

Charity registration number 1163743 (England and Wales)

Company registration number 09481209

UK FORUM ON HAEMOGLOBIN DISORDERS
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

UK FORUM ON HAEMOGLOBIN DISORDERS

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Dr Baba Inusa Dr Mary Petrou Dr Farrukh Shah (Chairwoman) Mrs Karen Madgwick (Secretary) Dr Rachel Kesse-Adu (Treasurer) Dr Subarna Chakravorty Dr A Lugmani Dr R Anderson A Blackmore
Charity number	1163743
Company number	09481209
Registered office	Galla House 695 High Road North Finchley London N12 0BT
Accountants	Lyons Leonidou Galla House 695 High Road North Finchley London N12 0BT
Bankers	National Westminster Bank Plc Queen Street Branch 96 Queen Street Cardiff CF10 2GR

UK FORUM ON HAEMOGLOBIN DISORDERS

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UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) *FOR THE YEAR ENDED 31 MARCH 2024*

The trustees (who are also directors of the charity for the purposes of the Companies Act) present their report and accounts for the year ended 31 March 2024.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's governing document, the Companies Act 2006 and the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005.

Objectives and activities

The charity's objects are specifically restricted to the advancement of health for the public benefit by promoting care for those with haemoglobin disorders and study and research in haemoglobin disorders and the publication of useful results.

The charity will continue to provide peer review and conduct courses for the advancement of the health profession on the subject of the blood disorders, sickle cell disease and thalassaemia.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024

The charity undertook the following activities:

Peer Review

The UKFHD contributed £45,000 and VAT towards the costs of the current and ongoing peer review program led by Dr Emma Drašar. Host Trusts were directly invoiced for the remainder of the costs of review including support for clinical leads to write the peer review reports at £5,900 per service. The review program has continued at pace, since 17th October 2023 when the first visit at Sheffield Teaching Hospital NHS Foundation Trust was successfully completed. Reviews are planned for all Specialist Haemoglobinopathy teams (SHTs) and Haemoglobinopathy Coordinating Centres (HCCs). As of March 2024, 18 visits to SHTs (total of 11 trusts) were completed.

For each visit, the review team completes a pre-visit review of submitted evidence from the specialist haemoglobinopathy and coordinating centre teams. This evidence assessment is completed virtually, before the physical visit to the Hospital site is undertaken. The administration/logistic support for the peer review programme is contracted to, and continues to be provided by an external company, NHS Midlands and Lancashire, led by Ms Sarah Broomhead, Professional Lead for Nursing and Urgent Care Directorate.

The onsite visits by peer reviewers commenced on 17th October 2023 at Sheffield Teaching Hospital NHS Foundation Trust and is expected continue with the last visit due to be completed in June 2025. For each visit, the review team completes a pre-visit review of submitted evidence from the specialist haemoglobinopathy and coordinating centre teams. This evidence assessment is completed virtually, before the physical visit to the Hospital site is undertaken. The administration/logistic support for the peer review program is contracted to, and continues to be provided by an external company, NHS Midlands and Lancashire Commissioning Support Unit, led by Ms Sarah Broomhead, Professional lead for Nursing and Urgent care directorate. The physical inspection of sites commenced on 17th October 2023 at Sheffield and is expected continue with the last visit due to be completed in Spring 2025

Educational meetings

We continue to organise 2 academic meetings per year, in 2023 these were held:

May 2023: 55th Educational Meeting: held on 3rd May 2023, it was a hybrid meeting with in person attendance as well as a virtual audience. The meeting was organised in partnership with the Hartley Taylor team LTD (04029300) to provide educational meeting and secretarial support. The morning focused on transfusion, and included an international speaker Dr Shirley Owusu Ofori, lead of the National Blood Service of Ghana. We acknowledged and gave thanks to Dr Lola Oni who has retired. Then a high-level presentation of transfusion cases discussed at the NHP, a difficult to transfuse case presentation and then an MDT panel discussion was had on the challenges and evidence for our current practice. The afternoon focused on a patient's and then a psychologists perspective on transfusions, the final sessions were focused on vascular access with a presentation from the UKTS and a renal vascular surgeon on the use of arterio-venous fistulae for exchange transfusion and the final item was a soft launch of the UKTS Thalassaemia standards.

Nov 2023: The 56th meeting was held on Wednesday 22nd November, this was also a hybrid meeting with in person and a virtual audience, we continued the successful in partnership with the Hartley Taylor team LTD. It was held at the Cavendish Conference centre. The morning focused on renal transplant in sickle cell, the role of transfusion and HLA sensitisation in SCD patients. A memorial was held to acknowledge the sudden, unexpected loss of committee member Melanie Percy. The late morning session focused on Medtech funding, screening for haemoglobinopathies and the nurse consultant role in practice. The afternoon session was on pain management with a case presentation, a psychologist's perspective on pain management and an update from the acute pain group.

Both academic meetings had excellent feedback from attendees.

UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2024

Trustee and committee meetings

3 trustee / committee meetings were held in June, September, November 2023.

Liaison and attendance with other committees (feedback to Trustees via rolling agenda)

National Screening Committee: committee members attended quarterly meetings. This committee promotes the antenatal and neonatal screening programme for haemoglobinopathies.

National Haemoglobinopathy Registry: committee members attended the quarterly steering group meetings till to support the work of the NHR.

Clinical Reference Group for Haemoglobinopathies: co-opted committee members attended meetings to represent the views of health professionals in the development of services for patients with Haemoglobinopathies.

UKFHD Chair is also a co-opted member of the Clinical reference group (CRG) and attends those committee meetings.

Research

Committee members attend the meeting of the non-malignant clinical research network (CRN). Attendance of the research subgroup as a collaborative group with colleagues nationally tailed off during the course of the year and a new member was co-opted to attend – Dr Sanne Lugthart to keep the committee updated.

Achievements and performance

The organisation of the peer review program, the academic sessions as well as our active involvement engagement with other organisations, including NICE with our organisation recognised as an key in submissions on new agents and technologies directed at patients including gene therapy for thalassaemia and sickle cell as well as contributing to the appeal for Voxelotor. Another achievement is the committee now has representation from all the devolved nations.

Financial review

The principal source of funding is from voluntary donations from individual and other organisations.

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level equivalent to between three and six month's expenditure. The trustees considers that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

The trustees have assessed the major risks to which the charity is exposed, and are satisfied that systems are in place to mitigate exposure to the major risks.

The charity will continue to meet the objectives of its constitution. It will also try to increase the incoming level of donation.

UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) *FOR THE YEAR ENDED 31 MARCH 2024*

Structure, governance and management

The charity is a company limited by guarantee, incorporated on 10th March 2015 and registered as charity on 28th September 2015 with Registered Charity No 11633743. The company was established under Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. Dr Fernando Pinto and Dr Louisa McIlwaine have joined committee as representatives of Scotland. Dr Farrukh Shah has submitted her resignation as chair in November 2023 and completed her term in March 2024. Dr Melanie Percy, Clinical scientist and member of the committee sadly died July 2023.

The trustees and who served during the year and subsequently were:

Dr Baba Inusa

Dr Mary Petrou

Dr Farrukh Shah (Chairwoman)

Mrs Karen Madgwick (Secretary)

Dr Rachel Kesse-Adu (Treasurer)

Dr Subarna Chakravorty

Dr A Lugmani

Dr R Anderson

A Blackmore

The trustees are selected for their understanding and sympathy with the aim and objective of the charity, who are prepared to offer their time and expertise to support it.

None of the trustees has any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

The charity does not provide the trustees with any indemnity insurance.

The trustees meet on a regular basis to agree the strategic direction and the policy of the charity. One of the trustee is responsible for the day to day administration to ensure that the charity can deliver timely and efficient service.

There are no connected charities.

The trustees' report was approved by the Board of Trustees.

Dr Rachel Kesse-Adu (Treasurer)

Trustee

Dated: 20 December 2024

UK FORUM ON HAEMOGLOBIN DISORDERS

CHARTERED ACCOUNTANT ACCOUNTANTS' REPORT TO THE TRUSTEES ON THE PREPARATION OF THE UNAUDITED STATUTORY FINANCIAL STATEMENTS OF UK FORUM ON HAEMOGLOBIN DISORDERS FOR THE YEAR ENDED 31 MARCH 2024

In order to assist you to fulfil your duties under the Companies Act 2006, we have prepared for your approval the financial statements of UK Forum on Haemoglobin Disorders for the year ended 31 March 2024, which comprise the statement of financial activities and the related notes from the charity's accounting records and from information and explanations you have given us.

As a practising member firm of the Institute of Chartered Accountants in England and Wales, we are subject to its ethical and other professional requirements which are detailed at <https://www.icaew.com/regulation>.

This report is made to the charity's trustees, as a body, in accordance with the terms of our engagement letter. Our work has been undertaken solely to prepare for your approval the accounts of UK Forum on Haemoglobin Disorders and state those matters that we have agreed to state to the charity's trustees, as a body, in this report in accordance with ICAEW Technical Release 07/16. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than UK Forum on Haemoglobin Disorders and the charity's trustees as a body, for our work or for this report.

It is your duty to ensure that UK Forum on Haemoglobin Disorders has kept adequate accounting records and to prepare statutory financial statements that give a true and fair view of the assets, liabilities, financial position and deficit of UK Forum on Haemoglobin Disorders. You consider that UK Forum on Haemoglobin Disorders is exempt from the statutory audit requirement for the year, and is not required to obtain an independent examiner's report.

We have not been instructed to carry out an audit or a review of the financial statements of UK Forum on Haemoglobin Disorders. For this reason, we have not verified the accuracy or completeness of the accounting records or information and explanations you have given to us and we do not, therefore, express any opinion on the statutory financial statements.

Lyons Leonidou
Chartered Accountant Accountants

21 December 2024

Galla House
695 High Road
North Finchley
London
N12 0BT

UK FORUM ON HAEMOGLOBIN DISORDERS

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

		Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
	Notes						
Income from:							
Donations and legacies	3	1,150	-	1,150	2,037	-	2,037
Charitable activities	4	42,844	-	42,844	47,250	-	47,250
Investments	5	151	-	151	49	-	49
Total income		44,145	-	44,145	49,336	-	49,336
Expenditure on:							
<u>Charitable activities</u>	6	49,246	27,000	76,246	49,210	-	49,210
Total expenditure		49,246	27,000	76,246	49,210	-	49,210
Net income/(expenditure) and movement in funds		(5,101)	(27,000)	(32,101)	126	-	126
Reconciliation of funds:							
Fund balances at 1 April 2023		163,999	126,505	290,504	163,873	126,505	290,378
Fund balances at 31 March 2024		158,898	99,505	258,403	163,999	126,505	290,504

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

UK FORUM ON HAEMOGLOBIN DISORDERS

BALANCE SHEET

AS AT 31 MARCH 2024

	Notes	2024 £	£	2023 £	£
Current assets					
Cash at bank and in hand		260,600		292,700	
Creditors: amounts falling due within one year	11	<u>(2,196)</u>		<u>(2,196)</u>	
Net current assets			<u>258,404</u>		<u>290,504</u>
The funds of the charity					
Restricted income funds	12		99,505		126,505
Unrestricted funds	13		<u>158,898</u>		<u>163,999</u>
			<u>258,403</u>		<u>290,504</u>
Warning: Support and governance cost to reallocate (5000 codes must balance to nil to balance BS)			(1)		-
Warning: Balance sheet net assets do not equal equity, or there is a suspense balance.			(1)		-

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2024.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

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

The financial statements were approved by the trustees on 20 December 2024

Dr Rachel Kesse-Adu (Treasurer)
Trustee

Company registration number 09481209 (England and Wales)

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

Charity information

UK Forum on Haemoglobin Disorders is a private company limited by guarantee incorporated in England and Wales. The registered office is Galla House, 695 High Road, North Finchley, London, N12 0BT.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's governing document, the Companies Act 2006, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a statement of cash flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, [modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value]. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the accounts.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

1.5 Resources expended

Resources expended on charitable expenditure comprise in meeting the charitable objective. Such cost includes direct cost of the charitable activities together with those identifiable support cost incurred that enable these activities to be undertaken.

Governance cost and support cost are cost incurred for the management and administration of the Charity. These cost are incurred so that the Charity can operate and meet its statutory and constitutional obligation.

Support cost is allocated where appropriate to an activity based on use of resource. Staff cost where appropriate has been allocated on a consistent basis.

1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.7 General Funds

General funds are unrestricted funds which are available for use at the discretion of the Trustees to further the objectives of the Charity. Investment income and gains are allocated to unrestricted funds.

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

3 Donations and subscriptions

	2024	2023
	£	£
Membership fees	1,150	2,037
	<u>1,150</u>	<u>2,037</u>

4 Income from charitable activities

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Heading #ac989		
Sale of goods	42,844	47,250
	<u>42,844</u>	<u>47,250</u>

5 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable	151	49
	<u>151</u>	<u>49</u>

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

6 Expenditure on charitable activities

	2024 £	2023 £
Direct costs		
Course costs - Hiring hall, catering and lecturers fees	73,838	46,471
Share of support and governance costs (see note 7)		
Governance	2,408	2,739
	<u>76,246</u>	<u>49,210</u>
Analysis by fund		
Unrestricted funds	49,246	49,210
Restricted funds	27,000	-
	<u>76,246</u>	<u>49,210</u>

7 Support costs

	Support costs £	Governance costs £	2024 £	2023 £
Legal and professional	-	2,196	2,196	2,196
General expense	-	212	212	543
	<u>-</u>	<u>2,408</u>	<u>2,408</u>	<u>2,739</u>
Analysed between				
Charitable activities	-	2,408	2,408	2,739
	<u>-</u>	<u>2,408</u>	<u>2,408</u>	<u>2,739</u>

Governance costs includes Accountancy fees of £2,196 (2022 £2,125).

8 Trustees

None of the trustees (or any persons connected with them) received any remuneration during the year or previous year, None of the trustees were reimbursed any expenses during current year or previous year.

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

9 Employees

The average monthly number of employees during the year was:

2024 Number	2023 Number
8	8
<u>8</u>	<u>8</u>

There were no paid employees in the year.

10 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

11 Creditors: amounts falling due within one year

	2024 £	2023 £
Accruals	2,196	2,196
	<u>2,196</u>	<u>2,196</u>

12 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations held on trust for specific purposes:

	At 1 April 2023 £	Resources expended £	At 31 March 2024 £
	126,505	(27,000)	99,505
	<u>126,505</u>	<u>(27,000)</u>	<u>99,505</u>
Previous year:			
	At 1 April 2022 £	Resources expended £	At 31 March 2023 £
	126,505	-	126,505
	<u>126,505</u>	<u>-</u>	<u>126,505</u>

Restricted funds should be applied for quality peer review programme and work on quality assurances for brain vessel scans for children with sickle cell disease.

13 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
General funds	163,999	44,145	(49,246)	158,898
	<u>163,999</u>	<u>44,145</u>	<u>(49,246)</u>	<u>158,898</u>

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

13 Unrestricted funds (Continued)

Previous year:	At 1 April 2022	Incoming resources	Resources expended	At 31 March 2023
	£	£	£	£
General funds	163,873	49,336	(49,210)	163,999
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

14 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	£	£	£
Fund balances at 31 March 2024 are represented by:			
Current assets	258,404	-	258,404
	<u> </u>	<u> </u>	<u> </u>
	258,404	-	258,404
	<u> </u>	<u> </u>	<u> </u>