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Charity Registration No. 1190390

**H-ABC FOUNDATION UK**  
**ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS**  
**FOR THE PERIOD ENDED 30 APRIL 2021**

# H-ABC FOUNDATION UK

## LEGAL AND ADMINISTRATIVE INFORMATION

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

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# H-ABC FOUNDATION UK

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# H-ABC FOUNDATION UK

## TRUSTEES REPORT

**FOR THE PERIOD ENDED 30 APRIL 2021**

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*The trustees present their annual report and financial statements for the period ended 30 April 2021.*

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.

# **H-ABC FOUNDATION UK**

## **TRUSTEES REPORT (CONTINUED)**

**FOR THE PERIOD ENDED 30 APRIL 2021**

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### **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 the impact of COVID19 and the impact on 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.

### **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 period and up to the date of signature of the financial statements were:

A Sheridan-Hill  
Dr M Teng  
Mr A Yuk Lun Tang  
G Hill  
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 – during the year a new Trustee was appointed after the Trustees received 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 its 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.

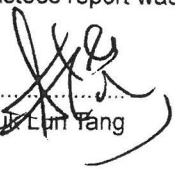
# H-ABC FOUNDATION UK

## TRUSTEES REPORT (CONTINUED)

*FOR THE PERIOD ENDED 30 APRIL 2021*

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The trustees report was approved by the Board of Trustees.

  
.....  
Mr A Yip Lun Tang

Date: ..... 28 Jan 2022



# H-ABC FOUNDATION UK

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

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I report to the trustees on my examination of the financial statements of H-abc Foundation UK (the charity) for the period ended 30 April 2021.

### 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

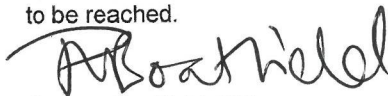
Your attention is drawn to the fact that the charity has prepared financial statements in accordance with Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting 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  
Cambridgeshire  
CB24 9ZR

Dated: 31/1/2022

## H-ABC FOUNDATION UK

### STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT FOR THE PERIOD ENDED 30 APRIL 2021

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	Notes	Unrestricted funds 2021 £
<b><u>Income from:</u></b>		
Donations and legacies	3	127,264
<b><u>Expenditure on:</u></b>		
Charitable activities	4	96,610
<b>Net income for the period/ Net movement in funds</b>		30,654
Fund balances at 25 November 2019		-
<b>Fund balances at 30 April 2021</b>		<u>30,654</u>

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The statement of financial activities includes all gains and losses recognised in the period.

All income and expenditure derive from continuing activities.



# H-ABC FOUNDATION UK

## TRUSTEES REPORT (CONTINUED)

**FOR THE PERIOD ENDED 30 APRIL 2021**

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### Achievements and performance

#### *Fundraising*

Since the charity started several fundraising events have been held. Unfortunately due to COVID some events had to be cancelled.

The events include an 80's Disco, an Art Exhibition, a Family Fun Day and a 'bring and buy' sale. The other main source of income has been a just giving page that has been shared amongst family, friends and social media.

Future plans - up and coming events planned in the next reporting period include a supporter of the charity running 5 marathons in 50 hours and attempting a 50km car pull.

#### *Connecting Families*

So far the charity has connected with 15 H-abc families in the UK. Due to confidentiality we have to wait for families to contact us but we believe we are in contact with over 80% of H-abc families.

We have set up a range of communication tools, and our website has been carefully designed to help H-abc families access information that is clear and concise. We have set up a Facebook, Instagram and Twitter account to help with our visibility. We have set up a WhatsApp group for the families of the known UK cases and when we identify a new case we encourage them to join the group. The group offers support and advice between the families.

The charity also takes part in regular global H-abc zoom calls – this helps connect parents globally and to update other parents on the charities work.

Future plans - We are in the process of writing to Neurologists in the UK to help identify any new families. Working with Dr Vanderver, one of the H-abc experts, it is believed that the prevalence of H-abc could be much higher than currently thought (which is less than 200 confirmed cases worldwide).

#### *Publicity*

One of our biggest achievements was 3 of the Trustees appearing on BBC Breakfast in August 2020. This gave us great publicity to increase awareness of H-abc.

We have had an article in the Daily Express and many local newspapers highlighting our fundraising efforts.

Future plans – publicity is very important in helping us reach new families, we have a PR company that help us pro bono and we are working on a plan for future publicity.

# H-ABC FOUNDATION UK

## TRUSTEES REPORT (CONTINUED)

**FOR THE PERIOD ENDED 30 APRIL 2021**

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### *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*

The charity will continue with their tireless fundraising and has plans for several events. The events are all run by volunteers and the charity is very fortunate to have lots of supporters. The charity is going to aim to increase awareness of H-abc by writing to Neurologists and have started work on a 360 degree MRI awareness video. The charity is also working on other awareness materials.

As this has been the charity's first year we will be evaluating our performance and ensuring all relevant policies and procedures are in place.

The charity is in contact with all known H-abc families and will continue to contact new families as they are identified. The charity will discuss other ways to support these families.

The charity has funded medical research into H-abc and this continues to be a priority. The charity hopes for further breakthroughs in research which will ultimately result in a treatment for H-abc.

### **Financial review**

The charity had income of £127,264, of which £96,610 was expended on charitable activities. Unrestricted funds at the year-end amounted to £30,654.

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 period.

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.

# H-ABC FOUNDATION UK

## BALANCE SHEET

AS AT 30 APRIL 2021

	Notes	2021 £	£
<b>Current assets</b>			
Cash at bank and in hand		31,854	
<b>Creditors: amounts falling due within one year</b>	9	(1,200)	
Net current assets			30,654
<b>Income funds</b>			
Unrestricted funds			30,654
			30,654

The financial statements were approved by the Trustees on .....

.....  
Mr A Yuk Lun Tang  
Trustee



# H-ABC FOUNDATION UK

## NOTES TO THE FINANCIAL STATEMENTS

### FOR THE PERIOD ENDED 30 APRIL 2021

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#### 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, 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.

These are the charity's first set of accounts and are presented for a period longer than one year.

##### 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 the impact of COVID19 and the impact on 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 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.

# H-ABC FOUNDATION UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE PERIOD ENDED 30 APRIL 2021

### 1 Accounting policies

(Continued)

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.

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 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.

# H-ABC FOUNDATION UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE PERIOD ENDED 30 APRIL 2021

### 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 legacies

	Unrestricted funds
	2021 £
Donations and gifts	127,264

### 4 Charitable activities

	2021 £
The Chop Foundation	84,086
Microsynth	8,182
Advertising	442
	92,710
Share of support costs (see note 6)	2,700
Share of governance costs (see note 6)	1,200
	96,610

### 5 Grants payable

During the period, the charity made grants amounting to £84,086 to a single institution: The Children's Hospital of Philadelphia Foundation (The CHOP Foundation). These grants have been made in order to fund the Foundation's work in developing a treatment for H-abc. The charity has no commitments in relation to any of these grants, and makes them at its discretion

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

No grants were made to individuals.



# H-ABC FOUNDATION UK

## NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE PERIOD ENDED 30 APRIL 2021

### 6 Support costs

	Support costs	Governance costs	2021	Support costs	Governance costs
	£	£	£	£	£
Website	2,696	-	2,696	-	-
Administration	4	-	4	-	-
Independent Examination	-	1,200	1,200	-	-
	<u>2,700</u>	<u>1,200</u>	<u>3,900</u>	<u>-</u>	<u>-</u>
Analysed between Charitable activities	<u>2,700</u>	<u>1,200</u>	<u>3,900</u>	<u>-</u>	<u>-</u>

### 7 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the period.

### 8 Employees

The average monthly number of employees during the period was:

	2021 Number
Total	<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 Creditors: amounts falling due within one year

	2021 £
Accruals and deferred income	<u>1,200</u>

### 10 Analysis of net assets between funds

	Unrestricted funds 2021 £
Fund balances at 30 April 2021 are represented by:	
Current assets/(liabilities)	<u>30,654</u>
	<u>30,654</u>

## **H-ABC FOUNDATION UK**

### **NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)** **FOR THE PERIOD ENDED 30 APRIL 2021**

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#### **11   *Related party transactions***

There were no disclosable related party transactions during the period.

No expenses were incurred by the trustees during the period.