

Haemochromatosis UK Trustees' Annual Report & Accounts

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www.haemochromatosis.org.uk

Statutory Information

We are Haemochromatosis UK.

Registered office

Henrith Business Centre, 3 Enterprise Way, Pinchbeck, Lincolnshire PE11 3YR

Regulators

Charity Commission for England and Wales (Charity No. 1001307)

The Office of the Scottish Charity Regulator (Charity No. SCO41701)

Companies House (Company Limited by Guarantee No. 2541361)

Independent Financial Examiner

Community Accounting Plus

Units 1 and 2, Northwest

41 Talbot Street

Nottingham

NG1 5GL

Bankers

CAF Bank Ltd (principal)

Shawbrook Bank

The Royal Bank of Scotland

Trustees at 1st February 2021

Tim Spring, Chair of Trustees

Katy Burns MBE, Safeguarding Trustee

Kim Hicks, Clinical Trustee

Rodger Houghton, Finance Trustee

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2. INTRODUCTION FROM THE CHAIR

The trustees are pleased to report that – despite the challenges of the Covid-19 pandemic – the charity has continued to develop and prosper as we seek to support people affected by genetic haemochromatosis.

We are extremely grateful to our members and donors who pledge their support for HUK, especially those who personally fundraise and volunteer for us. Without their financial support and commitment to our cause, we would simply be unable to do what we do.

During the year, our small team of staff was joined by Gerri Mortimore (as Education Programme Manager) and Elizabeth Lang (as Social Media Community & Volunteer Manager). We welcome them both and are delighted that they have already made a significant contribution to our education and community programmes.

We would also like to thank our Chief Executive, Neil McClements and Vicki Lunn (Membership Administrator) for their continuing hard work during what has proven to be a challenging and busy year.

The trustees understand there are currently no outstanding legal issues. This year some trustees have stepped down to pursue other interests. We would like to thank them for the time they have given to HUK in their roles. We welcome all new Board member colleagues.

We look forward to the year ahead, despite the ongoing Covid-19 pandemic. We will continue to raise awareness, educate healthcare professionals, support patients and families, and encourage research to help people live well with iron overload.

A handwritten signature in black ink, appearing to read 'TS', with a stylized flourish at the end.

Tim Spring
Chair of the Board of Trustees



3. A MESSAGE FROM THE CHIEF EXECUTIVE

For many people, 2020 will go down as the Year of Covid-19. It's fair to say that the pandemic caused a significant change to our plans within just 3 months of the New Year. It brought a range of challenges – but it also encouraged us to become yet more agile and innovative in our support for people affected by genetic haemochromatosis.

First, the challenges. Well, most of our well laid plans for members' events, clinician education and community fundraising had to be put on hold. The government lockdown prevented us from running any of our planned community fundraising events, including the popular Iron Games.

In previous years we have relied heavily on our community and corporate donors for their financial support. So, as our team moved to a remote working model in March we doubled-down on our grants and trusts fundraising. This proved to be more successful than we'd hoped and – alongside our new online donations capability – enabled us to largely bridge the financial gap presented by Covid-19. We are especially grateful for the ongoing and steadfast support of the Shears Foundation, National Lottery Community Fund and Google, to enable us to continue our vital work against such a turbulent national backdrop.

On an even more positive note, lockdown gave us the time and headspace to completely revamp our information and advice resources. We're blessed to enjoy the design talents of our volunteer Gail Pearce, who has totally transformed the branding and look of our publications. They are easier to read, look more professional and present our charity in a very positive light. Our new website has been well received and helps us provide even more support to people in need.

Our events programme

We also had to look at how to host and operate events remotely. With the help of the National Lottery Community Fund and the Scottish Government Wellbeing Fund, we have been able to re-establish our members' socials (also known as Iron Brews) as an online monthly event.

Paradoxically, our education programme went from strength-to-strength as NHS primary care practitioners flocked to our online "lunch and learn" sessions. These bite-sized 45 minute introductions to GH care diagnosis and care pathways have now reached as many clinicians online as in the previous two years at face-to-face events – remarkable, given the ravages of the pandemic on our colleagues in primary care.

Membership

We've worked hard to create additional value for members. This has included a free will writing service, access to a members-only legal helpline and a host of new information, resources and videos, which members get priority access to. We revamped our prized membership pack to include additional resources on key topics, including joint pain, cardiomyopathy, overcoming blood/needle phobia – and more. These initiatives helped HUK to increase its membership by 19% year-on-year. If you are not already a member of the charity, may I encourage you to join us – together we are stronger!

Our new families forum, working with children and young people

I'm also pleased to share details of some new initiatives we started in 2020 to better support families affected by GH. We continue to press for timely and early diagnosis as we know that this can save lives. Increasingly, children are being diagnosed (a good thing) but there are no resources to help under 18s understand the condition and address their worries. Our new families forum brings together mums, dads, grandparents and children and young people to help collaboratively devise new resources for schools and young people. The first fruits of this work are the new Kidszone resources, generously supported by the Ernest Hecht Foundation and Envision (a marketing and communications agency). These have already been warmly welcomed by the NHS – our first batch of 100 kids packs went to Birmingham's Children Hospital in early 2021. We look forward to rolling these out via a schools programme in 2021 (Covid-19 permitting).

Media and public awareness

Through our constant advocacy of our community's needs we are starting to see a real improvement in public awareness. Throughout the year we were featured on TV, radio and in the press many, many times. This included Marilyn's GH story which was published in Saga Magazine, which is read by over 250,000 people. Our involvement in medical research, including the work of Professor Melzer's team at Exeter University, has led to thousands of column inches in the press, with mentions in all the national papers and overseas, too.

We continue to seek opportunities to tell the world about GH to enable better understanding and diagnosis. In early 2021, we were supported by Stephen McGann (of Call The Midwife fame) with a broadcast on BBC Radio 4. This reached over 3 million people and was the culmination of over 14 months' work by the charity's team to convince the BBC of our cause, secure a presenter, draft the script and handle the associated administration from the appeal itself.

Advocacy to the NHS, policymakers and elected representatives

Our All-Party Parliamentary Group on GH continued to meet virtually throughout the year. Our State of the Nation report was well-received and given detailed consideration by APPG members. We continue to press for timely diagnosis of people at risk of GH and best practice in clinical pathways.

Following a review of the charity's strategy in early 2020, we have progressed several collaborations throughout the year. This has included working with the Samaritans and CRUSE Bereavement Care on training initiatives.

Significantly, the charity succeeded in lobbying NHS Blood & Transplant to introduce a special donation scheme for GH donors. This was a win-win for everyone concerned. The Covid-19 pandemic caused a dramatic drop in donated blood supplies and our community experienced difficulties in gaining ongoing venesection appointments. The charity's team worked hard on behalf of the community to co-design a new scheme which meant – for the first time – GH donors were recognised as a national resource, with their own bespoke donor appointments and flexible donor eligibility arrangements. Similar initiatives were initiated with ScotBlood and the charity has engaged with the Northern Ireland Blood Transfusion Service to promote the rollout of specific GH donor arrangements across the wider NHS.

Medical research

Research is a very expensive business, requiring deep pockets. Our limited resources constrain the amount of medical research we ourselves can commission. However, over the course of the year we introduced two new medical research awards available to NHS clinicians, academics and researchers to stimulate interest in GH. The inaugural Fernau Medical Research Award was awarded in late 2020 and the first Nursing Best Practice Award will be presented next year.

Although direct research is expensive, we have collaborated widely with better-funded research teams, notably Professor Melzer's team at Exeter Medical School, where we have shared interests. During the year we worked with researchers at the Winton Centre, University of Cambridge, to define and refine genetic test reports to improve their clarity, understandability and readability. Over 100 HUK members participated and the resulting reports have already been adopted by one large NHS genomics lab, with others to follow. We also worked with researchers at John Moores University in Liverpool to better understand the psychological impact of Covid-19 on people with GH. Thanks to the contributions of over 600 HUK members, the resulting research is due to be published later this year.

Sadly, the planned clinical trials with NCIMI (National Consortium of Intelligent Medical Imaging) have been cancelled due to Covid-19. We continue to work towards a restart of the trial at a later date, once lockdown conditions permit. In the interim, HUK has been active in NCIMI Consortium Management and participated in work to represent patient perspectives in the valuation and distribution of medical imaging data for machine learning purposes. This work is extremely active behind the scenes, and we continue to collaborate with several NHS hospital trusts and our research colleagues at the University of Oxford.

The real cost of Covid-19

Despite the many good things that we have achieved in 2020, we are mindful of the tragic loss of so many lives to Covid-19. We continue to support and encourage families bereaved by the virus as well as by ill-health caused by GH. It is humbling that so many families have sought to support the charity through in-memoriam donations following the loss of a loved one. We truly appreciate their resolve at the most difficult of times, as they seek to help others overcome GH.

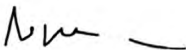
We will continue to tell peoples' stories to policymakers, our elected representatives and other stakeholders as we press for more timely diagnosis and better care and screening for genetic haemochromatosis. We stand with everyone affected by the virus and genetic haemochromatosis itself. Behind the numbers are real people, real families. We are thinking of you, especially at this difficult time.

A big thank you to our donors, volunteers and team

Crucially, I would like to thank our many volunteers and donors. Quite simply, we couldn't do it without you. I am continually humbled by the dedication and faithfulness of our community, especially our helpline volunteers and fundraisers. May I also pay tribute to the charity's small team of staff – Sara, Vicki, Izzie and Gerri - who work so diligently and passionately, behind-the-scenes? Their efforts often go unnoticed, but it's this quiet, determined focus on our charity's mission and members that lies behind so many of our successes.

So, I thank everyone for your support during 2020. It was tough year, but we look forward to better times in 2021 and beyond.

Take care, stay safe.



Neil McClements
Chief Executive Officer
April 2021

4. TRUSTEES' REPORT FOR 2020

Background

Genetic haemochromatosis (GH) is a condition that leads to a build-up of iron in the body to toxic levels. In turn this causes a wide range of symptoms and follow-on conditions, some of which can be very serious or indeed, in the worst cases, fatal.

Haemochromatosis UK (HUK) is a patient-led membership-based charity and patient organisation. HUK has over 1,850 paid-up members and over 800 clinician associates. The charity links thousands of people affected by GH through events, social media and other activities.

HUK has four key objectives:

- to provide information and support to patients and their families
- to educate healthcare professionals, patients and others about GH and its impact
- to raise public awareness of GH and of the importance of early intervention
- to stimulate and influence research into the science, impact and statistics of GH

Here, we report progress with these objectives during 2020 and outline plans and aspirations for the coming year. During 2020, the Board and our CEO began formulating our new three-year strategic plan that will focus on our vision for the future of the charity whilst ensuring that we continue to implement and uphold our four key objectives. This process continues into 2021, and we look forward to engaging with members as we refine our future plans.

The trustees follow the Charity Commission's guidance on public benefit when planning and reviewing spending, activities and budgets. Many of the trustees have GH themselves, which ensures that we do not lose sight of our priorities. We also recognise that having GH is not a prerequisite to joining the Board. We seek to draw upon a wide range of talents and skills, both within and beyond the GH community, to ensure that the Board is effective and focussed in supporting the charity's continuing development.

It's important to note that the charity's financial position remains sound, despite the significant challenges to community fundraising brought about by the Covid-19 pandemic. We continue to focus on stewarding the charity's financial resources to ensure the long-term sustainability of the organisation whilst delivering much-needed, effective services to the GH community. On the following pages, our Annual Financial Statements set out the financial position in more detail.

An important thank you message

As ever, the trustees would like to extend grateful thanks to volunteers, members, donors, fundraisers, activists, advisers and other supporters for their contribution over the year. There are too many individuals to mention here; many have undertaken challenges, made substantial donations, volunteered on our helpline, helped with our families forum, reviewed and contributed to information resources, taken part in videos ... the list goes on. Every charity relies on such support and it is difficult convey in just a few words the importance of what you do for us and for people affected by genetic haemochromatosis; we thank you all sincerely.

Trust grants

This year, we have enjoyed further increased support from charitable trusts, totalling almost £109,000. The trustees would like to extend their grateful thanks and public acknowledgment to our supporters:

- The Shears Foundation
- The Scottish Government Wellbeing Fund
- The National Lottery Community Fund Awards for All Programmes in England and Northern Ireland
- The National Lottery Covid-19 Emergency Response Fund
- The Independent Age Fund
- The Burdett Trust for Nursing
- The Medlock Trust
- The James Tudor Foundation
- The Ernest Hecht Foundation
- AbbVie
- South Holland District Council
- Foundation Scotland
- Kilpatrick Fraser Trust
- The February Foundation
- VIVID and Hampshire Community Foundation
- Society for Endocrinology
- Belfast Cathedral
- The NIE Pension Fund
- Local Spalding councillors on behalf of South Holland District Council's Covid-19 Emergency Response Fund
- The Grace Trust

Corporate donations

We were unable to run our popular Iron Games events in 2020, due to the Covid-19 pandemic. This had a significant impact on corporate donations. However, we gratefully acknowledge the support of the following donors for their support during this difficult year:

- Google Ireland
- Tesco plc
- Wesleyan Insurance
- Moore Barlow Solicitors
- Hootsuite LLC
- Zoho LLC

Information & support

One of our core aims is to provide information and advice to people affected by genetic haemochromatosis. This includes families, friends, colleagues and employers of people with the condition.

During 2020 we took advantage of the Covid-19 lockdown (which prevented physical events from running as usual) to develop a broad range of new information resources. This included the launch of our new website, which was visited by over 87,000 people over the course of the year, who collectively accessed almost 250,000 pages of content. We also revised and re-published our well-regarded Haemochromatosis Handbook, now in its sixth edition.

We also developed a totally new and up-to-date set of resources covering common areas of concern for people with genetic haemochromatosis. This included new guides on:

- Joint pain and GH
- Healthy eating and GH
- Covid-19 and GH
- Pituitary problems and GH
- A General Practitioners' Guide to GH
- A General Practitioners' Quick Guide to GH Genetics
- A guide to overcoming needle, blood and injury phobias
- A guide to understanding your blood test results
- A new guide to the genetics and care pathway for GH

We remain committed to delivering high quality information and advice, and all our new resources are reviewed for accuracy and completeness by our Clinical Advisory Panel.

The number of people using our social media channels has continued to increase. We have over 4,000 followers on our Facebook page and our Facebook Support Group has grown over the year by almost 10% to over 7,700 members. Our Twitter social media channel continues to report high levels of engagement, especially amongst clinicians, with almost 2,000 followers – a 21% increase year-on-year.

The Haemochromatosis Helpline responded to almost 700 calls and emails throughout the year. Our volunteer helpliners continue to report useful insights that inform much of how we strive to support our members. During 2020 we extended our helpline offerings to include genetic counselling and advanced GH nurse practitioner appointments – these have been well received, and continue to be available in 2021.

Education

Much of our education work is aimed at healthcare professionals in order to improve clinician awareness of genetic haemochromatosis, its diagnosis and best practice care. In early 2020, we secured endorsement from the Royal College of Nursing for our Venesection Best Practice Guidance. Since publication in February, we have distributed over 1,000 guides to NHS hospitals and healthcare practitioners. The book is also available via Amazon and has been downloaded in eBook format by clinicians in Australia, Thailand, Malaysia, Brazil, and Ireland, as well as across the UK. We have also distributed the book to the UK public library system, so it is available in every public library including those run by the British Library, Universities of Oxford and Cambridge libraries, Royal College of Nursing libraries and Trinity College Dublin Library.

This year, we moved our education events online due to Covid-19, and have been running monthly training seminars for GPs and other healthcare practitioners. Several hundred clinicians have been trained this way; the seminars are popular with busy healthcare professionals and the online format has been very well received.

Our 30-minute e-learning module on iron overload for GPs, in collaboration with The Royal College of General Practitioners (RCGP), continues to help GPs better understand the condition. Throughout 2020, we observed an average 95% improvement in candidates' knowledge when tested before and after the training module.

We also took the opportunity to create new educational videos on blood and needle phobia, in partnership with Guy's & St Thomas' NHS Foundation Trust. They include resources for people with GH to learn breathing techniques to reduce anxiety before and during venesection. We also published new video resources on what to do when things go wrong with NHS care and several introductions to the genetics of GH, to explain the condition.

Shortly after the Covid-19 pandemic began, we produced two "Ask the doctor" videos with Dr Susan Hancock (FRCGP). Susan is a member of our Clinical Advisory Panel and graciously answered dozens of members' questions about Covid-19 and GH. To date, these videos have been viewed over 4,000 times and they continue to provide useful support to people worried about Covid-19 and GH.

In February, we entered the Rare Disease Film Awards, with a film about the experiences of our member Anna. The film was narrated by our member Carrie Afrin, a professional voice artist. Although "Rare is Real" didn't win an award, it helped us to raise awareness of GH and has been viewed by over 1,300 people to date.

Awareness

Unfortunately, Covid-19 lockdown restrictions prevented us from running our planned series of events for World Haemochromatosis Week (WHW) in June. However, we moved our awareness raising activities online and saw a growing number of people contact the charity as a result of targeted online media and social media campaigns aimed at raising awareness of GH.

In August, we published a detailed study on NHS Clinical Care Pathways for people with GH. This State of the Nation report was the culmination of over a year's work and was studied in detail by members of the All-Party Parliamentary Group on GH. It led to many useful conversations with elected representatives and NHS policymakers on the often patchy care provided to people with GH across the UK.

Research

Medical research is an expensive endeavour. However, we were pleased to collaborate with several studies throughout the year. These included a project with the Winton Centre at the University of Cambridge to define and publish better genetics reports for GH and a study with John Moores University into the mental health aspects of Covid-19 within the GH community.

We also launched two new research awards. The Fernau Medical Research Award is available to a researcher(s) focussed on furthering our understanding of genetic haemochromatosis. The HUK Nursing Best Practice Award aims to highlight best practice in nursing care available to people with GH.

In late 2020 the Fernau Medical Research Award was presented to Dr Janice Atkins for a 2021 project to better understand the epidemiological aspects of GH in relation to three commonly associated conditions. This project will seek to understand the levels of excess disease caused by GH, a key factor in persuading policy-makers to take the condition more seriously.

The All Party Parliamentary Group for Genetic Haemochromatosis

Following the national elections in December 2019, the APPG was – by law – suspended. We re-convened the group in February 2020 under the strengthened leadership of the Rt Hon Sir John Hayes CBE MP (Chair) and Ben Lake MP (Vice-Chair). We are grateful to both members (and the other members of the APPG) for their continuing active interest in our cause and their regular support of the charity in the media as well as in the House of Commons.

The All-Party Parliamentary Group on GH met twice in 2020, including at a successful online session in December which was attended by almost 100 people. Our charity acts as secretariat for the APPG and we hope to run further meetings online to enable as many members of the public to get involved as possible. We are grateful to the parliamentary authorities, who have permitted us to film the online sessions. This has led to the publication of 4 awareness-raising videos, including two videos of members' accounts of their experiences of liver cancer and GH, a clinician/research video hosted by Dr Janice Atkins of Exeter University Medical School and a video by our Chief Executive, Neil McClements on the challenges posed by Covid-19 to the GH community. All 4 videos are available on our website and our Youtube channel, which has gone from strength-to-strength. In 2020, almost 19,000 people watched our videos on Youtube and our subscriber base rose by 83%.

We welcome the continued influence that the APPG provides over healthcare policymakers and opportunities for collaboration with other partners are growing monthly. We encourage the GH community to engage with our elected representatives, both directly and through the APPG.

Clinical Advisory Panel

Our Clinical Advisory Panel (CAP) continues to provide valuable information and advice to us in our work.

Due to Covid-19, the group met less frequently than planned. However, we enjoyed an enhanced level of engagement from CAP members directly – especially in the review and publication of our new information resources. We are grateful to all CAP members for dedicating so much of their free time to our cause, especially when there are so many challenges in the NHS concerning Covid-19.

Look out for our publications marked "CAP Reviewed & Approved", which have been rigorously reviewed to ensure medical accuracy, clinical effectiveness and helpful information for people with genetic haemochromatosis.

NCIMI (National Consortium of Intelligent Medical Imaging)

NCIMI is the National Consortium of Intelligent Medical Imaging. The consortium is funded by the UK government and industry. It aims to use medical imaging more intelligently to improve diagnosis and treatments of a wide range of diseases.

Haemochromatosis UK is a founding member of the consortium, which is being led by the University of Oxford and is funded by Innovate UK over 3 years. The programme is developing medical imaging diagnostic tools to help identify conditions including genetic haemochromatosis.

Unfortunately, Covid-19 has prevented the planned clinical trial from progressing. Following NHS England guidance and in view of the continuing infection control measures associated with the pandemic lockdown, our industrial partners Perspectum Diagnostics and GE have reluctantly suspended the project. However, our academic partners, including the University of Oxford and InnovateUK, continue to value the charity's contribution to patient representation, policy formation and this aspect of the programme is continuing with renewed vigour.

Fundraising

None of the activities described in this report would be possible without the necessary finance, and like every charity we invest time and resources in the generation of funding. We do this by bidding for grants for specific activities, encouraging individuals to donate and fundraise for us, and by building relationships with potential corporate donors.

Unfortunately, Covid-19 and the associated lockdowns made a significant dent in our fundraising capabilities. It was not possible to operate the face-to-face fundraising events planned (e.g. London Marathon, Iron Games). We look forward to happier times, when we can restart these community fundraising initiatives.

Happily, our new website has enabled us to bridge the gap caused by Covid-19. Online donations rose significantly over the year and provided three times the level of donations seen in the previous year. We are especially grateful to everyone who has donated online – every penny helps us to help others.

In 2020 we invested in further professional fundraising expertise to develop bids to various funders for some of our projects. This has yielded additional support from a range of grant awarding bodies and foundations. This support has been especially key for us at a time when community fundraising initiatives have been paused due to Covid-19.

In summary, HUK has enjoyed a very successful year, increasing influence and resources whilst maintaining and growing our core information and support services.

Statement of Fundraising Regulator and Fundraising Preference Service Compliance

Donors to our charity can be assured that we comply with the regulatory standards for fundraising. We are registered with the Fundraising Regulator and are committed to the Fundraising Promise and adherence to the Code of Fundraising Practice. This report covers the requirements charities must follow as set out in the Charities Act 2016.

In 2020, we spent just over £229,000 to provide our charitable services. Of our income of £317,667, almost 37% of our income came from grant awarding bodies and foundations (e.g. National Lottery, Shears Trust). Donations (including in-memoriam, community fundraising and ad hoc donations) accounted for almost 25% of income. A further 23% came from consultancy services delivered to NCIMI and the NHS. Membership subscriptions contributed almost 15% of income. The remaining balance of our income came from HMRC Gift Aid reclaims, bank interest and income from our online shop.

Our fundraising efforts involve encouraging community fundraising events, donations and gifts in wills, supporting challenge events and engaging with grant awarding bodies on specific projects. Our grants and trusts fundraising team work in-house to help us deliver fundraising initiatives. We aim to ensure those fundraisers we engage with observe the highest standards in terms of fundraising practice, including compliance with the Code of Fundraising Practice and the charity's own policies.

We are registered with the Fundraising Regulator and comply with all relevant standards set out in the Code of Fundraising Practice.

We occasionally use third-party partners to help us raise funds (for example, the Big Give), particularly where we do not have the expertise in-house. We have safeguards in place when working with partners so that we protect our supporters and the reputation of our charity. All donations are accepted and processed in line with the charity's published Donations Policy.

We aim to respond to all complaints relating to our fundraising activities within 28 days. Complaints are dealt with in accordance with our fundraising complaints policy. Any serious complaints are dealt with by our CEO and trustees so that they can consider lessons learnt. The trustees also review an annual report about complaints, from the CEO.

In the event that an individual wishes to make a complaint, our website provides our contact details to the public. Where we receive complaints during a year, we also report to the Fundraising Regulator on the totality of our complaints. In 2020, we had no complaints and so there were no complaints to report to the Fundraising Regulator.

We are also signed up to the Fundraising Preference Service (FPS) to enable individuals to opt out from receiving fundraising communications from us. In 2020, we received no requests from the FPS for action.

We publish our external policies publicly on our website here: **<https://www.haemochromatosis.org.uk/our-policies>**. These include our Safeguarding Policy. In addition to this policy we have an agreed operating procedure to protect vulnerable people. Our fundraisers (both staff and partners) are familiarised with the Code Of Conduct to ensure that it is applied properly and everyone fundraising for the charity undertakes annual mandatory safeguarding training and assessment.

5. GOVERNANCE

Our trustees are responsible in law for the financial and strategic management of the charity.

The trustees during 2020 were Philip Briggs, Phil Coathup, Lisa Flude, Simon Flude, Katharine Hough, Joshua Kaile, Roger Keyte, Stuart McDonald, Jeremy Shearman, Corrina Towers, Alan Walls, Michelle Weerasekera.

In July 2020, the Charity Commission commenced an inquiry into the charity's governance under sections 46 and 47 of the Charities Act 2011, in response to public concerns. In October 2020, the Commission issued the charity's trustees with regulatory advice under section 15(2) of the Charities Act 2011.

Their advice focussed on:

- The governance of the charity
- Ensuring the charity's safeguarding, complaints and whistleblowing policies are fit for purpose
- Internal financial controls and the importance of keeping up to date records
- GDPR and data protection policies and procedures

A new board of trustees was appointed on 1st February 2021. The Charity Commission has closed its case into the matter and will not be taking further action.

The trustees appointed on 1st February 2021 are Rodger Houghton (Finance Trustee), Katy Burns MBE (Safeguarding Trustee), Kim Hicks (Clinician Trustee), Tim Spring (Chair of Trustees).

Trustees are expected to attend all Board meetings and the charity's annual conference and AGM, contribute meaningfully to decision making, and to act in accordance with good practice guidance issued by the Charity Commission and Companies House.

When a trustee vacancy arises, it is advertised widely in accordance with Charity Commission best practice guidance. This includes on our own website, eBulletin and social media channels, plus external recruitment forums including ICAEW Volunteers, CharityJobs, Reach Volunteering, Law Society Volunteering, LinkedIn, the Young Trustees Movement and elsewhere. Each new trustee is provided with an induction training pack, which includes a guide to the legal and practical responsibilities of being a trustee. All trustees must undertake annual safeguarding training.

Our record with the commission can be found by searching on the www.charitycommission.gov.uk site using charity number 1001307.

Our full accounts can be found by searching Companies House for company 2541361.

The Executive

The trustees delegate responsibility for day-to-day operations to the Chief Executive, who is supported by a small part-time staff team comprised of the Education Programme Manager, Financial Controller, Social Media Community and Volunteering Manager and Membership & Clinical Trials Administrator. The team represents just over 3 full-time equivalent post-holders.

Strategic Planning

In early 2020, the executive team drafted an interim strategic plan with a continued focus on the delivery of our core objectives. This will be further refined by the Board throughout 2021.



6. FINANCE

2020 was a challenging year for everyone, as the Covid-19 pandemic dominated all our lives. The charity was not immune to the impacts of the virus, but overall our finances remain in good health – certainly much better than feared in the Spring.

The original budget for 2020 was revised in April to consider the likely impacts of Covid-19. We anticipated that fundraising would be harder than before, but it was the Autumn before the full scale of the challenges became clear. Our community fundraising initiatives – including the Iron Games – all succumbed to lockdown.

The planned extension of the staff team proceeded as planned. These additional team members helped to broaden our range of services.

So, it was a good overall outcome for the charity to end the year with a surplus of income over expenditure of £88,235. The steps taken earlier in the lockdown to review expenditure and boost non-community fundraising efforts paid off. This means that the charity's cash reserves have increased over the year by 32% to £356,707.

Income

Our income for the year was £317,667, which was down 13% on the previous year. Given the impact of Covid-19, this is a good outcome – we are better placed financially than many voluntary sector organisations.

The majority of our income came from 4 key sources:

- Trusts & foundations: 37%
- Donations (including in-memoriam, community fundraising, Friends Against Iron Overload): 25%
- Consultancy services: 23%
- Membership subscriptions: 15%

Members will note the growing importance of trusts and foundations to our income mix, especially as corporate donations (including Iron Games) were affected by the Covid-19 lockdown.

Restricted and designated funds

Total income comprises income received for different purposes: Restricted funds are those which a donor has specified must be used for a specific project or purpose. Designated funds are those allocated to specific projects by the trustees on a discretionary basis. Unrestricted funds have been received without any restriction and are used to achieve HUK's general objectives.

Included in the total income for the year is £67,159 of Restricted Funds and £142,279 of Designated funds. We expect to deploy most of these restricted funds incrementally over the next 12-18 months, as Covid-19 conditions permit.

Expenditure

Total expenditure for 2020 was £229,432, a decrease of 29% over the previous year. Significant efforts were made during the year to review expenditure. Where possible, services were re-tendered and new suppliers sought on a best value basis. This resulted in the appointment of our new independent examiners, Community Accounting Plus, alongside reduced costs for our IT and printing needs.

Our costs throughout the year related to ongoing operations including employment and associated costs, fundraising, and office and administration costs. Key costs included work on specific projects such as the Venesection Best Practice project and the training and development of our volunteers, including the helpline team.

Policy on Reserves

In developing the charity's reserves policy, the trustees are mindful of the need to provide a level of working capital that protects the continuity of the charity's work whilst providing a level of funding that enables the organisation to capitalise on unexpected opportunities.

Our policy provides cover for risks such as unforeseen expenditure or unanticipated loss of income. The trustees are especially mindful of these risks following the Covid-19 pandemic, where income has been adversely affected due to lockdown constraints, whilst the demand for the charity's services and support has increased significantly.

In this, the charity's 30th anniversary year, the trustees are mindful of the ongoing and growing needs of the genetic haemochromatosis community and the need to ensure the financial sustainability of the organisation for the long term.

To that end, the trustees of the charity resolve to pursue a policy of establishing and maintaining a contingency reserve fund sufficient to meet between six to nine months' unrestricted expenditure.

Conclusion

Despite the challenges of Covid-19, we can report that HUK remains in a strong financial position. The charity is planning to put the available funds to good use in 2021, thereby further enhancing the achievement of its objectives.



Rodger Houghton
Finance trustee

HAEMOCHROMATOSIS UK OBJECTIVES, STRATEGIES AND ACTIVITIES

Objects and aims

- (i) To provide for persons with hereditary haemochromatosis or associated diseases (hereinafter called "the Diseases") help with those problems (including but not limited to diagnosis, medical care, treatment and financial burden) resulting from the Diseases and to provide such other charitable relief as the Society may think fit;
- (ii) To undertake for the public benefit research into the Diseases and to publish the useful results of such research;
- (iii) To advance the education of the general public and the medical profession into the causes, effects and prevalence of the Diseases with the aim of:
 - (a) increasing the proportion of haemochromatotics diagnosed as such;
 - (b) promoting diagnosis at an early stage before the onset of irreversible organ damage.

Objectives, strategies and activities

HUK undertakes four key activities:

- to provide information and support to patients and their families;
- to educate healthcare professionals, patients and others about GH and its impact;
- to raise public awareness of GH and of the importance of early intervention;
- to stimulate and influence research into the science, impact and statistics of GH.

Public benefit

The charity's trustees have given due consideration to the Charity Commission for England & Wales' published guidance on the public benefit requirement under the Charities Act 2011. Our programme of activities also conforms to the charity's charitable objectives and aims.

We work to support anyone affected by genetic haemochromatosis, irrespective of age, gender, ethnicity or race, religion, sexual orientation or genetic status. In particular, our information, advice and helpline services are available to the general public free of charge. Our annual review illustrates several initiatives to advance patient safety through improved clinician education and our wider influencing work, in the public interest, to raise awareness of the needs of the genetic haemochromatosis community through engagement with elected representatives, policymakers and the public at large.

As such, the work carried out by Haemochromatosis UK is consistent with charitable purposes as identified in the Charities Act 2011 (The advancement of health or saving of lives).

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Statement of trustees' Responsibilities

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees 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 charitable company and of its incoming resources and application of resources, including its income and expenditure for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

Approved by the Board on 13th April 2021.



Tim Spring
Chair
April 2021



Rodger Houghton
Finance trustee
April 2021

7. ACCOUNTS

Statement of Trustees' Responsibilities

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees 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 charitable company and of its incoming resources and application of resources, including its income and expenditure for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The annual report was approved by the trustees of the charity on 13th April 2021 and signed on its behalf by:



Tim Spring
Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF HAEMOCHROMATOSIS UK

Independent examiner's report to the trustees of Haemochromatosis UK ('the Company')

I report to the charity trustees on my examination of the accounts of the company for the year ended 31 December 2020.

Responsibilities and basis of report

As the charity's trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member and Fellow of the Association of Charity Independent Examiners, which is one of the listed bodies. I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. The accounts do not accord with those records; or
3. The accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. The accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

John O'Brien

John O'Brien MSc, FCCA, FCIE, employee of Community Accounting Plus
Fellow of the Association of Charity Independent Examiners
Units 1 & 2 North West
41 Talbot Street
Nottingham
NG1 5GL

Date: 14 April 2021

Haemochromatosis UK
Statement of Financial Activities for the Year Ended 31 December 2020
(Including Income and Expenditure Account and Statement of Total
Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2020 £	Total 2019 £
Income and endowments from:					
Donations and legacies	3	83,804	-	83,804	222,136
Charitable activities	4	124,423	108,873	233,296	141,437
Investment income	2	567	-	567	1,122
Total income		208,794	108,873	317,667	364,695
Expenditure on:					
Charitable activities	6	(126,840)	(102,592)	(229,432)	(324,531)
Total expenditure		(126,840)	(102,592)	(229,432)	(324,531)
Net income		81,954	6,281	88,235	40,164
Transfers between funds		(3,655)	3,655	-	-
Net movement of Funds		78,299	9,936	88,235	40,164
Reconciliation of funds:					
Total funds brought forward		211,249	57,223	268,472	228,308
Total funds carried forward	14	289,548	67,159	356,707	268,472

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for the period is shown in note 14.

Haemochromatosis UK
Statement of Financial Activities for the Year Ended 31 December 2020
(Including Income and Expenditure Account and Statement of Total
Recognised Gains and Losses)

These are the figures for the previous accounting period and are included for comparative purposes

	Note	Unrestricted funds £	Restricted funds £	Total 2019 £
Income and endowments from:				
Donations and legacies	3	222,136	-	222,136
Charitable activities	4	85,376	56,061	141,437
Investment income	2	1,122	-	1,122
Total income		308,634	56,061	364,695
Expenditure on:				
Charitable activities	6	(324,531)	-	(324,531)
Total expenditure		(324,531)	-	(324,531)
Net (expenditure)/income		(15,897)	56,061	40,164
Net movement of funds		(15,897)	56,061	40,164
Reconciliation of funds:				
Total funds brought forward		227,146	1,162	228,308
Total funds carried forward	14	211,249	57,223	268,472

Haemochromatosis UK
(Registration number: 02541361)
Balance Sheet as at 31 December 2020

	Notes	2020 £	2019 £
Current assets			
Debtors	11	9,161	1,660
Cash at bank and in hand		352,258	273,736
		361,419	275,396
Creditors: amounts falling due within one year	12	(4,712)	(6,924)
Net assets		356,707	268,472
Funds of the charity:			
Restricted income funds			
Restricted funds		67,159	57,223
Unrestricted income funds			
Unrestricted funds		289,548	211,249
Total charity funds	14	356,707	268,472

For the financial year ending 31 December 2020 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements on pages 8 to 19 were approved by the trustees, and authorised for issue on 13th April 2021 and signed on their behalf by:



Rodger Houghton
Trustee

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

1 Accounting policies

Summary of significant accounting policies and key accounting estimates

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

Statement of compliance

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) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). They also comply with the Companies Act 2006 and Charities Act 2011.

Basis of preparation

Haemochromatosis UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The financial statements have been prepared on a going concern basis.

The trustees assess whether the use of going concern is appropriate, i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the charity to continue as a going concern. The trustees make this assessment in respect of a period of one year from the date of approval of the financial statements.

Exemption from preparing a cash flow statement

The charity opted to adopt Bulletin 1, published on 2 February 2016, and have therefore not included a cash flow statement in these financial statements.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Government grants

Government grants are recognised based on the accrual model and are measured at the fair value of the asset received or receivable. Grants are classified as relating either to revenue or to assets. Grants relating to revenue are recognised in income over the period in which the related costs are recognised. Grants relating to assets are recognised over the expected useful life of the asset. Where part of a grant relating to an asset is deferred, it is recognised as deferred income.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right at the end of the reporting period to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity. Designated funds are unrestricted funds set aside for specific purposes at the discretion of the trustees. Restricted income funds are those grants for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Pensions and other post-retirement obligations

The charity operates a defined contribution pension scheme for employees. The assets of the scheme are held separately from those of the charity. Pension costs charges in the Statement of Financial Activities represent the contributions payable by the charity during the year.

Haemochromatosis UK**Notes to the Financial Statements for the Year Ended 31 December 2020****2 Investment income**

	Unrestricted funds		
	General	Total 2020	Total 2019
	£	£	£
Interest receivable and similar income;			
Interest receivable on bank deposits	567	567	1,122

3 Income from donations and legacies

	Unrestricted funds		
	General	Total 2020	Total 2019
	£	£	£
Grants, including capital grants;			
Government grants	7,425	7,425	13,870
Grants from other charities	76,379	76,379	208,266
	83,804	83,804	222,136

4 Income from charitable activities

	Unrestricted funds			
	General	Restricted funds	Total 2020	Total 2019
	£	£	£	£
Grants & donations	-	108,873	108,873	-
Consultancy fees	72,527	-	72,527	-
Event ticket sales	772	-	772	-
Membership subscriptions	45,230	-	45,230	41,766
Merchandise	5,206	-	5,206	-
Sundry income	688	-	688	71,058
Charitable activities	-	-	-	28,613
	124,423	108,873	233,296	141,437

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

5 Grants & donations

	Unrestricted funds	Restricted funds	Total
	£	£	£
Shears Foundation	-	25,000	25,000
Big Lottery Community Fund	-	16,801	16,801
Corra Foundation	-	10,136	10,136
Independent Age	-	10,000	10,000
Burdett Trust	-	8,000	8,000
Abbie Fund	-	5,000	5,000
Ernest Hecht Fund	-	5,000	5,000
Foundation Scotland	-	5,000	5,000
James Tudor Foundation	-	5,000	5,000
Medlock Trust	-	5,000	5,000
Halifax Foundation	-	4,000	4,000
Kilpatrick Fraser Charitable Trust	-	2,880	2,880
February Foundation	-	2,500	2,500
Vivid - Hampshire	-	2,471	2,471
Society for Endocrinology	-	2,085	2,085
South Holland District Council	5,000	-	5,000
Gift Aid	17,425	-	17,425
Sundry grants & donations	61,379	-	61,379
	<u>83,804</u>	<u>108,873</u>	<u>192,677</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

6 Expenditure on charitable activities

	Unrestricted General funds	Unrestricted Designated funds	Restricted funds	Total 2020	Total 2019
	£	£	£	£	£
Accountancy	7,944	-	-	7,944	-
Advertising/Promotional	2,241	-	-	2,241	-
Bank charges	2,362	-	-	2,362	-
Equipment & computer costs	3,452	-	1,994	5,446	-
External events	3,962	-	834	4,796	-
Dues & subscriptions	1,324	-	-	1,324	-
Hosted events	2,220	-	-	2,220	-
Insurance	1,048	-	-	1,048	-
IT, repairs & servicing	1,722	-	-	1,722	-
Legal & professional	10,880	-	-	10,880	-
Materials stock	2,659	-	4,994	7,653	-
Office/General admin	308	-	-	308	-
Phone costs	1,805	-	525	2,330	-
Premises costs	17	-	-	17	-
Printing, postage & stationery	171	1,000	9,690	10,861	-
Publications	1,052	-	4,166	5,218	-
Raising funds	108	-	-	108	-
Recruitment	53	-	-	53	-
Rent	9,300	-	-	9,300	-
Software	2,837	-	2,834	5,671	-
Staff benefits	1,399	-	-	1,399	-
Sundry costs	697	-	-	697	-
Training	-	-	1,955	1,955	-
Travel & accommodation	2,518	-	-	2,518	-
Trustees expenses	1,997	-	-	1,997	-
Wages, NI & pension	62,104	-	75,600	137,704	-
Bad debts written off	1,660	-	-	1,660	-
Information & support	-	-	-	-	93,245
Education & awareness	-	-	-	-	133,281
Research	-	-	-	-	5,404
International expenses	-	-	-	-	5,404
Raising funds	-	-	-	-	68,562
Governance	-	-	-	-	18,635
	125,840	1,000	102,592	229,432	324,531

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

7 Trustees remuneration and expenses

During the year the charity made the following transactions with trustees:

Corrina Towers

£400 (2019: £Nil) of travel expenses were reimbursed to Corrina Towers during the year.

Katharine Hough

£45 (2019: £Nil) of travel expenses were reimbursed to Katharine Hough during the year.

Lisa Flude

£844 (2019: £Nil) of travel expenses were reimbursed to Lisa Flude during the year.

Roger Keyte

£392 (2019: £Nil) of travel expenses were reimbursed to Roger Keyte during the year.

Simon Flude

£264 (2019: £Nil) of travel expenses were reimbursed to Simon Flude during the year.

Information for trustee expenses in the previous period is unavailable.

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

8 Fees payable to independent examiner

During the period, the fees payable (excluding VAT) to the charity's independent examiner Community Accounting Plus are analysed as follows:

	2020	2019
	£	£
Independent examination	1,080	1,800

Haemochromatosis UK**Notes to the Financial Statements for the Year Ended 31 December 2020****9 Staff costs**

The aggregate payroll costs were as follows:

	2020
	£
Staff costs during the year were:	
Wages and salaries	118,301
Social security costs	7,473
Pension costs	1,248
Compensation payments	10,682
	<u>137,704</u>

Information on Staff costs for the previous period is unavailable.

The monthly average number of persons (including senior management team) employed by the charity during the year was as follows:

	2020	2019
	No	No
Average number of employees	<u>3</u>	<u>5</u>

3 (2019 -) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £1,248 (2019 - £Nil).

Information on Pension contributions and numbers for the previous period are unavailable.

During the year, the charity made redundancy and/or termination payments which totalled £10,682 (2019 - £Nil).

The total employee benefits of the key management personnel of the charity were £63,545 (2019 - £Nil).

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

10 Taxation

The charity is a registered charity and is therefore exempt from taxation.

11 Debtors

	2020	2019
	£	£
Trade debtors	535	1,660
Prepayments	8,626	-
	<u>9,161</u>	<u>1,660</u>

12 Creditors: amounts falling due within one year

	2020	2019
	£	£
Trade creditors	512	2,099
Other taxation and social security	2,928	3,025
Other creditors	192	-
Accruals	1,080	1,800
	<u>4,712</u>	<u>6,924</u>

13 Charity status

The charity is a company limited by guarantee and consequently does not have share capital. Each of the trustees is liable to contribute an amount not exceeding £1 towards the assets of the charity in the event of liquidation.

Haemochromatosis UK**Notes to the Financial Statements for the Year Ended 31 December 2020****14 Funds**

	Balance at 1 January 2020	Incoming resources	Resources expended	Transfers	Balance at 31 December 2020
	£	£	£	£	£
Unrestricted funds					
<i>General</i>					
General	206,249	208,794	(125,840)	(141,934)	147,269
<i>Designated</i>					
Education & Awareness	-	-	(1,000)	143,279	142,279
Irish Travellers Project	5,000	-	-	(5,000)	-
	5,000	-	(1,000)	138,279	142,279
Total Unrestricted funds	211,249	208,794	(126,840)	(3,655)	289,548
Restricted funds					
Information & Support	2,650	9,221	(6,995)	-	4,876
Education & Awareness	373	5,335	(5,373)	(335)	-
GH Education	30,000	38,000	(31,000)	-	37,000
Helpline	-	34,301	(23,823)	-	10,478
Northern Ireland Community Fund	11,000	4,000	(2,750)	-	12,250
Scottish Wellbeing	3,000	18,016	(17,651)	(1,010)	2,355
Irish Travellers Project	-	-	(5,000)	5,000	-
Your Patient Will See You Now	10,000	-	(10,000)	-	-
Medical Research	200	-	-	-	200
Total restricted funds	57,223	108,873	(102,592)	3,655	67,159
Total funds	268,472	317,667	(229,432)	-	356,707

	Balance at 1 January 2019	Incoming resources	Resources expended	Balance at 31 December 2019
Unrestricted funds				
General	227,146	308,634	(324,531)	211,249
Restricted funds	1,162	56,061	-	57,223
Total funds	228,308	364,695	(324,531)	268,472

Detailed information on the funds for the previous period is unavailable.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

The specific purposes for which the funds are to be applied are as follows:

- Information & support – funds provided for the production of materials to provide information and support on Haemochromatosis. This includes hospital packs, production of leaflets, booklets, website content and videos;
- Education & awareness – funds provided for the development of educational resources; GH Education – funds provided for the education of healthcare professionals; Helpline – funds provided towards the costs of providing a Helpline;
- Northern Ireland Community Fund – funding towards providing support and information specifically in Northern Ireland; Scottish Wellbeing – funds towards providing counselling services, education and support specifically in Scotland;
- Irish Travellers project – funding for the Breaking Down Barriers project to engage with Irish travellers throughout the country;
- Your Patient Will See You Now – funding to implement the Patient Expert Programme, a programme to empower patients by educating them about the condition.

The transfer from the General fund to the Education & Awareness designated fund is to reclassify those funds. The transfer from the Irish Travellers Project designated fund to the Irish Travellers Project restricted fund is to reclassify those funds. The transfer from the Education & Awareness restricted fund to the General fund was for expenses incurred in the previous financial period. The transfer from the Scottish Wellbeing fund to the General fund represents the release of any restrictions for the balance remaining of a grant received.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

15 Analysis of net assets between funds

	Unrestricted funds		2020 Total funds
	General	Restricted funds	
	£	£	£
Current assets	294,260	67,159	361,419
Current liabilities	(4,712)	-	(4,712)
Total net assets	289,548	67,159	356,707

	Unrestricted funds		2019 Total funds
	General	Restricted funds	
	£	£	£
Current assets	218,173	57,223	275,396
Current liabilities	(6,924)	-	(6,924)
Total net assets	211,249	57,223	268,472

16 Related party transactions

There were no related party transactions in the year.

Contact us

We work to support anyone affected
by genetic haemochromatosis.

Join us – together we're stronger

Become a member – signup on our website.

Haemochromatosis UK Advice & Help Line

Telephone (12-3pm weekdays): **03030 401 102**

Email (24/7): **helpline@huk.org.uk**

Website: **www.haemochromatosis.org.uk**

Company registration number: 02541361
Charity registration number: 1001307
Charity registration number - Scotland: SC041701

Haemochromatosis UK

(A company limited by guarantee)

Annual Report and Financial Statements

for the Year Ended 31 December 2020

Community Accounting Plus
Units 1 & 2 North West
41 Talbot Street
Nottingham
NG1 5GL

Haemochromatosis UK

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Haemochromatosis UK

Reference and Administrative Details

Trustees	Tim Spring Kim Hicks Katy Burns MBE Rodger Houghton
Senior Management Team	Neil McClements, CEO
Principal Office	Henrith Business Centre 3 Enterprise Way Pinchbeck Spalding Lincolnshire PE11 3YR
Company Registration Number	02541361
Charity Registration Number	1001307 England & Wales SC041701 Scotland
Independent Examiner	John O'Brien, employee of Community Accounting Plus Units 1 & 2 North West 41 Talbot Street Nottingham NG1 5GL

Haemochromatosis UK

Trustees' Report

The trustees, who are directors for the purposes of company law, present the annual report together with the financial statements of the charitable company for the year ended 31 December 2020.

Trustees

Tim Spring (appointed 1 February 2021)
Kim Hicks (appointed 1 February 2021)
Katy Burns MBE (appointed 1 February 2021)
Rodger Houghton (appointed 1 February 2021)
Katharine Hough (resigned 1 February 2021)
Dr Stuart McDonald (resigned 2 December 2020)
Michelle Weerasekera (resigned 26 June 2020)
Roger Keyte (resigned 4 April 2020)
Corrina Towers (resigned 6 March 2020)
Lisa Flude (resigned 24 February 2020)
Simon Flude (resigned 24 February 2020)
Dr Jeremy Shearman (appointed 17 March 2020 and resigned 1 February 2021)
Phil Coathup (appointed 22 April 2020 and resigned 1 February 2021)
Alan Walls (appointed 22 April 2020 and resigned 26 June 2020)
Joshua Kaile (appointed 22 April 2020 and resigned 30 October 2020)
Philip Briggs (appointed 5 May 2020 and resigned 26 June 2020)

Structure, governance and management

Nature of governing document

The charity is a company limited by guarantee and registered charity. It is operated under the rules of its memorandum and articles of association dated 20/09/1990 and most recently amended 24/07/2019. It has no share capital and the liability of each member in the event of winding-up is limited to £1.

Recruitment and appointment of trustees

We follow Charity Commission guidance and advertise all prospective trustee roles widely in accordance with our equal opportunities policy. All candidates are interviewed and successful applicants undertake an induction and training process to familiarise themselves with the charity and the role and responsibilities of being a trustee. This includes meetings with the Chair and CEO to discuss the charity's trustee information pack detailing the charity's work, governance, management policies and procedures.

Induction and training of trustees

All trustees are provided training in trustee-ship, from the National Council of Voluntary Organisations and others.

Haemochromatosis UK

Trustees' Report

Objectives and activities

Objects and aims

- (i) To provide for persons with hereditary haemochromatosis or associated diseases (hereinafter called “the Diseases”) help with those problems (including but not limited to diagnosis, medical care, treatment and financial burden) resulting from the Diseases and to provide such other charitable relief as the Society may think fit;
- (ii) To undertake for the public benefit research into the Diseases and to publish the useful results of such research;
- (iii) To advance the education of the general public and the medical profession into the causes, effects and prevalence of the Diseases with the aim of:
 - (a) increasing the proportion of haemochromatotics diagnosed as such;
 - (b) promoting diagnosis at an early stage before the onset of irreversible organ damage.

Objectives, strategies and activities

HUK undertakes four key activities :

- to provide information and support to patients and their families;
- to educate healthcare professionals, patients and others about GH and its impact;
- to raise public awareness of GH and of the importance of early intervention;
- to stimulate and influence research into the science, impact and statistics of GH.

Public benefit

The charity’s Trustees have given due consideration to the Charity Commission for England & Wales’ published guidance on the public benefit requirement under the Charities Act 2011. Our programme of activities also conforms to the charity's charitable objectives and aims.

We work to support anyone affected by genetic haemochromatosis, irrespective of age, gender, ethnicity or race, religion, sexual orientation or genetic status. In particular, our information, advice and helpline services are available to the general public free of charge. Our annual review illustrates several initiatives to advance patient safety through improved clinician education and our wider influencing work, in the public interest, to raise awareness of the needs of the genetic haemochromatosis community through engagement with elected representatives, policymakers and the public at large.

As such, the work carried out by Haemochromatosis UK is consistent with charitable purposes as identified in the Charities Act 2011 (The advancement of health or saving of lives).

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Haemochromatosis UK

Trustees' Report

Achievements and performance

Despite the challenges of Covid-19, the charity has been very active during the year and secured many achievements. These are set out in more detail in the charity's annual review, available for free download from our website - <https://www.haemochromatosis.org.uk/>

Notable achievements during 2020 included the revamp of our trusted information and advice resources. We launched our new website and delivered additional resources on key topics, including joint pain, cardiomyopathy, overcoming blood/needle phobia – and more.

Over the year, the charity provided assistance to over 1,800 families via its helplines and counselling services, over 10,000 people via its social media channels and support groups and almost 1,000 NHS clinicians via the charity's clinical education programme. We grew our membership by 19% year-on-year.

Financial review

2020 was a challenging year for everyone, as the Covid-19 pandemic dominated all our lives. The charity was not immune to the impacts of the virus, but overall our finances remain in good health, certainly much better than feared in the Spring.

The original budget for 2020 was revised in April, to consider the likely impacts of Covid-19. We anticipated that fundraising would be harder than before, but it was the Autumn before the full scale of the challenges became clear. The London Marathon, Great North Run and Sussex Hill Half-Marathon all succumbed to lockdown. Other community fundraising initiatives – including the Iron Games – were cancelled, too.

The planned extension of the staff team proceeded as planned. These additional team members help to broaden our range of services; much of the funding for these roles came from new supporters and grant awarding bodies.

So, it was a good overall outcome for the charity to end the year with a surplus of income over expenditure of £88,235. The steps taken earlier in the lockdown to review expenditure and boost non-community fundraising efforts paid off. This means that the charity's cash reserves have increased over the year by 32% to £356,707.

Income

Our income for the year was £317,667, which was down 13% on the previous year. Given the impact of Covid-19, this is a good outcome - we are better placed financially than many voluntary sector organisations.

The majority of our income came from 4 key sources:

- Trusts & foundations: 37%
- Donations (including in-memoriam, community fundraising, Friends Against Iron Overload): 25%
- Consultancy services: 23%
- Membership subscriptions: 15%

Members will note the growing importance of trusts and foundations to our income mix, especially as corporate donations (including Iron Games) were affected by the Covid-19 lockdown.

Haemochromatosis UK

Trustees' Report

Restricted and designated funds

Total income comprises income received for different purposes: Restricted funds are those which a donor has specified must be used for a specific project or purpose. Designated funds are those allocated to specific projects by the Trustees on a discretionary basis. Unrestricted funds have been received without any restriction and are used to achieve HUK's general objectives.

Included in the closing balances for the year is £67,519 of restricted funds and £142,279 of designated funds. We expect to deploy most of these restricted funds incrementally over the next 12-18 months, as Covid-19 conditions permit.

Expenditure

Total expenditure for 2020 was £229,432 a decrease of 29% over the previous year. Significant efforts were made during the year to review expenditure. Where possible, services were re-tendered and new suppliers sought on a best value basis. This resulted in the appointment of our new independent examiners Community Accounting Plus, alongside reduced costs for our IT and printing needs.

Our costs during the year related to ongoing operations including employment and associated costs, fund raising, office and administration costs. Key costs included work on specific projects, including the Venesection Best Practice project and the training and development of our volunteers, including the helpline team.

Conclusion

Despite the challenges of Covid-19, we can report that HUK remains in a strong financial position. The charity is planning to put the available funds to good use in 2021, thereby further enhancing the achievement of its objectives.

Policy on reserves

In developing the charity's reserves policy, the trustees are mindful of the need to provide a level of working capital that protects the continuity of the charity's work whilst providing a level of funding to enable the organisation to capitalise on unexpected opportunities.

Our policy provides cover for risks such as unforeseen expenditure or unanticipated loss of income. The trustees are especially mindful of these risks following the Covid-19 pandemic, where income has been adversely affected due to lockdown constraints, whilst simultaneously the demand for the charity's services and support has increased significantly.

In this, the charity's 30th anniversary year, the trustees are mindful of the ongoing and growing needs of the genetic haemochromatosis community and the need to ensure financial sustainability of the organisation for the long term.

To that end, the trustees of the charity resolve to pursue a policy of establishing and maintaining a contingency reserve fund sufficient to meet between six to nine months' unrestricted expenditure.

Haemochromatosis UK

Trustees' Report

Statement of Trustees' Responsibilities

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees 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 charitable company and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The annual report was approved by the trustees of the charity on 13/04/2021 and signed on its behalf by:

Timothy Spring

.....
Tim Spring
Trustee

Haemochromatosis UK

Independent Examiner's Report to the trustees of Haemochromatosis UK

Independent examiner's report to the trustees of Haemochromatosis UK ('the Company')

I report to the charity trustees on my examination of the accounts of the company for the year ended 31 December 2020.

Responsibilities and basis of report

As the charity's trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member and Fellow of the Association of Charity Independent Examiners, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

John O'Brien

.....
John O'Brien MSc, FCCA, FCIE, employee of Community Accounting Plus
Fellow of the Association of Charity Independent Examiners

Units 1 & 2 North West
41 Talbot Street
Nottingham
NG1 5GL

14 / 04 / 2021

Date:.....

Haemochromatosis UK

Statement of Financial Activities for the Year Ended 31 December 2020 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2020 £	Total 2019 £
Income and Endowments from:					
Donations and legacies	3	83,804	-	83,804	222,136
Charitable activities	4	124,423	108,873	233,296	141,437
Investment income	2	567	-	567	1,122
Total income		<u>208,794</u>	<u>108,873</u>	<u>317,667</u>	<u>364,695</u>
Expenditure on:					
Charitable activities	6	<u>(126,840)</u>	<u>(102,592)</u>	<u>(229,432)</u>	<u>(324,531)</u>
Total expenditure		<u>(126,840)</u>	<u>(102,592)</u>	<u>(229,432)</u>	<u>(324,531)</u>
Net income		81,954	6,281	88,235	40,164
Transfers between funds		<u>(3,655)</u>	<u>3,655</u>	<u>-</u>	<u>-</u>
Net movement in funds		78,299	9,936	88,235	40,164
Reconciliation of funds					
Total funds brought forward		<u>211,249</u>	<u>57,223</u>	<u>268,472</u>	<u>228,308</u>
Total funds carried forward	14	<u><u>289,548</u></u>	<u><u>67,159</u></u>	<u><u>356,707</u></u>	<u><u>268,472</u></u>

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for the period is shown in note 14.

Haemochromatosis UK

Statement of Financial Activities for the Year Ended 31 December 2020 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

These are the figures for the previous accounting period and are included for comparative purposes

	Note	Unrestricted funds £	Restricted funds £	Total 2019 £
Income and Endowments from:				
Donations and legacies	3	222,136	-	222,136
Charitable activities	4	85,376	56,061	141,437
Investment income	2	1,122	-	1,122
Total income		<u>308,634</u>	<u>56,061</u>	<u>364,695</u>
Expenditure on:				
Charitable activities	6	<u>(324,531)</u>	-	<u>(324,531)</u>
Total expenditure		<u>(324,531)</u>	-	<u>(324,531)</u>
Net (expenditure)/income		<u>(15,897)</u>	<u>56,061</u>	<u>40,164</u>
Net movement in funds		(15,897)	56,061	40,164
Reconciliation of funds				
Total funds brought forward		<u>227,146</u>	<u>1,162</u>	<u>228,308</u>
Total funds carried forward	14	<u><u>211,249</u></u>	<u><u>57,223</u></u>	<u><u>268,472</u></u>

Haemochromatosis UK

(Registration number: 02541361)

Balance Sheet as at 31 December 2020

	Note	2020 £	2019 £
Current assets			
Debtors	11	9,161	1,660
Cash at bank and in hand		<u>352,258</u>	<u>273,736</u>
		361,419	275,396
Creditors: Amounts falling due within one year	12	<u>(4,712)</u>	<u>(6,924)</u>
Net assets		<u><u>356,707</u></u>	<u><u>268,472</u></u>
Funds of the charity:			
Restricted income funds			
Restricted funds		67,159	57,223
Unrestricted income funds			
Unrestricted funds		<u>289,548</u>	<u>211,249</u>
Total funds	14	<u><u>356,707</u></u>	<u><u>268,472</u></u>

For the financial year ending 31 December 2020 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements on pages 8 to 19 were approved by the trustees, and authorised for issue on 13/04/2021 and signed on their behalf by:



.....
Rodger Houghton
Trustee

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

1 Accounting policies

Summary of significant accounting policies and key accounting estimates

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

Statement of compliance

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) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). They also comply with the Companies Act 2006 and Charities Act 2011.

Basis of preparation

Haemochromatosis UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The financial statements have been prepared on a going concern basis.

The trustees assess whether the use of going concern is appropriate i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the charity to continue as a going concern. The trustees make this assessment in respect of a period of one year from the date of approval of the financial statements.

Exemption from preparing a cash flow statement

The charity opted to adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Government grants

Government grants are recognised based on the accrual model and are measured at the fair value of the asset received or receivable. Grants are classified as relating either to revenue or to assets. Grants relating to revenue are recognised in income over the period in which the related costs are recognised. Grants relating to assets are recognised over the expected useful life of the asset. Where part of a grant relating to an asset is deferred, it is recognised as deferred income.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Designated funds are unrestricted funds set aside for specific purposes at the discretion of the trustees.

Restricted income funds are those grants for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme for employees. The assets of the scheme are held separately from those of the charity. Pension costs charges in the Statement of Financial Activities represent the contributions payable by the charity during the year.

2 Investment income

	Unrestricted funds	Total 2020	Total 2019
	General £	£	£
Interest receivable and similar income;			
Interest receivable on bank deposits	567	567	1,122

3 Income from donations and legacies

	Unrestricted funds	Total 2020	Total 2019
	General £	£	£
Grants, including capital grants;			
Government grants	7,425	7,425	13,870
Grants from other charities	76,379	76,379	208,266
	<u>83,804</u>	<u>83,804</u>	<u>222,136</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

4 Income from charitable activities

	Unrestricted funds	Restricted funds	Total 2020	Total 2019
	General £	£	£	£
Grants & donations	-	108,873	108,873	-
Consultancy fees	72,527	-	72,527	-
Event ticket sales	772	-	772	-
Membership subscriptions	45,230	-	45,230	41,766
Merchandise	5,206	-	5,206	-
Sundry income	688	-	688	71,058
Charitable activities	-	-	-	28,613
	<u>124,423</u>	<u>108,873</u>	<u>233,296</u>	<u>141,437</u>

5 Grants & donations

	Unrestricted funds	Restricted funds	Total
	£	£	£
Shears Foundation	-	25,000	25,000
Big Lottery Community Fund	-	16,801	16,801
Corra Foundation	-	10,136	10,136
Independent Age	-	10,000	10,000
Burdett Trust	-	8,000	8,000
Abbvie Fund	-	5,000	5,000
Ernest Hecht Fund	-	5,000	5,000
Foundation Scotland	-	5,000	5,000
James Tudor Foundation	-	5,000	5,000
Medlock Trust	-	5,000	5,000
Halifax Foundation	-	4,000	4,000
Kilpatrick Fraser Charitable Trust	-	2,880	2,880
February Foundation	-	2,500	2,500
Vivid - Hampshire	-	2,471	2,471
Society for Endocrinology	-	2,085	2,085
South Holland District Council	5,000	-	5,000
Gift Aid	17,425	-	17,425
Sundry grants & donations	61,379	-	61,379
	<u>83,804</u>	<u>108,873</u>	<u>192,677</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

6 Expenditure on charitable activities

	Unrestricted General funds £	Unrestricted Designated funds £	Restricted funds £	Total 2020 £	Total 2019 £
Accountancy	7,944	-	-	7,944	-
Advertising / Promotional	2,241	-	-	2,241	-
Bank charges	2,362	-	-	2,362	-
Equipment & computer costs	3,452	-	1,994	5,446	-
External events	3,962	-	834	4,796	-
Dues & subscriptions	1,324	-	-	1,324	-
Hosted events	2,220	-	-	2,220	-
Insurance	1,048	-	-	1,048	-
IT, repairs & servicing	1,722	-	-	1,722	-
Legal & professional	10,880	-	-	10,880	-
Materials stock	2,659	-	4,994	7,653	-
Office / General admin	308	-	-	308	-
Phone costs	1,805	-	525	2,330	-
Premises costs	17	-	-	17	-
Printing, postage & stationery	171	1,000	9,690	10,861	-
Publications	1,052	-	4,166	5,218	-
Raising funds	108	-	-	108	-
Recruitment	53	-	-	53	-
Rent	9,300	-	-	9,300	-
Software	2,837	-	2,834	5,671	-
Staff benefits	1,399	-	-	1,399	-
Sundry costs	697	-	-	697	-
Training	-	-	1,955	1,955	-
Travel & accommodation	2,518	-	-	2,518	-
Trustees expenses	1,997	-	-	1,997	-
Wages, NI & pension	62,104	-	75,600	137,704	-
Bad debts written off	1,660	-	-	1,660	-
Information & support	-	-	-	-	93,245
Education & awareness	-	-	-	-	133,281
Research	-	-	-	-	5,404
International expenses	-	-	-	-	5,404
Raising funds	-	-	-	-	68,562
Governance	-	-	-	-	18,635
	<u>125,840</u>	<u>1,000</u>	<u>102,592</u>	<u>229,432</u>	<u>324,531</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

7 Trustees remuneration and expenses

During the year the charity made the following transactions with trustees:

Corrina Towers

£400 (2019: £Nil) of travel expenses were reimbursed to Corrina Towers during the year.

Katharine Hough

£45 (2019: £Nil) of travel expenses were reimbursed to Katharine Hough during the year.

Lisa Flude

£844 (2019: £Nil) of travel expenses were reimbursed to Lisa Flude during the year.

Roger Keyte

£392 (2019: £Nil) of travel expenses were reimbursed to Roger Keyte during the year.

Simon Flude

£264 (2019: £Nil) of travel expenses were reimbursed to Simon Flude during the year.

Information for Trustee expenses in the previous period is unavailable.

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

8 Fees payable to independent examiner

During the period, the fees payable (excluding VAT) to the charity's independent examiner Community Accounting Plus are analysed as follows:

	2020 £	2019 £
Independent examination	<u>1,080</u>	<u>1,800</u>

9 Staff costs

The aggregate payroll costs were as follows:

	2020 £
Staff costs during the year were:	
Wages and salaries	118,301
Social security costs	7,473
Pension costs	1,248
Compensation payments	<u>10,682</u>
	<u>137,704</u>

Information on Staff costs for the previous period is unavailable.

The monthly average number of persons (including senior management team) employed by the charity during the year was as follows:

	2020 No	2019 No
Average number of employees	<u>3</u>	<u>5</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

3 (2019 -) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £1,248 (2019 - £Nil).

Information on Pension contributions and numbers for the previous period are unavailable.

During the year, the charity made redundancy and/or termination payments which totalled £10,682 (2019 - £Nil).

The total employee benefits of the key management personnel of the charity were £63,545 (2019 - £Nil).

10 Taxation

The charity is a registered charity and is therefore exempt from taxation.

11 Debtors

	2020 £	2019 £
Trade debtors	535	1,660
Prepayments	8,626	-
	<u>9,161</u>	<u>1,660</u>

12 Creditors: amounts falling due within one year

	2020 £	2019 £
Trade creditors	512	2,099
Other taxation and social security	2,928	3,025
Other creditors	192	-
Accruals	1,080	1,800
	<u>4,712</u>	<u>6,924</u>

13 Charity status

The charity is a company limited by guarantee and consequently does not have share capital. Each of the trustees is liable to contribute an amount not exceeding £1 towards the assets of the charity in the event of liquidation.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

14 Funds

	Balance at 1 January 2020 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2020 £
Unrestricted funds					
<i>General</i>					
General	206,249	208,794	(125,840)	(141,934)	147,269
<i>Designated</i>					
Education & Awareness	-	-	(1,000)	143,279	142,279
Irish Travellers Project	5,000	-	-	(5,000)	-
	<u>5,000</u>	<u>-</u>	<u>(1,000)</u>	<u>138,279</u>	<u>142,279</u>
Total Unrestricted funds	<u>211,249</u>	<u>208,794</u>	<u>(126,840)</u>	<u>(3,655)</u>	<u>289,548</u>
Restricted funds					
Information & Support	2,650	9,221	(6,995)	-	4,876
Education & Awareness	373	5,335	(5,373)	(335)	-
GH Education	30,000	38,000	(31,000)	-	37,000
Helpline	-	34,301	(23,823)	-	10,478
Northern Ireland Community Fund	11,000	4,000	(2,750)	-	12,250
Scottish Wellbeing	3,000	18,016	(17,651)	(1,010)	2,355
Irish Travellers Project	-	-	(5,000)	5,000	-
Your Patient Will See You Now	10,000	-	(10,000)	-	-
Medical Research	200	-	-	-	200
Total restricted funds	<u>57,223</u>	<u>108,873</u>	<u>(102,592)</u>	<u>3,655</u>	<u>67,159</u>
Total funds	<u>268,472</u>	<u>317,667</u>	<u>(229,432)</u>	<u>-</u>	<u>356,707</u>
	Balance at 1 January 2019 £	Incoming resources £	Resources expended £	Balance at 31 December 2019 £	
Unrestricted funds					
General	227,146	308,634	(324,531)	211,249	
Restricted funds	<u>1,162</u>	<u>56,061</u>	<u>-</u>	<u>57,223</u>	
Total funds	<u>228,308</u>	<u>364,695</u>	<u>(324,531)</u>	<u>268,472</u>	

Detailed information on the funds for the previous period is unavailable.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

The specific purposes for which the funds are to be applied are as follows:

Information & support – funds provided for the production of materials to provide information and support on Haemochromatosis. This includes hospital packs, production of leaflets, booklets, website content and videos;
 Education & awareness – funds provided for the development of educational resources;
 GH Education – funds provided for the education of healthcare professionals;
 Helpline – funds provided towards the costs of providing a Helpline;
 Northern Ireland Community Fund – funding towards providing support and information specifically in Northern Ireland;
 Scottish Wellbeing – funds towards providing counselling services, education and support specifically in Scotland;
 Irish Travellers project – funding for the Breaking Down Barriers project to engage with Irish travellers throughout the country;
 Your Patient Will See You Now – funding to implement the Patient Expert Programme, a programme to empower patients by educating them about the condition.

The transfer from the General fund to the Education & Awareness designated fund is to reclassify those funds. The transfer from the Irish Travellers Project designated fund to the Irish Travellers Project restricted fund is to reclassify those funds.

The transfer from Education & Awareness restricted fund to the General fund was for expenses incurred in the previous financial period.

The transfer from Scottish Wellbeing fund to the General fund represents the release on any restrictions for the balance remaining of a grant received.

15 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	2020 Total funds
	General £	£	£
Current assets	294,260	67,159	361,419
Current liabilities	(4,712)	-	(4,712)
Total net assets	<u>289,548</u>	<u>67,159</u>	<u>356,707</u>
	Unrestricted funds	Restricted funds	2019 Total funds
	General £	£	£
Current assets	218,173	57,223	275,396
Current liabilities	(6,924)	-	(6,924)
Total net assets	<u>211,249</u>	<u>57,223</u>	<u>268,472</u>

16 Related party transactions

There were no related party transactions in the year.

Company registration number: 02541361

Charity registration number: 1001307

Charity registration number - Scotland: SC041701

Haemochromatosis UK

(A company limited by guarantee)

Annual Report and Financial Statements

for the Year Ended 31 December 2020

Community Accounting Plus
Units 1 & 2 North West
41 Talbot Street
Nottingham
NG1 5GL

Haemochromatosis UK

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Haemochromatosis UK

Reference and Administrative Details

Trustees	Tim Spring Kim Hicks Katy Burns MBE Rodger Houghton
Senior Management Team	Neil McClements, CEO
Principal Office	Henrith Business Centre 3 Enterprise Way Pinchbeck Spalding Lincolnshire PE11 3YR
Company Registration Number	02541361
Charity Registration Number	1001307 England & Wales SC041701 Scotland
Independent Examiner	John O'Brien, employee of Community Accounting Plus Units 1 & 2 North West 41 Talbot Street Nottingham NG1 5GL

Haemochromatosis UK

Trustees' Report

The trustees, who are directors for the purposes of company law, present the annual report together with the financial statements of the charitable company for the year ended 31 December 2020.

Trustees

Tim Spring (appointed 1 February 2021)
Kim Hicks (appointed 1 February 2021)
Katy Burns MBE (appointed 1 February 2021)
Rodger Houghton (appointed 1 February 2021)
Katharine Hough (resigned 1 February 2021)
Dr Stuart McDonald (resigned 2 December 2020)
Michelle Weerasekera (resigned 26 June 2020)
Roger Keyte (resigned 4 April 2020)
Corrina Towers (resigned 6 March 2020)
Lisa Flude (resigned 24 February 2020)
Simon Flude (resigned 24 February 2020)
Dr Jeremy Shearman (appointed 17 March 2020 and resigned 1 February 2021)
Phil Coathup (appointed 22 April 2020 and resigned 1 February 2021)
Alan Walls (appointed 22 April 2020 and resigned 26 June 2020)
Joshua Kaile (appointed 22 April 2020 and resigned 30 October 2020)
Philip Briggs (appointed 5 May 2020 and resigned 26 June 2020)

Structure, governance and management

Nature of governing document

The charity is a company limited by guarantee and registered charity. It is operated under the rules of its memorandum and articles of association dated 20/09/1990 and most recently amended 24/07/2019. It has no share capital and the liability of each member in the event of winding-up is limited to £1.

Recruitment and appointment of trustees

We follow Charity Commission guidance and advertise all prospective trustee roles widely in accordance with our equal opportunities policy. All candidates are interviewed and successful applicants undertake an induction and training process to familiarise themselves with the charity and the role and responsibilities of being a trustee. This includes meetings with the Chair and CEO to discuss the charity's trustee information pack detailing the charity's work, governance, management policies and procedures.

Induction and training of trustees

All trustees are provided training in trustee-ship, from the National Council of Voluntary Organisations and others.

Haemochromatosis UK

Trustees' Report

Objectives and activities

Objects and aims

- (i) To provide for persons with hereditary haemochromatosis or associated diseases (hereinafter called “the Diseases”) help with those problems (including but not limited to diagnosis, medical care, treatment and financial burden) resulting from the Diseases and to provide such other charitable relief as the Society may think fit;
- (ii) To undertake for the public benefit research into the Diseases and to publish the useful results of such research;
- (iii) To advance the education of the general public and the medical profession into the causes, effects and prevalence of the Diseases with the aim of:
 - (a) increasing the proportion of haemochromatotics diagnosed as such;
 - (b) promoting diagnosis at an early stage before the onset of irreversible organ damage.

Objectives, strategies and activities

HUK undertakes four key activities :

- to provide information and support to patients and their families;
- to educate healthcare professionals, patients and others about GH and its impact;
- to raise public awareness of GH and of the importance of early intervention;
- to stimulate and influence research into the science, impact and statistics of GH.

Public benefit

The charity’s Trustees have given due consideration to the Charity Commission for England & Wales’ published guidance on the public benefit requirement under the Charities Act 2011. Our programme of activities also conforms to the charity's charitable objectives and aims.

We work to support anyone affected by genetic haemochromatosis, irrespective of age, gender, ethnicity or race, religion, sexual orientation or genetic status. In particular, our information, advice and helpline services are available to the general public free of charge. Our annual review illustrates several initiatives to advance patient safety through improved clinician education and our wider influencing work, in the public interest, to raise awareness of the needs of the genetic haemochromatosis community through engagement with elected representatives, policymakers and the public at large.

As such, the work carried out by Haemochromatosis UK is consistent with charitable purposes as identified in the Charities Act 2011 (The advancement of health or saving of lives).

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Haemochromatosis UK

Trustees' Report

Achievements and performance

Despite the challenges of Covid-19, the charity has been very active during the year and secured many achievements. These are set out in more detail in the charity's annual review, available for free download from our website - <https://www.haemochromatosis.org.uk/>

Notable achievements during 2020 included the revamp of our trusted information and advice resources. We launched our new website and delivered additional resources on key topics, including joint pain, cardiomyopathy, overcoming blood/needle phobia – and more.

Over the year, the charity provided assistance to over 1,800 families via its helplines and counselling services, over 10,000 people via its social media channels and support groups and almost 1,000 NHS clinicians via the charity's clinical education programme. We grew our membership by 19% year-on-year.

Financial review

2020 was a challenging year for everyone, as the Covid-19 pandemic dominated all our lives. The charity was not immune to the impacts of the virus, but overall our finances remain in good health, certainly much better than feared in the Spring.

The original budget for 2020 was revised in April, to consider the likely impacts of Covid-19. We anticipated that fundraising would be harder than before, but it was the Autumn before the full scale of the challenges became clear. The London Marathon, Great North Run and Sussex Hill Half-Marathon all succumbed to lockdown. Other community fundraising initiatives – including the Iron Games – were cancelled, too.

The planned extension of the staff team proceeded as planned. These additional team members help to broaden our range of services; much of the funding for these roles came from new supporters and grant awarding bodies.

So, it was a good overall outcome for the charity to end the year with a surplus of income over expenditure of £88,235. The steps taken earlier in the lockdown to review expenditure and boost non-community fundraising efforts paid off. This means that the charity's cash reserves have increased over the year by 32% to £356,707.

Income

Our income for the year was £317,667, which was down 13% on the previous year. Given the impact of Covid-19, this is a good outcome - we are better placed financially than many voluntary sector organisations.

The majority of our income came from 4 key sources:

- Trusts & foundations: 37%
- Donations (including in-memoriam, community fundraising, Friends Against Iron Overload): 25%
- Consultancy services: 23%
- Membership subscriptions: 15%

Members will note the growing importance of trusts and foundations to our income mix, especially as corporate donations (including Iron Games) were affected by the Covid-19 lockdown.

Haemochromatosis UK

Trustees' Report

Restricted and designated funds

Total income comprises income received for different purposes: Restricted funds are those which a donor has specified must be used for a specific project or purpose. Designated funds are those allocated to specific projects by the Trustees on a discretionary basis. Unrestricted funds have been received without any restriction and are used to achieve HUK's general objectives.

Included in the closing balances for the year is £67,519 of restricted funds and £142,279 of designated funds. We expect to deploy most of these restricted funds incrementally over the next 12-18 months, as Covid-19 conditions permit.

Expenditure

Total expenditure for 2020 was £229,432 a decrease of 29% over the previous year. Significant efforts were made during the year to review expenditure. Where possible, services were re-tendered and new suppliers sought on a best value basis. This resulted in the appointment of our new independent examiners Community Accounting Plus, alongside reduced costs for our IT and printing needs.

Our costs during the year related to ongoing operations including employment and associated costs, fund raising, office and administration costs. Key costs included work on specific projects, including the Venesection Best Practice project and the training and development of our volunteers, including the helpline team.

Conclusion

Despite the challenges of Covid-19, we can report that HUK remains in a strong financial position. The charity is planning to put the available funds to good use in 2021, thereby further enhancing the achievement of its objectives.

Policy on reserves

In developing the charity's reserves policy, the trustees are mindful of the need to provide a level of working capital that protects the continuity of the charity's work whilst providing a level of funding to enable the organisation to capitalise on unexpected opportunities.

Our policy provides cover for risks such as unforeseen expenditure or unanticipated loss of income. The trustees are especially mindful of these risks following the Covid-19 pandemic, where income has been adversely affected due to lockdown constraints, whilst simultaneously the demand for the charity's services and support has increased significantly.

In this, the charity's 30th anniversary year, the trustees are mindful of the ongoing and growing needs of the genetic haemochromatosis community and the need to ensure financial sustainability of the organisation for the long term.

To that end, the trustees of the charity resolve to pursue a policy of establishing and maintaining a contingency reserve fund sufficient to meet between six to nine months' unrestricted expenditure.

Haemochromatosis UK

Trustees' Report

Statement of Trustees' Responsibilities

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees 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 charitable company and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Small companies provision statement

This report has been prepared in accordance with the small companies regime under the Companies Act 2006.

The annual report was approved by the trustees of the charity on 13/04/2021 and signed on its behalf by:

Timothy Spring

.....
Tim Spring
Trustee

Haemochromatosis UK

Independent Examiner's Report to the trustees of Haemochromatosis UK

Independent examiner's report to the trustees of Haemochromatosis UK ('the Company')

I report to the charity trustees on my examination of the accounts of the company for the year ended 31 December 2020.

Responsibilities and basis of report

As the charity's trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since the Company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member and Fellow of the Association of Charity Independent Examiners, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

John O'Brien

.....
John O'Brien MSc, FCCA, FCIE, employee of Community Accounting Plus
Fellow of the Association of Charity Independent Examiners

Units 1 & 2 North West
41 Talbot Street
Nottingham
NG1 5GL

14 / 04 / 2021

Date:.....

Haemochromatosis UK

Statement of Financial Activities for the Year Ended 31 December 2020 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2020 £	Total 2019 £
Income and Endowments from:					
Donations and legacies	3	83,804	-	83,804	222,136
Charitable activities	4	124,423	108,873	233,296	141,437
Investment income	2	567	-	567	1,122
Total income		<u>208,794</u>	<u>108,873</u>	<u>317,667</u>	<u>364,695</u>
Expenditure on:					
Charitable activities	6	<u>(126,840)</u>	<u>(102,592)</u>	<u>(229,432)</u>	<u>(324,531)</u>
Total expenditure		<u>(126,840)</u>	<u>(102,592)</u>	<u>(229,432)</u>	<u>(324,531)</u>
Net income		81,954	6,281	88,235	40,164
Transfers between funds		<u>(3,655)</u>	<u>3,655</u>	<u>-</u>	<u>-</u>
Net movement in funds		78,299	9,936	88,235	40,164
Reconciliation of funds					
Total funds brought forward		<u>211,249</u>	<u>57,223</u>	<u>268,472</u>	<u>228,308</u>
Total funds carried forward	14	<u><u>289,548</u></u>	<u><u>67,159</u></u>	<u><u>356,707</u></u>	<u><u>268,472</u></u>

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for the period is shown in note 14.

Haemochromatosis UK

Statement of Financial Activities for the Year Ended 31 December 2020 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

These are the figures for the previous accounting period and are included for comparative purposes

	Note	Unrestricted funds £	Restricted funds £	Total 2019 £
Income and Endowments from:				
Donations and legacies	3	222,136	-	222,136
Charitable activities	4	85,376	56,061	141,437
Investment income	2	1,122	-	1,122
Total income		<u>308,634</u>	<u>56,061</u>	<u>364,695</u>
Expenditure on:				
Charitable activities	6	<u>(324,531)</u>	-	<u>(324,531)</u>
Total expenditure		<u>(324,531)</u>	-	<u>(324,531)</u>
Net (expenditure)/income		<u>(15,897)</u>	<u>56,061</u>	<u>40,164</u>
Net movement in funds		(15,897)	56,061	40,164
Reconciliation of funds				
Total funds brought forward		<u>227,146</u>	<u>1,162</u>	<u>228,308</u>
Total funds carried forward	14	<u><u>211,249</u></u>	<u><u>57,223</u></u>	<u><u>268,472</u></u>

Haemochromatosis UK

(Registration number: 02541361)

Balance Sheet as at 31 December 2020

	Note	2020 £	2019 £
Current assets			
Debtors	11	9,161	1,660
Cash at bank and in hand		<u>352,258</u>	<u>273,736</u>
		361,419	275,396
Creditors: Amounts falling due within one year			
	12	<u>(4,712)</u>	<u>(6,924)</u>
Net assets		<u><u>356,707</u></u>	<u><u>268,472</u></u>
Funds of the charity:			
Restricted income funds			
Restricted funds		67,159	57,223
Unrestricted income funds			
Unrestricted funds		<u>289,548</u>	<u>211,249</u>
Total funds	14	<u><u>356,707</u></u>	<u><u>268,472</u></u>

For the financial year ending 31 December 2020 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements on pages 8 to 19 were approved by the trustees, and authorised for issue on 13/04/2021 and signed on their behalf by:



.....
Rodger Houghton
Trustee

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

1 Accounting policies

Summary of significant accounting policies and key accounting estimates

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

Statement of compliance

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) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102). They also comply with the Companies Act 2006 and Charities Act 2011.

Basis of preparation

Haemochromatosis UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The financial statements have been prepared on a going concern basis.

The trustees assess whether the use of going concern is appropriate i.e. whether there are any material uncertainties related to events or conditions that may cast significant doubt on the ability of the charity to continue as a going concern. The trustees make this assessment in respect of a period of one year from the date of approval of the financial statements.

Exemption from preparing a cash flow statement

The charity opted to adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Government grants

Government grants are recognised based on the accrual model and are measured at the fair value of the asset received or receivable. Grants are classified as relating either to revenue or to assets. Grants relating to revenue are recognised in income over the period in which the related costs are recognised. Grants relating to assets are recognised over the expected useful life of the asset. Where part of a grant relating to an asset is deferred, it is recognised as deferred income.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Designated funds are unrestricted funds set aside for specific purposes at the discretion of the trustees.

Restricted income funds are those grants for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Pensions and other post retirement obligations

The charity operates a defined contribution pension scheme for employees. The assets of the scheme are held separately from those of the charity. Pension costs charges in the Statement of Financial Activities represent the contributions payable by the charity during the year.

2 Investment income

	Unrestricted funds		
	General	Total 2020	Total 2019
	£	£	£
Interest receivable and similar income;			
Interest receivable on bank deposits	567	567	1,122

3 Income from donations and legacies

	Unrestricted funds		
	General	Total 2020	Total 2019
	£	£	£
Grants, including capital grants;			
Government grants	7,425	7,425	13,870
Grants from other charities	76,379	76,379	208,266
	<u>83,804</u>	<u>83,804</u>	<u>222,136</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

4 Income from charitable activities

	Unrestricted funds	Restricted funds	Total 2020	Total 2019
	General £	£	£	£
Grants & donations	-	108,873	108,873	-
Consultancy fees	72,527	-	72,527	-
Event ticket sales	772	-	772	-
Membership subscriptions	45,230	-	45,230	41,766
Merchandise	5,206	-	5,206	-
Sundry income	688	-	688	71,058
Charitable activities	-	-	-	28,613
	<u>124,423</u>	<u>108,873</u>	<u>233,296</u>	<u>141,437</u>

5 Grants & donations

	Unrestricted funds	Restricted funds	Total
	£	£	£
Shears Foundation	-	25,000	25,000
Big Lottery Community Fund	-	16,801	16,801
Corra Foundation	-	10,136	10,136
Independent Age	-	10,000	10,000
Burdett Trust	-	8,000	8,000
Abbvie Fund	-	5,000	5,000
Ernest Hecht Fund	-	5,000	5,000
Foundation Scotland	-	5,000	5,000
James Tudor Foundation	-	5,000	5,000
Medlock Trust	-	5,000	5,000
Halifax Foundation	-	4,000	4,000
Kilpatrick Fraser Charitable Trust	-	2,880	2,880
February Foundation	-	2,500	2,500
Vivid - Hampshire	-	2,471	2,471
Society for Endocrinology	-	2,085	2,085
South Holland District Council	5,000	-	5,000
Gift Aid	17,425	-	17,425
Sundry grants & donations	61,379	-	61,379
	<u>83,804</u>	<u>108,873</u>	<u>192,677</u>

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 2020

6 Expenditure on charitable activities

	Unrestricted General funds £	Unrestricted Designated funds £	Restricted funds £	Total 2020 £	Total 2019 £
Accountancy	7,944	-	-	7,944	-
Advertising / Promotional	2,241	-	-	2,241	-
Bank charges	2,362	-	-	2,362	-
Equipment & computer costs	3,452	-	1,994	5,446	-
External events	3,962	-	834	4,796	-
Dues & subscriptions	1,324	-	-	1,324	-
Hosted events	2,220	-	-	2,220	-
Insurance	1,048	-	-	1,048	-
IT, repairs & servicing	1,722	-	-	1,722	-
Legal & professional	10,880	-	-	10,880	-
Materials stock	2,659	-	4,994	7,653	-
Office / General admin	308	-	-	308	-
Phone costs	1,805	-	525	2,330	-
Premises costs	17	-	-	17	-
Printing, postage & stationery	171	1,000	9,690	10,861	-
Publications	1,052	-	4,166	5,218	-
Raising funds	108	-	-	108	-
Recruitment	53	-	-	53	-
Rent	9,300	-	-	9,300	-
Software	2,837	-	2,834	5,671	-
Staff benefits	1,399	-	-	1,399	-
Sundry costs	697	-	-	697	-
Training	-	-	1,955	1,955	-
Travel & accommodation	2,518	-	-	2,518	-
Trustees expenses	1,997	-	-	1,997	-
Wages, NI & pension	62,104	-	75,600	137,704	-
Bad debts written off	1,660	-	-	1,660	-
Information & support	-	-	-	-	93,245
Education & awareness	-	-	-	-	133,281
Research	-	-	-	-	5,404
International expenses	-	-	-	-	5,404
Raising funds	-	-	-	-	68,562
Governance	-	-	-	-	18,635
	<u>125,840</u>	<u>1,000</u>	<u>102,592</u>	<u>229,432</u>	<u>324,531</u>

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Notes to the Financial Statements for the Year Ended 31 December 2020

7 Trustees remuneration and expenses

During the year the charity made the following transactions with trustees:

Corrina Towers

£400 (2019: £Nil) of travel expenses were reimbursed to Corrina Towers during the year.

Katharine Hough

£45 (2019: £Nil) of travel expenses were reimbursed to Katharine Hough during the year.

Lisa Flude

£844 (2019: £Nil) of travel expenses were reimbursed to Lisa Flude during the year.

Roger Keyte

£392 (2019: £Nil) of travel expenses were reimbursed to Roger Keyte during the year.

Simon Flude

£264 (2019: £Nil) of travel expenses were reimbursed to Simon Flude during the year.

Information for Trustee expenses in the previous period is unavailable.

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

8 Fees payable to independent examiner

During the period, the fees payable (excluding VAT) to the charity's independent examiner Community Accounting Plus are analysed as follows:

	2020 £	2019 £
Independent examination	<u>1,080</u>	<u>1,800</u>

9 Staff costs

The aggregate payroll costs were as follows:

	2020 £
Staff costs during the year were:	
Wages and salaries	118,301
Social security costs	7,473
Pension costs	1,248
Compensation payments	<u>10,682</u>
	<u>137,704</u>

Information on Staff costs for the previous period is unavailable.

The monthly average number of persons (including senior management team) employed by the charity during the year was as follows:

	2020 No	2019 No
Average number of employees	<u>3</u>	<u>5</u>

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3 (2019 -) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £1,248 (2019 - £Nil).

Information on Pension contributions and numbers for the previous period are unavailable.

During the year, the charity made redundancy and/or termination payments which totalled £10,682 (2019 - £Nil).

The total employee benefits of the key management personnel of the charity were £63,545 (2019 - £Nil).

10 Taxation

The charity is a registered charity and is therefore exempt from taxation.

11 Debtors

	2020 £	2019 £
Trade debtors	535	1,660
Prepayments	8,626	-
	<u>9,161</u>	<u>1,660</u>

12 Creditors: amounts falling due within one year

	2020 £	2019 £
Trade creditors	512	2,099
Other taxation and social security	2,928	3,025
Other creditors	192	-
Accruals	1,080	1,800
	<u>4,712</u>	<u>6,924</u>

13 Charity status

The charity is a company limited by guarantee and consequently does not have share capital. Each of the trustees is liable to contribute an amount not exceeding £1 towards the assets of the charity in the event of liquidation.

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Notes to the Financial Statements for the Year Ended 31 December 2020

14 Funds

	Balance at 1 January 2020 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2020 £
Unrestricted funds					
<i>General</i>					
General	206,249	208,794	(125,840)	(141,934)	147,269
<i>Designated</i>					
Education & Awareness	-	-	(1,000)	143,279	142,279
Irish Travellers Project	5,000	-	-	(5,000)	-
	<u>5,000</u>	<u>-</u>	<u>(1,000)</u>	<u>138,279</u>	<u>142,279</u>
Total Unrestricted funds	<u>211,249</u>	<u>208,794</u>	<u>(126,840)</u>	<u>(3,655)</u>	<u>289,548</u>
Restricted funds					
Information & Support	2,650	9,221	(6,995)	-	4,876
Education & Awareness	373	5,335	(5,373)	(335)	-
GH Education	30,000	38,000	(31,000)	-	37,000
Helpline	-	34,301	(23,823)	-	10,478
Northern Ireland Community Fund	11,000	4,000	(2,750)	-	12,250
Scottish Wellbeing	3,000	18,016	(17,651)	(1,010)	2,355
Irish Travellers Project	-	-	(5,000)	5,000	-
Your Patient Will See You Now	10,000	-	(10,000)	-	-
Medical Research	200	-	-	-	200
Total restricted funds	<u>57,223</u>	<u>108,873</u>	<u>(102,592)</u>	<u>3,655</u>	<u>67,159</u>
Total funds	<u>268,472</u>	<u>317,667</u>	<u>(229,432)</u>	<u>-</u>	<u>356,707</u>
	Balance at 1 January 2019 £	Incoming resources £	Resources expended £	Balance at 31 December 2019 £	
Unrestricted funds					
General	227,146	308,634	(324,531)	211,249	
Restricted funds	<u>1,162</u>	<u>56,061</u>	<u>-</u>	<u>57,223</u>	
Total funds	<u>228,308</u>	<u>364,695</u>	<u>(324,531)</u>	<u>268,472</u>	

Detailed information on the funds for the previous period is unavailable.

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Notes to the Financial Statements for the Year Ended 31 December 2020

The specific purposes for which the funds are to be applied are as follows:

Information & support – funds provided for the production of materials to provide information and support on Haemochromatosis. This includes hospital packs, production of leaflets, booklets, website content and videos;
 Education & awareness – funds provided for the development of educational resources;
 GH Education – funds provided for the education of healthcare professionals;
 Helpline – funds provided towards the costs of providing a Helpline;
 Northern Ireland Community Fund – funding towards providing support and information specifically in Northern Ireland;
 Scottish Wellbeing – funds towards providing counselling services, education and support specifically in Scotland;
 Irish Travellers project – funding for the Breaking Down Barriers project to engage with Irish travellers throughout the country;
 Your Patient Will See You Now – funding to implement the Patient Expert Programme, a programme to empower patients by educating them about the condition.

The transfer from the General fund to the Education & Awareness designated fund is to reclassify those funds. The transfer from the Irish Travellers Project designated fund to the Irish Travellers Project restricted fund is to reclassify those funds.

The transfer from Education & Awareness restricted fund to the General fund was for expenses incurred in the previous financial period.

The transfer from Scottish Wellbeing fund to the General fund represents the release on any restrictions for the balance remaining of a grant received.

15 Analysis of net assets between funds

	Unrestricted funds		2020 Total funds £
	General £	Restricted funds £	
Current assets	294,260	67,159	361,419
Current liabilities	(4,712)	-	(4,712)
Total net assets	<u>289,548</u>	<u>67,159</u>	<u>356,707</u>
	Unrestricted funds		2019 Total funds £
	General £	Restricted funds £	
Current assets	218,173	57,223	275,396
Current liabilities	(6,924)	-	(6,924)
Total net assets	<u>211,249</u>	<u>57,223</u>	<u>268,472</u>

16 Related party transactions

There were no related party transactions in the year.