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***FOR IMMEDIATE RELEASE***

**ANNOUNCING FUNDING FOR ALPORT SYNDROME RESEARCH**

[June 24, 2014 - Phoenix, Arizona] – The Alport Syndrome Foundation (ASF), Macquarie, Pedersen Family, Kidney Foundation of Canada (KFOC) Research Funding Program is pleased to announce that \$200,000 in joint funding has been awarded for two Alport Syndrome research projects in 2014 -2015.

ASF, Macquarie, Pedersen Family and KFOC will jointly fund researchers in the USA and Australia. “We were impressed with the response and quality of research which the program attracted this year,” said Harold Pedersen on behalf of the Pedersen Family. Wim Wolfs, National Director of Research for KFOC agreed. “We are very pleased to jointly fund these studies,” he said. “We hope to generate new knowledge that can lead to treatment and eventually a cure for Alport Syndrome.”

Dr. Stefano Da Sacco of Children’s Hospital Los Angeles was awarded \$100,000 for a one year study on *Podocyte response to injury in Alport Syndrome: an answer from human amniotic fluid kidney progenitors*. The study will evaluate recently identified renal progenitors from human amniotic fluid that can be differentiated in vitro into mature and functional podocytes. The physiology and pathology of the podocytes will be investigated in order to better understand the response of these cells to therapeutic compounds.

Dr. Judy Savige of the University of Melbourne and Dr. Sharon Ricardo of Monash University were awarded \$100,000 for a one year on the *Correction of the genetic defect in Alport syndrome using the TALEN approach*. This research study will attempt to repair the genetic mutations in cell lines from patients with Alport syndrome due to missense and nonsense mutations, confirm that these mutations are corrected in vitro and that the mutation is repaired, as well as to determine any increase in cell stress or apoptosis.

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

ASF and its partners have provided more than \$600,000 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), and University Medical Centre Göttingen (Germany).

ASF is the leading organization in the USA dedicated to helping families with this genetic kidney disease. The Foundation co-sponsored the first-ever International Workshop on Alport Syndrome at Oxford, UK, in January 2014, bringing together all stakeholders (patients, clinicians, researchers, biotech/pharma) in the community to discuss new ideas for research strategies on Alport Syndrome.

“Our vision is to make Alport Syndrome a treatable disease and find a cure,” said Sharon Lagas, President, ASF. “We recognize that global collaboration with others who share our vision is very important in garnering more resources to achieve this goal. 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 Alport Syndrome and the Alport Syndrome Foundation**

Alport Syndrome is a 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 many seeing more mild disease progression. Alport Syndrome is a rare disease which is often misdiagnosed or undiagnosed. There is no cure for Alport Syndrome.

ASF is a 501(c)(3), volunteer-led organization started by families impacted by this kidney disease that gives a voice to all those affected by Alport Syndrome and champions research to find a cure.

For more information, please visit [www.alportsyndrome.org](http://www.alportsyndrome.org).

### **About the Pedersen Family**

The Pedersen Family from Calgary, Alberta, actively fund Alport Syndrome research directly with the researchers and through collaboration with the Alport Syndrome Foundation and The Kidney Foundation of Canada.

### **About the Kidney Foundation of Canada**

*Kidney health and improved lives for all people affected by kidney disease* - for nearly 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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