



Alternating Hemiplegia of Childhood UK (AHC UK)

April 2023 – April 2024

Charity Registration Number: 1192701

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

Current Trustees:

Chair: Katherine Behl

Research Liaison: Katherine Behl

Treasurer: Jo Brown

Secretary: Lyndsey Chand

Communication and Social Media: Abhishek Behl

Adult AHC Liaison: Sue Kemp

Previous Trustees:

Adrian Kowal (2020-2023)

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, school teachers, 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) (resigned 2022/23) - for five years
- Vickey Lewis Kowal (resigned 2021/22) - 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 (resigned 2021/22) - 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.

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 2024

Income

Over the last year the majority of our income has been through fundraising and donations to our account. These have included those set up through Amazon and Just Giving.

It is encouraging that many of our supporters are using different means of donating to our charity. We recognise however, that it would be great to highlight the amazing work that they are doing. Going forward, we hope to learn more about those raising money and promote their activities.

Outgoings

Over the last year, we have completed a number of transactions related to the ATP1A3 and AHC conference that we hosted in 2022. These were outstanding and we had been waiting for the completed paperwork to do this.

We were able to support the hosts of the ATP1A3 conference in the USA in October with a financial donation. This was consolidated by attendance by AHC UK to the online presentations to provide feedback about the wider discussions.

Future Commitments

Discussions this year have included the commitment to a research project investigation the benefit of oxygen in AHC episodes based in France which started in 2024.

Financial Summary 2023-2024

Total Income	£8,732	Year end balance	£74,875
Total Expenditure	£11,486	Restricted funds	£141

Reserves Policy

At the current time, AHC UK does not have an operational Reserves Policy. This is something that the Trustees continue to develop.

Other Assets

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

Objectives and Activities: 2023 -2024

Month	Activities	Objectives ¹
April 23	Post AHC 10-year event tasks continue • Written reports for EJPRD • Working with researchers to prepare scientific papers for peer reviewed journals • Involvement with international discussions on research ideas since the AHC 10-year event Feedback to AHC organisations round the world and support for those considering applying to host	A,B,C,D,E
May 23	Post AHC 10-year event tasks continue • Working with researchers to prepare scientific papers. From AHC UK This was led by Katherine Behl and Jo Brown and continues across the year Katherine Behl presented at the Hot Brain Conference, a <i>Lancet Neurology</i> event, on the Lived Experience of AHC and Environmental Triggers.	A,B,C,D,E
June 23	Post AHC 10-year event tasks continue	A,B,C,D,E
July 23	Post AHC 10-year event tasks continue Discussions about supporting an upcoming research project based in France investigating the use of oxygen as a treatment begin. We engaged with this via email and virtual meetings. Promotion of the ATP1A3 conference 2023 to families in the UK	A,B,C,D,E
August 23	Post AHC 10-year event tasks continue Ongoing discussions with European organisations about how to best support research Promotion of the international ATP1A3 conference 2023 to families in the UK Host the AHC Sleep research information virtual question and answer event with Dr Simona Balestrini for families	A,B,C,D,E

¹ Objectives listed on page 2

September 23	Post AHC 10-year event tasks continue. Promotion of the ATP1A3 conference 2023 to families in the UK Discussions with Cure AHC in the USA about financial support for the international ATP1A3 conference in October 2023.	A,B,C,D,E
October 23	Post AHC 10-year event tasks continue Online meetings with European organisations about supporting research Promotion of the international ATP1A3 conference to families in the UK Committee members attended the international ATP1A3 conference online to keep up to speed with the latest research. . This was fed back to the AHC UK committee and trustees.	A,B,C,D,E
November 23	Post AHC 10-year event tasks continue	A,B,C,D,E
December 23	Post AHC 10-year event tasks continue AHC UK Charity Annual General Meeting (AGM) online and AHC UK Festive virtual Pub Quiz fundraiser	A,B,C,D,E
January 24	Working with European organisations to promote AHC Day (18 th January). Online and social media. AHC UK host CHat/share event online – including raising awareness of topics relevant to AHC in an A-Z of AHC by one of our trustees and committee members. Post AHC 10-year event tasks continue Confirmation of our financial support for a research project based in France investigating oxygen in AHC and supported by the European AHC organisations.	A,B,C,D,E
February 24	Post AHC 10-year event tasks continue Rare Disease Day virtual Pub Quiz fundraiser Katherine Behl attended the international group led by Professor Sanjay Sisodiya working to produce an article for the journal, <i>Nature</i> .(published early 2025). Katherine Behl will be a co-author on this paper.	A,B,C,D,E
March 24	Submission of our Annual Report and Accounts for 2022-2023 Katherine Behl presented on Lived Experience of AHC and temperature variations for section on Climate Change to the Journal <i>Nature</i> . This was later changed to a Personal Opinion Piece (published in 2024).	A,B,C,D,E

April 24	Ongoing strategic work Post AHC 10-year event tasks continue Discussions with Professor Sanjay Sisodiya led to AHC UK as collaborators on a joint research grant for climate change and epilepsy.	A,B,C,D,E
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Achievements and Performance

Following on from the large events undertaken in 2022-2023, the last year has been a year for smaller pieces of work and ongoing work associated with researchers in the UK.

We continue to provide online contact for families and carers through our social media presence. A particular success over January and February 2024 was the A-Z of AHC.

We have had families approach us with difficult circumstances unable to access expertise in AHC professionally. We have supported them. This has included giving them links to publications, information sheets about AHC. It has also included giving them information on expert clinicians for AHC in the UK for children and separately for adults. It has also included giving them support to ask their local teams for referrals to this experts and outlined their rights to do this under the UK Rare disease Framework.

Katherine Behl, as research liaison and later chair of AHC UK, has undertaken a number of meetings with AHC UK researchers and our medical advisors virtually or by email discussion. This included work with Dr Simona Balestrini regarding the sleep questionnaire in AHC, and separately a number of meetings with Professor Sanjay Sisodiya (one of our medical advisors) which led to developments later in 2024 including published papers (this will be outlined in next years report) and submission for a research grant.

We have worked with a number of charities and AHC organisations around the work to increase our understanding of the research taking place. We have been able to get involved in supporting a number of projects including financial support.

Over the year, we have had numerous donations through Amazon, Just Giving, Ebay and through the details on our website. It is clear that those who support

our charity are active and we look forward to hearing more from them about the events and activities they are involved in.

International Work

AHC UK rep is a member of AHCFE (this has since been renamed AHC Europe) - additionally- Katherine Behl was president of AHC Europe until December 2023 and Abhishek Behl remains on the executive board of AHC Europe

Katherine Behl continues to join multiple international meetings on research to discuss projects and collaboration as AHC International Alliance (AHCIA) no longer exists.

Katherine Behl has been invited to attend Cure AHC USA meetings on their Executive board for cross-collaboration.

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

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

AHC UK Charity Performance

AHC UK led on and hosted the AHC and ATP1A3 10-year anniversary conference and 10th Symposium on ATP1A3 in disease in October 2022. There are ongoing pieces of work associated with this including research publications. These publications have been contributed to by members of AHC UK and accepted for publication at the time of writing this report.

Continued to support families online

Promotion of the Sleep Questionnaire for AHC UK Researchers. This was supplemented by the hosting of an online question and answer event with the research to support families understanding of the project.

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

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.

Emails/Newsletters

Activity on social media platforms

Closed groups on social media for supporting families

Ongoing contact with AHC organisations internationally to share information and support research and engagement

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

Future:

Ongoing work to complete the reports required for the AHC and ATP1A3 10-year anniversary conference and 10th Symposium on ATP1A3 in disease. This includes research papers.

We are looking forward to further financial support in research including international studies and UK based studies.

Public Benefit

The Trustees have had regard to the Charity Commission's Guidance on Public Benefit.

Benefit

With regards to the benefit that AHC UK provides, this is inherent in our work with families, researchers and clinicians. In raising the profile of this ultra-rare condition, we increase awareness. It is through this, that we are able to highlight the need for research, education and support for individuals and families affected.

Public Benefit

Whilst AHC UK highlights the challenges faced by those diagnosed with the conditions, their families and carers it also seeks to provide wider benefit to the public through the engagement with clinicians and medical professionals as well as researchers. Public benefit is through the advancement of medical research for AHC and other associated conditions. These lead to the advancement of research approaches and techniques to benefit the wider public.

In addition to this, through engaging with other rare disease charities, we seek to improve public awareness of AHC and similar rare and ultra-rare conditions. In doing so, we support improving understanding of the impact of these conditions within communities.

Review and Sign Off

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



Katherine Behl (AHC UK) (Fri, 28th Feb 2025
8:55:31 GMT)

Katherine Behl

Chair

/02/2025

28 Feb 2025



Lyndsey Chand (AHC UK) (Thu, 27th Feb 2025
22:00:00 GMT)

Lyndsey Chand

Secretary

/02/2025

27 Feb 2025



Jo (AHC UK) (Thu, 27th Feb 2025 16:50:06
GMT)

Jo Brown

Treasurer

/02/2025

27 Feb 2025



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
Alternating Hemiplegia of Childhood UK

No (if any)
1192701

CC16a

Receipts and payments accounts

For the period from	Period start date	To	Period end date
	01/05/2023		30/04/2024

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year total funds to the nearest £
A1 Receipts					
Donations	3,253	-	-	3,253	70,876
Grants	-	4,985	-	4,985	42,641
Event income	-	-	-	-	9,284
Interest	154	-	-	154	89
Fundraising	340	-	-	340	250
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	3,747	4,985	-	8,732	123,140
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	3,747	4,985	-	8,732	123,140
A3 Payments					
Direct conference costs	-	-	-	-	38,112
Grants paid in relation to conference	-	2,000	-	2,000	1,395
Printing	-	-	-	-	820
Foreign charges	-	181	-	181	67
Professional fees	50	-	-	50	50
Travel costs	-	1,252	-	1,252	4,202
Insurance	-	-	-	-	622
Bank fees	60	-	-	60	243
Refunds	-	7,943	-	7,943	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	110	11,376	-	11,486	45,511
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	110	11,376	-	11,486	45,511
Net of receipts/(payments)	3,637	- 6,391	-	- 2,754	77,629
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	71,097	6,532	-	77,629	-
Cash funds this year end	74,734	141	-	74,875	77,629

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Bank balance	74,734	141	-
				-
		-	-	-
	Total cash funds	74,734	141	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

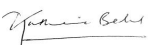
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Refunds in relation to conference costs	Restricted	3,711	
	Grant income to be repaid to funders	Restricted	3,349	
	Accountancy fees	Unrestricted	3,600	
	Refunds to Trustees	Unrestricted	1,175	
	Grants payable	Unrestricted	4,269	

Trustee expenses

During the period ended 30 April 2024, no expenses were reimbursed to Trustees (2023: £2,521 to 2 Trustees in relation to conference costs). As at 30 April 2024, £4,559 (2023: £3,384) is included in liabilities owing to 2 (2023: 1) Trustees).

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Katherine Behl	28 Feb 2025
 (Fri, 28th Feb 2025)	Lyndsey Chand	27 Feb 2025
 JK) (Thu, 27th Feb	Jo Brown	27 Feb 2025

Jo (AHC UK) (Thu, 27th Feb 2025 16:50:06 GMT)