

**Haemochromatosis • UK** <sup>+Fe</sup>  
Helping people live with iron overload

# Haemochromatosis UK Trustees' Annual Report & Accounts 2022



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## **HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

### **Haemochromatosis UK Trustees' Annual Report and Accounts**

For the year ending 31 December 2022

Published July 2023

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[www.haemochromatosis.org.uk](http://www.haemochromatosis.org.uk)

### **Statutory Information**

We are Haemochromatosis UK.

Registered as Charity number 1001307 and SCO41701.

Company Limited by Guarantee No. 2541361.

### **Registered office**

The Flaxmill, Flaxmill Lane, Pinchbeck, Lincolnshire, PE11 3YP

### **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

### **Trustees**

Katy Burns MBE, Chair of Trustees

Rodger Houghton, Finance Trustee

Catherine Wiggins, Finance Trustee

Kevin King, Legal Trustee

### **Board Observer**

Freya Dolby

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## 2. INTRODUCTION FROM THE CHAIR

**The Trustees are pleased to report on another successful year for HUK, building on the endorsement from the King's Fund Award that recognised the commitment from HUK's small staff team, its volunteers, Trustees and its members to diagnose and support those with haemochromatosis.**

This was most apparent at the successful two-day HUK event held in Cambridge in October, which brought together staff, volunteers, members and Trustees to discuss and revise our charity's strategy over the next three to five years. It offered an opportunity for interactions between the different groups that were clearly appreciated and enjoyed. The workshops, presentations and question and answer sessions all enhanced the collective understanding of HUK and a deeper understanding and appreciation of the different roles and challenges of those involved. Everyone enjoyed the opportunity to see the wider picture of HUK and its work and to be part of setting the future direction of the charity.

We're grateful to Gillian Fachiri and Catherine Wiggins for their contributions over the past year as they step down from the Board. We are delighted to welcome Julie Brown (Belfast), Serena ter Kuile (Amsterdam) and Jade Cassidy (Bonn) to the Board, initially as Board Observers. They each bring specific skills to enrich the governance of the charity, spanning nursing, legal/finance and the voluntary sector as we look to build upon the charity's work and success.

A membership survey conducted in the summer of 2022 highlighted the positive view of HUK from its membership and gave helpful details on their views. Headlines were that members rated highly recommending HUK to others (98.6%); value for money (96.5%); support (85%); research (78%); clinical education (76%) and public awareness (75%). The response identified 'Education for Clinicians' to be highest in 'what matters' and gave some suggestions of what areas HUK could progress further, with an emphasis on awareness raising.

The Trustees want to express their gratitude to the Chief Executive, Neil McClements, for his hard work and success in leading HUK forward to achieve greater impact and tackle new areas of work. The charity has moved to new offices locally following the end of our tenancy in Spalding and this has not been without its challenges. We recognise the hard work of the small staff team and what they have achieved in terms of raising funds, supporting members seeking medical guidance and facilitating events and the day to day work of the charity – team work at its best!

I would like to thank my fellow Trustees, Neil and our clerk, Deirdre, for their help and support throughout the year.

**Katy Burns MBE, Chair of the Board of Trustees**



### 3. A MESSAGE FROM THE CHIEF EXECUTIVE

**2022 proved to be another successful year in the life of our charity.**

We were thrilled to be selected from over 400 charities to receive a prestigious King's Fund/GSK IMPACT Award, in recognition of the charity's outstanding impact on the genetic haemochromatosis community that we serve.

This award was complemented in the autumn with the nomination for not one, but three, Third Sector awards including Best Service Delivery Innovation for our specialist nurse appointments service during the Covid-19 lockdowns and Breakthrough of the Year for our genetic screening service. We were delighted to be awarded runner-up Small Charity of the Year too.



These awards are hotly contested and heavily and independently scrutinised by the awards assessors, which makes these achievements all the more satisfying. I pay tribute to our very small team who have worked so hard all year, persistently seeking to improve care pathways and provide support to anyone affected by genetic haemochromatosis. There is a tremendous amount of work going on day-by-day and behind the scenes to improve diagnosis rates and ensure that people affected by the condition receive the best possible advice, care and support.

Our thanks also go to the many volunteers, community fundraisers, Board Observers and Trustees who dedicate so much of their free time and skills to our cause.

During the year, in response to members' feedback in the 2021 survey, we ramped up our clinical research efforts. This initiative resulted in our well-received Cost of Illness report in collaboration with the York Health Economics Consortium and the University of Exeter and three research reports in collaboration with two research interns, Maureen and Salma, in partnership with the 10K Black Interns programme.

Our genetic testing and screening services have gone from strength to strength. Towards the end of the year we processed more HFE genetic test samples than the whole of the NHS combined. This work helps families to achieve an earlier diagnosis, often following repeated difficulties in receiving a NHS test.

## **HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

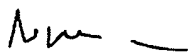
Building on the strength of our screening programmes in Derry-Londonderry and Carrickfergus, we expanded our reach to provide awareness raising and screening to almost 100,000 households across Worthing, Cardiff, Edinburgh and Merseyside. The results are currently being analysed with a view to publication to influence elected representatives and NHS policymakers – genetic haemochromatosis isn't "rare", it's rarely diagnosed.

Our advocacy through the All-Party Parliamentary Group on Genetic Haemochromatosis continues. This is a powerful forum at Westminster which enables us to raise our voice among the "powers that be".

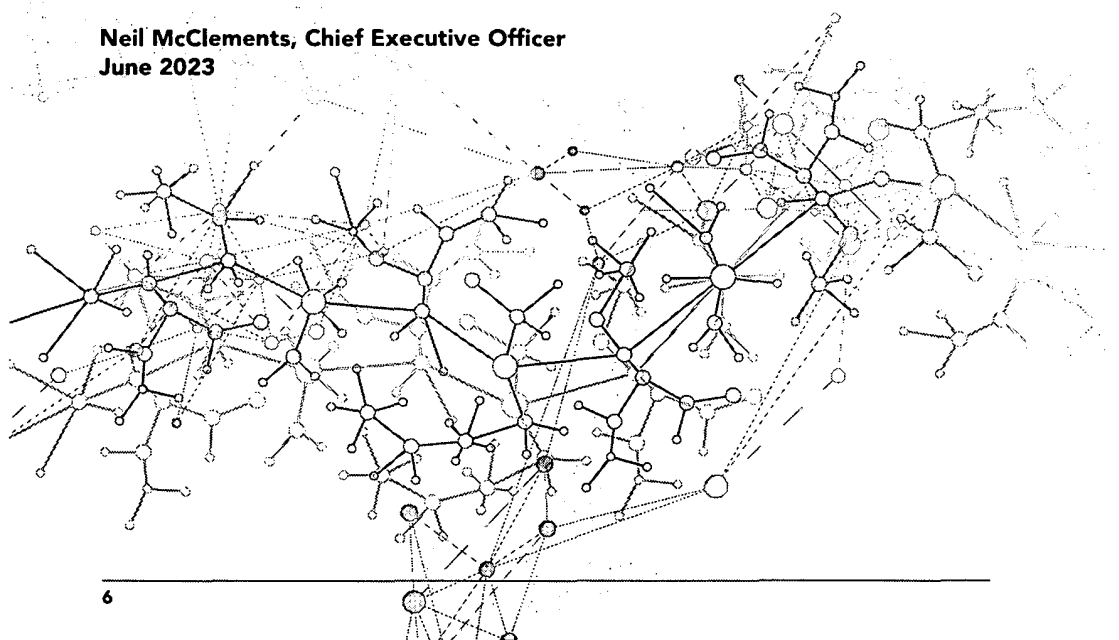
We continue to develop and deepen our relationships with key clinical stakeholders, including the blood donation services and the National Institute for Health and Care Excellence (NICE). We are actively involved in helping NICE to shape the forthcoming care guidelines for HFE in adults which we hope will be published in 2024/5.

We look forward to continuing our work in 2023, following the completion in the autumn of a comprehensive review of the charity's strategy for 2023 to 2028. Our thanks to the almost 40 stakeholders (including our Board, volunteers, community ambassadors, clinical advisors and many others) who joined us at the University of Cambridge strategy workshop in October who helped us to think through and focus on the key elements of our renewed strategy for the coming years.

Finally, we continue to value the support of our donors and Friends. Our charity receives no NHS or government funding. Everything we do is powered by donations and so we are especially thankful to our financial supporters, for everything they do – helping us, to help others.



**Neil McClements, Chief Executive Officer**  
**June 2023**



## 4. TRUSTEES' REPORT FOR 2022

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 2022.

### **The Trustees:**

Katy Burns MBE  
Rodger Houghton  
Catherine Wiggins from 1st October 2021  
Kevin King from 1st October 2021  
Tim Spring until 19th January 2022  
Kim Hicks until 16th May 2022  
Gillian Fachiri until 31st October 2022

### **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 2,400 paid-up members and over 1,600 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

In this report, we report progress with these objectives during 2022 and outline the plans and aspirations for the coming year.

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 join 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 focused in supporting the charity's continuing development.

It's important to note that the charity's financial position remains sound, despite the significant and continuing challenges to community fundraising brought by the Covid pandemic. We continue to focus on stewarding the charity's financial resources to

## **HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

ensure the long-term sustainability of the organisation whilst delivering much needed, effective services to the GH community. Our Annual Financial Statements set out the financial position in more detail on the following pages.

### **Trust grants**

This year, we have enjoyed further increased support from charitable trusts and donations from family foundations totalling £242,593.

The Trustees would like to extend their grateful thanks to and public acknowledgment of our supporters:

- Ulster Garden Villages Common Fund
- Shears Foundation
- Hospital Saturday Fund
- NL Awards for All - Wales
- NL Awards for All - NI
- Pilkington Charities Fund
- Awards for All England
- James Tudor Foundation
- Medicash Foundation
- Roger & Jean Jefcoate Charitable Trust
- Ernest Kleinwort
- Williams Brownhill CIO
- Cambridge Technology Fund
- TB & KL Thompson
- FB Coales Family Trust No 4
- The Guy Fawkes Charitable Trust
- Blunt Trust
- Esme Mitchell Trust
- Leng Trust
- Alexander Moncur Charitable Trust
- Mrs M A Lascelles Charitable Trust
- The Morton Charitable Trust (Dundee)
- Rosca Trust
- Gordon Fraser Charitable Trust
- NIE Networks Staff Fund
- Nancie Massey Charitable Trust
- Enkalon Foundation
- John Dawber Charity
- Douglas Heath Eves Charitable Trust
- Lillie Johnson Charitable Trust
- Walter Guinness
- The Grace Trust
- Sir John Sumners Trust
- Bartlett Taylor Trust
- The O'Hare family of Forkhill
- The Askew family

### **Corporate donations**

We gratefully acknowledge the support of the following donors:

- Google Ireland Limited
- Air Products Plc

### **An important thank you message**

The Trustees extend their grateful thanks to all the volunteers, members, donors, fundraisers, activists, advisers and other supporters who have made a contribution over the year. There are so many individuals who have helped to develop the life of our charity – too many to mention by name. It is difficult to convey the importance of what you do for us and for people affected by genetic haemochromatosis in a few words; we thank you all sincerely.



**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 that charities must follow as set out in the Charities Act 2016.

To raise funds for the charity, we apply to grant-making bodies, encourage volunteer participation in external fundraising events, ask for regular and spontaneous donations through online appeals and receive donations in memory and in lieu of gifts. Our staff work in-house to help us to deliver fundraising initiatives. We aim to ensure that any external fundraisers, professional or voluntary, we engage observe the highest standards in terms of fundraising practice, including compliance with the Code of Fundraising Practice and the charity's own policies. Our fundraiser is a diploma-qualified member of the Chartered Institute of Fundraising.

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

We occasionally use third-party partners to help us to 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 line 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 consider an annual report about complaints from the CEO.

Our website provides our contact details to the public in the event that an individual wishes to make a complaint. In 2022, we had no fundraising 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 2022, 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 mandatory safeguarding training and assessment annually.

## 5. GOVERNANCE

The Trustees are responsible in law for the financial and strategic management of the charity.

The 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.

In 2021, the charity enhanced its governance with the introduction of Board Observers. These people bring specific skills to the Board in an advisory capacity and are "trustees-in-training". After a suitable period of time, the Board and Observer may consider, but are not obliged to undertake, a progression to full trusteeship. Board Observers attend all Board meetings but do not have voting rights and are not directors of the charity's company limited by guarantee. However, they are encouraged to participate fully in the life of the charity and the Board's activities.

When a Trustee or Board Observer 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, Women On Boards, the Young Trustees Movement and elsewhere. Each new Trustee/Board Observer is provided with an induction training pack that includes a guide to the legal and practical responsibilities of being a Trustee/Observer. Formal training with the NCVO in the role and the legal responsibilities of a Trustee is also provided. All Board members must undertake safeguarding training annually.

Our record with the Charity Commission is at [www.charitycommission.gov.uk](http://www.charitycommission.gov.uk) and can be found by searching on that site using charity number 1001307.

### **The Executive**

The Trustees delegate responsibility for day-to-day operations to the Chief Executive, in accordance with a formally documented Scheme of Delegation.

The Chief Executive is supported by a small part-time staff team, comprised of an Advanced Nurse Practitioner, an Information & Advisory Nurse, a Philanthropy Manager, Finance Controller/Book-keeper and Charity Administrator. The team represents 4 full-time equivalent post-holders.

### Risk Management

Haemochromatosis UK recognises the importance of understanding and managing risk. As such, the Board of Trustees conducts a review of the major risks to which the charity is exposed at each Board meeting. As part of this process, a risk register has been established and is updated at least quarterly in order to identify and evaluate the risks faced and to formulate a response.

Where appropriate, systems or procedures have been established to mitigate the risks the charity faces. Policies and procedures are periodically reviewed to ensure that they continue to meet the needs of the charity. Responsibility for risk assessment and day-to-day risk management is defined in the charity's Scheme of Delegation.

Significant external risks to funding have led to the development of a strategic plan which will allow for the diversification of funding and activities. Internal control risks are minimised by the implementation of procedures for the authorisation of all financial transactions. Risks to operations due to Covid-19 are monitored and implemented in accordance with prevailing UK government guidance.

Procedures and training are in place to ensure compliance with safeguarding best practices and the health and safety of staff, volunteers and beneficiaries.

### Strategic Planning

The charity worked throughout 2022 to review and revise its organisational strategy. This included a 2-day workshop with staff, Trustees, Board Observers, volunteers, clinical advisors and other members of the GH community at Robinson College, Cambridge in October 2022.

The Board subsequently reflected upon the draft strategy developed at the workshop and this was formally endorsed and adopted in early 2023. An overview has been published online here: <https://www.haemochromatosis.org.uk/strategy-2023-to-2028>.



## 6. FINANCE

### Overview

2022 was another tumultuous year for the global economy and geo-politics in general. The cost-of-living crisis, with excess inflation, saw household budgets come under significant pressure. The war in Ukraine, a humanitarian catastrophe, has caused some reprioritisation of allocated budgets within the charitable trusts and foundations sector but, despite this, the financial position of the charity remains strong.

Overall, HUK delivered a £(20,497) net expenditure (2021: £40,118), with reserves of £376,328 (2021: £396,825). This net expenditure was not in fact as large as had been budgeted and was as a result of achieving higher levels of fund raising from trusts and foundations.

### Income

The income for 2022 was £436,806 (2021: £366,138), this was a 19% increase vs. 2021. The income of the charity comes from five key areas, which has changed from the previous year:

- Trusts and foundations 46% (2021: 25%)
- Donations (including in-memoriam, community fund raising, gift aid) 13% (2021: 32%)
- Membership subscriptions 16% (2021: 17%)
- Consultancy fees 11% (2021: 16%)
- Genetic testing 12% (2021: 8%)
- Other 2% (2021 : 2%)

The charity is becoming far more reliant on funding from trusts and foundations which is a function of having a full-time professional fundraiser as a member of staff.

The proportion of donations has shrunk year-on-year as overall income has grown and the amount of donations has reduced. There were some one-off fundraising efforts in 2021, such as the BBC Radio 4 Appeal, that were not repeatable in 2022. The normal level of community fundraising was down with the cost-of-living crisis again having an impact.

Our membership subscriptions, with income totalling £69,042 (2021: £62,545), were an improvement of 10% vs 2021 and remain a very important component of our income.

It should be noted that the charity's provision of consultancy services to NICIMI came to an end in 2022, as was anticipated, which is why focus and resources have been applied to fund raising from trusts and foundations.

Genetic testing is becoming a significant part of our revenue, which has been driven by the popularity of it as a service and the targeted awareness raising of campaigns in specific communities.

### Restricted and unrestricted funds

A large proportion of HUK's income is without restriction, for the charity to use how it deems best in order to meet the four key objectives detailed previously. These are termed unrestricted funds.

Designated funds form part of the unrestricted funds but have been designated by the Trustees for a particular purpose. Restricted funds are funds received for which the donor has specified a particular purpose. These funds can only be used for that purpose.

HUK began the year with £44,921 restricted funds (2021: £67,159), with a further £137,820 received throughout 2022 (2021: £90,499). Funds received in the year were either deployed in 2022 and Q1 2023 or are expected to be utilised across the coming year, finishing the year with a restricted funds balance of £70,259 (2021: £44,921).

Of the £306,069 unrestricted balance (2021: £351,904), £163,878 (2021: £113,896) has been designated for use in education and awareness.

### Expenditure

Total expenditure for 2022 was £457,303 (2021: £326,020), an increase of 40% over the previous year. This reflects a planned and deliberate attempt to deploy the reserves of the charity toward charitable benefit.

The charity again supported new medical research to the amount of £16,030 (2021: £26,755) but it has been the growth in genetic testing expenditure of £76,657 (2021: £30,875) that has seen a marked increase of 148% over last year. The Trustees support the CEO in the belief that such expenditure serves two main purposes. Firstly, it allows potential sufferers of GH to be diagnosed, who might not otherwise be able to access such services through their GP. Secondly, it provides evidence of the prevalence of the condition, which adds weight to our lobbying efforts that this should be a condition that is screened for by the NHS.

It should again be emphasised that the cost was substantially offset by the payments made by members which was itself heavily subsidised by non-members, which together raised £50,151 (2021: £29,527). This initiative cost a net of £26,506 (2021: £1,348) and so was partially self-funding.

### 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. These risks can arise not only from events such as the Covid-19 pandemic but from other world events such as the war in Ukraine where trusts and foundations can reprioritise how they wish to deploy their resources or to the cost-of-living crisis now being felt by so many in the UK which may lead to households reassessing their support for charities such as ours.

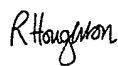
## **HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

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. This has also to balance with the need of the charity to deploy its reserves for charitable purposes.

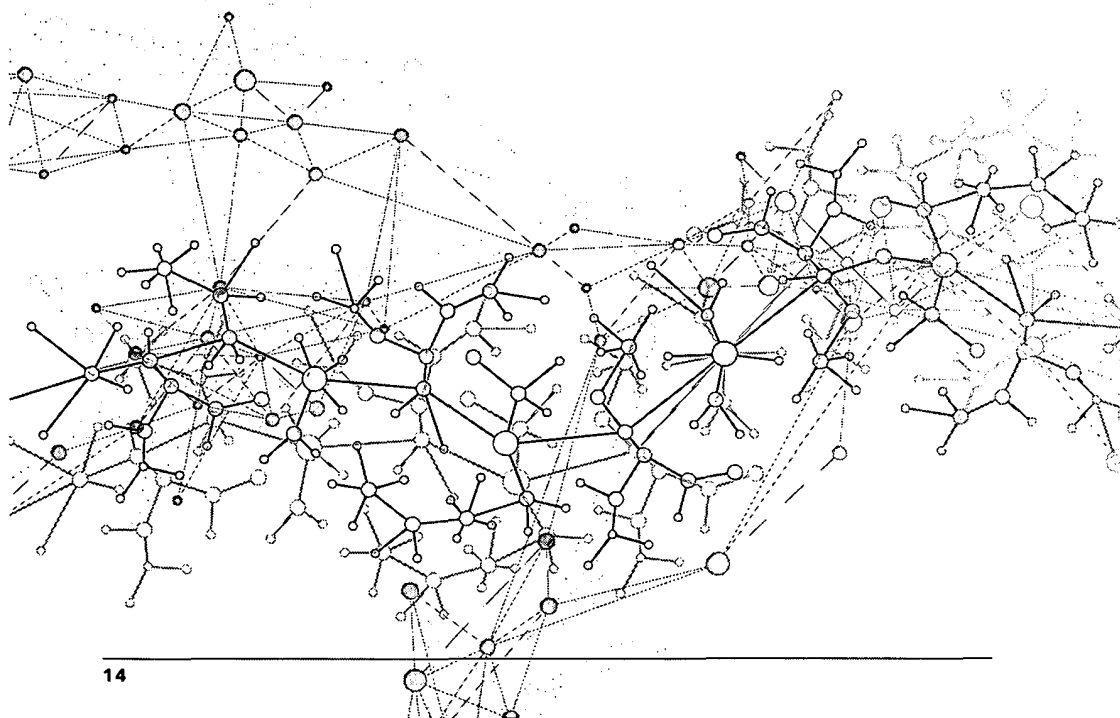
To that end, the Trustees of the charity resolve to pursue a policy of establishing and maintaining a contingency reserve fund to meet between six to nine months of unrestricted expenditure.

### **Conclusion**

This year has again seen the largest amount raised in the charity's history for a second successive year. The Trustees would like to thank the charity's CEO and the dedicated team supporting him. During 2023, further deployment of the charity's reserves is planned as part of a budgeted net expenditure. The Trustees will continue to closely monitor performance against that budget, and will seek to deploy any favourable variance by scaling up planned activities or by considering new initiatives that are presented to the Board. The charity remains in a sound financial position.



**Rodger Houghton, Finance Trustee**  
**June 2023**



## 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 charity 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' ANNUAL REPORT & 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 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 15th July 2023.

*Katy Burns*

**Katy Burns MBE, Chair  
July 2023**

*R Houghton*

**Rodger Houghton, Finance Trustee  
July 2023**



## 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's Trustees on my examination of the accounts of the company for the year ended 31 December 2022.

### 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)].

**HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

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 MSc, FAIA, FCCA, FCIE,  
employee of Community Accounting Plus  
Fellow of the Association of Charity Independent Examiners**

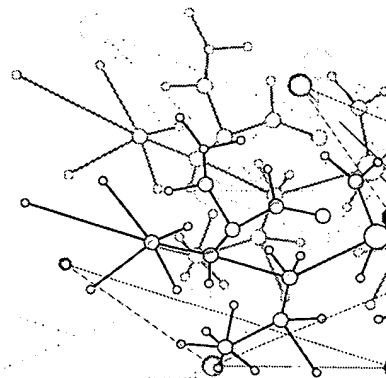
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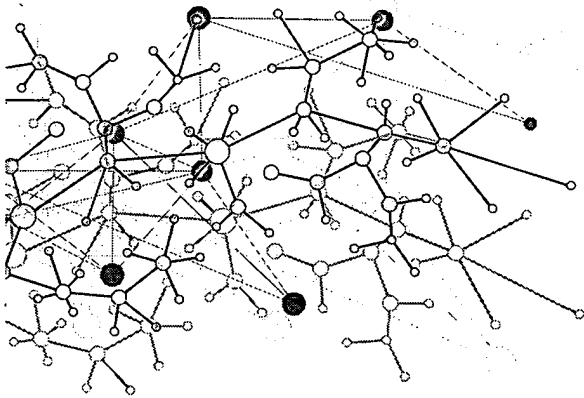
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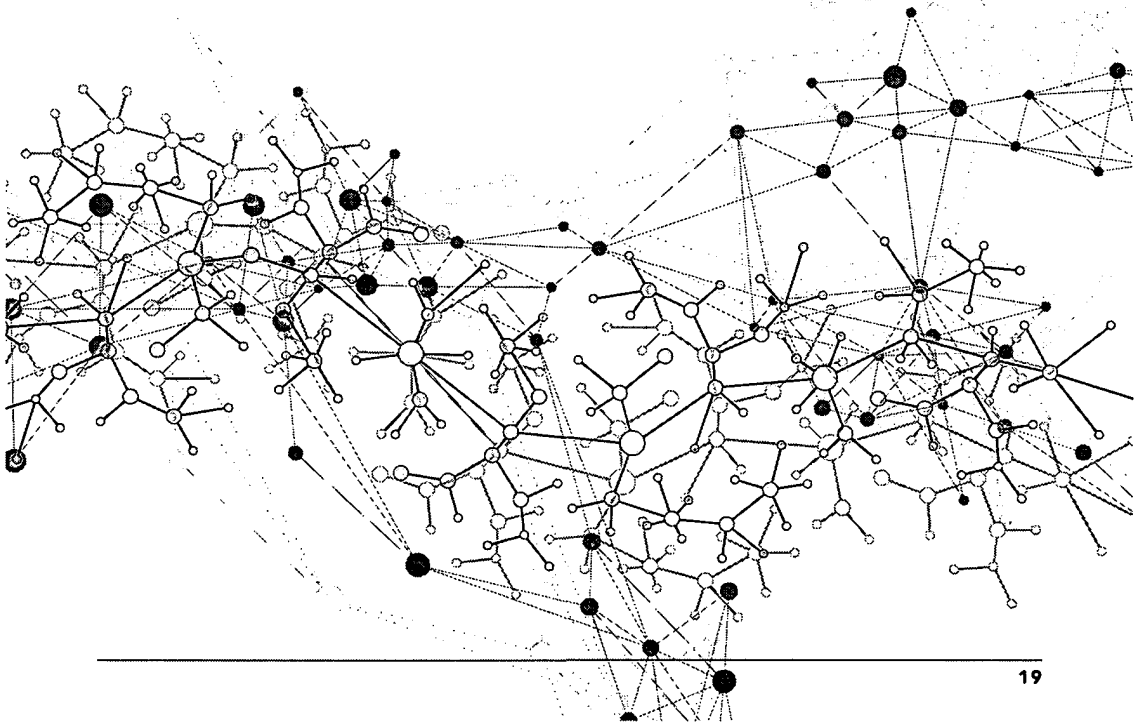
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**Date:** 19/07/2023





# ACCOUNTS



**HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

**Haemochromatosis UK**

**Statement of Financial Activities for the Year Ended 31 December 2022**

**(Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)**

	Note	Unrestricted funds	Restricted funds	Total 2022	Total 2021
		£	£	£	£
<b>Income and endowments from:</b>					
Donations and legacies	3	201,420	-	201,420	118,445
Charitable activities	4	96,726	137,820	234,546	247,453
Investment income	2	840	-	840	240
<b>Total income</b>		<b>298,986</b>	<b>137,820</b>	<b>436,806</b>	<b>366,138</b>
<b>Expenditure on:</b>					
Charitable activities	6	(349,632)	(107,671)	(457,303)	(326,020)
<b>Total expenditure</b>		<b>(349,632)</b>	<b>(107,671)</b>	<b>(457,303)</b>	<b>(326,020)</b>
Net income		(50,646)	30,149	(20,497)	40,118
Transfers between funds		4,811	(4,811)	-	-
Net movement of funds		(45,835)	25,338	(20,497)	40,118
<b>Reconciliation of funds:</b>					
Total funds brought forward		351,904	44,921	396,825	356,707
Total funds carried forward	11	306,069	70,259	376,328	396,825

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 11.

## Haemochromatosis UK

## Statement of Financial Activities for the Year Ended 31 December 2021

## (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 2021 £
<b>Income and endowments from:</b>				
Donations and legacies	3	118,445	-	118,445
Charitable activities	4	156,954	90,499	247,453
Investment income	2	240	-	240
<b>Total income</b>		<b>275,639</b>	<b>90,499</b>	<b>366,138</b>
<b>Expenditure on:</b>				
Charitable activities	6	(153,857)	(172,163)	(326,020)
<b>Total expenditure</b>		<b>(153,857)</b>	<b>(172,163)</b>	<b>(326,020)</b>
Net (expenditure)/income		121,782	(81,664)	40,118
Transfers between funds		(59,426)	59,426	-
Net movement of funds		62,356	(22,238)	40,118
<b>Reconciliation of funds:</b>				
Total funds brought forward		289,548	67,159	356,707
Total funds carried forward	11	351,904	44,921	396,825

# HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

## Haemochromatosis UK (Registration number: 02541361) Balance Sheet as at 31 December 2022

	Notes	2022 £	2021 £
<b>Current assets</b>			
Debtors	8	13,246	28,767
Cash at bank and in hand		378,762	379,871
		392,008	408,638
<b>Creditors: amounts falling due within one year</b>	9	(15,680)	(11,813)
<b>Net assets</b>		<u>376,328</u>	<u>396,825</u>
<b>Funds of the charity:</b>			
<b>Restricted income funds</b>			
Restricted funds		70,259	44,921
<b>Unrestricted income funds</b>			
Unrestricted funds		306,069	351,904
<b>Total charity funds</b>	11	<u>376,328</u>	<u>396,825</u>

For the financial year ending 31 December 2022, 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 financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

The Financial Statements on pages 3 to 17 were approved by the Trustees and authorised for issue on 15th July 2023 and signed on their behalf by:

*R Houghton*

**Rodger Houghton, Trustee**

**Haemochromatosis UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

**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)) (issued in October 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

**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 early adopt Bulletin 1 published on 2 February 2016 and has therefore not included a cash flow statement in these Financial Statements.

**Income and endowments**

Voluntary income including donations, gifts, legacies and grants that provides 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.

**Haemochromatosis UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

***Donations and legacies***

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

***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 aggregates 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.

***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.



**Haemochromatosis UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

**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 12 months after the reporting date. If there is an unconditional right to defer settlement for at least 12 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.

**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 2022**

**2 Investment income**

	Unrestricted funds	Total 2022	Total 2021
	General		
	£	£	£
Interest receivable and similar income			
Interest receivable on bank deposits	840	840	240

**3 Income from donations and legacies**

	Unrestricted funds		Total 2022	Total 2021
	Designated	General		
	£	£	£	£
Donations and legacies				
Gift aid reclaimed		17,396	17,396	8,806
Grants, including capital grants				
Grants from other charities	82,682	101,342	184,024	109,639
	82,682	118,738	201,420	118,445

**4 Income from charitable activities**

	Unrestricted funds		Total 2022	Total 2021
	General	Restricted funds		
	£	£	£	£
Grants & donations	-	58,569	58,569	90,499
Consultancy fees	19,343	29,100	48,443	57,675
Event ticket sales	-	-	-	262
Membership subscriptions	69,042	-	69,042	62,545
Merchandise	8,341	-	8,341	6,945
Genetic testing	-	50,151	50,151	29,527
	96,726	137,820	234,546	247,453

## HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

### Haemochromatosis UK

#### Notes to the Financial Statements for the Year Ended 31 December 2022

##### 5 Grants & donations

	Unrestricted funds	Restricted funds	Total
	£	£	£
Alexander Moncur Trust	1,500	-	1,500
Bartlett Taylor Charitable Trust	250	-	250
Douglas Heath Eves Charitable Trust	-	500	500
Enkalon Foundation	1,000	-	1,000
Ernest Kleiwort	-	4,000	4,000
Esme Mitchell	-	2,000	2,000
FB Coales	2,500	-	2,500
General donations	41,432	-	41,432
Gordon Fraser Trust	1,000	-	1,000
GSK Award	40,000	-	40,000
Guy Fawkes Charitable Trust	2,000	-	2,000
Hospital Saturday Fund (Birmingham)	10,000	-	10,000
Ian Askew Foundation	-	500	500
James Tudor Foundation	-	9,250	9,250
John Dawber Foundation	660	-	660
Lascelles Chart Trust	1,000	-	1,000
LC Johnson Trust	500	-	500
Leng Trust	-	1,500	1,500
Medicash Foundation	-	6,506	6,506
National Lottery	30,000	-	30,000
NI Electricity	1,000	-	1,000
Pilkington Charity	-	10,000	10,000
Shears Foundation	-	20,000	20,000
Sir John Sumners Trust	-	250	250
Southern Health & Social Care Trust	-	63	63
TB & KL Thompson Trust	2,750	-	2,750
The Grace Trust	500	-	500
The Nancie Massey Charitable Trust	-	1,000	1,000
Tony O'Hare	4,500	-	4,500
Ulster Garden Village	42,932	-	42,932
Walter Guinness Trust	500	-	500
Williams Brownhill	-	3,000	3,000
	184,024	58,569	242,593

## HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

### Haemochromatosis UK

#### Notes to the Financial Statements for the Year Ended 31 December 2022

#### 6 Expenditure on charitable activities

	Unrestricted General funds	Unrestricted Designated funds	Restricted funds	Total 2022	Total 2021
	£	£	£	£	£
Accountancy	-	11,773	-	11,773	7,346
Advertising/promotional	659	20,164	-	20,823	2,544
Bank charges	-	81	-	81	178
Equipment & computer costs	-	3,311	-	3,311	1,864
External events	3,052	1,656	582	5,290	6,292
Dues & subscriptions	-	3,137	-	3,137	1,879
Hosted events	2,160	8,020	-	10,180	5,979
Insurance	-	1,417	-	1,417	1,380
Legal & professional	-	5,706	-	5,706	9,357
Materials stock	-	3,214	-	3,214	4,491
Office/general admin	-	1,141	-	1,141	760
Premises costs	-	13,855	-	13,855	14,088
Printing, postage & stationery	59	26,091	384	26,534	22,734
Publications	-	1,505	16,335	17,840	22,635
Raising funds	-	590	-	590	591
Recruitment	-	41	-	41	95
Software	864	28,386	120	29,370	13,722
Staff benefits	-	2,699	-	2,699	-
Training	1,391	4,340	705	6,436	5,728
Travel & accommodation	6,527	15,683	-	22,210	5,272
Wages, NI & pension	22,799	143,281	12,888	178,968	141,455
Genetic testing	-	-	76,657	76,657	30,875
Medical research	-	16,030	-	16,030	26,755
	37,511	312,121	107,671	457,303	326,020

**Haemochromatosis UK**  
**Notes to the Financial Statements for the Year Ended 31 December 2022**

**7 Staff costs**

The aggregate payroll costs were as follows:

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
<b>Staff costs during the year were:</b>		
Wages and salaries	163,464	126,300
Social security costs	11,443	7,752
Pension costs	4,061	7,403
	<u>178,968</u>	<u>141,455</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:

	<b>2022</b>	<b>2021</b>
	<b>No</b>	<b>No</b>
Average number of employees	<u>4</u>	<u>4</u>

3 (2021 - 3) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £4,061 (2021 - £7,403).

No employee received emoluments of more than £60,000 during the year.

The total employee benefits of the key management personnel of the charity were £67,749 (2021 - £63,597).

## **HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS**

### **Haemochromatosis UK**

#### **Notes to the Financial Statements for the Year Ended 31 December 2022**

##### **8 Debtors**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Trade debtors	884	14,938
Prepayments	8,816	8,961
Accrued income	3,546	4,868
	<u>13,246</u>	<u>28,767</u>

##### **9 Creditors: amounts falling due within one year**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Trade creditors	8,105	5,939
Other taxation and social security	6,784	3,628
Other creditors	-	266
Accruals	791	1,980
	<u>15,680</u>	<u>11,813</u>

##### **10 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.

The principal place of business is:

The Flaxmill  
Flaxmill Lane  
Pinchbeck  
Spalding  
PE11 3YP

## Haemochromatosis UK

## Notes to the Financial Statements for the Year Ended 31 December 2022

## 11 Funds

	Balance at 1 January 2022	Incoming resources	Resources expended	Transfers	Balance at 31 December 2022
	£	£	£	£	£
<b>Unrestricted funds</b>					
<i>General</i>					
General	238,008	216,304	(312,121)	-	142,191
<i>Designated</i>					
Education & Awareness	113,896	82,682	(32,700)	-	163,878
GH Education	-	-	(4,811)	4,811	-
	113,896	82,682	(37,511)	4,811	163,878
<b>Total Unrestricted funds</b>	351,904	298,986	(349,632)	4,811	306,069
<b>Restricted funds</b>					
Information & Support	2,347	500	-	-	2,847
Education & Awareness	1,000	49,100	(4,032)	-	46,068
GH Education	4,811	-	-	(4,811)	-
Helpline	4,583	2,063	(6,646)	-	-
Northern Ireland Community Fund	500	-	-	-	500
Scottish Wellbeing	11,589	-	-	-	11,589
Irish Travellers Project	-	9,500	(9,046)	-	454
Wales Initiative	8,801	-	-	-	8,801
Volunteer training	705	-	(705)	-	-
Breaking Down Barriers	10,585	-	(10,585)	-	-
Genetic testing	-	76,657	(76,657)	-	-
<b>Total restricted funds</b>	44,921	137,820	(107,671)	(4,811)	70,259
<b>Total funds</b>	396,825	436,806	(457,303)	-	376,328

## HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

### Haemochromatosis UK

#### Notes to the Financial Statements for the Year Ended 31 December 2021

#### 11 Funds

	Balance at 1 January 2021	Incoming resources	Resources expended	Transfers	Balance at 31 December 2021
	£	£	£	£	£
<b>Unrestricted funds</b>					
<i>General</i>					
General	147,269	275,639	(125,474)	(59,426)	238,008
<i>Designated</i>					
Education & Awareness	142,279	-	(28,383)	-	113,896
<b>Total unrestricted funds</b>	<b>289,548</b>	<b>275,639</b>	<b>(153,857)</b>	<b>(59,426)</b>	<b>351,904</b>
<b>Restricted</b>					
Information & Support	4,876	9,345	(22,749)	10,875	2,347
Education & Awareness	-	5,960	(12,544)	7,584	1,000
GH Education	37,000	-	(16,895)	(15,294)	4,811
Helpline	10,478	5,000	(10,895)	-	4,583
Northern Ireland Community Fund	12,250	11,136	(31,193)	8,307	500
Scottish Wellbeing	2,355	12,000	(2,766)	-	11,589
Medical research	200	-	(26,755)	26,555	-
Wales Initiative	-	14,376	(10,943)	5,368	8,801
Volunteer training	-	4,160	(3,455)	-	705
Kids Work	-	1,000	(1,200)	200	-
Fundraising general	-	5,050	(20,503)	15,453	-
Hospital packs	-	500	(878)	378	-
Breaking Down Barriers	-	21,972	(11,387)	-	10,585
<b>Total restricted funds</b>	<b>67,159</b>	<b>90,499</b>	<b>(172,163)</b>	<b>59,426</b>	<b>44,921</b>
<b>Total funds</b>	<b>356,707</b>	<b>366,138</b>	<b>(326,020)</b>	<b>-</b>	<b>396,825</b>



**Haemochromatosis UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

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;
- Wales Initiative – community awareness activities and support to people resident in Wales; Volunteer training - training, resources and support for the charity's volunteers;
- Breaking Down Barriers – resources focused on the charity's screening programmes in Northern Ireland.

The transfer from the restricted GH Education fund to the designated GH Education fund represents the value of expenditure which is not subject to any restriction.

**Haemochromatosis UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

**12 Analysis of net assets between funds**

	Unrestricted		Restricted	2022 Total funds
	General	Designated		
	£	£	£	£
Current assets	157,871	163,878	70,259	392,008
Current liabilities	(15,680)	-	-	(15,680)
Total net assets	142,191	163,878	70,259	376,328

	Unrestricted		Restricted	2021 Total funds
	General	Designated		
	£	£	£	£
Current assets	249,821	113,896	44,921	408,638
Current liabilities	(11,813)	-	-	(11,813)
Total net assets	238,008	113,896	44,921	396,825

**13 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:

	2022	2021
	£	£
Independent examination	1,116	1,080

**Haemochromatosis UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

**14 Taxation**

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

**15 Trustees' remuneration and expenses**

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.

**15 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 – sign up on our website.

**Haemochromatosis UK Advice & Help Line**

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

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

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Website: **[www.haemochromatosis.org.uk](http://www.haemochromatosis.org.uk)**