

aHUS alliance Global Action Financial Report for the year ending 31 December 2016

Income and Expenditure Report for year ending 31 December 2016

| Income | Unrestricted funds | Restricted Funds | Other Funds | Total Funds | Last Year | Variance |
|------------------|---------------------------|-------------------------|--------------------|--------------------|------------------|-----------------|
| Donations | 15000.00 | - | - | 15,000.00 | 0.00 | 15000.00 |
| Grants | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Fundraising | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Other | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Sub Total | 15000.00 | 0.00 | 0.00 | 15.000.00 | 0.00 | 15000.00 |

| | | | | | | |
|-----------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|
| Total Receipts | 15000.00 | 0.00 | 0.00 | 15000.00 | 0.00 | 15000.00 |
|-----------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|

| Expenditure | | | | | | |
|---------------------|-------------|----------|----------|-------------|-------------|-------------|
| Management meetings | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Website | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Travelling | 0.00 | | | 0.00 | 0.00 | 0.00 |
| Equipment | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Sub Total | 0.00 | - | - | 0.00 | 0.00 | 0.00 |

| | | | | | | |
|-----------------------|-------------|----------|----------|-------------|-------------|-------------|
| Total Payments | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
|-----------------------|-------------|----------|----------|-------------|-------------|-------------|

| | | | | | | |
|------------------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|
| Net Receipts/Payments | 15000.00 | 0.00 | 0.00 | 15000.00 | 0.00 | 15000.00 |
|------------------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|

Cash Flow and Balance Statement as at 31 December 2016

| | Cash | Total |
|------------------------------------|-----------------|-----------------|
| Opening balance | 0.00 | 0.00 |
| Receipts | 15000.00 | 15000.00 |
| Transfers | 0.00 | 0.00 |
| Balance at 31 December 2016 | 15000.00 | 15000.00 |

Note: As the income of the aHUS alliance in the year was less than £25,000, no independent examination is needed

Annual Report

Trustees Annual Report for the period 28 June 2016 to 31 December 2016

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No 1167904). It held its Inaugural General Meeting on 11 July 2017 by Skype.

Governing Document

The aHUS alliance 's governing document is the Foundation Model for Incorporated Charitable Organisations and under its constitution clause 15 (3)(a) a quorum for a general meeting is 2 trustees entitled to vote. 3 trustees were in attendance for the Inaugural General Meeting.

Objects

aHUS alliance Global Action's objects are to:

- promote the relief and support of persons affected by aHUS,
- advance the education of the public and the medical profession about aHUS.

Note: atypical Haemolytic Uremic Syndrome (aHUS) is an ultra-rare disease affecting about 15000 to 40000 people globally. It is serious, progressive, debilitating, life-threatening and incurable. Largely genetic in origin, it can affect people at any age. Caused by unregulated activity in the normally well-controlled complement system, if unchecked the disease causes kidney and other organ failure.

The aHUS alliance Global Action ("alliance") existed for three months as an informal organisation until it was registered as an Incorporated Charitable Organisation in England & Wales on 28 June 2016. It exists to support the collaborative work of the aHUS alliance. The aHUS alliance has existed as an informal organisation of international aHUS patient organisations since Rare Disease Day (28 February) 2013. The aHUS alliance Global Action has 3 Trustees and is run entirely by volunteers.

Complementing the objects above its operational objectives are to:

- promote global awareness of aHUS
- work with International aHUS researchers
- support newly emerging national aHUS patient groups

by connecting, informing and collaborating with interested groups.

Trustees in post in the period 28 June 2016 to 31 December 2016.

| | |
|------------------------------|--------------|
| Trustee/ Director/ Secretary | Linda Burke |
| Trustee /Director/Treasurer | Len Woodward |
| Trustee/ Director/Chair | Kamal D Shah |

As no Trustee had completed their term of office, and no letters of resignations nor nominations for new Trustees been received, the Board of Trustees remained unchanged.

Activity in the period 28 June 2016 to 31 December 2016

aHUS Awareness Day

The alliance held the second aHUS Awareness Day on 24 September 2016 with the theme “rising above aHUS”. A common logo of a red balloon was used in graphics displayed on aHUS websites and throughout the social media. The alliance promoted a video by an alliance affiliate on YouTube to help raise awareness. A higher level of participation and reach was achieved compared to the first aHUS Awareness Day in 2015.

Website

The website www.ahusallianceaction.org had been created to support the 2016 aHUS Global Poll. It is the alliance’s main communication channel with the aHUS community and is linked to the social media. By the end of the year over 9000 views of the website content had been recorded.

aHUS Global Poll 2016

The second global poll of aHUS patients and families had produced an increased response from more countries, 233 respondents and 23 countries respectively. Several discussion papers have been written about results and posted on the website. In June, a Global Webinar was held in partnership with

EURORDIS Rare Connect and included a guest speaker Dr Christoph Licht of the Children's Hospital in Toronto, Canada.

KDIGO Consensus Conference on aHUS /C3/DDD

In November the KDIGO consensus report, to which the alliance had contributed in 2015, was published.

aHUS Registry

The alliance has been in a partnership with the aHUS Registry (US National Institutes of Health ClinicalTrials.gov Identifier: NCT01522183) since February 2015. It provides a patient representative on the Registry's Scientific Advisory Board. The work that the alliance undertook to set out the aHUS research priorities from a patient perspective was incorporated into a manuscript written by the SAB and published in the Orphanet Journal of Rare Diseases in November 2016.

United Nations NGO for Rare Diseases

Also, in November the alliance was represented by affiliate atypical HUS India's Kamal Shah in an address by video to the inaugural meeting of the United Nations' NGO for Rare Diseases.

IOWA aHUS Conference

alliance affiliated organisations from USA, Canada, Japan and The Netherlands attended the biennial aHUS conference at the University of Iowa in November.

Commentary on the accounts for the period 28 June 2016 to 31 December 2016 (see Annex A)

Treasurers Report

There is little to report on the financial performance for the aHUS alliance Global Action operations since it was given Charitable Incorporated Status on 28 June 2016.

A donation of £15,000 was received from aHUSUK on its dissolution in October 2016, and it is held by Kidney Research UK pending the setting up of the alliance's own bank account.

The sum received is regarded as sufficient for the first two years of alliance operations, excluding major projects.

It was estimated that 1000 hours of unpaid voluntary time was donated by Trustees in the period.

As the income of the alliance in the year was less than £25,000, no independent examination is needed.

Serious Incidents in the year.

There were no serious incidents in the year.

Linda Burke

Secretary

28 June 2017

Annex A

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| Fundraising | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Other | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Sub Total | 15000.00 | 0.00 | 0.00 | 15.000.00 | 0.00 | 15000.00 |

| | | | | | | |
|-----------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|
| Total Receipts | 15000.00 | 0.00 | 0.00 | 15000.00 | 0.00 | 15000.00 |
|-----------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|

| | | | | | | |
|---------------------|-------------|----------|----------|-------------|-------------|-------------|
| Expenditure | | | | | | |
| Management meetings | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Website | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Travelling | 0.00 | | | 0.00 | 0.00 | 0.00 |
| Equipment | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
| Sub Total | 0.00 | - | - | 0.00 | 0.00 | 0.00 |

| | | | | | | |
|-----------------------|-------------|----------|----------|-------------|-------------|-------------|
| Total Payments | 0.00 | - | - | 0.00 | 0.00 | 0.00 |
|-----------------------|-------------|----------|----------|-------------|-------------|-------------|

| | | | | | | |
|------------------------------|-----------------|-------------|-------------|-----------------|-------------|-----------------|
| Net Receipts/Payments | 15000.00 | 0.00 | 0.00 | 15000.00 | 0.00 | 15000.00 |
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