



Legislative & Awareness efforts in the Rare Disease and Kidney Health Community 2020

[EveryLife Foundation For Rare Diseases](#)

Staff and volunteer attended Rare Disease Week in Washington D.C. February 2020. Staff advocated with Rare Disease Legislative Advocates (RDLA). Staff joined the Community Congress, working to shape and advocate for policies that support the rare disease community.

[Global Genes](#)

Patient volunteer represented ASF in the Rare on the Road Meeting June 2020. Staff participated in the Fall 2020 Patient Summit.

[National Organization for Rare Disorders \(NORD\)](#)

Staff attended the NORD Summit October 2020.

[National Kidney Foundation](#)

Staff and volunteers participated in the Patient Summit September 2020. Staff participated in the 3-day NKF + FDA workshop October 2020.

[American Society of Nephrology](#)

National Kidney Week – Members of ASF’s Medical Advisory Committee presented a virtual session on Alport syndrome for thousands of nephrologist attendees October 2020. The proposed session was a year in the making, shaped and submitted by ASF and its Medical Advisory Committee members.

[World Orphan Drug Congress](#)

Volunteer Research Program Chair attended October 2020.

[Sanofi Genzyme Rare Disease Advocacy Summit](#)

Staff participated in a 2-day summit, representing the rare disease patient voice, sharing best practice recommendations with other patient organizations, August 2020.

[Revolutionizing Kidney Care Through Novel Therapies in Rare Nephrology – Dawn of a New Era of Kidney Disease Treatment](#)

Staff participated in a 3-week series of workshops and feedback sessions with other rare kidney disease patients, nephrologists, patient advocacy groups, and regulatory representatives to build consensus on challenges and solutions. Virtually presented findings to the Congressional Rare Disease Caucus and Kidney Caucus October 2020.

[KDIGO](#)

Volunteer Research Program Chair attended Controversies Conference on Genetics and Chronic Kidney Disease to represent Alport Syndrome Foundation February 2021.

[American Kidney Fund](#)

Staff participated in the Unknown Causes of Kidney Disease Summit December 2020.

[Honor the Gift](#)

ASF is an official partner of Honor the Gift. Staff participate in the Honor the Gift/Care DX advocacy event Fall 2020.