



Alternating Hemiplegia of Childhood UK (AHC UK)

December 2020 – April 2022

Charity Registration Number: 1192701

Charity Address: 75 Charlton Road, Southampton, SO15 5EU

Current Trustees:

Chair: Adrian Kowal

Vice Chair/Research Liaison: Katherine Behl

Treasurer: Jo Brown

Secretary: Lyndsey Chand

Communication and Social Media: Abhishek Behl

Adult AHC Liaison: Sue Kemp

Previous Trustees:

Vickey Lewis Kowal (2020-2021)

Jade Cook (2020-2022)

AHC UK Mission statement:

To assist and inspire all affected by Alternating Hemiplegia of Childhood through:

- Support for AHC families – provide a lifeline for families newly diagnosed as well as those struggling with the complexities of living with AHC;
- Information and advocacy – raise awareness of what AHC is and be the voice of AHC families in the UK to campaign on behalf of those affected by or caring for those with AHC;
- Research – promote, encourage and facilitate (through fundraising and connecting families with researchers) effective therapies, treatment and towards a cure of our “one-in-a-million” condition.

No one, no family, shall ever be alone

AHC UK Charity Objectives

To preserve and protect the physical and mental health of families and individuals affected by alternating hemiplegia of childhood and associated conditions by:-

- a. providing support and creating and maintaining communication channels between those persons who act as family carers and supporters so as to disseminate knowledge, experience and thereby promote both the health and quality of life of AHC patients and their families;
- b. raising awareness and education of the medical profession and other relevant professionals (including but not limited to psychologists, care workers, schoolteachers, therapists and suchlike), together with the general public, on the nature of AHC (and associated conditions) and its implication for families;
- c. acting as an advocate with public servants and organisations within the UK (other than those included in object 2) so as to become the voice of AHC families;
- d. promoting, encouraging and facilitating research into the diagnosis, effective management and therapies, and potential curative procedures; and
- e. establishing and maintaining close links with counterpart organisations, researchers and such like that are based outside the United Kingdom, and to disseminate the growing body of knowledge into this rare condition amongst interested persons and parties within the UK

Structure, Governance and Management

AHC UK is Charitable Incorporated Organisation (CIO) established on the 8th December 2020. Our constitution was adopted following this. The information included below is taken from this document and provides an outline of the roles of Trustees and their management of the charity.

Functions and duties of charity trustees

The charity trustees shall manage the affairs of the CIO and may for that purpose exercise all the powers of the CIO. It is the duty of each charity trustee:

- (a) to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and
- (b) to exercise, in the performance of these functions, such care and skill as is reasonable in the circumstances having regard in particular to:
 - a. any special knowledge or experience he or she has or holds himself or herself out as having; and,
 - b. if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business and profession.

Eligibility for trusteeship

- (a) Every trustee must be a natural person.
- (b) No individual may be appointed as a charity trustee of the CIO:
 - a. if he or she is under the age of 18 years; or
 - b. if he or she would automatically cease to hold office under the provisions of clause [12(1)(e)]; or
- (c) No one is entitled to act as a charity trustee whether on appointment or on any re-appointment until he or she has expressly acknowledged, in whatever way the charity trustees decide, his or her acceptance of the office of charity trustee.

Number of charity trustees

- (a) There must be at least three charity trustees. If the number falls below this minimum, the remaining trustee or trustees may act only to call a meeting of the charity trustees, or appoint a new charity trustee.
- (b) There is no maximum number of charity trustees that may be appointed to the CIO.
- (c) Where practical, at least one-half of the trustees should have a direct and demonstrable connection to Alternating Hemiplegia of Childhood. Furthermore at least one-third of the trustees should have a direct family connection to someone who has Alternating Hemiplegia of Childhood.

First charity trustees

The first charity trustees are as follows and are appointed for the term indicated against their name:

- Adrian Kowal (Chair) -for five years
- Vickey Lewis Kowal - for five years
- Katherine Behl (Vice-Chair) - for five years
- Abhishek Behl - for five years
- Johanna Brown (Treasurer) - for five years
- Lyndsey Chand (Secretary) - for five years
- Sue Kemp - for five years
- Jade Cook - for five years

Appointment of further charity trustees

- (a) Apart from the first charity trustees, every appointed trustee must be appointed for a term of three years by resolution passed at a properly convened meeting of the charity trustees.
- (b) In selecting individuals for appointment as appointed charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Information for new charity trustees

The charity trustees will make available to each new charity trustee, on or before his or her first appointment:

- (a) a copy of the current version of this constitution; and
- (b) a copy of the CIO's latest Trustees' Annual Report and statement of accounts.

Retirement and removal of charity trustees

A charity trustee ceases to hold office if he or she:

- (a) retires by notifying the CIO in writing (but only if enough charity trustees will remain in office when the notice of resignation takes effect to form a quorum for meetings);
- (b) is absent without the permission of the charity trustees from all their meetings held within a period of six months and the trustees resolve that his or her office be vacated;
- (c) dies;
- (d) in the written opinion, given to the company, of a registered medical practitioner treating that person, has become physically or mentally incapable of acting as a director and may remain so for more than three months;
- (e) is disqualified from acting as a charity trustee by virtue of sections 178-180 of the Charities Act 2011 (or any statutory re-enactment or modification of that provision).

Any person retiring as a charity trustee is eligible for reappointment.

If there are concerns about whether a charity trustee remains eligible, the Trustees will hold an emergency meeting where a Vote of Confidence/No Confidence will be held.

Taking of decisions by charity trustees

Any decision may be taken either:

1. at a meeting of the charity trustees; or
2. by resolution in writing or electronic form agreed by a majority of the charity trustees, which may comprise either a single document or several documents containing the text of the resolution in like form to each of which one or more charity trustees has signified their agreement.

Delegation by charity trustees

The charity trustees may delegate any of their powers or functions to a committee or committees, and, if they do, they shall determine the terms and conditions on which the delegation is made. The charity trustees may at any time alter those terms and conditions, or revoke the delegation.

This power is in addition to the power of delegation in the General Regulations and any other power of delegation available to the charity trustees, but is subject to the following requirements:

- (a) a committee may consist of two or more persons, but at least one member of each committee must be a charity trustee;
- (b) the acts and proceedings of any committee must be brought to the attention of the charity trustees as a whole as soon as is reasonably practicable; and
- (c) the charity trustees shall from time to time review the arrangements which they have made for the delegation of their powers.

Financial Review

Report Year ending April 2022

This report period has seen our establishment as a CIO at the start (December 2020) and setting up our bank account at the end (March 2022).

Due to the complexities in setting up a charity bank account, we were able to support ongoing research projects through arrangements with another charity, *Young Epilepsy* (Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy Charitable Trust. Registered Charity number 311877). This allowed support to go to projects that directly support AHC research when we were not in a position to accept donations.

December 2020 – April 2021

After being confirmed as having CIO status in December 2020, we set about exploring bank account options. We considered a large number of different banks and after weighing up options decided to complete the application for Natwest.

April 2021 – April 2022

Having submitted an application for a charity account with Natwest, we were contacted by them and informed that they were not taking any new applications. We contacted a number of other banks and were told the same thing. These difficulties in CIOs, charities and other small community organisations in starting new accounts was reported in the media throughout the year. Due to these delays we continued to update our supporters through the newsletter and social media.

We sent an application to Charities Aid Foundation in the later half of 2021. Their processes were slow due to the large number of applications they were also processing. We provided all the relevant information and were finally granted a bank account with them. This account was opened in late March 2022.

We did not receive any money as a charity until the financial year beginning April 2022.

We did not spend any money as a charity in the year 2021-2022.

Other Assets

As a charity, we do not hold any other assets.

Attachments

We have attached a summary of our finances for the year 2021-2022¹.

¹ See Appendix on pg 13

Objectives and Activities: 2021-2022

Month	Activities	Objectives ²
January 2021	18 th January – AHC Day. Led AHC awareness with a collaboration of other European and international AHC patient organisations.	a, e,
February 2021	28 th February – Rare Disease Day. Rare Coffee and Cake. Raising money for Young Epilepsy.	a, e,
May 2021	- AHC UK Family Day – virtual only; with UK and outside UK families - AGM - Sessions on: ketogenic diet; AHC and Sleep; AHC Natural history project; genetics and AHC; Associated conditions - Music Therapy session for families - Sunflower activity for family - Pub Quiz	a, b, d
September 2021	Research Symposium – accredited by the Royal College of Physicians	a, b
December 2021	- Online/Virtual Christmas Quiz for AHC and ATP1A3 research underway at Great Ormond Street and University College London (Funds collected via Young Epilepsy) - Grant application to EJPRD in collaboration with the European AHC patient organisations - Application to host the ATP1A3 Symposium submitted	a, b, c, d, e,
January 2022	18 th January – AHC Day. Online promotion.	a, e,

² Objectives listed on page 2

February 2022	28th February – Rare Disease Day. Rare Coffee and Cake. Raising money for Young Epilepsy.	a, e,
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Achievements and Performance

Publications

Shared Paper: Rare Revolution AHC – AHC UK, Katherine Behl and Rosaria Vavassori (IHCRC)

Epicare leaflets for families and professionals – AHC UK rep involved through AHC Federation Europe

AHC UK reps involved in documentary about AHC (finalist Berlin Rare Disease Festival)

Ongoing work on future publications

All of the above work represents objectives: a, b, c, d, e

International Work

AHC UK rep is a member of AHCFE

AHC UK rep is a member of AHC International Alliance (AHCIA)

All of the above work represents objectives: a, e

UK Work

AHC UK rep attended Scottish Parliament Cross Party Working Group meetings on Rare Diseases – 2021 and 2022

AHC UK rep attended virtual event for UK Parliament for Rare Diseases – 2021

All of the above work represents objectives: a, b, c,

AHC UK Charity Performance

Recruited Volunteers November 2021

Continued to support families online through COVID-19 pandemic

Validated the Sleep Questionnaire for AHC UK Researchers

Promoted involvement in research for a Natural History Study in UK and Ireland (children and adults)

Representation at the ATP1A3 Symposium on ATP1A3 in disease – Virtual attendance

All of the above work represents objectives: a, b, c, d, e

Online and IT Performance

AHC YouTube space - Interviews with researchers for families, clinicians and other researchers

Updated the website – ongoing work. Including blogs.

Organised Microsoft Not for Profit account – 2021 onwards for MS Teams etc. email accounts.

Emails/Newsletters

Activity on social media platforms

Closed groups on social media for supporting families

Ongoing contact with AHC organisations internationally to share information

All of the above work represents objectives: a, b, c, d, e

Future:

Plans to engage with Genetic Alliance

Engagement with more AHC organisations across the world

The above report has been reviewed and approved by the Charity Trustees.

Adrian Kowal

Chair

Lyndsey Chand

Secretary

Jo Brown

Treasurer

Appendix: Financial Summary 2021-2022

For the year 2021-2022	Total (£)
Income	
Donations and Legacies	0
Charitable Activities	0
Other activities	0
Total:	0
Expenditure	
To raise funds:	0
Charitable Activities	0
Other activities	0
Total:	0
Net Gains:	0
Net Loss:	0

For the year 2021-2022	Total (£)
Income	
Donations and Legacies	0
Charitable Activities	0
Other activities	0
Total:	0
Expenditure	
To raise funds:	0
Charitable Activities	0
Other activities	0
Total:	0
Net Gains:	0
Net Loss:	0

Source	April		Source	May		Source
	Amount (£)	comment		Amount (£)	comment	
		0			0	

Totals:

0

0

Annual Total:

0

June			July			August		
Amount (£)	comment	Source	Amount (£)	comment	Source	Amount (£)		
0			0			0		

0

0

0

		September				October	
comment	Source	Amount (£)	comment	Source	Amount (£)	comment	
		0			0		

0

0

Source	November		Source	December		Source
	Amount (£)	comment		Amount (£)	comment	
	0			0		

0

0

January			February			March		
Amount (£)	comment	Source	Amount (£)	comment	Source	Amount (£)		
0			0			0		

0

0

0

comment

Source	April		Source	May		Source
	Amount (£)	comment		Amount (£)	comment	
		0			0	

Totals:

0

0

Annual Total:

0

June			July			August		
Amount (£)	comment	Source	Amount (£)	comment	Source	Amount (£)		
0			0				0	

0

0

0

		September				October	
comment	Source	Amount (£)	comment	Source	Amount (£)	comment	
		0			0		

0

0

Source	November		Source	December		Source
	Amount (£)	comment		Amount (£)	comment	
	0			0		

0

0

January			February			March		
Amount (£)	comment	Source	Amount (£)	comment	Source	Amount (£)		
0			0				0	

0

0

0

comment