

Making Childhood Possible

2018 Annual Report



The Children's
Inn at NIH

OUR MISSION

The Children's Inn will fully and consistently meet the needs of children and families participating in groundbreaking research at the National Institutes of Health.

WE WILL:

- Respond to evolving family support needs for pediatric research and clinical care
- Provide a free, family-centered "place like home"
- Reduce the burden of illness through therapeutic, educational and recreational programming

OUR VISION

As partners in discovery and care, we strive for the day when no family endures the heartbreak of a seriously ill child.



Cover: Adam, 5, of San Antonio, Texas, is participating in a clinical trial for children with McCune Albright Syndrome, a rare genetic disorder affecting bones, skin and the production of certain hormones, at the National Institute of Child Health and Human Development (NICHD). Pictured on this page: Mohammed, 5, of Oman enjoys spending time at The Children's Inn while his sister, Muna, 8, pictured on page 8, is being treated for giant axonal neuropathy (GAN) at the National Institute of Neurological Disorders and Stroke (NINDS).

Letter From the Board Chair and Chief Executive Officer

Dear Friends,

Thank you for making a tremendous difference! Your caring support made it possible for more than 1,700 children, young adults and their families to participate in 546 groundbreaking clinical trials during the past fiscal year that push the boundaries of medicine and hope.

The children you helped include Amber, 8, of California who has undergone gene therapy for an untreatable disease as part of a revolutionary trial; Abram, 8, of Missouri who is helping doctors learn more about treating a rare fever disorder; and Faith, 17, of Trinidad and Tobago whose participation in clinical trials is vital in helping doctors find new treatments for a rare and, so far, incurable cancer. On the following pages, you will see how you are helping Amber, Abram and Faith take part in clinical trials that not only hold the best hope of treating their rare diseases but also of advancing medicine to benefit generations to come.

Your generosity means so much to the children and families who have called The Inn home over the years. Our vision for The Inn’s future, outlined in our #INN2025 strategic plan summary on page 17, is to do even more good for the children and their families who depend on The Inn during difficult times. We couldn’t achieve this vision without you. We’re confident that together, we can make it a reality.

Thank you for your continued support and for giving hope to seriously ill children and their families year after year!



A handwritten signature in black ink that reads "Timothy J. Atkin".

Timothy J. Atkin
Chair, Board of Directors

A handwritten signature in black ink that reads "Jennie Lucca".

Jennie Lucca
Chief Executive Officer

Abram

age 8,
periodic fever
disorder

"Abram is part of a natural history protocol where we see patients from infants to the elderly with autoinflammatory diseases. We do specific genetic testing to see if we can identify the pathways or maybe even the gene that is causing their symptoms. We also work toward finding an effective treatment, so patients can be more active — and Abram can go back to school and get back into the sports that he so loves." — Dr. Amanda Ombrello, associate research physician, Inflammatory Disease Section at the National Human Genome Research Institute's (NHGRI) Metabolic, Cardiovascular and Inflammatory Disease Genomics Branch



Searching for answers so Abram can play ball again

All Abram, 8, wants to do is play baseball and help his team make an out. But regular high fevers coupled with excruciating joint pain have disrupted this St. Louis, Missouri, boy's life for years, making it difficult for him to run and play his favorite position, third base. Abram and his family are drawing hope from an NIH study Abram takes part in and, thanks to you, the "place like home" they have found at The Children's Inn.

Doctors at the National Human Genome Research Institute (NHGRI) admitted Abram to a natural history study to help them learn more about periodic fever syndrome, a rare and little understood autoinflammatory disease that, in Abram's case, is caused by an unknown, innate immune system malfunction. To pinpoint the cause of his disease, his NHGRI care team has performed detailed genetic testing. "A rare disease is just a very weird beast," Abram's mom says. "It's overwhelming and confusing." Abram's family knows it may take a long time to get a definitive answer. They hope genetic testing will help steer doctors toward an effective treatment that one day may help Abram and other children like him.

What's important in Abram's world right now? Helping others and The Children's Inn. He loves doing arts and crafts at The Inn, especially painting flower pots to be auctioned off at The Inn's fundraising events. "My friends are sick. The Inn makes them happy, even when they're really sick. I want to help," he says.

In 2017, during his first of eight visits to The Inn, Abram refused painful injections administered by his parents — unless Zilly, The Inn's therapy dog, would sit by him. Zilly did, and with her support, Abram finished taking the injections. Impressed by her gentle and supportive nature, Abram's parents reached out to Zilly's breeder. Abram named his own therapy dog Zilly.

Recently, Abram has had to stop playing ball entirely. But thanks to Washington Area Toyota Dealers, an Inn supporter, Abram got back on the pitcher's mound this summer for the chance of a lifetime: to throw the first pitch at a Washington Nationals game. "It was the best day of my life," Abram beams.



Faith

age 16, alveolar
soft part sarcoma

“Many patients with alveolar soft part sarcoma (ASPS) have tumors that have spread beyond the primary site by the time they are diagnosed. In these cases, surgery is not curative, and ASPS doesn’t respond to standard chemotherapy. Through research studies, we aim to develop more effective therapies that target the mechanisms of tumor growth specific for this disease to provide a possible treatment. We would not be able to do that without the participation of patients like Faith.” — *Dr. Brigitte Widemann, chief of the Pediatric Oncology Branch at the National Cancer Institute’s Center for Cancer Research*



Your kind support makes a lasting impact on this young cancer patient and her family

When a bump appeared on 10-year-old Faith's shoulder, her family assumed it was an allergic reaction to a bug bite. But an MRI revealed it was one of several cancerous tumors. Thanks to the NIH and crucial help from people like you, Faith's family has found the support they need — support they could not find at home in Trinidad or anywhere else in the world.

Alveolar soft part sarcoma is a highly rare, slow-growing cancer that is difficult to diagnose — and treat. “Because the tumor had metastasized, I was told to take her home and care for her,” her mom says. “But I don’t give up. That’s not the kind of person I am.” By emailing her daughter’s scans to a number of U.S. hospitals, the family was referred to a clinical trial at the National Cancer Institute (NCI).

At the NIH, Faith participated in an experimental drug trial to halt the growth of her tumors. A couple of years later, she had a growing tumor removed from her arm, and in 2018, NIH surgeons removed part of her lung. During regular checkups at the NIH, Faith, now 16, and her family have found a second home at The Children’s Inn. Thanks to caring supporters like you, the family has stayed at The Inn free of charge more than 20 times. But their first visit will always stand out for them: “It was so cold, and we had never experienced winter,” Faith’s mom remembers. “The Inn gave us sweaters and pants, warm socks and pajamas. We were so grateful!”

For Faith and her mom, it’s The Inn’s many activities like horseback riding, weekend retreats, trips and outings — made possible by caring donors like you — that make trips to the NIH something more than just hospital visits. “It’s like going on a mini vacation,” Faith’s mom says. “As soon as we check in, Faith would ask me, ‘Mom, did you get the activities sheet?’”

“It’s magical,” Faith says about The Inn. “Everybody is so kind. They take care of us.”

If Faith’s tumors grow, she will return to The Inn next summer to undergo another experimental drug treatment at NIH.





Amber
age 9,
giant axonal
neuropathy (GAN)

"We are trying a first-in-human therapeutic approach to inject the healthy version of the defective gene into children with giant axonal neuropathy. We do that by using an engineered virus to serve as an envelope to carry the gene to the child's central nervous system. There is no other treatment approach for this disease. It's also a first for gene therapy because this is a new approach to try to deliver genes to the nervous system." — Dr. Carsten Bönnemann, a senior investigator at National Institute of Neurological Disorders and Stroke (NINDS), and chief of the Neuromuscular and Neurogenetic Disorders of Childhood Section

You lift this family up

When Amber started walking at 13 months, her mom noticed Amber could not step properly on her left heel. Their pediatrician suggested the little girl would grow out of it — but instead, it got worse. Eventually, genetic testing revealed Amber has a highly rare, incurable genetic disease called giant axonal neuropathy, or GAN. The disease progressively affects nerve functioning, gradually limiting children’s ability to walk, talk and breathe. Amber’s family finds hope in a revolutionary gene transfer trial at the National Institutes of Health and — thanks to you — The Children’s Inn.

Hearing the devastating diagnosis, Amber’s parents instantly knew they would do whatever it took for Amber to participate in a revolutionary gene transfer trial at the National Institute of Neurological Disorders and Stroke (NINDS). “We celebrated,” Amber’s mom says about the moment they learned Amber had been accepted into the trial. “We thanked God for this opportunity and the doctors.”

In early 2018, Amber, 9, became the 10th patient to be injected with a healthy GAN replacement gene at the NIH Clinical Center. “Amber is the strongest girl I know,” her dad says. “She didn’t complain even once about the injection or ask, ‘Why me?’ — not one single time.” To keep her muscles strong, Amber does physical and speech therapy, along with swimming and ballet. Supporters of The Children’s Inn’s INNRichment Fund make it possible for Amber to take piano lessons at home to help strengthen her fingers.

“She really loves The Inn,” Amber’s dad says. “She loves to go to the play room, play on the computer, play with Zilly [The Inn’s therapy dog], be in the kitchen, the large TV area. She has friends at The Inn. She thinks it’s her second house.” Amber’s mom and dad also have come to love The Inn and its dedicated supporters. “If you are feeling down, here you can bring yourself up,” Amber’s dad says. “There are people who are going through the same thing as we are. There is food for us. The Inn’s supporters make it easy for families — like we’re at home. For Amber, The Children’s Inn feels like family.”

It may take a couple of years before researchers know whether this experimental treatment can halt this disease. But with your support, Amber’s family has hope!



In Our 28 Years of Service



14,700+

Families
have stayed
at The Inn

Families have come to The Inn from



50 and
States



94
Countries

During Fiscal Year 2018 (July 1, 2017 - June 30, 2018)

1,703

Families stayed
at The Inn for
15,549 nights



The Children's Inn Offered



1,400

recreational, therapeutic,
educational and spiritual
programs that helped
reduce the burden of illness

There were:



2,500+
Volunteers



195
regularly scheduled



19,608
hours worked

equating to **9.4** employees

Children and young adults
ages 0-29 participated in



546

clinical trials representing
advances in the treatment
of cancer, bone and growth
disorders, mental illness
and more



Muna
age 8,
giant axonal
neuropathy

Muna, like Amber, whose story is featured on page 7, is participating in a gene transfer trial for giant axonal neuropathy (GAN) at the National Institute of Neurological Disorders and Stroke (NINDS). She and her family have spent more than two and a half months at The Inn so far and will continue to visit for checkups at the NIH for many years to come.

Meet Our Volunteers and Donors

Every way you support The Inn makes a difference. Over the past fiscal year, thousands of individuals, organizations and corporate supporters contributed financially to bring comfort and precious moments of joy to the seriously ill children who find a second home at The Inn. Our more than 2,500 volunteers, of whom 195 are scheduled weekly, gave more than 19,600 hours of their time. This is equal to the yearly hours worked by nine full-time staff. The Inn also acknowledges the many in-kind contributions you made to provide children with a Thoughtful Treasure in their mailbox every morning, warm hats and other needed items that help make them feel cared for.

This Businesswoman, Philanthropist and Cancer Survivor Finds Fulfillment in Supporting The Children's Inn at NIH

No matter how successful Cathy Bernard became in growing her business, she didn't feel satisfied. Instead, the real estate manager and investor found fulfillment as a volunteer, a college teacher, community supporter and philanthropist. Family and personal illness only strengthened her support of The Children's Inn and other causes she cares about.

Cathy was never afraid of challenges. She was one of only two female business students at George Washington University in the late 1960s and early 1970s. In 1983, she became one of very few women to start a real estate management and investment company, HCM Corporation. But business success and honors weren't enough to fulfill her.

"Being a landlord is not a lot of laughs — nobody calls you up and says, 'I really like living here,'" Cathy says. "I wanted to do something I love and that I can get a lot of joy and laughs out of." Through her synagogue, she and her children, Alex and Amanda, volunteered serving dinner at shelters and charities like The Children's Inn at NIH. Cathy also began serving on boards of directors of educational and arts organizations, and teaching college courses. When Cathy's mom, then her brother and, finally, Cathy herself got sick with cancer, her desire to help others became even more urgent. "When I had cancer, it was very important to be with people close to me who gave me hope and told me, 'You will get through this,'" she says. "It's important to be there for people."



Cathy Bernard finds fulfillment in supporting The Children's Inn and other philanthropic work.

In 2006, she established The Bernard Family Foundation to support the arts, education and cancer advocacy programs as well as The Children's Inn. "The Inn provides an incredible service for people who have serious health issues," Cathy says. "It is a very nurturing environment, and I think that is helpful when you are going through life-threatening illness." Officially retired now, Cathy continues to hold real estate, manage real estate supervisory companies and write business plans for budding entrepreneurs. Once a year, she hosts the Bernard Ebb songwriting awards to support local songwriters.

Cathy has been supporting The Children's Inn for more than 20 years and is a member of the Leadership Circle and Northern Stars.

Police Lieutenant Protects and Serves His Community While Bringing Smiles and Comfort to Sick Children

Ask a child what his or her favorite activity at The Children's Inn is, and the answer is most likely bingo. Great prizes are one reason for the event's popularity. Another is Montgomery County Police Lieutenant David McBain, who has been leading the police department's biweekly bingo nights at The Inn for more than two years, and who has led other MCPD volunteer efforts at The Inn for over five years.

When his important work permits, David enjoys nothing more than to spend Tuesday evenings calling bingo with fellow officers for the children and families at The Inn. The children are delighted to spend time with the uniformed officers after long days of medical appointments.

"When Lieutenant McBain enters The Inn, you can immediately see his warm smile and compassionate personality capture the hearts of our children and families," says Laura King, senior director of community engagement, The Children's Inn. "The children look up to him as a role model, and as they fight their courageous battles, they know that he is there to support them. He inspires our children, and we're so grateful for his personal commitment to The Inn."

In addition to bingo nights, at holiday time David organizes MCPD's annual Santa Police Ride. With lights flashing and sirens blaring, about 30 motorcycle officers escort Santa Claus, aka Officer Robert "Bobby" Ladany, to The Inn.



Montgomery County Police Lieutenant David McBain helps Reem, 8, of Egypt shop for toys during Christmas in July.

There, Santa and the officers take photos with the children, work on arts and crafts projects, and even dabble in face painting. It's a special treat for the children to see David ride home with a child's painted flower or rainbow on his face. Officers also help children choose holiday presents for their parents and other family members at The Inn's Gingerbread Gift Shop.

At The Inn's annual Christmas in July celebration, David and his fellow police officer elves escort a motorcade of Children's Inn families in festively decorated shuttle buses to a local store to help children pick out new toys for themselves. After the shopping spree, children and their families enjoy pizza with the officers.

David's wife, Lauren, likes to join her husband in attending The Inn's holiday festivities, and the couple generously supports The Inn.

Meet Our Volunteers and Donors

Booz Allen Hamilton: Corporate Support Children's Inn Families Can Count on

A supporter of The Children's Inn for more than 15 years, Booz Allen Hamilton, a management and technology consulting firm, has become one of The Inn's most reliable and generous corporate backers, guided by its purpose statement: "Empower People to Change the World."

Booz Allen's support of The Children's Inn started in 2001 with a sponsorship of The Inn's annual gala. Since then, Booz Allen has continually stepped up its support, from providing Inn families with regular meals, to sponsoring The Inn's annual golf tournament, organizing backpack and school supply drives, making bilingual staff available as interpreters, holding food drives to stock The Inn's pantries, donating concert tickets and even dressing up as elves to help children pick out and wrap holiday gifts for their family members from The Inn's holiday gift shop. Booz Allen Executive Vice President Susan Penfield, who has been serving as an Inn board member since 2013, says, "Community service, passionate service, is core to Booz Allen's DNA." She too is an elf at The Inn's holiday gift shop, calling it "the one Inn event that is most exciting."

The firm also offers its expertise to help The Inn implement new technologies, including a reservation system that gathers needed data, and a survey and analysis mechanism for The Inn to better communicate with and support families who are going through especially difficult times. Recently, Booz Allen began developing a welcome app for Inn families that is set to roll out in early 2019.



Inn board member and Booz Allen Hamilton Executive Vice President Susan Penfield, second from left, volunteers at The Inn's holiday gift shop with current and former Booz Allen employees.

This year, Booz Allen's top-level sponsorship of The Children's Inn's An Evening for Hope gala helped The Inn's most important fundraiser break the \$1 million mark for the first time. "Booz Allen Hamilton is one of The Inn's strongest corporate partners," says Inn CEO Jennie Lucca. "Their support comes on so many levels, helping relieve the burden of illness for more than 1,700 children and their families who call The Inn home every year."

Booz Allen President and CEO Horacio D. Rozanski credits the children and families of The Inn with being the ones who change lives. "When you get a chance to interact with one of the families, what they're going through is extraordinarily difficult," he says. "A child with an illness that may or may not have a cure has an uncertain future in treatment. And they are the ones talking about optimism. They are the ones picking you up. It gives you a whole new outlook on life. You walk away changed."

FY 2018 Donors

The Children's Inn at NIH is deeply grateful to all of you who generously made monetary donations and pledges between July 1, 2017, and June 30, 2018. The following list recognizes cash gifts and pledges of \$1,000 or more as well as the Innkeepers Society and our Northern Star supporters. The Inn also appreciates the many in-kind gifts and services donated throughout the year.

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Ren Hongzhu, 22, of New Jersey is being treated at the National Heart, Lung and Blood Institute (NHLBI) for severe aplastic anemia. She has spent seven months at The Children's Inn so far. Pictured with her is her boyfriend, Yiqing Fan.

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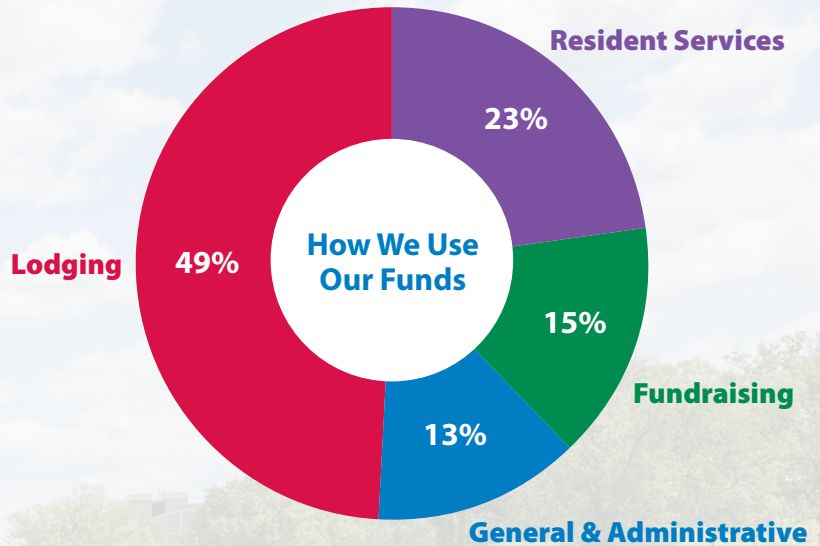
**Deceased*

Every effort has been made to ensure the accuracy of our records. Please contact Felicia Akoh at felicia.akoh@nih.gov or at 301-827-6053 if you have any questions.

There are many ways to support The Children's Inn, such as food drives and the Thoughtful Treasures program. Visit www.childrensinn.org and click on Get INNvolved to learn more about how you can help the many children and families who call The Inn "a place like home."

Financial Overview Fiscal Year 2018

Operating Expenses:



INCOME

Contributions:	\$5,051,000
In-kind contributions:	\$3,325,000
NIH Reimbursement:	\$1,246,000
Investment and Other Income:	\$3,369,000
Total:	\$12,991,000

NET ASSETS

Unrestricted Net Assets:	\$27,032,000
Temporarily Restricted Net Assets:	\$7,807,000
Permanently Restricted Net Assets:	\$25,200,000
Total:	\$60,039,000

OPERATING EXPENSES

Lodging:	\$5,725,000
Resident Services Program:	\$2,725,000
Fundraising:	\$1,820,000
General & Administrative:	\$1,521,000
Total:	\$11,791,000



Source: Audited financial statements as of June 30, 2018, 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.

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Maryam, 7, of Azerbaijan has stayed at The Inn 14 times since 2014 to be treated for an autoimmune disease at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

The Children's Inn Strategic Plan #INN2025

The Inn will accelerate our impact on medical discovery and care by achieving these #INN2025 strategic plan goals:

1. Creating a state-of-the-art "smart" living environment.
2. Developing even stronger support programs that better integrate discovery and care.
3. Growing our diverse group of leaders, supporters and volunteers ensuring The Inn's financial viability.



The Children's Inn at NIH

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A Special Thank You From Our CEO:

Thank You for Your Support During Our Emergency Closure

Since structural damage to The Inn's roof forced us to evacuate families and close The Inn's main wing in August, your caring support has meant more than ever to our children and families.

While The Inn is able to accommodate only 24 families in our E-wing, your emergency support keeps families as comfortable as possible by allowing us to lease 10 additional community apartments and rent hotel rooms as needed. Despite the limited space, dedicated volunteers and our staff provide a full schedule of family activities at The Inn, complemented by weekly activities at the community apartments.

Engineers estimate The Inn's roof will be fixed by early March, when The Inn's main wing is set to reopen. We invite you to stay updated on the many ways you can help by visiting childrensinn.org/emergency.

From the bottom of our hearts, thank you for your steadfast support.

Jennie Lucca
CEO, The Children's Inn at NIH

