

Annual Report

Trustees Annual Report for the period 1 January 2020 to 31 December 2020

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No 1167904). It held its fifth Annual General Meeting on 25 March 2021 by Zoom.

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 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 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 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 1 January 2020 to 31 December 2020.

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

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 been received. The Board of Trustees remained unchanged.

Activity in the period 1 January 2020 to 31 December 2020

COVID 19

As happened to all voluntary health organisations around the world, the alliance's programme of work from March was affected by the emerging COVID19 pandemic. From the outset the alliance saw the virus as a potential trigger of an infection TMA which, for those with susceptibility to Complement dysregulation, could lead to an aHUS onset. A publication in France confirmed that a COVID 19 infection had triggered a relapse in an aHUS patient who was in remission. However other anecdotal accounts suggested that those aHUS patients on eculizumab were only experiencing the non-serious course of the COVID 19 disease. It became evident

that more research publications were suggesting that Complement played a role in the more serious outcomes. Alliance articles about aHUS and COVID19 featured throughout the year and provided an extensive reference resource for global aHUS patients and their families.

Access to Complement Inhibitor treatments

A major review of Complement inhibitors development in progress was undertaken by the alliance to bring the list up to date since it was last done in 2018. Additionally, a survey on access to eculizumab in the rest of the world outside of USA and Europe was carried out by the alliance with 12 countries responding. The results were published and have provided insights into the difficulties experienced by nations in providing Complement inhibition treatment to those aHUS patients whose need is unmet.

Encouraging patient engagement.

The alliance again facilitated awareness videos, both for Rare Disease Day and aHUS Awareness Day. The theme of the latter was “Wellness and well-being”.

Following the Rare Disease Day Video, the theme of which was a patients’ vision for aHUS, a composite Global aHUS Patients’ Vision was drafted by the alliance using the key words used in patients’ individual vision statements by all who participated.

That vision is:

When enough aHUS/cTMA awareness helps everyone in the world get affordable access to the right treatment they need to be cured and be normal, it will be a good day.

aHUS alliance research

COVID 19 severely limited the opportunities for collaborative research. One project concerning genetic testing was postponed because the pandemic hampered project management for industry, academic and alliance participants. The consequence was that the alliance conducted its own research relating to topics in the aHUS Patients' Research Agenda.

The alliance studied Patient Reported Outcomes Reporting using data from the Alexion aHUS Registry. The results published on the alliance's website revealed a significant fall-off in PRO reporting compliance, and recommendations were made for improvement.

A call to action to the aHUS community for volunteers to participate in a study of their perception and experience of eculizumab and ravulizumab treatments. The results of the research were published on the alliance's website and have been used as patient evidence for several health policy reviews and evaluations of ravulizumab.

Finally, the alliance began a major study of the aHUS Diagnosis Process again from the patients' experience and perception. Launched in November responses were sought from global aHUS patients and families. The findings are to be published in 2021.

Social Media

Social Media Reach

Much expansion of our social media presence occurred this past year, to include the establishment of a new aHUS Global Advocate newsletter, as well as creation of an Instagram account. Our main Twitter account [@aHUSallianceAct](#) increased its followers to 626 with medical and research communities as our main target group. Those with interest in our Twitter account @aHUSallianceAct include a wide variety of professional groups and research organizations such as @goKDIGO, @CKJsocial, and @ERAEDTA. The

alliance was recognised as a top 25 “tweeter” out of around 10,000 tweeters active during the American Society of Nephrologists’ Kidney Week 2020. Our Twitter account promoting international aHUS Awareness Day at [@aHUS24Sept](https://twitter.com/aHUS24Sept) expanded in 2020 to over 300 followers. We continue to bring atypical HUS news and information to Facebook, growing our reach by more than 200 people last year to now reach over 2,700 followers through our public Facebook page [@aHUSalliance](https://www.facebook.com/aHUSalliance). Our efforts regarding aHUS global advocacy have been featured in articles by two online magazines, PatientWorthy and aHUS News.

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 2020 there were 50827* views of the website recorded, which is an increase of 3869 (7.9%) over 2019. The website has now had over 176,263 views cumulatively since its launch in 2016.

A website newsletter was introduced in August to let subscribers know about new events and content on the website. Ninety-nine website articles were published during the year.

*The website view counting facility stopped functioning for a period in April 2020.

Commentary on the accounts for the period 1 January 2020 to 31 December 2020 (see Annex A)

Having decided last year to accept donations to help finance the alliance’s work, the aHUS community has responded splendidly. Over £2.4k has been donated during 2020.

Given, also, that expenditure has been less in 2020 because alliance activity has been curtailed because of COVID 19, the alliance has built up a fund for several projects that have been put on hold.

A small sum was spent on the aHUS Awareness Day promotional mugs to give to several aHUS patients in recognition of the voluntary support they have given the alliance.

Bank charges were incurred for the charity bank account with CAF Bank.

It is estimated that over 2000 unpaid hours per annum are donated by volunteers to maintain the operational work of the alliance.

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

As the charity's income is 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

24 March 2021

Annex A

aHUS alliance Global Action Financial Report for the year ending 31 December 2020.

Income and Expenditure Report for year ending 31 December 2020.

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	2410.46	0.00	0.00	2410.46	1045.01	
Grants	0.00	0.00	0.00	0.00	0.00	
Fundraising	0.00	0.00	0.00	0.00	0.00	
Other	0.00	0.00	0.00	0.00	0.00	
Sub Total	2410.46	0.00	0.00	2410.46	1045.01	

Total Receipts	2410.46	0.00	0.00	2410.46	1045.01	
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Expenditure						
Management meetings	0.00	0.00	0.00	0.00	0.00	
Website	0.00	0.00	0.00	0.00	1303.38	
Travelling	0.00	0.00	0.00	0.00	88.70	
Promotional Materials	187.89	0.00	0.00	187.89	0.00	
Conference	0.00	0.00	0.00	0.00	0.00	
Printing & Postage	0.00	0.00	0.00	0.00	26.50	
Subsistence	0.00	0.00	0.00	0.00	0.00	
Bank Fees	60.00	0.00	0.00	60.00	104.00	
Sub Total	247.89	0.00	0.00	247.89	1522.58	

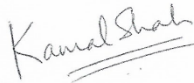
Total Payments	247.89	0.00	0.00	247.89	1522.58	
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Net Receipts/ (Payments)	2162.57	0.00	0.00	2162.57	(477.57)	
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Cash Flow and Balance Statement as at 31 December 2020

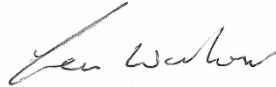
	Cash1	Cash2	PayPal	Bank	Total
Opening balance	500.00	0.00	0.00	2029.50	2529.50
Transfers	0.00	0.00	0.00	0.00	0.00
Receipts	0.00	95.68	1681.29	643.49	2420.46
Expenses	0.00	95.68	0.00	152.21	247.89
Balance as at 31 December 2020	500.00	0.00	1681.29	2520.78	4702.07

Approved and Certified



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Kamal Shah
Chair

25 March 2021



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Len Woodward
Treasurer

25 March 2021