

Company registration number 09481209 (England and Wales)

Charity registration number 1163743 (England and Wales)

UK FORUM ON HAEMOGLOBIN DISORDERS
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

UK FORUM ON HAEMOGLOBIN DISORDERS

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

Dr Mary Petrou (Treasurer)
Dr Rachel Kesse-Adu
Dr Subarna Chakravorty
Dr A Luqmani
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

CONTENTS

	Page
Trustees' report	1 - 4
Accountants' report	5
Statement of financial activities	6
Balance sheet	7
Notes to the financial statements	8 - 13

UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2025

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 2025.

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.

The charity undertook the following activities:

Peer Review

The UKFHD contributed £45,000 and VAT towards the costs of the peer review program led by Dr Emma Drašar, which commenced on 17th October 2024 at Sheffield Teaching Hospital NHS Foundation Trust, and is due to be completed with a final visit on 12th September 2025 at Barking and Havering NHS Foundation Trusts at Queens Hospital in Romford. Review aims to attend all SHTs and HCCs in England. Host Trusts are directly invoiced for the remainder of the costs of the review including support for clinical leads to write the peer review reports, at £5,900 per service.

For each visit, the review teams complete 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 was contracted to, and is undertaken by an external company, NHS Midlands and Lancashire, led by Ms Sarah Broomhead, Professional Lead for Nursing and Urgent Care Directorate.

Educational meetings

We continued to organise 2 academic meetings per year, in 2024 these were held:

8th May 2024, the 57th Educational meeting was held at the IET in Birmingham, this was originally planned to be an in person only meeting but then had to be changed last minute to a hybrid meeting due to industrial action on the railways. The meeting was organised, as usual in partnership with the Hartley Taylor team LTD (04029300).

The morning sessions focused on a case presentation from a resident doctor colleague, then a talk on gene therapy from Prof de la Fuente of Imperial College, London, followed by a talk on fertility preservation by Dr Vikram Talaulikar of UCH London. Then we had a vibrant and interactive round table with transplant colleagues; Dr Ben Carpenter, Dr Beki James and Dr Subarna Chakravorty, as well as red cell colleagues Dr Amy Webster, and Dr Perla Elftheriou and Ms Roanna Maharaj as a patient representative. The round table focused on the current pathways for curative therapies and gene therapy, indications, concerns and outcome. There was an update from the patient societies and the afternoon session chaired by Dr Kate Gardner focused on ageing in haemoglobinopathies, with talks from Dr Shivan Pancham, Dr Kate Gardner, Psychologist Dr Ruth Anderson and Frailty physician Dr Huma Naqvi from Birmingham and Sandwell Hospitals.

UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2025

19th Nov 2024: The 58th Educational meeting was a hybrid meeting with in person and a virtual audience, we continued the successful in partnership with the Hartley Taylor team LTD and the meeting was held at the Cavendish Conference centre. The morning session chaired by Dr Mary Petrou had an update from colleagues in Scotland on haemoglobinopathy there, we celebrated colleagues who have left the NHS, Dr Samah Babiker presented for Prof Inusa who has retired and moved into industry, Dr Clare Samuelson presented on behalf of Dr Josh Wright and Dr Emma Drasar on behalf of Dr Farrukh Shah who was the preceding Chair of the UK Forum. There were also presentations on the role of dietetics from Dr Claudine Matthes, Endocrinology in Thalassaemia by Dr Julian Waung. The afternoon sessions had presentations from Prof Noemi Roy on NEQAS, then we focused on strokes in adults with presentations by Dr Paul Holmes, Dr Anupama Krishnamoorthi (a case study) and Mr Cristos Tolias. Then we concluded with a CRG update and the launch of the new RCN Nursing competencies.

There was an additional symposium from Vertex on Gene Therapy, which members could elect to stay on for at the close of the day.

Both academic meetings had engagement from more than 100 attendees with excellent feedback.

Trustee and committee meetings

After November 2024, we moved two of the trustee and committee meetings to coincide with the educational meetings, aiming to encourage in person attendance, these were scheduled in the hour preceding the academic meetings. Additional committee meetings over MSTeams were held in June, and September 2024.

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

National Screening Committee: we had new members joining the committee for the antenatal and neonatal screening programme for haemoglobinopathies.

National Haemoglobinopathy Registry: Prof Noemi Roy was added to attendance after departure of Dr Farrukh Shah to support the work of the NHR.

Clinical Reference Group for Haemoglobinopathies: Dr Subarna Chakravorty who is a trustee as well as the CRG chair represented the CRG to update on the work of that group.

We added regular representation from colleagues from Scotland – Dr Fernando Pinto and Dr Louisa McIlwaine, we had continued representation from Wales with Dr Indu Thakur and Ms Annette Blackmore. Northern Ireland representation from Colleen Williamson

Research

The red cell collaborative research group was originally represented by Dr Paul Telfer, however his attendance tailed off after his resignation from the committee as a trustee, a new member – Dr Sanne Lugthart was co-opted to keep the committee updated.

Achievements and performance

We remained a key stake holder for NICE submissions and were actively involved in the ultimately successful, Casgevy submissions for both sickle cell and Thalassaemia.

We appointed a lead clinician and continued to support the organisation, implementation and active involvement of the clinical community in the haemoglobinopathies peer review program.

We continued to hold the twice-yearly academic sessions which have both excellent attendance and feedback as noted above, topics are selected from a combination of issues raised via the NHP and from attendee feedback.

We started an initiative to extend invitation to trainees to attend our Education days free of charge to encourage interest in the field.

UK FORUM ON HAEMOGLOBIN DISORDERS

TRUSTEES' REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) *FOR THE YEAR ENDED 31 MARCH 2025*

Financial review

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

The principal source of funding is from applications for independent funding grants from industry partners aimed at our education days, voluntary donations and membership dues.

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 consider 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.

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 2025

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.

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

Dr Mary Petrou (Treasurer)

Dr Farrukh Shah

(Resigned 28 April 2024)

Dr Rachel Kesse-Adu

Dr Subarna Chakravorty

Dr A Luqmani

Dr R Anderson

A Blackmore

The trustees are selected for their understanding and sympathy with the aim and objectives of the charity, and have confirmed they 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 Mary Petrou (Treasurer)

Trustee

Dated: 12 March 2026

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 2025

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 2025, 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

13 March 2026

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 2025

	Notes	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Income from:							
Donations and legacies	3	2,629	-	2,629	1,150	-	1,150
Charitable activities	4	38,500	-	38,500	42,844	-	42,844
Investments	5	161	-	161	151	-	151
Total income		41,290	-	41,290	44,145	-	44,145
Expenditure on:							
<u>Charitable activities</u>	6	<u>46,582</u>	<u>27,000</u>	<u>73,582</u>	<u>49,246</u>	<u>27,000</u>	<u>76,246</u>
Total expenditure		46,582	27,000	73,582	49,246	27,000	76,246
Net expenditure		(5,292)	(27,000)	(32,292)	(5,101)	(27,000)	(32,101)
Transfers between funds		(56,650)	56,650	-	-	-	-
Net movement in funds		(61,942)	29,650	(32,292)	(5,101)	(27,000)	(32,101)
Reconciliation of funds:							
Fund balances at 1 April 2024		158,898	99,505	258,403	163,999	126,505	290,504
Fund balances at 31 March 2025		96,956	129,155	226,111	158,898	99,505	258,403

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 2025

	Notes	2025 £	£	2024 £	£
Current assets					
Cash at bank and in hand		228,307		260,599	
Creditors: amounts falling due within one year	11	(2,196)		(2,196)	
Net current assets			226,111		258,403
The funds of the charity					
Restricted income funds	12		129,155		99,505
Unrestricted funds	13		96,956		158,898
			226,111		258,403

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 2025.

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 12 March 2026


Dr Mary Petrou (Treasurer)
Trustee

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

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 2025

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 2025

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

	2025	2024
	£	£
Membership fees	2,629	1,150
	<u>2,629</u>	<u>1,150</u>

4 Income from charitable activities

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Heading #ac989		
Sale of goods	38,500	42,844
	<u>38,500</u>	<u>42,844</u>

5 Income from investments

	Unrestricted funds 2025 £	Unrestricted funds 2024 £
Interest receivable	161	151
	<u>161</u>	<u>151</u>

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

6 Expenditure on charitable activities

	2025 £	2024 £
Direct costs		
Course costs - Hiring hall, catering and lecturers fees	70,777	73,838
Share of support and governance costs (see note 7)		
Governance	2,805	2,408
	<u>73,582</u>	<u>76,246</u>
Analysis by fund		
Unrestricted funds	46,582	49,246
Restricted funds	27,000	27,000
	<u>73,582</u>	<u>76,246</u>

7 Support costs

	Support costs £	Governance costs £	2025 £	2024 £
Legal and professional	-	2,196	2,196	2,196
General expense	-	609	609	212
	<u>-</u>	<u>2,805</u>	<u>2,805</u>	<u>2,408</u>
Analysed between				
Charitable activities	-	2,805	2,805	2,408
	<u>-</u>	<u>2,805</u>	<u>2,805</u>	<u>2,408</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 2025

9 Employees

The average monthly number of employees during the year was:

2025 Number	2024 Number
6	8

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

	2025 £	2024 £
Accruals	2,196	2,196

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 2024 £	Resources expended £	Transfers £	At 31 March 2025 £
	99,505	(27,000)	56,650	129,155
Previous year:	At 1 April 2023 £	Resources expended £	Transfers £	At 31 March 2024 £
	126,505	(27,000)	-	99,505

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 2024 £	Incoming resources £	Resources expended £	Transfers £	At 31 March 2025 £
General funds	158,898	41,290	(46,582)	(56,650)	96,956

UK FORUM ON HAEMOGLOBIN DISORDERS

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

13 Unrestricted funds (Continued)

Previous year:	At 1 April 2023	Incoming resources	Resources expended	Transfers	At 31 March 2024
	£	£	£	£	£
General funds	163,999	44,145	(49,246)	-	158,898

14 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total
	£	£	£
Fund balances at 31 March 2025 are represented by:			
Current assets	96,956	129,155	226,111
	96,956	129,155	226,111