

For Immediate Release
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Alport Syndrome Foundation Announces

Hiring of First Executive Director



Phoenix, AZ— March 21, 2016 — Today, the Alport Syndrome Foundation (ASF) Board of Directors announced the hiring of its first Executive Director, Gina Parziale, CFRE.

“This is a major and transformative step forward for ASF,” said ASF Board President, Sharon Lagas. “Instead of our previous all-volunteer structure since our founding nine years ago, we will now have a full-time professional directing our efforts. Gina will further expand ASF’s important work to achieve our vision with a special focus on fundraising.”

Gina brings to ASF more than 16 years of non-profit experience, mainly in the rare disease community. Most recently, she was a Chapter Executive Director for the Pulmonary Hypertension Association. Prior to that, she worked in Division, Program, and Development Director roles for the American Liver Foundation and the Muscular Dystrophy Association. Gina is a Certified Fund Raising Executive who is based in New York. She has a Certificate in Non-Profit Management from State University of New York and a Bachelor of Arts degree from Iona College. Most importantly, Gina is passionate about empowering patients and communities by increasing education, services and awareness, and helping to fuel research to find new treatments and a cure for Alport Syndrome.

Alport Syndrome is a rare hereditary kidney disease that causes a decline in kidney function, hearing loss and vision problems. The disease leads to kidney failure for most boys by the time they reach their 20s. Girls are affected too, with some impacted similarly to boys but

most seeing later disease progression.

An Alport Syndrome diagnosis devastates families because it often affects multiple family members across generations. There is no cure for Alport Syndrome. There is currently no treatment proven to prevent the development of kidney failure in people with Alport Syndrome; however, early diagnosis is essential as there are medications to delay the progression of the disease.

The Alport Syndrome Foundation is the leading independent nonprofit organization in the United States serving and giving a voice to the Alport Syndrome community. ASF's mission is to improve the lives of patients through education, empowerment, advocacy and research. For more information on Alport Syndrome or ASF, please visit www.alportsyndrome.org

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www.alportsyndrome.org