



The Children's
Inn at NIH



Making Childhood Possible

2017
Annual
Report

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OUR VISION

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

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



On the cover: Inn resident Avery Ponzar, 9, of Festus, Missouri, is being treated at National Institute of Allergy and Infectious Diseases (NIAID) and National Cancer Institute (NCI) for a rare immune deficiency. Read more about her on p. 5.



Letter From the Board Chair and Chief Executive Officer

Dear Supporters,

Your commitment helped The Children's Inn at NIH relieve the burden of illness for 1,717 children and their families who stayed with us over the past year. Together, we served nearly 200 more families than we did the year before. Your support also has made important changes to our programs and services possible, along with beautiful renovations to The Inn's interior.

Our recent age expansion, which allows residents up to age 30 to stay at The Inn, has been enthusiastically received by our young adults. Our goal for next year is to develop a top program to help young adults learn crucial independent living skills many haven't had the chance to develop due to the heavy tolls their illnesses have taken on their lives.

Your financial contributions help sustain The Inn and make it possible for children like Lucy, Marlon and Avery, and young adults like Aaron, who are featured in this annual report, to participate in lifesaving clinical trials — trials that have the potential to bring about medical breakthroughs that can help not only them but also generations to come.

We're grateful to you for your partnership in helping The Inn be "a place like home" for families of seriously ill children, and we look forward to starting the next year together to do even more for children, families and young adults residing at The Inn.

Thank you for all you do!

Tim Atkin
Chair, Board of Directors

Jennie Lucca
Chief Executive Officer

Marlon

By all appearances, Marlon Camacho Ceron was a healthy baby. As he grew, however, teachers noticed his speech and behavior were unusual. For years Marlon's symptoms were interpreted as attention deficit hyperactivity disorder, treated by a therapist.



In his teens, Marlon began slurring words and having trouble keeping his balance. Alarmed, his family took him to a number of doctors near their home in Tula de Allende, north of Mexico City.

Blood test results shocked the family. Their handsome, sociable boy who loves playing soccer and is a social media aficionado has a rare genetic condition called Niemann-Pick type C (NP-C). NP-C prevents cells from processing cholesterol and other fatty molecules. As these accumulate, they progressively impact organs like the brain, liver and spleen.

Without viable treatment options in Mexico, Marlon's parents contacted relatives in the United States, who helped Marlon enroll in a research study that brings the family to the NIH every two weeks for treatment.

"The willingness of families to participate in our research is critically important," says Dr. Forbes Porter, M.D., Ph.D., clinical director at NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). "This study will allow us to establish whether this therapy is safe and clinically effective."

While at the NIH, Marlon, 16, and his mom stay at The Children's Inn free of charge. Here they can unwind after a day of treatment, enjoy family meals or play air hockey in the game room. His family has made friends with another NP-C patient, the first they have ever met. The Inn's Spanish-speaking staff and families help them feel at home.

"We thank God for the chance we've received," Marlon's mom, Esmeralda, says in Spanish. "My friends don't believe me when I tell them about how wonderful The Inn is. We have never before experienced anything like this."





Lucy

From birth, Lucy suffered mysterious, recurring skin infections and other health issues. But nobody connected the dots.

In a stroke of luck, a doctor at MedStar Georgetown University Hospital in Washington, D.C., treating Lucy had heard an NIH lecture about a rare illness named Hyper IgE syndrome, or Job's syndrome. She recognized Lucy's unusual infections, skull malformation and gross motor delays as symptoms of the genetic illness, and referred the then 3-year-old to the National Institute of Allergy and Infectious Diseases (NIAID), which treats patients with rare immune disorders.

Job's syndrome patients have an incomplete immune system and are at risk of developing serious lung and skin infections. For Lucy, respiratory infections quickly turned life-threatening. Anxious about Lucy's future, her parents agreed to a clinical trial at the National Cancer Institute (NCI) to give Lucy a new immune system through bone marrow donated by her mother.

Throughout Lucy's months of treatment at the NIH, the Midlothian, Virginia, family spent more than 80 nights at The Inn, grateful for the free lodging, support services, meals and the chance for Lucy to feel joy and play.

"It's really fun at The Inn — there's a play room, an art room, a game room with video games and air hockey. On the playground, I like to swing and slide. I love Zilly," Lucy, 9, says, referring to The Inn's therapy dog.

After her transplant, Lucy caught another life-threatening lung infection and required surgery for a collapsed lung. But after recovering, bloodwork showed her mother's bone marrow cells were helping Lucy build a new immune system.

Still, doctors caution that building a fully working immune system after transplant takes months to years. Lucy's second transplant birthday is December 2017. Lucy and her family continue to visit The Inn and the NIH for regular checkups.



Aaron

As sickle cell trait carriers, Aaron Ramsay's parents of Folsom, California, tested all their children for sickle cell anemia. Two of them tested positive. But the illness always took the hardest toll on Aaron.

Growing up, Aaron experienced frequent infections and paralyzing pain. As an adolescent, he was hospitalized for a life-threatening blood clot in his lungs.

Sickle cell disease is a disorder in which the body produces misshapen red blood cells that clot easily and cannot supply the body with needed oxygen. It can cause fatigue, increased risk of infection and excruciating pain. Even with standard treatment, life expectancy for sickle cell patients is 40 to 60 years.

As a freshman in college, Aaron suffered weekly pain crises, prompting him to contemplate leaving school. But his dream of becoming a high school chemistry teacher kept him going. During winter break, Aaron's parents revealed to him that his younger brother, Luke, was a perfect donor match for him, making Aaron one of the few fortunate sickle cell patients eligible for a bone marrow transplant — the only known potential cure for the illness. His parents already had begun communicating with the National Heart, Lung and Blood Institute (NHLBI) at the NIH to get Aaron admitted to a clinical trial for sickle cell patients with matched donors.

Soon after, Aaron was at the NIH Clinical Center undergoing chemotherapy and radiation in preparation for his life-saving transplant. He and his family remained at The Inn during his three-month recovery, during which time they enjoyed participating in organized activities and outings. Using The Inn's family exercise studio, Aaron found he could work out without pain for the first time.

Today, Aaron, 20, is a college junior and feels great. "My brother is 14, and I don't think he fully realizes what he's done for me," he says. "But I'm just so grateful."



Avery

Avery Ponzar and her family were out to dinner when she started complaining of neck pain. By the end of the meal, the little girl was in tears, and her family rushed her to the emergency room.

Antibiotics didn't help, and doctors eventually removed the infected lymph nodes. But the infection returned, striking other lymph nodes in her body.

Avery's doctors in Missouri had been consulting with specialists at the National Institute of Allergy and Infectious Diseases (NIAID) who asked to see Avery in person. Testing at the NIH showed Avery's compromised immune system was caused by a rare mutation to the NFKB1 gene. As a result, Avery's body couldn't fight off even commonly occurring bacteria like the one affecting her lymph nodes.

The only potential cure for life-threatening immune deficiencies like Avery's is a bone marrow transplant. Thanks to cells donated by her father, Avery became the first patient with her particular mutation to undergo a transplant, conducted at the National Cancer Institute (NCI).

However, Avery's new immune system was not taking hold. To save the transplant, she received two additional lymphocyte infusions from her dad.

Whenever Avery, 9, was not inpatient at the NIH Clinical Center, she joined her mom at The Children's Inn, where she participated in summer camp, sailing trips, musical performances, family dinner nights and other entertainment. They also made friends with other Inn families.

"Everybody is so nice here," Avery's mom, Julie, of Festus, Missouri, says about The Inn, where the family spent more than three months. "We've met several families we've become close to. It's like our own little family here. It's comforting, even though we're far from our home. It helps."

Recently, the family learned Avery's transplant was not successful. Doctors hope a second transplant will help Avery build a healthy immune system. The Inn will welcome the family back, no matter how long their stay.



Meet Our Volunteers and Donors



Monica Granovsky, a Children's Inn Circle of Hearts volunteer, visits Farrah Mackenzie, 12, to help brighten her days being inpatient at the NIH Clinical Center.

Coming Full Circle to Bring Hope, Joy to Children and Families

Monica Granovsky left medicine to raise her children. But she felt a deep desire to continue helping children with serious illnesses, the reason she became a pediatric oncologist in the first place.

"I remembered The Children's Inn and all the important work they do," the former pediatric oncology fellow at the National Cancer Institute (NCI) says. "I thought, 'Let me check it out and see if I can be helpful even though I am not a practicing doctor anymore.'"

In 2015, Monica returned to the NIH Clinical Center twice a month as a Children's Inn Circle of Hearts volunteer, taking small items donated to The Inn to help brighten the days of Inn residents hospitalized at the NIH Clinical Center and their caretakers.

"We offer anything that might make their stay more comfortable," she explains. "Shampoo, treats for the kids, a magazine, a book of puzzles, a journal, a pillowcase to decorate their bed, a deck of cards."

But it's not just the items she lets children choose from her blue canvas basket that bring joy. It's also the time she spends with them and their families, chatting in English or her native language, Spanish, that allows families stressed by the burden of illness to relax for a while.

"It's very stressful for the parents to be 24/7 caretakers," Monica, who's originally from Puerto Rico, says. "These children and their families are participating in clinical trials to advance science. Some treatments will work, and others may not. What a gift they are giving to all of us! From the time I was a fellow, I saw firsthand how incredible the Clinical Center staff is. I wanted to be part of that effort."

As her daughter is heading to college and her son to high school, Monica considers what's next.

"I would like to become more involved with The Inn," she says. "I am a Spanish teacher and would love to be an academic tutor at The Inn as well, perhaps helping Spanish-speaking parents learn English."

The Davis Family Finds a Meaningful Way to Give Back

Desperately seeking help for their 14-month-old son, Kent and Lynn Davis arrived at The Children's Inn early in 1992. Brandon was experiencing uncontrollable seizures, and the Davises had come to the NIH to try to find a treatment or a cure.

While Brandon was inpatient at the Clinical Center, Kent and Lynn stayed at The Children's Inn.

"The minute we walked into The Inn, we could feel how warm, homey and welcoming it was," says Lynn. "Everyone was so friendly."

During their six-week stay at The Inn, Kent and Lynn met many other families who were experiencing the same stress as they were. They comforted one another during meals and shared experiences.

"Staying at The Inn relieved a huge burden for us, both mentally and financially, so that we could focus on Brandon," Lynn says.

With Brandon stabilized and knowing that they had explored every possible treatment, the family returned home to Indiana. Tragically, Brandon passed away only a few months later. Kent and Lynn never forgot their experience at The Children's Inn.

PwC Cares to Make a Difference

The folks at PricewaterhouseCoopers will tell you that PwC really stands for "People who Care." That care makes for a perfect partnership with The Children's Inn at NIH. For more than a decade, PwC's local employees have shown their care by volunteering at and for The Children's Inn in many different ways.

PwC Public Sector Health & Benefits Leader and Inn board member Jill Olmstead explains the relationship between her firm and The Children's Inn as something that is personal: "In 2005, our firm started working with NIH. Through that work, we were able to spend some time in the NIH Clinical Center. It was really there that we first encountered families who were Inn residents. Their personal stories really touched all of us. After that, we just had to get involved."

Since that time, PwC's partners and staff have supported The Children's Inn in a number of ways. From serving dinner to making 'thoughtful treasures' gift bags for kids, PwC takes pride in their work with The Children's Inn.

More than two decades later, Kent, Lynn and their son, Zachary, 22, contacted The Inn to discuss how they might "give back" in a special way. While Kent has been giving to The Inn annually through his workplace giving campaigns, the Davis family decided the time was right to make a more significant contribution to honor Brandon's memory and help other Inn families.

When they learned about Zilly and The Inn's animal therapy program, the family decided to establish a named endowed fund to support the animal therapy program in perpetuity.

"We are big animal lovers," says Lynn. "We understand how important animals and pets can be for the healing process."

Recently, the Davises returned to The Inn to see how it has grown and to meet Zilly. "When we walked in, Zilly's face popped up from behind the desk, and we understood immediately why the children and families love her so much."



PwC also takes an active role in special events for The Children's Inn, including An Evening for Hope and A WINNter Affair, both of which are sponsored by the firm. PwC recognizes that both events are about more than raising money.

"Getting involved with A WINNter Affair showed me I could do more — and in a really fun way," says Vito Capezio, PwC senior associate and Young Ambassador for The Inn. "I was able to introduce other friends to the mission of The Inn. It's a great feeling to grow a broader community of support for such an important cause."

FY2017 Donors

The Children's Inn at NIH is deeply grateful to the generous donors who gave gifts of cash and made pledges between July 1, 2016 and June 30, 2017. The following list recognizes cash gifts of \$1,000 or more as well as the Innkeepers Society and our Northern Star supporters. Corporate and foundation donors are listed first, followed by our individual and estate donors. The Inn also appreciates the many in-kind gifts and services we receive throughout the year.

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Colorful, brightly lit mailboxes donated by MedImmune now greet families as they enter our Inn lobby, allowing children easy access to the daily Thoughtful Treasures our volunteers and donors create for them.





On Dec. 21, 2016, members of the Vilardo family, along with many friends and supporters, dedicated The Inn's new outdoor terrace and patio area in memory of Dick and Jody Vilardo, who were long-time Inn volunteers and donors. The beautiful garden and seating area were made possible through a generous grant from the Dick and Jody Vilardo Foundation and memorial contributions.

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Anonymous (6)
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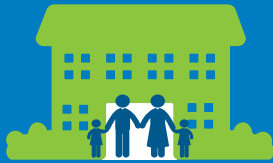
* Deceased

Every effort has been made to ensure the accuracy of our records. Please contact Felicia Akoh at felicia.akoh@nih.gov or at 301-451-9455 if you have any questions.

Where the Power of Childhood Meets the Power of Research

Fiscal Year 2017 (July 1, 2016 - June 30, 2017)

Families



1,717

families stayed at
The Children's Inn

Since 1990, families have come to The Inn from



50
States

and



94
Countries

to help advance
medical discoveries
around the world

Children



1,305

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



Children participated in

283

clinical trials representing advances
in treatment for cancer, bone and
growth disorders, mental illness and
other life-threatening conditions

Volunteers



2,400+
Volunteers, with



222
who are regularly
scheduled



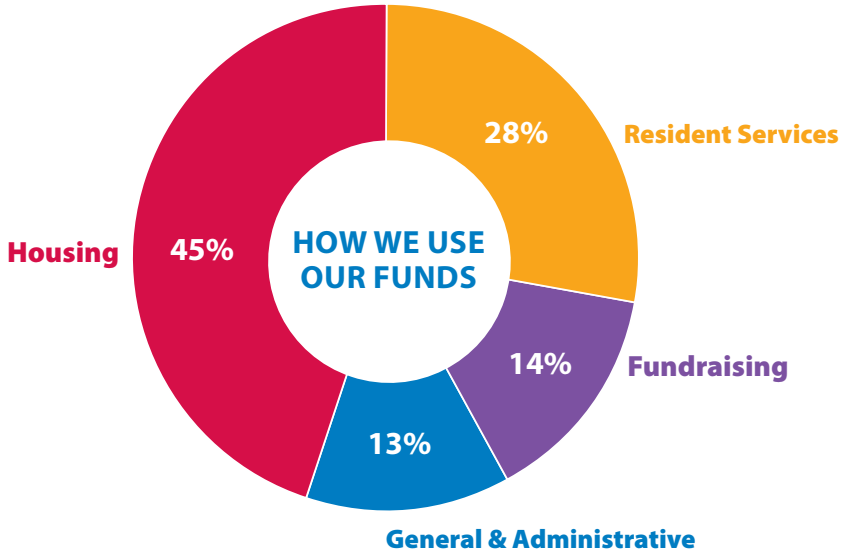
20,299
hours worked

equating to **9.5** employees

Financial Overview

Fiscal Year 2017

Operating Expenses:



OPERATING EXPENSES

Housing Program:	\$4,974,000
Resident Services Program:	\$3,113,000
Fundraising:	\$1,605,000
General & Administrative:	\$1,478,000
Total:	\$11,170,000

NET ASSETS

Unrestricted Net Assets:	\$25,735,000
Temporarily Restricted Net Assets:	\$10,025,000
Permanently Restricted Net Assets:	\$23,079,000
Total:	\$58,839,000

INCOME

Contributions:	\$5,395,000
In-kind contributions:	\$3,360,000
NIH Reimbursement:	\$1,090,000
Investment and Other Income:	\$4,521,000
Total:	\$14,366,000



Source: Audited financial statements as of June 30, 2017, available upon request. 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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7 West Drive, Bethesda, MD 20814-1509
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