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The Global aHUS Advocate

Our global patient advocacy depends on collaboration with researchers and emerging national patient groups. This can be done by promoting and spreading awareness of aHUS research as well as using research skills to undertake research ourselves and involve multiple national aHUS patient communities. Look at what aHUS alliance has been doing and is doing right now.

The aHUS Global Poll 2024 has reached the half way point in the time allotted for survey questionnaires to be completed. Hundreds of people have already visited the page on our website so far and there is still time in the next 3 weeks for hundreds more to do the survey.

The more included the bigger the voice.

If you have not done so yet and you are an aHUS patient or a family member of a patient please use this opportunity to say what living with a rare disease is like for you. Here is a quick link to the page.

<https://bit.ly/2024aHUSglobalPoll>

This poll shows how important patient researchers are becoming in finding new

insights in to their disease of interest. By patients with patients for patients and on topics which others are unlikely to research.

- aHUS alliance Global Action

All the Action from the Alliance Action Website

Continuing on the research theme Global Action is constantly on the look out for new research related to aHUS as this website article shows.

Research is available but doesn't always delve into the patient experience as the poll does. But [this is what](#) Global Action has recently found has been happening in the world of aHUS research.

A specific example of Global Action awareness of cutting edge research was when some USA researchers brought a new aHUS blood test to our attention. It is one of the most exciting developments for diagnosis and prognosis of aHUS patients. Read more [here](#).

This month marks the 70th anniversary of the first patient to be officially diagnosed with HUS. 7 month old Barbara Flammer - Frey was one of five children Included in Conrad Von Gasser's research which described the disease for the first time. The story can be found at [this link](#).

Scientific advances help to fill the knowledge gaps and vitally important for physicians and therefore treatment and patient care. The KDIGO guidelines are physician-facing to improve diagnosis and treatment and management of aHUS and talk about what still needs to be done. Read our article about this important publication [here](#).

Sometimes mature patient organisations like Global Action can make the connections to help patients understand what might be available over dozens of research articles to make things simpler. The aHUS patients treatment discontinuation decision making model is a good example of that. Two articles explain the reasons for having a model for discontinuing decision making and then explaining the model proposed by Global Action. You can find these articles [here](#) and [here](#).

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

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