Atypical Hemolytic Uremic Syndrome (aHUS)

Atypical hemolytic uremic syndrome (aHUS) is a genetic, chronic, ultra-rare disease that can cause progressive injury to vital organs—primarily the kidneys—via damage to the walls of blood vessels and blood clots.[1,2]

Signs and Symptoms Can Include:[1-16]

- Kidney dysfunction that can lead to end-stage renal disease
- Cardiovascular symptoms, such as heart attack and high blood pressure
- Neurological symptoms, including stroke and seizure
- Pulmonary symptoms, including trouble breathing and pulmonary edema
- Thrombosis outside of the kidneys
- Gastrointestinal complications, such as diarrhea, abdominal pain, nausea and vomiting

aHUS can cause sudden organ failure or a slow loss of function over time, potentially resulting in the need for a transplant, and in some cases, death.[17]

Within one month after onset of aHUS, 46% of adults and 17% of children reached **end-stage renal disease or died**.[18]

JULIA (RIGHT) AND HER SISTER
LIVING WITH aHUS

JUSTICE AND HIS PARENTS
LIVING WITH aHUS

Kidney failure is one of the most common signs of aHUS.[1-5]

Within 1 year of follow-up, 56% of adults and 29% of children **required renal replacement therapy or died**.[18]

What Causes aHUS?

aHUS is caused by chronic, uncontrolled activation of complement, a part of the body's natural immune system, resulting in complement-mediated thrombotic microangiopathy (TMA)—the formation of blood clots in small blood vessels throughout the body.[1-4] TMA can lead to stroke, heart attack, kidney failure and premature death. aHUS is caused by a mutation in one or more genes, which results in the uncontrolled and excessive activation of the complement system.[4,5,6] In healthy individuals, complement is used to attack foreign particles, and the system is highly regulated to prevent it from causing damage to tissues and organs. However, in patients with aHUS, when complement is activated, it cannot be controlled due to underlying genetic mutations.[4]

More information about aHUS is available at ahussource.com.

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How Is aHUS Diagnosed?

aHUS can be difficult to diagnose. Because it's so rare, many doctors have never encountered a case of it. Additionally, symptoms can vary among patients. While some may not have symptoms for extended periods of time, others may feel sick frequently.[19-20]

aHUS shares symptoms with two other diseases, but laboratory tests can help differentiate aHUS.[8,21] If aHUS is suspected, laboratory tests should be conducted. Low red blood cell and platelet counts, as well as elevated creatinine levels, may be signs of aHUS.[1,6] Although 50-70% of patients with aHUS have identifiable genetic mutations, genetic testing is not required for diagnosis.[22,23]

How Is aHUS Managed?

Disease management approaches—such as plasma therapy, dialysis or kidney transplant—do not specifically target uncontrolled complement activation, the underlying cause of TMA in patients with aHUS.[1,5,6]

In recent years, increased understanding of the role of complement in aHUS has led to major advances in diagnoses and care.

The prognosis of aHUS can be poor in many cases, so a timely and accurate diagnosis—in addition to treatment—is critical to improving patient outcomes.[1,2]

DONNAN (CENTER) WITH HIS KIDS
LIVING WITH aHUS

> **"Knowing now what I have brings a real peace to my life because I can sum up multiple things into one. I can chase my kids and play again."**
>
> **DONNAN**
> LIVING WITH aHUS

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