



The **AVALON**
Foundation

kidscaringforkids.orgTM

Youth Leadership Program

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YOUTH LEADERSHIP ACADEMIC OUTREACH PROGRAM

For the last five years, The Avalon Foundation has engaged with area youth to develop their leadership skills through service to the Rare Disease Community.

Available to kids ages 10 and up, our #KC4K Youth Leadership Program is dedicated to creating self-awareness of one's abilities and power to make a positive impact through service.

Some of your exceptional students are already involved and doing great work with The Avalon Foundation, and we're excited to include you as we work toward the launch of our Academic Outreach Program to schools in the area.

Your students will have an opportunity to explore philanthropy with their peers, learn from our youth leaders and adult mentors, and develop leadership skills that will support them in their academic journey and beyond.

We hope this information will help you talk to your students about the importance of volunteering and leadership skills development and identify those who would benefit from getting involved with our organization. And we'd be thrilled for you to refer those who are interested!

If you have any questions, please call our Programs Director, Jennifer Gruber, at 419.467.4762 or email outreach@kidscaringforkids.org.



DEVELOPING SERVICE-MINDED YOUTH

We're **looking for great youth leaders** in the Toledo area.

The Avalon Foundation **connects kids to other kids** who are battling rare diseases to create a network of understanding through ambassadorship and provide support programs for successful treatment.

Our goal is to encourage more kids to **volunteer** their time, **offer peer support** to kids going through treatment for rare disease and, ultimately, help kids **succeed**.

Our hope is that our new youth volunteers will develop an affinity for service and want to **join our #KC4K Youth Leadership Team**. There are also a variety of opportunities for adults to volunteer as individuals and with their children!

YOUTH LEADERSHIP OPPORTUNITIES

We're looking for kids who have a natural inclination to lead or help others, want to be involved in the community, have good follow-through, or want to share their compassion with others.

- Advisory Board
- #Painbox Shopping Team Leader
- #Painbox Wrapping Team Leader
- Peer Support Team
- Event Assistant



ADULT & FAMILY OPPORTUNITIES

Volunteering as an adult or a family is a wonderful way to share your values, spend quality time together, learn new skills and help others. There are many ways for the whole family to volunteer together or separately.

- Shopping for #PainBox supplies
- #Painbox packing and wrapping
- Helping with fundraising
- Hosting an event
- Mentoring our Youth Leaders



BENEFITS OF VOLUNTEERING

Volunteering can foster a strong sense of personal fulfillment. People who feel like they have a purpose and are making a positive impact on the world tend to have better emotional and physical health.

Youth volunteers often work in groups, which helps them **develop a sense of community** and connectedness.

Benefits for youth include:

- Increased self-esteem and self-worth
- Real world experience
- Strengthened social and professional networks
- Improved communication skills

Student volunteers have a **positive impact on their schools**, too, by modeling philanthropy, service and community engagement to their peers, as well as their teachers and administrators.

Benefits for schools include:

- Teaching collaboration
- Philanthropic opportunities
- Unity and inclusion among students and staff
- Positively highlighted in the community

Volunteerism is contagious in the best possible way. What could be more inspiring than a young person committed to helping others?

The whole community benefits from:

- Positive social change
- Increased community engagement
- New perspectives and ideas

OUR MISSION

The Avalon Foundation promotes and teaches **youth leadership** through offering **support to kids** and their families receiving life-altering treatment for a rare disease.

Our #KC4K Youth Leadership Program creates self-awareness of an individual's abilities and power to make a **positive impact on the world** through the pillars of leadership, compassion, commitment, and contribution.

HISTORY

The Avalon Foundation began with an act of kindness from a 10-year-old girl who wanted to help ease the pain and distress of other children who, like her, live with a rare disease.

Avalon was just 9 months old when her pediatrician became concerned with her gross motor skill development, but it took three years to get a diagnosis.

Hypophosphatasia (HPP) is a rare genetic disorder. There was very little research and no treatment, which is common to 85% of rare diseases.

Avie walked with gait issues, using a wheelchair and electric scooter to maximize her mobility instead of running and jumping through her childhood years. She also experienced energy, cognition and sensory processing challenges.

In 2016, at age 10, Avalon was prescribed the newly FDA-approved, first-ever treatment for HPP – a series of enzyme replacement therapy injections.

It took time to start seeing improvements and Avie struggled with the regular injections, which felt like "hot lava under her skin" and rendered her practically immobile. She desperately wanted to quit the treatment.

Avie's grandmother assembled a "PainBox" with incentives to get through each injection.

The treatment worked! After 10-12 weeks of 100% compliance, she finally experienced noticeable improvements in her physical ability, endurance and overall comfort level. She was even running and jumping around the volleyball court!

Avie told her mom that she wanted to help other kids like her through treatment. Nine months later,

The Avalon Foundation was formalized as a 501(c)(3).

YOUTH-LED ORGANIZATIONS

Having a youth founder has shaped the way The Avalon Foundation operates from day one, and we're committed to being **KID-LED**.

Our #KC4K Youth Leadership Board drives our organizational initiatives with guidance from the adults on the TAF Board of Directors and program mentors.

Through service to the rare disease community, our youth develop lifelong leadership skills, cultivate compassion and commitment, and learn to personally contribute to the betterment of society. By instilling these skills and values at a young age, we are creating a lifelong imprint that positively impacts the world.

BENEFITS OF YOUTH-LED ORGANIZATIONS

Connecting an adolescent's interest with a sense of their voice strengthens the outcome.

A national study surveyed more than 1,800 15-year-olds to determine how empowered they felt to make civic contributions. 23% reported being involved with a youth development program in which they developed trusting relationships, experienced teamwork, and were empowered to make decisions.

"The culture of the youth-driven program model promotes and demonstrates a high degree of youth ownership of the program.

The more a model is youth-driven, the more potential it provides for youth to develop not only as program participants, but also as empowered leaders learning how to change the institutions that serve them.

This experience can carry over into many other aspects of their lives and create a new level of youth engagement in our communities."

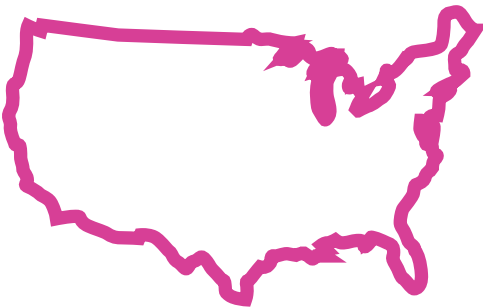
(Edelman et al., 2004)

#KC4K ACHIEVEMENTS

The #KC4K Leaders have raised awareness in the medical, corporate, youth, and public communities locally, nationally and globally. These are some of their recent achievements.



- Avalon honored with **Jefferson Award** (2021)
- Finalist for **Best of Toledo: Nonprofit** (2020)
- Youngest organization to be a finalist for the Greater Toledo Community Foundation **Innovation & Excellence Award** (2019)
- Speakers at local school and corporate events for Rare Disease Day, volunteerism, and fundraising support
- Selected by Bowling Green State University EMOD Program as an organization of focus
- Partnerships and corporate support from many local organizations



- Speaker leaders at National Organization of Rare Disorders (NORD) conferences
- NORD **Rare Impact Award** winner (2022)
- Speaker and booth attendees at the Pediatric Endocrinology Nurses (PENS) Association conferences
- National speakers for podcasts and media appearances



- Kelsey Gruber nominated for Global Genes **RARE Rising Star Award** (2022)
- Kelsey Gruber, Kaden Heldt and Grace Jeffer nominated for Global Genes **Champion in Advocacy Award** (2021)
- Katy Gruber nominated for Global Genes **RARE Founder's Award** (2021)
- Avalon Ayres and #KC4K nominated for Global Genes **RARE Champion of Hope Award** (2020, 2018)

DEVELOPING YOUTH LEADERS

Made up of at least a dozen kids ages 10 and up, the #KC4K Leadership Program is dedicated to creating self-awareness of an individual's own abilities and power to make a positive impact through service to the rare disease community.

Our program is designed to help them:

- Develop life-long **leadership** skills
- Cultivate **compassion** and **commitment**
- Teach them to personally **contribute** to society

By instilling these skills and values in kids at a young age, we are creating a lifelong imprint that positively impacts the world.

PATHWAY SUPPORT

Whether you have a small amount of time to give or can jump in at full speed, The Avalon Foundation has a multitude of volunteer options available!

Volunteers can use the QR Code below to join explore opportunities and find a way to participate.

- Send cards of support and encouragement to our patients
- Become a wrapping volunteer individually or as a family
- Volunteer to help with events
- Assist in shopping trips for our patients
- Participate in leadership opportunities and workshops
- Become a shopping trip leader
- Interview for the KC4K Leadership Board



RESOURCES

Connect



@theavalonfoundation



@theavalonfoundation



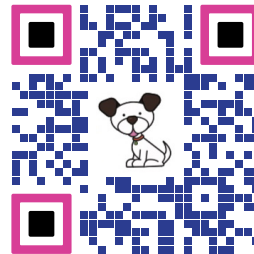
@kc4kteam



@kc4ktaf

Download

- Parent Letter
- Newsletter Insert Content
- #KC4K Volunteer Program Summary



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