

aHUS Awareness Day is 24 September, Raising Visibility for Rare Disease Patients with Atypical HUS

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BARNHART, Mo., Aug. 12, 2015 /PRNewswire-USNewswire/ -- The aHUS Alliance, a confederation of 14 nations with atypical HUS patient organizations, has announced plans for a global awareness campaign on 24 September 2015, dedicated to sharing information and insights into the extremely rare disease Atypical Hemolytic Uremic Syndrome and the issues facing aHUS patients.



Atypical Hemolytic Uremic Syndrome is a life-threatening disease characterized by the systemic formation of blood clots (TMAs) throughout the body potentially causing damage to the kidneys and other organs, with complications that may include serious or fatal events including stroke, cardiac issues, and kidney failure. It affects both adults and children and is often associated with an uncontrolled activation of the complement system, part of the body's protective immune system.

The theme for aHUS Awareness Day is 'Communication'. There are many common concerns that affect aHUS patients regardless of nation, culture, or language such as: the need for quick and accurate diagnosis, access to treatment and healthcare options, shared data and information among aHUS researchers worldwide, and increased physician education about atypical HUS. Noted Linda Burke, an American representative with the aHUS Alliance, "Issues facing rare disease patients affect not only the individual with the disease, but also include the social, financial and societal impact among family members, the workplace, the healthcare system, and many other areas."

At the core of patient treatment, caregiver concerns, medical team coordination, and disease research is communication of information and issues. Len Woodward, a UK representative of the aHUS Alliance remarked, "Our goal for international aHUS Awareness Day was to provide families affected by aHUS and patient organizations to have an opportunity to join together and to shine a spotlight on aHUS around the world. We encourage medical and research teams, pharma, healthcare professionals, geneticists and policy makers to communicate their own message about aHUS issues and their team's commitment to improved patient outcomes."

September 24, 2015 was selected as the inaugural date for the first aHUS Awareness Day because during this same week 60 years ago the term *Haemolytic Uraemic Syndrome* first appeared in medical literature. HUS was given its name by Conrad von Gasser, when he and his research team described in an article for a Swiss clinical publication the illness they had been studying which caused blood clotting, anemia and kidney failure. On 24 September the aHUS Alliance invites all stakeholders in aHUS community to join together and aid visibility to highlight information, insights, and issues specific to aHUS.

The aHUS Alliance encourages every nation, all individuals affected by aHUS, and corporate or medical teams to create an aHUS Awareness Day event, plan, or project for September 24 that centers on the importance of communications. Whether the choice is to focus on global aHUS issues, key national concerns, insights into patient life, supportive messages, or innovative programs, stakeholders in the aHUS arena will join together to provide an authentic view of issues and healthcare concerns facing aHUS patients today.

aHUS Alliance - About Us:

The **aHUS Alliance** is an umbrella organization of Atypical Hemolytic Uremic Syndrome Patient Organizations from around the world.

Our coordinated efforts center on the common goals of supporting aHUS patients and their families, discussing and addressing common concerns, and improving access to drugs and therapies that can save lives and improve outcomes.

LEARN MORE about the aHUS Alliance at <http://www.ahusalliance.org/>
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