



The **AVALON**
Foundation

kidscaringforkids.orgTM

A Rare Approach

connecting rare disease treatment
and youth leadership development

RARE

adj: seldom occurring or found; marked by unusual quality, merit, or appeal.



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. It took almost **3 years to get a diagnosis: Hypophosphatasia (HPP), a rare genetic disorder** in which defective mineralization (the process by which bones and teeth take up minerals such as calcium and phosphorus) causes abnormal development. Her parents poured over all the research they could get their hands on, finding very little. There was no treatment available, either.

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**. This injectable enzyme replacement therapy (ERT) called Strensiq® is produced by Alexion®, a global biopharmaceutical developing life-changing therapies for rare disorders.

In just three months, Avie went from using a wheelchair to running and jumping around the volleyball court! The results were nothing short of **miraculous**, but it took time to start seeing improvements and Avie struggled with the pain of the treatment.

Injections are painful and mentally challenging, no matter what condition you have or how old you are. Avie said the injections, required three times a week, felt like hot lava under her skin. Other side effects were practically unbearable and rendered her immobile. She desperately wanted to stop treatment, and it became increasingly difficult to maintain compliance with therapy protocol.

Avie's grandmother put together a "PainBox" with incentives to get through each injection, supporting and motivating Avie to continue with her treatment. With 100% compliance, **by 10-12 weeks she finally experienced noticeable improvements** in her physical ability, endurance and overall comfort level.

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).



Patient & Family Support

The core components of the Patient and Family Support program are:

- Peer/Parent Support
- #PainBox
- Ambassadorship



Peer/Parent Support

Peer support and social connections have profound implications on overall treatment success and long-term outcomes, especially for children.

The Avalon Foundation team conducts a thorough assessment of the individual patients and families in our program to determine their unique challenges and struggles as well as their interests and strengths.

We then customize a support program to address those challenges and struggles specifically in a way that will build long-term success for the family living with this rare disease. Recommendations may include individual and family counseling, support group participation, parent coaching, and practices that build family unity.

#PainBox

Successful treatment requires much more than just completion of injections. It requires the child, their family support system and their medical team to have complete buy-in and believe that the treatment will yield positive results.

Children need to be supported, motivated and encouraged to brave the critical medical treatment and resultant side effects.

Parents need to be educated on how to best comfort and encourage their child during this painful process as well as properly administer injections.

And siblings still need attention and support at a time when their parents are stretched very thin.



Ambassadorship

At the conclusion of treatment, patient families are invited to become Ambassadors of The Avalon Foundation and grow our network of understanding, support and commonality.

Ambassadors provide support and encouragement to others being diagnosed. Completely voluntary, this role can be vital to the psychological rebalancing of those who have experienced disempowerment through diagnosis, helping restore independence, value, and dignity.



Outside the

#PAINBOX



“The #PainBox is a marriage of science and support. Specifically tailored incentives reward compliance with therapy protocol, a strategy supported in scientific literature as behavioral therapy intervention, which is effective with adolescents. The #PainBox provides not only physical pain relief remedies, but also essential psychosocial support.”

— Dr. Clark D. Ausloos | PhD, LPC, LPSC, NCC

Avalon’s results with the incentive system of the #PainBox are paralleled by significant research regarding the importance of positive reinforcement and pain management in children.

Many studies in the last decade have focused on the best way to manage this pain, surveying the relative successes of distraction methods, analgesics, reward motivation, and comforting verbal feedback. A 2014 study looked to the most effective methods of minimizing perceived pain in children during subcutaneous methotrexate injections (treatment for pediatric rheumatic disorders) (Bechard, et al., 2014).

RESEARCHERS SURVEYED
SIX TYPES OF PAIN RELIEF:

REWARDS

REASSURANCE

COMFORT POSITIONS

ICE

DISTRACTIONS

MEDICINAL RELIEF

They found that rewarding children with toys and fun activities after the injections relieved pain in 65% of children surveyed. Only administering ice and sitting in comfort positions (hugging, holding hands) were more effective – and only marginally so – than the incentive system.

A similar study noted that once children have found effective pain relief methods, they become more willing to self-manage their pain and ultimately report better treatment outcomes than those who do not self-manage their pain (Logan, Conroy, Sieberg & Simons, 2012).

Inside
the

#PAINBOX:

MAKING MEDICINE MINDFUL

“How we think and feel about the medicines we take into our bodies significantly impacts their effect on our health, well-being, and quality of life.”

— Deborah Ayres, President
The Avalon Foundation

The #PainBox Program is Avalon’s original vision – a customized care package, tailored to each patient and their family.

The first #PainBox every child receives is special.

Our very own overstuffed mascot, Taffy the dog, arrives as a comfort companion for the child to hold onto during injections or even practice injections on to build feelings of confidence and control.

Taffy brings along a hot/cold animal for immediate analgesic relief and other supplies patients report success with.

A self-care gift bag is included for the parent(s), along with an introductory letter that provides important information about the #PainBox Program and best practices, such as comforting verbal cues and body language, that help parents ensure successful compliance with therapy protocol.

The second #PainBox includes materials for an extensive, customized incentive system that gives the child something to look forward to after the injections – usually a small game or toy. The 90-day program is executed differently based on age and injection schedule.

Acknowledging the stress that a life-altering, intensive treatment program places on the family unit, our program also include small surprises for parents and siblings, too, such as relaxation teas and board games to play as a family.

In our first 3 years,
we successfully supported over
35 families,

helping all enrolled in the #PainBox
program maintain

100% compliance

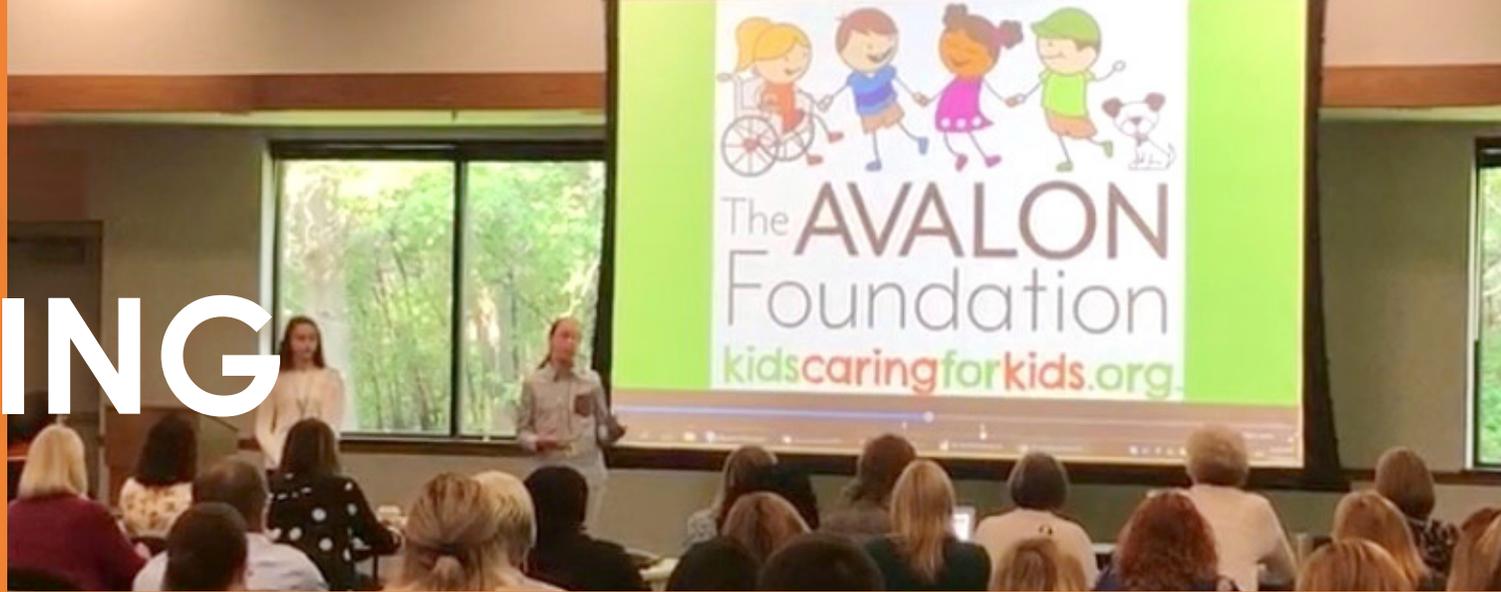
with their injection therapy.

Avalon’s experience led us to believe there must be a way to ease a child’s transition into the treatment regimen, as well as provide emotional and psychological support to children and their families.

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KIDS CARING FOR KIDS



Peer support and social connections have profound implications on overall treatment success and long-term outcomes, especially for children.

Research studies show social support:

- Increases life expectancy
- Increases knowledge of a disease
- Improves self-efficacy
- Improves self-reported health status and self-care skills, including medication adherence
- Reduces use of emergency services



Providing social support has benefits, too:

- Heightened self-esteem and self-efficacy
- Improved quality of life
- Lowered incidence of depression

To carry out her vision, Avalon established the Kids Caring for Kids (#KC4K) Advisory Board, made up of kids ages 10-16.

#KC4K created the #PainBox with help from mental health and wellness professionals.

The #KC4K board selects a team leader who reviews the patient's profile to identify what types of items may encourage them as well as other possible needs to include in their #PainBox. They account for siblings as well as parent/s, including a family-focused package for a game or movie night.

Then the team:

- Creates a budget
- Shops for the personalized gifts
- Wraps them with love and packs the boxes for shipment

They also continually reach out via phone calls, video chats and cards to the children for moral support.

Our #PainBox patients tell us the encouragement and support from other kids who understand what they're going through gives them determination and strength to get through their treatments.



BY KIDS - FOR KIDS

Every kid deserves a chance to overcome obstacles and succeed. Our #PainBox offers mental and emotional support to kids and their families fighting rare disease.

Through our care and compassion, our patients develop resilience, strength, courage, trust, and family unity during critical treatment that can restore joy and wellness."

- The #KC4K Youth Advisory Board



A RARE YOUTH-LED LEADERSHIP PROGRAM

The #KC4K Program is dedicated to creating self-awareness of an individual's own abilities and power to be able to make a positive impact on the world through the pillars of:

**Leadership, Compassion, Commitment,
and Contribution**

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 in kids at a young age, we are creating a lifelong imprint that positively impacts the world.



Having a youth founder has shaped the way The Avalon Foundation operates from day one. We're committed to being kid-led.

Our #KC4K youth board drives our organizational initiatives with guidance from the adults on the TAF Board of Directors.

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THE LASTING IMPACT OF OF YOUTH LEADERSHIP



“[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 [help] create a new level of youth engagement in our communities.”

Edelman et al., 2004)



The #KC4K Leaders have raised awareness in the medical, corporate, youth, and public communities nationally.

Their #PainBox Program and work received attention from the Pediatric Endocrinology Nurses Association, which invited representatives from The Avalon Foundation to speak as well as have a booth at their annual conference.



#KC4K achievements:

- Garnered attention of a major insurance company that offered a partnership
- Avalon Ayres and #KC4K Leadership Team nominated for the Global Genes Champion of Hope award
- Youth and adult leaders invited to speak at national NORD conference, as well as local school events
- Selected by the BGSU EMOD program to be an organization of focus
- Selected by the NOHRA and many other local organizations for fundraising recipients
- Youngest organization to be finalist for GTCF Innovation & Excellence Award 2019
- Best of Toledo Nonprofit finalist 2020
- Multiple invitations for media appearances because of rare kid-led structure
- Avalon Ayres honored with Jefferson Award in 2021

BIG GOALS

for #KC4K and Youth Leadership

- Enrich programs to support youth patients and their families with other rare diseases struggling with compliance with painful treatment
- Enhance youth leadership programming with mentorship opportunities
- Expand the #KC4K Leadership Program nationally to give more young leaders an opportunity to make an impact through service



- Hire staff for key positions to help grow the organization and expand our support
- Explore collaborative opportunities with organizations and businesses to further our mission
- Create educational opportunities to raise awareness about rare disease
- Recruit dedicated individuals to serve on our Board of Directors and committees
- Recruit volunteer kids and families to support our patient families
- Connect with more families living with rare disease

\$350,000 in renewable financial support

from Champions, Superheros, Warriors and Heros





YOUR GIFT HELPS

give a better tommorrow

Every gift offers hope and courage to **RARE PEDIATRIC PATIENTS & FAMILIES** and develops dynamic youth leaders profoundly and positively impacting the future.

CHAMPION

\$12,000+

Sustains and expands Kids Caring for Kids (#KC4K) Youth Leadership Program, empowering kids through Leadership, Compassion, Commitment and Contribution.

SUPERHERO

\$7,500 – \$11,999

Benefits our wellness team who provides direct support to patients and families with assessment, trauma response, coaching, education, peer support through #PainBox and referrals through critical transitions of medical care.

WARRIOR

\$3,500 – \$7,499

Establishes customized Patient & Family Support Program, which includes #PainBox, peer support and parent support.

HERO

\$1,000 – \$3,499

Funds Patient and Family Support Program new patient assessment, which includes a customized plan and tools for successful treatment compliance by establishing a stable psycho-emotional environment for everyone in the household.



Checks can be sent to: The Avalon Foundation | 3328 Brantford Rd. | Ottawa Hills, OH 43606
Donations can also be made online at kidscaringforkids.org.



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 @KC4Kids

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