



Medical Advisory Committee Member Spotlight: Dr. Caitlin Carter

Why did you choose to become double certified in both pediatric and adult nephrology?

After finishing my residency in internal medicine and pediatrics, I decided to focus on kidney disease because the kidney is one of the most interesting and complicated organs in the body. I knew nephrology would keep me learning for my whole career. In addition, I wanted to be able to continue to care for patients across the spectrum of their lives and disease. Unlike many pediatric illnesses, which are often acute and curable, kidney disease diagnosed in childhood often persists. Currently my practice is mostly caring for children, but I believe there is great power in understanding the entire course of an illness and being able to frame that for patients at any age.

What sparked your interest in helping support Alport research?

I've been fortunate to have several families with Alport syndrome (AS) who were willing to share with me their experiences with the disease. This includes their medical journey but, more importantly, the impact the diagnosis has had on who they are and how they face the world. After sitting with teenage boys with impending renal failure, girls who are uncertain about their future health, and many mothers who are so saddened by the unlucky genetic circumstances of their children, it seems so obvious that the impact of AS goes beyond the quantifiable things that we focus on in our clinic visits like GFR and urine protein measurements. The research that is moving the field forward is so important to slow disease progression and ultimately cure Alport syndrome but equally because of the hope it provides to the patients and their families in those difficult moments in the clinic.

How has your membership of ASF's Medical Advisory Committee changed your relationship to Alport syndrome care and research?

Having the opportunity to connect with scientists doing the fundamental research that is going to lead to change in how we care for patients with AS gives me hope for the future of how we will treat this long term. As part of the Medical Advisory Committee, I've been able to keep informed

about potential developments and opportunities for patients to participate in improving our understanding of the disease.

What are some of your favorite memories from Alport Connect 2023 in San Diego?

I have so many good memories from my first Alport Connect meeting. The most meaningful memories are the conversations with individual patients and families about their particular circumstances, since each family and each instance of AS is slightly different. I enjoyed meeting with the teen group (even if they were a little slow to warm up to me). Finally, I was amazed by the informed and supportive community within the women's group session – the strength that came from the shared vulnerability in that group was really empowering.

This interview was conducted in December 2023. Learn more about Dr. Carter and Alport Syndrome Foundation's (ASF) Medical Advisory Committee [on the ASF website](#).