HAEMOCHROMATOSIS UK

England & Wales · Charity number 1001307

Details

Other names	THE HAEMOCHROMATOSIS SOCIETY, HAEMOCHROMATOSIS UK, HUK
Status	Registered
Legal form	Charitable company
Company number	02541361
Registered	1990-12-17
Register	View on the Charity Commission register

Contact

Address	The Flaxmill Flaxmill Lane Pinchbeck Spalding Lincolnshire PE11 3YP
Phone	03030401101
Email	office@huk.org.uk
Website	http://www.haemochromatosis.org.uk

Activities

Objects: 1)TO PROVIDE FOR PERSONS WITH HEREDITARY HAEMOCHROMATOSIS OR ASSOCIATED DISEASES HELP WITH THOSE PROBLEMS(INCLUDING BUT NOT LIMITED TO DIAGNOSIS,MEDICAL CARE,TREATMENT & FINANCIAL BURDEN) RESULTING FROM THE DISEASES & TO PROVIDE SUCH OTHERS CHARITABLE RELIEF AS THE SOCIETY MAY THINK FIT.2.)TO UNDERTAKE FOR THE PUBLIC BENEFIT RESEARCH INTO THE DISEASES & TO PUBLISH THE USEFUL RESULTS OF SUCH RESEARCH. 3.)TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC & THE MEDICAL PROFESSION INTO THE CAUSES OF:(A) INCREASING THE PROPORTION OF HAEMOCHROMATOTICS DIAGNOSED AS SUCH (B) PROMOTING DIAGNOSIS AT AN EARLY STAGE BEFORE THE ONSET OF IRREVERSIBLE ORGAN DAMAGE.

Activities: To SUPPORT and inform people with genetic haemochromatosis. To promote public AWARENESS of genetic haemochromatosis.To encourage and support RESEARCHinto haemochromatosis.To EDUCATE healthcare professionals and others with an interest in genetic haemochromatosis.

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Classification

- **How:** Makes Grants To Organisations, Provides Other Finance, Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£575,107	£622,646	£358,402	7
2023-12-31	£423,698	£394,085	-	-
2022-12-31	£436,806	£457,303	-	-
2021-12-31	£366,138	£326,020	-	-
2020-12-31	£317,667	£229,432	-	-

Trustees

Name	Role	Appointed
Aaron Venables		2025-02-28
Dieter Krapp		2024-06-28
Guillaume Fillias		2025-02-28
Pippa Randolph		2024-06-28
Sarah Vousden		2024-06-28

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HAEMOCHROMATOSIS UK

England & Wales - Charity number 1001307

Accounts

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 2024

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	Nigel Brunyee Dieter Krapp Sarah Vousden Guillaume Fillias Aaron Venables Pippa Randolph
Senior Management Team	Neil McClements, CEO
Charity Registration Number	1001307 England & Wales SC041701 Scotland
Company Registration Number	02541361
Principal Office	The Flaxmill Flaxmill Lane Pinchbeck Spalding PE11 3YP
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 2024.

Trustees and officers

The trustees and officers serving during the year and since the year end were as follows:

Trustees:	Rodger Houghton (resigned 20 February 2024)
	Kevin King (resigned 2 February 2024)
	Serena ter Kuile (resigned 17 May 2025)
	Dr Heidi Fuller (resigned 17 May 2024)
	Dr Florian Jaeckle (resigned 17 May 2024)
	Nigel Brunyee (appointed 28 June 2024)
	Dieter Krapp (appointed 28 June 2024)
	Sarah Vousden (appointed 28 June 2024)
	Guillaume Fillias (appointed 28 February 2025)
	Aaron Venables (appointed 28 February 2025)
	Pippa Randolph (appointed 28 June 2024)

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 28/06/2024. 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

Recruitment Consultant TPP

Induction and training of trustees

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

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.

Haemochromatosis UK

Trustees' Report

Objectives, strategies and activities

Provide support to Haemochromatosis UK (HUK) members and non-members through means of an email newsletter, social media and our Helpline and Buddy scheme,
Educate healthcare professionals about the condition, the possible / potential complications and the provision of treatment.
Raise awareness of the condition through volunteer weeks, fundraising activities, exhibitions.

Activities:
-Support People at Risk of GH by:
improving access to reliable information resources for patients and their families
expanding access to support services, including digital services.
delivering support services in response to NHS unmet needs.
Developing consistent care pathways/guidelines for excellent GH diagnosis
-Educate Healthcare professionals
increasing clinician awareness of GH
improving access to clinician information resources
advocating for best practices care pathways across healthcare settings
campaigning for improvement in relevant NHS services
-Stimulate medical research into GH by:
increasing research effort into understanding the causes and impact of GH
improving the evidence base that inform our community support and clinicians education
driving collaborative campaigns for better care pathways, standards and protocols
-Raise Public Awareness by:
campaigning to reach and engage communities at risk with information and advice
improving awareness of GH, symptoms and consequences
engaging with healthcare professionals

Public benefit

The public values the organisations support, particularly to the newly diagnosed. It advises professionals, offers support to sufferers by listening, providing genetic testing, the knowledge of and Advanced Practice Nurse and literature to members.. The organisation supports grants to promote research. The public is invited to feedback via a Member Survey.

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.

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

Early in 2024, we secured additional funding from the National Lottery in England for a five-year project across England. This has led to the establishment of a Steering Group to help shape the delivery of this work. We were pleasantly surprised to receive over 150 volunteer applications to get involved, which underlined a significant growth in the number of active volunteers across all aspects of our work this year. This funding is ring-fenced for use in England, however we are actively applying to the National Lottery for further funding to advance our work in Wales, Scotland and Northern Ireland.

This year we were also finalists in the Third Sector Awards for our awareness campaigning and MyIron+ digital app, finalists in the prestigious Health Services Journal Awards for Acute Sector Innovation of the Year for our collaboration with the Welsh Blood Service to improve access to donor services for people with GH in Wales, finalists in the Nursing Times Awards for our clinician education and specialist nurse helpline services. In the Autumn, we started a collaboration with multi-award-winning photojournalist, Cathal McNaughton, to raise awareness of GH through photography. Volunteers from across Northern Ireland were photographed and their photographs and stories are being curated in a book and exhibition that showcases life with haemochromatosis. Through this initiative we hope to dispel misunderstandings of who is affected by the condition, and how it presents itself person-to-person.

Financial review

Deficit at the end of 2024 was anticipated £47.5k. The Charity had carried forward large funding of £406k from 2023 and it was a Board decision to reduce this amount. Large funds balances are detrimental to secure future funding for the charity.

Policy on reserves

The Charity has a policy on reserve policy establishing a contingency reserve fund sufficient to meet between six to nine months' unrestricted expenditure. There is no proposed change to this policy.

Principal risks and uncertainties

Financial Risk
The Charity examiners opinion has been given on a going concern basis in relation to the 2024 financial year. At the time of finalising this report, the Charity is managing material financial risks connected with ongoing matters relating to its former CEO. The Board of Trustees is actively monitoring and assessing the potential impact of these issues on the Charity's financial position, and appropriate notifications have been made to the Charity Commission.

Plans for future periods

Aims and key objectives for future periods

The FY2025/2026 operating plan consolidates the work undertaken in 2024 and aligns with the strategic plan from Q4 2022. Activities and projects are organized under five strategic themes.
1. Early Diagnosis Saves Lives

Ongoing Initiatives:
- Cascade screening for members and their families
- Genetic testing for the public

New Initiatives:
- Saliva-based genetic testing (late 2025/early 2026)
- NHS BT call centre in Bangor (NI), funded by Hagan Homes
- Geo-targeted screening based on external fundraising
- Launch of "Vita Vibes" – vitamins for GH individuals
2. Support People at Risk of GH

Ongoing Initiatives:
- Helplines for various support needs
- ANP appointments
- GH Buddies scheme
- Facebook support group
- Membership bursaries
- MyIron+ app with enhancements

New Initiatives:
- Prototype MyFerritin+ app (Project Mavis) (late 2025/early 2026, subject to additional financing)
- Additional publications including revised GP guide
- Exploratory mobile venesection service
3. Educate Healthcare Professionals

Ongoing Initiatives:
- Clinical conferences and exhibitions
- Accredited training modules (Venesection, RCN, GP)
New Initiatives:
- GH pathway publication (alternative to NICE guidelines)
- Nursing study days in Newcastle and southern UK
4. Stimulate Medical Research into GH

Haemochromatosis UK

Trustees' Report

Ongoing Initiatives:
- Research and nursing awards
- Support for 3 research projects

New Initiatives:
- Relaunch of CAP
- GH prevalence study via Our Future Health
- Register MyIron+ dataset with REC
5. Raise Public Awareness of GH

Ongoing Initiatives:
- Exhibitions (Balmoral, Great North, Royal Highland)
- We are Overloaded - Photographic exhibition at Edinburgh Fringe and future events across UK
- Marketing campaigns and awareness week
- Advocacy efforts
- Continue working with APPG at Westminster

New Initiatives:
- Enhanced mass media and press campaigns

Grants out (Fernau Award) process

1.Applications opened and advertised on the website + social media channels + email to mailing lists (clinicians, members, newsletter)
2.Applications form completed (Typeform) on website - email notification of form received by CEO
3.Grant Committee including CEO, HUK’s Advanced Nurse Practitioner and Nurse for discussion and selection reviews applications and shares shortlisted applications
4.Successful applicant is chosen and notified by the CEO
5.Grants agreements signed by both parties

Haemochromatosis UK

Trustees' Report

Statement of Trustees' Responsibilities

Statement of 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 applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland". The report and accounts have been prepared in accordance with the provisions in the Companies Act 2006 relating to small companies.

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 the incoming resources and application of resources, including its income and expenditure, of the charitable company 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 accounting standards, comprising FRS 102 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 proper accounting records that can 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.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

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 ...28 Sep 2025..... and signed on its behalf by:

.....
Guillaume Fillias
Trustee

.....
Aaron Venables
Trustee

Haemochromatosis UK

Independent Examiner's Report to the trustees of Haemochromatosis UK ('the Company')

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 2024.

Responsibilities and basis of report

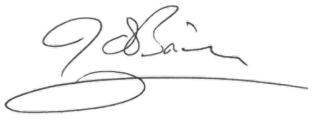
As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

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 MSc, FAIA, 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: 26/09/25

Haemochromatosis UK

Statement of Financial Activities for the Year Ended 31 December 2024 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted £	Restricted £	Total 2024 £	Total 2023 £
Income and Endowments from:					
Donations and legacies	3	209,251	-	209,251	144,118
Charitable activities	4	257,772	101,250	359,022	274,442
Investment income	2	6,834	-	6,834	5,138
Total income		473,857	101,250	575,107	423,698
Expenditure on:					
Charitable activities	6	(525,548)	(97,098)	(622,646)	(394,085)
Total expenditure		(525,548)	(97,098)	(622,646)	(394,085)
Net (expenditure)/income		(51,691)	4,152	(47,539)	29,613
Transfers between funds		(7,270)	7,270	-	-
Net movement in funds		(58,961)	11,422	(47,539)	29,613
Reconciliation of funds					
Total funds brought forward		298,453	107,488	405,941	376,328
Total funds carried forward	11	239,492	118,910	358,402	405,941

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 2024 (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 2023 £
Income and Endowments from:				
Donations and legacies	3	144,118	-	144,118
Charitable activities	4	219,644	54,798	274,442
Investment income	2	5,138	-	5,138
Total income		368,900	54,798	423,698
Expenditure on:				
Charitable activities	6	(376,516)	(17,569)	(394,085)
Total expenditure		(376,516)	(17,569)	(394,085)
Net (expenditure)/income		(7,616)	37,229	29,613
Net movement in funds		(7,616)	37,229	29,613
Reconciliation of funds				
Total funds brought forward		306,069	70,259	376,328
Total funds carried forward	11	298,453	107,488	405,941

The notes on pages 13 to 23 form an integral part of these financial statements.

Haemochromatosis UK

(Registration number: 02541361)
Balance Sheet as at 31 December 2024

	Note	2024 £	2023 £
Current assets			
Debtors	8	3,448	4,328
Cash at bank and in hand		390,451	422,791
		393,899	427,119
Creditors: Amounts falling due within one year	9	(35,497)	(21,178)
Net assets		358,402	405,941
Funds of the charity:			
Restricted income funds			
Restricted funds		118,910	107,488
Unrestricted income funds			
Unrestricted funds		239,492	298,453
Total funds	11	358,402	405,941

For the financial year ending 31 December 2024 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 9 to 23 were approved by the trustees, and authorised for issue on ..... and signed on their behalf by:

.....
Guillaume Fillias
Trustee

.....
Aaron Venables
Trustee

Haemochromatosis UK

Statement of Cash Flows for the Year Ended 31 December 2024

	Note	2024 £	2023 £
Cash flows from operating activities			
Net cash (expenditure)/income		(47,539)	29,613
Adjustments to cash flows from non-cash items			
Investment income	2	(6,834)	(5,138)
		(54,373)	24,475
Working capital adjustments			
Decrease in debtors	8	880	8,918
Increase in creditors	9	14,319	5,498
Net cash flows from operating activities		(39,174)	38,891
Cash flows from investing activities			
Interest receivable and similar income	2	6,834	5,138
Net (decrease)/increase in cash and cash equivalents		(32,340)	44,029
Cash and cash equivalents at 1 January		422,791	378,762
Cash and cash equivalents at 31 December		390,451	422,791
Reconciliation of net cash flow to movement in net funds			
(Decrease)/increase in cash		(32,340)	44,029
Net funds at 1 January 2024		422,791	378,762
Net funds at 31 December 2024		390,451	422,791

All of the cash flows are derived from continuing operations during the above two periods.

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.

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.

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 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.

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.

2 Investment income

	Unrestricted funds General £	Total 2024 £	Total 2023 £
Interest receivable and similar income;			
Interest receivable on bank deposits	6,834	6,834	5,138

3 Income from donations and legacies

	Unrestricted funds		Total 2024 £	Total 2023 £
	Designated £	General £		
Donations and legacies;				
Donations from companies, trusts and similar proceeds	12,700	20,792	33,492	-
Donations from individuals	-	127,867	127,867	85,183
Grants, including capital grants;				
Grants from other charities	-	-	-	54,935
Grants from companies	-	47,892	47,892	4,000
	12,700	196,551	209,251	144,118

4 Income from charitable activities

	Unrestricted funds		Restricted funds £	Total 2024 £	Total 2023 £
	Designated £	General £			
Grants & donations	-	-	101,250	101,250	53,128
Consultancy fees	-	-	-	-	484
Membership subscriptions	-	107,478	-	107,478	87,039
Merchandise	-	-	-	-	2,944
Sundry income	-	163	-	163	56
Genetic testing	125,614	-	-	125,614	81,997
Corporate sponsorship	-	3,091	-	3,091	21,121
Gift aid	-	-	-	-	27,673
Sales & Fees	-	21,426	-	21,426	-
	125,614	132,158	101,250	359,022	274,442

5 Grants & donations

	Unrestricted funds £	Restricted funds £	Total £
Bromley Golf Club	3,654	-	3,654
Bramhall Methodist Church	1,000	-	1,000
Anne Russell	5,000	-	5,000
Jane Lanning Foundation	12,700	-	12,700
Wiggin Family Trust	100	-	100
Moore Barlow LLP	3,091	-	3,091
DMG Roper Trust	-	150	150
Florence Turner Trust	-	500	500
Blunt Trust	-	2,000	2,000
The Hopper Trust	-	5,000	5,000
The Lannx Hannay Charitable trust	-	5,000	5,000
The Callendar Charitable Trust	-	1,000	1,000
Hugh Strenhouse	-	550	550
James Wood Trust	-	2,000	2,000
Northern Ireland Community	-	3,000	3,000
Michelle Grant	-	3,000	3,000
Adviceline, ANP appointments	-	2,500	2,500
Dorinda Lady Dunleath Charitable Trust	-	1,000	1,000
WED Charitable Foundation	-	500	500
National Lottery	-	75,050	75,050
Other donations	183,706	-	183,706
	209,251	101,250	310,501

6 Expenditure on charitable activities

	Unrestricted funds		Restricted	Total	Total
	Designated	General	funds	2024	2023
	£	£	£	£	£
Accountancy	-	8,920	3,000	11,920	9,425
Advertising/ Promotional	20,494	289	6,257	27,040	13,538
Bank charges	-	60	-	60	72
Equipment & computer costs	219	2,783	34	3,036	11,417
External events including The Furnau Award 2024	-	75,562	-	75,562	4,310
Dues & subscriptions	-	1,275	769	2,044	4,523
Hosted events	-	15,092	825	15,917	7,897
Insurance	785	172	-	957	404
Legal & professional	-	9,135	-	9,135	1,828
Materials stock	-	-	-	-	787
Office / General admin	569	3,494	2,680	6,743	5,335
Phone costs	250	377	1,563	2,190	2,223
Printing, postage & stationery	25,000	2,315	14,287	41,602	31,359
Raising funds	49	12,390	-	12,439	2,131
Recruitment	-	2,984	-	2,984	313
Rent	-	2,393	1,500	3,893	4,762
Software	1,283	20,308	13	21,604	12,988
Staff benefits	-	2,596	-	2,596	1,434
Sundry costs	128	20,903	199	21,230	-
Training	-	1,708	965	2,673	5,243
Travel & accommodation	813	14,036	2,844	17,693	15,604
Trustees expenses	-	-	-	-	518
Wages, NI & pension	67,400	129,129	42,826	239,355	199,016
Genetic testing	54,030	-	18,596	72,626	39,119
Merchandise cost	-	10,351	571	10,922	6,419
Utilities	-	1,286	-	1,286	2,877
App fees	3,594	-	169	3,763	4,921
Collection fees	-	13,376	-	13,376	5,622
	174,614	350,934	97,098	622,646	394,085

7 Staff costs

The aggregate payroll costs were as follows:

	2024 £	2023 £
Staff costs during the year were:		
Wages and salaries	213,283	176,679
Social security costs	21,292	18,271
Pension costs	4,780	4,066
	239,355	199,016

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

	2024 No	2023 No
Average number of employees	7	4

5 (2023 - 3) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £4,780 (2023 - £4,066).

The number of employees whose emoluments fell within the following bands was:

	2024 No	2023 No
£60,001 - £70,000	1	1

The total employee benefits of the key management personnel of the charity were £96,857 (2023 - £64,930).

8 Debtors

	2024 £	2023 £
Trade debtors	1,752	1,583
Prepayments	1,696	2,745
	3,448	4,328

9 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	10,207	14,707
Other taxation and social security	5,593	4,456
Accruals	19,697	2,015
	35,497	21,178

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.

11 Funds

	Balance at 1 January 2024 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2024 £
Unrestricted funds					
General					
General	25,431	335,543	(350,934)	18,799	28,839
Designated					
Education & Awareness	179,822	12,700	-	(51,074)	141,448
Genetic Testing	-	125,614	(156,257)	30,643	-
Project Mavis	65,200	-	(16,357)	(5,638)	43,205
MyIron+	3,000	-	-	-	3,000
Medical Research	25,000	-	(2,000)	-	23,000
	273,022	138,314	(174,614)	(26,069)	210,653
Total unrestricted funds	298,453	473,857	(525,548)	(7,270)	239,492
Restricted funds					
Information & Support	1,747	650	(9,666)	7,270	1
Education & Awareness	46,068	7,000	(2,000)	-	51,068
Northern Ireland Community Fund	9,000	9,500	(16,562)	-	1,938
Scottish Wellbeing	8,665	8,550	(8,443)	-	8,772
Irish Travellers Project	454	-	-	-	454
Medical Research	4,000	-	-	-	4,000
Wales Initiative	8,801	-	-	-	8,801
Forrester Family Trust	5,000	-	-	-	5,000
Helpline	13,103	-	(12,978)	-	125
Campaigning & Advocacy	10,650	500	(9,014)	-	2,136
TNL England Pass It On Grant	-	75,050	(38,435)	-	36,615
Total restricted funds	107,488	101,250	(97,098)	7,270	118,910
Total funds	405,941	575,107	(622,646)	-	358,402

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;
Forrester Family Trust - dedicated towards advancing the general purposes of the charity in aiding people at risk of genetic haemochromatosis;
Helpline – funds provided towards the costs of providing a Helpline;
Scottish Wellbeing – funds towards providing counselling services, education and support specifically in Scotland;
Project Mavis - activities working towards improving the diagnosis and care of people with genetic haemochromatosis;
Northern Ireland Community Fund – funding towards providing support and information;
Medical Research - stimulating and conducting medical research to improve our understanding of and treatment approaches towards genetic haemochromatosis;
Wales initiative - community awareness activities and support to people resident in Wales;
Irish Travellers project - funding for the Breaking Down Barriers project to engage with Irish travellers throughout the country;
Campaigning & Advocacy - supporting activities focussed on the advocacy of policymakers, elected representatives and clinicians towards the objectives of the charity and the community it works to support.
TNL England Pass It On Grant – a five-year programme restricted to England, to improve awareness of GH within families, ensure cascade screening of those at risk and to increase uptake of blood donation in collaboration with NHS BT

	Balance at 1 January 2023 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2023 £
Unrestricted funds					
General					
General	142,191	229,484	(259,435)	(86,809)	25,431
Designated					
Education & Awareness	163,878	22,485	(6,541)	-	179,822
Genetic Testing	-	103,931	(110,540)	6,609	-
Project Mavis	-	13,000	-	52,200	65,200
MyIron+	-	-	-	3,000	3,000
Medical Research	-	-	-	25,000	25,000
	163,878	139,416	(117,081)	86,809	273,022
Total unrestricted funds	306,069	368,900	(376,516)	-	298,453
Restricted					
Information & Support	2,847	13,545	(14,645)	-	1,747
Education & Awareness	46,068	-	-	-	46,068
Northern Ireland Community Fund	500	8,500	-	-	9,000
Scottish Wellbeing	11,589	-	(2,924)	-	8,665
Irish Travellers Project	454	-	-	-	454
Medical Research	-	4,000	-	-	4,000
Wales Initiative	8,801	-	-	-	8,801
Forrester Family Trust	-	5,000	-	-	5,000
Helpline	-	13,103	-	-	13,103
Campaigning & Advocacy	-	10,650	-	-	10,650
Total restricted funds	70,259	54,798	(17,569)	-	107,488
Total funds	376,328	423,698	(394,085)	-	405,941

12 Analysis of net assets between funds

	Unrestricted			
	General £	Designated £	Restricted £	2024 Total funds £
Current assets	64,336	210,653	118,910	393,899
Current liabilities	(35,497)	-	-	(35,497)
Total net assets	28,839	210,653	118,910	358,402

	Unrestricted			
	General	Designated	Restricted	2023 Total funds
	£	£	£	£
Current assets	46,609	273,022	107,488	427,119
Current liabilities	(21,178)	-	-	(21,178)
Total net assets	25,431	273,022	107,488	405,941

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:

	2024	2023
	£	£
Independent examination	1,560	1,135

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.

16 Related party transactions

There were no related party transactions in the year.

HAEMOCHROMATOSIS UK

England & Wales - Charity number 1001307

Accounts

Haemochromatosis UK
Trustees' Annual Report & Accounts 2023

Haemochromatosis • UK
Helping people live with iron overload
+Fe

Haemochromatosis UK Trustees' Annual Report and Accounts
For the year ending 31 December 2023
Published April 2024
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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
Dr Heidi Fuller (appointed 12 November 2023), Interim Co-Chair
Serena ter Kuile (appointed 12 November 2023), Interim Co-Chair
Rodger Houghton, Finance Trustee
Kevin King, Legal Trustee
Dr Florian Jaeckle (appointed 12 November 2023)
Katy Burns MBE, Chair of Trustees (resigned 12 November 2023)
Catherine Wiggins (resigned 12 November 2023)

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2. A MESSAGE FROM THE CHIEF EXECUTIVE

It's been an amazing and busy 2023!

Despite a range of cost of living pressures, we've grown our membership base by almost 20% during 2023. Our clinician education programme is busier than ever, with our Royal College of General Practitioners and Royal College of Nursing accredited eLearning resources both securing re-accreditation and growing healthcare professional usage. Our medical research programme, over-seen by an expanded Clinical & Research Advisory Panel, is also growing as we seek clinical solutions to many of the problems commonly experienced by people with GH.

Our genetic testing service continued it's exciting growth trajectory. What started almost 3 years ago as a tentative toe-in-the-water has developed into a core service, helping families understand their genetic risk of iron overload and facilitating research into the often under-reported prevalence of the condition. We regularly receive positive feedback on the life changing impact of this service and our pro-active efforts to provide screening to communities at risk:

> *"I was a participant in your first testing project in Derry, Northern Ireland two years ago...as a result of my diagnosis, several of my siblings and their children have been diagnosed…so I am very grateful that you have initiated this testing programme."*

Haemochromatosis UK now conducts more HFE genetic tests most weeks than the entire NHS. We continue to press for better access to testing and a pro-active, preventative healthcare approach by the NHS to the condition. It's important to us that we deliver this service to a very high standard, something which is recognised in a net promoter score of 94% by people who have received a test from us. This is tribute to the diligence of our staff team, who work hard to deliver the majority of test results within 2 weeks in a format which is readily understood, complemented by a counselling appointment with our specialist nurses. This feedback from someone who recently completed a test and received support and advice from our specialist nurses Diogo and Victoria is representative:

> *"I must say I'm amazed by Haemochromatosis UK. You are a really sharp, smart and effective outfit, especially in the way that you link your excellent advice service so smartly to your research and advocacy. "*

2023 saw our first multi-channel TV, radio and billboard awareness campaign. With the help of local businesses in Northern Ireland we launched a £300k awareness campaign that garnered great feedback from the community as well as screening over 100 people who would otherwise been unaware of their risks of iron overload. We hope to do more of this in other parts of the UK, but funding is always a challenge.

During the year we doubled-down on our commitment to our volunteers and the vital role they play in many aspects of our work. This was recognised independently with the award of Investing In Volunteers accreditation, a significant milestone in our efforts to professionalise our approach to volunteering across the charity's activities.

Early in 2023 we launched our new GH Buddy Scheme. This matches up people seeking information and ongoing support following a recent diagnosis with our amazing trained volunteer Buddies. We've been taken aback at just how well received this new service has been. Almost 100 people have been buddied in this first year and we look forward with excitement to expanding the service in 2024.

We continue to press "the powers that be" for improvements in care for people affected by genetic haemochromatosis. Our advocacy through the All-Party Parliamentary Group on Genetic Haemochromatosis at Westminster continues. It's now complimented by similar initiatives at Stormont and Holyrood.

Our work in Northern Ireland has been particularly well-received. In March 2023, we published our NI Cost of Illness report which builds upon the health economics model we developed in 2021 with YHEC for the UK as a whole. Revising the model to incorporate the results of our NI screening programme reveals that the costs to the NHS in Northern Ireland by not pro-actively diagnosing the condition are disproportionate, something that has spurred the Northern Ireland Blood Transfusion Service to improve donor registration processes to enable faster and easier GH donor registration, mirroring arrangements we secured in England and Wales in 2021/2.

In June we launched our new smartphone app, MyIron+. We were thrilled to see thousands of people with GH install the app to help manage blood test results, appointments and to access our range of trusted information resources. Within 6 months of launch we had measured 5 times as many app users as we had projected for the whole year, a pattern of growth that has continued into 2024.

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.

Thank you to everyone who has helped us in 2023 – we look forward to 2024 with excitement!

Neil McClements, Chief Executive Officer
January 2024

3. TRUSTEES' REPORT FOR 2023

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 2023.

The Trustees:

Dr Heidi Fuller (appointed 12 November 2023), Interim Co-Chair
Serena ter Kuile (appointed 12 November 2023), Interim Co-Chair
Rodger Houghton, Finance Trustee
Kevin King, Legal Trustee
Dr Florian Jaeckle (appointed 12 November 2023)
Katy Burns MBE, Chair of Trustees (resigned 12 November 2023)
Catherine Wiggins (resigned 12 November 2023)

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. At year-end HUK had almost 2,900 paid-up members and over 2,700 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 2023 and outline 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 focussed 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 ensure the long-term sustainability of the organisation whilst delivering much-need, 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 £197,246.

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

- Shears Foundation
- Robert Luff Foundation
- De Laszlo Foundation
- National Lottery Northern Ireland
- Boots plc
- Forrester Family Trust
- UKH Foundation
- Zedra Trust
- The Batchworth Trust
- Harry Cureton Fund
- Cambridgeshire Community Fund
- Guy Fawkes Charitable Trust
- M Boal Charitable Trust
- FB Coales No 4 Family Trust
- Lascelles Charitable Trust
- Oakdale Trust
- Callendar Charitable Trust
- Chapman Trust
- BCH
- Tesco
- Doris Field Trust
- Astor Foundation
- Michael Cornish Charitable Trust
- An Anonymous Foundation
- JRC
- Northcott Devon Foundation
- Society for Endocrinology
- DMG Roper Trust

Corporate donations

We gratefully acknowledge the support of the following donors for their support during 2023:

- Google Ireland Limited
- Genesis Advertising (for services in kind)
- Hagan Homes
- Air Products Plc
- BDO LLP

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 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 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 deliver fundraising initiatives. We aim to ensure 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 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 2023, 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 2023, 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.

4. GOVERNANCE

Trustees are responsible in law for the financial and strategic management of the charity. They are accompanied on the board by Board Observers, who are "trustees-in-training".

Board members 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. During 2023, Serena ter Kuile, Dr Heidi Fuller and Dr Florian Jaeckle progressed from Board Observership to Trusteeship at the invitation of the board.

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, which includes a guide to the legal and practical responsibilities of being a trustee/observer. Formal training with NCVO in the role and legal responsibilities of a trustee is also provided. All board members must undertake safeguarding training, annually.

Our record with the commission is at www.charitycommission.gov.uk and can be found by searching on this 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 Advanced Nurse Practitioner, Information & Advisory Nurse, 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 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 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. The organisational strategy was formally endorsed and adopted in early 2023 by the board. An overview has been published online here : https://www.haemochromatosis.org.uk/strategy-2023-to-2028.

5. HAEMOCHROMATOSIS UK OBJECTIVES, STRATEGIES AND ACTIVITIES

Objects and aims

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 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 8th March 2024.

Dr Heidi Fuller
Interim Co-Chair
March 2024

Serena ter Kuile
Interim Co-Chair
March 2024

6. 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 2023.

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 MSc, FAIA, 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
26th March 2024

ACCOUNTS

Haemochromatosis UK

Statement of Financial Activities for the Year Ended 31 December 2023 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds	Restricted funds	Total 2023	Total 2022
		£	£	£	£
Income and endowments from:					
Donations and legacies	3	144,118	-	144,118	201,420
Charitable activities	4	219,644	54,798	274,442	234,546
Investment income	2	5,138	-	5,138	840
Total income		368,900	54,798	423,698	436,806
Expenditure on:					
Charitable activities	6	(376,516)	(17,569)	(394,085)	(457,303)
Total expenditure		(376,516)	(17,569)	(394,085)	(457,303)
Net (expenditure)/income		(50,646)	37,229	29,613	(20,497)
Net movement of funds		(7,616)	37,229	29,613	(20,497)
Reconciliation of funds:					
Total funds brought forward		306,069	70,259	376,328	396,825
Total funds carried forward	11	298,453	107,488	405,941	376,328

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 2023 (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 2022
		£	£	£
Income and endowments from:				
Donations and legacies	3	201,420	-	201,420
Charitable activities	4	96,726	137,820	234,546
Investment income	2	840	-	840
Total income		298,986	137,820	436,806
Expenditure on:				
Charitable activities	6	(349,632)	(107,671)	(457,303)
Total expenditure		(349,632)	(107,671)	(457,303)
Net (expenditure)/income		(50,646)	30,149	(20,497)
Transfers between funds		4,811	(4,811)	-
Net movement of funds		(45,835)	25,338	(20,497)
Reconciliation of funds:				
Total funds brought forward		351,904	44,921	396,825
Total funds carried forward	11	306,069	70,259	376,328

Haemochromatosis UK
(Registration number: 02541361)
Balance Sheet as at 31 December 2023

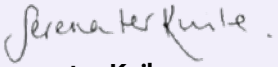
	Notes	2023	2022
		£	£
Current assets			
Debtors	8	4,328	13,246
Cash at bank and in hand		422,791	378,762
		427,119	392,008
Creditors: amounts falling due within one year	9	(21,178)	(15,680)
Net assets		405,941	376,328
Funds of the charity:			
Restricted income funds			
Restricted funds		107,488	70,259
Unrestricted income funds			
Unrestricted funds		298,453	306,069
Total charity funds	11	405,941	376,328

For the financial year ending 31 December 2023 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 16 to 31 were approved by the trustees, and authorised for issue on 8th March 2024 and signed on their behalf by:



Serena ter Kuile
Trustee

Dr Heidi Fuller
Trustee

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

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 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.

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

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 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.

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.purposes.

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

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 2023

2 Investment income

	Unrestricted funds	Total	Total
	General	2023	2022
	£	£	£
Interest receivable and similar income			
Interest receivable on bank deposits	5,138	5,138	840

3 Income from donations and legacies

	Unrestricted funds		Total	Total
	Designated	General	2023	2022
	£	£	£	£
Donations and legacies;				
Donations from companies, trusts and similar proceeds	-	-	-	17,396
Donations from individuals	-	85,183	85,183	-
Grants, including capital grants;				
Grants from other charities	33,985	20,950	54,935	
Grants from companies	3,000	1,000	4,000	184,024
	36,985	107,133	144,118	201,420

4 Income from charitable activities

	Unrestricted funds		Restricted	Total	Total
	Designated	General	funds	2023	2022
	£	£	£	£	£
Grants & donations	-	-	53,128	53,128	58,569
Consultancy fees	434	-	50	484	48,443
Membership subscriptions	-	87,039	-	87,039	69,042
Merchandise	-	1,411	1,533	2,944	8,341
Sundry income	-	(31)	87	56	-
Genetic testing	81,997	-	-	81,997	50,151
Corporate sponsorship	20,000	1,121	-	21,121	-
Gift aid	-	27,673	-	27,673	-
	102,431	117,213	54,798	274,442	234,546

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

5 Grants & donations

	Unrestricted funds	Restricted funds	Total
	£	£	£
Astor Foundation	1,000	-	1,000
BCH	1,000	-	1,000
Blunt Trust	1,000	-	1,000
Boots plc	-	9,978	9,978
Caf Donate	850	-	850
Callendar Charitable Trust - Glasgow screening	1,000	-	1,000
Cambrideshire commerce	3,000	4,000	7,000
Chapman Trust	1,000	-	1,000
De Laszio Foundation	10,000	-	10,000
DMG Roper Trust	-	150	150
Doris Field Charitable Trust	1,000	-	1,000
FB Coales No 4 Family Trust	-	2,500	2,500
Forrester Family Trust	-	5,000	5,000
Guy Fawkes Charitable Trust	2,500	-	2,500
Harrow Trust	500	-	500
JK Foundation	2,500	-	2,500
JRC	-	500	500
Lascelles Chart Trust	2,000	-	2,000
M Boal Charitable Trust	-	2,500	2,500
Michael Cornish Charitable Trust	-	1,000	1,000
Much Loved	1,656	-	1,656
National Lottery Northern Ireland	1,500	8,500	10,000
Northcott Devon Foundation	250	250	500
Oakdale Trust	-	2,000	2,000
Robert Luff Foundation	-	10,000	10,000
Shears Foundation	20,000	-	20,000
Society for Endocrinology	485	-	485
Stripe Fundraising	722	-	722
Tesco	-	1,000	1,000
The Ardwick Trust	200	-	200
The Batchworth Trust	-	5,000	5,000
UKH Foundation	5,000	-	5,000
Zedra Trust	5,000	-	5,000
Other donations	81,955	750	82,705
	144,118	53,128	197,246

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

6 Expenditure on charitable activities

	Unrestricted General funds	Unrestricted Designated funds	Restricted funds	Total 2023	Total 2022
	£	£	£	£	£
Accountancy	-	9,425	-	9,425	11,773
Advertising/ Promotional	6,005	7,351	182	13,538	20,823
Bank charges	-	72	-	72	81
Equipment & computer costs	258	11,159	-	11,417	3,311
External events	947	3,363	-	4,310	5,290
Dues & subscriptions	-	4,523	-	4,523	3,137
Hosted events	3,296	4,601	-	7,897	10,180
Insurance	-	404	-	404	1,417
Legal & professional	-	1,828	-	1,828	5,706
Materials stock	-	787	-	787	3,214
Office / General admin	294	2,118	2,923	5,335	1,141
Phone costs	500	1,723	-	2,223	-
Premises costs	-	-	-	-	13,855
Printing, postage & stationery	10,490	20,869	-	31,359	26,534
Publications	-	-	-	-	17,840
Raising funds	-	2,131	-	2,131	590
Recruitment	-	313	-	313	41
Rent	-	4,762	-	4,762	-
Software	-	12,988	-	12,988	29,370
Staff benefits	-	1,434	-	1,434	2,699
Training	2,546	2,697	-	5,243	6,436
Travel & accommodation	828	14,697	79	15,604	22,210
Trustees expenses	-	518	-	518	-
Wages, NI & pension	56,310	128,321	14,385	199,016	178,968
Genetic testing	35,607	3,512	-	39,119	76,657
Medical Research	-	-	-	-	16,030
Merchandise cost	-	6,419	-	6,419	-
Utilities	-	2,877	-	2,877	-
App fees	-	4,921	-	4,921	-
Collection fees	-	5,622	-	5,622	-
	117,081	259,435	17,569	394,085	457,303

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

7 Staff costs

The aggregate payroll costs were as follows:

	2023 £	2022 £
Staff costs during the year were:		
Wages and salaries	176,679	163,464
Social security costs	18,271	11,443
Pension costs	4,066	4,061
	199,016	178,968

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:

	2023 No	2022 No
Average number of employees	4	4

3 (2022 - 3) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £4,066 (2022 - £4,061).

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 £64,930 (2022 - £67,749).

8 Debtors

	2023 £	2022 £
Trade debtors	1,583	884
Prepayments	2,745	8,816
Accrued income	-	3,546
	4,328	13,246

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

9 Creditors: amounts falling due within one year

	2022 £	2021 £
Trade creditors	14,707	8,105
Other taxation and social security	4,456	6,784
Accruals	2,015	791
	21,178	15,680

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 2023

11 Funds

	Balance at 1 January 2023	Incoming resources	Resources expended	Transfers	Balance at 31 December 2023
	£	£	£	£	£
Unrestricted funds					
General					
General	142,191	229,484	(259,435)	(86,809)	25,431
Designated					
Education & Awareness	163,878	22,485	(6,541)	-	179,822
Genetic Testing	-	103,931	(110,540)	6,609	-
Project Mavis	-	13,000	-	52,200	65,200
MyIron+	-	-	-	3,000	3,000
Medical Research	-	-	-	25,000	25,000
	163,878	139,416	(117,081)	86,809	273,022
Total Unrestricted funds	306,069	368,900	(376,516)	-	298,453
Restricted funds					
Information & Support	2,847	13,545	(14,645)	-	1,747
Education & Awareness	46,068	-	-	-	46,068
Northern Ireland Community Fund	500	8,500	-		9,000
Scottish Wellbeing	11,589	-	(2,924)	-	8,665
Irish Travellers Project	454	-	-	-	454
Medical Research	-	4,000	-	-	4,000
Wales Initiative	8,801	-	-	-	8,801
Forrester Family Trust	-	5,000	-	-	5,000
Helpline	-	13,103	-	-	13,103
Campaigning & Advocacy	-	10,650	-	-	10,650
Total restricted funds	70,259	54,798	(17,569)	-	107,488
Total funds	376,328	423,698	(394,085)	-	405,941

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

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;
- Forrester Family Trust - dedicated towards advancing the general purposes of the charity in aiding people at risk of genetic haemochromatosis;
- Helpline – funds provided towards the costs of providing a Helpline;
- Scottish Wellbeing – funds towards providing counselling services, education and support specifically in Scotland;
- Project Mavis - activities working towards improving the diagnosis and care of people with genetic haemochromatosis;
- Northern Ireland Community Fund – funding towards providing support and information;
- Medical Research - stimulating and conducting medical research to improve our understanding of and treatment approaches towards genetic haemochromatosis;
- Wales initiative - community awareness activities and support to people resident in Wales;
- Irish Travellers project - funding for the Breaking Down Barriers project to engage with Irish travellers throughout the country;
- Campaigning & Advocacy - supporting activities focussed on the advocacy of policymakers, elected representatives and clinicians towards the objectives of the charity and the community it works to support.

Haemochromatosis UK

Notes to the Financial Statements for the Year Ended 31 December 202

	Balance at 1 January 2022	Incoming resources	Resources expended	Transfers	Balance at 31 December 2022
	£	£	£	£	£
Unrestricted funds					
General					
General	238,008	216,304	(312,121)	-	142,191
Designated					
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
Total unrestricted funds	351,904	298,986	(349,632)	4,811	306,069
Restricted					
Information & Support	2,347	500	-	-	2,847
Education & Awareness	1,000	49,100	(4,032)	-	46,068
GH Education	4,811	-	-	(4,811)	-
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)	-	-
Total restricted funds	40,338	135,757	(101,025)	(4,811)	70,259
Total funds	392,242	434,743	(450,657)	-	376,328

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

12 Analysis of net assets between funds

	Unrestricted			
	General	Designated	Restricted	2023 Total funds
	£	£	£	£
Current assets	46,609	273,022	107,488	427,119
Current liabilities	(21,178)	-	-	(21,178)
Total net assets	25,431	273,022	107,488	405,941

	Unrestricted			
	General	Designated	Restricted	2022 Total funds
	£	£	£	£
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

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:

	2023	2022
	£	£
Independent examination	1,135	1,116

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2023

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.

Haemochromatosis • UK
Helping people live with iron overload

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**

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

COMMUNITY FUND

HAEMOCHROMATOSIS UK

England & Wales - Charity number 1001307

Accounts

Haemochromatosis • UK
Helping people live with iron overload

Haemochromatosis UK Trustees' Annual Report & Accounts 2022

2022 Winner
GSK IMPACT Awards
In partnership with The King's Fund

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

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

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.

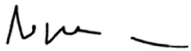
Building on the strength of our screening programmes in Derry-Londonderry and Carrickfergus, we expanded our reach to provide awareness raising and screening to almost 100,000 households across Worthing, Cardiff, Edinburgh and Merseyside. The results are currently being analysed with a view to publication 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

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
- Liilie 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 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.

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.

R Houghton

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.

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)].

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
Units 1 & 2 North West
41 Talbot Street
Nottingham
NG1 5GL
Date: 19/07/2023

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
		£	£	£	£
Income and endowments from:					
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
Total income		298,986	137,820	436,806	366,138
Expenditure on:					
Charitable activities	6	(349,632)	(107,671)	(457,303)	(326,020)
Total expenditure		(349,632)	(107,671)	(457,303)	(326,020)
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
Reconciliation of funds:					
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
		£	£	£
Income and endowments from:				
Donations and legacies	3	118,445	-	118,445
Charitable activities	4	156,954	90,499	247,453
Investment income	2	240	-	240
Total income		275,639	90,499	366,138
Expenditure on:				
Charitable activities	6	(153,857)	(172,163)	(326,020)
Total expenditure		(153,857)	(172,163)	(326,020)
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
Reconciliation of funds:				
Total funds brought forward		289,548	67,159	356,707
Total funds carried forward	11	351,904	44,921	396,825

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

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

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	Restricted funds	Total 2022	Total 2021
	General			
	£	£	£	£
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
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 Guiness Trust	500	-	500
Williams Brownhill	-	3,000	3,000
	184,024	58,569	242,593

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:

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

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:

	2022 No	2021 No
Average number of employees	4	4

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

8 Debtors

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

9 Creditors: amounts falling due within one year

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

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 £
Unrestricted funds					
General					
General	238,008	216,304	(312,121)	-	142,191
Designated					
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
Total Unrestricted funds	351,904	298,986	(349,632)	4,811	306,069
Restricted funds					
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)	-	-
Total restricted funds	44,921	137,820	(107,671)	(4,811)	70,259
Total funds	396,825	436,806	(457,303)	-	376,328

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 202

11 Funds

	Balance at 1 January 2021	Incoming resources	Resources expended	Transfers	Balance at 31 December 2021
	£	£	£	£	£
Unrestricted funds					
General					
General	147,269	275,639	(125,474)	(59,426)	238,008
Designated					
Education & Awareness	142,279	-	(28,383)	-	113,896
Total unrestricted funds	289,548	275,639	(153,857)	(59,426)	351,904
Restricted					
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
Total restricted funds	67,159	90,499	(172,163)	59,426	44,921
Total funds	356,707	366,138	(326,020)	-	396,825

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			2022
	General	Designated	Restricted	Total funds
	£	£	£	£
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			2021
	General	Designated	Restricted	Total funds
	£	£	£	£
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.

Haemochromatosis • UK
Helping people live with iron overload
+Fe

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**

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

HAEMOCHROMATOSIS UK

England & Wales - Charity number 1001307

Accounts

Haemochromatosis • UK +Fe
Helping people live with iron overload

Haemochromatosis UK Trustees' Annual Report & Accounts

Haemochromatosis UK Trustees' Annual Report and Accounts
For the year ending 31 December 2021
Published July 2022
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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
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

Trustees at 31st May 2022
Katy Burns MBE, Chair of Trustees (from 11 December 2021)
& Safeguarding Trustee
Rodger Houghton, Finance Trustee
Catherine Wiggins, Finance Trustee
Kevin King, Legal Trustee
Gillian Fachiri, Board Observer

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2. INTRODUCTION FROM THE CHAIR

The trustees are pleased to report that, despite the challenges of the on-going Covid-19 pandemic, HUK has managed to sustain most of its activities.

There has been further development of the important work to increase the diagnosis of haemochromatosis and continue to support people whose lives are affected by the condition.

One of the most impactful aspects of this was the opportunity to provide access to genetic testing, both for HUK members and the public. Work has continued on the key projects plus the community and education work as detailed in this report.

The trustees wish to express their gratitude to the Chief Executive, Neil McClements, and his small team of staff for their continuing hard work in another challenging year. We welcome two new members of staff, Neil Irwin (Fundraiser) and Diogo Gomes (Advanced Nurse Practitioner) and our new trustees, Kevin King and Catherine Wiggins, and Gillian Fachiri as Board Observer, who bring valuable skills and experience to the charity.

Tim Spring has retired from his role as the Chair and the trustees wish to extend their sincere gratitude to him for his commitment and significant contributions to the work of HUK and to the Board. Kim Hicks has stepped down as trustee from May 2021; we record our thanks for her support over the year.

I take on the role of Chair with my sincere thanks to both Tim and Neil for their generous support.

Katy Burns

Katy Burns MBE
Chair of the Board of Trustees

3. A MESSAGE FROM THE CHIEF EXECUTIVE

After the Covid challenges of 2020, we hoped for an easier 2021. But it was not to be...

Despite the continuing ravages of the pandemic, we've been working diligently to progress the interests of people affected by genetic haemochromatosis (GH). This has included a significant expansion of our membership as well as the launch of several exciting initiatives.

Membership

Since our earliest beginnings in 1990, we have been a membership organisation. Whilst we work to support anyone affected by genetic haemochromatosis, member or not, we particularly value our members for keeping us true to our mission.

We were pleased to note during 2021 an almost 50% increase in membership over the preceding two years. We increasingly welcome members from outside the UK – as far as Singapore and South America.

If you are not already a member of the charity, may I encourage you to join us – together we are stronger.

Our events programme

The Covid-19 pandemic continued to limit our face-to-face activities during the year. We took the opportunity to raise awareness at the Balmoral Show (80,000 visitors), the Royal College of GPs Conference (2,000 attendees) and the Nursing & Primary Care Best Practice Show (7,000 attendees).

Given the on-going pandemic response, we continue to look for opportunities to raise awareness amongst clinicians and the general public wherever such events are possible.

Our clinical education programme

Members frequently share their concerns that clinicians are less familiar with GH than they might be. We're trying to address this in several ways.

Our popular "lunch and learn" sessions for GPs have developed into a broader programme of talks for medical students and specialist trainees. There's a real interest in GH amongst people early in their careers, something we welcome.

In May, with the support of the Royal College of Nursing (RCN), we launched a new eLearning course for nurses and healthcare practitioners. This initiative is accredited by the RCN and has trained over 400 nurses in the first six months of operation. We continue to promote this initiative with clinicians through our day-to-day contacts as it has been well-received and is very popular with delegates.

In the late autumn, we started developing a companion eLearning module for General Practitioners and Allied Healthcare professionals. This will take several months to complete and we hope to launch it in the autumn of 2022.

Genetic testing and screening

Early in 2021, we were invited by the UK National Screening Committee to respond to their consultation on genetic screening for adults with GH. Our response is a treasure trove of information about GH and this can be downloaded from our website here: https://www.haemochromatosis.org.uk/time-for-change-towards-genetic-screening.

We firmly believe that genetic screening is a useful and valuable approach to improving the timeliness of diagnosis. Unfortunately, the UK National Screening Committee currently disagree, and their resulting report published in June 2021 confirmed the status quo (no screening). We will continue to press for changes in approach, both directly and with the support of the All-Party Parliamentary Group on GH.

Undeterred, in June we launched a genetic testing service for members and their families. Many members told us of the profound difficulty they faced in arranging testing for loved ones following a confirmed diagnosis. Almost 70% of members who used the new service reported that their GP had previously refused to provide a test for family members.

Our genetic testing service has exceeded all expectations. We thought initially we'd do 10 to 15 tests per month. We now test hundreds of people every month. Due to demand for the service, we expanded it from July to include non-members and their families. Feedback from people using our service has been encouraging – it scored 9.6 out of 10 overall during 2021, with 95% of people confirming that the results letters are clear and understandable. Everyone going through testing is invited to a 45 minute video appointment with Diogo, our Advanced Nurse Practitioner, to help to answer any questions and to allay any concerns about diagnosis.

This new genetic testing capability has led to other exciting initiatives. These include our cross-community genetic screening programme in Derry-Londonderry (see https://www.haemochromatosis.org.uk/News/cross-community-genetic-screening-launches-in-derry-londonderry). Thanks to the support of the Sylvia Adams Charitable Trust, the National Lottery Community Fund and the Esme Mitchell Trust, we screened several hundred people during 2021. Presently, one in 10 have the

genotype which predisposes genetic haemochromatosis. Of these, the majority are now receiving treatment and on-going monitoring. These figures are important, not just to the families affected but also from a policy perspective. Thus far, earlier studies into the prevalence of GH in the UK have been based largely on the UK Biobank. This dataset doesn't have any representation from Northern Ireland – something of an omission. With our screening programme, we're able to fill in the gaps and provide reliable data that is being used to inform service delivery and changes within the Northern Ireland Blood Transfusion Service and the Health and Social Care Board services too.

We aim to run more screening projects like this around the country as funding is secured.

Information resources

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 2021, we continued the development of a broad range of new information resources, of interest to and in support of people affected by genetic haemochromatosis. This included new resources for children and young people plus specialist resources on GH and cardiomyopathy, skin conditions and mental health. With the support of the Moondance Foundation, many of our core resources have been translated and published in Welsh, including public awareness posters and guides to GH. Thanks to the NI Pharmacies Limited Trust Fund and the Esme Mitchell Trust, we've also developed and published a new suite of resources for community pharmacists and have published new public awareness posters for public libraries.

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

Our support groups and helplines

Our Iron Brew peer support socials continued to be popular with several held via Zoom during the year. These are a great opportunity for people to meet others with the condition – often this is the first time someone newly diagnosed gets to meet fellow GHers, and so these can be a real encouragement to people affected by the condition.

Our Facebook Support Group continues to grow – we now support over 9,000 members across our Facebook Support Groups – plus a further 6,000 people across other social media channels.

During 2021, the helpline assisted almost 900 families by phone and email. This shows a continuing growth on earlier years. More and more, we see people using email as their helpline channel of choice.

Media and public awareness

In February, we were very fortunate to be selected by the BBC for a Radio 4 Charity Appeal, hosted by Stephen McGann of Call the Midwife fame. The broadcast reached over 2.5 million people over the week it ran, raising over £15,000 for charity funds. We're tremendously grateful to Stephen for his support. The broadcast can be found online here: https://www.haemochromatosis.org.uk/Appeal/bbc-radio-4

We collaborated with NHS Blood and Transplant in June to run a joint media campaign on the benefits of blood donation for people with GH. This followed our successful project in 2020 to open up donation sessions more widely to people with GH. Over the week of the campaign, we reached over 1 million people on social media. We continue to work closely with NHS Blood and Transplant and have collaborated with the Scottish National Blood Transfusion Service and the Northern Ireland Blood Transfusion Service throughout the year to deliver similar schemes in those areas too.

We attracted a lot of media coverage during the year, including from BBC Radio and several front pages including the Irish News (twice), Belfast Telegraph, Ely Standard and elsewhere. We continue to look for opportunities to share the news about GH and its symptoms with the public – and hope to expand this work in 2022 and beyond.

Medical research

During 2021, we worked behind the scenes on a new medical research report. This revealed the true costs to the NHS of the burden of ill-health arising from genetic haemochromatosis, including key conditions such as liver disease, cancer, diabetes and joint pain arising from the condition. The initiative represented the culmination of a year's work by researchers at York Health Economics Consultancy, our clinical advisors, and the University of Exeter Medical School. Our accompanying report discusses policy measures that will not only save lives, but also save money. The reports are available in hard copy from our office, in public libraries and also online here: https://www.haemochromatosis.org.uk/cost-of-illness

We're grateful to the Shears Foundation and the Thackray Medical Research Trust for their generous support of this initiative.

Elsewhere, we completed research into the frequency and types of treatment for people with GH. Not everyone receives venesection – and for those that do, how often? This research proved vital in informing the cost of illness study and was made possible through members' purchases from our online shop. The proceeds from every shop purchase help to fund work like this into the condition.

Advocacy to elected representatives

Our All-Party Parliamentary Group on GH continued to meet virtually throughout the year. Uniquely, our APPG is truly "all party" and includes members from all the parties, including those who do not normally accept their seats at Westminster.

Our Time for Change report, calling for adult screening, was given detailed consideration by APPG members. We continue to press for the timely diagnosis of people at risk of GH – and best practice in clinical pathways.

Other collaborations

In 2021, we continued our successful collaborations with the Samaritans and CRUSE Bereavement Care on helpline training initiatives. These were expanded to include work on mental health in association with Mind and a series of training events with the Genetic Alliance UK.

Finally, a big thank you to our donors, volunteers and team

Our charity receives no NHS funding or government financial support. And so, I am continually humbled by the dedication and faithfulness of our community, especially our fundraisers and community donors. Our especial thanks go to all our corporate, trust and foundation donors whose continuing financial support enables us to do so much of our work.

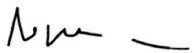
As a small charity, we rely on the dedication and selflessness of many volunteers who help us to help others. A special mention goes to all our helpline volunteers and members of the clinical community who help to review our publications ensuring they are accurate, up-to-date and useful to people affected by genetic haemochromatosis, whatever their personal situation.

I would also like to pay tribute to the charity's small team of four (full-time equivalent) staff who work so diligently and passionately behind the scenes. Their efforts often go unnoticed, so we were thrilled to receive a prestigious GSK/King's Fund Impact Award for our work in 2021. The award judges noted this quiet, determined focus on our charity's mission and members that lies behind so many of our successes:

"We were inspired by the way HUK places people with the condition at the centre of everything it does, and how it works to target the communities most affected by haemochromatosis.."
Katie Pinnock, Director of UK Charitable Partnerships, GSK

Finally, thank you to our all members and the wider community for all your support during 2021 – we look forward to 2022 and beyond!

Take care, stay safe.



Neil McClements
Chief Executive Officer
June 2022

4. TRUSTEES' REPORT FOR 2021

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 2021.

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

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 2,300 paid-up members (an increase of 50% over the past two years) and over 1,600 clinician associates (a three-fold increase since 2019). The charity links thousands of people affected by GH through events, social media and other activities.

HUK has four key objectives:
1 to provide information and support to patients and their families
2 to educate healthcare professionals, patients and others about GH and its impact
3 to raise public awareness of GH and of the importance of early intervention
4 to stimulate and influence research into the science, impact and statistics of GH

In this report, we report progress with these objectives during 2021 and outline 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 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, totalling £90,499. The trustees would like to extend their grateful thanks and public acknowledgment to our supporters:

- The Sylvia Adams Charitable Trust
- The National Lottery Scotland
- The National Lottery Wales
- The Northern Pharmacies Ltd Trust Fund
- The PG Jenkins Legacy
- The Souter Trust
- The Thackray Medical Research Trust
- The Harry Cureton Fund
- The Moondance Foundation
- The D'Oyly Carte Trust
- The F B Coales No 4 Family Trust
- The Evan Cornish Charitable Foundation
- The Gill's Charity Fund (NI)
- The Stafford Trust
- WG Edwards
- The Esme Mitchell Trust
- The Arnold Clark Community Fund
- The Aston Foundation
- The Chapman Trust
- The Leech Fourteenth Trust
- The NI Pressure Group
- The Oakdale Trust
- The Sylvia Waddilove Foundation
- Anonymous Charitable Foundation
- The Hemby Trust
- The Annie Tranmer Charitable Trustr
- The Anson Charitable Trust
- The Doris Field Charitable Trust
- The Girls Welfare Fund
- The Lillie C Johnson Trust
- The Torus Foundation
- The Ulster Bank Community Staff Fund
- The WD Charitable Trust
- Baron Davenport's Charity
- The Eddie Dinsaw Foundation

Corporate donations

We were unable to run our popular Iron Games events in 2021 due to the Covid pandemic. This had a significant impact on corporate donations. However, we gratefully acknowledge the following donors for their support during this difficult year:

- Google Ireland
- Arnold Clarke
- TK Maxx

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

In 2021, we spent just over £326,000 to provide our charitable services. Of our income of £366,138, donations (including in memoriam, community fundraising and ad hoc donations) totalling £99,160 accounted for 27% of income. Almost 25% (£90,499) of our income came from grant awarding bodies and foundations (e.g., the Sylvia Adams Charitable Trust, the National Lottery). Membership subscriptions contributed £62,545, 17% of income. A further 16% worth £57,675 came from consultancy services delivered to the National Consortium of Intelligent Medical Imaging. Our new genetic testing service (launched May 2021) delivered £29,527 of income representing just over 8% of total income. The balance of our income worth 7% of total income came from HMRC Gift Aid reclaims (£19,285), income from our online shop/events (£7,207) and bank interest (£240).

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 to deliver fundraising initiatives. We aim to ensure those fundraisers 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.

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.

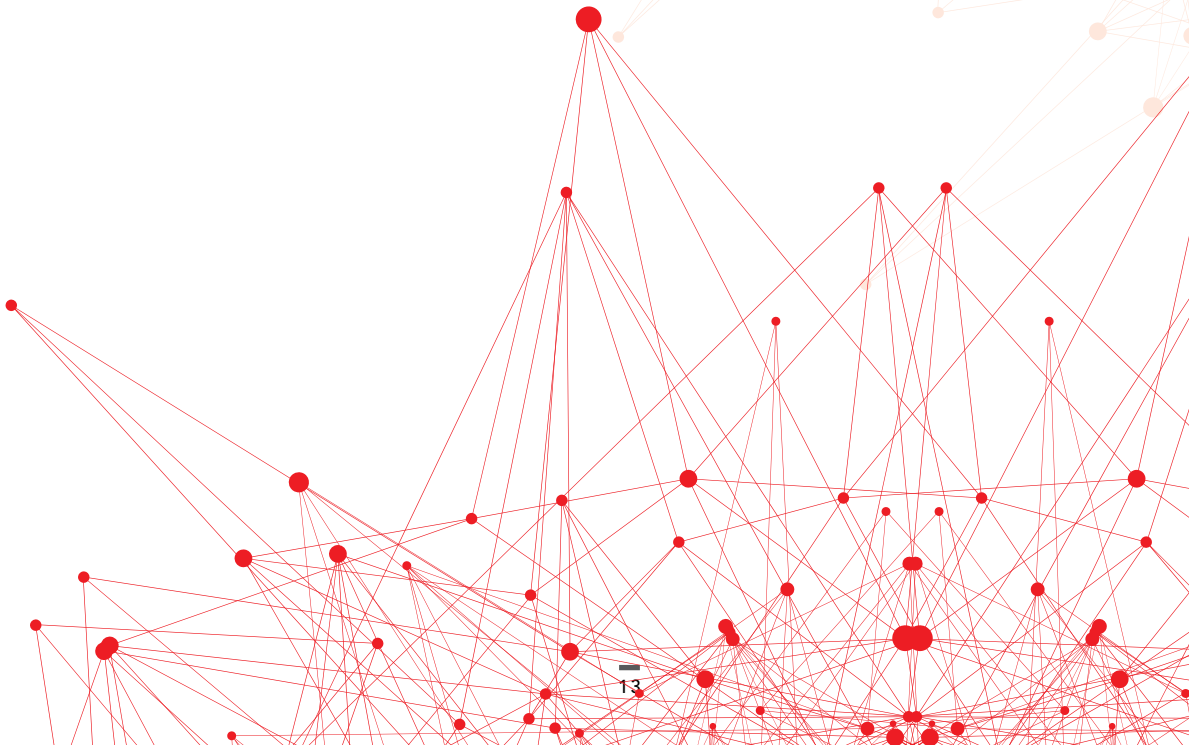
HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

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 for the public in the event that an individual wishes to make a complaint. In 2021, 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 2021, 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.



5. GOVERNANCE

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

Trustees are expected to attend all Board meetings and the charity's 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, Board Observers 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.

During 2021, two Board Observers progressed to full trusteeship. An additional Board Observer was recruited for their CQC/clinical services experience.

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 which includes a guide to the legal and practical responsibilities of being a trustee/Board Observer. Formal training with the NCVO in the role and the legal responsibilities of a trustee are also provided. All Board members must undertake safeguarding training annually.

Our record with the Charity Commission can be found at www.charitycommission.gov.uk by searching on this site using Charity number1001307.

HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

The Chief 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 a Social Media Community and Volunteering Manager, an Advanced Nurse Practitioner, a Fundraiser and a Charity Administrator. The team represents just four 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 Board continues to reflect upon the interim strategic plan drafted in early 2020, with a continued focus on the delivery of our core objectives. This will be further refined by the Board during 2022.

6. FINANCE

Overview

Whilst 2021 was certainly not a year without challenge, the financial position of the charity remains strong. The dynamic environment has meant we have had to adapt to new operating conditions and we have used innovative strategies to raise funds, increase awareness and support the beneficiaries of the charity.

We are confident of our ability to raise funds and deploy resources in the best way possible and, as such, are pleased to have created a new fundraising role within the team to maximise upon the opportunity in this area.

It is critical moving forwards that the charity continues to employ resources in the best interests of the people affected by GH. We will therefore have a focus on utilising our healthy cash reserves to support the launch and on-going operations of the exciting initiatives we have in place, including our genetic testing, support groups and helpline and a range of other ideas in the early stages of development.

Overall, HUK delivered a £40,118 net income, increasing reserves to £396,825.

Income

The income for 2021 was £366,138, this was a 15% increase vs. 2020. The income of the charity largely comes from four key areas:

- Trusts and foundations 25%
- Donations (including in memoriam, community fund raising) 32%
- Membership subscriptions 17%
- Consultancy fees 16%

It is worth noting the significant increase in our membership subscriptions over the course of the year, with income totalling £62,545, an improvement of 38% vs 2020.

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 previously detailed. 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 where the donor has specified a particular purpose. These funds can only be used for that purpose.

HUK began the year with £67,159 restricted funds, with a further £90,499 received throughout 2021.

Funding provided throughout the year was largely towards budgeted work, with almost all the brought forward restricted funds deployed. Funds received in the year were either deployed in 2021 and Q1 2022 or are expected to be utilised across the coming year, 2022. HUK made great use of donor funds throughout 2021, finishing the year with a restricted funds balance of £44,921.

Of the £351,904 unrestricted balance, £113,896 has been designated for use in education and awareness.

Expenditure

Total expenditure for 2021 was £326,020, an increase of 42% over the previous year. This reflects a planned and deliberate attempt to deploy the reserves of the charity toward charitable benefit. Without the restriction of face-to-face meetings and events due to Covid-19, this expenditure would have been higher.

The increased expenditure also reflects the deployment of the charity's reserves in two new key areas. Firstly, medical research, which was supported to the amount of £26,755, is the first major research the charity has funded in recent years. Secondly, the genetic testing service that the charity promoted this year cost £30,875. It should be emphasised that the cost of the latter was substantially offset by the payments made by members and non-members, whereby non-members payments heavily subsidised members, which together raised £29,527. Therefore, this new initiative was virtually 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 Ukraine crisis, where trusts and foundations can reprioritise how they wish to deploy their resources. We also face 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.

The trustees are mindful of the on-going and growing needs of the genetic hemochromatosis community and the need to ensure the financial sustainability of the organisation for the long term. This must be balanced 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' unrestricted expenditure.

Conclusion

This year has seen the largest amount raised in the charity's 32 year history which has been down to the efforts of the charity's CEO and the dedicated team supporting him. Whilst significant resources have been deployed in 2021 as planned, the charity finishes the year in a strong financial position.

The charity is looking forward to finding further innovative ways to support its charitable objectives in 2022 and beyond.

Rodger Houghton ACA & Catherine Wiggins CGMA
Finance Trustees
June 2022

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.

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 7th June 2022.

Katy Burns MBE
Chair
June 2022

Rodger Houghton ACA & Catherine Wiggins CGMA
Finance Trustees
June 2022

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF HAEMOCHROMATOSIS UK

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2021.

Respective responsibilities of trustees and examiner

As the trustees of the Charitable 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 Charities and Trustee Investment (Scotland) Act 2005 ('the 2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Companies Act 2006 ('the 2006 Act'). You are satisfied that the accounts of the Company are not required by charity or company law to be audited and have chosen instead to have an independent examination.

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 the Company's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since Haemochromatosis UK is required by company law to prepare its accounts on an accruals basis and is registered as a charity in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I can confirm that I am qualified to undertake the examination because I am a registered 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 as required by section 386 of the 2006 Act and Regulation 4 of the 2006 Accounts Regulations; or
2 the accounts do not accord with those records with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006; 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: 17 June 2022

7. ACCOUNTS

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)

	Note	Unrestricted funds £	Restricted funds £	Total 2021 £	Total 2020 £
Income and endowments from:					
Donations and legacies	4	118,445	-	118,445	83,804
Charitable activities	5	156,954	90,499	247,453	233,296
Investment income	3	240	-	240	567
Total income		275,639	90,499	366,138	317,667
Expenditure on:					
Charitable activities	7	(153,857)	(172,163)	(326,020)	(229,432)
Total expenditure		(153,857)	(172,163)	(326,020)	(229,432)
Net income		121,782	(81,664)	40,118	88,235
Transfers between funds		(59,426)	59,426	-	-
Net movement of funds		62,356	(22,238)	40,118	88,235
Reconciliation of funds:					
Total funds brought forward		289,548	67,159	356,707	268,472
Total funds carried forward	14	351,904	44,921	396,825	356,707

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

The funds breakdown for 2021 is shown in note 14.

Haemochromatosis UK
(Registration number: 02541361)
Balance Sheet as at 31 December 2021

	Notes	2021 £	2020 £
Current assets			
Debtors	12	28,767	9,161
Cash at bank and in hand		379,871	352,258
		408,638	361,419
Creditors: amounts falling due within one year	13	(11,813)	(4,712)
Net assets		396,825	356,707
Funds of the charity:			
Restricted income funds			
Restricted funds		44,921	67,159
Unestricted income funds			
Unestricted funds		351,904	289,548
Total charity funds	14	396,825	356,707

For the financial year ending 31 December 2021 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 23 to 37 were approved by the trustees and authorised for issue on 7th June 2022 and signed on their behalf by:

Rodger Houghton
Trustee

Catherine Wiggins
Trustee

Haemochromatosis UK
Notes to the Financial Statements for the Year Ended 31 December 2021

1 Charity status

The charity is limited by guarantee, incorporated in England & Wales and Scotland, 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.

2 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 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 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.

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.

Other trading income

Other trading income has been raised from genetic testing services.

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.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees' meetings and reimbursed expenses.

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 the 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 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.

Restricted income funds are those donated 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 cost charges in the Statement of Financial Activities represent the contributions payable by the charity during the year.

3 Investment income

	Unrestricted funds		
	General £	Total 2021 £	Total 2020 £
Interest receivable and similar income;			
Interest receivable on bank deposits	240	240	567

4 Income from donations and legacies

	Unrestricted funds		
	General £	Total 2021 £	Total 2020 £
Donations and legacies:			
Gift aid received	8,806	8,806	
Grants, including capital grants:			
Government grants	-	-	7,425
Grants from other charities/foundations	109,639	109,639	76,379
	118,445	118,445	83,804

5 Income from charitable activities

	Unrestricted funds			
	Genera £l	Restricted funds £	Total 2021 £	Total 2020 £
Grants and donations	-	90,499	90,499	108,873
Consultancy fees	57,675	-	57,675	72,527
Event ticket sales	262	-	262	772
Membership subscriptions	62,545	-	62,545	45,230
Merchandise	6,945	-	6,945	5,206
Sundry income	-	-	-	688
Genetic testing	29,527	-	29,527	-
	156,954	90,499	247,453	233,296

6 Grants and donations

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total 2021 £
Lillie C Johnson Trust	-	500	500
PG Jenkins Legacy	-	5,000	5,000
Baron Davenport	-	460	460
Harry Cureton Fund	-	3,495	3,495
Doris Field Charitable Trust	-	500	500
Anson Charitable Trust	-	500	500
Chapman Trust	-	1,000	1,000
Oakdale Trust for Welsh community Ambassador	-	1,000	1,000
Stafford Trust (Scottish Ambassadors)	-	2,000	2,000
D'Oyly Carte Trust	-	2,500	2,500
WD Charitable Trust	-	500	500
Anonymous Charitable Foundation	-	750	750
Arnold Clark Community Fund	-	1,000	1,000
Hemby Trust	-	750	750
WG Edwards	-	1,800	1,800
Leech Fourteenth Trust	-	1,000	1,000
Northern Pharmacies Ltd Trust Fund	-	7,636	7,636
Thackery Medical Research	-	3,500	3,500
Esme Mitchell Fund	-	1,500	1,500
Ulster Bank Community Staff Fund	-	500	500
Aston Foundation	-	1,000	1,000
Sylvia Adams	-	14,863	14,863
Evan Cornish	-	2,360	2,360
Souter Trust	-	5,000	5,000
E Dinshaw Grant	-	350	350
National Lottery Scotland	-	10,000	10,000
Girls Welfare	-	500	500
Torus Foundation	-	500	500
National Lottery Wales	-	9,740	9,740
Moondance	-	3,295	3,295
Waddilove	-	1,000	1,000
Annie Tranmer	-	500	500
Community NI - Gills Charity Fund	-	2,000	2,000
NI Pressure Group	-	1,000	1,000
F B Coales No 4 Family Trust	-	2,500	2,500
Gift Aid	19,285	-	19,285
Sundry grants and donations	99,160	-	99,160
	118,445	90,499	208,944

7 Expenditure on charitable activities

	Unrestricted General funds 2021 £	Unrestricted Designated funds 2021 £	Restricted funds 2021£	Total 2021 £	Total 2020 £
Accountancy	7,346	-	-	7,346	7,944
Advertising and promotional	294	-	2,250	2,544	2,241
Bank charges	178	-	-	178	2,362
Equipment and computer costs	832	-	1,032	1,864	5,446
External events	(24)	-	6,316	6,292	4,796
Dues and subscriptions	1,658	-	221	1,879	1,324
Genetic testing	15,875		15,000	30,875	
Hosted events	2,571	-	3,408	5,979	2,220
Insurance	1,380	-	-	1,380	1,048
IT repairs and servicing	-	-	741	741	1,722
Legal and professional	9,357	-		9,357	10,880
Medical research		-	26,755	26,755	-
Materials stock	4,491	-	-	4,491	7,653
Office and general admin	309	-	104	413	308
Phone costs	1,304	-	744	2,048	2,330
Premises costs	600	-	-	600	17
Printing, postage and stationery	10,575	-	12,159	22,734	10,861
Publications	3,558	-	19,077	22,635	5,218
Raising funds	591	-	-	591	108
Recruitment	95	-	-	95	53
Rent	6,440	-	5,000	11,440	9,300
Software	11,888	-	1,093	12,981	5,671
Staff benefits	-	-	-	-	1,399
Sundry costs	347	-	-	347	697
Training	2,300	-	3,428	5,728	1,955
Travel and accommodation	2,289	-	2,983	5,272	2,518
Trustees expenses	-	-	-	-	1,997
Wages, NI and pension	41,220	28,383	71,852	141,455	137,704
Bad debts written off	-	-	-	-	1,660
	125,474	28,383	172,163	326,020	229,432

8 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.

Corrina Towers £nil (2020 - £400) of travel expenses were reimbursed to Corrina Towers during the year.

Katharine Hough £nil (2020 - £45) of travel expenses were reimbursed to Katharine Hough during the year.

Lisa Flude £nil (2020 - £844) of travel expenses were reimbursed to Lisa Flude during the year.

Roger Keyte £nil (2020 - £392) of travel expenses were reimbursed to Roger Keyte during the year.

Simon Flude £nil (2020 - £264) of travel expenses were reimbursed to Simon Flude during the year.

9 Fees payable to independent examiner

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

	2021 £	2020 £
Independent examination	1,080	1,080

10 Staff costs

The aggregate payroll costs were as follows:

	2021 £	2020 £
Staff costs during the year were:		
Wages and salaries	126,300	118,301
Social security costs	7,752	7,473
Pension costs	7,403	1,248
Compensation payments	-	10,682
	141,455	137,704

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

	2021 No	2020 No
Average number of employees	4	3

3 (2020 - 3) of the above employees participated in the Defined Contribution Pension Schemes.

Contributions to the employee pension schemes for the year totalled £7,403 (2020 - £1,248).

During the year, the charity made redundancy and/or termination payments which totalled £Nil (2020 - £10,682).

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 £63,597 (2020 - £63,545).

11 Taxation

The charity is a registered charity and exempt from corporation taxation for activities associated with its charitable objectives.

12 Debtors

	2021 £	2020 £
Trade debtors	14,938	535
Trade debtors	8,961	8,626
Prepayments	4,868	-
	28,767	9,161

13 Creditors: amounts falling due within one year

	2021 £	2020 £
Trade creditors	5,939	512
Other taxation and social security	3,628	2,928
Other creditors	266	192
Accruals	1,980	1,080
	11,813	4,712

14 Funds

	Balance at 1 January 2021 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2021 £
Unrestricted funds					
General					
General	147,269	275,639	(125,474)	(59,426)	238,008
Designated					
Education & Awareness	142,279	-	(28,383)		113,896
	142,279	-	(28,383)	-	113,896
Total Unrestricted funds	289,548	275,639	(153,857)	(59,426)	351,904
Restricted funds					
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
Wales Initiative	-	14,376	(10,944)	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
Medical research	200	-	(26,755)	26,555	-
Total restricted funds	67,159	90,499	(172,163)	59,426	44,921
Total funds	356,707	366,138	(326,020)	-	396,825
Unrestricted funds					
General	211,249	208,794	(126,840)	(3,655)	289,548
Restricted funds	57,223	108,873	(102,592)	3,655	67,159
Total funds	268,472	317,667	(229,432)	-	356,707

During the year, the charity spent in excess of the restricted funds that were brought forward and therefore the expenditure identified in excess of this was brought back down to nil by an applicable transfer.

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

- Information and support – funds provided for the production of materials to provide information and support on Haemochromatosis. This includes hospital packs and the production of leaflets, booklets, website content and videos;
- Education and 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 Travelling 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.
- Breaking Down Barriers – funding to support the genetic screening of disadvantaged communities at high risk of GH.

15 Analysis of net assets between funds

	Unrestricted funds General £	Restricted funds £	Total funds at 31 December 2021 £
Current assets	363,717	44,921	408,638
Current liabilities	(11,813)	-	(11,813)
Total net assets	351,904	44,921	396,825

	Unrestricted funds General £	Restricted funds £	Total funds at 31 December 2020 £
Current assets	294,260	67,159	361,419
Current liabilities	(4,712)	-	(4,712)
Total net assets	289,548	67,159	356,707

16 Related party transactions

There were no related party transactions in the year.

NOTES

HAEMOCHROMATOSIS UK TRUSTEES' ANNUAL REPORT & ACCOUNTS

Haemochromatosis • UK
Helping people live with iron overload
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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**

HAEMOCHROMATOSIS UK

England & Wales - Charity number 1001307

Accounts

Haemochromatosis UK Trustees' Annual Report & Accounts

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Haemochromatosis UK Trustees' Annual Report and Accounts
For the year ending 31 December 2020
Published May 2021
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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.

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.

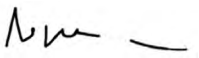
We will continue to tell peoples' stories to policymakers, our elected representatives and other stakeholders as we press for more timely diagnosis and better care and screening for genetic haemochromatosis. We stand with everyone affected by the virus and genetic haemochromatosis itself. Behind the 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.

R Houghton

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').

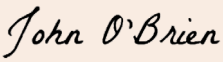
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). 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 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
Unestricted income funds			
Unestricted 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:

R Houghton

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
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
	83,804	108,873	192,677

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
	137,704

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	3	5

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	-
	9,161	1,660

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
	4,712	6,924

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					
General					
General	206,249	208,794	(125,840)	(141,934)	147,269
Designated					
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 General	Restricted funds	2020 Total 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 General	Restricted funds	2019 Total 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.

Haemochromatosis • UK
Helping people live with iron overload
+Fe

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

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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

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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.

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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.

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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.

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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.

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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

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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:.....

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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 in 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.

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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 in 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

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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		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 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 13/04/2021 and signed on their behalf by:

R Houghton

.....
Rodger Houghton
Trustee

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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.

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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.

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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
	83,804	83,804	222,136

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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

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
	83,804	108,873	192,677

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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

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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

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
	137,704

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	3	5

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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	-
	9,161	1,660

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
	4,712	6,924

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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14 Funds

	Balance at 1 January 2020 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2020 £
Unrestricted funds					
General					
General	206,249	208,794	(125,840)	(141,934)	147,269
Designated					
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.

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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 General £	Restricted funds £	2020 Total 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 General £	Restricted funds £	2019 Total 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.

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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

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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

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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.

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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.

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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.

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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.

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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

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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:.....

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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 in 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.

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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 in 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

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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		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 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 13/04/2021 and signed on their behalf by:

R Houghton

.....
Rodger Houghton
Trustee

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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.

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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.

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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
	83,804	83,804	222,136

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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

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
	83,804	108,873	192,677

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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

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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

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
	137,704

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	3	5

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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	-
	9,161	1,660

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
	4,712	6,924

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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14 Funds

	Balance at 1 January 2020 £	Incoming resources £	Resources expended £	Transfers £	Balance at 31 December 2020 £
Unrestricted funds					
General					
General	206,249	208,794	(125,840)	(141,934)	147,269
Designated					
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.

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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 General £	Restricted funds £	2020 Total 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 General £	Restricted funds £	2019 Total 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.

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