AAKP Cystinosis Patient Education and Activity Scholarship Program

About the scholarship program

The American Association of Kidney Patients (AAKP) is the oldest and largest fully independent kidney patient organization in America. The AAKP is a leader in the fields of patient engagement, patient-centered education and public advocacy efforts. Governed by a National Board of Directors that is majority patient led, AAKP understands first-hand what it means to be diagnosed with kidney disease and the necessary life adjustments that come with a chronic condition.

While a variety of factors may cause an individual to be diagnosed with kidney disease, genetic and rare causes can be especially difficult for patients and family members to manage. Understanding the need to support individuals who have kidney diseases caused by a genetic or rare condition, AAKP has expanded its education, advocacy efforts and services to those affected.

In support of AAKP's Pediatric and Rare Disease Initiatives, we are pleased to offer the AAKP Cystinosis Patient Education and Activity Scholarship Program for those affected with Cystinosis.

The objective of the scholarship program is to provide an exclusive opportunity for people living with cystinosis to provide inspiration, further their education and pursue opportunities toward long-term career goals and life aspirations.

Scholarship eligibility

This scholarship program is open to individuals diagnosed with Cystinosis. Scholarship funds are available to age groups 5-17 years of age and 18+. Scholarship funds are available to support various programs, activities and advanced educational opportunities including, but not limited to: athletic activities, art/creative programs, camps, certification programs, and furthering education. Scholarships awarded may not exceed $2,500 per individual. If applicant is a minor (age group 5-17 years of age) a parent or legal guardian must complete the scholarship application and forms on their behalf.

This educational program is supported by Horizon Therapeutics. The AAKP is the sole owner and manager of this scholarship program. Identifiable applicant information will never be shared with program supporters.

Scholarship Application Guidelines

- **Due to limited available funding, the AAKP Cystinosis Patient Education and Activity Scholarship Program is not able to approve all Scholarship requests.**

- Scholarship requests may not exceed $2,500 per individual.

- AAKP will only consider COMPLETE applications, this includes answering all questions and including a photo. If any information is missing, a denial will be made.

- Prior to submitting a scholarship application, please check with the establishment where the applicant's activity will be taking place to make sure they will accept a check from the AAKP as payment for their services. If applicant has already paid out-of-pocket for the activity, reimbursement is possible with proof of prior payment.

- Applicants may only submit one type of Scholarship application at a time.

- The **annual financial information** for the household (including ALL members in the household) that we ask for helps us to evaulate financial need. Leaving this field blank may have a negative impact on the review of your application.

- Applications should be completed by the person with Cystinosis (assistance is acceptable for adult applicants that require help due to a disability and/or physical limitations). If applicant is a minor (age group 5-17 years of age) a parent or guardian must complete the scholarship application and forms on their behalf. We encourage minors that are able to write to complete the essay portion themselves. If a child is unable to write, the parent or legal guardian may transcribe for them, but we encourage the words come from the applicant.

- **Applications are reviewed bi-annually with deadlines on:**
  - June 1st
  - November 1st
  - Applications must be received no later than midnight on the day of the deadline.

- AAKP will pay directly for activities (within six months following the deadline) to the billing activity company or organization. Reimbursement for past actvities, will NOT be paid directly to the scholarship recipient provided proof of prior payment is available.

- Funds may not be requested for the purchase of equipment, unless a necessary exception has been deemed appropriate. (Please contact us ahead of time to discuss).

- If an applicant is denied, the applicant may reapply for the same, or different activity, with a new application as soon as they would like.

- Only one Scholarship can be awarded per recipient per grant cycle.

- We ask that applicants agree to provide feedback during the period of their scholarship at intake and post-activity.

- A Letter of Reference *may* be included with the application, but it is not mandatory. If one is included, it should be from someone who is familiar with the applicant (non-relative). Examples include, member of the healthcare team, community or faith-based leader, teacher/coach.

- Please remit all final documents and accompanying materials to Valerie Gonzalez, Program Coordinator, at vgonzalez@aakp.org, fax to (813) 636-8122 or mail to AAKP, 14440 Bruce B. Downs Blvd., Tampa, FL 33613. For questions, please contact Valerie Gonzalez at (813) 400-2395 or toll-free at (800) 749-2257.

Individual Scholarship Request

(Please be sure that ALL sections of the application are filled out)

Date:_____

Have you applied for an AAKP Cystinosis Patient Education and Activity grant in the past?

No ☐ Yes ☐

Have you ever received an AAKP Cystinosis Patient Education and Activity grant?

No ☐ Yes ☐

Household Information:

How many people are in your household? _____

How many in your household have diagnosed Cystinosis? _____

What is your current **ANNUAL** combined household income? _____

Personal Information of Applicant:

First name: _____ Last name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone:_____

E-mail: _____

Age: _____ Date of Birth: _____

Applicant Signature: _____

If under the age of 18:

Parent/Legal Guardian name: _____

Parent/Legal Guardian signature: _____

Patient Education/Activity Request Information

Please be as specific as possible when providing the following information. If any information is missing or left blank we will not be able to process your request. No more than one activity is eligible per application. Please remember that the total dollar amount may not exceed $2,500. You must call or visit the establishment you are requesting funds for, before applying, to make sure they will accept a check from the AAKP as payment. If applicant is a minor (age group 5-17 years of age) a parent or legal guardian must complete the scholarship application and forms on their behalf.

Type of activity: _____

(i.e., Gym membership, summer camp, certification program, continued education, recreational/sport activity, etc.)

Name of business or organization where funds will be paid to:

_____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone number: _____ **E-mail:** _____

Contact Person: _____

Start date of activity: _____

(If there is no specific date, write ASAP)

Duration of activity: _____

(Ex. one year, 6 months, 4 weeks, etc. – may not exceed one year)

Amount requested: $_____

(EXACT dollar amount is required, there is a $2,500 maximum. Proof of cost must be provided by applicant and/or business/organization of activity and accompany this application for consideration.)

Applicant Essay

Essay Question:

How do you feel *you* will benefit from receiving an AAKP Patient Education & Activity Scholarship?

Please be as specific and thorough as possible as it will help us to determine eligibility. (If content exceeds space, please attach additional information on separate paper).

For individuals who have received a scholarship in the past, please tell us about the impact it had and what impact receiving another grant will have.

CONSENT, RELEASE AND ASSUMPTION OF RISK

1. In support of the American Association of Kidney Patients' ("AAKP") Pediatric and Rare Disease Initiatives, AAKP offers the Cystinosis Patient Education and Activity Scholarship Program (the "Program") for those affected with cystinosis. The objective of the scholarship program is to provide an exclusive opportunity for people living with cystinosis to provide inspiration, further their education and pursue opportunities toward long-term career goals and life aspirations.

2. I have voluntarily sought to participate in the Cystinosis Scholarship Program, a patient scholarship program for individuals who have cystinosis. Scholarships are intended to support furthering education, recreational activities and other events help improve a patients quality of life.

2. I understand that some activity presents a risk of injury, serious bodily harm, or death. In particular, the risks include, but are not limited to, ankle sprains, broken bones, and wrist, knee, or head injuries.

3. In consideration of being allowed to participate in the Program, I expressly agree and promise to accept and assume all such risks including personal injury and death, arising in any way out of my participation in the Program. My participation in the Program is completely and purely voluntary, and I elect to participate in the Program and related activities despite the inherent risks.

4. I represent that I have no physical or mental condition that prevents me from participating in the Program or related activities in a manner that is safe for others and myself. It is my responsibility to take all appropriate actions in advance of, and while performing any activity associated with the Program.

6. In consideration of the benefits I will receive from participating in the Program, I hereby, on behalf of myself and on behalf of my assignees, descendants, dependents, heirs, next of kin, distributees, parents, guardians, executors, administrators, successors, estate, agents, and legal or personal representatives, release and discharge and promise not to sue AAKP, as well as any person acting in his/her capacity as an employee, officer, director, agent, contractor, or representative of either (collectively referred to as "Released Parties"), from and with respect to any and all claims, losses, demands, actions, suits, causes of action, and liabilities of whatever kind or nature in law, equity or otherwise, that may arise from, are related to, or are in any way connected with the Program, including injury, death, damage or loss, whether it results from the negligence of AAKP and/or any of the other Released Parties, or from any other cause. I knowingly and voluntarily waive any and all rights and benefits conferred upon me by the provisions of Section 1542 of the California Civil Code or by any similar law or provision, which Section reads as follows: "A GENERAL RELEASE DOES NOT EXTEND TO CLAIMS WHICH THE CREDITOR DOES NOT KNOW OR SUSPECT TO EXIST IN HIS OR HER FAVOR AT THE TIME OF EXECUTING THE RELEASE, WHICH IF KNOWN BY HIM OR HER MUST HAVE MATERIALLY AFFECTED HIS OR HER SETTLEMENT WITH THE DEBTOR."

7. I understand and agree that if a claim, suit, or attachment is brought or sought against me as a result in any way of my participation in the Program, I shall not be entitled to any defense or indemnification by AAKP and/or any of the other Released Parties in connection with such claim, suit, or attachment.

8. I represent and warrant that I have the full right, power and authority to enter into and execute this Consent, Release and Assumption of Risk (this "Release") and to grant all rights granted under it, unless I am a minor, in which event my parent or legal guardian will co-sign this Release and, together, we will have the right, power and authority to enter into this Release and grant all rights granted under it.

9. This Agreement shall be governed by, construed and interpreted in accordance with the laws of the State of California.

I HAVE CAREFULLY READ THIS RELEASE AGREEMENT AND FULLY UNDERSTAND ITS CONTENTS. I AM AWARE THAT THIS IS A RELEASE OF LIABILITY, AN ASSUMPTION OF RISK, AND A PROMISE NOT TO SUE OR MAKE A CLAIM, AND I SIGN THIS OF MY OWN FREE WILL.

I DECLARE UNDER PENALTY OF PERJURY UNDER THE LAWS OF THE STATE OF CALIFORNIA THAT THE FOREGOING IS TRUE AND CORRECT.

EXECUTED (insert date): _____

Signature: _____

Print Name: _____

Parent or Guardian Signature (if applicable): _____

Print Name: _____

Contract of Agreement

Please read and ***initial EACH*** of the points below, and upon agreeing to these conditions sign at the bottom of the page.

_____ I understand I am undertaking in the education/activity requested in this application under my own (or my child's) risk, and will not hold the American Association of Kidney Patients (AAKP), nor any of its partners/sponsors, liable for any injury or negative health impact related to this activity.

_____ I understand the spirit of these funds is to help improve my lifestyle, which includes my physical, emotional, and social well-being. I will do my best to use this Scholarship funding to improve my life, and to use it toward an activity that I believe to be beneficial to my health and life aspirations.

_____ I will not sell, trade, or profit from any goods or services rendered with this Scholarship funding.

_____ I understand that the AAKP may contact my doctor to review and request endorsement of the activities requested in this application.

_____ I will update the AAKP with any address, e-mail, or phone changes.

_____ I give permission to AAKP to utilize my (or my child's) photographs, parts of my (or my child's) essay, e-mail content, thank you notes, etc. to help demonstrate the impact of this program to the public through the AAKP website, e-mails, mailings, and/or social media. ***(OPTIONAL)***

_____ _____

Applicant's Signature Date

_____ _____

Parent/Legal Guardian Signature (if under 18) Date

Contract of Agreement

*** Please fill out the top portion of this page yourself, then have your Healthcare Provider fill out the rest of this page and the following page.**

Applicant's Name:_____Applicant's DOB:_____

Applicant's chosen activity:_____

Healthcare Provider (MD only, information will only be accepted by a treating physician) (Page 1 of 2)

Scholarship Application - Request for Information

Healthcare Provider's Name:_____

Healthcare Provider's E-mail: _____

Center/Facility Mailing Address:_____

_____

City:_____ State:_____ Zip code: _____

Contact Person:_____Position: _____

Phone: _____E-mail (required):_____

Dear Healthcare Provider,

We have received an application from the applicant listed above for a Patient Education & Activity Scholarship from the American Association of Kidney Patients (AAKP). Part of our application review process is to verify with their Healthcare Provider their current health status.

The information we would like from you is as follows:

1. How long have you treated this patient?

   _____

   _____

Contract of Agreement

2. This patient has a diagnosis of Nephropathic Cystinosis (please check one)

   ____ Yes ____ No ____ Unknown

3. Do you endorse their participation in the activity listed above as potentially beneficial to their health?

   _____
   _____
   _____
   _____

4. Do you have any concerns about their participation in this activity?

   _____
   _____
   _____
   _____

As the primary Healthcare Provider for the patient listed above, I support and encourage their participation in this activity as a part of their well-being. I understand that AAKP is not promoting any form of interaction between Cystinosis patients, and the funds being applied for are strictly for individual purposes of promoting education and recreation. I feel that he/she is an excellent candidate to receive a Scholarship through the AAKP.

_____ _____

Healthcare Provider (Signature) Date

_____

Specialty

_____

Medical License