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## The Global aHUS Advocate

The world of aHUS is changing and that change is gathering pace. The 2020s are going to see more innovative treatment options accessible in more parts of the world. More good is on its way but do the tens of thousands of aHUS patients old and new know about it?

The internet is full of information about aHUS and TMA; some may say it is too full. Our website is a digest of it. Throughout its seven year existence (officially launched 28 May 2016), the website has looked at the disease from all angles. Written by those living with aHUS for not just those now living with aHUS but in place for those who will soon be living with aHUS.

Something to dip into from time to time to keep up to date or to learn about what has brought us together. Almost a “mini aHUS magazine” in itself, this newsletter brings suggested aHUS content, which is both global but also country specific for all to browse.

- aHUS alliance Global Action

## All the Action from the Alliance Action Website

### Silver Lining: from aHUS Diagnosis to Dialysis Centre Entrepreneur

We're excited to announce the release of this new book: 'Silver Lining: Overcoming Adversity to Build NephroPlus - India's Largest Dialysis Provider' (author: Kamal Shah)

Kamal D Shah takes readers on his journey from a diagnosis of atypical HUS and kidney failure to co-founding NephroPlus which grew to become not only India's largest dialysis centre network but expanded to over 320 dialysis centres across 4 nations. Read more [HERE](#).

### Global aHUS at the Baltimore Conference

All the action from the aHUS conference in Baltimore, USA which was attended by aHUS Alliance Action. Read more [HERE](#).

### 4th Edition of Indian Dialysis Olympiad held in New Delhi, India

Who said dialysis patients cannot play a sport? Given good quality dialysis, dialysis patients can do everything that people with healthy kidneys do – work, play, travel, exercise and have fun. A Dialysis Olympiad was organised in India to prove just this! Read more [HERE](#).

### The ethics of aHUS patient involvement

Over the past 10 years the movement of involvement of patients in the development of medicines, their regulation and use has grown enormously. aHUS alliance Globaly Action watched its growth and added its own opinions about including patients. If , individually, all aHUS patients cannot be involved around the world then patients organisations can at least listen to what they say and amplify their voice for them. Read more [HERE](#).

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

## Your World in Research

In the first months of 2023 there's been a raft of new publications which are important to those affected by aHUS and to the medical professionals who treat them.

Our April update mentions a small selection of new aHUS-specific research from various topics of high interest released, but more than 3 dozen were recently added to our 'Research & Publications' page which begins with the 'New Research' scroll. Read more [HERE](#).

## News & Events

### aHUS in Turkey

In Turkey, the patient group 'Association of the Fight against PNH and aHUS Diseases' is continuing to lead the way in advocating for better patient outcomes. National patient organizations are vital to voice the issues and needs of patients, and to assist families as they navigate rare diseases.

We were pleased to feature resources and materials in Turkish from their website and social media campaign for Rare Disease Day 2023. Accompanying these was our interview with Gülin Kayserili, board member of this Turkish 'PNH VE AHÜS İLE MÜCADELE Derneği', and who also is a valued member of the global atypical HUS Community Advisory Board. Read more [HERE](#).

### aHUS Community: Gathered in Baltimore

Patients and aHUS family caregivers met in Baltimore MD on 28-30 April 2023 at the '1st since COVID' in-person event, hosted by the USA patient group 'The aHUS Foundation'. Also attending were several members of the global aHUS Community Advisory Board, who arrived a bit early prior to the aHUS CAB meetings on 1-3 May. The aHUS Foundation created a program of outstanding speakers and provided a wonderful opportunity for all present to connect on a variety of levels. Read more [HERE](#).

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