



- The launch of the International Society of Glomerular Disease (ISGD) coincided with this Podocyte conference. Its goal as a professional society is to advance knowledge of glomerular diseases within the field of nephrology. Dr. André Weinstock, ASF's volunteer Research Director has been invited to serve on the clinical trials committee for the ISGD.
- Research presentations from across the globe highlighted that Alport syndrome is the single most common cause of monogenetic glomerular disease. Since Alport syndrome is more common than originally understood, researchers are starting to see patients who have both Alport syndrome and non-genetic glomerular diseases such as IgA nephropathy. It remains unknown if this is just an outcome of statistical probability or if there is an underlying risk factor to Alport genetic variants that trigger a compliment response.
- Several research papers and presentations focused on intronic genetic variants of diseases, including Alport syndrome. Intronic genetic variants cannot be detected by today's standard genetic testing making it possible for a genetic test report to be negative or inconclusive even when a patient very clearly has a disease. Historically, it was thought that intronic genetic variants of Alport syndrome were exceedingly rare. However, this latest research shows that 5% - or maybe as high as 10% - of all Alport syndrome variants may be intronic. With this information, ASF is re-emphasizing its dedication to educating clinicians and geneticists that a negative genetic test result from standard modern genetic screening does not preclude an Alport diagnosis. A wholistic approach including family history, kidney biopsy results, and hearing and eye health metrics should remain the standard-of-diagnosis.
- ASF's natural history study in collaboration with the [NEPTUNE research consortium](#) was featured in a poster at the conference. There was great interest in the study as a tool for researchers as well as pharmaceutical companies considering exploration of Alport syndrome.
- Some presentations from rare kidney disease researchers referred to our disease as a type of steroid resistant nephrotic syndrome (SRNS) or steroidal resistant focal segmental glomerular sclerosis (SR-FSGS), noting the genetic cause as COL4A3, COL4A4, COL4A5 mutations. When published, this research will not easily be identified as related to Alport syndrome. ASF will follow up to encourage researchers to include the name of our disease as Alport syndrome. Many of the rarer SRNS diseases do not have names yet.