

Annual Report

Trustees Annual Report for the period 1 January 2025 to 31 December 2025

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No. 1167904). It held its tenth Annual General Meeting on 5 March 2026.

Governing Document

The aHUS alliance Global Action'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. Three 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 three 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 2025 to 31 December 2025.

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

Linda Burke and Kerri Mariani had completed their term of office. Linda Burke expressed her willingness to continue to serve for two more years. Kerri Mariani did not seek re-election. Linda Burke was duly re-elected to the Board of Trustees. No nominations for new Trustees have been received. The Board of Trustees remained at three.

Activity in the period 1 January 2025 to 31 December 2025

aHUS alliance Global Action research

A repeat of the Global Poll about living with aHUS conducted in 2014 had been carried out in 2024. Work has continued in 2025 on the analysis the results of the Polls.

USTMA Consortium

Global Action's collaboration with the USTMA Consortium on a study of US aHUS patients' reported outcomes was concluded when an article was published in October 2025.

<https://pubmed.ncbi.nlm.nih.gov/41404419/>

Trustee Linda Burke represented our organisation and spoke at the Consortium's Patient Meeting in Raleigh , North Carolina, USA on 15-17 August 2025.

Stopping Eculizumab Treatment Safely (SETS)

Global Action's participation in the UK SETS clinical trial concluded with the publications of report articles about the trial outcome. Trustee Len Woodward was co-author on one of the reports.

[ISPOR - Is Protocolized Stopping Lifelong Therapy With Eculizumab With Disease Monitoring and Retreatment for Eligible Atypical Hemolytic Uremic Syndrome \(aHUS\) Patients Cost-Effective? An Economic Evaluation of the SETS aHUS Trial](#)

aHUS Awareness Day Video

Proposed by the aHUS alliance Rest of World's aHUS China, the theme of the 2025 aHUS Awareness Day video was about the "best decisions made to aid recovery from an episode of aHUS". An analysis of the replies by participants showed the following themes from the decisions reported:

1. Psychological adjustment
2. Treatment management
3. Self-caring
4. Altruism
5. Social support
6. Spiritual support

Complement Inhibitor Treatment Discontinuation: Patient Decision Aid

An "aHUS patient's treatment discontinuation model" was proposed by aHUS alliance Global Action in July 2024. A potential collaboration with Alexion on the use of such a patient decision aid was proposed in early 2025 had not materialised by the end of the year.

aHUS unmet treatment needs

Global Action was invited to the UK's "Rare Haematology & Blood Disease Patient Group and Industry Partnering Cohort kick off meeting" to be held in December (although later deferred to March 2026). Whilst "core aHUS" has and will have more treatments for the condition, there are sub sections within the broader disease category which have unmet treatment needs. The aim of the meeting is to interest one of the attending Pharmaceutical companies in researching and developing a solution for those patients.

aHUS Global Town

Global Action launched an initiative to boost reach and connection with more countries with aHUS patients. As the potential global patient population size would be typical for a "town" the *Global aHUS Town* name was assigned to the project. Starting with less than 60 countries in which there are known aHUS patients, the objective is to drive known connection up to over 100.

Social Media

In 2025 social media presence for the aHUS Alliance continued its outreach regarding aHUS information and awareness, seeing steady and organic growth across five accounts on four platforms. On X (formerly Twitter) original content posts occurred 3 to 5 times a week throughout 2025 on @aHUSallianceAct, with our @aHUS24Sept account activating to host aHUS Awareness Day information over two months prior to our annual 24 September campaign.

The @aHUS24Sept account on Twitter featured multiple posts daily, culminating with posts every 3 hours on aHUS Awareness Day itself. Followers of aHUS Alliance social media expanded all platforms outreach in 2025, for each of our five accounts: Twitter/X @aHUSallianceAct (1035 people/groups), Twitter/X @aHUS24Sept (440 people/groups), Facebook (3.3K people/groups), Instagram (342 people/groups), and LinkedIn (625 people/groups). Across platforms, we continued to see new involvement from physicians, researchers, medical organizations/societies, advocacy groups, and industry as well as people living with this rare disease.

Website

The website www.ahusallianceaction.org continues to be the alliance's main communication channel with the wider aHUS community and is linked to the social media. During 2025 there were 43862 views of the website recorded, which is a decrease of 1588 (3.5%) from 2024. A second successive annual reduction. Encouragingly, however, was the substantial growth of views from China, increasing by over 3000 on the level of Chinese views in 2024.

Our website's 'Virtual Library' of aHUS-specific research and journal articles added over 100 new publications on a variety of aHUS topics, separated into 20 categories for easy reference.

Commentary on the accounts for the period 1 January 2024 to 31 December 2024 (see Annex A)

The aHUS community has once again been generous by donating to the charity via our PayPal Giving Account. This year £2714 has been donated by supporters as well as trustees (by defraying some of the costs they incurred) and we continue to build funds for future work.

Again, maintaining the website and related social media platforms, incurred the highest cost. The cost of translating the 1955 Gasser et al article about the naming of HUS from German to English was next highest. Bank fees remain a small administration cost.

Trustees and volunteers have donated over 1500 unpaid hours in 2025 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 2025.

Income and Expenditure Report for year ending 31 December 2025.

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	2713.64	0.00	0.00	2713.64	1657.72	
Grants	0.00	0.00	0.00	0.00	0.00	
Fundraising	0.00	0.00	0.00	0.00	0.00	
Other	33.07	0.00	0.00	33.07	31.95	
Sub Total	2746.71	0.00	0.00	2746.71	1689.67	

Total Receipts	2746.71	0.00	0.00	2746.71	1689.67	
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Expenditure						
Management meetings	0.00	0.00	0.00	0.00	0.00	
Website	1026.63	0.00	0.00	1026.63	972.29	
Travelling	0.00	0.00	0.00	0.00	219.50	
Promotional Materials	0.00	0.00	0.00	0.00	0.00	
Conference	0.00	0.00	0.00	0.00	0.00	
Printing, translation & Postage	657.29	0.00	0.00	657.29	733.16	
Subsistence	0.00	0.00	0.00	0.00	0.00	
Bank Fees	73.50	0.00	0.00	73.50	61.50	
Sub Total	1757.42	0.00	0.00	1757.42	1986.45	

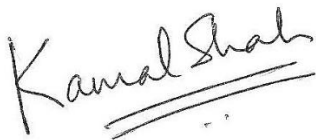
Total Payments	1757.42	0.00	0.00	1757.42	1986.45	
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Net Receipts/ (Payments)	989.29	0.00	0.00	989.29	(296.78)	
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Cash Flow and Balance Statement as of 31 December 2025

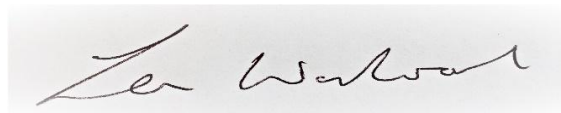
	PayPal	Cash	Bank	Total
Opening balance as at 1/1/2025	1070.02	0.00	15391.70	16461.72
Transfers	(2493.18)	0.00	2493.18	0.00
Receipts	1853.64	500.00	393.07	2746.71
Outgoings	0.00	500.00	1257.42	1757.42
Balance as of 31/12/2025	430.48	0.00	17020.53	17451.01

Approved and certified



Kamal D Shah

Chair



Len Woodward

Treasurer