

Annual Report

Trustees Annual Report for the period 1 January 2021 to 31 December 2021

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No 1167904). It held its Sixth Annual General Meeting on 25 January 2022 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 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 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 2021 to 31 December 2021.

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

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 been received. The Board of Trustees remained unchanged.

Activity in the period 1 January 2021 to 31 December 2021

COVID 19

The COVID 19 pandemic continued to affect the alliance's activity in 2021. 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 be an aHUS onset. During the year evidence emerged of COVID 19 being an aHUS trigger in those who were genetically predisposed, even after a mild COVID 19 disease course.

Another topic of considerable interest to aHUS patients was the decision to be vaccinated against COVID 19. The website featured updates on patient vaccination experience and the views of doctors on the advisability of being vaccinated.

COVID 19 was the reason for the postponement of a major aHUS advocacy event for the alliance when the already once postponed ISN Symposium about aHUS and MPGN, planned for July 2021, was once more postponed until June 2022.

Access to Complement Inhibitor treatments

The alliance were invited to participate in an evaluation of ravulizumab as a treatment for aHUS by the English and Scottish health technology policy committees NICE and SMC. With the research conducted in 2020 about the experience and expectations of patients being treated with ravulizumab at the core of its evidence submission, the alliance attended several meetings with the decision-making bodies. There was a successful outcome to both evaluations by June 2021. aHUS patients throughout the UK have begun converting from eculizumab to ravulizumab when appropriate. Eculizumab remains the therapy of first resort for new onset patients.

The alliance entered a dialogue with Hoffmann-Roche about Crovalimab its new technology for treating aHUS. Adult and Paediatric Trials began for aHUS by Q3. Details of the trials were published in articles on the alliance website. aHUS alliance Global Action were invited to speak to an audience of nearly a thousand of Roche employees about aHUS and aHUS patient advocacy on Rare Disease Day 2021.

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 attracting much interest. Two further reports, at least , are to follow in 2022.

aHUS patients are known to share anecdotes about their lived experience of an aHUS diagnosis in social media and at aHUS patient gatherings. To the best of our knowledge this is the first study of the aHUS diagnosis process relying on patients recalled experience, rather than medical records. Its assembly and analysis shifts anecdotes to shared perception of health care practice in a very difficult time. It collectively reflects the reality of what it is like to go through the process to be diagnosed with the rare disease, aHUS.

Just before the year ended, the alliance was approached by a genetic testing laboratory to participate in a research collaboration studying the impact of aHUS genetic results.

USTMA Consortium Collaboration

In November, an alliance representative met with the secretary of the USTMA consortium, a network of expert clinical researchers in TMA, including aHUS. The discussion was about ways in which both organisations could work together, and a dialogue continues and shows much promise.

Global aHUS Community Advisory Board.

The alliance was instrumental in the development of an expert patient panel to engage with aHUS Pharma and other researchers in a formal and structured way. At meetings on 2nd December 2021, a

Global aHUS Community Advisory Board was proposed using the EURORDIS model of CAB engagement for research.

aHUS Awareness Day

Awareness Day continued to be a focal point for the year. An aHUS awareness video “United in Fighting aHUS” and the publication of an aHUS Diagnosis Process research article featured on the day.

aHUS Name Change

Momentum built in 2021 for a revision of the name of our disease. A workshop was begun to look at the implications but by the end of the year patients advocates had not been invited to participate. The alliance has been prominent in explaining why a name change may be needed.

Social Media

Our social media presence continued outreach regarding aHUS information and awareness in 2021, seeing steady growth across multiple platforms.

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 academic groups such as the University of Colorado Pediatric Nephrology @CUPedsNeph as well a variety of international organizations such as the Indian Society of Pediatric Nephrology @IspnSocial. While this main Twitter account has attracted 100 new followers from last December to December of this year, 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 just over 5,500 Tweets from our main account (created in 2016) and 825 Tweets issues from our 24 Sept account (created Sept 2015).

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. We would like to see these new social media forums gain as much traction as our Facebook page, now at more than 2,800 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 2021 there were 41451 views of the website recorded, which is a reduction of 9376 (18.5%) over 2020. The website has now had nearly 220,000 views cumulatively since its launch in May 2016.

A refreshed new design of the website was implemented in September prior to aHUS Awareness Day 2021.

Commentary on the accounts for the period 1 January 2021 to 31 December 2021 (see Annex A)

The aHUS community has continued being generous by donating to the alliance via our PayPal Giving account. Nearly £6.5k has been donated during 2021 by supporters and trustees. The alliance also received other fee income from Roche for a Rare Disease Day talk about aHUS, and advisory meetings.

Apart from usual website maintenance fees and bank charges (our Bank increased its fees by 60% in the year) , the prime expense in 2021 was for IT consultants to undertake the website updating. The alliance also paid for an upgrade to its Zoom account to hold longer meeting etc.

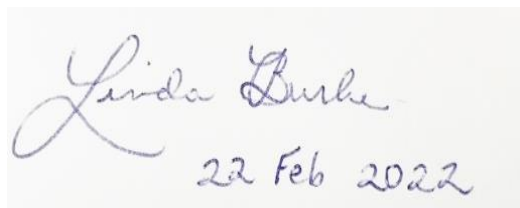
Trustees and volunteers have donated over 2500 unpaid hours in 2021 to maintain the operational work of the alliance and work on its research.

At the current level of activity, the Trustees are confident that enough reserves are held for more than two years of operating, including the potential costs of having a presence at the deferred ISN Symposium about aHUS in Bergamo from July 2021 to June 2022.

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.

A handwritten signature in blue ink that reads "Linda Burke" followed by the date "22 Feb 2022". The signature is written in a cursive style.

Secretary

Annex A

aHUS alliance Global Action Financial Report for the year ending 31 December 2021.

Income and Expenditure Report for year ending 31 December 2021.

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	6497.54	0.00	0.00	6497.54	2410.46	
Grants	0.00	0.00	0.00	0.00	0.00	
Fundraising	0.00	0.00	0.00	0.00	0.00	
Other	1100.00	0.00	0.00	1100.00	0.00	
Sub Total	7597.54	0.00	0.00	7597.54	2410.46	

Total Receipts	7597.54	0.00	0.00	7597.54	2410.46	
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Expenditure						
Management meetings	107.90	0.00	0.00	107.90	0.00	
Website	911.00	0.00	0.00	911.00	0.00	
Travelling	0.00	0.00	0.00	0.00	0.00	
Promotional Materials	0.00	0.00	0.00	0.00	187.89	
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	0.00	
Bank Fees	109.00	0.00	0.00	109.00	60.00	
Sub Total	1127.90	0.00	0.00	1127.90	247.8	

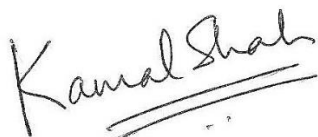
Total Payments	1127.90	0.00	0.00	1127.90	247.89	
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Net Receipts/ (Payments)	6469.64	0.00	0.00	6469.64	2162.57	
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Cash Flow and Balance Statement as of 31 December 2021

	PayPal	Cash	Bank	Total
Opening balance	1681.29	500.00	2520.78	4702.07
Transfers	-5788.47	-500.00	6288.47	0.00
Receipts	5352.18	0.00	2,245.36	7597.54
Outgoings	0.00	0.00	1,127.90	1127.90
Balance at 31 December 2021	1245.00	0.00	9926.71	11171.71

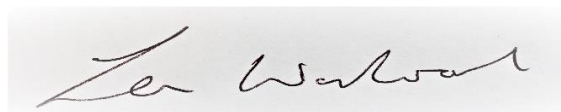
Approved and certified



Kamal D Shah

Chair

22/02/2022



Len Woodward

Treasurer

22/02/2022