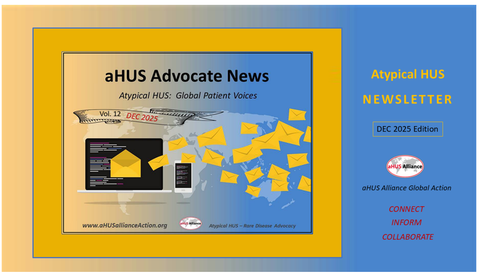

Editorial

It has been some time since our last newsletter. In that time Global Action has continued to provide answers to the questions patients frequently ask about aHUS as well as keep up to date with news about research and treatment access progress.

In a time when websites and even social media platforms are perhaps becoming old fashioned communication media technologies and more use is made of AI for disease information, it is noticeable that aHUS alliance Global Action website content is increasingly cited by the most common AI Apps.

Maybe AI will be the way that overall global aHUS advocacy reach expands to others in the global community. So far only around a third of countries with populations big enough to have at least one aHUS patient are known to us. And not all have reached out to us. Global Action has set up a challenge for all in the known aHUS community to find patients in the yet to be known community. Progress has been slow!

- aHUS alliance Global Action

All the Action from the Alliance Action Website

The Alliance Action website foccussed on several key aspects over the last few months. Here are some recent articles of interest.

The article **"Finding New Neighbours- Global aHUS Town"** describes an ongoing effort to identify more countries where people with atypical HUS (aHUS) live, expanding the *Global aHUS Town* of known countries with at least one patient. Starting with 59 countries, four more (Nepal, Tunisia, Ireland and Iceland) have recently been added, but many more nations remain unconfirmed and the community is encouraged to help find and verify them.

The article "Hope Emerges for aHUS Patients in India" reports that **India's drug regulator (CDSCO) approved the life-saving aHUS treatment eculizumab (Soliris) in January 2025**, offering rare disease patients new hope after years without approved therapy in the country. However, it notes **major challenges remain**, including high drug costs, limited access through designated Centres of Excellence, and pending local safety studies, meaning real impact will depend on pricing, access, and supportive policies.

The article **"From aHUS Ashes: Rise of the Phoenix"** shares inspiring stories of three people whose lives were dramatically affected by atypical Hemolytic Uremic Syndrome (aHUS), showing how they turned severe challenges into purpose and resilience. It highlights how each individual—through personal recovery, raising awareness, and patient advocacy—has transformed adversity into strength and meaningful impact for themselves and others in the rare-disease community.

The article **"Decision making in aHUS Health Recovery"** highlights how participants in an aHUS Awareness Day video shared their most meaningful decisions in recovering from aHUS, with themes including psychological adjustment, treatment management, self-care, altruism, social support, and spiritual support. It emphasizes that actively deciding how to regain control over one's life after aHUS is an important milestone toward rebuilding confidence and self-esteem.

The **"Atypical HUS Facts: 2025 – Sept 2026"** article is an overview pointing readers to a downloadable fact sheet that summarizes the latest information, research, and resources on atypical Hemolytic Uremic Syndrome (aHUS) as a rare disease. It highlights that medical knowledge is rapidly evolving, directs people to the aHUS Alliance's information centre and virtual library, and lists key research publications used to compile the fact sheet.

Global Action has probably done the most over the years to look at the withdrawal from complement treatment from a patients viewpoint, including a creating a patients decision making model. The article, **"Withdrawing from treatment - patients' perception"** has a published study on the withdrawal decision from a patients perspective during a clinical trial on stopping treatment. Patients thoughts on the matter seem ubiquitous.

The **"What's New in aHUS Research – Dec 2025 Edition"** article highlights recent scientific publications added to the aHUS Alliance's *virtual library*, showcasing updates across genetics, treatment, and extra-renal manifestations of atypical HUS. It points to new studies on ocular involvement, genetic mutations (like CD46), registry data showing possible gender differences in prevalence, and research on tailored treatment strategies and complement inhibitor use — all underscoring the complexity of aHUS and the importance of personalized care and continued research.

Please visit the news section of the website for more such articles.

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