RSS 🔊

View this email in your browser



#### **Editorial**

It has been a while since our last newsletter. In that time the world has opened up a bit after COVID and Global Action has been involved in major international aHUS Conferences <u>ISN</u> and <u>KDIGO</u>. We have also been helping the development of a <u>Global Community Advisory Board</u> for aHUS. In that time our major study of the <u>aHUS Diagnosis Process</u> was also concluded.

2023 looks already to be a year with even more opportunities for Global aHUS advocacy. Global Action started the year with a new Trustee / Director Kerri Grey from Australia. Global Action now has members in four continents.

- aHUS alliance Global Action

### All the Action from the Alliance Action Website

"What would happen if robots wrote the aHUS Global articles"

https://www.ahusallianceaction.org/a-chatgpt-about-ahus/

"There are more incidents each year of secondary aHUS caused by bone marrow transplants than primary aHUS cause by complement dysregulation, who advocates for them?"

https://www.ahusallianceaction.org/hst-is-it-a-tma-or-an-ahus-treatment/

" aHUS Global Action answer questions about how it did its research on the aHUS diagnosis process"

https://www.ahusallianceaction.org/study-of-the-ahus-diagnosis-process-the-whys-whats-and-hows/

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

### Your World in Research



There's been some interesting aHUS research released to begin 2023 and during the final month of 2022, and many of these hold implications likely to expand the atypical HUS knowledge base for the diagnosis and treatment of this very rare disease.

Topics for both patients and clinicians are increasingly found with 'complement-mediated TMA', as the key search team. Our website maintains an aHUS Research page (HERE), and we're pleased to note a substantial number of publications added to each category so that our 'virtual library' contains over well 1,000 aHUS-specific publications. Read more about recent highlights of aHUS publications HERE.

# News & Events



We are pleased to announce that Kerri Grey (AU) has been unanimously elected as a new Trustee of aHUS Alliance Global Action, a legally registered incorporated charity No. 1167904 in England and Wales. As noted within their overview from the Charity Commission regarding the focus of this team, "Its operational activities objectives are to promote global awareness of aHUS,work with International aHUS researchers and support newly emerging national aHUS patient groups by connecting, informing and collaborating with interested groups." We're fortunate to have Kerri Gray as a new Trustee on the aHUS Alliance Global Action team, which is in addition to the experience and insights she has brought to the aHUS Global Community Advisory Board (aHUS CAB). Kerri brings a wealth of experience in aHUS advocacy, click HERE to read our interview with her.

# Rare Disease Day 2023

Rare Disease Day is observed every year on the last day of February. The aHUS Alliance also participates every year. Click <u>here</u> to see what we are planning to do this year and <u>here</u> to see why we are doing this!

# **Subscription Options**

Please click here to subscribe to this newsletter.

Please click here to unsubscribe from this newsletter.







Copyright © 2023 The aHUS Alliance, All rights reserved.

Want to change how you receive these emails?
You can <u>update your preferences</u> or <u>unsubscribe from this list</u>.

