



## Fast Facts: Alport syndrome

1. You are not alone! There are tens of thousands of people all over the world living satisfying, productive lives with Alport syndrome. While it's estimated that less than 200,000 people in the U.S. have Alport syndrome, research suggests it's likely that more people have the condition than previously thought.
2. Alport syndrome causes a decline in kidney function and can cause hearing loss and eye abnormalities. While rare, some patients may experience diffuse leiomyomatosis, which causes noncancerous tumors found in smooth muscle tissue, including the esophagus. There are also clinical reports and increasing patient reports of instances of aortic and abdominal aneurysms in Alport families, especially in those with a history of cardiac complications.
3. Alport syndrome is caused by genetic mutations that affect the type IV collagen found in the kidneys, ears, and eyes. It is passed down genetically in families and sometimes occurs spontaneously, meaning you might be the first in your family to have it. The three commonly studied types of Alport syndrome are X-linked (the most documented), autosomal recessive, and autosomal dominant.
4. Both males and females are affected by Alport syndrome. While many females may initially have milder symptoms and experience a later onset of disease progression, it is not accurate to think of them as genetic "carriers." Seeing a nephrologist regularly and following [recommended treatment guidelines](#) for Alport syndrome patients is important for both females and males.
5. The current standard of treatment is ACE/ARB medications, which research shows can delay decline of renal function. These medications are prescribed to Alport patients as young as 12 to 24 months of age to slow the spilling of protein from the kidneys, which causes scarring and a decline in kidney function. Although this class of medications is widely used to treat high blood pressure, they are recommended as standard treatment for Alport syndrome whether patients have high blood pressure or not.