

[View this email in your browser](#)



1st Year Anniversary Edition

Half the year has passed so quickly since our last newsletter and it is approaching 12 months since the website newsletter was launched. In that time, more and more aHUS people have subscribed to receive it.

The website content has been diverse and informative and is well worth catching up on.

The next few months are going to be busy with the 7th International aHUS Awareness Day, September 24th, and the publication of the results of the aHUS Diagnosis Process Study.

Wishing wellness and well-being this summer.

aHUS alliance Global Action

All the Action from the Alliance Action Website

The aHUS Alliance Global Action website has a constant stream of informative articles and original content on a variety of topics related to atypical HUS. Make sure you check out the latest aHUS news [here](#). These are some of the recent topics covered:

aHUS Trials Watch

This is your handy guide to all news on trials on new drugs for aHUS. The spotlight these days has been on Crovalimab. Read more [here](#).

COVID-19 triggers aHUS

Not unexpectedly, as aHUS Global Action had postulated it in March last year, a COVID 19 infection can trigger aHUS in those predisposed to it. Read more [here](#). Also see [this article](#) about the COVID-19 vaccines and aHUS.

Ravulizumab approvals in the UK

There's been news on the approval of Ravulizumab from the UK. Read here about [England recommending it](#), [Scotland approving it](#) and [NICE evaluating it](#).

Discontinuing aHUS treatment

This topic is a very sensitive one with no easy answers. Read more [here](#) for an incisive, well-researched article on this important aspect of aHUS treatment.

Other News

There was also a [Webinar by Marina Norris](#), one on [unintentionally misinforming posts on the internet](#), one on the [importance of registries](#) and one on [Kidney Disease and Dental Health](#).

One can hardly do justice in covering the wide variety of topics our experts write on. Please visit the [news section of the website](#) to see updates as they get written.

Your World in Research

There's been a wealth of important aHUS research released during the 1st half of 2021, and many of these hold implications likely to expand the atypical HUS knowledge base for the diagnosis and treatment of this very rare disease.

Key topics for both patients and clinicians relate to questions regarding optimal duration of treatment, as well as risk for potential aHUS relapse when treatment has been discontinued. Our website maintains an [aHUS Research page](#), and we're pleased to note a substantial number of publications added to each category, as well as our introduction of a NEW topic scroll specific to 'Treatment Discontinuation and Relapse Risks'. Read more [here](#).

News

24 Sept is aHUS Awareness Day

The theme of aHUS Awareness Day 2021 is "United in Advocacy" The aHUS Alliance created the 1st aHUS Awareness Day in 2015 to raise visibility about the rare disease Atypical Hemolytic Uremic Syndrome (atypical HUS). Since then, the aHUS Alliance Global Action team has continued to lead this annual 24 September campaign by raising issues, promoting efforts, and creating resources for aHUS families and the general public.

What's the meaning and history behind aHUS day and this annual campaign? Resources and general info about aHUS Awareness Day are available [here](#). Read more about being "United in Advocacy" for aHUS Awareness Day 2021 [here](#).

aHUS Events

aHUS Diagnosis Process Study

aHUS Alliance Action launched the first ever multi-nation [study on the complexities around the diagnosis process of aHUS](#). The response was overwhelming. The responses are currently being analysed and the results will be published soon. So, watch this space!

24 Sept is aHUS Awareness Day

The theme of aHUS Awareness Day 2021 is "United in Advocacy" The aHUS Alliance created the 1st aHUS Awareness Day in 2015 to raise visibility about the rare disease atypical hemolytic uremic syndrome (atypical HUS). Since then, the aHUS Alliance Global Action team has continued to lead this annual 24 September campaign by raising issues, promoting efforts, and creating resources for aHUS families and the general public.

What's the meaning and history behind aHUS day and this annual campaign? Resources and general info about aHUS Awareness Day are available [here](#). Read more about being "United in Advocacy" for aHUS Awareness Day 2021 [here](#).

ISN Frontiers Symposium in Bergamo, Italy now on June 23-25, 2022

The International Society of Nephrology and the Mario Negri Institute for Pharmacological Research have announced that the 2022 ISN Frontiers Meeting in 'Complement-related kidney diseases: classification, genetics, and treatment' will be held from June 23-25, 2022, in Bergamo, Italy. More details are available [here](#).

Subscription Options

[Please click here to subscribe to this newsletter.](#)

[Please click here to unsubscribe from this newsletter.](#)



Copyright © 2021 The aHUS Alliance, All rights reserved.

Want to change how you receive these emails?
You can [update your preferences](#) or [unsubscribe from this list](#).

