

Annual Report

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

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No 1167904). It held its Seventh Annual General Meeting on 2 May 2023.

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, three in person and one by zoom.

*Kerri Grey elected as trustee on 4 January 2023

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 2022 to 31 December 2022.

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

Linda Burke had completed her term of office and had formally expressed her willingness to continue to serve for two more years. She was duly re-elected to the Board of Trustees. No nominations for new Trustees been received. The Board of Trustees remained unchanged.

Activity in the period 1 January 2022 to 31 December 2022

International aHUS Conferences

The twice postponed International Society of Nephrology Symposium about aHUS and MPGN was held on 23-25 June 2022 in Bergamo, Italy. aHUS alliance Global Action was invited to provide a speaker and Len Woodward was nominated to attend and address the conference about Global aHUS patient advocacy and aHUS patients research priorities that matter.

Following the ISN Symposium aHUS alliance Global Action was invited to participate in the Kidney Disease Improving Global Outcomes(KDIGO) Controversy Conference on Complement Kidney Diseases in Florence , Italy on 29 September- 1 October 2022. Len Woodward was nominated to represent aHUS patients on the Thrombotic Microangiopathy Working Group at the Conference.

Access to Complement Inhibitor treatments.

aHUS alliance Global Action continued the dialogue with Hoffman Roche about its trials of crovalimab, a subcutaneous injection. for the treatment of aHUS.

Also, during the year talks began with Novartis about the trial of iptacopan its new orally administered pill for aHUS patients.

Both technologies would offer more alternatives for aHUS patient in the mid to late 2020s if their trials are successful.

USTMA Consortium Collaboration

The 2021 Annual Report noted a new connection with the USTMA Consortium and collaboration, with discussion of how both organizations could work together. This relationship continued to grow throughout 2022, with dialogue that created the inaugural USTMA Patient Meeting as an online event in Aug 2022. The aHUS Alliance Global Action team was invited to present information during a session which focused on our information

assets and advocacy efforts. The charity will look forward to exploring a continued, meaningful partnership initiatives with this group.

aHUS alliance research

COVID 19 had severely limited the opportunities for collaborative research.

Time and work was devoted to a study, which began in 2020, of the aHUS Diagnosis Process from the patients' viewpoint. 227 patients and carers had responded, providing a high volume of data to be analysed. The first of four "reports" was published on aHUS Awareness Day 2021 and a second report was published on 18th December 2021 attracting much interest. In 2022 two further reports were published on 28 February 2022 and 16th June 2022. Like those published in 2021 these reports were well received by aHUS patients and experts alike and provide real world data on what living through an aHUS diagnosis is like. They show that considerable process improvement is needed.

The potential research collaboration with a genetic testing laboratory on the impact of aHUS genetic results reported in 2021 did not materialise.

Global aHUS Community Advisory Board.

Global Action were part of a Global aHUS Partnership which worked together to create an expert patient panel to engage with aHUS Pharma and other researchers in a formal and structured way. The Global aHUS Community Advisory Board was announced in June 2022. Along with other CAB members Trustees Linda Burke and Len Woodward participated in the first programme of CAB/Pharma meeting on 16th, 17th, and 18th November 2022 in Barcelona, Spain.

aHUS Awareness Day

Awareness Day continued to be a focal point for the year on 24th September. An aHUS awareness day video was created using contributions from patients about which personal qualities helped them living with disease and was released on the day.

aHUS Name Change

Nothing to report on the recommendation of the work group looking into the name change for aHUS. There has been no communication from the group and patients remain unaware of what, if anything, is proposed.

Social Media

aHUS Alliance Global Action connects with the public on the social media outlets: Twitter (@aHUSallianceAct and @aHUS24Sept), Facebook, Instagram, and LinkedIn. Its social media presence continued outreach regarding aHUS information and awareness in 2022, seeing steady growth across multiple platforms.

Twitter has 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 (TMA) and complement. Content across social media has remained aHUS-specific and patient-centred, providing visibility for both advancements in aHUS research and treatments as well as providing insight into patient experiences and concerns.

Twitter account followers @aHUSallianceAct have steadily grown during 2022 to over 870 individuals and groups, and illustrate the effectiveness of broadening outreach in key areas of interest to the aHUS Alliance Global Action among them: Newcastle Clinical Trials Unit (UK) and ASH 2023 President Dr Robert Brodsky (Chief of Hematology, Johns Hopkins).

The official Twitter account for aHUS Awareness Day @aHUS24Sept currently has 375 followers and remains dedicated to our annual campaign to raise visibility for the global aHUS community and the broad key issues that transcend national borders. Many new 'aHUS Day' images featured medical advancements and facts, while other content featured patient viewpoints and advocacy news from around the globe. Both Twitter feeds continue to be active accounts since they were initiated, with 6,500 Tweets cumulatively from our main account (created in 2016), up from 5,500 Tweets last year and 975 Tweets issued in total from our 24 Sept account (created Sept 2015) , increased from 825 Tweets accumulated by last year.

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. Overall, our social media presence continues to gain traction, and it is pleasing to note that the Facebook page passed the milestone of over 3K followers after the base increased by more than 200 followers in 2022.

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 2022 there were 40,575 recorded views of the website, which is a reduction of 876 (2.1%) from 2021. The website has now had over 250,000 views cumulatively since its launch in May 2016.

Commentary on the accounts for the period 1 January 2022 to 31 December 2022 (see Annex A)

The aHUS community has continued to be generous by donating to the aHUS alliance via our PayPal Giving account. Nearly £2.4k has been donated during 2022 by supporters. Trustees made donations to defray some of the costs they incurred. £9 was received from the Bank for interest on bank account balance during the year.

Travel costs increased from the COVID-19 years. Some consultancy costs were incurred on the website's aHUS publications portal and the enhanced Zoom account was retained for meetings for a further year The charity's bank account fees reduced.

Trustees and volunteers have donated over 3000 unpaid hours in 2022 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

28 April 2023

Annex A

aHUS alliance Global Action Financial Report for the year ending 31 December 2022.

Income and Expenditure Report for year ending 31 December 2022.

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	3611.97	0.00	0.00	3611.97	6497.54	
Grants	0.00	0.00	0.00	0.00	0.00	
Fundraising	0.00	0.00	0.00	0.00	0.00	
Other	9.19	0.00	0.00	9.19	1100.00	
Sub Total	3621.16	0.00	0.00	3621.16	7597.54	

Total Receipts	3621.16	0.00	0.00	3621.16	7597.54	
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Expenditure						
Management meetings	182.31	0.00	0.00	182.31	107.90	
Website	358.60	0.00	0.00	358.60	911.00	
Travelling	1766.61	0.00	0.00	1766.61	0.00	
Promotional Materials	0.00	0.00	0.00	0.00	0.00	
Conference	0.00	0.00	0.00	0.00	0.00	
Printing & Postage	0.00	0.00	0.00	0.00	0.00	
Subsistence		0.00	0.00	0.00	0.00	
Bank Fees	83.00	0.00	0.00	83.00	109.00	
Sub Total	2390.52	0.00	0.00	2390.52	1127.90	

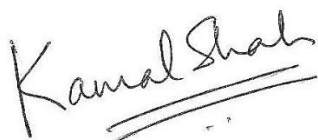
Total Payments	2390.52	0.00	0.00	2390.52	1127.90	
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Net Receipts/ (Payments)	1230.64	0.00	0.00	1230.64	6469.64	
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Cash Flow and Balance Statement as of 31 December 2021

	PayPal	Cash	Bank	Total
Opening balance	1245.00	0.00	9926.71	11171.71
Transfers	-3498.37	0.00	3498.37	0.00
Receipts	2253.37	358.60	1009.19	3621.16
Outgoings	0.00	358.60	2031.92	2390.52
Balance as of 31 December 2022	0.00	0.00	12402.35	12402.35

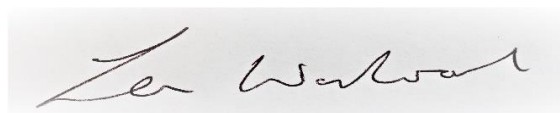
Approved and certified



Kamal D Shah

Chair

28 April 2023



Len Woodward

Treasurer

28 April 2023

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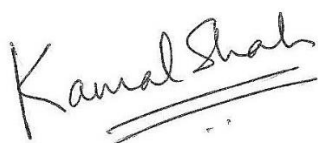
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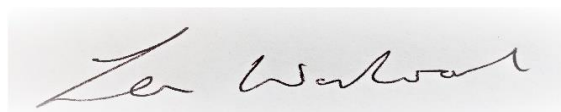
Approved and certified



Kamal D Shah

Chair

28 April 2023



Len Woodward

Treasurer

28 April 2023