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The Global aHUS Advocate

Welcome to our 9th edition of The Global aHUS Advocate.

The Global aHUS Advocate sees the 2020s as a time of [great opportunity for the aHUS patients](#) and families community. We are in a period like the early 2010s and the advent of eculizumab which transformed the aHUS scene. The science of aHUS has progressed enormously and patients' priorities along with it. In 2024 we are likely to hear about the up to date treatment guidelines from KDIGO, the plans to rename aHUS with new names. And another treatment withdrawal study will report later this year.

Global Action's website content also moves with the times, sometimes ahead of the times. As the sample of articles in this newsletter illustrates, the range of information, connectivity and collaboration continues at a fast pace.

- aHUS alliance Global Action

All the Action from the Alliance Action Website

[Dr Leonard Bell – Before aHUS Endeavours Fade](#)



(The "Before aHUS endeavours fade" series of articles continued with the story of Dr Lenny Bell and how eculizumab came about. It is an amazing tale where success could have been a disaster for us all!)

Those new to the disease aHUS may not know the significant contribution that Dr Leonard Bell has made to their treatment today. Leonard, or Lenny as he was called ...[CONTINUE READING](#)

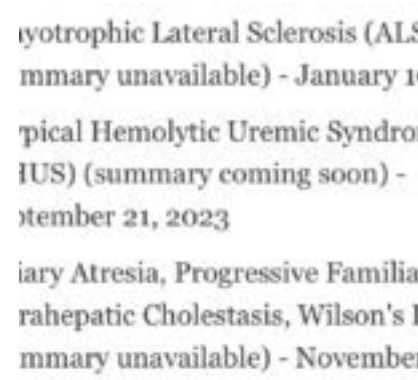
[MENINGOCOCCAL INFECTION – JAAC'S STORY](#)



(Continuous awareness raising of meningococcal infection has been something Global Action has taken on. Meningitis and Septicemia are scary diseases. But with vigilance and prompt action a good outcome is possible as was the case the young boy in this real life story.)

aHUS patient Jaac and his mother Ria are from the UK. Ria spoke to Global Action about her son's meningococcal infection encounter. Global Action: Hi Ria when did Jaac become...[CONTINUE READING](#)

[AHUS patients met with FDA and this is what they said](#)



(It is important to keep up the awareness of aHUS among a multitude of audiences. A small group of patients told FDA what having and living with aHUS is like and a report of this listening session has been listed on FDA's website.)

In September last year a group of aHUS patients and parent/carers met with FDA and told them about aHUS. A summary report about what happened at the meeting has now...[CONTINUE READING](#)

[Research into aHUS – an interview with a researcher](#)



(aHUS alliance's mission has been from its outset to work with aHUS researchers. We connect. In this article a researcher Dr Vicky Brocklebank explains how one of the best pieces of aHUS research in 2023 was carried out to meet its aims)

Last year Global Action brought attention to a research article (Closing the CaHUS knowledge gap) which stood out as one of the best contributions to aHUS knowledge we...[CONTINUE READING](#)

[Aspirations for aHUS- a to do list](#)



You know how when a group forms and they create ideas of what the group can do together - they have aspirations. Well, the aHUS alliance did just that at...[CONTINUE READING](#)

[Exploring the aHUS Patients' Research Agenda](#)

The current Global aHUS Research agenda is being thoroughly reviewed and debated. Catch up with what has been happening using the link below.

An in depth exploration of the aHUS Patients' Global Research Agenda, this series of articles dives deeply into 15 key questions that patients & caregivers would like researchers and clinicians...[CONTINUE READING](#)

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

Your World in Research

Ever wonder if there's new information out about atypical HUS that might affect your medical team's ideas about treatment, and what care plan might be best for your situation? We do, and that's why we seek out and post updated information, organized by topic in our aHUS-specific 'virtual library'.

Check out recent highlights in research [HERE](#).

With over 1300 unique entries in our online 'library' for aHUS-specific publications, we invite you to search 20 categories 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](#).

What do Patients & their families want Researchers to Explore?



As an international aHUS project spanning over 4 years, the aHUS Patients' Research Agenda was formed and consists of 15 core questions organized by 5 topics areas.

Over the last 4 months, Len Woodward of aHUS Alliance Global Action set about framing a series of deeper dives into both the questions and the complexities involved with answering each core question. Click [HERE](#) to visit our website's new resource, Exploring the aHUS Global Patients' Research Agenda.

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