

# Alport Syndrome Fast Facts

Most people have never heard of Alport Syndrome. The following are 10 basic facts about this hereditary disease.

1. Alport Syndrome is a rare kidney disease\*. It causes a decline in kidney function, hearing loss and vision problems.
2. It is significant inherited cause of kidney failure in children, adolescents and young adults.
3. Alport Syndrome is caused by genetic mutations that affect the type IV collagen family of proteins in the connective tissue or basement membrane of the kidneys, ears and eyes.
4. Alport Syndrome leads to kidney failure in 50% of the boys with the predominant, X-linked form of Alport Syndrome by age 25 and 90% by age 40. These patients require dialysis or a kidney transplant.
5. Some girls with Alport Syndrome are impacted similarly to boys but most see later disease progression because of the way the disease is inherited. Because girls and women often have milder symptoms, they may believe they are simply carriers; however, as many as 12% of female patients develop kidney failure by the age of 40; this rate increases to 30% by the age of 60 and 40% by age 80.
6. Much has been learned about Alport Syndrome in recent years, but it is still often misdiagnosed or undiagnosed. The average amount of time for a patient to get a diagnosis is 2 years.
7. An early and accurate diagnosis is essential as people with Alport Syndrome (or any chronic kidney disease) lose most of their kidney function before they start to have symptoms.
8. There is currently no treatment proven to prevent the development of kidney failure in people with Alport Syndrome; however, some medications can delay disease progression if begun early.
9. An Alport Syndrome diagnosis devastates families because it often affects multiple family members across generations.
10. As a disease classified as both rare\* and orphan\*\*, Alport Syndrome receives relatively little attention and funding. By raising awareness, ASF is working to change this and hopes to find better treatments and a cure to prevent kidney failure and hearing loss in all patients.

Go to [www.alportsyndrome.org](http://www.alportsyndrome.org) to learn more.

- In the U.S., a rare disease is any one which affects fewer than 200,000 people. It is estimated there are between 30,000 and 60,000 people in the US with Alport Syndrome.

\*\* An orphan disease is one not adopted by the pharmaceutical industry as it provides little financial incentive to make and market medications.