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FOR IMMEDIATE RELEASE

SMALL NONPROFIT HAVING A BIG IMPACT DURING NATIONAL KIDNEY MONTH

[February 18, 2014 - Tempe, Arizona] – The 7th annual family-friendly *5K for Healthy Kidneys* will be held on Sunday, March 30, at Kiwanis Community Park in Tempe off Baseline Road and Ash Avenue. This is the signature event for the Alport Syndrome Foundation (ASF), which hosts the *5K for Healthy Kidneys* every March in recognition of National Kidney Month. This March, in addition to the local 5K event, Alport Syndrome patients and family members across the country will host activities throughout the month as part of Alport Awareness Month to increase awareness of the risks of kidney disease, Alport Syndrome, and the need for organ donors. ASF will also participate with other kidney organizations in the Kidney Advocacy Patient Summit in Washington, DC, on March 3-4 aimed at educating legislators on the need for greater government investment in prevention, early detection and delaying progression of kidney disease as a matter of saving lives and federal dollars.

National Kidney Month emphasizes the importance of kidneys to general health and raises awareness of the impact of chronic kidney disease. Millions of Americans have chronic kidney disease that can usually be successfully treated early in the disease progression; however, because there are often no symptoms until the kidneys fail, most people don't know to seek preventative medical care. The national recognition seeks to educate Americans, legislators, and the medical community on the importance of routine testing to detect kidney disease in the early stages. The Kidney Advocacy Patient Summit will increase legislators' awareness of chronic kidney disease when they hear directly from kidney patients representing the gamut of kidney

disease causes, but who speak with one united voice on the need for greater government investment in preventing, detecting and treating kidney disease.

Alport Awareness Month is designed to increase the visibility of Alport Syndrome through a variety of grassroots efforts by patients and families across the country. Alport Syndrome is a hereditary kidney disease that causes a decline in kidney function that leads to kidney failure, and eventually dialysis or a transplant. Like many other kidney diseases, early diagnosis can significantly prolong kidney function in patients with Alport Syndrome. The disease is considered a rare disease. Most people have never heard of Alport Syndrome unless they know someone who has been diagnosed with it. “Our goal is to expand available resources to make Alport Syndrome a treatable disease. Increasing awareness of the disease is a significant step toward that goal,” said Sharon Lagas, president and co-founder of ASF. “Although the Foundation has raised over \$1 million dollars to increase patient resources and support research for this disease, Alport Syndrome still gets relatively little attention and funding.” ASF works tirelessly to change that.

All Valley residents are invited to participate in the annual *5K for Healthy Kidneys* in Tempe on March 30 as part of the annual recognition activities. The annual 5K race will tour the park on their pre-established closed-course 5K trail, and will include a deejay, vendors, refreshments, great door prizes, and awards for the top racers. Nearly 300 runners and walkers participated in last year’s *5K for Healthy Kidneys* event. Members of the Alport Syndrome Foundation, Donate Life, Arizona Kidney Foundation, Alport Syndrome Patient Registry, and others in the community will be at the event to raise awareness of the risks of kidney disease and the need for organ donations.

Registration is \$25 for adults and \$15 for children 13 and under. Beginning March 29, registration fees increase to \$30 for adults and \$20 for children.

Please visit <http://alportsyndrome.kintera.org/arizona5k2014> for more information or to register. Volunteer and sponsor/vendor opportunities are also available online or by contacting Sharon Lagas at (480) 800-3510.

About Alport Syndrome and the Alport Syndrome Foundation

As noted above, Alport Syndrome is an inherited disease of the kidney that can also affect hearing and vision. It is estimated to affect at most 1 in 5,000 people

Patients of all ages can exhibit symptoms of the disease; however, the majority of those affected by Alport Syndrome are boys who require dialysis or a kidney transplant by their early 20s.

There is currently no treatment that has been proven to prevent the development of kidney failure in people with Alport Syndrome, which is why ASF has directed the majority of the Foundation's resources to medical research to identify an effective treatment and ultimately find a cure.

The Alport Syndrome Foundation (ASF) is an all-volunteer-led, non-profit organization founded by a group of families affected by the disease and guided by a Medical Advisory Committee of renowned Nephrologists. ASF is the leading independent non-profit organization in the United States serving and giving a voice to the Alport Syndrome community. In just six years, the Foundation has grown to become an international voice in outreach, education and research of Alport Syndrome.

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

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