



# Alternating Hemiplegia of Childhood UK (AHC UK)

## April 2022 – April 2023

**Charity Registration Number:** 1192701

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

**Current Trustees:**

Chair: Katherine Behl [acting chair]

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:**

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 8<sup>th</sup> 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 2023

Following our bank account's establishment in March 2022, we received funds from the AHC Parents Support Group. This group was the predecessor of AHC UK and we continue to be in awe of the work they did in supporting families across the UK and are grateful for the agreed transfer of funds to AHC UK. These monies represented the fundraising work that has been done over the years and we will see continue.

Our work continued with plans to host the AHC and ATP1A3 10-year anniversary conference and 10<sup>th</sup> Symposium on ATP1A3 in disease in October 2022. As the event was hosted in the UK, we were financially responsible for delivering the event and worked with AHC charities round the world to ensure that the event was accessible for families and carers. Significant work was done alongside AHC charities around Europe in applying for, and successfully being awarded, a grant to host this from the European Joint Programme for Rare Diseases (EJPRD). Pledges were made from AHC charities around the world to ensure that the event was a success. Money from these pledges that was not used was returned to these charities for their use. Completion of the grant report has been submitted and accepted. The final written parts from the event are being completed and the final funding for the event will go towards these being open access for families, researchers, clinicians and supporters.

At the end of the year, 2022, we received a significant donation from work done by one of our committee members and their family. Again, we are grateful for the incredible work done by family and friends who are offer their time and efforts to raise money for the charity.

Other work this year has seen the establishment of AHC UK as being a charity you can donate to through Facebook, JustGiving and Ebay.

## Financial Summary 2022-2023

|                          |          |                         |         |
|--------------------------|----------|-------------------------|---------|
| <b>Total Income</b>      | £123,140 | <b>Year end balance</b> | £77,629 |
| <b>Total Expenditure</b> | £45,511  | <b>Restricted funds</b> | £6,532  |

## Reserves Policy

At the current time, AHC UK does not have an operational Reserves Policy. This is something that the Trustees will be addressing across the next financial year.

## Other Assets

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

## Objectives and Activities: 2022 -2023

| Month            | Activities                                                                                                                                                                                                                                                               | Objectives <sup>1</sup> |
|------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------|
| <b>April</b>     | Planning for AHC 10-year event <ul style="list-style-type: none"> <li>• Confirmation of support from ATP1A3 Committee</li> <li>• Grant award from EJPRD</li> <li>• Planning with European Organisations</li> </ul>                                                       | <b>A,B,C,D,E</b>        |
| <b>May</b>       | Planning for AHC 10-year event <ul style="list-style-type: none"> <li>• Liaison with researchers UK and worldwide</li> <li>• Development of programme</li> <li>• Working with AHC organisations</li> </ul>                                                               | <b>A,B,C,D,E</b>        |
| <b>June</b>      | Newsletter published<br>Setting up of grants for researchers and clinicians to attend conferences<br>Planning for AHC 10-year event <ul style="list-style-type: none"> <li>• Ensuring family bookings are available</li> <li>• Planning accommodation options</li> </ul> | <b>A,B,C,D,E</b>        |
| <b>July</b>      | Donation from AHC Family Support Group<br>Planning for AHC 10-year event <ul style="list-style-type: none"> <li>• Publicity drive for supporting families to attend event</li> <li>• Working with worldwide organisations</li> </ul>                                     | <b>A,B,C,D,E</b>        |
| <b>August</b>    | Planning for AHC 10-year event <ul style="list-style-type: none"> <li>• Ensuring family contribution to the event</li> <li>• Setting up of questionnaires for all to contribute to event discussions</li> </ul>                                                          | <b>A,B,C,D,E</b>        |
| <b>September</b> | Planning for AHC 10-year event <ul style="list-style-type: none"> <li>• Ensuring that families who have lost someone with AHC are remembered at the event. Liaising with families across the world for this.</li> </ul>                                                  | <b>A,B,C,D,E</b>        |
| <b>October</b>   | AHC 10-year event takes place in Edinburgh <ul style="list-style-type: none"> <li>• Three day hybrid event</li> <li>• Conference dinner</li> <li>• Included AHC UK family meeting</li> </ul>                                                                             | <b>A,B,C,D,E</b>        |
| <b>November</b>  | Post AHC 10-year event tasks <ul style="list-style-type: none"> <li>• Written reports for EJPRD</li> <li>• Working with researchers to prepare papers</li> </ul>                                                                                                         | <b>A,B,C,D,E</b>        |

<sup>1</sup> Objectives listed on page 2

|                 |                                                                                                                                                                                                                                                                                                                                              |                  |
|-----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| <b>December</b> | Post AHC 10-year event tasks continue <ul style="list-style-type: none"> <li>• Written reports for EJPRD</li> <li>• Working with researchers to prepare papers</li> </ul>                                                                                                                                                                    | <b>A,B,C,D,E</b> |
| <b>January</b>  | Working with European organisations to promote AHC Day (18 <sup>th</sup> January). Online and social media<br>Post AHC 10-year event tasks continue                                                                                                                                                                                          | <b>A,B,C,D,E</b> |
| <b>February</b> | Post AHC 10-year event tasks continue<br>Submission of completed conference report to EJPRD<br>Rare Disease Day Pub Quiz                                                                                                                                                                                                                     | <b>A,B,C,D,E</b> |
| <b>March</b>    | Post AHC 10-year event tasks continue<br>Feedback to AHC organisations round the world and support for those considering applying to host<br>Publication: <i>Rare. The Importance of research, analysis, reporting and education in 'solving' the genetic epilepsies: A perspective from the European patient advocacy group for EpiCARE</i> | <b>A,B,C,D,E</b> |
| <b>April</b>    | Post AHC 10-year event tasks continue<br>Feedback to AHC organisations round the world and support for those considering applying to host                                                                                                                                                                                                    | <b>A,B,C,D,E</b> |

## Achievements and Performance

Throughout the year, we have been planning, hosting and completing the work on the AHC and ATP1A3 10-year anniversary conference and 10<sup>th</sup> Symposium on ATP1A3 in disease. This met all of our charitable objectives: a, b, c, d and e.

This is referenced in the above table as the *AHC 10-year event*.

As a small charity, this has been the most significant piece of work we have undertaken this year (2022-2023)

## Publications

In March 2023, the article “Rare. The Importance of research, analysis, reporting and education in ‘solving’ the genetic epilepsies: A perspective from the European patient advocacy group for EpiCARE” was published in *European Journal of Medical Genetics*, Volume 66(3). One of our AHC UK Trustees was part of the writing of this paper and involved in the editing of the final article.

## 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 – 2022/2023

*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 10<sup>th</sup> Symposium on ATP1A3 in disease in October 2022. There are ongoing pieces of work associated with this including research publications.

Continued to support families online

Promotion of the Sleep Questionnaire for AHC UK Researchers

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 10<sup>th</sup> Symposium on ATP1A3 in disease. This includes research and Grant reports.

# 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) (Feb 29, 2024,  
3:21pm)

**Katherine Behl**

**Acting Chair**

**And Vice Chair**

**29/02/2024**



Lyndsey Chand (AHC UK) (Feb 29, 2024,  
5:47pm)

**Lyndsey Chand**

**Secretary**

**29/02/2024**



Johanna Brown (AHC UK) (Feb 29, 2024,  
6:04pm)

**Jo Brown**

**Treasurer**

**29/02/2024**



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
Alternating Hemiplegia of Childhood UK

No (if any)  
1192701

## Receipts and payments accounts

CC16a

For the period  
from

Period start date  
06/04/2022

To

Period end date  
30/04/2023

### Section A Receipts and payments

|                                                       | Unrestricted funds | Restricted funds | Endowment funds  | Total funds      | Last year        |
|-------------------------------------------------------|--------------------|------------------|------------------|------------------|------------------|
|                                                       | to the nearest £   | to the nearest £ | to the nearest £ | to the nearest £ | to the nearest £ |
| <b>A1 Receipts</b>                                    |                    |                  |                  |                  |                  |
| Donations                                             | 70,876             | -                | -                | 70,876           | -                |
| Grants                                                | -                  | 42,641           | -                | 42,641           | -                |
| Event income                                          | -                  | 9,284            | -                | 9,284            | -                |
| Interest                                              | 89                 | -                | -                | 89               | -                |
| Fundraising                                           | 250                | -                | -                | 250              | -                |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
| <b>Sub total (Gross income for AR)</b>                | <b>71,215</b>      | <b>51,925</b>    | <b>-</b>         | <b>123,140</b>   | <b>-</b>         |
| <b>A2 Asset and investment sales, (see table).</b>    |                    |                  |                  |                  |                  |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
| <b>Sub total</b>                                      | <b>-</b>           | <b>-</b>         | <b>-</b>         | <b>-</b>         | <b>-</b>         |
| <b>Total receipts</b>                                 | <b>71,215</b>      | <b>51,925</b>    | <b>-</b>         | <b>123,140</b>   | <b>-</b>         |
| <b>A3 Payments</b>                                    |                    |                  |                  |                  |                  |
| Direct conference costs                               | -                  | 38,112           | -                | 38,112           | -                |
| Grants paid in relation to conference                 | -                  | 1,395            | -                | 1,395            | -                |
| Printing                                              | -                  | 820              | -                | 820              | -                |
| Foreign charges                                       | -                  | 67               | -                | 67               | -                |
| Professional fees                                     | 50                 | -                | -                | 50               | -                |
| Travel costs                                          | -                  | 4,202            | -                | 4,202            | -                |
| Insurance                                             | -                  | 622              | -                | 622              | -                |
| Bank fees                                             | 68                 | 175              | -                | 243              | -                |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
| <b>Sub total</b>                                      | <b>118</b>         | <b>45,393</b>    | <b>-</b>         | <b>45,511</b>    | <b>-</b>         |
| <b>A4 Asset and investment purchases, (see table)</b> |                    |                  |                  |                  |                  |
|                                                       | -                  | -                | -                | -                | -                |
|                                                       | -                  | -                | -                | -                | -                |
| <b>Sub total</b>                                      | <b>-</b>           | <b>-</b>         | <b>-</b>         | <b>-</b>         | <b>-</b>         |
| <b>Total payments</b>                                 | <b>118</b>         | <b>45,393</b>    | <b>-</b>         | <b>45,511</b>    | <b>-</b>         |
| <b>Net of receipts/(payments)</b>                     | <b>71,097</b>      | <b>6,532</b>     | <b>-</b>         | <b>77,629</b>    | <b>-</b>         |
| <b>A5 Transfers between funds</b>                     | <b>-</b>           | <b>-</b>         | <b>-</b>         | <b>-</b>         | <b>-</b>         |
| <b>A6 Cash funds last year end</b>                    | <b>-</b>           | <b>-</b>         | <b>-</b>         | <b>-</b>         | <b>-</b>         |
| <b>Cash funds this year end</b>                       | <b>71,097</b>      | <b>6,532</b>     | <b>-</b>         | <b>77,629</b>    | <b>-</b>         |

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

| Categories    | Details                                                | Unrestricted funds<br>to nearest £ | Restricted funds<br>to nearest £ | Endowment funds<br>to nearest £ |
|---------------|--------------------------------------------------------|------------------------------------|----------------------------------|---------------------------------|
| B1 Cash funds | Bank balance                                           | 71,097                             | 6,532                            | -                               |
|               |                                                        |                                    |                                  | -                               |
|               |                                                        | -                                  | -                                | -                               |
|               | <b>Total cash funds</b>                                | <b>71,097</b>                      | <b>6,532</b>                     | <b>-</b>                        |
|               | (agree balances with receipts and payments account(s)) | OK                                 | OK                               | OK                              |

|                          | Details        | Unrestricted funds<br>to nearest £ | Restricted funds<br>to nearest £ | Endowment funds<br>to nearest £ |
|--------------------------|----------------|------------------------------------|----------------------------------|---------------------------------|
| B2 Other monetary assets | Accrued income | -                                  | 4,985                            | -                               |
|                          |                | -                                  | -                                | -                               |
|                          |                | -                                  | -                                | -                               |
|                          |                | -                                  | -                                | -                               |
|                          |                | -                                  | -                                | -                               |
|                          |                | -                                  | -                                | -                               |

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

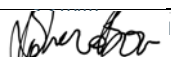
|                                              | Details | Fund to which asset belongs | Cost (optional) | Current value (optional) |
|----------------------------------------------|---------|-----------------------------|-----------------|--------------------------|
| B4 Assets retained for the charity's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

|                | Details                                 | Fund to which liability relates | Amount due (optional) | When due (optional) |
|----------------|-----------------------------------------|---------------------------------|-----------------------|---------------------|
| B5 Liabilities | Refunds in relation to conference costs | Restricted                      | 4,963                 |                     |
|                | Grant income to be repaid to funders    | Restricted                      | 10,801                |                     |
|                | Accountancy fee                         | Unrestricted                    | 1,920                 |                     |
|                |                                         |                                 | -                     |                     |
|                |                                         |                                 | -                     |                     |

### Trustee expenses

During the period ended 30 April 2023, expenses totalling £2,521 were reimbursed directly to 2 Trustees (2022: £nil). All expenditure reimbursed was in relation to conference costs.

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

| Signature                                                                           | Print Name     | Date of approval |
|-------------------------------------------------------------------------------------|----------------|------------------|
|  | Katherine Behl | 29 Feb 2024      |
|  | Lyndsey Chand  | 29 Feb 2024      |
|  | Jo Brown       | 29 Feb 2024      |

**ALTERNATING HEMIPLEGIA OF CHILDHOOD UK  
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF ALTERNATING HEMIPLEGIA OF CHILDHOOD UK  
FOR THE PERIOD ENDED 30 APRIL 2023**

I report to the charity trustees on my examination of the accounts of the charity for the period ended 30 April 2023 which are set out on pages 1 to 15.

**Responsibilities and basis of report**

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

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

**Independent examiner's statement**

I have completed my examination. I confirm that no material 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 Act; or
2. the accounts do not accord with those records.

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 accounts to be reached.



**Suzanne Goldsmith FCA  
Price Bailey LLP, Chartered Accountants**

Anglia House, 6 Central Avenue  
St Andrews Business Park  
Thorpe St Andrew  
Norwich, Norfolk  
NR7 0HR

Date: 1 Mar 2024