

AHK Update

Spring Summer 2024





About Almost Home Kids

Almost Home Kids coordinates all the community-based medical and social services that a child and their family will need while providing respite care in a home-like setting.

Mission

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.

Impact

Statistics* about children with medical complexities and Almost Home Kids impact:

- There are over **3 million children** in the U.S. who are medically complex.
- The population of children with medical complexities is growing at an **annual rate of 5%**.
- In 2023, children with medical complexities accounted for **11% of Medicaid population** and **42% of the spend** (\$98 Billion Medicaid spending).
- Almost Home Kids is unique in that we save nearly **\$10 million in Medicaid expenses per year**, per site, that's almost **\$30 million of savings** for the state of Illinois.

*Summary of Available Evidence and Methodology for Determining Potential Medicaid Savings from Improving Care Coordination for Medically Complex Children, author Dobson and DaVanzo.

Learn more about our services, mission, impact, and team members at **almosthomekids.org**.

Hamad's Long Journey Home

International Patient Services at Ann & Robert H. Lurie Children's Hospital of Chicago provides a wide range of services to children coming to the U.S. for ground-breaking surgeries and to see respected physicians in select specialties. The AHK Case Management team liaises with the hospital care team whenever the parents of a child with medical complexities could benefit from training before transitioning to their home country. There have been numerous children over the last few years who have used these services, including Hamad who came from the United Arab Emirates in the Middle East at age 6 months for critical care he was unable to receive in the UAE. He received lifesaving care and was able to stabilize and eventually transfer to Almost Home Kids to begin his journey back to home.

Hamad's parents struggled at first with the idea that their son could thrive outside of an intensive care unit, however they quickly settled in and with the kind, supportive approach of the AHK nursing team, quickly became fully trained in all of Hamad's complex needs. Hamad and his family enjoyed the day pass program that allows fully trained caregivers to venture out of the facility for the day and was also able to receive intensive PT, OT and ST services at nearby Shirley Ryan AbilityLab day rehab program. Our Social Worker, Molly Kim and Case Manager, Mimi Le helped with providing the family with coordinator of care and communication with Hamad's multiple care teams. They successfully transitioned home after the Consulate Office, Lurie Children's International Patient Services and Hamad's care team at AHK paved the way.

Hamad's parents, Khalid and Mariam continue to keep us updated with Hamad's progress and have shared recent photos of his 2nd birthday. They are all thriving and enjoy being back home.



To infinity and beyond! Hamad loved being Buzz Lightyear for his 2nd birthday

Show your support today by visiting almosthomekids.org or by mailing a check via the attached donation envelope.



Hamad at his 2nd birthday celebration



Almost Home Kids clinical team wishing Hamad and his family a fond farewell



Ribbon Cutting for the 1999 Respite House Opening

We are Celebrating our 25th Anniversary!

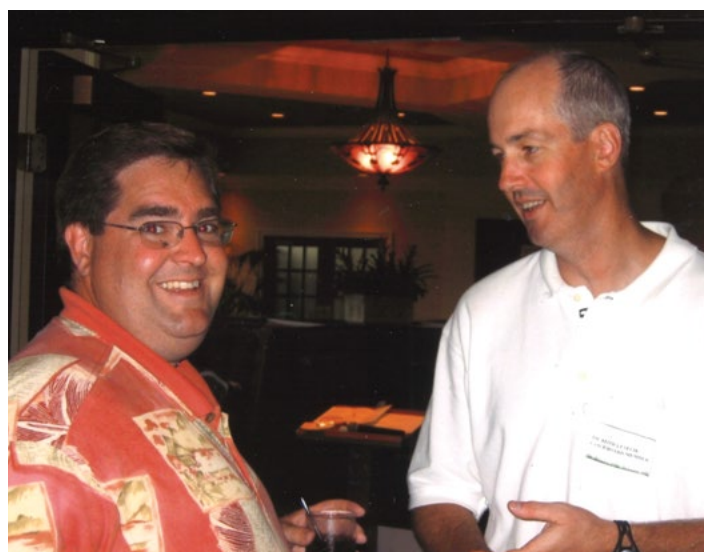
From Respite House, to COACH Care Center to Almost Home Kids, we're celebrating 25 years of providing quality care in the community for children with medical complexities.

It was 1992 and the biggest selling single of the year, was Whitney Houston's cover of "I Will Always Love You", taken from the film *The Bodyguard*. That year, the two mothers who founded Respite House (renamed Almost Home Kids in 2008) were likely humming or singing that tune to their newborn sons, Danny and Jake. Their boys were born with developmental challenges, medical complexities, and had very limited options for community-based care. After meeting in the waiting room of their children's pediatrician (Dr. Keith Veselik), they decided things needed to change and they made it their mission to create a safety net in the community for families like theirs with children with complex medical needs. They recruited their pediatrician, Dr. Veselik as AHK's first Medical Director, who then helped lay the groundwork for the clinical policies and procedures that continue to evolve and keep the children in our care safe and well to this day through our Medical Advisory Council. We stand on the shoulders of two humble yet extraordinary visionaries, the founding mothers of AHK, Leanne and Denise.

Almost Home Kids was incorporated as a 501(c)(3) not-for-profit in 1992 and our founders' dedicated years of grassroots fundraising and legislative change before opening our doors in 1999 for Respite Care. In the early years, nearly everything

was donated by supporters and volunteers—furniture, supplies, professional services like accounting and tax preparation as well as physician services.

Some of you may remember that we sold chocolate houses to raise money around the holidays. These houses were stored in an area of the Naperville house called, "the Chocolate Room", after the infamous houses—it is simply a large closet near an entrance that made it easy to load each chocolate house into a donor's vehicle, but the throw-back name has endured.



AHK Medical Directors Dr. Mike Hoffman and Dr. Keith Veselik

In 2004 there was an amendment to Alternative Healthcare Delivery Act to include Transitional Care, and following a White Paper authored by Dr. Keen, Dr. Steinhorn and Dr. Msall in 2010, it was clear there was a need to open an Almost Home Kids in Chicago. We opened our doors in Chicago in the Ronald McDonald House in 2012 and a year later entered into a formal affiliation with Ann & Robert H. Lurie Children's Hospital of Chicago. This affiliation allowed us to bring our expansion efforts to the forefront and in 2018 we opened our third location in partnership with OSF HealthCare Children's Hospital of Illinois in Peoria. Throughout this journey we have kept the needs of the children and families we serve at the forefront of every decision made.

All of these amazing accomplishments have been achieved thanks to exceptional leadership by each of our Board Chairs, Executive Board members and President's Advisory Council members. Each person has provided very thoughtful consideration to our ever-evolving mission encompassing what it is we do, adding a set of Values and expanding on our Vision alongside Debbie Grisko, our President & Executive Director who continues to transform and grow Almost Home Kids through her dynamic leadership since 2008.

Twenty-five years later we are celebrating our three Almost Home Kids homes serving children from countless counties across Illinois and beyond. We are proud to state that each AHK saves \$10 million annually in Medicaid expenses and continues to provide that safety net in the community that Leann and Denise envisioned all those years ago.

“My sincere congratulations to Almost Home Kids as you celebrate 25 years. It is a huge milestone and very well earned. It is widely recognized that it takes a village to raise a child. However, it is not so widely recognized that in the case of children with medical complexities, that village needs specialized training and services to safely care for these children so they can thrive within the community. The extensive services and support you offer such as transitional care, respite care, and training, are truly a lifeline for the families you serve and is a win-win for the child, their family, and the “village” as a whole. As one of the cofounders, I can honestly say that the brilliant execution of our vision and growth of the program is awe inspiring. Happy Anniversary and best wishes for your continued success.”

—Leann Lazzari, Co-Founder of AHK



Nursing leadership, when Almost Home Kids (Respite House) opened, included Marilyn Berg (right) and Cindy Fisher (left)



Transformational support from The Coleman Foundation with Debbie Grisko, Doug Truax (Former Board Chair, 2009–2012) and Leann Lazzari



Dr. Peter J. Smith inspires medical students, residents and fellows to embrace pediatrics

Volunteer Spotlight

Chicago

Megan Cote has been an amazing volunteer for the past year helping in any way she can. We connected at the Students of Osteopathic Pediatric Association meeting on the campus of Northwestern University when she was beginning her second year of medical school last year. Megan knew she wanted to join our Recreational Volunteer Program to not only to make an impact in the lives of the children we serve but also to gain an understanding of the care we provide for her future career in Pediatrics. Earlier this year, she began her third year of medical school, she moved to the city and continued to volunteer at our Chicago location. Her third-year schedule is filled with medical placement rotations that keep her extremely busy and driving all over the Chicagoland area, but she still finds time to embrace our mission by continuing to volunteer on-site at AHK. She shared that volunteering allows her to keep a purpose and passion through medical school. Megan has also stepped up to volunteer at our annual Spring Gala and she even joined the AHK Shamrock Shuffle team this year. We are delighted to recognize Megan as our Chicago Volunteer of the Quarter and truly appreciate her desire to support our mission.



Megan Cote, Chicago Volunteer of the Quarter with Amia

“Almost Home Kids has been a beacon of compassion and resilience, consistently reminding me of the simple yet profound truth that children, above all, just want to be kids. Its commitment to fostering an environment where children can learn, grow and play while receiving individualized care is truly inspiring. As an aspiring pediatric neurologist, witnessing firsthand the dedication of the team and the strength of [the children] has been invaluable to my professional and personal growth. The sense of community and belonging that permeates Almost Home Kids has taught me that true healing extends beyond medical treatment—it encompasses emotional support, understanding, and the creation of a nurturing environment where children can thrive. Thank you, AHK!”

“I began volunteering at the beginning of my undergraduate studies and I have enjoyed making a positive impact on the children at Almost Home Kids. This experience is always a breath of fresh air as I studied for school at Northwestern University. I am truly honored to be able to make a difference in their lives!”

For more volunteer information contact Lisa Snow at lsnow@almosthomekids.org



Lindsay Rakowski, Naperville Volunteer of the Quarter with Aiden

Events



The Art for Hope Foundation musicians and their parents

Ready, Set, Give!

The **AHK Running Team** kicked off our fundraising season this year with the Shamrock Shuffle. We had new and returning runners representing AHK in their signature orange running shirts, and despite chilly weather, spirits were warm as they ran for a reason—thank you Peter Smith, Bob Danko, Megan Cote and Fiona Busser for being at the starting line at the Shamrock Shuffle. Next up is the Soldier Field 10 Miler Run with Aari Patel and Jigna Patel leading the charge with over \$1,250 raised so far! The AHK Running Team has already raised over \$2,000 and with five months still to go, we are hoping for great things from the team. If you would like to participate in an upcoming run or set up a personal fundraising page for AHK please contact Andrea at ankerr@almosthomekids.org or (312) 227-7954.

Naperville's **Fire & Ice Spring Gala** was a sensory experience, from the cool ice luge to the fiery lights that illuminated the room. The committee worked tirelessly to bring this concept to life and never forgetting inspiration for the Fire & Ice theme (Fire for the passion of our volunteers, clinicians and supporters and Ice for the determination of the children and their families). Our fabulous duo-hosts Lakesha and Jim Rose captivated our audience and kept them engaged, helping us raise almost \$250,000. The Standing Room Only (SRO) band kept the dance floor packed. A special thanks goes out to Samuel Slennett for generously sharing a parent testimonial about his son Tobias' journey at AHK. We were also grateful to celebrate our honorees Keith Veselik, MD Share the Care Exemplar, Christine Sajous, MD Share the Care Champion, and Maul Paving Sealcoating and Concrete the Distinguished Donor and thank them for all their support and dedication to our mission and vision. Masses of thanks to the wonderful Naperville committee led by Stacie Gannon & Erin LaMantia who were joined by Jeff Brown, Terry Gallagher, Yonhee Gordon, Julia Hennelly, Bethany Keown, Becky Olson, Stephen Price, Suzy Shinkle, Kathy Wennerstrum, and Katreina York-Koprowski. A big thanks goes to the young musicians at Art for Hope Foundation, who entertained us with their talents during the cocktail hour and of course to the 290 extremely generous attendees. We also are very grateful for the following sponsors Baker McKenzie, ECI, Forvis, Fifth Third Bank, HUB, Mullarkey, Nueco, Phoenix

Closures, USI, and Wintrust for their generosity and support and to Andrew Ushakov for his creativity in setting the scene for our theme (Art Designer).

The **Young Associates Board** always knows how to throw a party. This year's No Place Like Home event continues the theme of celebrating our 25th Anniversary and showing the growth of AHK. Led by Nazanin Salehitezangi (President), Courtney Sturgeon (Vice President), Caroline McClendon (Secretary) and Julia Nehf (Event and Volunteer Coordinator), the YAB is also celebrating their own milestone with its 10th year anniversary. The NPLH event will be held May 31st from 7:00pm to 10:00pm at Porter Kitchen & Deck (150 N. Riverside Plaza in Chicago). Tickets are still available for this FUNdraiser in the city—visit our website almosthomekids.org for more information.

Calling all wine lovers and AHK supporters, our annual wine tasting event **Tasting for a Cause** will be on Tuesday June 18th. This year's event will be held at the newly renovated Verve Wine + Provisions—we love it for its dual functionality of a beautiful wine store and a fabulous restaurant (what a treat). Our very own wine experts and committee members Michelle Baker, Karin Prangley, Brenda Davis, Milena Fay, Bregan Herrold, Rolanda Shine, and Sophia Worden will be hosting and are getting ready for an evening of fun. Last year we had the battle of U.S. versus French wines, this year the committee is planning on spotlighting the Paris Olympics! Grab a friend, register for the event, and enjoy a beautiful summer evening with some amazing wine and delicious appetizers in support of a great cause. The committee is planning another amazing raffle with super exciting items; this may be your lucky year! Register through our website or contact Andrea for more info at ankerr@almosthomekids.org.

Come out for **Pitch & Putt for a Purpose** (formally known as Golf Marathon) yes, we have changed our name, but the fundraising is still the same. This is golf re-imagined for anyone who wants to support Almost Home Kids and is interested in trying something completely different on the golf course. A round in the traditional sense of the golf marathon of old, plus a round of golf games such as closest to the hole, longest putt, and a few completely new ones you have never probably heard of before! This event will be on Tuesday September 10th at Zigfield Troy Golf Course. We will be providing the golfers with a boxed lunch, prizes galore and a BBQ meal at the conclusion of the event. Please contact Andrea Kerr at ankerr@almosthomekids.org for more information or to sign up your foursome.

Let's end the year strong, with our premier black-tie event, the **25th Anniversary Ball, Sharing the Care Since 1999**. This glamorous gala is always a fun night with dining, dancing, and donating and will be held in a new venue the Palmer House Hotel. We will "Party Like It's 1999", so save the date for October 25th, for this end of the year gala. Our Chicago gala committee is super excited to spend the evening with all of you.

For more event information, contact Andrea at ankerr@almosthomekids.org



Affiliated with

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

7 South 721 Route 53
Naperville, IL 60540

Ways to Support

Donate Money

Help Almost Home Kids make a difference in the lives of children and families today by donating at almosthomekids.org/give or by enclosing a check in the attached donation envelope.

Donate to Our 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 Amazon.com and click on Baby Registry and in the Search bar type in Almost Home Kids/Naperville. Items will be shipped directly to our Naperville site to be shared between both our Naperville & Chicago sites. You can also 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
- Baby earmuff noise-cancelling headphones
- Crib and/or twin jersey knit mattress sheets

- Johnson & Johnson baby wash & lotion
- Desitin diaper rash cream
- Rubbermaid 2-Quart Servin' Saver container for formula
- Glad food containers with lids

House/Office Supplies Wish List:

- Forever postage stamps
- K-Cups for Keurig coffee maker
- Sticky post-it-notes
- Batteries – AAA, AA, & C sizes
- ORCA 65 Quart insulated rolling cooler with wheels & pull handle

Volunteer

If you're interested in volunteering, reach out to Lisa, our Community Relations Manager at lsnow@almosthomekids.org

Sponsor an Event

Adopt Almost Home Kids as the beneficiary of a fundraising event such as a run, happy hour, private party, or golf outing! We can help with collateral material, provide a website platform for crowd fundraising efforts, and onsite volunteers for your event. Please reach out to Andrea, our Development Coordinator at ankerr@almosthomekids.org to learn more.

Please remember the children of Almost Home Kids in your will.

Contact us at **630.271.9155** or visit almosthomekids.org

Follow us on Facebook, Instagram, X and LinkedIn for daily Almost Home Kids updates!    