

Charity registration number 1163743

Company registration number 09481209 (England and Wales)

**UK FORUM ON HAEMOGLOBIN DISORDERS**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE YEAR ENDED 31 MARCH 2023**

# UK FORUM ON HAEMOGLOBIN DISORDERS

## LEGAL AND ADMINISTRATIVE INFORMATION

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<b>Trustees</b>	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	(Appointed 8 March 2023)
	Dr R Anderson	(Appointed 8 March 2023)
	A Blackmore	(Appointed 8 March 2023)
<b>Charity number</b>	1163743	
<b>Company number</b>	09481209	
<b>Registered office</b>	Galla House 695 High Road North Finchley London N12 0BT	
<b>Accountants</b>	Lyons Leonidou Galla House 695 High Road North Finchley London N12 0BT	
<b>Bankers</b>	National Westminster Bank Plc Queen Street Branch 96 Queen Street Cardiff CF10 2GR	

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# 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 2023

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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 2023.

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 revised Peer review standards have built the frame work for the next cycle of peer reviews. A Peer review lead Dr Emma Drasar has been appointed and has now along with her deputy leads initiated the peer review programme. The plan is to undertake a paper based assessments and then physical site visit. The administration/logistic support for the peer review programme will be provided by an external company who will be contracted to do this. The remainder of the expenses for the peer review including support for inspection leads to write the inspection reports will be funded through the fees being charged to the hospitals for the peer review. The physical inspection of sites is expected to take place over 2 years with the first inspection planned to take place in Autumn 2023.

### **Educational meetings**

The following educational meetings were organised during the year:

May 2022: 53<sup>rd</sup> Educational Meeting: This meeting was held on 18<sup>th</sup> May and was a hybrid meeting with face to face and virtual audience and was hugely successful in partnership with the Hartley Taylor team LTD (04029300) to provide educational meeting and secretarial support. The meeting included a broad range of topics including genomics testing, the BSH pregnancy in sickle cell disorders and iron chelation guidelines. The afternoon included our first international speaker for several years talking about new therapeutic agent crizanlizumab and an update on the NHSE BLT policy for sickle cell disease, and an introduction to the new race and health observatory sickle cell lead. Our Patient society colleague spoke about concordance to chelation treatment and we bid farewell to Dr Jo Howard who has resigned from the UKFHD committee.

Nov 2022: The 54<sup>th</sup> meeting was held on 23<sup>rd</sup> November and was also a hybrid meeting at Cavendish Conference centre and on line. This meeting was primarily focused on updates from key groups supporting care for patients with haemoglobinopathies' and included updates on the peer review programme, the National haemoglobinopathy registry, the National haemoglobinopathy panel and the Race and Health Observatory. There were presentations on learning from the APPG report and the afternoon included a presentation by the UKTS

Both academic meetings had excellent feedback from attendees.

### **Website and rebranding:**

The website was redesigned to reflect a more modern look and the redesigned UKFHD logo was approved for use by the committee.

# UK FORUM ON HAEMOGLOBIN DISORDERS

## TRUSTEES' REPORT (CONTINUED)(INCLUDING DIRECTORS' REPORT) FOR THE YEAR ENDED 31 MARCH 2023

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### Trustee and committee meetings

Four trustee / committee meetings were held in March, June, September and December.

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 to support the work of the NHR.

Clinical Reference Group for Haemoglobinopathies: committee members attended quarterly meetings to represent the views of health professionals in the development of services for patients with Haemoglobinopathies. We also worked with the CRG on the service review and on production of policies. The Sickle cell Bone marrow transplantation policy and thalassaemia bone marrow transplant policies and iron chelation policies were all worked upon in this financial year.

APPG for sickle: Committee members attended meetings following the publishing of the No ones Listening report to help advocate/support improvements in patient care in England.

### Research

Committee members attend the meeting of the non-malignant clinical research network (CRN). This national body supports research and the UK Forum promotes research into haemoglobin disorders by liaison with this group. The committee members have developed the UKHFD research subgroup as a collaborative group with colleagues nationally and have worked to support data collection on patients with haemoglobinopathies and rarer anaemias and Covid 19 infections during the pandemic.

### Achievements and performance

The organisation of the above activity demonstrates the achievements of the charity during the year.

### 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 2023

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### 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. Teresa Baines and Claire Gillson have joined committee as representatives of NHSBT. Professor Paul Telfer has resigned as vice chair in December 2022. New committee members joining Dr Emma Drasar, Dr Joe Sharif, Dr Indu Thakur, Dr Melanie Percy, Dr Coleen Williamson and Dr Ruth Anderson. 3 New trustees are appointed March 2023: Dr Asad Luqmani, Dr Ruth Anderson and Dr Annette Blackmore.

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

Dr Baba Inusa	
Dr Mary Petrou	
Dr Farrukh Shah (Chairwoman)	
Dr Paul Telfer (Vice Chairman)	(Resigned 8 March 2023)
Dr Joanna Howard	(Resigned 31 May 2022)
Mrs Karen Madgwick (Secretary)	
Ms Helen de Marco	(Resigned 8 March 2023)
Dr Rachel Kesse-Adu (Treasurer)	
Dr Subarna Chakravorty	
Dr A Luqmani	(Appointed 8 March 2023)
Dr R Anderson	(Appointed 8 March 2023)
A Blackmore	(Appointed 8 March 2023)

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: 14 December 2023

# 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 2023

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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 2023, 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 surplus 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**

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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 2023**

		Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Unrestricted funds 2022 £	Restricted funds 2022 £	Total 2022 £
	Notes						
<b>Income from:</b>							
Donations and legacies	3	2,037	-	2,037	1,302	-	1,302
Charitable activities	4	47,250	-	47,250	31,238	-	31,238
Investments	5	49	-	49	1	-	1
<b>Total income</b>		49,336	-	49,336	32,541	-	32,541
<u>Charitable activities</u>							
Heading #ac982	6	49,210	-	49,210	25,702	-	25,702
<b>Net income and movement in funds</b>		126	-	126	6,839	-	6,839
<b>Reconciliation of funds:</b>							
Fund balances at 1 April 2022		163,873	126,505	290,378	157,034	126,505	283,539
<b>Fund balances at 31 March 2023</b>		163,999	126,505	290,504	163,873	126,505	290,378

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 2023

	Notes	2023 £	£	2022 £	£
<b>Current assets</b>					
Cash at bank and in hand		292,700		294,375	
<b>Creditors: amounts falling due within one year</b>	<b>11</b>	2,196		3,997	
Net current assets			290,504		290,378
<b>The funds of the charity</b>					
Restricted income funds	<b>12</b>		126,505		126,505
Unrestricted funds			163,999		163,873
			290,504		290,378

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 2023.

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 14 December 2023

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 2023

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#### 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" ("FRS 102") 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)" (effective 1 January 2019). 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 2023

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### 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 2023

### 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

	2023	2022
	£	£
Membership fees	2,037	1,302
	<u>2,037</u>	<u>1,302</u>

### 4 Income from charitable activities

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
<b>Heading #ac989</b>		
Course fees and sponsorship for the course	<u>47,250</u>	<u>31,238</u>

### 5 Income from investments

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Interest receivable	<u>49</u>	<u>1</u>

# UK FORUM ON HAEMOGLOBIN DISORDERS

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

### 6 Expenditure on charitable activities

	2023 £	2022 £
<b>Direct costs</b>		
Course costs - Hiring hall, catering and lecturers fees	46,471	22,510
Peer review	-	501
	<u>46,471</u>	<u>23,011</u>
<b>Share of support and governance costs (see note 7)</b>		
Governance	2,739	2,691
	<u>49,210</u>	<u>25,702</u>
<b>Analysis by fund</b>		
Unrestricted funds	<u>49,210</u>	<u>25,702</u>

### 7 Support costs

	Support costs £	Governance costs £	2023 £	2022 £
Legal and professional	-	2,196	2,196	2,125
General expense	-	543	543	566
	<u>-</u>	<u>2,739</u>	<u>2,739</u>	<u>2,691</u>
Analysed between				
Charitable activities	-	2,739	2,739	2,691
	<u>-</u>	<u>2,739</u>	<u>2,739</u>	<u>2,691</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 2023

### 9 Employees

The average monthly number of employees during the year was:

2023 Number	2022 Number
8	9

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

	2023 £	2022 £
Accruals	2,196	3,997

### 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 2022 £	At 31 March 2023 £
	126,505	126,505
<b>Previous year:</b>	<b>At 1 April 2021 £</b>	<b>At 31 March 2022 £</b>
Peer review	126,505	126,505

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.

# UK FORUM ON HAEMOGLOBIN DISORDERS

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

### 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 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>
<b>Previous year:</b>	<b>At 1 April 2021 £</b>	<b>Incoming resources £</b>	<b>Resources expended £</b>	<b>At 31 March 2022 £</b>
General funds	157,034	32,541	(25,702)	163,873
	<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 2023 are represented by:			
Current assets	290,504	-	290,504
	<u>          </u>	<u>          </u>	<u>          </u>
	290,504	-	290,504
	<u>          </u>	<u>          </u>	<u>          </u>