

Annual Report

Trustees Annual Report for the period 1 January 2024 to 31 December 2024

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No. 1167904). It held its Ninth Annual General Meeting on 6 May 2025.

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. 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 four 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 2024 to 31 December 2024.

Trustee/ Director/Chair	Kamal Shah
Trustee/Director/Treasurer	Len Woodward

Trustee/ Director/ Secretary
Trustee/ Director

Linda Burke
Kerri Mariani

Len Woodward 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 2024 to 31 December 2024

aHUS alliance Global Action research

A repeat of the Global Poll conducted in 2014 was carried out in 2024. The aim was to see what change, if any, there was to the lived experience of the Global aHUS community after ten years. The Poll used the 2014 set of twenty-eight questions covering living with a rare disease, including genetics and diagnosis, availability of an expert centre, treatment, societal impact, research and registries, and information and support. The questions were translated into eleven languages. The Poll was open for participation from the 8 July until the 18 August and there were 296 consenting participants from 29 countries. The plan is to have the findings published in a journal in 2025.

aHUS Awareness Day Video

The theme for the aHUS Awareness Day video was mental health and aHUS. Forty-six aHUS patients/carers from 12 countries participated, and the resulting video was released on 24 September 2024. An analysis of what the video participants said was reported later and provided important insights of their lived experience. [Mental health aHUS Day video- insights - aHUS Alliance Action](#)

FDA Patient Listening Session

In 2023 aHUS alliance 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 (FDA) 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 was published in 2024 can be read on FDA's website. [aTYPICAL HEMOLYTIC UREMIC SYNDROME \(aHUS\) 01102024 \(fda.gov\)](#)

Conrad von Gasser's seminal HUSs article translation

aHUS alliance Global Action commissioned a translation of the article which described the disease hemolytic uremic syndromes for the first time. It was published in German on 20 September 1955, but it is no longer in print or online. A copy of Conrad von Gasser's original article was used for the English translation. Apart from the science, the names of the first

patients to be given an “HUSs” diagnosis are revealed. It was published on our website on 20 September 2024. [The first ever aHUS research study patient cohort - aHUS Alliance Action](#)

aHUS Name Change

The report of the findings of the working group examining the future nomenclature for aHUS and other thrombotic microangiopathies was published in Kidney International in September 2024. The report authors gratefully acknowledged the Trustee Directors of aHUS Alliance Global Action for their thoughtful feedback on the article. Further information about its implementation is still awaited.

Complement Inhibitor Treatment Discontinuation

An “aHUS patient’s treatment discontinuation model” was proposed by aHUS alliance Global Action in July 2024. Intended as a patient decision aid to help aHUS patients in a discussion with their doctors about potentially discontinuing complement inhibitor treatment. The model covers the factors for chances of a relapse and mitigating the risks of harm if it happened. Before the end of the year talks had taken place with a complement inhibitor manufacturer about its further use.

Social Media

aHUS alliance social media presence continued its outreach regarding aHUS information and awareness in 2024, seeing steady growth across five platforms.

On X (formerly Twitter) its total postings on *@aHUSallianceAct* exceeded 7800, with a further 1200 on its aHUS Awareness Day account *@aHUS24Sept*. Items were posted about aHUS research and medical updates through the year. Connection and visibility of the charity was also raised at major events, e.g. American Societies of Nephrology (ASN) and Hematology (ASH). During 2024 account followers reached 1000.

Other platforms including Facebook, Instagram and LinkedIn target different audiences with more than 3200, 300, and 575 followers respectively.

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 2024 there were 45045 views of the website recorded, which is a decrease of 417 (0.9%) over 2023. The website’s Research Database exceeded 1300 publications during the year. The virtual library of aHUS documents and information leaflets continued to grow with additional materials in the Portuguese language. A periodic website newsletter continues to be sent to subscribers. [Keeping aHUS connected - aHUS Alliance Action](#)

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 nearly £1000 has been donated by supporters. Trustees have also contributed to defray some of the costs they incurred and to build resources for future work.

Maintaining the website and related social media platforms, incurred the highest cost. Costs of translation of the Global Poll questionnaires were the next highest. The traveling cost incurred was to attend a meeting of Rare Renal. Bank fees remain an administration cost.

Trustees and volunteers have donated over 2000 unpaid hours in 2024 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 2024.

Income and Expenditure Report for year ending 31 December 2024.

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	1657.72	0.00	0.00	1657.72	1131.17	
Grants	0.00	0.00	0.00	0.00	0.00	
Fundraising	0.00	0.00	0.00	0.00	0.00	
Other	31.95	0.00	0.00	31.95	4610.28	
Sub Total	1689.67	0.00	0.00	1689.67	5741.55	

Total Receipts	1689.67	0.00	0.00	1689.67	5741.55	
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Expenditure						
Management meetings	0.00	0.00	0.00	0.00	0.00	
Website	972.29	0.00	0.00	972.29	652.43	
Travelling	219.50	0.00	0.00	219.50	517.37	
Promotional Materials	0.00	0.00	0.00	0.00	14.70	
Conference	0.00	0.00	0.00	0.00	66.00	
Printing, translation & Postage	733.16	0.00	0.00	733.16	56.15	
Subsistence	0.00	0.00	0.00	0.00	0.00	
Bank Fees	61.50	0.00	0.00	61.50	56.15	
Sub Total	1986.45	0.00	0.00	1986.45	1385.40	

Total Payments	1986.45	0.00	0.00	1986.45	1385.40	
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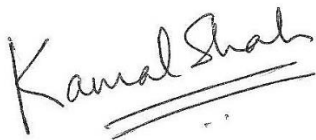
Net Receipts/ (Payments)	(296.78)	0.00	0.00	(296.78)	4356.15	
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Cash Flow and Balance Statement as of 31 December 2024

	PayPal	Cash	Bank	Total
Opening balance as at 1/1/2024	164.38	139.51	16454.61	16758.50
Transfers	0.00	0.00	0.00	0.00
Receipts	905.64	79.99	704.04	1689.67
Outgoings	0.00	219.50	1766.95	1986.45
Balance as of 31/12/2024	1070.02	0.00	15391.70	16461.72

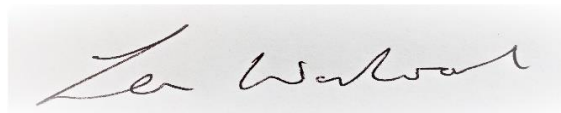
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Approved and certified



Kamal D Shah

Chair



Len Woodward

Treasurer