

## Atypical HUS: An extremely Rare Disease

- *Atypical Hemolytic Uremic Syndrome* is a life-threatening and life-long disease that affects patients of all ages –it has different spellings and abbreviations (aHUS, SHUa, more)
- Nations define ‘rare disease’ differently, so statistics vary. Research estimates vary between 2 to 5.5 aHUS patients per million people
- With about 7.5 billion people on earth, statistics of aHUS incidence indicate there could be between 15,000 to 41,000 atypical HUS patients worldwide
- Caused by a change in genes, aHUS symptoms and severity vary greatly among patients. Episodes of aHUS activity can flare unpredictably and without warning, through the person’s lifetime

## Multiple Organs are Affected

- Atypical HUS displays signs of thrombotic microangiopathy (TMA), where tiny clots forming in small blood vessels may cause damage anywhere in the body
- Organs most often affected are the kidneys, the brain and central nervous system, and the heart (but also lungs, GI tract, skin, eyes, more)
- Issues caused by aHUS activity can seem mild (stomach pain or headaches, memory issues) or be more severe (seizures or stroke, cognitive impairment)
- High blood pressure and kidney function issues are common, and monitored closely as they can complicate medical care for aHUS patients

## Symptoms Vary Widely & Differ in Severity

- People with aHUS face ongoing and future risks of serious, sudden medical events. As a result of damage caused by the disease, dialysis or a kidney transplant may become necessary
- Many symptoms are vague, or mimic other illnesses, which makes diagnosis of atypical HUS difficult, such as: Stomach or Intestinal Issues (ranging from stomach or GI pain to pancreatitis)
- Fatigue (due to destruction of red blood cells). Bruising or excessive bleeding (due to low platelet counts, consumed in clotting) which may appear as a pinpoint skin rash (petechiae)
- Memory Difficulties (ranging from mild to more serious cognitive impairment, related to poor kidney function or central nervous system issues)
- Trigger mechanisms for overactive immune responses (complement dysregulation) are unclear, but include infections (bacteria or viruses), pregnancy, certain drugs, more.

## Impact as an Invisible Illness

- Most symptoms not visible to the casual observer. Symptoms vary dramatically for the same person over time, so accommodations at work or school may be necessary at times.
- Atypical HUS can affect performance and cause abilities to vary at work or school. Patients and physicians can inform employers or school staff about changes in individuals' needs.
- Physical health can change rapidly and with dramatic medical presentations of aHUS activity, usually with little or no warning signs.
- Social impact & economic burden can affect all areas of life for aHUS and their caregivers (such as mental health, daily routines, relationship issues, lifestyle impact on the family, more).



For further information, including aHUS research, articles and resources, see *aHUS Key Info & Facts* at [www.aHUSallianceAction.org](http://www.aHUSallianceAction.org)

GeneReview® (Detailed Medical Info about aHUS) <https://www.ncbi.nlm.nih.gov/books/NBK1367/>