



The **Children's Inn** at NIH



## 2023 ANNUAL REPORT

**A Year Filled with  
Extraordinary Gratitude**

# Letter from the CEO and Board Chair



“

Thank you to everyone who supported our mission this year. You play a vital role in safeguarding The Inn's ability to provide comfort and care to families while accelerating pediatric research at the NIH.”

We are delighted to present The Inn's 2023 Annual Report. In doing so, we extend our sincere appreciation to the individuals, organizations, and friends whose generosity and volunteer commitments are showcased throughout these pages. It is because of your enduring support that we can continue to reduce the burden of illness for families and uphold the dedication of our remarkable staff.

Over the past year, 730 families have stayed at The Inn free of charge for a total of 15,000 nights. These families traveled from all over the world to participate in more than 460 clinical trials representing advances in treatments of cancer, bone and growth disorders, mental illness, genetic conditions, rare diseases, and other profound health challenges. For these families, the NIH represented their best hope for a cure.

Your unwavering commitment to The Inn not only makes a difference in the lives of these families, but enables NIH clinical researchers to make pioneering medical breakthroughs each and every day.

A special note of gratitude to our dedicated volunteers: whether it's greeting visitors at the welcome desk,

providing and serving meals, decorating for the holidays, tutoring, or leading recreational activities, you bring The Inn to life and we are grateful for your continued support.

With a focus on the future, our dedicated team continues to strive to make The Inn a true “Place Like Home.” Highlights from the past year include an increasing number of off-campus field trips for families, such as the annual White House Easter Egg Roll hosted by President and Dr. Biden, and exploring the iconic monuments and museums in the heart of DC, the Inner Harbor in Baltimore, Great Falls Park, and the National Zoo.

Thanks to your generosity, we witnessed the transformation of our playground into a thoughtfully designed, state-of-the-art recreational haven that caters to children of all abilities throughout the year.

Furthermore, we are thrilled to share that our ambitious five-year, \$50 million capital campaign is well underway, with written and verbal commitments totaling nearly \$22 million. The campaign, called “Building Extraordinary,” will strengthen our impact on medical discovery and care while introducing new capabilities

to our facilities that will support children, families, and NIH researchers at every step along their medical journeys. “Building Extraordinary” will comprehensively transform our physical space, accelerate cutting-edge pediatric research, and ensure the well-being of The Children's Inn for generations to come.

Thank you to everyone who supported our mission this year. You play a vital role in safeguarding The Inn's ability to provide comfort and care to families while accelerating pediatric research at the NIH. We look forward to another extraordinary year ahead.

**Susan Penfield**  
Chair, Board of Directors

**Jennie Lucca**  
CEO, The Children's Inn at NIH



# Our Impact

July 2022 - June 2023

**Where the power  
of childhood  
meets the power  
of research.**



**730**

Families stayed at The Inn.

**15,077**

The total number of nights  
spent at The Inn.

**3-5 DAYS**

Average short-term stay.

**82 DAYS**

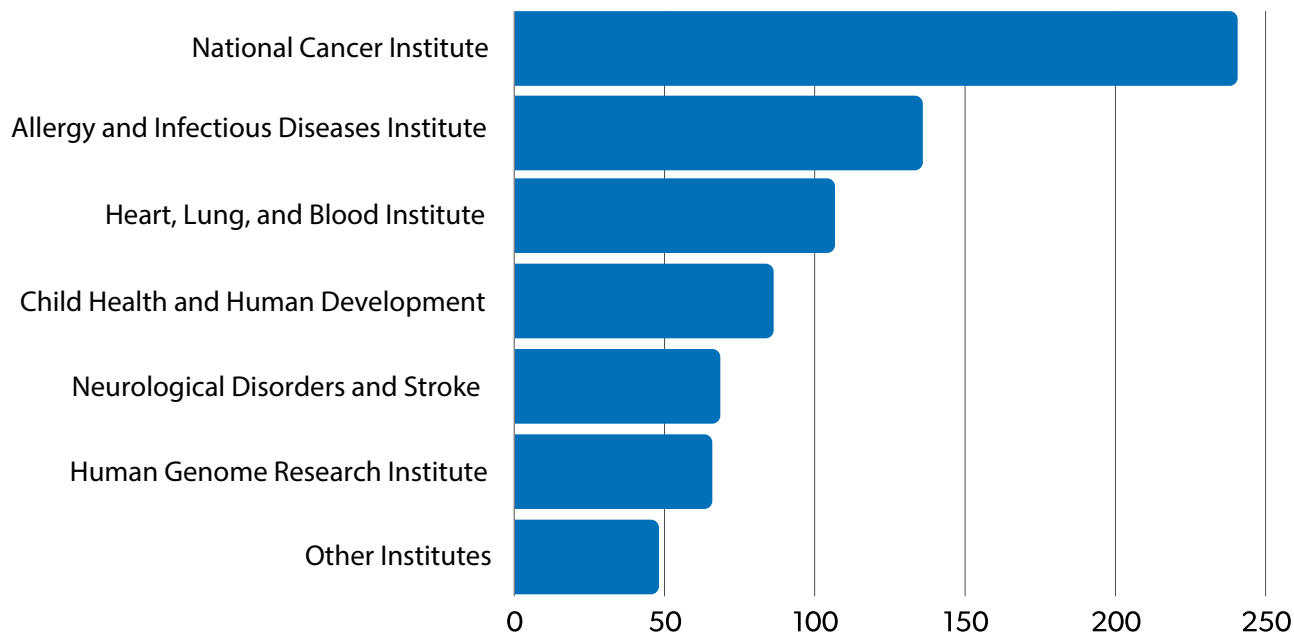
Average long-term stay.



**1 IN 10**

Stays were long-term.

# Our Impact



Patients staying at The Inn represented **87 different medical conditions** and participated in studies at **12 of the 27** institutes and centers at the National Institutes of Health.

**728**

occurrences of therapeutic, educational & recreational family programs, including exercise classes, therapy dog visits, sports programs, tutoring, cooking, and special events.



**168**

volunteers provided support equal to 4 full-time employees.



**7,386**

hours worked by volunteers at The Inn.

## Our Impact

“

At The Inn, you're always greeted by smiling faces. Everyone at The Inn is dealing with something, and you don't feel different. You are not stared at. Adults and children see you for you, not your illness. They are trying to get to know you, not your disease. That's an amazing feeling. For my mom, The Inn also showed her that she wasn't alone as a caretaker.

– Noah, has been coming to The Inn since 2007

### Since 1990

More than **16,000** families have stayed at The Inn free of charge.



Families have come from **50 states & 106 countries** to help advance medical discoveries.

### A PLACE LIKE HOME

The mission of The Children's Inn is to provide a free "Place Like Home" to children, teens, and young adult NIH patients from across the United States and the world while they participate in life-changing clinical research studies at the National Institutes of Health's Clinical Center. Everything we do strives to reduce the burden of illness on families, make childhood possible, and help advance NIH clinical research.

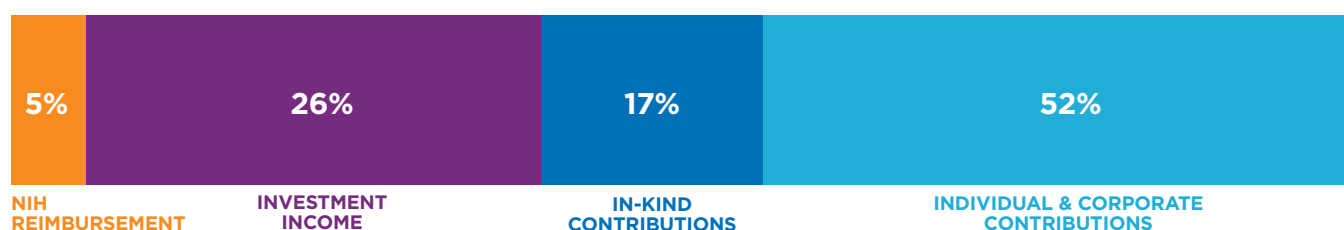
[www.childrensinn.org](http://www.childrensinn.org)

# 2023 Financial Overview

The National Institutes of Health (NIH) is the world's premier biomedical research institution—and 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 give families the hope NIH offers, as they advance medical breakthroughs.

## Income & Investments

NIH Reimbursement	\$1.1M
Investment Income	\$5.1M
In-Kind Contributions	\$3.3M
Individual & Corporate	\$10.2M
<b>Total:</b>	<b>\$19.7M</b>



## Net Assets

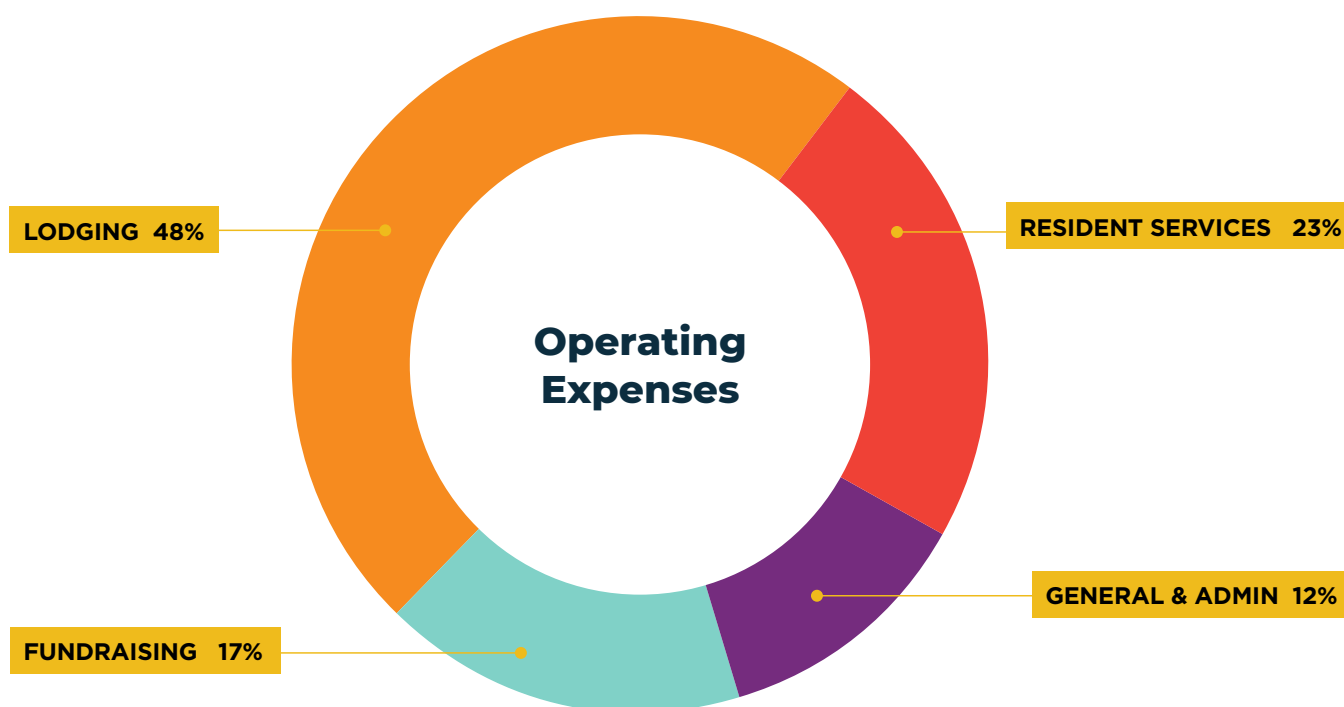
Without Donor Restrictions	\$22M
With Donor Restrictions	\$42M
<b>Total:</b>	<b>\$64M</b>



# 2023 Financial Overview

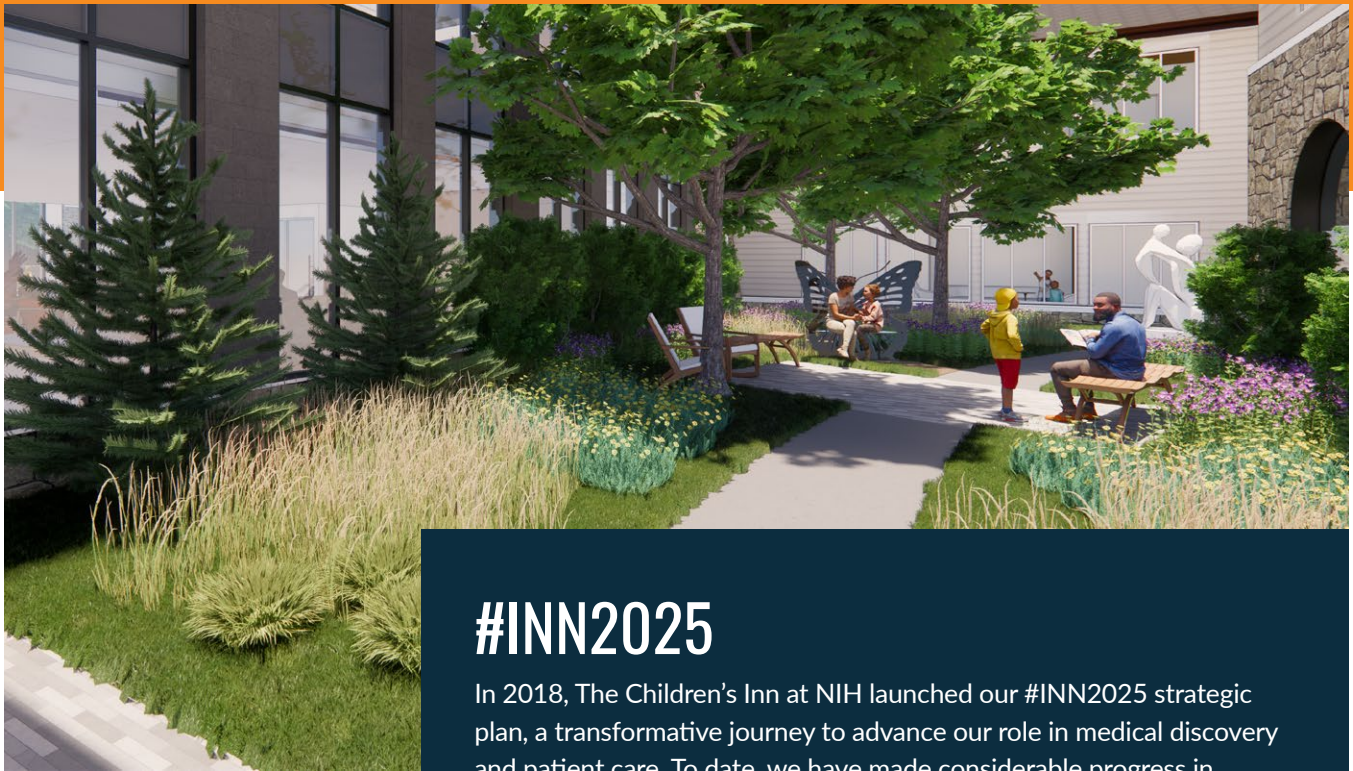
## Operating Expenses

Lodging	\$7.1M
Resident Services Program	\$3.4M
Fundraising	\$2.6M
General & Administrative	\$1.8M
<b>Total:</b>	<b>\$14.9M</b>



Source: Audited financial statements as of June 30, 2023, 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.





## #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, and 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**

First and foremost, we have made great strides in solidifying our vision of designing a state-of-the-art living environment, which we call The Inn of Tomorrow.

We engaged Whiting-Turner Contracting to assist with planning as The Inn's Pre-Construction Contractor to assist with planning and Perkins + Will to design the renovation of existing guest rooms and communal spaces and an expansion of The Inn's current footprint. With immersive plans and refined architectural details in hand, our vision is rapidly becoming a reality.

Key design elements of this transformation include a two-story Tower of Hope, an ADA-accessible pedestrian bridge that provides access to the sidewalk across from the Clinical Center sidewalk, a contact respiratory isolation wing, and additional shared multipurpose spaces to foster a sense of community and support for families during their challenging medical journeys.





And all of this will be made possible through a groundbreaking, \$50-million capital campaign, “Building Extraordinary.” This campaign, unprecedented in our 33-year history, will strengthen our impact on medical discovery and care, with a reimagined “Place Like Home” that brings new capabilities to our facilities to support children, families, and NIH researchers at every step along their medical journey from hopes to cures. To learn more about Building Extraordinary, please contact our Campaign Director, Christine Clemons, at [christine.clemons@nih.gov](mailto:christine.clemons@nih.gov).

Groundbreaking in 2024 is no longer an implausible dream, but a tangible milestone on our journey.

## Goal Two

### Strengthen the integration of discovery and care

The goal of developing vital support programs that better integrate discovery and care also progressed from concept to reality over the past year, as we formed and strengthened critical partnerships.

During FY23, we met with medical teams from six of the 14 NIH institutes who refer their families to The Inn to discuss how we can further collaborate and support their pediatric clinical research priorities. During these meetings, we discussed how The Children’s Inn could be involved in preparing for families as soon as clinical trials are approved. This collaboration will allow us to anticipate families’ needs before their arrival and identify barriers that might otherwise keep them from enrolling or continuing to participate in clinical trials.

Through our ongoing collaboration with the National Library of Medicine, All of Us, and the NIH’s Office of Patient Recruitment, we continue identifying resources and new approaches to support patients and their families and removing obstacles to participation in critical research studies. We also continue to work with Clinicaltrials.gov to provide feedback on the website’s instructional content for patient families.



## Goal Three

### **Maximize Community Support and Promote Financial Viability**

We are proud of our work in goal three: cultivating a diverse group of leaders, supporters, and volunteers and fostering health equity. Over the past year, the Board Task Force on Health Equity gathered resources to educate our community on the importance of health equity and how we actively advance this initiative in line with The Children's Inn's mission.

The task force acknowledged the imperative of integrating The Inn's commitment to health equity into all aspects of strategic planning, support for patients and families, and partnerships with the NIH. While this goal is still in its early stages, we are prepared to undertake the work required to ensure that Inn leadership, including staff, volunteers, board members, trustees, and our community of supporters, are well-versed in matters of health equity.

To that end, the task force dedicated significant effort this past year to develop a clear statement on The Inn's unwavering commitment to health equity and devise plans for its continued promotion. These plans include strategic and practical recommendations that align with the #INN2025 strategic framework. The task force also completed a robust interview process last spring, including with Inn families, NIH leaders, and external health equity experts. The insights from these conversations will inform recommendations for Inn leadership as we continue our journey toward creating a more equitable and inclusive environment for all we serve.



## OUR STORIES



### BENJAMIN'S PLACE LIKE HOME A Long-Awaited Return for Benjamin

“

We came here without food, without enough clothing, and without knowing anyone. This has been a refuge for our family and a place where we are hopeful about his continued treatment.”

– Benjamin's Father,  
Cristian

It would not quite be accurate to say that Benjamin has grown up at The Children's Inn. But for the native of Coquimbo, Chile, who will turn 18 years old in 2023, that isn't far from the truth.

Benjamin recently returned to The Inn for the first time in three years, where he was greeted by familiar faces who have gotten to know him and his family since he started coming as a toddler. He was accompanied by his parents, Cristian and Alejandra, and the trio was delighted not only with the reception at The Inn but with the updates they got from his medical team.

When Benjamin was just a year old, it became clear that something was wrong. He ran extreme fevers and vomited constantly. He was very weak and developed an abscess on his arm. His parents took him to the best clinic and hospital in Chile, both of which required a six-hour bus trip to Santiago from his hometown.

Eventually, doctors in Chile diagnosed Benjamin with Disseminated Nontuberculous Mycobacteria (NTM), an immunodeficiency in which mycobacteria disseminate infections throughout the body, affecting his development and leading to other infections. Despite the diagnosis, he was not showing improvement. Doctors ultimately recommended that Cristian and Alejandra simply take Benjamin home to be in a peaceful environment. But his parents did not give up and decided to come to the United States in an effort to find treatment for their little boy.

After a few months in Utah, doctors referred Benjamin to the National Institutes of Health. Cristian remembers the difficulty of that first visit, not only extending his family's absence from home but going to a strange new place with very little resources at their disposal.





### BENJAMIN'S PLACE LIKE HOME

"We are very thankful for The Children's Inn," Cristian said through an interpreter. "We came here without food, without enough clothing, and without knowing anyone. This has been a refuge for our family and a place where we are hopeful about his continued treatment."

Benjamin was three by the time his family arrived at The Inn in 2008, and they would stay for three years before finally being able to return home. During that time, The Inn lived up to its reputation as "A Place Like Home."

"There is no slogan more perfect than The Children's Inn's," Cristian laughed. "It really is a place like home for us."

During those first three years, the precocious young boy loved spending time in the playroom. He ingratiated himself not only with other families staying at The Inn but to the staff who saw him grow up every day. Many of those staffers, particularly among The Inn's leadership team, were still at The Inn for Benjamin's return in 2023.

After returning home in 2011, Benjamin would return to The Inn annually for the next eight years. Always accompanied by one of his parents, he would undergo a series of tests and treatments at each visit. In part, the treatments were meant to attack the tumors that had formed on Benjamin's brain.

In 2020, Benjamin's family was among the many whose regularly scheduled visits to NIH and The Inn were interrupted by the COVID-19 pandemic. It would be three years before he could return and resume his course of treatment. For perhaps the first time since that first visit, Benjamin's parents felt some trepidation about what they would encounter on the trip to Bethesda. Cristian, an engineer specializing in risk prevention in mining, and Alejandra, an accountant, both decided to put their jobs on hold to accompany Benjamin for the nervously anticipated tests and any decisions that may have been needed about his medical future.

Those fears were thankfully put to rest when Benjamin was examined by his medical team. The tumors on his brain are "on pause" and no longer growing, Cristian happily explained. His only remaining significant symptoms are infrequent epileptic seizures, but treatment is neutralizing those as well. The family saw familiar faces and met new people. Benjamin's tastes have shifted from the playroom to the games room, where he plays pool and video games. But the constant in his family's life has been The Inn's joyful and welcoming environment, as much of a respite now as it was on that first visit more than a decade ago.

At home, Benjamin goes to school in Chile that teaches him day-to-day life skills. He spends his free time working with ceramics, making beautiful mosaics that he shares with family and friends. As a young child, Benjamin barely knew of a world outside of The Inn. Now, he and his family are optimistic for the life ahead of him at home in Chile. But The Children's Inn will always be their "Place Like Home," and for that they will be forever grateful.



## OUR STORIES



### TAKING ON GIANT AXONAL NEUROPATHY

## A Star Finds Hope at The Inn

Some people are just born with an innate star quality. Jordan is one of those people. A 12-year-old from Edmonton, Alberta, and the middle of three children, Jordan has a presence and poise that belies her young age. With a warm smile and bright red hair, she commands the room from her perch on her motorized wheelchair. Because Jordan was also born with something else. She is one of less than a hundred worldwide childhood sufferers of Giant Axonal Neuropathy.

[Giant Axonal Neuropathy](#), or GAN, is a rare inherited progressive disorder that affects the peripheral and central nervous systems. It can lead to problems walking and loss of control of body movement, and there is no cure at the moment. But Jordan may be playing a role in changing that.

GAN often presents itself through clumsiness or muscle weakness in children younger than five years old, which was the case with Jordan. Her parents signed her up for preschool when she was three-and-a-half. The school routinely screened incoming students to get them on track for kindergarten. In the process, administrators at the school noted warning signs in Jordan's motor skills and suggested to her parents that she see a neurologist. Jordan's mother, Christa, still remembers what a shock that suggestion was.

"At that point, we thought she was just a little bit clumsy," she recalled. "She was only three-and-a-half. She was fine. She was walking. I thought she just kind of stomped around a little bit and was clumsy. So that threw us for a loop."

Jordan and her mother arrived at the neurologist for a 1 p.m. appointment, and the doctor referred them immediately to a series of specialists. Christa and Jordan didn't get home until after 11 p.m. that night. At that point, they knew whatever Jordan was facing was a big deal.

Canada did not have access to the same genetic testing available in the United States, so Jordan's tests were sent across the border for evaluation. Six months passed before they returned a diagnosis of GAN.

"We had received this diagnosis that was life-shattering," Christa remembered. "But there was this piece of hope attached to it because there was an active trial [at NIH] and treatment available. It gave us hope. And so, we came there very hopeful and expectant that this would help us and be the right thing for us."

### TAKING ON GIANT AXONAL NEUROPATHY

Jordan explained that there was no pain as the disorder took hold, and the prospect of an international trip to the NIH did not intimidate her. In fact, the opposite was true. “I thought it was really exciting,” she smiled. “We were someplace new, and people knew different things and could find out different things about me.”

That excitement only grew when she and her mother checked in to The Children's Inn at NIH for the first time in 2015. Being the outgoing and curious person that she is, Jordan wanted to involve herself in as many activities as possible.

The pair took advantage of field trips to visit the National Mall and the monuments around Washington, D.C. They joined other families for games and activities. Bingo, in particular, was a favorite. In fact, on in-patient visits to the NIH Clinical Center, Jordan, and Christa would often take advantage of any downtime they could find to pop down the hill and join in a round of Bingo at The Inn. Jordan ingrained herself remarkably in the diverse community populating The Inn. “I don't know how she does it,” her mom laughed. “Everyone in there knew her name by the time we left at the end of the week.”

Jordan began receiving opportunities to appear in various media in Alberta and beyond. She did a travel commercial for her home province and got an audition for a modeling runway. She also appeared in a Canadian reality show about people in wheelchairs called Push, which airs on the Canadian Broadcasting Corporation. Recently, she appeared in an ad for an international retailer, which is expected to air soon.

Jordan entered a gene therapy treatment trial. She also participated in a general trial that did not administer treatments but simply aimed to track the history of neuropathies. For more than seven years now, she has remained in both trials.

But that has not defined Jordan's life. Back home, Jordan became interested in performing and joined a competitive cheerleading team for special-needs people who do shows throughout the Edmonton area. She also signed with a talent agency, [Kello Inclusive](#), that exclusively represents “disabled and visibly different talent,” according to its website, “because the beauty of disabilities, diversities, and differences deserve to be represented fairly and fully.”



As she adds more and more to her plate, Jordan has continued to return to The Children's Inn for her clinical check-ins. Typically, those visits have occurred annually. She was at The Inn in March 2020 as Maryland shut down in response to the COVID-19 pandemic and only recently returned for the first time.

Though there were protocol changes in the wake of COVID-19 and their visit did not align with a field trip, Jordan and Christa were still grateful to be back and are optimistic that the trial will lead to a breakthrough in the fight against GAN.

“I'm always grateful that she has received the gene therapy, and I think she is less progressed than other GAN kids her age,” Christa said. She expressed hope that the experimental treatment Jordan has received as part of her gene therapy study will eventually be available on the market for others. Meanwhile, The Inn remains a refuge for Jordan and her mother. “We're very grateful for everything the volunteers and donors do to make The Inn such a comfortable place in a really hard time,” Christa said. “To have a soft place to land with everything that goes into making it so comfortable, like the Thoughtful Treasures or the food and transportation, it really is quite appreciated.”

## OUR STORIES



### THE MAYOR OF THE INN

## Rayne Gets Comfort, Gives Warmth at The Inn

When you first meet Rayne—and if you have been to The Children's Inn over the past several months, you have likely met Rayne—you wouldn't suspect that there was anything wrong with this bubbly three-year-old from the Bahamas. Known to some staffers as the Mayor of The Inn, Rayne is a bundle of energy who has been eager to make friends with babies, grandmothers, and everyone in between. From helping volunteers decorate for the holidays to riding her tricycle up and down the halls, Rayne has brought unbridled joy and light to The Inn since arriving last August.

Her mother, Agnes, didn't suspect anything was amiss either. "There was nothing unusual," she remembered of the day last spring when she discovered the problem. "Just a week or two before that, she had some bruises on her skin that I thought was an allergic reaction. A doctor prescribed some medication, and it seemed to work. But one day, I don't know why, but I just looked in her mouth. And when I looked in, I saw blood all over."

Rayne's doctors at home couldn't pinpoint a cause, though early testing indicated that her blood platelet level was abnormal. She was airlifted from Grand Bahama, her home island, to Nassau, where doctors put her through a series of tests. Four weeks later, the official diagnosis came in. Rayne had severe aplastic anemia, a blood condition that occurs when bone marrow cannot make enough new blood cells for a body to work normally. With the limited resources available in the Bahamas, Rayne underwent blood transfusions daily. It was enough to get her stabilized, Agnes explained, but she still bled, and her platelet levels remained low. That was when her doctor reached out to the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health, which accepted her for a clinical trial. Many people who suffer from severe aplastic anemia experience extreme fatigue. Not Rayne. The rambunctious girl never slowed down or lost her burgeoning sense of independence. The bruising, which had initially been mistaken for an allergic reaction, was the only outward sign of the disease.





### THE MAYOR OF THE INN

“The doctors caught it early, and she has so much energy that it’s definitely helping,” Agnes said. At the NIH, Rayne has undergone ATG treatments, an immunosuppressive therapy that attacks the T-lymphocyte cells attacking bone marrow. “Her body is 100% responding to treatments. At first, they thought she may have needed a bone marrow transplant, but by the second month [at NIH], that was already written off. She is now in what they call a robust response.”

Agnes does not doubt that staying at The Children’s Inn has played a large role in Rayne’s rapid recovery. “Rayne is a people person,” she laughed. “When she was in the hospitals back home, she was engaged in a metal crib because her levels were so low. The only people allowed to see her were myself and my husband. She was potty trained, but she couldn’t go to the bathroom, so they put diapers on her. That made it worse because she knew that she was a big girl. She was completely traumatized when we came here, but now she has all this freedom to move. She’s met a lot of different kids and socializes and plays with anyone. This has definitely helped a lot with her treatment and her overall outlook as well.”

That enthusiasm for meeting people and learning new things extends to her medical journey. Rayne is an active participant in conversations with her doctor and understands a lot about what happens at her appointments. “She understands a biopsy,” Agnes said. “She knows when they need to change a dressing. She’s grown a lot [since coming to The Children’s Inn]. She knows what she wants, and she is going to figure out a way to get it.”

Although her doctors are optimistic that she is making a full and lasting recovery, Rayne and Agnes will remain at The Inn until mid-February, a full six months after their arrival. They celebrated Christmas at The Inn, although that meant being apart from Rayne’s father and five-year-old brother. They keep in touch regularly, though, and are looking forward to the reunion in a couple of months. In the meantime, Rayne will continue performing her mayoral duties at The Inn with boundless energy and enthusiasm. Last month, she helped CEO Jennie Lucca and Board Chair Susan Penfield countdown to the [official illumination of Christmas lights](#). She counted down from three, then absconded with the microphone when she realized she had a captive audience. Rayne also enjoyed meeting Santa during the annual Montgomery County Police Department [Santa Ride](#) and [spoke with Gwen Tolbart of Fox 5](#) that night. Agnes credits the community at The Inn with having a major impact on Rayne’s recovery, but there is no doubt that the impact Rayne has had on that community has been just as great.



## OUR STORIES



### A PASSION FOR SPORTS Travis Does More, Not Less, in Fight Against NF1

For the past three years, Travis and his family have lived the motto: “Do More, Not Less.” A 10th grader in Salt Lake City, Travis has found ways to stay active and indulge his passion for sports despite growing up with neurofibromatosis type 1 (NF1), but that motto took on particular importance for him and his family in the spring of 2021 when his left leg was amputated.

Diagnosed in Travis when he was just six months old, NF1 is a medical disorder involving the development of tumors that affect the brain, spinal cord, and nerves that send signals to all parts of the body. In him, it left one leg significantly longer than the other—a disparity that grew to more than three inches by the time he was seven years old—and a long, deep plexiform neurofibroma tumor running from his lower spine down across his hip to below his knee.

For the first several years of Travis’ life, his treatment came at home—sometimes literally. His family moved to Salt Lake City to be closer to the hospital where he got treatment. During one clinical trial his mother, Kelly, was personally responsible for giving him a weekly injection of peg interferon, a weekly chemotherapy shot. The injections left Travis with flulike symptoms two days a week, and Kelly suffering physical symptoms as well, from the psychological stress of their situation. She was spared when a school nurse eventually stepped in and took over the role; but Travis’ journey was just beginning.

Despite his diagnosis, Travis immersed himself in the world of sports. He enjoyed watching favorites like the Utah Jazz, Denver Broncos, and Kyle Busch of NASCAR, and began actively participating on wheelchair basketball and tennis teams. He took a particular interest in racing, too, starting with go-karts. Travis was always enthralled with motorsports more than anything else, and eventually joined J.R. Smith Racing’s Team Fight Cancer as a crew chief.

Travis’ medical journey first brought him to The Children’s Inn at NIH with his mother when he joined the peg interferon clinical trial at the National Cancer Institute in 2014. The next year, he was enrolled in a second clinical trial at NIH, this one aimed at shrinking or slowing down his tumors. He was put on a drug then known as Selumetinib.

## OUR STORIES



### A PASSION FOR SPORTS

At first, the trial required Travis and Kelly to make the cross-country flights every two months, but that gradually slowed to a four-month cycle. The drug was having the desired effect, shrinking the tumors, but things proved problematic in his left leg. There, the tumors had attached themselves to his femur—the largest and normally strongest bone in the human body—and weaved themselves into the bone. That left the left femur dramatically more vulnerable than usual, and twice Travis suffered painful femur fractures.

A third femur fracture followed in the fall of 2020. He wore a full leg cast and had four large screws inserted to help the bone heal, but it was too fragile. Travis was facing the possibility of not being able to participate in sports anymore due to the vulnerability of his leg. With his family's and doctor's support, he made the brave decision to undergo a hip disarticulation—an amputation of his entire left leg.

The procedure was undergone in Utah in April of 2021. Though it had become a liability for him, Travis made sure that his leg would still be able to provide some good. Pieces of it were donated to research facilities across the country, including at NIH, to help further the chances of a cure for NF1. He was fitted for a prosthetic leg and resumed his active lifestyle as soon as he could.

Not long after his third femur fracture, Travis and his family got a dog named Lady, a companion for Travis who may have a unique understanding of what her boy is going through. Lady was born with only three fully-grown legs. That made the decision to bring her home easy for Travis, who told his parents that “the kid with the stumpy leg gets the dog with the stumpy leg.”

That resilient outlook has helped Travis get to where he is today and is evident to everyone who sees him at The Inn. Travis and Kelly now visit every six months. During his visits, he has connected with other Inn families and enjoyed programs such as Bingo night and, of course, spending time with Zilly. In early 2023, Travis and his family were recognized at the annual An Evening for Hope gala, where over \$2 million was raised to benefit The Children's Inn. His doctors detailed his medical journey to the audience at the Ritz-Carlton in Tysons that night, and then Travis gave an emotional and memorable speech thanking The Inn and its supporters for their impact on his life.

Meanwhile Selumetinib, the drug he had been on, got FDA approval and was renamed Koselugo—outstanding news for Travis and so many other children with plexiform neurofibromas.

Prior to the COVID-19 pandemic, Travis' father and two older brothers came to NIH with him and Kelly on one of their visits. His brothers loved getting to see the sights around Washington, D.C.—something Travis had always enjoyed as well—but found the days of medical appointments difficult to sit through. They are not Travis' favorite part of the visits either, of course, but his smile is a constant and his determination never waivers. He credits The Inn with being an encouraging, calming place full of welcoming staff and other families, and looks forward to his visits because of the atmosphere The Inn provides. In addition to his wheelchair teams and crew chief responsibilities with Team Fight Cancer, Travis has taken up standing skiing and river rafting since his amputation. As he goes through high school, he shows no signs of slowing down. With his family and his dog by his side, Travis will continue finding inspiring ways to “Do More, Not Less.”

## DIFFERENCE MAKERS



### Making Connections Is Essential to Masood

Masood Ahmed

**Making connections is essential to Masood. Whenever he can talk about what The Inn does and who The Inn serves, he jumps at the opportunity.**

Masood Ahmed was introduced to The Children's Inn at NIH in late 2019. He was starting to have conversations with his Leidos colleagues and Inn staff members about a variety of ways in which he could support our families. Then, March 2020 happened.

The COVID-19 pandemic changed almost all the ways The Inn had historically engaged with its volunteers and how its volunteers were allowed to support Inn families. For many of our volunteers during this time, the challenges and restrictions facing The Inn fueled further action to help. And Masood's enthusiasm for all-things-Children's-Inn was hard to beat!

In the spring of 2020, he began supporting the Feeding Families program with his good friend, colleague, and longtime Inn supporter Erika Killian. Masood and Erika would order pre-packaged dinners from Bethesda-area commercial kitchens and have the meals delivered directly to The Inn. Masood kept supporting from a distance for the better part of two years until he was finally allowed to enter The Inn's doors for the first time in the spring of 2022.

"I think I am there at least twice a month now; once for the halal meat [deliveries] and once for doing a dinner," he humbly admits.

During one of his early visits to The Inn, Masood recognized a particular dietary need he could help meet for Muslim families staying there. These families require that any meats they consume be halal. An Arabic word meaning 'permissible' in English, halal is mainly associated with Islamic dietary laws, especially meat processed and prepared in accordance with those requirements. As Masood is a practicing Muslim, he makes regular trips to his local halal meat store, Mahi Bazaar, for his family. He thought, "Why not triple the monthly order for Inn families?"

Nearly every month for the past year and a half, Masood and various family members have ordered eight to ten pounds of halal chicken, goat, lamb, and beef, which they personally deliver to The Inn. The size of their order depends on the number of Muslim families staying at The Inn and any special requests they make, often talking to Masood when he is there for monthly dinners with his Leidos team. Additionally, Mahi Bazaar is aware of who they are feeding through the Ahmed family's orders.



## DIFFERENCE MAKERS



“They ask where the families are from and what the families are facing,” Masood explains. “It’s not just about buying the meats from there, but there’s an awareness about The Inn.”

Making connections is essential to Masood. Whenever he can talk about what The Inn does and who The Inn serves, he jumps at the opportunity. As a patron of Barcelona Wine Bar and a member of Leidos’s Civilian Health

team, a nearly 25-year corporate sponsor of The Inn, Masood recognized another opportunity for collaboration. For the past year, Leidos has served dinners to Inn families once a month exclusively through Barcelona. Masood explains that they provide various family dishes, from vegetarian options to chicken dishes to beef stews. All meats are halal, eliminating the question of what foods Inn Muslim families can and cannot consume. It’s streamlined, it’s plentiful, it’s delicious!

Reflecting on the importance of giving back, Masood shares that philanthropy was a concept he was introduced to at a young age. “The message from my mom and dad was that you’re given the money that belongs to somebody else,” Masood remembers. “You’re just a carrier. I think that part has passed on quite strongly, not just with me but with my siblings as well...After [Mom’s] death, we found out there were so many things she was doing [and supporting] but keeping it hidden. And she used to say that if your right hand is giving, your left hand shouldn’t even know about it. I wanted to carry on [her legacy], and there is no better place than The Children’s Inn. I have kids, and Mom had cancer, so [The Inn] resonates with me. I wanted to do a lot more. I wanted to understand where else I could help—not just time, not just money, but any other support...I was all in from there on.” Thank you to Masood Ahmed and his family, the Leidos team, the Barcelona Wine Bar team, and Mahi Bazaar. They say it takes a village to raise a family. Indeed, The Children’s Inn has a village of supporters that makes everything we do for our families possible.

“

I think I am there at least twice a month now; once for the halal meat [deliveries] and once for doing a dinner.”

– Masood Ahmed





## DIFFERENCE MAKERS



## Bringing Enthusiasm and Optimism to The Inn

### Timaron

On Monday mornings, the families at The Inn can count on seeing a perpetually smiling face around the building. Timaron has been volunteering through the Neurodiversity at Work Department at Kennedy Krieger Institute since late 2022, bringing enthusiasm and optimism to his work and a unique understanding of the challenging path forward for some of the families he meets.

Timaron is a 23-year-old from Potomac, where he lives with his parents, Mandy and John, and his dog, Lulu. He was born with [Rubenstein-Taybi syndrome](#), a genetic intellectual disability, the cause of which is unknown. After he graduated from Walter Johnson High School, he joined the CORE Foundations community. Through that, he learned about The Children's Inn and began helping where he could. Hannah Wayne, the Director of Meaningful Community Services at Kennedy Krieger, explained the connection.

"Kennedy Krieger Institute is a licensed Developmental Disabilities Administration provider," she said. "We provide support to people with developmental disabilities who are accessing meaningful engagement in the community, whether that is through volunteer work, paid employment, or engagement through fitness, leisure, and other daily activities. Part of Timaron's day is volunteering at The Children's Inn, and he has support while he's on-site from staff who work for our department."

Each Monday, Timaron goes to The Inn with Austin, a Kennedy Krieger employee who helps him navigate the days' jobs. His primary task is labeling food in the pantries, checking for expiration dates, and applying color-coded labels for food safety. He also helps maintain and organize the community refrigerators and playroom at The Inn. But when asked what his favorite responsibility at The Inn has been, there was no hesitation. He burst into a wide grin and playfully exclaimed: "Walking Zilly!"

"Timaron enjoys working with kids," Austin smiled. "And walking Zilly is one of his favorite parts of the day here at The Children's Inn. Meghan actually had to schedule him to be here between 12 and 12:30 because she realized he was so connected to Zilly. And he wants to volunteer even more days here."

For Timaron, these volunteer efforts are a first step towards securing a paying job for himself. "That's the idea," Austin agreed. "Timaron wants to volunteer as much as he can and start practicing. We want the population out there to see that there are opportunities for all individuals to be useful in society and work like anybody else."

## DIFFERENCE MAKERS



“

Walking Zilly is one of his favorite parts of the day here at The Children's Inn.”

– Austin, a Kennedy Krieger employee

The partnership between Kennedy Krieger and The Children's Inn began prior to the COVID-19 pandemic and has evolved in the ensuing years. Currently, Timaron is one of two volunteers at The Inn from the CORE Foundations program, along with Jared, who comes to The Inn on Fridays.

“Our partnership with Kennedy Krieger has been a wonderful addition to our volunteer program at The Inn,” said Smith. “We are looking forward to seeing it grow.”

“The Children's Inn has been a fantastic partner,” added Wayne. “We would absolutely love to find additional volunteer opportunities for the young adults who we support. And we want to thank The Children's Inn for providing these opportunities and for being so warm and welcoming for us.”

Austin described Timaron as “jovial,” an understatement for the young man whose smile never seems to leave his face and whose eyes lit up at the thought of spending time with Zilly and the children at The Inn. “He interacts with people very well. He has had a chance to meet some of the families, and because of his jovial mood, they are always smiling at him and happy to interact with him.”

That mood has made Timaron a valued part of life at The Inn, not just for the families he meets but for the staff he helps out. “Timaron is a joy to have at The Inn,” Smith said. “He brings so much energy and light when he enters the building. He is always ready to tackle any projects we have for him each week, and I know Zilly looks forward to her walks with him in the afternoons!”

## DIFFERENCE MAKERS



### A Unique and Valuable Partner

Dr. Cyrus Katzen  
Foundation, Inc.

The Dr. Cyrus Katzen Foundation, Inc. has been a unique and valuable partner of The Children's Inn at NIH for more than four years, helping The Inn create practical long-term programs while also ensuring its continued operation through the depths of the COVID-19 pandemic.

Started by Dr. Cyrus Katzen in 1993, the Foundation reflects the late Dr. Katzen's strong interests in philanthropy and cancer research, using a strategic focus to find meaningful ways to make a difference.

After its inception, the Foundation made one of its first substantial donations to George Washington University to create the Dr. Cyrus and Myrtle Katzen Cancer Research Center. Its goal was to enhance the recruitment of top scholars in the field and the development of innovative approaches to battling and treating cancer. As it became integrated into the medical community, the Foundation also became involved with the pediatric cancer researchers at Children's National Hospital in Washington, D.C.

Soon, childhood cancer became a particular focus of the Katzen Foundation. Though support for research that would lead to a cure remained at the core of its mission, the Foundation found ways to use its strategic vision to improve the lives of children and their families already suffering from the disease.

Millard Bennett, who became involved with the Foundation as Dr. Katzen's attorney and is now one of its Board members, described the path that brought the Foundation and The Children's Inn together.

"The Katzen Foundation became uniquely focused on trying to be very strategic in providing seed money for programs that it believed, if successful, could become self-sustaining within the next few years," Bennett explained.

Most Board members for the Katzen Foundation live in Montgomery County and were familiar with The Children's Inn. In 2019, the Board arranged their first official visit to The Inn. "We asked [The Inn], 'If money were to fall from the sky one time, what program do you have in the works that is not being funded and has an opportunity to succeed, and if so, become self-sustaining?' Bennett described. "We wanted it to be something very significant to the child's experience while they are being treated."

The Inn returned to The Foundation with an idea that had been in the works for quite some time, but had not yet reached the scale they had been hoping to achieve: a personalized airport transportation program.



## DIFFERENCE MAKERS

Since The Children's Inn opened its doors in 1990, families have come to The Inn from 106 countries and all 50 states. To get there, many of them fly into the Washington, D.C. area for the first time and have difficulty navigating their way through the airport and to the Bethesda campus of the National Institutes of Health. The transportation program would remove a number of barriers for these families, getting them to and from airports to make their visits to The Inn as smooth and simple as possible.

The program was an instant success, so much so that it was able to be funded and included in the annual budget of The Inn after the Katzen Foundation provided its seed funding. And thus began a trusting partnership, spurring other creative ways to work together.

By then, the COVID-19 pandemic had hit and life at The Inn was adjusting to strict safety protocols that limited contact with outside visitors. Volunteers, who had given their time and resources to sponsoring and serving meals to the families, were no longer allowed at The Inn. When the Foundation asked The Inn how else they could help, the answer came back quickly.

"Food," Bennett said. "They didn't have the volunteers coming in to be able to provide the food for the families staying at the Inn during COVID, so the Foundation indicated that instead of seed money for a program that year, the Foundation offered to provide funds to help the Inn continue to provide meals for the families during that period."

Last year, the Katzen Foundation worked with Inn staff to create a strategic fund that allowed for experimentation on new and improved ways to serve Inn families. So far, the fund has enabled the acquisition of a robotic room cleaner and the testing of new room options as The Inn prepares for a renovation over the next few years. The Foundation also answered the call by helping meet a required State of Maryland match in private funding for a \$1.4 million bond to renovate The Inn.

"It has been very gratifying to the Board members of the Foundation that in each of the recommendations that The Inn has made, and we have funded, the goal has been met," Bennett said. "Things have succeeded."



“

There is an overwhelming awe that we have for the children and their families and care providers.”

– Millard Bennett



# Leadership Circle FY23

## Individuals & Estates

The Children's Inn at NIH salutes these individual donors whose generous contributions of \$1,000 or more between July 1, 2022 and June 30, 2023, help to sustain the mission of The Inn.

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The Children's Inn at NIH salutes these donors whose generous contributions of \$10,000 or more between July 1, 2022 and June 30, 2023, help to sustain the mission of The Inn.

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\* Deceased

Every effort has been made to ensure the accuracy of our records. Please contact Peter Spring at [peter.spring@nih.gov](mailto:peter.spring@nih.gov) if you have any questions.

# Women for The Inn (WINN) Community

## FY23 WINN Members

Women for The Inn is a community of women who support the mission of The Children's Inn at NIH. Joining this group provides members with the opportunity to connect with healthcare luminaries, volunteer their time, donate (and direct) funds towards Inn projects, and network with like-hearted women.

**Debra Cohen**, WINN Co-chair

**Monica Granovsky**, WINN Co-chair

Sarah Abdow  
Linda Abravanel  
Lauren Alperstein  
Lois Alperstein  
Arti Arthur  
Jennifer R. Azar  
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Ann Birns  
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Sandra Davis  
Prachee Devadas  
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Anita Lynn  
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Padmini Mahurkar  
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Priya Narang  
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Jodi Paci  
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Anna Pugh  
Shimul Ray  
Carrene Ressa  
Kristine Ribas  
Robyn Richardson  
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Christine Smith  
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Diane Yarnell  
Meredith Yentis  
Victoria Zagaria  
Shirli Zelcer

To learn more about WINN, please visit [childrensinn.org/ways-to-give/winn](https://childrensinn.org/ways-to-give/winn).



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