



The **Children's Inn** at NIH



2024 ANNUAL REPORT

**A Year Filled
with Extraordinary
Gratitude**

Letter from the CEO and Board Chair



We are delighted to share The Inn's 2024 Annual Report, highlighting the generous individuals, organizations, and volunteers whose contributions are essential to our mission. This report reflects our collective efforts to enrich the lives of these courageous children and their caregivers who call The Inn home.

Over the past year, 954 families stayed with us free of charge. These families traveled from all over the world to participate in pioneering clinical trials at the National Institutes of Health, seeking advancement in treatments for genetic conditions, cancer, bone and growth disorders, mental illness, rare diseases, and other profound health challenges. For many, the NIH offers their best hope for a cure and brighter future.

As you will read in this report, we made tremendous progress in our vision for the future of building The Inn of Tomorrow. In December 2023, we began construction on the Young Adult Residence, a dedicated space across West Drive. This renovated building will focus primarily on the unique needs of the young adult population that comes

to The Inn. The residence will include six guest rooms and communal spaces, including a spacious kitchen, dining room, and living room, designed to foster comfort and community.

This summer, the National Institutes of Health reviewed the final design development drawings, which were submitted by Perkins&Will, the global design firm leading our architectural efforts. While timelines for large-scale construction projects can shift, we anticipate the following two phases of construction: Phase 1, from November 2024 to January 2026, will focus on the renovation of the north side of our existing facility. Phase 2, from January 2026 to Summer 2027, will include the expansion of our facility, with project completion expected by the summer of 2027. This project aims to enrich the services we offer to our families while strengthening our ability to support the groundbreaking work of the NIH.

In this report, you will also find stories of resilience and commitment to our work. From special programs that support siblings during challenging

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Together, we are making a difference in the lives of the children and families who need it most.”

times, to investing in our infrastructure developments that help us better serve families, to taking families sailing on the Chesapeake Bay, The Children's Inn remains a beacon of hope – a place of rest and refuge where optimism and healing intersect.

Thank you for being a vital part of this journey. Together, we are making a difference in the lives of the children and families who need it most. We look forward to another year of providing care, comfort, and hope to all who call The Inn home.

With gratitude,

Jennie Lucca
CEO, The Children's Inn at NIH

Brian Kelly
Chair, Board of Directors,
The Children's Inn at NIH

Our Impact

July 1, 2023–June 30, 2024

Where the power of childhood meets the power of research.



In partnership with NIH researchers, Inn residents have contributed to many medical milestones:



Demonstrating bone marrow transplants cure sickle cell disease.



Making HIV/AIDS a treatable disease.



Pioneering effective treatments for many rare and serious genetic diseases.

Our Impact



Advancing new ways to **diagnose and treat** serious mental health conditions such as schizophrenia and depression.



Curing 90% of children with the most common form of blood cancer—and using CAR-T cell therapy for very advanced forms of leukemia.

954 Families stayed **19,129 nights** at The Inn—a total of 1,450 reservations.

Inn residents participated in studies at **12 of the 27 institutes** and centers at the NIH. About one-third of the 1,500 NIH clinical research studies include children. There were 478 protocols for infants up to 30 years old.

Since 1990, families have traveled to The Inn from **all 50 US States** and **106 countries**.

Our Impact



The Inn's Programming Team offered **803 activities** designed to be culturally inclusive, thoughtful, and responsive to the needs of each family.

35 full-time and **six** part-time staff.

299 volunteers supported The Inn, contributing 9,570 volunteer hours.



2024 Financial Overview

The National Institutes of Health (NIH) is the world's premier biomedical research institution; the breakthroughs that happen here are the first steps toward eradicating diseases, easing pain, and making better lives possible. None of these medical advances would be possible without the people who drive them: children, families and caregivers, clinicians, and staff—the community The Children's Inn brings together. Supporters like you help us bring hope to the families who need our services, even as we advance medical breakthroughs.

Income & Investments

NIH Reimbursement	\$1.4M
Investment Income	\$8.5M
In-Kind Contributions	\$3.5M
Individual & Corporate	\$14.7M
Total:	\$28.1M



Net Assets

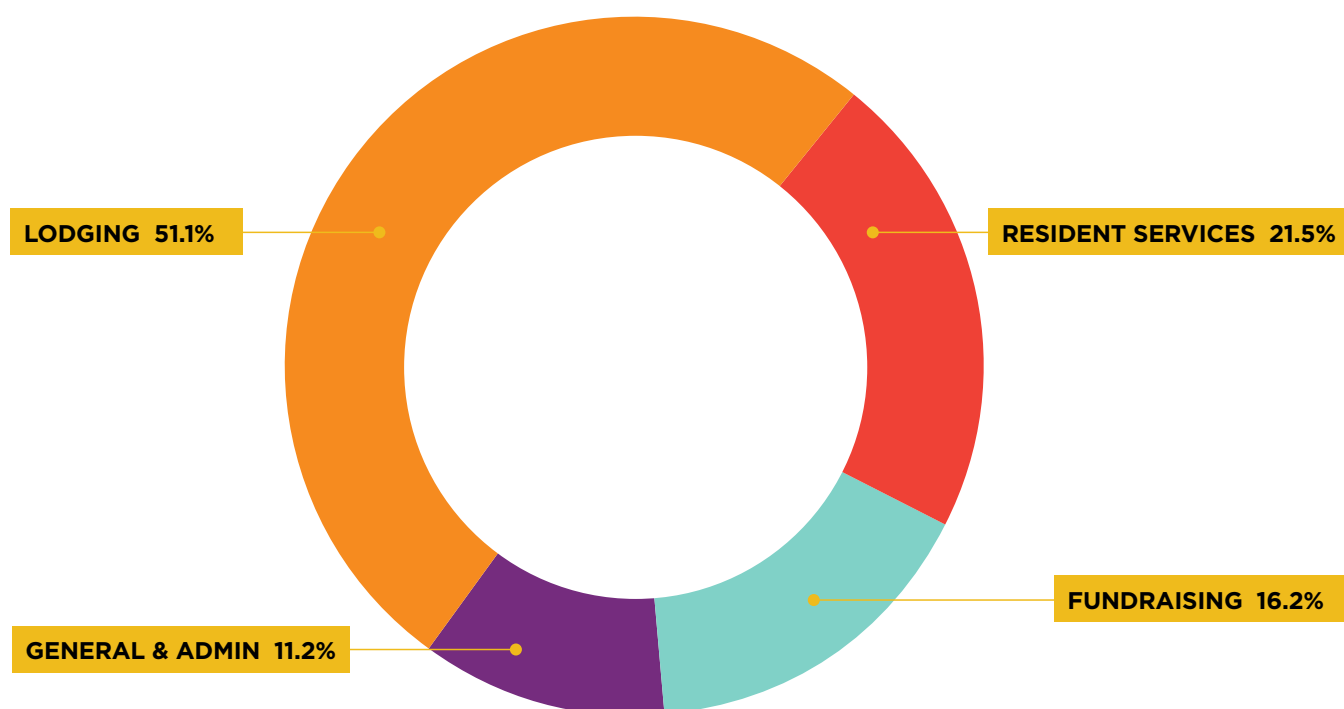
Without Donor Restrictions	\$23.3M
With Donor Restrictions	\$54.5M
Total:	\$75.8M



2024 Financial Overview

Operating Expenses

Lodging	\$8.4M
Resident Services Program	\$3.6M
Fundraising	\$2.7M
General & Administrative	\$1.8M
Total:	\$16.5M



Source: Audited financial statements as of June 30, 2024, available upon request or on The Inn's website. The Children's Inn holds the Better Business Bureau seal of approval and is recognized by Charity Navigator and Guide Star, indicating that we fulfill our mission in a fiscally responsible way. These exceptional designations demonstrate to supporters that we are worthy of their trust.



Groundbreaking for the Young Adult Residence December 2023. From left to right: Brian Kelly Executive V.P., U.S. News & World Report Board Chair, The Children's Inn at NIH; Colleen McGowan, Director, Office of Research Services (ORS), NIH; Jennie Lucca, CEO, The Children's Inn, Alfred C. Johnson, Ph.D., Deputy Director of Management, Office of Research Services (ORS), NIH

#INN2025

In 2018, The Children's Inn at NIH launched our #INN2025 strategic plan, a transformative journey to advance our role in medical discovery and patient care. To date, we have made considerable progress in our three strategic goals: evolving to a state-of-the-art "smart" living environment, strengthening the integration of discovery and care, and maximizing community support to promote financial viability.

As we reflect on our journey over the past four years, we recognize we have reached a pivotal moment. While there is much work to be done, there are many accomplishments to be proud of; many seeds planted in the early days are taking root and growing into reality.

Goal One

Evolve to a State-of-the-Art "Smart" Living Environment

Progress continues at an exciting pace with our plans for The Inn of Tomorrow. We are excited to report several notable milestones from the past year.

In December 2023, we held a groundbreaking event for the Young Adult Residence across the street from the Inn. The Young Adult Residence is an extension of The Children's Inn and part of our vision for The Inn of Tomorrow. The facility will provide six additional guest rooms as well as living, dining, and kitchen facilities for young adults. This project is fully funded and is projected to open in early 2026.

Additionally, The Inn and its architectural partners Perkins&Will have engaged the design agency Local Projects to work specifically on the new Merck Tower of Hope, a beacon with two interior spaces that will serve as the centerpiece of the newly renovated Inn of Tomorrow. Local Projects is responsible for the National September 11 Memorial & Museum in New York City and Planet Word, the world's first voice-activated museum in Washington, DC. Their design for the



Merck Tower of Hope promises to be an awe-inspiring, multi-sensory, inclusive space for all families at The Inn. It will be a flexible information hub and an invitation for creative exploration, allowing families to immerse in unexpected, imaginative worlds.

Throughout this project, The Inn will remain fully operational 24 hours a day, seven days a week, as we have successfully done during previous construction projects. Our primary focus is minimizing disruption to families and staff during construction, with their safety and comfort as our highest priority; we are carefully phasing construction to maximize room availability and preserve community spaces.

Goal Two

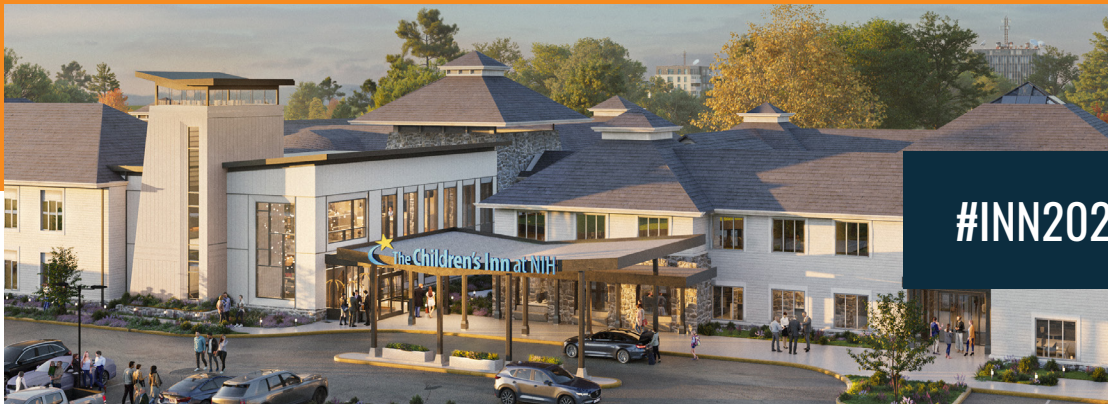
Strengthen the Integration of Discovery and Care

Over the past year, we have continued to strengthen our partnership with NIH leadership and researchers, who are performing groundbreaking work. As The Inn of Tomorrow becomes a reality, that partnership has never been more critical. It has led to valuable new support programs that better integrate discovery and care for our families now and in the future such as the Pediatric Support Program.

Inn Teams connected with five new studies actively recruiting pediatric patients. Through our communications with these five groups, we learned how to better anticipate families' needs even before their arrival at The Inn. It's one more way that we continuously work to ensure that we are doing everything we can—now and in the future—to ensure both their access to clinical trials and comfort at The Inn.

We were able to support two nine-year-old, first-time patients with visual and psychomotor issues (balance and coordination, difficulty walking, involuntary movements, slow reaction time) by:

- developing navigation tips for the families, ensuring the easiest and safest routes from their resident rooms to the Clinical Center,
- providing grocery cards ahead of their visit to accommodate dietary needs,
- and facilitating pre-visit discussions with medical teams to manage expectations around procedures.



#INN2025

This past year, Inn staff participated in NIH's Rare Disease Day, joining representatives from across the NIH campus to highlight the resources we provide at The Inn to support families battling rare diseases.

In May, The Inn was excited to launch a new partnership with [Hope for Henry](#). This pediatric patient incentive program improves coping skills and medical outcomes for children whose chronic, serious illness requires lengthy hospitalizations and invasive treatment.



Goal Three

**Maximize
Community
Support and
Promote Financial
Viability**

Our Board Task Force on Health Equity continues to provide pioneering leadership and momentum in advancing health equity by cultivating a diverse group of leaders and ensuring a continued focus on health equity in all aspects of our strategic planning.

Last spring, we hosted a webinar, [Leadership and Momentum in Advancing Health Equity](#), which featured an insightful conversation on health equity in clinical research with a spotlight on youth mental health. Featuring representatives of The Inn and several NIH institutes, the conversation gave participants a greater understanding of how diversity contributes to improved health outcomes and how the NIH and The Inn address inclusivity within their research and programs.



We were honored to be recognized for our work in this area when the National Association of Corporate Directors named The Inn a finalist for their prestigious Diversity, Equity, and Inclusion Award. Additionally, The Inn was recognized as Kennedy Krieger’s 2024 Business of the Year. At the ceremony in June, Kennedy Krieger recognized The Inn as a business partner that supports workplace volunteer experiences for its community members. Through Kennedy Krieger’s CORE Foundations, volunteers have come to The Inn for more than five years to help with tasks such as managing kitchen supplies, organizing the playrooms, helping with administrative duties, and walking Zilly.

At The Inn, our programming team works tirelessly to develop educational, therapeutic, and recreational programming that promotes a diverse and vibrant community. This year, such programming included various field trips around the Washington and Baltimore areas. They gave Inn families opportunities to experience cultural activities they would never have done—such as a sailing trip on the Chesapeake Bay that allowed them to explore Maryland’s natural beauty while getting some much-needed relaxation away from the medical environment. At The Inn, the programming team also regularly organizes International Nights and cultural activities, allowing residents to share their cultural backgrounds with the wider Inn community.



Meghan Arbegast Smith Senior Volunteer Engagement Manager and Mary Miller Program & Services Manager accept the Business of the Year Award



NIAID DOCTORS CURE SEVERE NEUTROPENIA WITH LIFE-SAVING TRANSPLANT

Faith and Confidence Provide a Miracle for Ellis

From the moment you meet her, it is impossible not to like Ellis. She greets new people with a hug and calls them her best friend within minutes. A six-year-old native of Vancouver who now lives in Canton, Georgia, Ellis is a bright and bubbly girl. She is gregarious, funny, and curious about the world around her. Fortunately for that world, she will be sticking around for a while.

“When she was born, everything was perfect until it wasn’t,” Ellis’ mother Yataa remembered. When she was about a year old, Ellis developed a persistent fever that doctors initially dismissed as nothing alarming. However, Yataa sensed something was seriously wrong and, before long, her worst fears were realized.

“At one o’clock in the morning one night, I walked into her room,” Yataa recalled. “She was out. She was vomiting in her sleep, and she was as cold as the wall, and she was chalk-white. We rushed her to the emergency room. They tested her blood and saw that there was something wrong. They rushed her into ICU, and it all began that night.”

What began was a five-year struggle first to diagnose and then treat Ellis in order to save her life. After her harrowing stay in the ICU at a Vancouver hospital, Ellis was seen by pediatricians who were unable to identify any significant issues with the child. Yataa and her husband, Marius, pushed for a hematologist to review her bloodwork and make determinations. At last, they got the attention they wanted. But the situation was dire.

Ellis was diagnosed with chronic severe [neutropenia](#), a rare and life-threatening disorder that impacts the production of white blood cells, weakening the immune system. Already a rare disease, Ellis’ neutropenia was complicated by a genetic mutation in the [SRP-54 gene](#), further isolating her case within the medical community.

The hematologists that Ellis’ family consulted did not offer an optimistic outlook. They told Yataa and Marius to enjoy their time with their daughter and that there was no cure or treatment. But as they discovered, that was not the case.

NIAID DOCTORS CURE SEVERE NEUTROPENIA WITH LIFE-SAVING TRANSPLANT

For two years, Yataa searched. She reached out to all the best hospitals—not just in Canada but around the globe. It became evident that a transplant could be the cure, but the uncertainty left doctors and insurance providers wary of authorizing it. In Canada, with taxpayer-funded healthcare, she was denied access to an experimental procedure. If they were to move to the United States, as they would by 2022, insurance would cover Ellis’ procedure, but doctors were unwilling to take the chance on a transplant that, as Yataa described it, “did not have a protocol.”

Consistently getting no for an answer, especially when there was the prospect of a transplant out there, took a toll on Ellis’ parents. “After two years of trying, we kept hearing no,” Yataa sighed. “There was a boy [with neutropenia but without Ellis’ genetic mutation] who was cured at St. Jude’s through cell therapy. I reached out to St. Jude’s, and they did not respond. I found his parents and contacted them through Facebook, and I asked them if they could reach out to the doctors and help my child. They responded and said that the doctors had said they had nothing for us. That was the last strike. That night, after we put the kids to sleep, I sat down with my husband and told him, ‘When everybody tells you that you’re dead, it’s time to lay down. We’re laying down.’ And so, we hugged, and we cried, and that was it. And then a week later, NIH responded to us.”

[Dr. Harry Malech](#) made the initial connection with Ellis’ family. The Chief of the Genetic Immunotherapy Section at the National Institute of Allergy and Infectious Diseases (NIAID), Dr. Malech enthusiastically accepted Ellis as a candidate for transplant at NIH. The initial meeting was in early 2020, just prior to the COVID-19 pandemic. Though the pandemic delayed Ellis’ procedure, Dr. Malech remained reassuring as Ellis’ family moved to the United States and settled in Canton, a northern suburb of Atlanta. He also introduced the family to Dr. Corina Gonzalez, who would ultimately perform the transplant. At long last, the family not only had their own faith and hope but were also seeing confidence in their doctors’ eyes.



Ellis and her mother, Yataa, meet Screech from the Washington Nationals at The Inn

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They give your child a hug. You become family. It’s not just the material support; it’s the spiritual support, the constant love.

—Yataa, Ellis’ mother

NIAID DOCTORS CURE SEVERE NEUTROPENIA WITH LIFE-SAVING TRANSPLANT

“When you meet her, you see that she is a special doctor,” Yataa said of Dr. Gonzalez. “The power and the knowledge that she demonstrates—I did not doubt her for a second. She was so confident that this would cure Ellis. And afterward, when she looked my husband in the eyes and told him definitively that the transplant had been successful, he fell on the floor and cried. That sentence did so much. There is no doubting it. That’s it.”

It wasn’t just the medical care Ellis received at NIH that made a lasting impact. Ellis and Yataa arrived at The Children’s Inn late on Mother’s Day 2023. For Yataa, walking through the doors of The Inn seemed to lift the burdens of the past five years off her shoulders. “It was late, and I didn’t expect to see anybody, but the staff immediately asked if we were hungry and needed anything like toys, books, or toiletries. The facility is amazing, but it’s also the staff—the support, love, and care. The staff sees you coming, and they give your child a hug. You become family. It’s not just the materialistic support; it’s the spiritual support, the constant love.”

Ellis embraced life at The Inn, becoming involved in activities and wandering the halls with her mother, making new friends among the other families and the staff working in the building. With her little brother, also named Marius, back home in Georgia, Ellis had no shortage of playmates. A bright girl who would be entering first grade this year, she can already read at a third-grade level and has read the many books available to families staying at The Inn. She also loves *Paw Patrol* and *Bluey*, demonstrating some of the indefatigable energy of the puppies who star in both those shows.



Ellis regularly took part in Soccer for the Future events at The Inn

On June 1, after two weeks of testing, Ellis was admitted to the Clinical Center for her transplant. Two weeks later was the big day—Cell Day, as Yataa calls it—when the transplanted cells of an anonymous 25-year-old female American were transplanted into Ellis’ body and took hold. During her hospital stay, Ellis developed an extraordinary bond with her doctors before and after her transplant. Yataa described how Ellis now has to seek out Dr. Gonzalez for a hug on any of their medical trips up the hill to the Clinical Center. Hearing her mother talk about this one afternoon at The Inn, Ellis said she wished she could give Dr. Gonzalez a hug that minute.

NIAID DOCTORS CURE SEVERE NEUTROPENIA WITH LIFE-SAVING TRANSPLANT

“It’s been a successful transplant,” Yataa smiled. “Her white blood cells are going up. It’s been amazing. NIH was the only place in the world that gave Ellis a chance. Otherwise, she probably wouldn’t be there. And what is major about this transplant is that there is now evidence that this would cure this disease. So, for other kids who have chronic severe neutropenia or this SRP-54 gene mutation, it would give them the option of a transplant. Because not everybody can get to NIH to get this done.”



Ellis and the flight crew that brought her back home to Georgia after her transplant

As she recovered from her transplant, The Inn flew Ellis’ father and brother from Georgia to spend a weekend with her and Yataa. The siblings were delighted to reunite, and their parents immediately noticed her brother’s impact on her. The one problem that Ellis had encountered post-transplant was a lack of appetite. She would not eat, but when her brother was with her, she willingly ate meals alongside him.

As she regained her strength, Ellis was once again a constant presence at the programs and events that took place almost daily at The Children’s Inn. A soccer player at home, she was particularly excited on the day that members of the D.C. United team came to The Inn. The precocious

six-year-old appreciates the time she has been given. When asked about her favorite day at The Inn, she smiled broadly and said, “Every day is my favorite.”

Three months after Cell Day, on September 22, Yataa and Ellis returned home to Georgia. They will be back for regular check-ups with Dr. Malech and Dr. Gonzalez, but they also look forward to settling down to a new life in the United States.

“This is the country that saved my daughter,” Yataa said. “The government of America saved a kid that is not even from this country from their own funding. That’s huge. And I have my kid to run around and play. The Children’s Inn kept me standing. You have your family, you have your friends, and you go to church. This has been like my church. You come in, and they have you surrounded, asking what you need and how they can help with anything. They have us all cared for.”



RENEWED OPTIMISM

Family is Life for Elyas' Fight Against Sickle Cell

Viewers of the popular AppleTV show *Ted Lasso* know that for many, “Football is life.” But for Elyas, a 12-year-old from Kenya, football is only a tiny part of it. To him, family is life, and thanks to his parents and brother, Elyas has a renewed optimism for his future and a deep appreciation of the opportunity he has been given.

As a newborn, Elyas was always getting sick and worrying his parents, who already had a young son at home to care for. His mother, Zuleikha, and father, Nadeem Mohamedali, brought him from doctor to doctor, looking for answers, but the doctors dismissed it as recurring infections. But his parents knew there was more to it. They traveled from their hometown in Mombasa to the capital city of Nairobi to consult with some of the foremost medical professionals in the country.

Before the trip to Nairobi, Elyas temporarily lost the use of his left hand and leg, turning what had already been a determined effort by his parents into an urgent one. He spent his first week in Nairobi in the hospital, where they discovered hairline fractures in both his hand and leg. They also ran tests and, after 18 months of constant medical tribulations, determined that the toddler had sickle cell beta thalassemia.

With a diagnosis now secured, Elyas' parents focused on seeking a cure. Zuleikha joined various social media groups for parents of children suffering from sickle cell anemia and eventually came in contact with a mother who recommended a doctor back in Nairobi who specialized in sickle cell.

“He was a wonderful man,” Zuleikha remembers. “His friend had passed away due to sickle cell, and he dedicated his life to fighting it. He recommended Hydrea, which is a chemotherapy drug, to manage it. And it became a bit more manageable. Elyas' crises would only happen once or twice a year.”

As his parents and doctors managed his disease, Elyas was growing up. Despite his diagnosis, Elyas had a passion for soccer—or football, as it is known in most countries outside the United States. Although it made Zuleikha nervous every time he got into a game, Elyas persevered and could be found kicking a ball whenever his pain levels allowed.

When the pain came, though, it was debilitating. “It’s like someone is punching you with so much force,” Elyas described. “You’re basically being beaten up. It’s a lot of pain.”

RENEWED OPTIMISM

In the face of such suffering, many would have been tempted to hide away from the world and avoid as many triggers as possible. Not Elyas. He was too in love with football. He kept striving to be a center midfielder, a spot where he could distribute the ball to his teammates and set the stage for the team's ultimate success. Off the field, though, his family played a similar role in helping him succeed in his fight against sickle cell anemia.

The chemo medication did help manage his crises, but it was not a long-term solution for Elyas. By the time he was 11, he was experiencing liver problems as a side effect of the drug. An Italian doctor determined that his older brother, Mohamedali Nadeem, was a perfect match as a potential bone marrow donor. But the procedure remained prohibitively expensive.

In the meantime, Zuleikha continued building a network of support online. There, an online acquaintance told Zuleikha how her son—[Caesar](#)—was having his bone marrow transplant done at the National Institutes of Health, where he would stay at The Children's Inn. The same day, another person online gave her contact information for the NIH. It sounded too good to be true to Elyas' parents, but they reached out to the National Heart, Lung, and Blood Institute ([NHLBI](#)) doctors and were accepted into the trial. As the calendar turned to 2023, Elyas—now 12—was on his way to Bethesda alongside his parents and brother.



A different kind of football: Elyas and his family pose at Baltimore Ravens training camp on a field trip with The Inn

His brother, Mohamedali Nadeem, is four years older than Elyas and remembers how he felt when his little brother was born. "At first, I was excited," he recalled. "Then, when he came out, I wasn't excited anymore." His life of being the only child, getting all the attention of his parents and grandparents, was over.

But the brothers grew close, and when it was discovered that he would be a perfect match for the transplant, Mohamedali Nadeem was thrilled. Despite being a strong competitive swimmer in Kenya, Mohamedali Nadeem gave up that pursuit for a break that has now stretched to over six months, knowing that the break would help cure his brother.

He didn't realize the impact it would have on his own health, though. During the check-up process prior to the transplant, it was discovered that he had coarctation of the aorta, a heart disorder that almost put a stop to his serving as a donor. Fortunately, doctors determined that his case was mild enough that the procedure would not impact his overall well-being. And on March 30 he served as the donor for Elyas' transplant.

Zuleikha explained that the transplant effectively killed off half of Elyas' sickle cells, replacing them with healthy cells from his brother using an antibody known as Jasper 191. The remaining sickle cells would, in turn, be overtaken by his brother's cells, allowing for a less intensive recovery and the same result. He is, she explained, the first child and only fourth person ever to undergo that sort of procedure.

RENEWED OPTIMISM

Elyas and his family stayed at The Children's Inn in the weeks leading up to the transplant. Concerns about the price of the life-saving procedure were a distant memory, replaced by the welcoming atmosphere of The Inn and the complimentary amenities it provides. More important to them, though, was the community itself.

"I love the community here," Elyas smiled. "They make you feel so welcomed. It makes me happy how supportive they are. When I was going through the transplant and recovering in the hospital, they knew I loved to play soccer, so they brought a soccer ball, and everyone at The Inn signed it."

Elyas will remain at The Inn for six months following his transplant, regularly visiting his doctors across the NIH campus. His recovery has had ups and downs, but overall, the doctors are pleased. He is too.

"I never thought this would happen," Elyas admitted, his voice full of gratitude for the many people who had helped him reach this point. "For me, this is a very good miracle."



Elyas and his older brother, Mohamedali Nadeem, who served as his bone marrow donor

“

I love the community here, they make you feel so welcomed. It makes me happy how supportive they are. When I was going through the transplant and recovering in the hospital, they knew I loved to play soccer, so they brought a soccer ball, and everyone at The Inn signed it.”

—Elyas



A FAMILY'S NEW LEASE ON LIFE AFTER A 20-YEAR JOURNEY

There For Each Other: Zachary and Avery's Remarkable Story

Zachary's life was in jeopardy. An 11-year-old from Pahrump, Nevada, he suffered from [Fas-associated protein with death domain](#) (FADD) deficiency, an ultra-rare and severe gene mutation characterized by recurrent infections, encephalopathy, cardiac abnormalities, and short life expectancy.

The diagnosis was the beginning of a long and, at times, confusing medical journey for Zachary and his family, with doctors facing challenges they had never encountered before. By the fall of 2022, he and his family were on their way to The Children's Inn at NIH so that Zachary's eight-year-old sister, Avery, could serve as his bone marrow donor as part of a potentially life-saving treatment at the NIH.

As rare and serious as his diagnosis was, it seemed straightforward enough to those who met him in those early days at The Inn. His sister would save his life, and the family would begin to move past this devastating time. But for Zachary, Avery, and their family, it was never quite that simple. And the story stretched back further than either of them had been alive.

Zachary is the fifth-born child of Shawn and Erin Holmes. Three of his older siblings, Paul, Sarah, and Alyssa, were grown and living on their own by the time their kid brother arrived in Bethesda, MD at the NIH Clinical Center. But for Shawn and Erin, this was unfortunately not their first experience confronting the painful reality of caring for a sick child. In 2001, more than a decade before Zachary was born, the couple's second son, Jacob, developed seizures and passed away when he was just 18 months old.

At the time, Shawn, Erin, and their doctors believed that Jacob's tragic passing was the result of a bad reaction to the MMR vaccine given at his one-year checkup. There was nothing wrong with their eldest child, Paul, and before long, two more healthy children, daughters Sarah and Alyssa, were born.

"There was what I call the dark period right after Jacob's passing," Shawn remembered. "What got us through is that when we buried Jacob, Erin was eight-and-a-half months pregnant with Sarah, and we still had Paul at



Zachary and Avery's older brother Jacob, who passed away at age 18 months in 2001

A FAMILY'S NEW LEASE ON LIFE AFTER A 20-YEAR JOURNEY

home. Ultimately, I could have buried my head and probably ruined the lives of our son and daughter-to-be. Or I could, as I called it, 'fake it 'til I make it.' Put on the fake smile and try not to live in the darkness. All that would do is make for a worse life. What got me through was those kids who needed us."

As the family continued forward with their grief, they welcomed another child in 2012, Zachary. At first, he seemed to be healthy and thriving. But when Zachary was 14 months old, he came down with the flu and ended up in the hospital, where he experienced a grand mal seizure.

By the time Zachary was two years old, his life was already full of chilling déjà vu moments for his parents. Fortunately, doctors at the UCLA Medical Center discovered a gene mutation that explained Zachary's seizures and offered some retrospective answers about what had happened to Jacob.

Zachary seemed to recover after the first grand mal seizure but it was only two years before he suffered a second seizure, then two more years before the third. His doctors referred him to immunologists who recommended that his parents do everything they could to keep him healthy, thinking that the genetic mutation was weakening his immune system. But over time, it became apparent that there was more going on medically than just seizures.

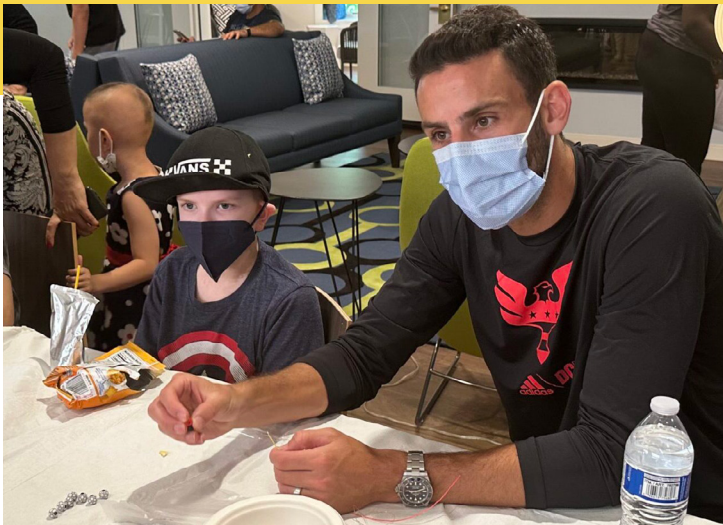
"There weren't any people living with this disease," Erin explained. "The doctors didn't know what to do. His immune system was attacking his brain." As they explained, no matter how many prestigious doctors examined Zachary, they would inevitably come away with some new reason to tell his parents, "I've never seen that before."

"Welcome to our Zach," Shawn laughed. "If we didn't surprise you, we didn't do our job."

Doctors figured out over the years that the viruses Zachary would acquire were not necessarily what was hurting him. "He would get sick and easily beat whatever it was, but the FADD [affected] the messaging system for the immune system," Shawn said. "So, it would not stop producing white blood cells after he got better, and they would start eating other parts of his body—organs and the brain specifically. We were fighting the wrong fight for the first eight years."

In 2020, Zachary was at a low point. More than 30 percent of his brain was inflamed. Then, the COVID-19 virus hit. Ironically, it was the blessing in disguise that the family needed.

When his doctors enacted strict quarantining protocols, they referred Zachary to colleagues at Children's Hospital Los Angeles. Right away, his parents described, the doctors began to recognize what was happening. At first, the message to Shawn and Erin was not encouraging.



Zachary mingles with a DC United player on the team's visit to The Inn

A FAMILY'S NEW LEASE ON LIFE AFTER A 20-YEAR JOURNEY

"They told us to prepare for the worst," Shawn said. "To provide palliative care. He was not strong enough for a bone marrow transplant."

Already grieving the loss of a child, Shawn and Erin refused to accept that as the best course for their son. "I think that's why we made it this far," Erin smiled. "We couldn't let that happen again."

With his parents pressing for alternate options, Zachary's doctors took a chance on a multiple sclerosis drug which, they hoped, would block his

immune system from reaching his brain. Miraculously, it worked. But it was not a long-term solution. Though the drug prevented the immune system from attacking the brain, it also prevented the immune system from healing any external disease which might attack it. "As our doctors called it, it's a bit of Russian Roulette," Shawn said. "There might be 1,000 chambers in the gun, but eventually, it will get you if you don't do something. The bone marrow transplant is the something."

Enter Avery. Born three years after Zachary, Avery is a bright, caring girl who grew up loving gymnastics. By 2022, Zachary's brain inflammation had been significantly improved thanks to the experimental treatment, reducing 90 percent in size. But he still needed a transplant, and Avery proved to be a perfect match as a donor. So a year ago, in November 2022, the parents and two younger children came east to the NIH Clinical Center, where they would stay at The Children's Inn as they prepared for, underwent, and recovered from the procedure.

When a patient receives a bone marrow transplant, their doctors put them through a series of tests designed to ensure their safety and preparedness for the grueling procedure and recovery. What may not be as well known is that the bone marrow donor also goes through tests for the same reason. As part of the preparation for the procedure, Avery underwent an EKG test, and doctors discovered something that immediately and dramatically threw a wrench in everyone's plans.

"They found a hole in the atrial vein leaking into the right chamber," Avery explained about the congenital heart defect discovered by doctors at the NIH.

Instead of saving her brother's life, Avery found herself back in the car, driving across the country to Los Angeles, where the seven-year-old underwent open heart surgery on December 30 that may have saved her own.

"Zachary's doctors felt that it was urgent that they get her in quickly and get her recovered quickly because he needed this transplant as quickly as possible," Erin said. "They pulled strings to get her in for her surgery, and two weeks after we found out about her heart, it was done."



A FAMILY'S NEW LEASE ON LIFE AFTER A 20-YEAR JOURNEY

“They said this is something you can’t hear through a stethoscope,” Shawn said. “She probably would have had a heart attack in her teens or early 20s.”

Eleven weeks of recovery followed, but Avery remained determined to play a part in saving her brother. After all, he had essentially helped

save her life too. And though she had been nervous about the procedure in November, after going through emergency open heart surgery, the prospect of bone marrow donation was more straightforward.

At long last, the family returned east to Bethesda, making their third cross-country drive in five months, and the transplant took place on May 9. It was a momentous occasion for the family and the entire American medical community, as it was the first transplant of his type involving FADD deficiency to be done in the United States.

Playdates had not been an option for Avery back home. Her brother’s illness precluded that, and she had been home-schooled for third grade during the 2022-23 school year in preparation for the transplant. So on their visits to The Children’s Inn, she relished the opportunity to be just one of the kids.

“I mostly just like the kids here,” Avery said. “You can just play with other kids. Back home, I couldn’t do that at all.” She has taken full advantage of The Inn’s programming opportunities, participating in special events and field trips she never dreamed of a year ago. She also has loved the newly refurbished playground and the indoor play spaces that make The Inn such a “Place Like Home” for children like her.

“I got the better end of the stick,” Shawn laughed as he described splitting parenting duties with Erin. After Avery’s single night in the Clinical Center recovering from the transplant, Shawn has been with her at The Inn most of the time while Erin stayed with Zachary, whose in-patient tenure at the Clinical Center lasted several weeks. “Avery was very lucky [for those] six weeks. There was a group of girls around the same age, and they would play from 8:00 in the morning to when I dragged her back in the room at midnight, telling her that we had to cut it off eventually! It was the families that made it work. The kids used every activity and every space to draw themselves together. The kids made the activities fun, and the activities made for a place where the kids could have that fun. It was a great balance.”

Zachary, meanwhile, has taken pleasure in the little things after he returned to The Inn to continue his recovery. The fridge in the Bistro, for example, has captivated him, with its

“

The Inn made an unthinkable thing possible. It provides this great community, which makes you more comfortable as kids and parents.”

—Zachary & Avery’s dad, Shawn

A FAMILY'S NEW LEASE ON LIFE AFTER A 20-YEAR JOURNEY

constantly refilling supply of chocolate milk, string cheese, and juice. He also has made appearances at Bingo and painting nights. He was not feeling up to a field trip when The Inn hosted its annual Christmas in July event, but Avery made sure to factor him into her plans, buying presents for Zachary in addition to herself.

Zachary's recovery has had its ups and downs over the ensuing months. He initially returned to The Inn from the Clinical Center only to have a seizure send him right back across the street for an additional week. "They said that's typical of the timing," Erin explained. "We don't anticipate anything else."

On the Saturday before Thanksgiving, a year after their first visit to The Inn, Zachary, Avery, Shawn, and Erin went home at long last. They will return at least once a year for the next five years for follow-ups to Zachary's groundbreaking procedure, but doctors and everyone around him are optimistic about his long-term outlook.

Over the last six months, as Zachary recovered from his transplant and Avery displayed just what a strong heart she has, their parents were grateful that they have had the whole family together, even after months away from home. "It's easier that we are all together," Erin said. "We have been anticipating this for a long time, so it was worth being here. It's convenient and super easy [at The Inn]. It is an amazing place."



Avery rides the escalator with Santa at The Inn's annual Christmas in July

"The Inn made the whole experience tolerable," Shawn smiled. "It made an unthinkable thing possible. It provides this great community, which makes you more comfortable as kids and parents. You pick where you want to do a transplant like this based on the doctors, of course, but a big part of doing this here rather than back in Los Angeles was The Children's Inn. The ability for the kids to be around other kids creates a family. It's a lot easier to be one-of-a-kind in a group of hundreds of one-of-a-kinds."

With a hopeful eye toward the future, Zachary, Avery, and their parents are excited about the opportunity to put the medical saga in the rearview mirror, but doing the same with The Children's Inn will be bittersweet. They are not sure exactly what will come next. But they know they'll be ready for it.

"There's no simple answer for what we hope is the end of a 20-year journey," Shawn said. "Is someone writing our script? If you wrote a movie, it would be too unbelievable. But our attitude has always been that this is the hurdle in front of us, so we jump it and see what's next. We've had a lot of luck and a lot of angels praying for us."



RESIDENT THERAPY DOG CELEBRATES HER VALENTINE'S DAY BIRTHDAY WITH THE CHILDREN'S INN FAMILY

A Perfect Tenth for Zilly

What do you get for the dog who gives everything? Since Zilly joined The Children's Inn at NIH as its resident therapy dog in 2015, that has been the question each Valentine's Day as the Australian Labradoodle celebrates her birthday. On Wednesday, Zilly was the star of the show as Inn staff and residents gathered to celebrate her 10th birthday as part of the broader Valentine's Day parties taking place at The Inn.

For most of her life, Zilly has played a unique and integral role for the families staying at The Inn. A gentle yet playful dog, Zilly has a knack for bonding quickly with newcomers both young and old, making The Inn even more of "A Place Like Home" for anyone seeking a furry friend.

RESIDENT THERAPY DOG CELEBRATES HER VALENTINE'S DAY BIRTHDAY WITH THE CHILDREN'S INN FAMILY



Zilly and her friends at her birthday party on Valentine's Day

“

She does so much all year to make The Inn such a welcoming place, and we love taking every opportunity we can to show her how much she is loved by everyone here at The Children's Inn.”

—Family Program
Operations Manager
Kristin Arabian

Through her role as a certified therapy dog, Zilly also makes [regular visits to families undergoing inpatient treatments at the NIH Clinical Center](#). She provides soothing companionship to children, teens, and young adults undergoing what can be difficult testing and treatments.

Wednesday's party started in The Inn's main lobby, where staff and families gathered to sing Happy Birthday to the dog of honor. Georgetown Cupcakes provided sweet treats for Zilly and all her friends, and families presented her with birthday cards they had made over the last several days.

The party continued with Valentine's Day activities including cookie decorating stations, a Zilly-shaped paper craft, a photo booth, and a Valentine-themed art class put on by Dave, a longtime volunteer at The Inn.

“Zilly's birthday party is one of our favorite events of the year,” said Family Program Operations Manager Kristin Arabian. “She does so much all year to make The Inn such a welcoming place, and we love taking every opportunity we can to show her how much she is loved by everyone here at The Children's Inn.”



Sailing with Aram Remains a Favorite Inn Activity

For 15 years, Aram Nersesian has provided families with an opportunity to explore the Chesapeake Bay.

On a Thursday in late May, a group from The Children's Inn at NIH climbed aboard a sailboat in Lusby, MD, for a day trip on the Patuxent River and Chesapeake Bay. The weather was warm, and a blue sky with wispy white clouds was overhead. It was the first sailing trip of the

Aram, left, advises a young sailor and his caregiver

season for Aram Nersesian, now in his 15th year volunteering as a sailboat captain to the families staying at The Inn.

Nersesian, an Armenian-American from New York, fell in love with sailing as a young man. For several years, he even lived on his boat, a 60-foot custom aluminum schooner built in France in 1984. At the same time, he developed a passion for photography and began searching for impactful ways to give back to the community.

At first, that was through his photography. In 1979, not long after the end of the Vietnam War, 28-year-old Nersesian volunteered as a photojournalist, trading his work to The Catholic Relief Services and the International Rescue Committee for them to use in fundraising efforts. In return, they guided him safely to the refugee camps.

Nersesian settled in Lusby and returned to his love of sailing, but the experience working in Vietnam stuck with him. "I always tried to have both my work and personal projects have 'intrinsic value,'" he explained. "By that, I mean that somehow, the projects would help people."

One day, he heard a report about the revitalizing impact sailing could have for breast cancer patients. He called an oncologist, a friend of a friend, offering to take patients out on the water for relaxing sails that would invigorate them at a stressful and scary time. Though the offer was appreciated, the oncologist referred him to The Children's Inn instead. As it turned out, it was a perfect match.



He did not know what to expect on the first day that The Inn was scheduled to come on board. “A bus pulled up with 15 people,” he laughed. “They were all ready to sail.”

The process has repeated itself over the years. Sometimes, there are familiar faces, but often, the trip out into the Bay with Aram is a first for all the families on board. “His enthusiasm is always evident,” said Family Program Operations Manager Kristin Arabian. “Aram takes the time

to share his passion with the families and make them feel welcome in what can be a scary activity. When we leave, our families always feel like they’ve made a new friend.”

With life jackets secured on the younger sailors, Nersesian has been shipping out of his private dock during the summer months with a boat full of grateful families from The Inn for 15 years. On Thursday, his first sail of the year after a shoulder injury over the winter, he was joined by friends Susan and Red, both longtime sailors themselves who acted as his crew. The couple lives in Herndon, VA, and has been looking for similar ways to give back to the broader community through their love of sailing.

Most families who stay at The Inn are not from the local area, and many come to NIH from other countries. While their days are primarily spent in the presence of doctors and researchers, the families also get an opportunity to explore everything that Maryland and the Washington, D.C. area have to offer through the field trips set up by The Inn’s dedicated programming team. Sailing with Aram, which involves a 90-minute bus ride from the campus in Bethesda, allows them to truly leave their stresses ashore and enjoy some salt air and some of the most beautiful natural views the region offers.

Though he has been providing the intrinsic value for which he strives to families at The Inn for 15 years, Nersesian is reluctant to take credit. “My captain’s hat goes off to the folks who arrange these activities,” he said, referring to The Inn’s Residents Services and Programming teams. “And also to all the organizations who donate their time, activities, facilities, and energy to give a little something to these families. Each month, I am awed by the courage of the parents and the smiles and strength of the children. After each sailing trip, I am left more inspired, stronger, and more appreciative of everything around me. Each month, I am a better person for having met the families and staff who arrive on that bus, meet a total stranger, and get onto the boat!”





The Kahlert Foundation Provides Support Behind the Scenes



Early support from the Maryland-based organization proves vital to The Inn of Tomorrow

As The Children's Inn at NIH has developed plans for The Inn of the Tomorrow, it has received support from many sources. One of those sources has been The Kahlert Foundation, a family philanthropic organization based in Carroll County, Maryland, which has partnered with The Inn over the past two years to provide early grant support for the necessary infrastructure upgrades to transform the existing Inn and meet the needs of young patients and families well into the future.

"The thought that The Kahlert Foundation can impact kids and families who are going through the unimaginable is rewarding for us," said Ellen Myers, The Kahlert Foundation Executive Director. "Really, you're helping kids in Maryland and all over the world with very rare diseases. It's unique that The Inn is in our backyard ... I don't think enough people recognize the significant impact that The Inn has for families and young kids. So to be able to have a place like home to go to when you're going through treatment just spoke to the Kahlert Family."

The Kahlert Foundation has focused on strengthening the Maryland community since its founding more than 30 years ago. In fact, the commitment to community goes back even further than that.

"William E. Kahlert, 'Bill' who was the founder of the foundation, started a company in Maryland back in the 1970s that make commercial HVAC and industrial refrigeration," explained Kahlert Foundation Executive Director Ellen Myers, who is a member of the Capital Campaign Committee. "It's an employee-owned company. What's great is that over the last 50 years, when the company has had success, the employees have been part of that."

In 1991, after more than 15 years running the industry-leading Evapco, Inc., Bill Kahlert founded The Kahlert Foundation with a desire to make a difference in the communities where he lived and worked. A small family foundation focused primarily in its home territory of Carroll, Howard, and Baltimore Counties, The Kahlert Foundation expanded its reach when its founder passed away in 2011 and bequeathed part of his estate to the foundation.

The foundation focuses on health care and education, with more than 60% of the grants awarded each year going to support causes in those areas.

In 2022, Myers and Greg Kahlert, Bill's son and the current president of the Foundation, toured The Inn, and they were excited about what they saw. At first, they made a gift to support family programming. But soon, the foundation was directly involved in the development of the plans for The Inn of Tomorrow.

Kahlert grant support was instrumental in securing \$1.4 million in capital funds from the State of Maryland, which required that The Inn raise the same amount in matching funds.

"We started our support early in the infrastructure (renovation) phase," Myers said. "That is not always the most attractive things to fund. They're things behind the scenes, like air handling and electricity—all the operational stuff that you have to do in order to ultimately create the beautiful kids' playground and welcome area and renovated rooms."

It was a natural fit for the foundation born out of the success of Evapco, a manufacturing company dedicated to designing and manufacturing the highest quality products for the evaporative cooling and industrial refrigeration markets around the globe.

“

I don't think enough people recognize the significant impact that The Inn has for families and young kids. So to be able to have a place like home to go to when you're going through treatment just spoke to the Kahlert Family."

—Ellen Myers, *The Kahlert Foundation*
Executive Director

Though the support The Kahlert Foundation provides may not catch the attention of many of The Inn's younger residents, the opportunity to make a positive difference in their lives remains important to the Foundation. With a geographic focus on making an impact in Maryland, The Kahlert Foundation also welcomes the opportunity to have a global impact through The Inn.

Thanks to the dedication of The Kahlert Foundation, The Inn of Tomorrow is closer to becoming a reality. And the partnership has no end in sight.

"We would love to continue to support The Inn and see The Inn of Tomorrow come to fruition," Myers said. "I've personally been involved on the Campaign Committee, so I've been learning more about so many generous people and companies who have made this come together. I've also gotten to know the staff at The Children's Inn, and they're just amazing. As a foundation, we have enjoyed getting to know the team, and we are happy to be a part of that [future]."





Happy 5-Year Anniversary to WINN!

In October 2023, the Women for The Inn (WINN) Community celebrated its fifth anniversary. Since its inception in 2018, WINN has grown into a dynamic group of over 100 members dedicated to supporting The Children’s Inn. Joining this group provides members with opportunities to volunteer their time, donate (and direct) funds toward Inn projects, network with like-minded women, and connect with healthcare luminaries.

Under the leadership of co-chairs Debra Cohen and Monica Granovsky, WINN brings together women who embrace The Inn’s mission. They strive to maximize their creativity, personal philanthropy, and professional networks to provide meaningful support to Inn families.

This past year has been an active one for the WINN community. In addition to hearing from NIH leaders during triannual member meetings and forming friendships at WINN socials, this incredible group of women has dedicated countless hours, generous donations, and lots of love to Inn families by:

- Sponsoring and volunteering monthly to serve meals to our residents.
- Engaging with families during Valentine’s Day, St. Patrick’s Day, Cinco de Mayo, and Halloween parties.
- Decorating our halls and wrapping gifts during the winter holidays.
- Reading books to our youngest residents during Pets & Pajamas Storytime.
- Writing notes of encouragement to fill The Inn’s Thoughtful Treasure mailboxes.
- Serving as ambassadors for The Inn within their companies and friend groups.

WINN takes pride in having directed over \$540,000 in yearly membership donations over the past five years toward resident welcome packages, playground renovations, kitchen supplies, and The Inn’s Feeding Family and Education Funds. We look forward to continuing this tradition of support and welcome any women who would like to contribute the minimum annual amount of \$1,000 to join us.

To learn more about the WINN Community, including ways to join, please visit [WINN](#).





Kathy Pomerenk, Fundamentals of Literacy Program



When Kathy Pomerenk walked through The Children's Inn's doors for the first time in the summer of 2022, the magic of "A Place Like Home" hit her immediately. The retired Montgomery County Public School system special education and reading initiative teacher felt a tug on her heart to use her experiences and expertise to give back to Inn families as a reading tutor.

While a family's primary goal is the health and well-being of their child, their continuing education remains important as they look forward to a healthy future. The Inn's [Learning Center](#), run by Family Program Coordinator for Education Cristian Lemus, serves as a vital resource for NIH patients, their siblings, and caregivers staying at The Inn.

"The Children's Inn is focused on bridging the gaps in educational literacy and language for our families," says Cristian. "Education is important to them, and the Learning Center allows them to continue to learn at their own pace while undergoing treatment at the NIH."

It was in that spirit that in October 2022, Kathy started working with Bina (age 6) and Nza (age 9), two

sisters from Kurdistan, Iraq whose brother Aza was participating in a clinical research study for Proteus syndrome. Kathy had never formally taught English as a second language before, let alone to children whose native language, Sorani, has no one-to-one correspondence with the Roman alphabet. So she did what any trained reading teacher would do: she started with sounds. She segmented the sounds of speech in words, stretching each one so the children could isolate and blend them. She taught the girls to use small colored tiles to represent and manipulate those sound patterns, adding and deleting tiles to create new words.

"We were playing this phonemic awareness game and Bina, the-six-year-old got how to represent the individual sounds in a word," Kathy recalls with a smile. "She looked up and I could see the pride on her face. She wanted to continue with this activity because she knew she could do it. That's a remarkable moment in a child's development of understanding language."

Kathy worked with Bina and Nza, each one in separate private lessons, twice a week for a total of ten months

Kathy, center with Nza and Bina



and over 100 lesson plans. Even after their family moved to Virginia to enroll the children in school full time, they continued to participate in Zoom lessons with Kathy from time to time.

Inspired by young readers like Bina and Nza, in early 2024, Cristian, Kathy, and two other volunteer educators—Susan Jaffe and Jaime Banks—piloted The Inn’s *Fundamentals of Literacy Program*. Using The [Really Great Reading Program](#) as a guide while focusing on the five pillars of reading—phonemic awareness, phonics, fluency, vocabulary, and comprehension—the program’s aim is to enhance literacy skills and close gaps in reading, writing, and spelling amongst young readers at The Inn. Currently, ten children between the ages of five and twelve have been assessed in its inaugural year.

While they have attracted participation from a few other siblings, most of their students are the patients themselves—all staying at The Inn for at least a few weeks or months at a time. The three tutors and Cristian meet monthly through the new Academic Instruction and Mentoring Committee (A.I.M.) to discuss their lesson plans, student updates, and effective ways to reach and teach the children.

In the future, *Fundamentals of Literacy* strives to reach more kids, more often, taught by more trained teachers. Kathy is encouraged by early successes and looks forward to both watching the fundamentals program evolve and adding more pilots like this one to address different educational needs at The Inn.

Kathy’s favorite thing about The Inn? “The kids, of course!” she quickly exclaims. “It’s the same thing that every teacher lives for; it’s that moment when a child looks up and they’ve got whatever concept you’re trying to teach and they feel proud, they feel ownership. And it just feels like such a celebration every time! It doesn’t matter how little it is. It can be the smallest incremental step in learning to read but when they get it, they know it, and we try to celebrate.”

Indeed, at The Inn, all big and little steps towards any goal are celebrated. The past year has been full of those milestones and accomplishments at The Inn’s Learning Center thanks to educators like Kathy.

To learn more about the Learning Center and volunteer tutoring opportunities, contact Cristian Lemus at Cristian.Lemus@nih.gov.





Above, GDIT Team serves family dinner, far right GDIT President Amy Gilliland reads to Inn children



GDIT Takes Time to Get to Know the Families at The Children's Inn

On a quiet Wednesday in early May, when the weather in the Washington area was warming up, the families of The Children's Inn at NIH were lacing up their skates and hitting the ice at the Washington Capitals' MedStar Iceplex in Arlington. They were guests of General Dynamics Information Technology (GDIT), a longtime partner of the Capitals and The Children's Inn.

"That was really fun to offer something that's a little different for the families," said Sarah Swedberg, a Senior Marketing Manager at GDIT. "They learn something new—some of our folks were there to help. Ice skating is hard!"

Based in Falls Church, Virginia, GDIT is a global technology and professional services company that delivers consulting, technology, and mission services to every major agency across the U.S. government, defense, and intelligence community. Its commitment to the National Institutes of Health is deep, as is its commitment to The Inn.

"We support a lot of health agencies on the IT side," Swedberg explained. "I can't describe how beneficial it is to get to know the people who benefit from some of that and find a way to connect directly with them."

The partnership with GDIT dates back prior to The Inn's opening in 1990. GDIT has been directly involved with family activities, event sponsorship and volunteer help for Inn events such as An Evening for Hope, Snowed Inn, and the Golf Innvitational. Their generous support has resulted in over \$900,000 for overall operations at The Inn to date.



“

We support a lot of health agencies on the IT side. I can't describe how beneficial it is to get to know the people who benefit from some of that and find a way to connect directly with them.”

—Sarah Swedberg, a Senior Marketing Manager at GDIT

The day at the rink—the first time on skates, for many families who attended—was a perk offered to GDIT through its sponsorship of the Capitals. Senior Vice President for Federal Health Kamal Narang opted to invite the families at The Inn, turning the ice time into a lasting memory and helping The Inn make childhood possible for residents. “We are proud to partner with The Children’s Inn to support the evolving needs of families,” says Vice President and General Manager Federal Health Sector and Inn Board member Kamal Narang.

GDIT prioritizes making individual connections with the families staying at The Inn, and not just on the skating outing that it hopes becomes an annual tradition. Volunteers from the company visit The Inn once a month to serve dinner, taking the time to interact with families and share in their successes. In December of last year, GDIT President Amy Gilliland joined her team and read several seasonal books to young guests.



GDIT also served as a room night sponsor for a week in July, allowing more than 75 families to take part in The Inn’s annual Camp Incredible programming that week. This included field trips to see *Inside Out*, a Washington Mystics game, and visits to The Inn from superheroes like the Incredible Hulk and Spiderman.

Andrea Mercadante, a Senior Diversity and Inclusion Analyst at GDIT, emphasized the importance of GDIT giving back to the local community.

“People are familiar with the concept of having a place for these families to stay,” she explained. “It can be financially devastating to have a critically sick family member. We do work with NIH in a lot of different ways, so there are a lot of individual connections there. It’s part and parcel of everything we’re doing with NIH because it’s not just the business side, these are the people that our business is impacting.”

The opportunities to interact with families, whether at The Inn or special events like the day at the Iceplex, are ones that the GDIT family values. “Our people just really like doing it,” Mercadante smiled as she discussed the monthly dinners. “It’s something simple. They love meeting the families and they want to do it again and again.”

2024 Annual Donors

Individuals & Estates

The Children's Inn at NIH salutes these individual donors whose generous contributions of \$1,000 or more between July 1, 2023, and June 30, 2024, help to sustain the mission of The Inn.

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 Anton Cohen, CPA
 William L. Dahut, M.D.
 Prachee J. Devadas
 Jamie Gentile, MPH, CCLS
 Christine Grady, MSN, Ph.D.*
 Philipia Hillman, Ph.D.
 Kavita Kalatur
 Jill Olmstead
 Susan Penfield
 Scott Royal, Ph.D.
 Zoe Sharp, CPA, J.D.
 Michelle Taylor
 Scott Vogel
 Ken Wojdon



*Dr. Grady is serving on the Board in her personal capacity

Trustees

Dale A. Adams
 Timothy J. Atkin
 Diane Baker
 Matthew Bell, Ph.D.
 Abigail Blunt
 Sandra Davis
 Congresswoman Deborah I.
 Dingell
 Pepe Figueroa

John I. Gallin, M.D.*
 Edward Greissing
 Robert (Rob) Guerra
 Lee J. Helman, M.D.
 Molly Mahoney Matthews
 Beth Maloney
 Beth Meagher
 Edward Orton, Ph.D.
 Todd Pantezzi

Holly Cobb Parker
 Philip A. Pizzo, M.D.
 Jay C. Planalp
 Mark J. Raabe
 Kristine Ribas
 Ryan A. Riel
 Kathy L. Russell
 Randy Schools
 Porter Shifflett

Sandeep Somaiya
 Constantine Stratakis, M.D.
 Robert J. Vogel
 Dennis Webster
 Lori Wiener, Ph.D.
 Lauren V. Wood, M.D.

*Deceased

Committee Members Not Serving on the Board

Annette Abrams, *Art Committee*

Dale A. Adams, *Audit Committee*

Masood Ahmed, *Capital Campaign Committee*

Capt. Jeasmine Aizvera, MSSW, LCSW-C, BCD, *Clinical Advisors' Committee*

Momodou Bojang, *Finance Committee and Investment Subcommittee*

Julie (Goldfarb) Bush, *Capital Campaign Committee*

Tony Clifford, *Master Planning Advisory, Ad Hoc Committee*

Dr. Alexandra Freeman, *Clinical Advisors' Committee*

Tim Gray, *Audit Committee*

Alison Han, M.D., MS, *Clinical Advisors' Committee*

Stephanie Hixson, PE, LEED AP, *Master Planning Advisory, Ad Hoc Committee*

Capt. Antoinette L. Jones, MSOD, RN, *Clinical Advisors' Committee*

Lindsay Joyce, *Investment Subcommittee*

Pamela Kanstoroom, *Capital Campaign Committee*

Lauren Kingsland, *Art Committee*

Dr. David Lang, *Clinical Advisors' Committee*

Danielle Myers, *Audit Committee*

Dr. Maryland Pao, *Clinical Advisors' Committee*

Peter Miller, *Capital Campaign Committee*

Ellen Finnerty Myers, *Capital Campaign Committee*

Dr. Ruth Parker, *Clinical Advisors' Committee*

Crystal L. Parmele, *Art Committee*

Susan Due Percy, *Art Committee*

Kristine Ribas, *Master Planning Advisory Ad Hoc Committee*

Benjamin Rose, *Finance Committee, Investment Subcommittee*

Mark Rotariu, *Finance Committee*

Dr. Jill Rothschild, *Clinical Advisors' Committee*

Dr. Nirali Shah, *Clinical Advisors' Committee*

Lori Wiener, Ph.D., *Art Committee, Clinical Advisors' Committee*

Alan Zawatsky, *Master Planning Advisory, Ad Hoc Committee*

Juan Zavala, *Investment Subcommittee*

Dr. Deena Zeltser, *Clinical Advisors' Committee*