



## Alagille Syndrome Alliance Accepting Applications for Alaina Kaitlyn Hahn Celebratory Scholarship

FOR IMMEDIATE RELEASE

January 15, 2017

Contact: Cindy Luxhoj, Executive Director  
Alagille Syndrome Alliance  
[alagille@alagille.org](mailto:alagille@alagille.org) or [cluxhoj@alagille.org](mailto:cluxhoj@alagille.org)  
(503) 970-1255 or (503) 885-0455

Tualatin, Oregon – The Alagille Syndrome Alliance (ALGSA), a nonprofit organization dedicated to furthering awareness and understanding of Alagille Syndrome (ALGS), today announced opening of applications for the Alaina Kaitlyn Hahn Celebratory Scholarship for the 2017-2018 academic year.

The Alaina Kaitlyn Hahn Celebratory Scholarship funds the education of high school graduates or GED credential recipients with ALGS who are entering or enrolled in an accredited US university, college or vocational school and choose to pursue higher education in the human biological, medical, or health sciences. This is a \$500 scholarship for a single year and is renewable one time, subject to open competition with other applicants, for a total possible award of \$1,000.

Application materials are available on the ALGSA website at [www.alagille.org](http://www.alagille.org) or by request via email to [alagille@alagille.org](mailto:alagille@alagille.org) (include “AKH Scholarship” in the subject line). The application deadline is March 31, 2017 (11:59 pm in the recipient’s time zone when submitted by email; or postmarked by for mailed applications). Award notification will occur after May 1, 2017.

The Alaina Kaitlyn Hahn Celebratory Scholarship was established in February 2015 in honor of the daughter of ALGSA Founder and Executive Director, Cindy Luxhoj. Alaina was born with ALGS on September 30, 1990, and died from this debilitating disease on January 15, 2015, when she was only 24 years old.

“Alaina cared deeply about other children and adults who battle ALGS,” said her mother, Cindy Luxhoj. “She talked, texted and emailed her many ALGS friends daily and was constantly sharing advice and experiences with parents and patients through social media. Alaina lived and breathed this disease, but never let it limit or define her.”

Alaina was a resident of Tualatin and graduated in 2009 from Tualatin High School. She went on to pursue higher education resulting in an Associate’s degree from Portland Community College in 2011 and a Bachelor’s Degree in Human Physiology from University of Oregon in 2013. Alaina was an active member of the Tualatin community, representing youth interests through the Tualatin Tomorrow Visioning Steering Committee, serving on the Tualatin Youth Advisory Council, and becoming a youth delegate to the National League of Cities Congress of Cities Conference in 2008. Throughout college and after graduating, Alaina served as a camp counselor at several summer and youth camps in Oregon, Washington, New York, and Idaho, including Camp No Limits, a camp for children with limb loss. After receiving her Bachelor’s degree in Human Physiology from University of Oregon in 2013, Alaina planned to pursue certification as an Orthotics and Prosthetics (O&P) Technician and then obtain her Master’s in O&P at the University of Washington. She hoped to one day operate her own O&P clinic for children with limb loss.

“As someone who overcame obstacles to pursue higher education and live a life full of laughter and love, Alaina was a remarkable inspiration to the Alagille and rare disease community,” noted Roberta Smith, ALGSA Director for Communications and Outreach. “The Alliance wants to remember Alaina by supporting other young adults as they pursue their dreams.”

The Alaina Kaitlyn Hahn Celebratory Scholarship fund balance is currently over \$16,000. Thanks to the ALGS Community and individual donors, the fund will help ALGS teens and young adults for years to come. The ALGSA would like the fund to be self-sustaining so any young person with ALGS who desires to follow a career in human biological, medical, or health sciences will receive a crucial financial boost in the pursuit of their educational dreams. Individuals interested in donating to the Alaina Kaitlyn Hahn Celebratory Scholarship may do so via the ALGSA's website at [www.alagille.org](http://www.alagille.org) or by contacting the ALGSA at [alagille@alagille.org](mailto:alagille@alagille.org).

### About Alagille Syndrome

Affecting roughly 8,000 individuals worldwide, Alagille Syndrome (ALGS) is a rare genetic disorder that can affect some, if not all organ systems in the body. Issues can range from severe liver disease, kidney disease, or heart disorders that could require transplantation to more mild symptoms like facial features, butterfly vertebrae, and eye anomalies.

Complications associated with ALGS generally become evident in infancy or early childhood, however due to the varying degrees of severity per individual, some go undiagnosed into adulthood.

### About the Alagille Syndrome Alliance

Founded in 1993, the Alagille Syndrome Alliance (ALGSA) is a nonprofit patient advocacy organization dedicated to *mobilizing resources, facilitating connections, promoting unity, and advocating for a cure to inspire, empower, and enrich the lives of people affected by Alagille Syndrome*. Representing the global community, the ALGSA seeks to connect individuals with ALGS to resources and education while furthering scientific understanding and treatment options for this complex condition.

###