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Focus on Research

Another aHUS awareness day is behind us and aHUS alliance Global Action continues its work to connect, collaborate and inform on all things aHUS.

There has been a focus on aHUS research lately, including our own about the aHUS Diagnosis Process. The first report was published on 24th September and can be read on our website. A second report about the “primary care” step in the process is to follow soon.

Global Action has also supported another study by giving a platform to a post graduate researcher in Nebraska, USA for research on the treatment cost burden of aHUS in the USA.

Our website articles continue to include new aHUS knowledge as it is found. Research publications about Eculizumab treatment withdrawal and aHUS pregnancy and Ravulizumab have been featured.

The Global aHUS Patients Research Agenda is being addressed by the Global aHUS community for the Global aHUS community.

- aHUS alliance Global Action

All the Action from the Alliance Action Website

The aHUS Alliance Global Action website continued its focus on research over the past few months. Here are some of the articles on this important topic that were featured recently:

The aHUS Diagnosis Study

Like was mentioned in the last edition of this newsletter, aHUS Alliance Action has been working on the analysis of the results of the first ever global diagnosis survey of aHUS. The first report from this survey was published and you can see an article that talks about it and has a link to the full report [here](#).

Spotlight on aHUS Research

This [article](#) covered the library of publications on topics of interest like aHUS, TMA and so on.

Withdrawal - Need for a consensus

Withdrawal of Eculizumab is an important topic given the costs of the drug. This [article](#) summarises these findings of a paper recently published and suggests the way forward.

Pregnancy and aHUS

A case study from Missouri, USA is summarised in this [article](#) on Pregnancy and aHUS. The topic of pregnancy and aHUS is included in the Global aHUS Patients' Research Agenda.

USA aHUS – treatment costs study

aHUS Alliance Action was approached by a Master's student for support on a study on treatment costs in the USA for aHUS. This [article](#) has more about that.

Please visit the [news section of the website](#) for more such articles.

Your World in Research

We marked aHUS Awareness Day (24 Sept) with our own advocacy-based research, releasing the 1st report of data and insights from the 2021 global survey of aHUS patients' experiences about the diagnostic process. Whether by serendipity or considerate design, the team of aHUS researchers and clinical care at the Mario Negri Institute in Bergamo Italy marked aHUS Day with release of an updated version of what we consider the 'book of aHUS', [GeneReviews®: Genetic Atypical Hemolytic-Uremic Syndrome](#) (Authors: Marina Noris, Elena Bresin, Caterina Mele, and Giuseppe Remuzzi).

We continue to see bursts of enlightenment and insights about atypical HUS via new knowledge related to thrombotic microangiopathy and the role of complement. How so, and what are some recent highlights in aHUS research on topics such as pregnancy and the impact of COVID-19? Read more [here](#).

aHUS Events

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](#).

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