

Tobias' Story by Ashlee Kieler

When Amy and Samuel learned their nine-month-old Tobias would be going to Almost Home Kids rather than their own home after spending the entirety of his young life in the NICU, they felt a sense of disappointment. That feeling dissipated nearly as soon as they arrived at the Naperville facility.

"I think we went into it with preconceived notions that it would be a downgrade because we wanted to bring him home," Amy said. "But it was a worthwhile experience. Everyone went out of their way to make sure we had what we needed and that it was an easy experience for us."

The Winfield couple knew that a stay at AHK was likely in their future after Tobias was born at just 30 weeks, weighing only 580 grams. Tobias, who has a tracheostomy and requires a ventilator 24 hours a day, was diagnosed with chronic lung disease, adrenal insufficiency and struggled to swallow, often aspirating on his saliva.

"The first time we saw anything about AHK was in the elevator at Ronald McDonald House, where it was listed as a floor," Amy said. "Then our neonatologist brought it up. When we started talking about it, a lot of people knew about it."

Still, the family, which includes Tobias' older siblings—Isabelle, 9, Isaac, 7, Chloe, 5, and Jacob, 3, didn't know what to expect with their transition to AHK after nine and a half months in the NICU.

"I assumed it would be clinical and like the hospital," Amy said. "So, I wasn't excited to go at first. But I realized that it wasn't like that, and it truly was as close to home as you could replicate."

"[At AHK], we could start envisioning what it was like to have him home. We could see what we needed to modify at our home and envision certain activities based on what he was doing at AHK."

Tobias adapted to his new surroundings smoothly, Amy recalls. "I think he was taken aback by seeing other children," she said. "Up until then, he was in the NICU, there are other babies, but they are in their own areas. At AHK, he was so focused on the other kids, he watched them like crazy. He was fascinated."

Amy and Samuel quickly began to learn more about Tobias' care needs, how to work vent settings and scheduling home nursing. While each of those things were important to Tobias' future at home, Amy said watching other families at AHK was perhaps the most beneficial.



AHK staff gave Tobias a fond farewell as he transitioned home with his family



Tobias' family at home: Amy, Samuel, Isabelle, Isaac, Chloe, Jacob, and Tobias

"I think the biggest takeaway was just seeing other families, visualizing what our life would look like," she said. "It's not what we are used to, but it's not necessarily hard or scary. These kids are flourishing and there's so much love there. Being able to see what it might be like when Tobias is older, that was really encouraging to us."

Today, Tobias has been home since just before his first birthday and hasn't required any return trips to the hospital. He continues to have home nursing care, but his favorite nurse is older sister Chloe.

"She likes to call herself Tobias' nurse and help as much as she can," Amy said. "All the kids love him so much and are happy he's home. Tobias is doing great. He sits up, which was a huge goal. He smiles so much now, especially at his siblings."

Our Volunteers

Volunteer of the Quarter Awards

The staff and families at Almost Home Kids know how fortunate we are to have a strong Volunteer Program with caring and dependable volunteers. Our Recreational Volunteers who engage the children one-on-one make a huge impact on the lives of the children by creating a nurturing environment that feels like home. Singing a soft lullaby, holding their hands, rocking a baby to sleep, crawling on the mat with playful sensory toys, taking them out for fresh air, reading story books or just hanging out playing games and puzzles. No matter what comforting act they are doing, our volunteers are making a measurable difference.

We appreciate and value each and every volunteer at Almost Home Kids and each quarter we like to highlight a volunteer at each location and recognize them for going above and beyond!

Naperville

Lori Hroza has come full circle with her AHK journey. She worked as an RN at Almost Home Kids Naperville for over 17 years before retiring. As one of our original nurses from when we opened in 1999, her love of our mission and her connection to us runs deep, so it didn't take long for her to come back as a volunteer. For the past two years Lori has been volunteering with the children once a week, logging in over 150 volunteer hours! The nurses rely on her dependability and her skill and compassion to know just what our kids need in the form of attention and comfort. We all know what a gem Lori is, and we are lucky to have her back on Team AHK and to recognize her as our Naperville Volunteer of the Quarter!

How and when did you come to be involved with Almost Home Kids?

"I started working at Almost Home Kids in November of 1999. At that time, it was called Respite House. I worked and watched this facility grow for 17 years."

Tell us about a typical day for you as a volunteer at AHK.

"I enjoy holding and playing with the kids. I have played games with children and have strolled outdoors with them. I even played out one child's story with her My Little Pony."

What is the most enjoyable and rewarding aspect of your work at AHK?

"I have watched children develop and grow. The care I see by the staff is very inspiring."



Lori Hroza, Naperville Volunteer of the Quarter with Christopher

Does your volunteer role give you the chance to use talents that you love sharing? Or to build new skills you're glad to have?

"I understand the special skills and love that is needed to nurture each child. I am retired, but still know and remember those special skills."

What keeps bringing you back as a volunteer and would you recommend AHK to friends as a good place to volunteer?

"I missed that feeling that you get just by walking in the front door. The warm caring feeling that cannot be found in a normal medical setting. Why would you not keep coming back to Almost Home Kids? It may take a special love to volunteer, but the staff will guide a new volunteer to keep wanting to come back."

Chicago

Kirsten Buelow joined our volunteer team seven months ago and her positive impact has been shining through since day-one! Her career plans are to become a Child Life Specialist and it is quite evident that she will be amazing in that role. She is so great with our children and can always find the right activity that will put a smile on a child's face. She loves to join the kids on the mat, playing along with developmental toys or even singing to a child if that is what makes them happy. She has a positive, caring personality which translates to our children in a very calming way. Kirsten can be counted on when we need shifts filled and clinical staff love when they see her on the schedule. We are delighted to recognize Kirsten as our Chicago Volunteer of the Quarter!

How and when did you come to be involved with Almost Home Kids?

"I became involved with Almost Home Kids over the summer. I had just moved to Chicago for graduate school and was looking for a place to volunteer at."

Tell us about a typical day for you as a volunteer at AHK.

"A typical day as a volunteer at AHK would be having a nurse greet and open the door to greet me. Then I login and wash my hands before being placed with a child that needs some support or one-on-one time. Depending on the child, I usually either read books and sing songs or I grab some toys and try to engage the child to play with the toys and me."

What is the most enjoyable and rewarding aspect of your work at AHK?

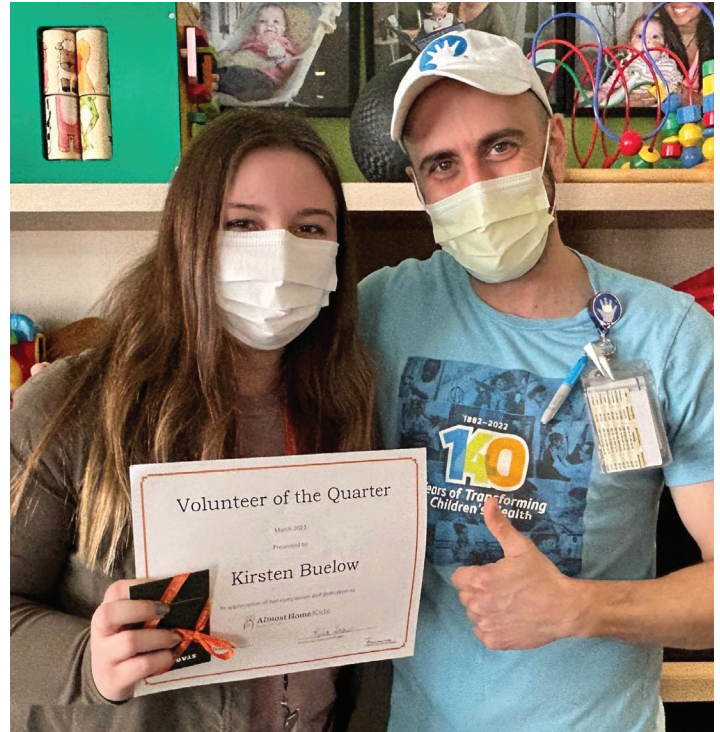
"The most rewarding aspect of volunteering at AHK is getting to spend time with the children."

Does your volunteer role give you the chance to use talents that you love sharing? Or to build new skills you're glad to have?

"My volunteering role gives me a chance to share my knowledge of child development and learn more about medical terminology."

What keeps bringing you back as a volunteer and would you recommend AHK to friends as a good place to volunteer?

"The children and the nurses that I work with bring me back as a volunteer. Everyone is so friendly and inviting and I would recommend AHK as a good place to volunteer especially if you are going into a medical profession."



Kirsten Buelow receives her Chicago Volunteer of the Quarter recognition from our RN Matt



If you're interested in volunteering, reach out to Lisa, our Community Relations Manager at lsnow@almosthomekids.org (Photo: Alex Schober, CCLS and Lisa at a recent Volunteer Orientation)

Our Community

Ace Hardware Foundation Makes Transformational Gift

During the tumultuous lockdowns of 2020, volunteerism abruptly shut down everywhere especially in healthcare settings. Ann & Robert H. Lurie Children's Hospital turned to Almost Home Kids in hopes of providing outdoor on-site volunteer opportunities for the employees of Ace Hardware's corporate office in Oak Brook. Ace has been Lurie Children's top fundraising corporate partner via the Children's Miracle Network for many years and in addition to financial support, supplies volunteers for events and programs throughout the year including during their annual "Ace Cares Week."

Little did we know what a beautiful partnership was ahead when the team from Lurie Children's suggested Almost Home Kids as an opportunity to allow the Ace team to continue to volunteer, in a safe, outdoor setting. Volunteering in the gardens and yards of AHK quickly became a beloved opportunity by Ace employees—and in turn, they soon became more like members of our family at AHK. To this day, they continue to volunteer for projects throughout the year. Thanks in large part to the creativity of Lisa Snow (AHK Community Relations Manager) and Gail Linhart (AHK Director of Operations), Ace has helped with maintenance projects like planting, weeding, mulching, painting and more. The Ace Garden Club, organized by Ace Foundation team member Catherine Jones, donated many hours to enhance our garden areas. They also adopted a garden area at our entrance which welcomes guests. They maintain it and often bring plants from their own homes to transplant into AHK's newly re-designed welcome garden.

All of this helps us defray operational costs and additionally Ace has donated countless items from our wish list including gardening supplies, holiday décor and our ever-popular leaf blower. Now, everyone wants to help clear leaves! However, it wasn't just the sweat and product donations that have made a difference—it was simply spending time together in the community which was a type of healing for everyone involved. We were craving socialization; wanted to help and feel a sense of purpose during such an uncertain time. All the volunteer work was done outside in keeping with guidelines before COVID-19 vaccines became available.

Our partnership has grown and strengthened over the past 3 years and with that we are thrilled to share that the Ace Hardware Foundation has awarded \$1.1 million to Almost Home Kids over the next 5 years. The donation represents the single largest gift in our 24-year history, and it came as a complete surprise. Even the check presentation last August was orchestrated as a surprise announcement to our staff in Naperville. "Once we met the team at AHK and learned about the amazing care they provide for kids and families we knew we wanted to support their mission in a larger way than

simply volunteering," said Chris Doucet, Director of Communications, Engagement & Ace Foundation. "We are honored to be able to provide this gift that we know will impact the lives of so many and look forward to continuing to grow our partnership."

"We wish to thank the entire Ace Foundation team. We are so grateful also to Aaron Conn from Lurie Children's for envisioning such an impactful partnership. This gift will be transformational to Almost Home Kids' future. I am proud of the entire team at AHK as together they embody our culture of caring and kindness. We treat every visitor like a million dollars!" —Deborah A. Grisko, AHK President & Executive Director.



The Ace Garden Club sprucing up the gorgeous Ace Garden at AHK Naperville



Everyone at Almost Home Kids was thrilled to accept this amazing check from the Ace Foundation



Children's Supplies Wish List: (items must be new, please)

The items on our Wish List are things we will utilize at both our sites. If it is convenient for you—we have an Amazon Baby Registry that is constantly updated with current needs for the children and/or household items. Please visit our Amazon.com and click on Baby Registry and in the Search bar type in Almost Home Kids/Naperville. It's easy to order there and the items will be shipped directly to our Naperville site to be shared between both our Naperville & Chicago sites. Or you can shop on your own and drop off at the Naperville site ideally Monday-Friday when we have a full staff to welcome you and accept the donations. Thank you for your kindness and generosity!

Therapist Supplies Wish List:

Switch Adaptive Toys & Games – Enabling Devices

- Musical & light up caterpillar, LED fan & musical bear stacker (\$157)
- Fubbles Fun Bubble Machine (\$47)
- Peek-a-Boo Mirror Adapted Sensory Toy (\$180)

Children's Supplies Wish List:

- Diapers – Sizes 2, 3, 4, 5 & 6
- Unscented baby wipes
- Pacifier clips
- Johnson & Johnson baby wash & lotion
- Large bath towels
- Twin jersey knit sheets
- Crib jersey knit sheets
- Infant play gym activity mat
- Walkie-talkies for use when outdoors with the children—Amazon WokTok brand 4-Long Range Walkie Talkies Rechargeable for Adults (\$69.99/set)
- Baby monitor – Amazon Vtech VM924 Remote Pan-Tilt zoom video baby monitor w/5" LCD screen (\$69.95) – Need 2 of these

House/Office Supplies Wish List:

- Cordless Screw Gun
- Forever postage stamps
- K-Cups for a 2.0 Keurig coffee maker
- Sticky Post-It Notes
- Batteries – AAA, AA & C
- iPad for children

Please reach out to Lisa at lsnow@almosthomekids.org for details or more information about any item listed above.

Our Events

AHK 2023 Event Calendar

Let Us Catch You Up on The Latest at AHK for 2023!

The Shamrock Shuffle is always a crowd pleaser, and this 2023 edition did not disappoint. As a crisp spring breeze off Lake Michigan gave way to perfect morning for a run, the Almost Home Kids team showed up with 38 runners ready to “Run for a Reason”. This annual event raised almost \$2,000 much-needed funds for AHK. Our team was easy to spot wearing their bright AHK orange running shirts and crossing the finish line lets everyone know that it’s the kids and our mission that they were supporting. Thanks to everyone who ran—special shout out to the team from Rainforest Learning Centers who brought out over 30 runners and to the Grant Thornton team, who led the individual fundraising efforts, and to Bob Danko, Josh Prangley, Kati Ardaugh and Nahlah Daddino, you are all our champions.

The Naperville committee dazzled us with the spring gala **“Art in the Park”** on April 21, 2023, at the Hyatt Lodge Oak Brook. This event heightened our creativity and focused our commitment to exploring the beauty that is all around us. Our host Dave Savini (CBS2 news) kicked things off and the G-Man (auctioneer Greg Bellinger) energized the attendees, helping us raise over \$225,000—and the Standing Room Only (SRO) band kept the party going! We recognized David Cotton (Volunteer Extraordinaire), Daniel J. Cronin (Share the Care Champion), David Koehler (Share the Care Exemplar), and Ryan Spain (Share the Care Exemplar) for their amazing contributions to Almost Home Kids, and Dyan McIntire, who gave a heartwarming parent testimonial about their daughter Caitlyn’s journey at AHK. Special thanks to the Naperville committee led by Stacie

Gannon & Erin LaMantia who were joined by Jeff Brown, Terry Gallagher, Yonhee Gordon, Bethany Keown, Becky Olson, Stephen Price, Suzy Shinkle, Kathy Wennerstrum, and Katreina York-Koprowski. Also, a big thanks to Johnny Barone (guitarist), Kathy Kelly (painter), and Andy Head (juggler) who entertained us with their artistry during the cocktail hour. Many thanks to the following sponsors ECI, Forvis, Fifth Third Bank, HUB, JMG Financial Group, Mullarkey, Nueco, Paylocity, John Salvino, Phoenix Closures and USI for their generosity and support, and Andrew Ushakov for his incredible creativity and design work on all the event collateral material.



Spring Gala Committee: Stacie Gannon (Co Chair), Yonhee Gordon, Kathy Wennerstrum, Suzy Shinkle, Katreina York-Koprowski, Stephen Price, Judith McLean, Becky Olson, Bethany Keown, Andrea Kerr, Lisa Snow and Erin LaMantia (Co Chair), Terry Gallagher (not pictured)



The AHK Running Team at the Bank of America Shamrock Shuffle

The AHK **Young Associates Board** led by Nazanin Salehitezangi (President), Courtney Lefevre (Vice President), Caroline McClendon (Secretary) and Julia Nehf (Event and Volunteer Coordinator) have embarked on their 9th annual event, "No Place Like Home" which will be held on June 9th 7:00pm to 10:00pm at the Fremont (15 W. Illinois Street in Chicago). Tickets are still available for this afterhours mixer in the city—visit our website almosthomekids.org for more information.

Our annual wine tasting event "**Tasting for a Cause**" will be on Tuesday, June 27th, 2023. This year's event will be held at the newly renovated Verve Wine + Provisions—two offerings in one, a beautiful wine store and a fabulous restaurant owned by Somm documentary star and Master Sommelier Dustin Wilson. Our very own wine experts (and committee members) Michelle Baker, Karin Prangley, Carley Diedrich, Bregan Herrold, Rolanda Shine, and Sophia Worden are putting together a fabulous event. Come and enjoy some spectacular wine and delicious appetizers and see what wonderful raffle items the committee has assembled this year—it promises to be a fun evening out! Register through our website or contact Andrea for more info at ankerr@almosthomekids.org.

Come out and golf with us! The **2023 Golf Marathon, brought to you by Enterprise Car Rental**, will be on Tuesday September 19th, 2023, at Zigfield Troy Golf Course. Start planning your foursomes OR support one of our golfers. This marathon is a peer-to-peer fundraiser where golfers collect donations for completing 100 holes of golf! You do not need to be a good golfer to participate. After completing 100 holes of golf, we will be providing the golfers with a boxed lunch and a BBQ meal at the conclusion of the golf. Please contact Andrea Kerr at ankerr@almosthomekids.org for more information or to sign up your foursome.

This year's **Share the Care Ball, A Secret Garden** will be a magical experience—save the date for November 3rd, 2023, for this end of the year gala, and our signature black-tie event in the city. The committee is super excited to spend the evening with all of you, back at the beautiful Hotel InterContinental. For more information, please contact Andrea at ankerr@almosthomekids.org or (312) 227-7954.



Join our Young Associates Board at their 9th Annual "No Place Like Home" Event on June 9th



Don't miss our annual premium wine tasting event at Verve Wine + Provisions on June 27th

Affiliated with

 Ann & Robert H. Lurie
Children's Hospital of Chicago

7 South 721 Route 53
Naperville, IL 60540

Almost Home Kids provides a bridge from hospital to home through an innovative community-based care system for children with medical complexities. We respond to the needs of families, train caregivers, offer respite care, advocate for accessibility and inclusion and educate healthcare professionals.

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