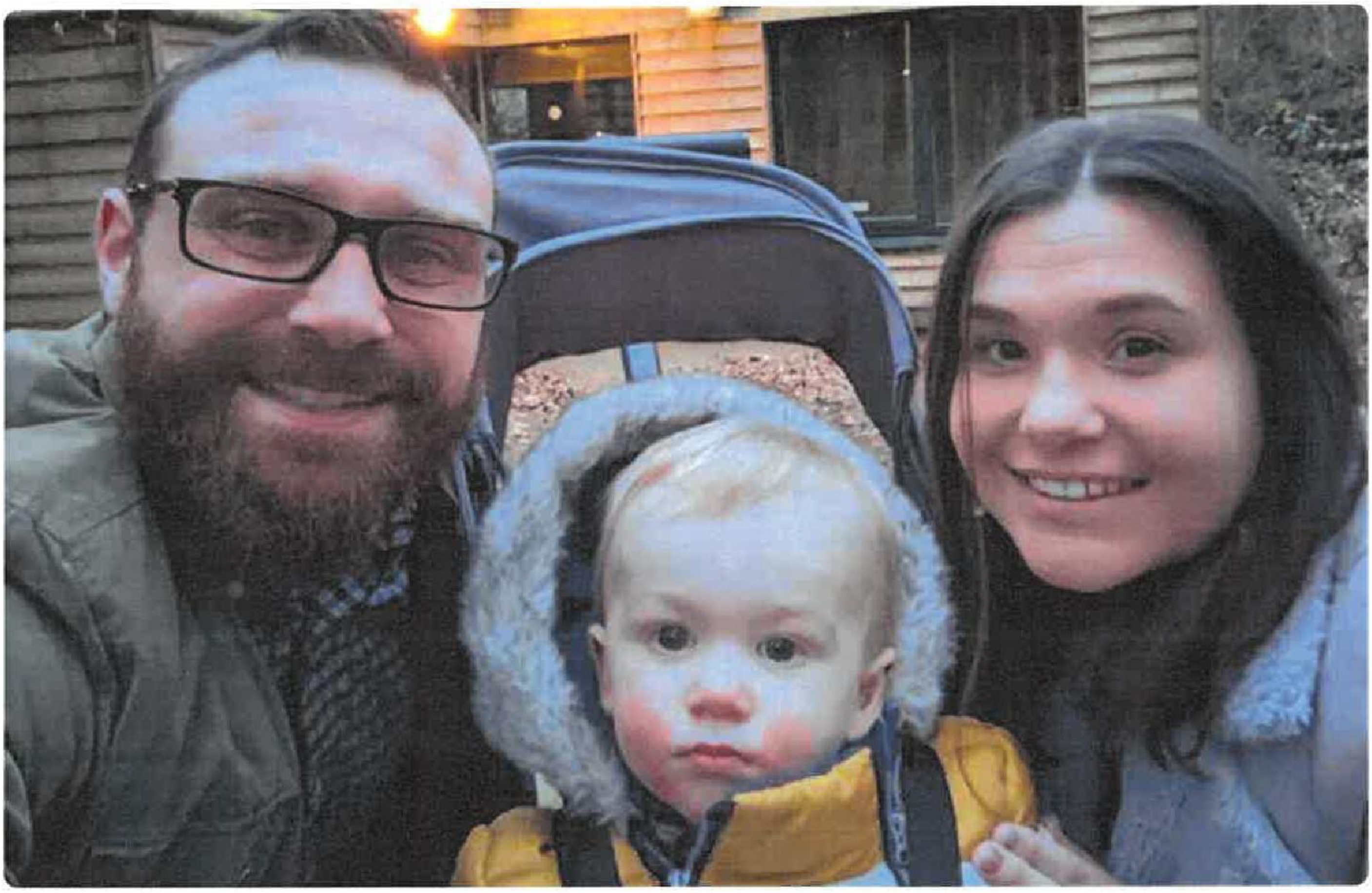
Newly Diagnosed Family Weekends

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.



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
SOCIETY

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.

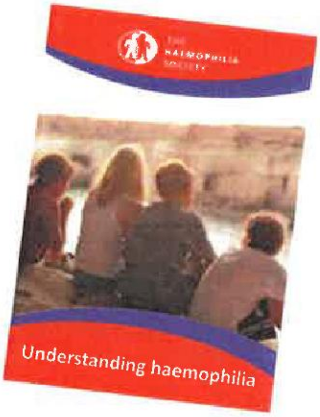
Service of Thanksgiving and Remembrance

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.



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.

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.

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.

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 uncertainly 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.

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 o 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 or 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 or 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 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 affect 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.

THE
HAEMOPHILIA
SOCIETY

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 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

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.

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.

C. Smith

Clive Smith, 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 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 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. 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

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.

Azets Audit Services
John Howard (Senior Statutory Auditor)
for and on behalf of Azets Audit Services
Statutory Auditor
2nd 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	Total
	Note	£	£	£	£	£
Income and endowments from:						
Donations and legacies	2	382,318	274,380	625	657,323	756,472
Charitable activities	3	72,941	3,750	-	76,691	117,210
Investments	4	40,643	934	-	41,577	39,620
Other		39,364	-	-	39,364	11,442
Total income and endowments		535,266	279,064	625	814,955	924,744
Expenditure on:						
Raising funds	5	86,352	28,868	-	115,220	99,041
Charitable activities	6	534,474	121,824	-	656,298	850,830
Total expenditure		620,826	150,692	-	771,518	949,871
Net (losses) / gains on investments		111,609	-	-	111,609	(16,145)
Net income / (expenditure)	9	26,049	128,372	625	155,046	(41,272)
Transfers between funds		-	-	-	-	-
Net movement in funds		26,049	128,372	625	155,046	(41,272)
Reconciliation of funds:						
Total funds brought forward		1,379,544	22,635	14,125	1,416,304	1,457,576
Total funds carried forward		1,405,593	151,007	14,750	1,571,350	1,416,304

All income and expenditure derive from continuing activities.

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

Balance sheet

Year ended 31 March 2021

	Note	2021 £	2020 £
Fixed assets			
Tangible assets	13	11,084	15,609
Investments	14	1,395,552	1,183,943
		1,406,636	1,199,552
Current assets			
Debtors	15	181,251	84,605
Cash at bank and in hand		56,016	201,892
		237,267	286,497
Creditors: amounts falling due within one year	16	(72,553)	(69,745)
Net current assets		164,714	216,752
Net assets		1,571,350	1,416,304
Charity funds			
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
Total charity funds	18	1,571,350	1,416,304

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

Signed on behalf of the board of trustees

Clive Smith, Chair

C. Smith

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 £
Net cash flow from operating activities	19	(84,448)	89,888
Cash flow from investing activities			
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
Net cash flow from investing activities		(61,428)	(23,762)
Net increase / (decrease) in cash and cash equivalents		(145,876)	66,126
Cash and cash equivalents at 1 April 2020		201,892	135,766
Cash and cash equivalents at 31 March 2021		56,016	201,892

Cash and cash equivalents consists of:

	2021 £	2020 £
Cash at bank and in hand	56,016	201,892
Cash and cash equivalents at 31 March 2021	56,016	201,892

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.

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
	657,323	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.

3 Income from charitable activities

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

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
	41,577	39,620

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
	115,220	99,041

£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
	164,718	1,000	490,580	656,298

£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
Total		82,883	490,580	573,463

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.

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

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

14 Fixed asset investments (continued)

Investments at fair value compromise:

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

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
	181,251	84,605

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
	72,553	69,745

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.

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.

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
Total	1,347,827	57,766	151,007	14,750	1,571,350

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)
Net cash flow from operating activities	(84,448)	89,888

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
	41,451	36,220	40,400	67,374

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, 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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HaemoSocUK
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