



## **Alaina Kaitlyn Hahn Celebratory Scholarship For Students with Alagille Syndrome (ALGS)**

### **2024 Application Information**

<b>Sponsored by:</b>	<b>Alagille Syndrome Alliance (ALGSA)</b>
<b>Scholarship Value:</b>	<b>\$1,000 (renewable for one year, subject to open competition with other applicants, for a total possible award of \$2,000)</b>
<b>Applications Open:</b>	<b>April 1, 2024</b>
<b>Application Deadline:</b>	<b>April 30, 2024 (11:59 pm in the recipient's time zone when submitted by email; or postmarked by April 15, 2024, for mailed applications)</b>
<b>Award Notification After:</b>	<b>May 15, 2024</b>

#### **Background**

In February 2015, the Alagille Syndrome Alliance (ALGSA) established the Alaina Kaitlyn Hahn Celebratory Scholarship in honor of the daughter of ALGSA Founder, Cindy Luxhoj. Alaina was born with Alagille Syndrome (ALGS) on September 30, 1990, and died from this debilitating disease on January 15, 2015, when she was only 24 years old. 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. The Scholarship is for \$1000 for a single year and is renewable for one year, subject to open competition with other applicants, for a total possible award of \$2,000.

Alaina cared deeply about other children and adults who battle ALGS. She talked, texted and emailed her many ALGS friends daily and was constantly sharing advice and experiences with parents and patients through social media. She lived and breathed this disease, but never let it limit or define her. A graduate in Human Physiology from the University of Oregon, Alaina was pursuing certification in Orthotics and Prosthetics with plans to obtain a Masters in O&P from the University of Washington when she died. This scholarship honors Alaina's legacy. Our goal is to make the Alaina Kaitlyn Hahn Celebratory Scholarship 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.

## Eligibility

To be eligible an applicant must:

- Be a high school graduate, expect to graduate high school by July 1, 2024, or be a GED credential recipient
- Be diagnosed with Alagille syndrome (ALGS)
- Be currently enrolled or planning to enroll at an accredited US university or college as an undergraduate student, or in a US vocational school
- Be planning to major and pursue a career in human biological, medical, or health sciences
- Be a US citizen or legal and permanent resident of the US
- Not be an employee or an immediate family member of an employee of the ALGSA
- Not be a member of the Board of Directors or an immediate family member of a member of the Board of Directors of the ALGSA
- See also Additional Program Disclosures

## Additional Program Disclosures

- ALGSA reserves the right to change, discontinue, or cancel this program at any time without notice.
- Applicants are solely responsible for submitting all required application materials by the application deadline.
- Each applicant selected to receive an award must notify ALGSA of their acceptance within 30 days of being selected, or their award will be forfeited.
- Questions about the program may be directed to ALGSA by emailing [alagille@alagille.org](mailto:alagille@alagille.org).
- Void where prohibited by law. This Program is subject to all federal, state and local laws.

## Scholarship Value

One \$1,000 scholarship will be awarded for a single year. The award may be applied to educational expenses at an accredited US university or college (undergraduate), or US vocational school. The award is renewable for one year, subject to open competition with other applicants, for a total possible award of \$2,000.

## Award Notification

All applicants will be notified about the results of the selection process. Each applicant selected to receive an award must notify ALGSA of their acceptance within 30 days of being selected, or their award will be forfeited. Award recipients will have the option to participate in publicity about the scholarship. Publicity details will be outlined at the time of notification. If the awardee accepts the scholarship, the award will be deposited with the financial aid office at the recipient's university, college or vocational school to be applied toward the recipient's educational expenses.

## How to Apply

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). Applicants may complete the application process by email or mail to the ALGSA. All submitted application materials are reviewed by the ALGSA Board of Directors Scholarship Team. The ALGSA Scholarship Team

administers the program, evaluates applications, and selects the award recipient. The award recipient will be selected based on their planned program of study, evidence of academic achievement, and personal goals and aspirations.

Primary forms and required documentation:

- Application form
- Official high school and/or university, college or vocational school transcripts from all academic institutions attended
- Letter of acceptance from university, college or vocational school, and proof of enrollment for all terms in the academic year of the award
- Signed letter from the applicant's treating physician verifying that they have ALGS. The treating physician must include his or her Medical Education (ME) number. The ME number is a 10 digit number assigned to every physician in the US by the American Medical Association for identification and recording of basic physician information. To qualify for the award, the applicant must provide permission for the ALGSA Scholarship Team to confirm their diagnosis with their treating physician.

Secondary application steps:

- Two letters of recommendation from teachers or professors, academic advisors, guidance counselors, or other individuals familiar with your academic potential and likelihood of success in higher education; recommendations from the applicant's family members or employers will not be accepted
- One- to two-page personal statement (maximum of 500 words) discussing some or all of the following:
  - How has being an ALGS Warrior helped you achieve your goals?
  - What are your academic and professional plans?
  - Why are you majoring and intending to pursue a career in human biological, medical, or health sciences?
- 3-minute video recording (provided on flash drive with application submittal or uploaded to personal YouTube channel or other platform with access information) explaining your proudest moment to date and why you deserve to be the recipient of the Alaina Kaitlyn Hahn Celebratory Scholarship
- 15-minute in-person interview (by phone or Zoom) with the ALGSA Scholarship Team

Submit application materials by email to [alagille@alagille.org](mailto:alagille@alagille.org), or mail printed copies of these materials in a single envelope to:

Alagille Syndrome Alliance  
Attn: Scholarship Team  
PO Box 22  
Collierville, TN 38027

For the 2024-2025 school year, the deadline for application materials to be submitted by email is 11:59 pm (in the applicant's time zone) on April 30, 2024. If application materials are mailed, the envelope must be postmarked no later than April 20, 2024. Incomplete or late applications will not be accepted.

**Alaina Kaitlyn Hahn Celebratory Scholarship  
For Students with Alagille Syndrome (ALGS)  
2024 Application Form**

Completion of all portions of the application is necessary for consideration.  
Please print legibly.

Last Name: \_\_\_\_\_ First Name: \_\_\_\_\_ Middle Initial: \_\_\_\_\_

Permanent Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Home Phone: (\_\_\_\_) \_\_\_\_\_ Cell Phone: (\_\_\_\_) \_\_\_\_\_

E-mail: \_\_\_\_\_ Birthdate: \_\_\_\_/\_\_\_\_/\_\_\_\_ (mm/dd/yyyy)

Gender: ( ) M ( ) F

Are you: ( ) ALGS Warrior ( ) ALGS Sibling ( ) ALGS Parent/Caregiver ( ) ALGS Child

If not you, who is the ALGS Warrior in your family: \_\_\_\_\_

Name of Current School: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

School Phone: (\_\_\_\_) \_\_\_\_\_ FAX: (\_\_\_\_) \_\_\_\_\_

Principal (if applicable): \_\_\_\_\_

Guidance Counselor (if applicable): \_\_\_\_\_

Date of High School Graduation: \_\_\_\_/\_\_\_\_/\_\_\_\_ (mm/dd/yyyy) Cum. GPA \_\_\_\_\_

Name of University or College Planning to Attend or Currently Attending:

\_\_\_\_\_

Major or Planned Course of Study: \_\_\_\_\_

Expected Graduation Date: \_\_\_\_\_ (month and year)

Address of Financial Aid Office (to which scholarship check, if awarded, should be sent):

\_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

University or College Phone: (\_\_\_\_) \_\_\_\_\_ FAX: (\_\_\_\_) \_\_\_\_\_

Academic Adviser (if applicable): \_\_\_\_\_

Registrar or Financial Aid Office Contact (if applicable): \_\_\_\_\_

First Day of Next Quarter or Semester Classes: \_\_\_\_/\_\_\_\_/\_\_\_\_(mm/dd/yyyy)

Fee Payment Deadline: \_\_\_\_/\_\_\_\_/\_\_\_\_(mm/dd/yyyy)

**Alaina Kaitlyn Hahn Celebratory Scholarship  
For Students with Alagille Syndrome (ALGS)  
Or Immediate Family Members**

**2024 Diagnosis Verification Form**

Instructions for Scholarship Applicant: Please complete Part 1 below, and then ask your treating physician to complete Part 2. You must include this completed and signed form when you submit your scholarship application materials. Please print legibly.

**PART 1 (to be completed by Scholarship Applicant)**

Applicant name: \_\_\_\_\_

Applicant relationship to person with ALGS: \_\_\_\_\_

I give permission to Dr. \_\_\_\_\_ to complete Part 2 of this Diagnosis Verification Form. I further give permission to the Alagille Syndrome Alliance (ALGSA) or an agent working on the ALGSA's behalf to contact this physician to verify my diagnosis stated in Part 2 below.

Applicant signature: \_\_\_\_\_ Date (MM/DD/YYYY): \_\_\_\_\_ (if Applicant is at least 18 years of age)

Parent/guardian signature: \_\_\_\_\_ Date (MM/DD/YYYY): \_\_\_\_\_ (if Applicant is <18 years of age)

**PART 2 (to be completed by treating physician)**

Name of treating physician: \_\_\_\_\_

Street address: \_\_\_\_\_ City: \_\_\_\_\_

\_\_\_\_\_ State: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Phone number: \_\_\_\_\_

Medical Education (ME) number\*: \_\_\_\_\_

My patient, named as the Scholarship Applicant in Part 1 above, has the following rare disease diagnosis (name of rare disease): \_\_\_\_\_

Physician signature or stamp: \_\_\_\_\_

Date (MM/DD/YYYY): \_\_\_\_\_

\*A Medical Education (ME) number is a 10-digit number assigned to every physician in the United States by the American Medical Association for identification and recording of basic physician information.