



## ASF Top 5 Goals Reached in 2021

- Established an 8-person [Scientific Advisory Research Network](#). The role of this collaborative, international group of Alport syndrome experts is to provide guidance on how to best achieve targeted research objectives. ASF invested over \$230,00 in targeted research and research-related activities in 2021.
- Established a 6-person [Emerging Leadership Council](#) (ages 25–35) and subsequent creation of a [downloadable Patient Guide](#). The purpose of this group is to ensure the voice of diverse patients and families is well represented in ASF’s decision making and to help develop the next set of leaders to sustain ASF into the future.
- Increased registration of our annual Alport Connect meeting by 93%. 484 people registered to attend this patient-focused event from all 50 states, the District of Columbia and Puerto Rico, as well as from 25 additional countries. An educated, empowered, and engaged community leads to better outcomes for patients and families.
- Implemented a new way to connect patients through Alport Direct Connect Meeting Groups: Ages 18-35, 35-50, 50+, as well as transplant-focused meetings. Look for these meetings to increase in groups and frequency in 2022.
- Expanded patient-focused capacity by hiring a third full-time [Staff Member](#), Afton DeLucca, as Patient Engagement Coordinator.