

Annual Report

Trustees Annual Report for the period 1 January 2022 to 31 December 2023

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No 1167904). It held its Eighth Annual General Meeting on 18 March 2024

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 two trustees entitled to vote. Four Trustees were in attendance for the Annual 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 16,000 to 40,000 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 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 4 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 1 January 2023 to 31 December 2023.

Trustee/ Director/Chair	Kamal Shah
Trustee/Director/Treasurer	Len Woodward
Trustee/ Director/ Secretary	Linda Burke
Trustee/ Director	Kerri Mariani

Kamal Shah had completed his term of office and had formally expressed his willingness to continue to serve for two more years. He was duly re-elected to the Board of Trustees. No nominations for new Trustees have been received. The Board of Trustees remained unchanged.

Activity in the period 1 January 2023 to 31 December 2023

aHUS Conferences

aHUS alliance Global Action was invited to participate in an aHUS patients conference organised by the USTMA Consortium on 30 September/2 October 2023 in Raleigh, North Carolina. Director Linda Burke created a video presentation which covered aHUS patient advocacy and the disease.

aHUS alliance research

Global Action was approached by SciFiMed to provide an aHUS patients' perspective for its study of Complement. This EU Horizon 2020 funded project aims to study the Factor H family of proteins in Complement to find a blood test which may be of diagnostic, prognostic and familial screening value for aHUS patients. Global Action was able to provide information to support the project aims.

The opportunity of the Rare Disease Day 2023 video about adverse events reported by aHUS patients permitted a study of not only what adverse events patients reported but also their attribution of them to treatment side effect or sequelae from the acute episode of aHUS. The report was published on the website. [RDD23 VIDEO - RESULTS REPORT - aHUS Alliance Action](#)

aHUS Awareness Day

Awareness Day continued to be a focal point for the year. An aHUS awareness video was produced with the theme “ Capabilities and possibilities”. A report on what patients said was published on the website [What are aHUS people capable of? - aHUS Alliance Action](#)

Meningococcal Infection Awareness

Meningococcal infection is a significant side effect of the treatment of aHUS by a complement inhibitor. This year Global Action participated in World Meningitis Day to raise awareness of this serious illness and added a warning message on its home page.

“WARNING: Serious Meningococcal infection can happen in patients treated with complement inhibitors. Follow precautions and be vigilant. Keep up to date with vaccinations and boosters. Be vigilant and act quickly on possible symptoms.”

FDA Patient Listening Session

Global Action joined a partnership of USA aHUS advocacy groups, the USA aHUS Patient Advisory Partnership, to host a listening session with employees of the US Food & Drug Agency about aHUS. The hour and half long meeting covered the disease and what having, and living with it, was like and what FDA related issues mattered to aHUS patients. A copy of the Report of the meeting can be read FDA's website. [aTYPICAL HEMOLYTIC UREMIC SYNDROME \(aHUS\) 01102024 \(fda.gov\)](https://www.fda.gov/oc/ohrt/aHUS-01102024)

aHUS Name Change

aHUS alliance Global Action was approached by the leadership of the aHUS Name Change Project Group to comment on its proposals for name changes. Global Action was grateful to contribute its feedback and awaits further progress in 2024.

Social Media

Our social media presence continued outreach regarding aHUS information and awareness in 2023, seeing steady growth across multiple platforms.

X (formerly Twitter) continued to be an avenue for those in medical and research fields, with marked interest from people and groups on the topics of thrombotic microangiopathy and complement. New followers of our main Twitter account @aHUSallianceAct include BioWorld (news source, with 38.9K followers) and Robert Brodsky (2023 President ASH and Chief of Hematology Johns Hopkins) . While this main Twitter account has grown to 933 followers, our aHUS Awareness Day account at @aHUS24Sept also grew and continued to provide articles, images, and resources for the 24 September awareness campaign. Both continue to be quite active accounts since they were initiated with our 24 Sept account, created Sept 2015, newly reaching a milestone with 404 followers.

Our Instagram and LinkedIn accounts were established more recently, but the former provides outreach to patients and the

public while the latter is more business or industry focused. The alliance would like to see these new social media forums gain as much traction as our Facebook page, now at more than 3.1K followers. Progress with outreach is encouraging, as our LinkedIn network grew to over 200 connections, and with our 1,018 posts on Instagram expanded to 194 followers.

Website

The website www.ahusallianceaction.org continues to be the alliance's main communication channel with the aHUS community and is linked to the social media. During 2023 there were 45462 views of the website recorded, which is an increase of 4887 (12%) over 2022.

Commentary on the accounts for the period 1 January 2023 to 31 December 2023 (see Annex A)

The aHUS community has once again been generous by donating to the charity via our PayPal Giving Account. This year over £1100 has been donated by supporters. Trustees have also contributed to other income to defray some of the costs they incurred and build resources for future work.

Maintaining the website and related social media platforms ,including Zoom, incurred the highest cost. Traveling costs to attend meetings and conferences were the next highest expenses along with Bank Fees. Costs of promotional materials and printing of handouts were incurred at the conferences,

Trustees and volunteers have donated over 2000 unpaid hours in 2023 to maintain the operational work of the alliance and work on its research projects.

At the current level of activity, the Trustees are confident that reserves are held for more than two years of operating.

As the charity's income was less than £25,000 an independent examination is not required.

Serious Incidents in the year.

There were no serious incidents in the year.

Linda Burke

Secretary

Annex A

aHUS alliance Global Action Financial Report for the year ending 31 December 2023.

Income and Expenditure Report for year ending 31 December 2023.

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	1131.17	0.00	0.00	1131.17	3611.97	
Grants	0.00	0.00	0.00	0.00	0.00	
Fundraising	0.00	0.00	0.00	0.00	0.00	
Other	4610.28	0.00	0.00	4610.28	9.19	
Sub Total	5741.55	0.00	0.00	5741.55	3621.16	

Total Receipts	5741.55	0.00	0.00	5741.55	3621.16	
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Expenditure						
Management meetings	0.00	0.00	0.00	0.00	182.31	
Website	652.43	0.00	0.00	652.43	358.60	
Travelling	517.37	0.00	0.00	517.37	1766.61	
Promotional Materials	14.70	0.00	0.00	14.70	0.00	
Conference	66.00	0.00	0.00	66.00	0.00	
Printing & Postage	56.15	0.00	0.00	56.15	0.00	
Subsistence	0.00	0.00	0.00	0.00	0.00	
Bank Fees	56.15	0.00	0.00	56.15	83.00	
Sub Total	1385.40	0.00	0.00	1385.40	2390.52	

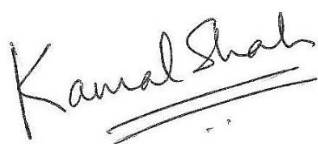
Total Payments	1385.40	0.00	0.00	1385.40	2390.52	
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Net Receipts/ (Payments)	4356.15	0.00	0.00	4356.15	1230.64	
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Cash Flow and Balance Statement as of 31 December 2023

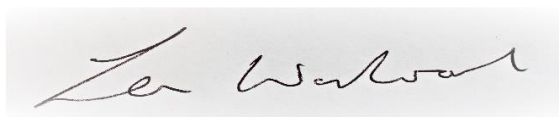
	PayPal	Cash	Bank	Total
Opening balance as at 1/1/2023	0.00	0.00	12402.35	12402.35
Transfers	0,00	139.51	-139.51	0.00
Receipts	164.38	0.00	5577.17	5741.55
Outgoings	0.00	0.00	1385.40	1385.40
Balance as of 31/12/2023	164.38	139.51	16454.61	16758.50

Approved and certified



Kamal D Shah

Chair



Len Woodward

Treasurer