

ALPORT SYNDROME

Alport Syndrome Occurs In Approximately 1 In 50,000 Newborns

Over 95% Of Women With Alport Syndrome Have Blood In The Urine, So They Have The Disease

Alport Syndrome is a rare genetic disorder characterized by progressive kidney disease and abnormalities of the ears and eyes. It most often affects males. Women can pass the gene for the disorder to their children, even if they have no symptoms.

This resource is intended to help educate patients on Alport Syndrome symptoms, treatment and prevention options.

01 | Alport Syndrome Symptoms

Alport Syndrome damages the tiny blood vessels in the glomeruli of the kidneys. The destruction of the glomeruli over time leads to blood in the urine and may decrease the effectiveness of the kidney's filtering system.

In women, the disorder is usually mild with few to no symptoms. In men, the symptoms are more severe and get worse faster, symptoms may include:

- Abnormal urine color
- Ankle, feet, and leg swelling
- Blood in urine
- Protein in the urine
- Decreased or loss of vision (more common in males)
- Flank pain
- Loss of hearing (more common in males)
- Swelling overall and around the eyes

02 | Treatment

The goals of treatment include monitoring and controlling the disease and treating the symptoms. It is most important to strictly control blood pressure. Angiotensin-converting enzyme inhibitors and

angiotensin receptor blockers can control blood pressure and slow the rate at which the disease gets worse.

You may need to treat chronic kidney disease. This can include changing your diet, limiting fluids, and other treatments.

There is also surgery that may be needed to repair cataracts or bulging of the lens in the eye. Finally, hearing loss is likely to be permanent. Counseling and education to increase coping skills can be helpful.

03 | Prevention

This uncommon disorder is inherited. Awareness of risk factors, such as a family history of the disorder, may allow the condition to be detected early.

It's important to raise awareness and understanding in order to provide better care of patients, improve the future of sufferers and ultimately facilitate faster diagnosis. For additional resources on Alport Syndrome, please visit: <http://alportsyndrome.org>

Did You Know?
Alport Syndrome causes progressive kidney damage

References

- <https://www.kidney.org/atoz/content/alport>
<http://alportsyndrome.org/>