

**The
Haemophilia
Society**



Annual Report

and financial statement 2022/23

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.

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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

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%

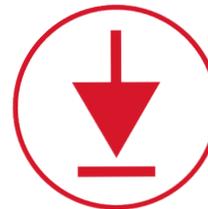
increase in new followers on social media

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!



'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 Scarlet, 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



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.



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

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.

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 us 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.

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

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 multidisciplinary 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.



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.

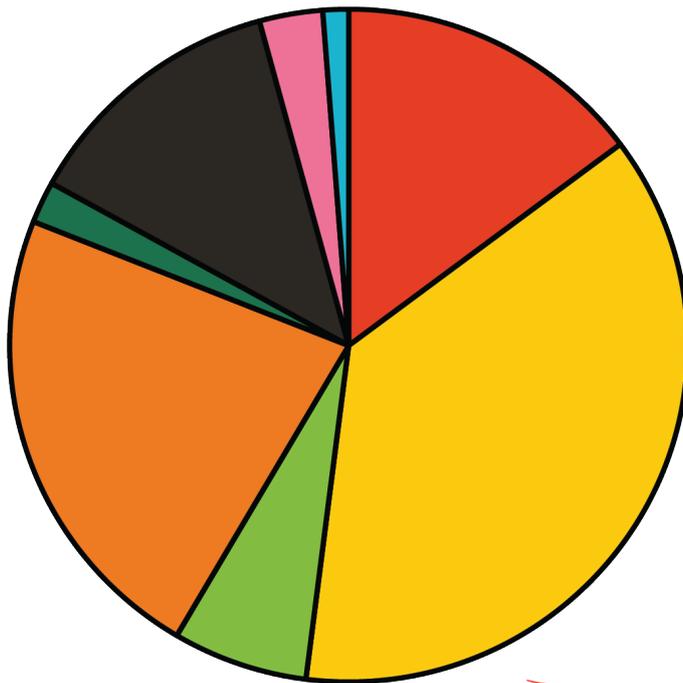


THS at the International Society of Thrombosis and Haemostasis (ISTH) in London.

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



How we manage your money

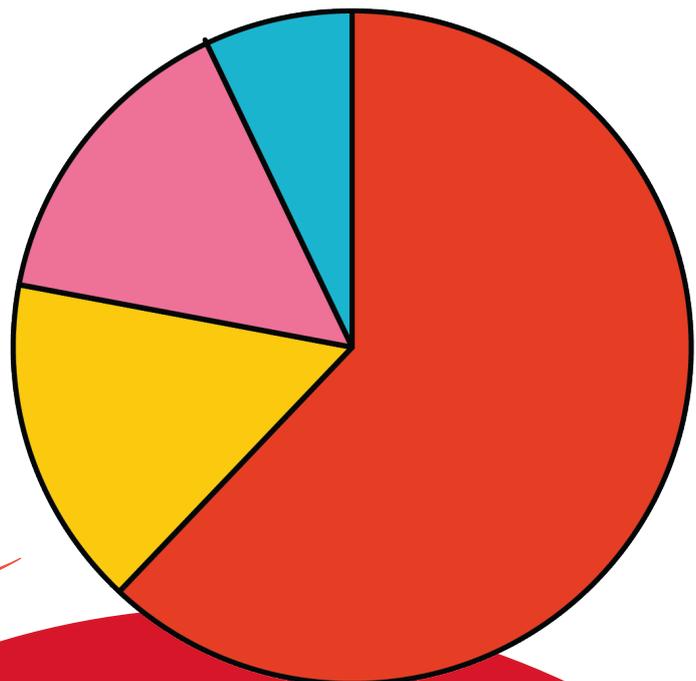


Income Composition 2022-23

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.

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.



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



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.



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)

Subcommittees

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 SE11TJ
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



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

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 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

		2023			2022	
	Note	Unrestricted funds £	Restricted funds £	Endowment funds £	Total £	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
		<u>734,926</u>	<u>1,035,580</u>
Current assets			
Debtors	15	71,730	90,936
Cash at bank and in hand		140,796	130,997
		<u>212,526</u>	<u>221,933</u>
Creditors: amounts falling due within one year	16	(103,457)	(88,906)
Net current assets		<u>109,069</u>	<u>133,027</u>
Net assets		<u>843,995</u>	<u>1,168,607</u>
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	<u>843,995</u>	<u>1,168,607</u>

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	<u>(263,056)</u>	<u>(354,770)</u>
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		<u>272,855</u>	<u>429,751</u>
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		<u>140,796</u>	<u>130,997</u>
Cash and cash equivalents consists of:			
Cash at bank and in hand		140,796	130,997
Cash and cash equivalents at 31 March 2023		<u>140,796</u>	<u>130,997</u>

1. Summary of significant accounting policies

(a) General information and basis of preparation

The Haemophilia Society is a company limited by guarantee in the United Kingdom. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 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
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(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
	<u>96,331</u>	<u>120,259</u>

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
	<u>24,891</u>	<u>35,538</u>

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
	<u>183,153</u>	<u>287,175</u>

£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		<u>166,254</u>	<u>597,369</u>	<u>763,623</u>

8. Governance costs

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

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	<u>11,100</u>	<u>8,880</u>

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
	<u>675,805</u>	<u>603,401</u>
Recruitment and training	4,840	20,495
	<u>680,645</u>	<u>623,896</u>

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	<u>101,117</u>
Depreciation:	
At 1 April 2022	89,892
Charge for the year	6,053
At 31 March 2023	<u>95,945</u>

13. Tangible fixed assets (continued)

Net book value:	
At 31 March 2023	<u>5,172</u>
At 31 March 2022	<u>9,189</u>

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	<u>728,805</u>	<u>949</u>	<u>729,754</u>

Investments at fair value comprise:

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

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
	<u>71,730</u>	<u>90,936</u>

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) 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	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
	<u>42,771</u>	<u>26,798</u>	<u>29,351</u>	<u>6,869</u>

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 language, please speak to our
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