

Contact: Sharon Lagas
Alport Syndrome Foundation
Email: events@alportsyndrome.org
Phone: (480) 800-3510
FOR IMMEDIATE RELEASE

WOMAN CREATES FOUNDATION AFTER BROTHER DIES FROM RARE DISEASE

[January 20, 2015 - Tempe, Arizona] – Sharon Lagas and her brother Paul had been treated for a familial (hereditary) kidney disorder since they were preschoolers. Although Sharon’s symptoms were relatively mild, Paul suffered kidney failure at age 16, received dialysis for two years, and eventually received two kidney transplants. He died at the age of 38, about the same time the family received a diagnosis for his condition: Alport Syndrome.

Alport Syndrome is a rare hereditary disease that causes kidney failure, 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 milder disease progression later in life. Alport Syndrome is estimated to affect about 1 in 10,000 people, but the disease is still often misdiagnosed or undiagnosed. There is no cure for Alport Syndrome.

Although the family finally had a name for the disease that had impacted Sharon, her brother Paul and their mother, they received even more devastating news. Sharon’s two sons (ages 6 and 7) and Paul’s two daughters (ages 1 and 4) were also diagnosed with Alport Syndrome. The possibility that these four young cousins would experience the same symptoms and challenges that Paul had was devastating to the family.

Like anyone else whose family members are first diagnosed with a rare disease, Sharon wanted to connect with others dealing with this disease to get support, resources and information. However, her research efforts proved to be frustrating and time consuming. Much of the information available through existing organizations applied to kidney disease in general

rather than specifically to Alport Syndrome. The specific information she did find on Alport Syndrome was scattered in bits and pieces throughout numerous organizations and painted a very bleak picture for patients, providing no hope for the future. “It was a very difficult time,” she says. “I felt depressed, isolated, and scared.”

Sharon was disappointed that the information and resources that would help Alport Syndrome patients and families cope with this disease were not more centralized or more positive. With the encouragement of her doctor, Sharon and her friend Margaret Blue decided to create an organization to help other Alport families. In 2007 their vision became the Alport Syndrome Foundation (ASF). “Our initial goal was to gather accurate, hopeful information and help Alport families connect with others,” says Sharon, who now serves as the organization’s president. “We are here so no one ever feels alone when diagnosed with Alport Syndrome.” The Foundation started receiving international inquiries as soon as their website went live. “There was no other organization in the world dedicated to Alport Syndrome at that time.” ASF has since helped patients establish Alport Syndrome advocacy organizations in several other countries and continues to be a major voice in the international Alport community.

The newly-formed ASF Board was soon reaching out to the medical community to both obtain and distribute clear, accurate information about Alport Syndrome, the treatments available, and research being conducted. Board members attended the American Society of Nephrology (ASN) in 2007 and continues to attend their annual Kidney Week event each year. ASF has also hosted symposiums on Alport Syndrome at the International Pediatric Nephrology Association (IPNA) Congress in New York in 2010 and at the Shanghai Congress in 2013. The Board’s association with two of the largest medical associations in the world specifically for kidney specialists led to connections with physicians and researchers in these

organizations that were invaluable when ASF created a research program in 2011. ASF and their partners have since funded over \$700,000 in Alport Syndrome research, raised primarily through the *Annual Campaign for Healthy Kidneys* each fall and the *Arizona 5K for Healthy Kidneys* each spring.

The 8th annual *5K for Healthy Kidneys* will be held on Sunday, April 19, at Kiwanis Community Park in Tempe off Baseline Road and Ash Avenue. This is the signature event for ASF, which hosts the race every spring to raise awareness of the risks of chronic kidney disease - including Alport Syndrome – and raise funds for education and outreach, including patient and academic conferences.

The first *5K for Healthy Kidneys* was held in 2007, the same year ASF was founded. Sharon and her family have played a key role in organizing the event each year. In addition to the 5K race, which will tour the park on their pre-established closed-course 5K trail, the event will include a deejay, vendors, refreshments, great door prizes, and awards for the top racers. Nearly 350 runners and walkers participated in last year's *5K for Healthy Kidneys* event.

Registration is \$30 for adults and \$15 for children 13 and under. Beginning April 18, registration fees increase to \$35 for adults and \$20 for children.

Please visit <http://alportsyndrome.kintera.org/arizona5k2015> for more information or to register. The registration site also has free online fundraising tools available. Fundraisers will receive a raffle ticket for every \$100 raised for the event. See the registration site for more details on the raffle. Sponsor/vendor opportunities are also available online or by contacting Sharon Lagas at (480) 800-3510.

About Alport Syndrome and the Alport Syndrome Foundation

Alport Syndrome is a rare hereditary kidney disease that impacts the kidneys, ears, and eyes. An Alport Syndrome diagnosis devastates families because it often affects multiple family members in every generation. There is currently no treatment proven to prevent the development of kidney failure in people with Alport Syndrome; however, some medications can delay it. There is no cure for Alport Syndrome.

The Alport Syndrome Foundation (ASF) is the leading non-profit organization in the United States serving and giving a voice to the Alport Syndrome community and has grown to become an international presence in outreach, education and research.

For more information, please visit www.alportsyndrome.org.

###