

Annual Report

Trustees Annual Report for the period 1 January 2019 to 31 December 2019

Introduction

aHUS alliance Global Action is a Registered Charity in England and Wales (No 1167904). It held its third Annual General Meeting on 4th February 2020 by Skype.

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 2019 to 31 December 2019.

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

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 2019 to 31 December 2019

Access to Complement Inhibitor treatments

The alliance continued to monitor complement inhibitor trials of interest to aHUS patients through its “aHUS trials watch” series.

Additionally, the alliance continued its extensive annual overview of complement inhibitor news, drug pipelines, knowledge advancements for similar diseases and market factors which may affect development of new aHUS treatment or disease management including biosimilars.

It was the first advocacy group to bring forth, to the attention of the global aHUS community, the licensing approval of ravulizumab as a

new therapeutic drug for aHUS via an FDA announcement on 18 October 2019.

Encouraging patient engagement.

The alliance again facilitated awareness videos for both for Rare Disease Day and aHUS Awareness Day. The theme of the latter was “Family and Community Support” and included a “call to action” for blood and organ donor registration efforts to which patients, families and Alexion responded.

The alliance continued to add more patient-made videos to its aHUS Patient Voices channel on YouTube. The alliance reach out on social media to engage and involve aHUS patients, caregivers, and national patient organisations continued to grow.

Its initiative, aHUS Rest of the World (aHUS RoW), continues to build with new groups from China, Norway and Slovakia commencing participation during the year.

Several alliance articles on its website were devoted to accounts by patients and carers on how they adjusted to life following a catastrophic aHUS episode, including the consequences of long-term kidney dialysis by those unable to access eculizumab for a transplant.

aHUS alliance research network collaboration

The alliance was invited to address a conference about “rare genetic diseases” held by Cleveland Clinic, Ohio, USA. aHUS alliance Global Action Director Linda Burke talked about international aHUS advocacy and its issues such as access to complement inhibitors, personalized therapeutic treatments, and patient inclusion in research.

The alliance contributed to the publication titled “Optimal management of atypical hemolytic uremic disease – challenges and solutions”, with Linda Burke listed as co-author for the section on challenges from the Patients’ Perspectives.

This collaboration with the medical community and website articles written by Director Len Woodward led to an increase of physicians, industry, and researchers among the over 2,400 Facebook followers and 480+ Twitter followers - with the addition this year of social media influencers like the International Complement Society and IPNA society of international paediatric nephrologists.

aHUS Patients Research Agenda

As agreed at the Fourth aHUS alliance Meeting in November 2018 the Global aHUS Patients Research Agenda was officially launched on Rare Disease Day 2019. Under a theme of “You are not alone; we can find a way”, support to the launch was given by several international aHUS researchers.

aHUS Expert Centres

A report by the alliance on its findings from the 2018 tour of European aHUS Expert Centres was shared on its website. It was welcomed by the Centres themselves who regarded it as important feedback for improvement in the quality of what they do.

The alliance website articles continued to stress the importance of such centres and to highlight that their research efforts often included multiple valuable components to their programmes, advising medical personnel, working collaboratively with teams in other nations, presenting at conferences, and inclusion of aHUS advocates as valuable partners in their efforts.

Future of aHUS advocacy

The alliance was invited to talk at an Alexion event “The Big Discussion”. Attended by nearly 200 Alexion employees from around the world, the alliance representative described the journey to aHUS

advocacy, the strengths and weakness of advocacy/ pharma relations and the changes envisaged in the future.

Following the conference, the alliance published several articles about changes to come in patient centricity, a disease renaming movement and a refocus of what aHUS alliance Global Action is doing to meet its objectives.

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, which has also expanded its online footprint and impact. During 2019 there were 47105 views of the website recorded, which is an increase of 8649 (22%) on 2018. The website has now had over 125,436 views cumulatively since its launch in 2016.

Commentary on the accounts for the period 1 January 2019 to 31 December 2019 (see Annex A)

The alliance has decided to receive donations to help finance its work, including donations by the trustees themselves. Several small anonymous donations were received via PayPal Giving.

Expenditure has been incurred mostly on the continued development of the alliance website including acquisition of approved security certificates for the site and the "atypicalHUS.org" domain.

Bank charges are incurred for international payments and standing charges for the charity bank account with CAF Bank.

It is estimated that between 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

4 February 2020

Annex A

aHUS alliance Global Action Financial Report for the year ending 31 December 2019

Income and Expenditure Report for year ending 31 December 2019

Income	Unrestricted funds	Restricted Funds	Other Funds	Total Funds	Last Year	
Donations	1045.01	0.00	0.00	1045.01	0.00	
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	1045.01	0.00	0.00	1045.01	0.00	

Total Receipts	1045.01	0.00	0.00	1045.01	0.00	
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Expenditure						
Management meetings	0.00	0.00	0.00	0.00	0.00	
Website	1303.38	0.00	0.00	1303.38	193.22	
Travelling	88.70	0.00	0.00	88.70	2229.52	
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	26.50	0.00	0.00	26.50	40.80	
Subsistence	0.00	0.00	0.00	0.00	0.00	
Bank Fees	104.00	0.00	0.00	104.00	94.00	
Sub Total	1522.58	0.00	0.00	1522.58	2557.54	


Total Payments	1522.58	0.00	0.00	1522.58	2557.54	
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Net Receipts/(Payments)	(477.57)	0.00	0.00	(477.57)	(2557.54)	
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Cash Flow and Balance Statement as at 31 December 2019

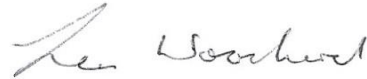
	Cash	Bank	Total
Opening balance	88.70	2918.37	3007.07
Transfers	500.00	-500.00	0.00
Receipts		1045.01	1045.01
Expenses	88.70	1433.88	1522.58
Balance as at 31 December 2019	500.00	2029.50	2529.50

Approved and Certified



Kamal Shah
Chair

29 February 2020



Len Woodward
Treasurer

29 February 2020