



THE
HAEMOPHILIA
SOCIETY



Annual report and financial statements: 2019/20

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



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THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society
Charity reference and administrative details
Year ended 31 March 2020

President Baroness Meacher
Chief Executive Vacant

Board of Trustees

Lisa Bagley
Catherine Benfield
Gordon Dixon
Barry Flynn
Kate Khair
Conan McIlwrath
Sonia O'Hara
Paul Sartain
Clive Smith - Chair
Jo Traunter

Subcommittees

Resources & Audit Committee

Lisa Bagley
Barry Flynn
Clive Smith
Kate Khair
Gordon Dixon - Chair

Nominations Committee

Barry Flynn
Clive Smith

Public Inquiry Committee

Barry Flynn
Eileen Ross
Paul Sartain
Clive Smith - Chair



THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society
Charity reference and administrative details
Year ended 31 March 2020

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

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

SCO39732



Chair's statement Year ended 31 March 2020

Any organisation that has been in existence for 70 years will inevitably have seen its ups and downs. For all, 2020 has posed a unique challenge, but particularly for charities. It has tested us in ways we could never have envisaged only 12 months ago. In the short term this meant closing the office and staff working from home. It meant staff being furloughed. It meant tough decisions being made about what services we could continue to provide, all against the background of our then CEO Liz Carroll's resignation. The fortitude, flexibility and professionalism of the staff team and wider community has been humbling to see. On behalf of every one of us, my heartfelt thanks to you all.

Strictly speaking, this report should cover April 2019 to March 2020. However, with some exceptional events taking place right on the cusp of the end of the financial year, it would seem incongruous not to mention them now. The start of April 2020 saw the resignation of our CEO Liz Carroll. Having been in post for 6 years, Liz felt the time was right to move on and seek a new challenge. During Liz's tenure, much has been achieved. Undoubtedly the highlight was the World Federation of Hemophilia (WFH) Congress in 2018 in Glasgow. Liz's leadership and stewardship of this event saw the biggest and arguably best Congress in WFH's history. It brought together over 4,000 members of the community, creating friendships and bonds that will last a lifetime. In addition, the announcement of the public inquiry into contaminated blood was finally achieved: two highlights of a very successful period in our history. We thank Liz for all her hard work and wish her the very best of luck for the future. The recruitment for a new CEO who can drive the Charity forward, is at the final stages and by the time you read this report, I anticipate we will have made an announcement in relation to our new CEO.

The first casualty of the COVID-19 pandemic was our "Talking Red" event in York in March. We had planned to launch our new Women's Committee at this event. Whilst we couldn't formally launch it then, the committee is now up and running and we will continue to shine a light and raise awareness of the challenges faced by women with bleeding disorders. We have still been able to hold two very successful Talking Red events in Belfast and Birmingham, and will continue to grow this increasingly vital area of our work. We attended the first EHC Women's Conference held in Frankfurt. One of our new trustee's Dr Jo Traunter has also been appointed to the EHC Women & Bleeding Disorders Committee.

Over this financial year we were able to hold another three of our newly diagnosed weekends. I have seen first-hand how prized these are to the newest members of our community. As such I know the team have sought to redesign these slightly, to see if we can provide more of them, within the existing budget. This will mean a move away from the usual Center Parks location. In doing this, we hope to be able to reach more of our community at the time of arguably their greatest need.

In August of 2019, we held our residential youth camp for those aged 9-15, over 4 days in Dorking, Surrey. The days were packed with activities such as high-ropes, orienteering and archery. I've heard several stories over the months from staff and trustees who attended. I'm not sure who had more fun – the children or the adults!

In September we attended both the Conservative Party and Labour Party Conferences. The aim of this was to highlight the need for better services and access to treatment.



Chair's statement Year ended 31 March 2020

With so many new products coming to market, it's imperative that access is granted to these, for those who want them. In a supposedly "recombinant for all" country, it's unacceptable that recombinant Von Willebrand factor is still to be licensed for use. As part of our work on this area, we have been working on our "Access to Treatment" report with the All Party Parliamentary Group. The launch of this has had to be delayed, but we hope to be able to launch this in the next financial year.

In October of 2019 we attended the EHC Conference in Macedonia. Two of our youth ambassadors, Matty Minshall and Josh Crombie attended and undertook further youth leadership training. Both have previously been part of the EHC Youth Leadership Training programme held annually in April in Amsterdam. Another of our youths, William McKeown was selected to take part in the youth debate on Friday evening, alongside experienced members of the community. William's contribution to the debate was lauded by many present. Many of our other new Youth Ambassadors are starting to make their presence known in the community. Back in February, we held a weekend of training with them and it has been encouraging to see them becoming more active within the community. I'm sure we will continue to see and hear more from them in the future.

In November we held our AGM and Conference in Liverpool. We continue to vary our conference locations to reach as many of you as possible. We had an excellent attendance and were able to put on several "tracks" to ensure there was something for everyone. It was great to see so many new faces and we had an excellent attendance from health care professionals, who were instrumental in the weekend being such a success. My thanks to so many of you for giving up your precious weekends.

One area we have not been able to develop as well as we had hoped is our local groups. We hope that as life starts to return to the new normal, we will be able to redouble our efforts here. I want to reassure you that this remains a priority for us.

Lastly, I must mention the Infected Blood Inquiry. This year has seen further harrowing and tragic testimony from those infected and affected by contaminated blood. In February the Inquiry heard evidence from expert groups about the long-term damage that has been inflicted on our community. As a Society we have attended many of these hearings and held local meetings in all regions at the start of each new session. I have had the privilege of attending in London, Leeds and Edinburgh to meet with members of the community. The courage of those speaking about their individual struggles continues to humble us all. We've also worked hard with both Haemophilia Scotland and Haemophilia Northern Ireland (NI) in relation to the infected blood support schemes.

In February I was part of a delegation who met with Robin Swann, the NI Health Minister to raise the issue of disparity for our members in Northern Ireland (NI). At the time of writing this, Northern Ireland have now confirmed that they will level up payments for this year and the future. The work of those based in Northern Ireland has been vital to achieving this. My thanks to everyone involved for their hardwork. This leaves our members in Wales unforgivably behind in terms of the levelling up process. We will continue to do what we can to redress this unacceptable imbalance.



Chair's statement Year ended 31 March 2020

Earlier this year The Society waived legal privilege in relation to documents it holds. The Inquiry has no power to demand that we submit these documents to them, but like many other bodies, we are of the view that it is only by being completely open and transparent, that a full investigation of what happened can be achieved. In parallel with the Inquiry, we continue our efforts to improve both financial and psychological support for the community. In January we were part of a significant group of community representatives who met with Oliver Dowden MP and Nadine Dorries MP. Governments procrastination in engaging with the community continues. At the time of writing, we are onto our fourth sponsoring minister for the Inquiry. We met with Oliver Dowden MP and Nadine Dorries MP in January 2020 and we are yet to see any progress. Like many other groups, we will continue to hold governments feet to the fire over this. With political will, government has shown what can be achieved in a short space of time when faced with a deadly virus.

And so, to the next 70 years. My earnest hope is that in 70 years we will no longer exist. Every charity's aim is to reach a stage where it is no longer needed; where its charitable aim has been fulfilled. With the revolution in treatment we are currently seeing, I hope that aim may even be fulfilled in my lifetime.

Footnote (April 2020 onwards)

As mentioned at the start, the COVID-19 pandemic has meant straightened times for us all, but particularly charities. Whilst outside the scope of the financial year ending March 2020, it's only right that I should set out what steps we as a charity took in response to COVID-19, whilst it is fresh in our minds.

Like so many others, we immediately shut the office and moved to home working. We moved to new offices in December 2019 which meant a review of all our systems had only recently taken place. That meant our staff team were set up and ready to go immediately as a result of the team's preparations, particularly our office manager, Fiona. We spent time providing information and answers to FAQs about what COVID-19 meant for our community. We supplied extra advice to those particularly vulnerable members of our community who might be shielding. The week after lockdown, we already had a board meeting scheduled. This took place via Zoom and regular board meetings have continued to take place online. We initially held weekly virtual meetings of our resources committee to keep a firm handle on our finances. Staff were furloughed. Two staff positions became vacant, one due to a member of staff finding a new job and another due to resignation. We took the decision not to recruit during this time, meaning when full-time furlough came to an end, all our remaining staff returned to working their full hours. Our head of finance, Anna, spoke to many of our suppliers to see if discounts or delayed payments could be put in place. All these steps led to immediate savings and has meant we continue to be in robust financial health.



C. Smith

Clive Smith
Chair of the Board of Trustees
The Haemophilia Society



Trustees' Annual Report Year ended 31 March 2020

The trustees present their report and the audited financial statements of the charity for the year ended 31 March 2020. 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
Gordon Dixon (appointed 21/11/19)
Barry Flynn
Kate Khair
Conan McIlwrath (appointed 16/11/19)
Sonia O'Hara
Paul Sartain
Clive Smith
Jo Traunter (appointed 16/11/19)
Andrew Martin (resigned 16/11/19)
Simon Mower (resigned 16/11/19)
Eileen Ross (resigned 16/11/19)



Trustees' Annual Report Year ended 31 March 2020

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 2020

Objectives and activities

Specific objectives and activities providing public benefit include:

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

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

Advocating for fair treatment and support for those impacted by the contamination of blood products supplied by the NHS in the 1970s and 1980s and cooperating with the public inquiry into infected blood.

Fundraising regulation

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

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

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

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



Trustees' Annual Report Year ended 31 March 2020

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 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 2020

Activities

Members Conference

This year we held our members conference in Liverpool with almost 400 people attending over the two days. There was a packed agenda as always with updates in new advances in services and treatments as well as sessions on women's issues and health and wellbeing.

We held a gala dinner with a lively auction and the chance to socialise with other members and build connections to others in the community. Children's activities included a trip to Chester Zoo and bowling on Sunday.



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 them 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.



Trustees' Annual Report Year ended 31 March 2020

This year we held three weekends for families with a newly diagnosed child, with one focusing specifically on mild and moderate bleeding disorders, while the others focused on children with a severe bleeding disorder. This year we have included information on women with bleeding disorders, recognising that the needs of girls ought to be highlighted and addressed at an early stage.

Youth Activities

This year our younger children attended summer camp at a dedicated outdoor activity centre in Surrey. Attending camp reduces the isolation of living with a bleeding disorder and raises the confidence levels of our younger members. Siblings are invited to attend as it is important that the impact of living with a brother or sister who has a bleeding disorder are understood and managed.

From learning to give your treatment for the first time and understanding what your condition really means for you, to understanding how teamwork and determination can help you make huge leaps and in some cases learn new skills such as those who learnt to ride a bike for the first time this year.

Youth Ambassador Engagement

Our Youth Ambassadors have attended two training weekends to enhance their skills in communication and storytelling, learning about clinical trials structure, personality types and teamwork. They have been developing three works teams concentrating on mental health, exercise and wellbeing and women's bleeding disorders.

They continue to support us at all of our events talking about their experiences, engaging with the community and helping staff deliver services as well as engaging in social media and advocating for our community.



Trustees' Annual Report Year ended 31 March 2020

Two of the Youth Ambassadors attended the EHC Conference, one as part of the Youth development programme and one representing us at the inhibitor working group. We also had one youth ambassador attending the EHC new technologies workshop.

Additionally, they organised the 'Lads and Dads' activity weekend in the Brecon Beacons continuing the friendly rivalry between parents and their children across a range of outdoor events and activities.

Talking Red Programme

This year we held two Talking Red conferences in Belfast and Birmingham with tailored sessions from a range of health care professionals talking about the challenges women with bleeding disorders face, from diagnosis and dentistry to periods, pregnancy and childbirth.

These events allow women living with bleeding disorders to connect with others who understand their challenges and provide a safe environment to share their experiences, reducing the isolation some people feel.

We surveyed women to understand more comprehensively the issues that were important to women living with bleeding disorders and the issue of 'period poverty'. The findings were to be presented at our third Talking Red event scheduled for March 2020 but due to COVID-19 this had to be cancelled and rescheduled for 2021.





Trustees' Annual Report Year ended 31 March 2020

Family Days

We held 7 family days at various fun locations across the UK from Zoo's and Aquariums to Science Parks. These were attended by over 250 people and is a great way for families to get to know each other share experiences and build support networks over lunch. Some of the families had met previously at newly diagnosed weekends and had the chance to meet up again a few years later to compare their journeys.

Service of Thanksgiving and Remembrance

With the start of the Inquiry hearings and it was of particular importance this year to remember those who could not be with us and lost their lives through contaminated blood. The personal testimonies heard this year have been deeply moving and for many have brought back many painful memories so therefore it was not surprising that we had 150 people attending this year to honour lost friends and family.

Publications

We produced this year new booklets on dental care for adults, sex and bleeding disorders as well as factsheets on applying for PIP. An updated version of the understanding VWD was released and work started on a series of rare disease factsheets.

Volunteering

As always, we rely on the generosity of so many volunteers to help us run our events and support us in a range of amazing ways. Without the help of the many healthcare professionals who give up their time to speak at events for us, the Youth Ambassadors and newly appointed LGBTQ Ambassador, local group volunteers, reading panels and a whole host of volunteers who rise to the challenge we would not be able to deliver the range of services we do.

This year we began a plan to expand our volunteering process to offer a larger range of opportunities, however due to COVID-19 this process was put on hold at the end of the financial year and will be initiated again in the future.

Advocacy

This year we have continued 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.

Trustees' Annual Report Year ended 31 March 2020

Issues highlighted included access to innovative new treatments, access to specialist nursing and physio care, and sharing people's experiences of their haemophilia centres.

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

We have also worked closely with EIBSS (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 called 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. This has been collated, however launch was postponed due to timings with Brexit, General election and the COVID-19 situation.

Database and Processes

We have been working hard this year to examine our background processes and database and ensure we have a solid foundation to move forward from. It is vital for us that we have good procedures in place and the right information to allow us to engage effectively with our community. This work is ongoing to help us become more efficient in the future and provide the right information to our members.

Public inquiry into infected blood

This year saw the start of the hearings of the Statutory Public Inquiry into Infected Blood. We heard from personal witnesses across the devolved nations. It was both heart-breaking and yet inspirational to hear the experiences of people and their families of living through the impact of contaminated blood and losing loved ones. No one attending could help but be moved by the bravery of those who spoke out, vividly bringing to life the tragedy they had lived through.

We have continued to keep our members updated via a dedicated section on our website, producing newsletters and articles in HQ, daily updates on social media during the hearings and meeting with people attending the hearings around the UK. We have ensured all our documentation was provided to the Inquiry and have waived legal privilege on all of our documents. We have inputted to the experts reports and attended the hearings of these in February.

We continue to campaign for increased expert psychological support for those affected by contaminated blood and to support our members through these difficult times.



Trustees' Annual Report Year ended 31 March 2020

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 your feedback about different activities and stories of success, especially with the ongoing challenges of COVID-19.

We are grateful that people are running, walking, cycling and swimming to raise money for us and we thank you all for your commitment and the personal sacrifices and hours of training you have put in.

We have launched our virtual shop so you can buy merchandise from us including Christmas cards and are looking to expand this in the future to include our publications. Thank you to all who have contributed to our campaigns so we can continue to provide information and support to our members free of charge.

This year we held our Big Red Glasgow Bridge Walk but unfortunately had to cancel our Big Red London Walk due to COVID-19 lockdown restrictions. This was a real blow for us as it was such a great event attended by so many the year before. We hope we can reinstate this event.





Trustees' Annual Report Year ended 31 March 2020

What we are proud of

- Developing our new Youth Ambassadors and the work they have done
- Developing our communications via website and social media
- Our Services to youth and families
- Our work with the public inquiry

What we could do better

- Engaging with local groups
- Improving relationships with haemophilia centres to engage more people affected with bleeding disorders
- Developing a more structured volunteering process
- Increasing 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 has been increasingly hard as the Inquiry has begun to hear the personal testimony of individuals and families affected, bringing back difficult and traumatic memories.

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 2019-20 we reviewed our strategy and will continue to work on this to build our resilience and adapt for the future. We will continue to develop our Talking Red programme, committing to integrating womens' issues into all of our events and programmes to ensure the issues they face are at the forefront of our work.

We are looking to increase our range of publications to include publications on gene therapy, ageing, and rare diseases as well as updating our school's booklet. We are looking to increase our accessibility by beginning to translate our materials.

We are developing our fundraising function to increase the diversity of our income.

As we continue to adapt to a new environment, we are seeking new ways to engage our community with increased online activities, virtual events and increased social media engagement. We continue our work to further develop our background processes to improve efficiency and engagement with our members.



Trustees' Annual Report Year ended 31 March 2020

Financial review - Income and expenditure overview

The results for this financial year demonstrate the level of continued activity being undertaken by The Society.

The infected blood Inquiry continued this year and in order to be able to support the proceedings and our community we have incurred costs of £198,081 in this financial year. This is significantly lower than the previous year and we expect this 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 sufficiently cover the period of the Inquiry. Funds not used in this respect can be freely redesignated to general reserves.

Overall, we have generated a loss for the year of £25,127 (before the impact of gains and losses on investments), which results in The Society continuing to be well capitalised. This loss was distorted by the inclusion of the Inquiry expenditure, which is funded from our designated reserves. Excluding the impact of this individual item, our outcome for the year would have been a surplus of £172,954. Nonetheless, and given the planned expenditure from reserves over the coming years, fundraising remains a critical challenge for The Society.

Income (including legacies) for the financial year ended 31 March 2020 was £924,744, as compared to £1,264,750 in FY19. This included corporate funding of £274,086 in FY20 (down from £325,956 in FY19) and an increase in individual donations and community fundraising (combined) from £177,960 in FY19 to £208,433 in FY20.

We very gratefully benefited from legacy income of £351,226 during the year (FY19: £34,846).

Expenditure for FY20 decreased by £122,702 to £949,871 from £1,072,573 in FY19. Excluding the expenses relating to the Inquiry, expenditure for the year was £751,790.

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



Trustees' Annual Report Year ended 31 March 2020

Fundraising and volunteers

The Society's members have participated in many fundraising activities this year and have made significant donations of £208,433, with additional Gift Aid receipts of £16,496. We have benefited from members participating in a wide range of events alongside individual giving, for all of which we are very grateful.

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

The charity also benefits from a number of 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.

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

Grant and trust income

We have received income from trust applications of £21,390 this year (FY19: £21,010). Broadening our sources of income is an area we continue to focus on.

Corporate income

Corporate income decreased from £325,956 in FY19 to £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

We have been very fortunate to receive legacy income during FY20 of £351,226 (£34,846 in FY19).

Costs

Costs in FY20 were £949,871. Against a total income of £924,744, this represents a deficit of £25,127 before net (losses/gains on investments).

Reserves

The board of trustees reviewed and updated the reserves policy in March 2020. As COVID-19 may have significant impact on our income streams, they made the decision to designate 6 months of running costs to create a liquidation fund.

Recognising the significant financial and general resource impact of the current public inquiry into infected blood, last year the board designated £600,000 of reserves to fund the charity's work on the Inquiry over

Trustees' Annual Report Year ended 31 March 2020

four years. 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. Designated funds will be reviewed annually to ensure appropriate use of reserves.

As at 31 March 2020, unrestricted general reserves (excluding local group funds) stood at £1,326,157. As noted, the board of trustees continually reviews potential opportunities to invest for the good of The Society, while prudently managing reserves in an uncertain environment.

Under the Memorandum and Articles of Association the trustees may invest surplus funds in any investment they consider appropriate. To this end we have invested in COIF Charities Investment Fund, which invests based on a diversified and prudent investment strategy directly into assets to mitigate concentration of risks. As at the end of FY20 our funds had a market value of £1,183,943.

Key risks and uncertainties

Key risks to the charity fell into two 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 40+ years are scrutinised. This will increase this year as the actions of The Society will be heard by the Inquiry and witnesses called to give evidence.

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

COVID-19

The need to follow government procedure and lockdown guidance which began in March 2020 will significantly impact the way we work and our ability to deliver face to face service events and fundraising activities. This could have a long term effect on the workings of The Society and our ability to engage with the community and we must remain agile and adapt to a changed environment.

At the date of approval of these financial statements, the full impact cannot be fully quantified, which gives rise to a potential uncertainty as to whether the financial statements should be prepared on a going concern basis. The potential threat of COVID-19 has been assessed and we have concluded that it is reasonable to prepare the accounts on a going concern basis, as on all realistically, plausible scenarios we are sufficiently resilient to continue in operation for the foreseeable future.



Trustees' Annual Report Year ended 31 March 2020

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 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.



Trustees' Annual Report Year ended 31 March 2020

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 7 September 2020 Group Audit Services Limited trading as Wilkins Kennedy Audit Services changed its name to Azets Audit Services Limited. The name they practice under is Azets Audit Services and accordingly they have signed their report in their new name.

On behalf of the board

C. Smith

Clive Smith, Chair

Date: 15 September 2020

Gordon Dixon

Gordon Dixon, Treasurer

Date: 15 September 2020

The Haemophilia Society

Year ended 31 March 2020

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 2020 which comprise the statement of financial activities, the balance sheet, the statement of cash flows and the notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2020 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

However, because the extent of the impact of COVID-19 is unclear and it is difficult to evaluate all the potential implications on the charitable company's income, customers, suppliers and the wider economy, this statement is not a guarantee as to the charitable company's ability to continue as a going concern.

We draw attention to the trustee's going concern assessment in note 1 of these financial statements.

Other information

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

The Haemophilia Society

Year ended 31 March 2020

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

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

The Haemophilia Society

Year ended 31 March 2020

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

Auditor's responsibilities for the audit of the financial statements

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

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

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

23rd September 2020

Date:

The Haemophilia Society

Statement of financial activities (including income and expenditure account)

Year ended 31 March 2020

	Note	2020			2019	
		Unrestricted funds £	Restricted funds £	Endowment funds £	Total £	Total £
Income and endowments from:						
Donations and legacies	2	513,689	242,783	-	756,472	478,494
Charitable activities	3	117,133	77	-	117,210	746,395
Investments	4	38,654	966	-	39,620	35,122
Other		11,442	-	-	11,442	4,739
Total income and endowments		680,918	243,826	-	924,744	1,264,750
Expenditure on:						
Raising funds	5	85,707	13,334	-	99,041	132,054
Charitable activities	6	588,136	262,694	-	850,830	940,519
Total expenditure		673,843	276,028	-	949,871	1,072,573
Net (losses) / gains on investments		(16,145)	-	-	(16,145)	41,301
Net income / (expenditure)	9	(9,070)	(32,202)	-	(41,272)	233,478
Transfers between funds		-	5,219	(5,219)	-	-
Net movement in funds		(9,070)	(26,983)	(5,219)	(41,272)	233,478
Reconciliation of funds:						
Total funds brought forward		1,388,614	49,618	19,344	1,457,576	1,224,098
Total funds carried forward		1,379,544	22,635	14,125	1,416,304	1,457,576

All income and expenditure derive from continuing activities.

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

The Haemophilia Society

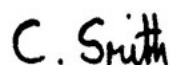
Balance sheet

Year ended 31 March 2020

	Note	2020 £	2019 £
Fixed assets			
Tangible assets	13	15,609	10,795
Investments	14	1,183,943	1,150,088
		<u>1,199,552</u>	<u>1,160,883</u>
Current assets			
Debtors	15	84,605	265,897
Cash at bank and in hand		201,892	135,766
		<u>286,497</u>	<u>401,663</u>
Creditors: amounts falling due within one year	16	(69,745)	(104,970)
		<u>216,752</u>	<u>296,693</u>
Net current assets		<u>1,416,304</u>	<u>1,457,576</u>
Net assets		<u>1,416,304</u>	<u>1,457,576</u>
Charity funds			
Endowment funds	17	14,125	19,344
Restricted funds	17	22,635	49,618
Unrestricted general funds	17	586,773	734,713
Local group funds	17	53,387	53,901
Designated funds	17	739,384	600,000
Total charity funds	18	<u>1,416,304</u>	<u>1,457,576</u>

The financial statements were approved and authorised for issue by the board on 15 September 2020

Signed on behalf of the board of trustees



Clive Smith, Chair

The notes on pages 29 to 44 form part of these financial statements.

Company registration number: 01763614

The Haemophilia Society

Statement of cash flows

Year ended 31 March 2020

	Note	2020 £	2019 £
Net cash flow from operating activities	19	<u>89,888</u>	<u>(31,478)</u>
Cash flow from investing activities			
Payments to acquire tangible fixed assets		(13,382)	(8,555)
Net cash flow from sale and purchase of fixed asset investments		(50,000)	(5,000)
Interest received		39,620	35,122
		<u> </u>	<u> </u>
Net cash flow from investing activities		<u>(23,762)</u>	<u>21,567</u>
Net increase / (decrease) in cash and cash equivalents		66,126	(9,911)
Cash and cash equivalents at 1 April 2019		135,766	145,677
		<u> </u>	<u> </u>
Cash and cash equivalents at 31 March 2020		<u>201,892</u>	<u>135,766</u>
Cash and cash equivalents consists of:			
Cash at bank and in hand		201,892	135,766
		<u> </u>	<u> </u>
Cash and cash equivalents at 31 March 2020		<u>201,892</u>	<u>135,766</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 2 of these financial statements. The nature of the charity's operations and principal activities are to provide support and services to everybody affected by inherited bleeding disorders in the UK.

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

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

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

(b) Funds

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

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

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

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

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

1 Summary of significant accounting policies (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, 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.

1 Summary of significant accounting policies (continued)

(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.

(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.

1 Summary of significant accounting policies (continued)

(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.

(m) Tax

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

(n) Going concern

The Trustees have considered the potential emerging impact of the COVID-19 virus on the future viability of The Society. The need to follow government procedure and lockdown guidance which began in March 2020 will significantly impact the way The Society work and the ability to deliver face to face service events and fundraising activities. This could have a long-term effect on the workings of The Society and the ability to engage with the community and The Society must remain agile and adapt to the changed environment.

At the date of these financial statements, the full impact on The Society cannot be quantified which gives rise to a material uncertainty as to whether the financial statements should be prepared on a going concern basis.

The Trustees continue to take all the available steps to maintain sufficient resources in order that The Society can continue and, based on projections and available information, have a reasonable expectation that The Society will have sufficient funds to continue to meet its liabilities as they fall due for the foreseeable future and therefore have prepared the financial statements on a going concern basis.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

2 Income from donations and legacies

	2020	2019
	£	£
Donations from individuals	93,274	70,423
Legacies	351,226	34,846
Grants and trust income	21,390	21,010
Corporate income	274,086	325,956
Gift Aid	16,496	26,259
	<hr/>	<hr/>
	756,472	478,494

Income from donations and legacies includes £242,783 (2019: £282,387) attributable to restricted funds, and £513,689 (2019: £196,107) attributable to unrestricted funds.

3 Income from charitable activities

	2020	2019
	£	£
Local group activities	2,051	6,332
Exceptional income from the WFH	-	632,526
Community fundraising and events	115,159	107,537
	<hr/>	<hr/>
	117,210	746,395

Exceptional income and expenditure was recognised last year relating to the WFH conference held in Glasgow in May 2019. This generated significant exceptional activity from both an income and expenditure perspective.

Income from charitable activities includes £77 (2019: £Nil) attributable to restricted funds, and £117,133 (2019: £746,395) attributable to unrestricted funds.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

4 Income from investments

	2020	2019
	£	£
Interest - fixed interest securities	39,619	35,122
Interest - deposits	1	-
	<u>39,620</u>	<u>35,122</u>

Income from investments includes £966 (2019: £1,620) attributable to restricted funds, and £38,654 (2019: £33,502) attributable to unrestricted funds.

5 Analysis of expenditure on raising funds

	2020	2019
	£	£
Direct costs	31,366	45,899
Support costs	67,675	86,155
	<u>99,041</u>	<u>132,054</u>

£Nil (2019: £9,041) of the above direct costs relates to grant application agency costs.

£13,334 (2019: £Nil) of the above costs were attributable to restricted funds. £85,707 (2019: £132,054) 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	22,074	-	49,693	71,767
Membership	17,758	-	17,062	34,820
Services	122,357	-	308,908	431,265
Advocacy and influencing	43,075	-	55,402	98,477
Corner stone project	15,000	-	-	15,000
Public inquiry	71,001	-	127,080	198,081
Tanner Fund grants	-	1,420	-	1,420
	<u>291,265</u>	<u>1,420</u>	<u>558,145</u>	<u>850,830</u>

£262,694 (2019: £252,018) of the above costs were attributable to restricted funds. £588,136 (2019: £688,501) of the above costs were attributable to unrestricted funds.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

7 Allocation of support costs

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

Support cost 2019	Basis of allocation £	Raising funds £	Charitable activities £	Total £
Governance	% of direct costs	3,781	28,972	32,753
Travel, postage and carriage	% of direct costs	3,043	7,218	10,261
Information technology	% of direct costs	3,768	28,875	32,643
Salary costs	% of staff time	64,176	436,445	500,621
Depreciation	% of direct costs	720	5,518	6,238
Office costs (incl. rental)	% of direct costs	5,382	41,241	46,623
Recruitment, training and temp staff	% of direct costs	2,373	18,183	20,556
Other expenses	% of direct costs	2,912	22,323	25,235
Total		86,155	588,775	674,930

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

8 Governance costs

	2020 £	2019 £
Trustee expenses	2,536	3,950
Auditors' remuneration - current year	8,100	6,750
Auditors' remuneration - prior year	-	1,050
Other expenses	1,613	21,003
	<hr/>	<hr/>
	12,249	32,753
	<hr/>	<hr/>

9 Net income / (expenditure) for the year

Net income / (expenditure) is stated after charging:

	2020 £	2019 £
Depreciation of tangible fixed assets	8,568	6,238
Operating lease rentals	42,110	47,838
Auditors' remuneration	8,100	6,750
	<hr/>	<hr/>

10 Auditors' remuneration

	2020 £	2019 £
Fees payable to the charitable company's auditor for the audit of the charitable company's annual accounts	8,100	6,750
	<hr/>	<hr/>

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

11 Trustees' and key management personnel remuneration and expenses

The trustees neither received nor waived any remuneration during the year (2019: £nil).

The Charity considers its key management personnel to be the board of trustees and the Chief Executive, Liz Carroll. The aggregate benefits of key management personnel amounted to £89,306 (2019: £93,222).

The reimbursement of trustees' expenses was as follows:

	2020	2019	2020	2019
	Number	Number	£	£
Travel, subsistence and accommodation	7	7	2,536	3,950

Included in trustees' expenses was £1,387 (2019: £nil) 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:

	2020	2019
	Number	Number
	11	12

The total staff costs and employee benefits was as follows:

	2020	2019
	£	£
Wages and salaries	409,019	436,905
Social security	34,971	37,998
Defined contribution pension costs	26,092	25,718
Interim staff	13,956	14,487
Recruitment and training	5,935	1,049
	<u>489,973</u>	<u>516,157</u>

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

12 Staff costs and employee benefits (continued)

Two employees received emoluments of more than £60,000 during the year ended 31st March 2020 (2019: two) and within the following bands:

	2020	2019
£60,000 - £70,000	1	
£70,001 - £80,000	1	1
£80,001 - £90,000		-
£90,001 - £100,000		1

13 Tangible fixed assets

	Computers and Office Equipment £
Cost:	
At 1 April 2019	76,907
Additions	13,382
At 31 March 2020	<u>90,289</u>
Depreciation:	
At 1 April 2019	66,112
Charge for the year	8,568
At 31 March 2020	<u>74,680</u>
Net book value:	
At 31 March 2020	<u>15,609</u>
At 31 March 2019	<u>10,795</u>

14 Fixed asset investments

	COIF Investment £	Other investments £	Total £
Cost or valuation			
At 1 April 2019	1,149,139	949	1,150,088
Additions	200,000	-	200,000
Disposals	(150,000)	-	(150,000)
Revaluation	(16,145)	-	(16,145)
At 31 March 2020	<u>1,182,994</u>	<u>949</u>	<u>1,183,943</u>

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

14 Fixed asset investments (continued)

Investments at fair value comprise:

	2020 £	2019 £
Equities	949	949
Securities	1,182,994	1,149,139
	<hr/>	<hr/>
	1,183,943	1,150,088

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

15 Debtors

	2020 £	2019 £
Prepayments and accrued income	26,719	199,122
Other debtors	57,886	66,775
	<hr/>	<hr/>
	84,605	265,897

Last year accrued income included a final payment from the WFH for The Society share in the surplus income of Congress held in May 2019 following the WFH audited accounts confirmation that was received in June 2020.

16 Creditors: amounts falling due within one year

	2020 £	2019 £
Trade creditors	11,733	36,807
Accruals and deferred income	47,499	58,361
Other creditors	10,513	9,802
	<hr/>	<hr/>
	69,745	104,970

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

17 Fund reconciliation

Unrestricted funds

	Balance at 1st April 2019 £	Income £	Expenditure £	Gains / (losses) £	Transfers £	Balance at 31st March 2020 £
Local groups	53,901	2,051	(2,565)	-	-	53,387
General funds	734,713	678,867	(473,197)	(16,145)	(337,465)	586,773
Designated funds – Public inquiry	600,000	-	(198,081)	-	-	401,919
Designated funds – Liquidation fund	-	-	-	-	337,465	337,465
	1,388,614	680,918	(673,843)	(16,145)	-	1,379,544

Restricted funds

	Balance at 1st April 2019 £	Income £	Expenditure £	Transfers £	Balance at 31st March 2020 £
Talking Red	-	25,124	(25,124)	-	-
Tanner Fund	3,934	-	(1,420)	-	2,514
Memorial Service	6,010	-	(3,482)	-	2,528
Local Group Forum Event	-	13,355	(13,355)	-	-
Ageing	-	2,990	(2,990)	-	-
Newly Diagnosed	-	78,319	(78,319)	-	-
AGM	-	33,810	(33,810)	-	-
Ambassadors	-	63,000	(63,000)	-	-
APPG Project	30,000	-	(25,761)	-	4,239
Overseas Research	5,500	-	(2,505)	-	2,995
Advocacy (Party Conference)	-	20,000	(20,000)	-	-
Training Device	-	2,500	(2,500)	-	-
Patient Info	-	1,250	(1,250)	-	-
EHC Activity Grant (Mediation)	-	2,512	(2,512)	-	-
Philip Morris Art Award	2,465	513	-	3,273	6,251
Howard Abrahams Memorial Award	1,709	453	-	1,946	4,108
	49,618	243,826	(276,028)	5,219	22,635

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

17 Fund reconciliation (continued)

Endowment Funds

	Balance at 1st April 2019 £	Income £	Expenditure £	Transfers £	Balance at 31st March 2020 £
Philip Morris Art Award	13,344	-	-	(5,844)	7,500
Howard Abrahams Memorial Award	6,000	-	-	625	6,625
	<hr/> 19,344	-	-	(5,219)	<hr/> 14,125

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, last year the board designated £600,000 of reserves to fund the charity's work on the Inquiry over four years. It is anticipated our work to participate in the Inquiry, support and inform members of the community affected by the Inquiry may cost up to £150,000 per year until Autumn 2022. 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 the 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.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

17 Fund reconciliation (continued)

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

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

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

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

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

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.

Advocacy (Party Conference): sponsorship for the Conservative and Labour Party Political Conferences to highlight the work of APPG for haemophilia and contaminated blood

Training Device: Funding to purchase intravenous infusion training devices for IV training)

Patient Info: Funding to publish Hemlibra patient information leaflets

EHC Activity Grant: Fund to improve local group communication

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.

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

17 Fund reconciliation (continued)

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	1,185,427	-	-	14,125	1,199,552
Net current assets	140,730	53,387	22,635	-	216,752
Total	<u>1,326,157</u>	<u>53,387</u>	<u>22,635</u>	<u>14,125</u>	<u>1,416,304</u>

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

	2020	2019
	£	£
Net (expenditure) / income for year	(41,272)	233,478
Interest receivable	(39,620)	(35,122)
Depreciation of tangible fixed assets	8,568	6,238
Losses / (gains) on investments	16,145	(41,301)
Decrease / (increase) in debtors	181,292	(180,190)
Decrease in creditors	(35,225)	(14,581)
Net cash flow from operating activities	<u>89,888</u>	<u>(31,478)</u>

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 £26,092 (2019: £25,718).

The Haemophilia Society

Notes to the financial statements

Year ended 31 March 2020

21 Financial commitments

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

	2020 Within 1 year £	2020 Within 1-5 years £	2019 Within 1 year £	2019 Within 1-5 years £
Land and buildings	36,300	60,500	52,285	7,525
Other	4,100	6,874	1,494	-
	<hr/>	<hr/>	<hr/>	<hr/>
	40,400	67,374	53,779	7,525

22 Related party transactions

The charity received donations from four trustees during the period £625 (2019: £nil).

23 Contingent assets

As at 4 June 2019, the charity had been notified of one legacy held solely in shares. At the date of signing the financial statements, the value cannot be estimated with sufficient reliability and so this legacy has not been accrued.




24 Events after the reporting date

In present circumstances and based on the current COVID-19 situation we had to postpone all future live events until the foreseeable future. We are looking at practical and innovative ways in which we can deliver events in the future, if the COVID-19 pandemic is not eradicated.



THE HAEMOPHILIA SOCIETY

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President: Baroness Meacher
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For everyone affected by a genetic bleeding disorder