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FOR IMMEDIATE RELEASE

ANNOUNCING FUNDING FOR ALPORT SYNDROME RESEARCH

[June 22, 2015 - Phoenix, Arizona] – The Alport Syndrome Foundation (ASF), Pedersen Family, Kidney Foundation of Canada (KFOC) Research Funding Program is pleased to announce that joint funding has been awarded for two research projects on Alport Syndrome, a rare genetic kidney disease.

“We are pleased with the response and quality of research which the program has attracted and the progress which is being made in finding new drugs to further delay the progression of this disease,” said Harold Pedersen on behalf of the Pedersen Family. Elisabeth Fowler, National Director of Research for KFOC agreed. “We are very pleased to continue this productive partnership and to jointly fund these studies,” she said. “We hope to generate new knowledge that can lead to better treatments and eventually a cure for Alport Syndrome.”

Alport Syndrome is a rare hereditary kidney disease that causes kidney failure, hearing loss, and vision abnormalities. Most boys experience kidney failure by the time they reach their early 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 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. Current research is advancing our knowledge of other drugs which could potentially further delay the onset of this disease while work continues on a cure.

Research projects awarded this year by ASF, Pedersen Family and KFOC include:

- Dr. James Scholey of the University of Toronto was awarded \$100,000 for a one year study on *Drug Repurposing for the Treatment of Experimental Alport Syndrome*. This study will target the patterns of gene expression in the kidney associated with the progression of kidney injury using an FDA-approved drug vorinostat. It will be determined if this drug prolongs the lifespan of mice and if combined treatment with ACE inhibitors (current first line of treatment for Alport Syndrome patients) provides additional benefit.
- Dr. Jeffrey Miner of Washington University was awarded \$76,500 for a one year study on *WISE Antibody as a Treatment for Alport Syndrome*. The goal of this study is to test the effectiveness of two antibodies at slowing the progression of kidney failure both separately and with ACE inhibition in mice models.

For full abstracts on these studies, please go to the ASF [website](#).

ASF and its partners have provided over \$1 million for Alport Syndrome research and have funded researchers at the University of Minnesota, Washington University, Saban Research Institute/Children's Hospital Los Angeles, University of Melbourne (Australia), Monash University (Australia), University Medical Centre Göttingen (Germany), and University of Toronto (Canada), in addition to funding the patient registry.

ASF is collaborating with its partners and others in the international community to build a research agenda that will lead to better treatments for Alport Syndrome patients. ASF co-sponsored the first-ever International Workshop on Alport Syndrome at Oxford, UK, in January 2014, and a follow-up meeting in Philadelphia, PA, in November 2014. These workshops bring together all stakeholders (patients, clinicians, researchers, biotech/pharma) in the community. The next research workshop will be at the University of Göttingen, Germany, in September 2015.

“Our vision is to make Alport Syndrome a treatable disease and find a cure,” said Sharon Lagas, President, ASF. “We are thankful to have partners to work with us to realize this vision and recognize that global collaboration is very important in garnering more resources for this rare kidney disease. It is our hope that other Alport Syndrome organizations around the world will partner with us in the future to advance our shared vision.”

About the Alport Syndrome Foundation

ASF is the leading independent, all-volunteer 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 to realize the vision of making Alport Syndrome a treatable disease and finding a cure.

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

About the Pedersen Family

The Pedersen Family from Calgary, Alberta is the largest funder of Alport Syndrome research in Canada. Funding to date is \$1 million. Funding has been directly to researchers and through the KFOC in collaboration with the Alport Syndrome Foundation as well as to the patient registry program (ASTOR).

About the Kidney Foundation of Canada

Kidney health and improved lives for all people affected by kidney disease - for over 50 years, this vision has guided The Kidney Foundation of Canada to be a collaborative, inventive and focused leader in the development of programs, services, research opportunities and awareness campaigns that have had a positive impact on the millions of Canadians living with, or at risk of developing, kidney disease.

For more information, please visit <http://www.kidney.ca/>.

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