********** **FOR IMMEDIATE RELEASE – September 16, 2020** **********

TO: All Media Outlets
FROM: Alport Syndrome Foundation - United States
RE: 2020 Research Program Grant Recipients
CONTACT: research@alportsyndrome.org

In the milestone 10th year of awarding research funding, the Board of Directors and Medical Advisory Committee of Alport Syndrome Foundation (ASF) are honored to announce the 2020 Research Award of $125,000 to collaborators Dr. Moumita Barua (Toronto General Hospital Research Institute, University of Toronto) and Dr. Andrew Paterson (Hospital for Sick Kids, University of Toronto). Their project, "Sex Specific Genotype Penetrance for Predictive Diagnosis in Alport Syndrome," takes research a step further in helping answer patients' critical questions about disease progression patterns related to their specific sex and genetic mutation. Funding for ASF's Research Program is made possible by contributions from the Alport community of patients, families and friends.

In their proposal, Drs. Barua and Paterson note Alport syndrome studies in the past have been biased toward individuals with more classic and severe manifestations. They hypothesize the prevalence of Alport syndrome is higher than previous estimates as a result of this inherent bias. Defining disease prevalence and genetic factors that influence its clinical spectrum will be achieved by studying participants in the UK Biobank, and patients with severe disease diagnosed in Canadian nephrology clinics. They will also focus on examining genetic factors that lead to clinical variability amongst females with X-linked Alport syndrome.

Dr. Moumita Barua notes, "By the project's completion, our work will define Alport syndrome prevalence while also investigating novel genetic modifiers for disease progression. In doing so, our findings will improve the ability to make diagnosis to facilitate early intervention and aid in the selection of high-risk patients for clinical trials." Dr. Andrew Paterson says, "Large population-based studies along with detailed genetic data now allow us to examine how specific genetic variants in the genes related to Alport syndrome impact measures of kidney function in the general population."

2020 was the most competitive funding cycle to date, with triple the number of applicants over the prior year. This year's award selection included a rigorous peer review process of applicants from six countries. ASF is appreciative of this exponential increase in Alport syndrome research interest, and for the efforts of its Medical Advisory Board members to thoroughly and thoughtfully review all the applicants' proposed projects. The funding cycle was delayed by several months to allow researchers to regain access to their laboratories and work during pandemic quarantines. ASF expects the 2021 Research Program to return to its regular application and award cycle beginning January 2021.

For direct inquiries regarding Alport Syndrome Foundation's Research Program, contact André Weinstock, PhD, MSAS, Volunteer Research Committee Chair, at research@alportsyndrome.org

The principal goal of the Research Program is to find novel treatments to prevent kidney failure and hearing loss in all patients with Alport syndrome. Over the course of the past decade, together with its funding partners, ASF has directly invested close to $2 million in Alport research. More information available at: www.alportsyndrome.org. ********** **END**