

Charity registration number 1190390

H-ABC FOUNDATION UK
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 APRIL 2023

H-ABC FOUNDATION UK

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Mrs A Sheridan-Hill Dr M Teng Mr A Yuk Lun Tang Mr G Hill Mrs A E Candy-Waters
Charity number	1190390
Registered office	42 Buxton Avenue Caversham Reading RG4 7BU
Independent examiner	Joanna Boatfield ACA Ensors Accountants LLP Victory House Vision Park Chivers Way, Histon Cambridge CB24 9ZR

H-ABC FOUNDATION UK

CONTENTS

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

H-ABC FOUNDATION UK

TRUSTEES REPORT

FOR THE YEAR ENDED 30 APRIL 2023

The trustees present their annual report and financial statements for the year ended 30 April 2023.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's constitution, the Charities Act 2011 and "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 has a Charity number of 1190390.

The registered office of the charity is:

42 Buxton Avenue
Caversham
Reading
RG4 7BU

Objectives and activities

The Trustees have referred to the Charity Commission's general guidance on Public Benefit when reviewing our aims and objectives and in planning the charity's future activities and believe that the activities of the charity clearly demonstrate a direct public benefit.

H-ABC Foundation was set up in 2019 by 4 parents who have children with H-ABC (Hypomyelination with Atrophy of the Basal Ganglia and Cerebellum) which is a progressive neurological disease. There is currently no treatment for H-ABC, but promising research has started on gene therapy. Due to the rarity of the disease there is very little accurate information currently available that families can easily access. The charity wants to push forward research into the disease and ensure parents of children diagnosed with the disease have easy access to accurate information.

The charity's objective is:

To provide relief and assistance for sufferers of Hypomyelination with Atrophy of the Basal Ganglia and Cerebellum (H-ABC) and their families in particular, but not exclusively, by:

- a. Providing help, support and advice to families from our own experience
- b. Promoting awareness and understanding of Hypomyelination with Atrophy of the Basal Ganglia and Cerebellum (H-ABC)
- c. Supporting research that is dedicated to H-ABC, the useful results of which shall be published.

Achievements and performance

Family Grant Programme

This year we launched our Family Grant Programme. We have had 2 applications this year:

- Child S was funded to attend the Leukodystrophy Centre of Excellence. The family have expressed how useful the visit was to help understand the conditions and current therapies to help their child.
- Child F was funded a table that moved up and down to make school life easier.

We have been working closely with Synaptix Bio and our Trustees have monthly meetings with Synaptix to keep up to date with the progress. Clinical Trials are planned for 2024 although we understand due to regulations things can take longer than expected.

Two of our Trustees attended the Leukodystrophy conference which was hosted at the Children's Hospital of Philadelphia. This was an excellent networking event for the charity who met with clinicians, pharmaceuticals, families and other charities. It took a lot of organisation due to our Trustees being carers for disabled children but was very worthwhile.

H-ABC FOUNDATION UK

TRUSTEES REPORT (CONTINUED)

FOR THE YEAR ENDED 30 APRIL 2023

Fundraising

This year has been quiet on the fundraising front. We have had donations from companies through H-ABC family and friends. We also continue to have income from our JustGiving page which has included:

Donations in memory of Ray Youens who was close to one of our H-ABC families.

Donations through a school book sale.

Donations for a Paris marathon.

We are lucky to have many supporters that help us raise money and we have more plans for fundraising next year.

Connecting Families

We continue to link with families as they receive a diagnosis. This year we have connected with 4 new families taking our UK total to 25.

We know there are many more out there and continue to contact hospitals and clinicians to get the charity details passed onto these families.

This is an important aspect of our charity as when diagnosed it is a very lonely place. It is very hard to make contact with these families and we hope that they find us through google or clinics passing on our details. We are continuously thinking of ideas to make us more visible and are working with a PR company and writing to hospitals to help with this.

Publicity

We have had another great year of publicity! Some of our Trustees have been working with a PR company to secure interviews and articles for the charity. The publicity is really important for us as a small charity as it enables us to reach families that would otherwise not know about us. Some of the publicity this year includes:

Frankie and mum being interviewed by ITV

A Trustee interviewed by Metro newspaper

A Trustee and Synaptix bio joint interview on BBC Oxford radio

Aggie and mum being interviewed

A Trustee interviewed by the Independent about H-ABC diagnosis

Scientific update

Amazing progress has been made this year on the path to the first treatment option for H-ABC and Tubb4a. Synaptix Bio have raised over £13m to fund a clinical trial which is planned for 2024. A lead candidate for an ASO treatment has been agreed and the start of the regulation process has started.

Michelle Teng, H-ABC Foundation Trustee, is the co-founder of Synaptix Bio and is working tirelessly to move to clinical trials. Synaptix Bio have entered into a contract with Children's Hospital of Philadelphia (CHOP) to work together on a gene therapy treatment.

H-ABC FOUNDATION UK

TRUSTEES REPORT (CONTINUED)

FOR THE YEAR ENDED 30 APRIL 2023

Scientific Advisory Board

The charity has a Scientific Advisory Board (SAB) which is led by Dr Michelle Teng, Trustee. The SAB consists of:

Dr Michelle Teng - Michelle is a scientist entrepreneur and a rare disease advocate. She followed an academic path in research after obtaining a PhD in Immunogenetics from University of Cambridge followed by a postdoctoral fellowship at the Wellcome Trust Sanger Institute before venturing into industry.

Dr Adeline Vanderver - Adeline Vanderver, MD, is an attending physician in the Division of Neurology, Program Director of the Leukodystrophy Center, and Jacob A. Kamens Endowed Chair in Neurologic Disorders and Translational Neurotherapeutics at Children's Hospital of Philadelphia.

Dr Nicole Wolf - Dr Wolf is a Neurologist who works at Centre for Childhood White Matter Disorders at VU University Medical Centre, Amsterdam. Her major research and clinical interest is hypomyelination.

Dr Tony Hall - Dr Anthony Hall (Tony) graduated from King's College London with first class honours in physiology and pharmacology before going on to qualify as a doctor in 1991 from the Royal Free Hospital London. He joined the pharmaceutical industry in 1994 and has spent many years working on the development of drugs for rare diseases.

The SAB advise the Trustees on scientific issues. The Charity has produced a Grant Making Policy with SAB input for any application of research grants. This year we have funded the Children's Hospital of Philadelphia to progress work on ASO gene therapy. We plan to investigate other avenues of research that could be funded by the charity to help find a treatment option for H-ABC patients.

Looking Forward

We have had a successful year and are connecting more families of this very rare disease. We hope to continue to grow our community and reach out to H-ABC families when they receive a diagnosis. We have had lots of positive news regarding the work on a treatment for H-ABC and we are positive this will continue and enable clinical trials in the near future. As the research continues to be funded by Synaptix Biotech we are now looking at how we can support families with equipment and therapies. A focus in the next year will be supporting families through our Family Fund Grant and funding needed equipment and services to Tubb4a families in the UK. We aim to reach all UK H-ABC families and support them both emotionally and with any equipment that might be needed to make their child's life easier.

Financial review

During the year the charity had income of £28,461 (2022 - £51,188), of which £15,690 (2022 - £5,169) was expended on charitable activities. Unrestricted funds at the year-end amounted to £89,444 (2022 - £76,673).

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. Reserves at the year end amounted to £87,999 (2022 - £75,490) which exceeds this target, though as the charity continues to establish itself and increases its activities it is expected that further expenditure will be incurred.

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.

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 have adopted the going concern basis of accounting in preparing these financial statements.

H-ABC FOUNDATION UK

TRUSTEES REPORT (CONTINUED)

FOR THE YEAR ENDED 30 APRIL 2023

Structure, governance and management

The charity is a Charitable Association. Its governing document is the constitution adopted on 25th November 2019, amended on 2nd July 2020.

The trustees who served during the year and up to the date of signature of the financial statements were:

Mrs A Sheridan-Hill
Dr M Teng
Mr A Yuk Lun Tang
Mr G Hill
Mrs A E Candy-Waters

H-ABC Foundation UK follows their constitutional document clause 18 to appoint new Trustees. When a new trustee is to be appointed a members' vote is required.

The Charity is wholly administered by its Trustees, none of whom receive any remuneration or compensation for costs incurred in performing their duties. The Trustees meet at least quarterly. Trustees manage the financial and day-to-day administration. Trustees keep detailed minutes of Trustee meetings and records of any decision made outside of these meetings.

Trustees are appointed at the annual members meeting – we currently have 5 Trustees after legal advice suggesting it would be beneficial to have an odd number of Trustees to avoid any decisions being unresolved by a Trustee vote.

Risk Review

The Trustees have conducted their own review of the major risks to which the charity is exposed and mechanisms have been established to mitigate those risks. The charity has sufficient financial reserves to fund its activities for 6 months in the event of unforeseen circumstances.

The charity relies on volunteers and has the commitment of Trustees and H-ABC families to keep the charity active. It provides an important support for newly diagnosed families. Running costs for the charity are minimal and enable us to invest in research and further raise awareness.

Charity volunteers support the charity through fundraising, admin support and general awareness. Volunteers play a large role in helping the charity to raise money. Without any paid employees, the charity is reliant on volunteers to support the charity. Volunteer support includes helping to produce data reports on H-ABC, PR support for fundraising events, and spreading awareness through social media.

The trustees report was approved by the Board of Trustees.

Mr A Yuk Lun Tang

26 February 2024

H-ABC FOUNDATION UK

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF H-ABC FOUNDATION UK

I report to the trustees on my examination of the financial statements of H-ABC Foundation UK (the charity) for the year ended 30 April 2023.

Responsibilities and basis of report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 (the 2011 Act).

I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act. In carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn.

I understand that this has been done in order for financial statements to provide a true and fair view in accordance with Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

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 charity as required by section 130 of the 2011 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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 financial statements to be reached.

Joanna Boatfield ACA
Ensors Accountants LLP

Victory House
Vision Park
Chivers Way, Histon
Cambridge
CB24 9ZR

Dated: 27 February 2024

H-ABC FOUNDATION UK

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 30 APRIL 2023

	Notes	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Income from:			
Donations and legacies	3	28,461	51,188
Charitable activities	4	15,690	5,169
Net income and movement in funds		12,771	46,019
Reconciliation of funds:			
Fund balances at 1 May 2022		76,673	30,654
Fund balances at 30 April 2023		89,444	76,673

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

H-ABC FOUNDATION UK

BALANCE SHEET

AS AT 30 APRIL 2023

	Notes	2023 £	£	2022 £	£
Fixed assets					
Tangible assets	10		1,445		1,183
Current assets					
Cash at bank and in hand		89,439		76,762	
Creditors: amounts falling due within one year	11	1,440		1,272	
Net current assets			87,999		75,490
Total assets less current liabilities			89,444		76,673
The funds of the charity					
Unrestricted funds			89,444		76,673
			89,444		76,673

The financial statements were approved by the trustees on 26 February 2024

Mr A Yuk Lun Tang
Trustee

H-ABC FOUNDATION UK

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 APRIL 2023

1 Accounting policies

Charity information

H-ABC Foundation UK is a Charitable Incorporated Organisation, established on the 25th November 2019.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's constitution, the Charities Act 2011 and "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 applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

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. 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. The charity has considered its forecasts and working capital requirements for a period of 12 months from the date of signing these financial statements. Thus, the trustees have adopted the going concern basis of accounting in preparing these 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 or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

1.4 Income

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.

H-ABC FOUNDATION UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 30 APRIL 2023

1 Accounting policies

(Continued)

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

1.5 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Office equipment	20% straight line basis
------------------	-------------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.6 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.7 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.

H-ABC FOUNDATION UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 APRIL 2023

1 Accounting policies

(Continued)

Derecognition of financial liabilities

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

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 Income from donations and legacies

	Unrestricted funds 2023 £	Unrestricted funds 2022 £
Donations and gifts	28,461	51,188

4 Expenditure on charitable activities

	Charitable activities 2023 £	Charitable activities 2022 £
Direct costs		
Depreciation and impairment	436	296
Family Grant Programme	4,983	-
Advertising	170	133
	5,589	429
Share of support and governance costs (see note 6)		
Support	8,661	2,808
Governance	1,440	1,932
	15,690	5,169
Analysis by fund		
Unrestricted funds	15,690	5,169

H-ABC FOUNDATION UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 APRIL 2023

5 Grants payable

During the period, the charity made grants amounting to £4,984 to two individuals (2022 - £nil). These grants funded medical treatment and specialised equipment. The charity has no commitments in relation to these grants, and makes them at its discretion.

Support costs have been allocated in full against grant-making activities.

One grant recipient was the child of two of the Trustees, as disclosed in note 7.

6 Support costs allocated to activities

	2023 £	2022 £
Website and IT costs	499	285
Administration	88	39
Event costs	3,000	1,600
Bank charges	191	884
Travel costs	4,883	-
Governance costs	1,440	1,932
	<u>10,101</u>	<u>4,740</u>
Analysed between:		
Charitable activities	<u>10,101</u>	<u>4,740</u>

7 Trustees

None of the trustees (or any persons connected with them) received any remuneration during the year, but two of them were reimbursed a total of £4,883 (2022 - £nil) for travelling expenses and £1,698 (2022 - £nil) of other payments paid on behalf of the charity.

During the year Alan Tang and Michelle Teng, two of the trustees, applied for funding and were granted it under the Family Grant Programme. A grant of £4,322 was made to fund a child of the Trustees to see a clinician at the Children's Hospital of Philadelphia in relation to treatment of H-ABC.

8 Employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
Total	<u>-</u>	<u>-</u>

There were no employees who received employee benefits of more than £60,000.

There were no employees whose annual remuneration was more than £60,000.

9 Taxation

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

H-ABC FOUNDATION UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 APRIL 2023

10 Tangible fixed assets

	Office equipment £
Cost	
At 1 May 2022	1,479
Additions	698
	<hr/>
At 30 April 2023	2,177
	<hr/>
Depreciation and impairment	
At 1 May 2022	296
Depreciation charged in the year	436
	<hr/>
At 30 April 2023	732
	<hr/>
Carrying amount	
At 30 April 2023	1,445
	<hr/>
At 30 April 2022	1,183
	<hr/>

11 Creditors: amounts falling due within one year

	2023 £	2022 £
Accruals and deferred income	1,440	1,272
	<hr/>	<hr/>

12 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 May 2022 £	Incoming resources £	Resources expended £	At 30 April 2023 £
General funds	76,673	28,461	(15,690)	89,444
	<hr/>	<hr/>	<hr/>	<hr/>
Previous year:				
	At 1 May 2021 £	Incoming resources £	Resources expended £	At 30 April 2022 £
General funds	30,654	51,188	(5,169)	76,673
	<hr/>	<hr/>	<hr/>	<hr/>

H-ABC FOUNDATION UK

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 30 APRIL 2023

13 Analysis of net assets between funds

	Unrestricted funds 2023 £
Fund balances at 30 April 2023 are represented by:	
Tangible assets	1,445
Current assets/(liabilities)	87,999
	<hr/>
	89,444
	<hr/>
	Unrestricted funds 2022 £
Fund balances at 30 April 2022 are represented by:	
Tangible assets	1,183
Current assets/(liabilities)	75,490
	<hr/>
	76,673
	<hr/>