



The Children's Inn at NIH

A PLACE
LIKE HOME,
A PLACE WITH

HOPE

2019
ANNUAL
REPORT

You deserve
cheers for making
a difference for
children at
The Inn!

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.

Your support of The Inn helped Amani, 14, participate in a lifesaving clinical trial that cured his sickle cell disease.

LETTER FROM THE CEO AND BOARD CHAIR

DEAR FRIEND OF THE CHILDREN'S INN,

You are a guiding star for the more than 1,500 children and families who have found a home at The Inn over the past year. Your support helped children and young adults participate in 524 studies conducted at the NIH Clinical Center that are leading to new treatment options for them and countless patients around the world. In this report, we are pleased to introduce you to three of the special young people for whom your support has made a world of difference:

- ★ Thanks to you, **Paige**, 9, has been able to participate in a clinical trial that has successfully shrunk her dangerous facial tumor by 28 percent. This successful trial is giving hope to children around the world with neurofibromatosis type 1 that the first treatment for their devastating disease is on the horizon.
- ★ **Jules**, 25, now lives a life free from pain—and he has you and his doctors to thank. Your support allowed Jules to spend months at The Inn to undergo a curative bone marrow transplant for severe sickle cell disease at the NIH. His trial participation also is helping his doctors make transplants safer for other patients.

- ★ Your support has allowed **Noah**, 22, to comfortably access the expert care that has been keeping her rare disease manageable for 20 years and participate in the Undiagnosed Diseases Program (UDP) that is giving her—and many others with unknown diseases—hope.

These achievements are only possible thanks to you and your generous, visionary support of The Inn's mission. As we are approaching The Inn's 30th anniversary in 2020, we look forward to creating The Inn of the future with you. Together, we can help **thousands more** children and their families, and do our part in supporting the development of new treatments and cures.

Sincerely,



BETH MALONEY
CHAIR, BOARD OF
DIRECTORS



JENNIE LUCCA
CHIEF EXECUTIVE
OFFICER

YOU HELP PAIGE LIVE LIFE TO THE FULLEST

Paige was born with unusual swelling on one side of her face that doctors predicted would subside on its own. When it didn't, an MRI revealed growing tumors on baby Paige's face and spinal cord.



Paige loves spending time at The Inn with her sister, Madison, and her parents, Shelley and Kevin.

"I was told if she moved her head the wrong way, she could stop breathing," Paige's mom, Shelley, recalls.

A biopsy confirmed Paige had neurofibromatosis type 1 (NF1), a genetic tumor predisposition disorder with no available treatment. When doctors broke the news to the new parents that their infant daughter might never walk or talk, the couple sought hope in clinical trials at the NIH.

By age 5, Paige's growing tumor had begun to distort her face, and she had trouble walking and hearing. Unfortunately, the first trial medication didn't help. Undeterred, her parents signed Paige up for a second trial testing a medication called Selumetinib.

"Within a couple of months on the drug, her ear canal opened, and she got her strength back,"

Shelley says. "Three years later, she is talking and walking like a regular second grader."


"For all of our patients, being here at The Children's Inn is absolutely invaluable, and it's their favorite part of the experience," says Dr. Andrea Gross, an assistant research physician in the Pediatric Oncology Branch of the National Cancer Institute's (NCI) Center for Cancer Research. "They like playing with Zilly and all the experiences they have here. I think for the families to know that at the end of every day they get to be back here and be part of this warm, welcoming environment and know that it is just a safe haven for them is huge."

In addition to free lodging, Paige and her family appreciate The Inn for its many fun activities, warm meals, the chance to stay together

during Paige's hospital appointments, and the ability to bond with other children and families affected by rare diseases.

"I just want to thank everyone who donates to make The Children's Inn possible," Paige's mom says. "I cannot imagine being away from Paige while she is an inpatient or driving back and forth to make outpatient care possible without The Children's Inn. Paige and her sister feel like they're on a vacation when they're here. Thank you very much for making our lives easier during this time!"

Your support has helped Paige—and many children like her—participate in this successful trial that has put the first treatment for NF1 on the path toward FDA approval. Thanks for giving hope to children like Paige and their families! ★



Your donation to
The Children's Inn is a gift of
hope for children like Paige.

Donate at
www.childrensinn.org/give
or complete the
enclosed envelope.

Thank you!

THIS IS
PAIGE

Age 9
Neurofibromatosis
Type 1 (NF1)



Watch Paige's video online
and read her full story at
www.childrensinn.org/paige.



THIS IS
JULES

Age 25

Severe Sickle Cell Disease

 Watch Jules' full story online at www.childrensinn.org/jules.



Your support allowed Jules to spend many months at The Inn while he recovered from a lifesaving bone marrow transplant. During that time, he formed close relationships with other young adults at The Inn and Children's Inn staff.

Thanks to you, Jules has many happy memories of fun activities he took part in during his stay at The Inn, along with new friendships that will last a lifetime. Most importantly, thanks to your support, Jules is finally free from pain and able to pursue his dream of becoming a doctor, so he can help other sickle cell patients.

In addition to making transplants safer for sickle cell patients, in 2018, the NIH launched an initiative to accelerate gene therapies to find a widespread cure for sickle cell disease within the next decade. ★

YOU HELPED JULES BEAT HIS DEADLY DISEASE

Jules, 25, was born with severe sickle cell disease. The treacherous blood disorder caused him excruciating pain from frequent clotting of his misshapen red blood cells, led to kidney failure and left him vulnerable to serious infections.

"It feels like sharp pain, like shards of glass in your blood," says Jules, describing a sickle cell pain crisis. "Children die from sickle cell every day. Not just adults—but children, young adults, older people. A lot of times we don't make it until 40 years old."

Jules' greatest hope was a bone marrow transplant trial conducted by the National Heart, Lung and Blood Institute (NHLBI).

"The day that I found out I was eligible for the trial, I was ecstatic," Jules says. "I saw endless

opportunities in the future. I didn't know what to expect, but I knew it was something good."

Jules became the first patient in kidney failure to undergo a bone marrow transplant at the NIH Clinical Center. Surpassing expectations, he sailed through the procedure without complications.

"Now I'm cured of sickle cell disease, and I can do so much more than I could ever do," he says. "It's a blessing to be here at the NIH and The Children's Inn."

Your support
changes lives.

Donate at
www.childrensinn.org/give

or complete the
enclosed envelope.

Thank you!

YOUR KINDNESS NURTURES NOAH'S SPIRIT AND STRENGTH

Early ultrasounds indicated to Gisela and Carlos that their baby girl's health was in jeopardy. But nothing could prepare them for the lifelong search for answers they'd begin with the birth of their daughter.

Yet, they were lucky. Surrounded by expert medical staff, they soon had the first answer to their daughter's growing health puzzle. Noah became one of the youngest patients diagnosed with abetalipoproteinemia, a highly rare metabolic disorder that prevents her body from processing dietary fats. Thanks to the specialized care she has received through the National Heart, Lung and Blood Institute (NHLBI) for more than 20 years, Noah has been able to avoid the serious impairments—like blindness and motor function problems—that typically come with her disease.

Over the years, Noah developed other confounding health issues. She needed surgery for painful, perforated wrist and ankle bones. At 14, she began experiencing nearly constant nausea, disabling fatigue and extreme, generalized pain that have dominated her life since.

Noah eventually was admitted to the NIH's Undiagnosed Diseases Program (UDP). Genome sequencing revealed a large number—15—of genetic mutations. One of these finally explained Noah's skeletal issues, caused by an ultra-rare disorder. However, none of the other genetic mutations

correlate with any known diseases—yet—and Noah's wait for answers continues.

Through the years of uncertainty, Noah has been grateful to be able to count on you and The Children's Inn for providing her with a nurturing safe haven.

"The thing I like about The Children's Inn is—I actually feel normal here," she says. "Unlike, outside in the real world, I know I'm different.

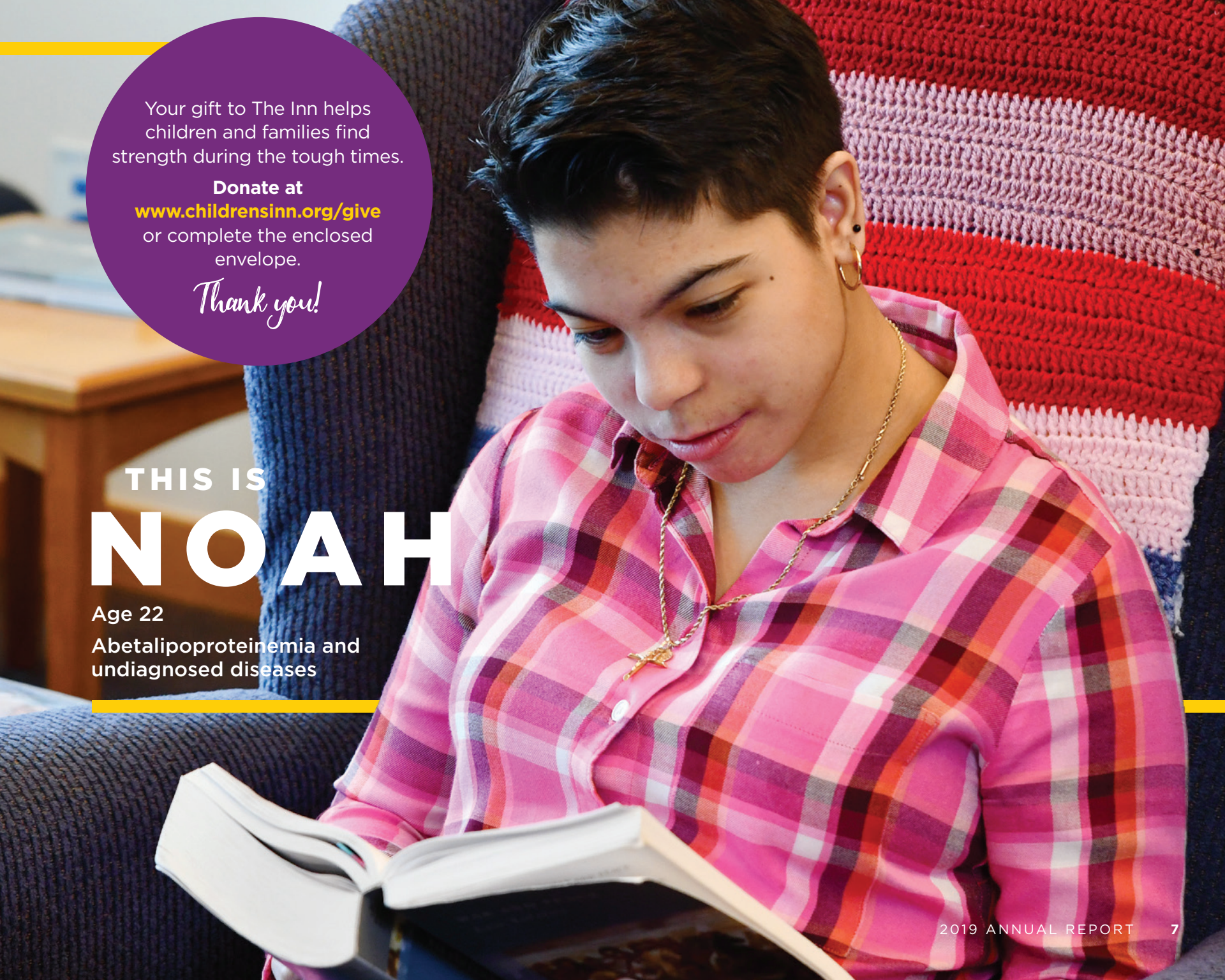
[The Children's Inn] It's just a really awesome place to be."

As a child, Noah loved The Inn's playroom, bingo nights and arts and crafts activities that your support makes possible. Today, she cherishes spending time with Cantor Mike, an NIH chaplain who sings songs and discusses scripture and spirituality with Inn families.

Now 22, Noah stays busy writing short stories and plays, and working on her first poetry collection, illustrated by her mother. With your support of The Inn, Noah knows that good things will continue to come her way, and she stays hopeful that she and other young people like her will get the answers they are looking for. ★



Noah and her parents, Carlos and Gisela, attend The Inn's 2019 An Evening for Hope gala with Aisha Campell, second from right, The Inn's associate director of programs and services.



Your gift to The Inn helps children and families find strength during the tough times.

Donate at
www.childrensinn.org/give
or complete the enclosed envelope.

Thank you!

THIS IS
NOAH

Age 22

Abetalipoproteinemia and
undiagnosed diseases

WHERE INNOVATION AND CARE GO HAND-IN-HAND

Just like any home, a lot happens at The Inn every year—and this year was no different. From the families we serve and the kids who receive medical and emotional support to the selfless volunteers and donors who make our home run seamlessly, we're committed to ensuring every year is a great one for our residents.

IN OUR 29 YEARS OF SERVICE:



More Than

14,306

families have stayed at The Inn

Families have come to The Inn from



50

States

and



94

Countries

to help advance medical discoveries around the world

DURING FISCAL YEAR 2019: (JULY 1, 2018 - JUNE 30, 2019)



1,519

families stayed at **The Children's Inn** for **12,079 nights**

We provide relief, support and strength to families journeying into the unknown: they are the pioneers whose participation in medical trials at the NIH can change the story for children around the world.

THE CHILDREN'S INN PROVIDED:



988

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

THERE WERE:



2,400+

volunteers



206

regularly scheduled
volunteers



18,059

hours
volunteered

equating to **9** employees

FY19 ANNUAL BUDGET:



\$12.2 Million

*Operating plus capital
less depreciation

FINANCIAL OVERVIEW

Fiscal Year 2019

INCOME

Contributions	\$5,010,000
In-Kind Contributions:	\$3,354,000
NIH Reimbursement:	\$986,000
Investments and Other Income:	\$4,041,000
Total:	\$13,391,000

NET ASSETS

Without Donor Restrictions:	\$26,396,000
With Donor Restrictions:	\$34,978,000
Total:	\$61,374,000

OPERATING EXPENSES

Lodging:	\$6,042,000
Resident Services Program:	\$2,685,000
Fundraising:	\$1,853,000
General & Administrative:	\$1,476,000
Total:	\$12,056,000

OPERATING EXPENSES



Source: Audited financial statements as of June 30, 2019, 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.

DRIVEN TO MAKE A DIFFERENCE, THIS POWER COUPLE HAS SUPPORTED THE INN SINCE 2004

With a smile on her face and a cup of coffee in her hand, Phyllis Rienzo arrives at The Children's Inn at 10 a.m. every Wednesday, all year long, ready to be put to work.



A senior account executive at Microsoft, Phyllis found herself on the NIH campus for the first time in 2004. In her capacity as a vendor to NIH, she learned all about The Inn—what it provides to the children participating in research studies at the NIH Clinical Center, what it means to the families who benefit from its support system—and was immediately hooked. In 2005, she began volunteering as a committee member for The Inn's signature gala, and in 2009, she became a member of the Leadership Circle, a group of donors who have contributed more than \$1,000 to support The Inn's mission.

Over the years, Phyllis' sales and marketing acumen would take her from Microsoft to NetApp to Dell; and as any good salesperson is accustomed to do, she immediately engaged each company with The Inn. From sponsoring The Inn's annual gala and the annual golf tournament to catering dinners for Inn residents, The Inn's corporate support would not be the same without Phyllis. And as she had done with these and numerous other companies, Phyllis began bringing her husband, Scott Parr, along to The Inn.

In 2013, Scott had the opportunity to attend the unveiling of The Inn's state-of-the-art playground and park. With such features as a putting green, sound garden, amphitheater, swings and sliding boards, he was "wowed." But it was what he observed inside the Inn that was even more powerful: tutors helping residents with their studies, volunteers giving tours and checking in families, staff members making it all run so smoothly. On the hottest

day of the summer, and the very first time he got to see with his own eyes this magical place he had learned to love through Phyllis, it all became clear.

“Without The Children’s Inn,” Scott reflects, “a family’s choices would be bad, worse ... With The Inn, there is hope! For [young patients] to come here with their families, the financial burden is lifted and they don’t feel so alone. They get to be with, and talk to, others in similar circumstances.”

When Phyllis and Scott were planning their retirement a couple of years ago, they both prioritized giving of their time and treasures. Scott works with Catholic Charities as a leader for financial education and Phyllis spends time with The Inn.

“I always thought ‘I just want to have a healthy baby,’” says Phyllis. “We’ve been so blessed to have four healthy kids. They’re my motivation! And The Inn is local. I feel it’s so important to give back to a place in our own community.”

And Phyllis and Scott have done just that! Whether donning cocktail attire or golf apparel, they show up to every single one of The Inn’s signature events, to committee meetings and other special gatherings for their favorite philanthropic cause. For Phyllis, on Wednesday mornings, she sits at her assigned cubicle working on business and sponsorship plans with ease and a purpose: to make as many people in as many organizations as possible aware of this “place like home.” ★

MAKING A DIFFERENCE

Every bubble that’s blown, every face that’s painted, every party that’s thrown, every dream that comes true at The Inn happens because of our amazing volunteers and donors. The time, financial donations and in-kind contributions of thousands of individuals, organizations and corporate supporters make childhood possible at The Inn.



“With The Inn, there is hope! ... The financial burden is lifted and they don’t feel so alone.”

Phyllis Rienzo (right) and Scott Parr pose with Inn CEO Jennie Lucca after playing The Inn’s 2019 Golf INNvitational tournament.

BARBARA AND BARRY GORDON FIND MEANING IN MAKING FAMILIES' LIVES COMFORTABLE

Barbara and Barry Gordon don't keep track of the number of years or hours they've volunteered at The Inn—though it's been many. For them, volunteering has always been about the impact on Inn families and their own lives.

The couple first learned about the NIH after Barry's job transferred them to the DC area in the 1960s. Barbara, a former elementary school teacher, and Barry, who worked in marketing at IBM, soon befriended a family who also had just moved to their new neighborhood from Baltimore, Maryland—albeit for very different reasons. One of their

daughters had leukemia, and the best place to treat her was at the National Cancer Institute at the NIH.

"Their daughter lost her life, but her family couldn't stop praising how wonderful the NIH was," Barbara says. "We realized they were doing pioneering, groundbreaking work in curing childhood leukemia. That always stayed in the back of my mind. I thought, 'What a wonderful facility where your taxpayer money goes to a cause you believe in.'"

Over the years, the couple learned more about the NIH from news stories. When their synagogue asked for volunteers to drive vans for The Children's Inn at NIH, Barry immediately said, "Yes."

"He'd drive the vans and come home with stories about this child and that," Barbara said. "That's what got me interested. I knew it was the perfect match."

Eventually, the NIH's buses began serving Children's Inn families, and volunteer van drivers were no longer needed. Barry started volunteering at The Inn's welcome desk instead, helping families check in, find their

way around The Inn, store luggage and more. Barbara also joined The Inn, helping stock the kitchen pantries with food donations for families to cook quick meals. But over time, her position evolved into more.

"If I can help anyone in a little way and make a difference, I love to do it," she says.

For Barbara, that means finding the foods families crave, like a child's favorite cereal or Asian noodle bowls, when the pantries have run out. For Barry, it means encouraging children to open their personal Inn mailbox and watch their faces light up in excitement as they discover the "thoughtful treasures" hidden inside. The couple also donates to The Inn.

"Making families' lives more comfortable, that's the main goal," Barry says about their roles.

"Barbara and Barry make The Inn a brighter and more fun place," says Meghan Arbegast, community engagement and volunteer program manager. "They greet everyone with a smile, and they go the extra mile to make our families feel special and cared for. We are so grateful to have them as volunteers and for their dedication to The Children's Inn."

Both in their early 80s, Barbara and Barry have volunteered regularly at The Inn for a combined total of over 24 years and are determined to keep going as long as physically possible.

"Sometimes, you hear families say what a wonderful place The Inn is," Barbara says. "It's as if someone gave you two million dollars. They are so grateful. As are we." ★



Barbara and Barry Gordon pose with their grandson, Eli Lorenzi, before he ran the 2018 Marine Corps 10K in support of The Children's Inn.



“If I can help anyone in a little way and make a difference in some way, I love to do it.”

Barry and Barbara Gordon have been volunteering regularly at The Children’s Inn for a combined total of 24 years. They are also donors to The Inn.

“The company’s leadership and staff have given so much in so many areas—it’s become impossible to imagine The Inn without Accenture Federal Services.”

Accenture Federal Services staff pose for a photo with Civilian Health Lead Greg Adler, third from left, his wife, Heather, left, and their son, Jake, now 16, after running the 2018 Marine Corps 10K in support of The Children’s Inn.





CORPORATE SUPPORT THAT COUNTS: ACCENTURE HELPS THE INN MOVE INTO THE FUTURE

Accenture may not mention The Children's Inn in its mission statement, but considering the many ways its civilian health team supports The Inn, it's clear that helping our children and families is a top priority.

“Accenture Federal Services is honored to support the mission of The Children's Inn,” says Greg Adler, civilian health lead, Accenture Federal Services (AFS). “The work being done at The Inn is vitally important and allows children and families to participate in the groundbreaking research at the NIH. Our support of The Inn is our way of giving back to those who work tirelessly to improve the lives of others.”

The company's support of The Inn started with a sponsorship of The Inn's annual An Evening for Hope gala—a sponsorship that the consulting services corporation has stepped up year after year. Accenture Federal Services has also sponsored The Inn's annual Golf INNvitational tournament. Its staff and leadership volunteers regularly serve dinner to the children and families at The Inn and have created “thoughtful treasures”—small gifts children find in their Inn mailboxes to start every day off with a smile.

In 2017, Adler joined The Inn's Marine Corps Marathon (MCM) and 10K charity team and raised funds for The Inn in the process. He's kept up his support of The Inn's MCM team since, and his volunteer spirit has spilled over to a growing number of his staff. This year, Accenture staff made up Team #RunINN4Kids' largest corporate team, boasting 19 runners and raising \$12,000 for The Inn. Accenture

Federal Services' ties to The Inn recently tightened even more when Inn board member Jill Olmstead joined the company as managing director in the federal practice.

However, Accenture Federal Services' most critical support to date has come in the form of pro-bono consulting services that are helping The Inn's staff and board of directors execute its strategic plan to help lead The Inn into the future.

To move the strategic plan forward, the company's consulting experts have helped analyze and streamline The Inn's procedures to recognize, report and address maintenance issues. Based on Accenture Federal Services' recommendations, The Inn is now evaluating new initiatives that will allow us to maximize family room availability and, as a result, serve more families.

“Accenture Federal Services is an invaluable partner for The Children's Inn,” says Jennie Lucca, CEO of The Inn. “The company's leadership and staff have given so much in so many areas—it's become impossible to imagine The Inn without Accenture Federal Services. This is especially evident as we're planning for The Inn's future by heavily relying on the expertise and strategic support of their consultants—all provided pro-bono. We're beyond grateful!” ★

2019 DONORS

The Children's Inn at NIH is deeply grateful to you for your generous monetary donations and pledges made between July 1, 2018, and June 30, 2019. 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.

CORPORATIONS AND FOUNDATIONS

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\$100,000+

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DMI
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Dovel Technologies, Inc.
Educational and Charitable
Fund Committee
Enterprise Resource
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Erica Burns Interiors, Inc.
Erica Lodish Charitable Fund
Ethan Alperstein
Memorial Fund
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Every effort has been made to ensure the accuracy of our records. Please contact Felicia Akoh at felicia.akoh@nih.gov or 301-827-6053 if you have any questions.

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The Children's Inn is grateful to our hard-working board of directors, trustees, and board committee members for providing guidance and support to our organization over the past fiscal year. The recent, untimely death of our long-time board member and friend Cokie Roberts is a tremendous loss for our board and our organization. We are thankful for her dedicated service and her family for requesting that contributions in Cokie's memory be made to The Inn.

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#INN2025 STRATEGIC PLAN UPDATE

Since the 2018 #INN2025 launch, The Inn has made considerable progress in accelerating our impact on medical discovery and care through our three strategic goals:

1 GOAL 1

State-of-the-art “smart” living environment—Gensler developed a master facility plan for the purposeful redesign of The Inn. Additionally, Accenture created a set of initiatives to improve our reporting, tracking and management of maintenance issues.

2 GOAL 2

Integrating Discovery and Care—To make it easier for children and young adults to participate in clinical research trials, two surveys were developed. Westat designed and administered a clinician survey to learn about issues encountered when recruiting families for clinical research studies. Deloitte’s survey identified decision points families experienced when determining their child’s participation in clinical research studies. The results will inform future program direction.

3 GOAL 3

Grow a diverse group of Inn supporters—Women for The Inn (WINN) was launched in October 2018 and has 76 members and growing. In addition to WINN, several other outreach activities have been initiated to strengthen, diversify and grow our base of supporters.



To learn more about our progress visit
www.childrensinn.org/inn2025



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