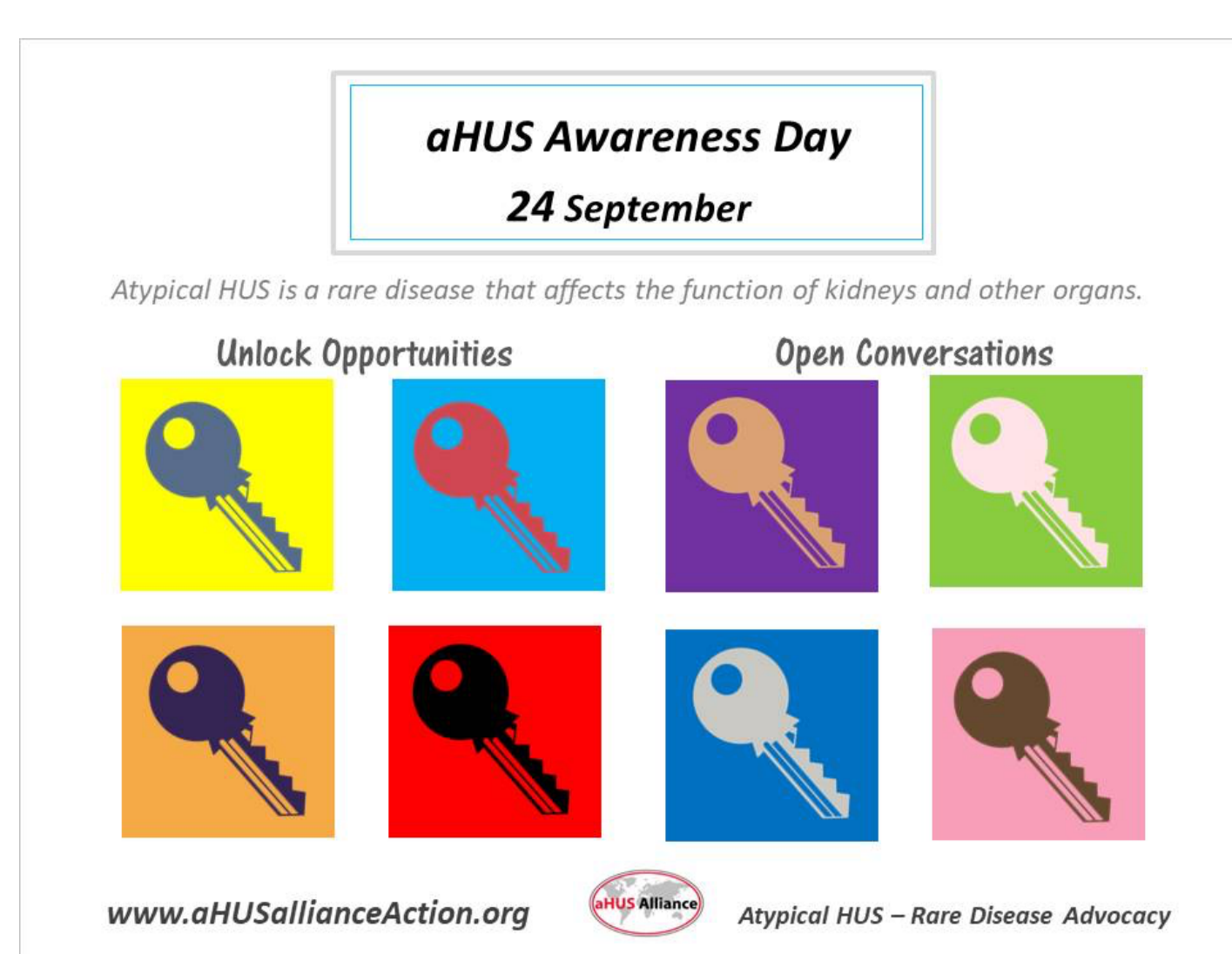


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The Global aHUS Advocate

Hello and welcome to the second edition of the aHUS alliance Global Action newsletter which has been sent out on aHUS Awareness Day itself.

Not for many yet but as this Newsletter is distributed it has just turned 24th September on Tuvalu in the Pacific ocean midway between Hawaii and Australia.

aHUS Awareness Day is a good time to catch up on what has been happening on matters aHUS, as well join in and spread aHUS awareness.

As we have done in the past, there is a page devoted to the day which has a link with an aHUS Awareness Day video produced with contributions from aHUS patients and carers from around the world. The theme this year has been how wellness and well-being has been regained, An important message on aHUS patients' own day.

aHUS alliance Global Action

All the Action from the Alliance Action Website

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:

IT'S AHUS AWARENESS DAY 2020!!!

It is hard to believe it's September already let alone aHUS Awareness Day. Six or more months of a COVID 19 year is having that affect on all that is happening this year.

But hear we are. For many when this blog is published it is still the 23rd September but aHUS Awareness Day has just started in the mid Pacific Ocean. aHUS Awareness Day is a global event and so lasts more than 24 hours. [Read more...](#)

AHUS KIDNEY TRANSPLANT-MORE INSIGHTS

aHUS and kidney transplants is an important research topic for aHUS patients with end stage renal failure. aHUS alliance Global Action has featured several research studies of aHUS transplants.....A recent study released by the Jose Portoles group from Madrid, Spain adds new insights for aHUS patients about the topic. [Read more...](#)

ATYPICAL HUS KEY FACTS & INFO – 2020 SEPT 2021

What's new in the past year for information related to the ultra rare disease atypical HUS (atypical hemolytic uremic syndrome)? Quite a bit, but it's quite challenging to sort through the many different categorizations and wide variety of terms to find current and accurate information about aHUS. [Read more..](#)

TTP AND AHUS- DIFFERENT DISEASES BUT STILL LINKED

It is not unheard of for someone with atypical Haemolytic Uremic Syndrome (aHUS) to have had an initial diagnosis of Thrombotic Thrombocytopenia Purpura (TTP). There is no statistic for how many have been misdiagnosed, just anecdotal evidence popping up over the years. Such misdiagnosis is often discovered when a patient receiving a kidney transplant presents with another episode of aHUS triggered by the transplant. It may only be then that genetic tests reveal that the patient was indeed predisposed to aHUS. [Read more..](#)

ACCESS TO ECULIZUMAB

Earlier this year, aHUS alliance Global Action wrote to a number of contacts it has around the world. Some information was sought about access to eculizumab in their countries. These contacts were from continents other than Europe (including the EU) and also other than the USA in the Americas. Nineteen contacts were identified , some clinicians and some patient advocates.

Twelve replies were received from all but one continent and then sadly "events" overtook our programme of work.

With aHUS awareness day approaching, it is timely that we now report on what we were told by those respondents. [Read more...](#)

ATTAINING AHUS WELLNESS AND WELL BEING

The theme for aHUS awareness day this year is **wellness and well-being**. Two words which look similar but with different meanings. Together they sum up what recovery from a severe health event is about :

wellness-the state of being in good health, especially as an actively pursued goal.

well-being the state of being comfortable, healthy, or happiness.

[Read more...](#)

THINK AHUS 60K THIS COMING AWARENESS DAY

One thing is certain, no one knows how many aHUS patients there are in the world. Neither how many onset each year, nor how many are surviving. There are no complete records anywhere, no database nor disease registry does that job. [Read more...](#)

YOUR SUPPORT MEANS A LOT

As we approach aHUS Awareness Day 2020, the trustees have decided for the first time make a call for people to fundraise for aHUS alliance Global Action. We have no target in mind , just an intention to use it for the benefit of aHUS people. [Read more...](#)

LIKE AN AGATHA CHRISTIE STORY!

Complement is in at the beginning when dealing with the virus. Its job is to recognise it and play an early part in the immune response, i.e. messaging other parts of the innate immune system for action against that specific virus. [Read more...](#)

Your World in Research

When new research and journal articles about atypical HUS appear, they add information and insights into this very rare disease. Our organization has created an extensive list of aHUS-specific publications, categorized by key topics such as: critical care, diagnosis, pregnancy, treatment, aHUS impact on multiple organs (extra-renal), genetics, and more.

Visit our aHUS Research pages HERE:

<https://www.ahusallianceaction.org/research-publications/>

Since we're a global aHUS patient organization, new information about this rare disease affects us and our families. The aHUS Alliance Global Action team does what no others can do: showcase news about research and aHUS patient care and directly connect it to the lives and experiences of aHUS patients and families around the world.

This edition of the aHUS Global Advocate looks at a case study involving a pregnant aHUS patient in Central Africa. As seen from two quotes from this 27 Aug 2020 case study, there is no quick and definitive test for atypical HUS and this means that mis-diagnosis or delayed treatment still has a negative effect on aHUS patient outcomes. Furthermore, physicians remain frustrated that most nations still do not have access to eculizumab or ravulizumab, since cost drives governmental healthcare policy. These two problems need to be the focus of aHUS advocacy: to improve care and save patient lives, to lessen the burdens of this disease, and to improve quality of life for those people with aHUS.

"In practice, patients with TMA are treated with plasma exchange therapy until all non-aHUS causes of TMA have been excluded. As soon as all non-aHUS causes of TMA have been eliminated, aHUS is retained as the diagnosis..."

AND

"Clinicians must be able to recognize the signs of TMA early on and to narrow down the diagnosis to aHUS. However, governments must invest more in the health system to provide underresourced physicians with the tools to conveniently manage diseases such as aHUS."

Research:

Tshilanda et al. Diagnostic dilemma in postpartum associated hemolytic uremic syndrome in a 38th week pregnant 31-year-old Congolese: a case report

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7457258/>

Coming soon from aHUS Global Action

A very important article on the impact of Eculizumab and Ravulizumab treatments will be published on the Alliance Action website soon. The report includes the testimonies of 20 patients and carers who volunteered to participate.

Later in October , aHUS Global Action will be focusing on the diagnosing opportunity of aHUS. There will be a potential opportunity for the aHUS community to contribute to another study about aHUS.

So please visit the Alliance Action website from time to time.

aHUS Events from around the world

- The ISN Frontiers Symposium in Bergamo has been rescheduled to the July 1- 3, 2021. For more information, please click [here](#).
- The 13th International Conference on Complement Therapeutics has been rescheduled to June 17-22, 2021.

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