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The Global aHUS Advocate

Hi!

The aHUS alliance Global Action website was created as a platform for the aHUS Global community to connect, inform and collaborate.

It has become a place where aHUS people, from around the world no matter what their interest in aHUS, visit for up to date news and opportunities to enhance awareness of aHUS in an open and inclusive way. Keeping in touch is important in an ever changing environment and so we are offering a new way to connect via a regular newsletter, The Global aHUS Advocate and this our first edition.

Future editions can be subscribed by using [this link](#) or by going to our website www.ahusallianceaction.org. Thanks for reading and hope to hear from you.

The aHUS alliance Global Action Team

The aHUS Alliance Action website has a constant stream of informative blog posts on a variety of topics. Make sure you check out the blog [here](#). These are some of the recent posts:

aHUS: Time is a Great Healer

The data revealed that patients say that they can, in time, recover from their encounter with aHUS. Measures of fatigue show aHUS patients can return to levels of fatigue felt by the general population. Similarly incidents of other symptoms fall in time, but "anxiety", in particular, can linger for some though that would be hardly surprising given what had happened to them. [Read more...](#)

aHUS health, well-being and work

Over half of aHUS patients are working or in education, possibly nearly two thirds , if some of those in the "other" category who are self employed and homemakers are included. This is surprising but welcoming data which shows what normality aHUS patients are reaching. [Read more...](#)

aHUS Patient Fatigue

Earlier this year aHUS Global Action published a major four part report on the importance of patient reported outcome data in aHUS care research. The report ends with a case study of the utility of such data for aHUS fatigue in the Alexion aHUS Registry. [Read more...](#)

Global aHUS Advocacy

Participants in the creation of a Global aHUS Patients' Vision advocated that treatment of aHUS everywhere was needed. Everywhere is Global. [Read more...](#)

2020 Atypical Drug Discovery Review

The aHUS Alliance has announced the release of its new overview on the 2020 atypical HUS therapeutic drug landscape, which includes a table containing in-depth links to pharmaceutical companies, research, and drug discovery information. [Read more...](#)

Voicing a Global aHUS Vision

There are many languages spoken around the world and those affected by aHUS may only speak one of them but not English. But if "everyone in the world Is to get the affordable access" as envisaged then that needs to be visible in every aHUS patient's own language. [Read more...](#)

Connecting the aHUS community to recent publications of global interest, the aHUS Alliance presents:

1. [The case of Complement activation in COVID-19 multiorgan impact](#). Noris M, Benigni A, Remuzzi G. *Kidney Int.* 2020 May 24 doi: 10.1016/j.kint.2020.05.013

Overactivation of the complement system caused by the coronavirus leads to tiny clots that cause organ damage, especially to the kidneys and lungs. There may be a cross-over of new information learned through COVID-19 issues regarding thrombotic microangiopathy and complement which expands the aHUS knowledge base. (View the aHUS Alliance resource page on aHUS & COVID-19 [HERE](#))

“The novel coronavirus disease COVID-19 originates in the lungs, but may extend to other organs, causing, in severe cases, multiorgan damage, including cardiac injury and acute kidney injury. In severe cases, the presence of kidney injury is associated with increased risk of death, highlighting the relevance of this organ as a target of SARS-CoV-2 infection.”

2. [Atypical hemolytic uremic syndrome in Brazil: clinical presentation, genetic findings and outcomes of a case series in adults and children treated with eculizumab](#), Palma et al, on behalf of the Brazilian TMA and aHUS Study Group, *Clinical Kidney Journal*, sfaa062. doi.org/10.1093/ckj/sfaa062

A multicenter study of 34 patients in Brazil, this publication provides detailed data on varied clinical subtypes for patients of all ages. Their aHUS & TMA study group found that half the patients participating had their first episode of aHUS before 18 years of age, and noted “*Discontinuation of eculizumab was associated with a 30% relapse of aHUS.*” The authors noted that distinguishing secondary TMAs from aHUS remains a diagnostic challenge. (FMI on aHUS & TMA study centres, click [HERE](#))

Coming soon from aHUS Global Action

Our 6th annual aHUS Awareness Day: 24 Sept

Created by the aHUS Alliance as an international initiative to raise awareness for the rare disease atypical hemolytic uremic syndrome (atypical HUS or aHUS), we invite all interested in the global aHUS community to participate with

Save the date, and watch for 2020 aHUS Day campaign updates on our website and on [@aHUS24Sept](#) on Twitter. Look back at the 5th annual 2019 aHUS Awareness Day campaign, [HERE](#).

aHUS Events from around the world

Participate in the Global aHUS Awareness Day Image campaign

Calling for aHUS advocates in all nations to participate in the creation of aHUS Awareness Day images to become part of the 24 Sept 2020 social media campaign. Read more about the need for aHUS awareness outreach to appear multiple languages [HERE](#).

ISN Frontiers Event Postponed

Organisers of this important event announced that the event is being postponed until July next year. For more details please click [here](#).

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