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The Global aHUS Advocate

Welcome to our 8th edition of The Global Advocate. Each November the international nephrology community meets for “Kidney Week” to share scientific advancements, recently at the ASN Annual Meeting on November 2-5, 2023, in Philadelphia, PA. Topics related to atypical HUS were few at ASN 2023, though past years have had multiple sessions related to complement mediated kidney disease and thrombotic microangiopathy. December will feature an annual hematology conference, so it’s hoped that aHUS topics will appear as part of the 65th ASH Annual Meeting and Exposition to take place December 9-12, 2023, in San Diego, California.

We'll continue to showcase information and events of interest to the atypical HUS community on our aHUS Alliance Global Action website, such as these recent highlights from www.aHUSallianceAction.org.

- aHUS alliance Global Action

All the Action from the Alliance Action Website

aHUS Algorithms - What Is That?

Did you know there are several tools physicians can use to help diagnose atypical HUS? These [aHUS/TMA algorithms](#) are available as an assist to foster more rapid and accurate diagnoses. As step-by-step flowcharts such algorithms have been developed to guide medical teams as they sort out whether a patient has aHUS or another condition with similar symptoms. These algorithms have been available for several years - so why is ‘delayed diagnosis’ still a reality within aHUS patient experiences?

Closing the CaHUS Knowledge Gap

While there’s still debate among experts considering changes to address confusion caused by wide variations in aHUS terminology, one thing remains clear. There’s also great variety among how aHUS affects patients in terms of severity, duration of aHUS activity, and organs affected.

A recent UK study of characteristics and clinical experiences of 300+ CaHUS (complement mediated/associated HUS) patients has been compiled in a UK database maintained by the aHUS expert center in Newcastle upon Tyne. [Read Why](#) this is of such broad importance.

aHUS & Compromised Immunity

Some degree of being ‘immunocompromised’ (weakened immune system) has been a long-held premise for those who’ve experienced atypical HUS episodes, as well as for people with a genetic predisposition to have aHUS trigger at some point during their life. We still have much to discover about how aHUS activity is triggered, and why part of a patient’s immune system loses its ability to self-regulate. There’s a new initiative underway that globally bonds across different diseases, read more [HERE](#).

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

Your World in Research

As new research and information becomes available, it seems to be intertwined in a way that begs the question, “What subtype of aHUS are we looking at?” We’re here to help. Cutting through the confusing terminology and classification system in need of an update, the aHUS Alliance Global Action team offers a selection of highlights from recent atypical HUS research [HERE](#).

Now with more than 1300 unique entries in our online ‘library’ for aHUS-specific publications, we invite you to search categories for regarding research about Diagnosis, Treatment, Pregnancy, Transplant, Multi-Organ Involvement, Triggers & more. Updated with links to easily jump to a specific topic of interest, visit our [aHUS Virtual Library HERE](#).

News & Events

Listening Sessions with the FDA (US Food & Drugs Administration)

A new advocacy partnership, called the USA aHUS Patient Advisory Partnership (PAP), was formed by the Atypical HUS Foundation, aHUS Network Action, Global Families and aHUS Alliance Global Action organization. [Read about this initiative](#) to discover why it has broad importance globally.

Silver Lining: from aHUS Diagnosis to Dialysis Centre Entrepreneur

This new book, written by Kamal D Shah, is an inspiring and unique mix of entrepreneurial spirit and exceptional achievement combined with the challenges of living with aHUS, such as an unsuccessful kidney transplant and knowledge built upon more than two decades of Kamal’s experiences as a dialysis patient himself.

One of the world’s largest sites for readers and book recommendations, GoodReads reviewed ‘Silver Lining’ and noted, “This is a unique business memoir, with a strong, moving touch of the deeply personal. Kamal writes with raw honesty about pain and fear and the darker side of healthcare in India. Yet this is also a story of faith, of grit and determination and, ultimately, of success.” [Click HERE](#) to read more (inc. order links).

aHUS Awareness Day: the campaign for 2023

24 September 2013 marked our 9th annual was aHUS Awareness Day campaign to highlight the people, needs, and research in the atypical HUS global community. This year’s theme was ‘Capabilities and Possibilities’. [Read more](#) about our 2023 global project for aHUS families, and see the completed project [HERE](#).

We invite you to read about more aHUS topics on our website, and to view other resources within our [Atypical HUS Info Centre](#). The aHUS Alliance Global Action team is an independent not-for-profit organization composed of international volunteers who are aHUS patients or family caregivers. [FMI](#) - Email Us at: info@aHUSallianceAction.org

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