



Talking Points

The following talking points have been provided as a tool for promoting awareness of Alport Syndrome.

Introduce Yourself

- Include your name, city and state (if they don't know this already).
- Thank people for taking the time to listen to you.
- Explain that Alport Syndrome is a kidney disease that affects your family.
- You are raising awareness of this rare disease and the Alport Syndrome Foundation as part of Alport Awareness Month during March in conjunction with National Kidney Month.

Introduce Alport Syndrome

- Alport Syndrome is a rare hereditary kidney disease that causes a decline in kidney function, hearing loss and vision problems.
- 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. Girls are affected too, with some impacted similarly to boys but most seeing later disease progression because of the way the disease is inherited.
- There is no cure for Alport Syndrome and no treatment proven to prevent the development of kidney failure; however, early diagnosis is essential as there are medications to delay the progression of the disease.

Tell Your Personal Story

- Briefly tell your family's journey with Alport Syndrome.

Ask for Their Support

- The Alport Syndrome Foundation is focused on finding novel treatments and a cure to prevent kidney failure and hearing loss in all patients.
- The majority of funds have gone directly to fund Alport Syndrome research and other programs benefiting the Alport Syndrome community.
- Alport Syndrome remains a rare disease that gets relatively little attention and funding. Your support can help build the amount of resources applied to finding more effective treatments for Alport Syndrome.
- Can I count on you for a \$25, \$50 or \$100 donation? Any amount is appreciated.

Thank Them Again

- Express appreciation for their time and interest. If they make a donation, acknowledge their generosity.

Follow Up

- If they don't make a donation when you speak with them, follow up in a few days. Be sure to send them a personal thank you note for any donation they make.
- You can refer them to the ASF website for more information or to make an online donation in your honor.
- www.alportsyndrome.org