

a place
like home
for me



The Children's Inn at NIH
2014 Annual Report

Established in 1990, The Children's Inn at NIH is a private, nonprofit residence for children and families participating in pediatric research at the National Institutes of Health Clinical Center.

vision

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

mission

The Children's Inn at NIH 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

core values

At The Children's Inn at NIH, the following core values guide our daily actions as we strive to create an optimal healing environment:

Integrity

We are honest and trustworthy and take personal responsibility for our actions.

Open Communication

We listen and encourage others to share their ideas and knowledge in a cooperative manner.

Community

We share a passion to create "a place like home," where all feel a sense of belonging, safety, support and care.

Helping Others

We respond to the needs of others as we individually and collectively care for and work with each other.

Respect

We honor the unique qualities of each individual, treat others with kindness, and value the strength that comes from our diversity.

chief executive officer

As The Children's Inn approaches its 25th anniversary, we look back at the journey of our residents over the

years and how The Inn has supported pediatric patients and their families during life-threatening medical illness.

I am particularly proud of the important role The Inn plays in developing new therapies for children with serious illnesses. The Inn empowers the work of the NIH clinicians and researchers who work tirelessly to improve the quality of life for our children. The clinical trials in which these brave kids participate provide new information and knowledge to the scientific community for the benefit of generations to come. As part of our ongoing mission to provide for the comfort and well-being of children and their families, we completed the renovation of bathrooms, HVAC and kitchens in the original part of the building this past year.

The stories that we share with you in this annual report reflect just a small slice of the hope, healing, and courage in the face of adversity that our families experience. On behalf of those families, and for all of the seriously ill children we will see in the future, I extend our deepest gratitude.



Kathy L. Russell
Kathy L. Russell
Chief Executive Officer

chair of the board of directors

The upcoming 25th anniversary of The Children's Inn is a time to reflect on all that has been accomplished regarding the remarkable advances in the treatment of HIV, pediatric cancers, and in many rare, genetic diseases.

The Inn continues to grow and evolve to meet the needs of those enrolled in pediatric medical research. More children are coming to us with severely weakened immune systems due to either the disease or from their treatment, and are at risk for developing a secondary infection. In the past, when a child had an antibiotic-resistant infection, the family was forced to stay in hotels or off-campus apartments and bear significant financial cost and social isolation.

To answer this need, The Inn launched a unique isolation pilot project this past year, creating four specially constructed "isolation rooms" for pediatric patients with infectious diseases who normally would not be allowed to stay at The Inn. This pilot has the potential to be a groundbreaking initiative, and on behalf of the Board of Directors, I am deeply grateful to all those who continually commit to improving the quality of life for our families.



Lee J. Helman
Lee J. Helman, MD
Chair, Board of Directors

progress time



high- lights 2013-2014

From July 1, 2013 through June 30, 2014, 1,502 children and families stayed 13,349 nights at The Children's Inn and its associated facilities. Fiscal year 2014 was a busy and exciting year for The Inn as we reaffirmed our commitment to providing high quality programs and services to pediatric patients and their families being treated at the NIH. The Inn's updated vision statement, "*As partners in discovery and care, we strive for the day when no family endures the heartbreak of a seriously ill child,*" reflects the need to expand our services as a response to changes in clinical care needs. This is most notable in our Woodmont House for transitional housing, and our Isolation Pilot to address the needs of children with drug resistant infections that limit their access to communal lodging. As we look forward to our 25th year, we have enhanced and improved our facility and its infrastructure while, at the same time, making major investments in the development of our staff. Our accomplishments this year include:

resident services

- 16,870 children and their families participated in 1,113 therapeutic and diversionary programs
- Participated in the COMPASS-Booz Allen Hamilton Community Leadership Project to evaluate the impact of programs
- Encouraged healthy eating for residents by implementing new grant-funded programs, such as:
 - The Sampson Family Foundation grant funds our new healthy breakfast cart each morning and healthy snack table each afternoon
 - The Mead Family Foundation grant funds a new monthly healthy cooking program for residents called CookINN Together
- Expanded tutoring instruction to include professional services for high school students enrolled in advanced level classes
- Implemented a successful pilot program to house five families who are on contact isolation due to antibiotic resistant organisms
- Completed a three-month comprehensive family satisfaction survey to measure organizational effectiveness and mission impact
- Implemented a program providing financial and psychosocial support for families residing in the community, no longer eligible to stay at The Inn due to infectious disease status
- Received a grant for an Imagination Station playground by KaBOOM! - a giant indoor play space for children who are unable to play outside
- Introduced a new set of discussion groups on Inspire.com, our online support community, tailored to the needs of our residents
- Hosted 77 children and their families a total of 1,125 nights at The Woodmont House
- Implemented a satisfaction survey at Woodmont in order to improve customer service and expand programs for families staying more than six months
- Increased transportation frequency and options for families residing at Woodmont





community outreach program

- 1,164 individuals, businesses, organizations, and faith-based groups provided in-kind donations of goods and services
- Hosted our first Weekend Respite Program in Baltimore for nine Inn families, in partnership with The Children's Cancer Foundation
- Developed A Call To Remember Program to connect Inn residents with professional talent that correlates with their future aspirations
- Created online fundraising accounts for receiving in-kind donations through AmazonSmile.com and EBay Giving

human resources & business operations

- Implemented Individual Development Plans for employees to assist in career and personal growth, as well as a 360 degree evaluation tool to aid in employee development
- Updated both the Employee Handbook to ensure compliance with regulations and mitigate risk, and the organization's Crisis Response Plan to ensure readiness in the event of a crisis situation
- Implemented new health insurance benefit for employees aimed at continuing to provide a rich plan while controlling costs



Top left: The Raballand family enjoys the Respite Weekend in Baltimore.

Above: The Inn's Young Ambassador Council Volunteer Service Day.

facility services

- Renovated the kitchen and dining areas serving the C and D corridors
- Renovated the bathrooms in the sleeping rooms and the HVAC system in the C and D corridors
- Replaced the beds and mattresses in all sleeping rooms, thanks to a donation by Tempur-Pedic
- Installed new translator phones to better communicate with non-English speaking families
- Implemented a new facility management software, enabling staff to manage work orders and generate reports more efficiently

volunteer program

- 201 volunteers and groups provided 22,995 hours of service, equating to 11 full-time employees
- Established Saturday Welcome Desk Volunteer Program with Booz Allen Hamilton
- Developed Shining Star Volunteer Program for alumni volunteers
- Hosted 20 volunteer service days with organizations in the community
- Recruited 33 new volunteers
- Received the Presidential Volunteer Service Award for The Inn's Volunteer Program, as well as individual awards given to 43 Inn volunteers
- Awarded a Volunteer Certificate for The Inn's Volunteer Program from the Governor of Maryland



information technology

- Upgraded ResInn hotel management software with additional features
- Upgraded resident FIOS internet from 150 to 300 MB
- Upgraded resident Wi-Fi hot spots to latest technology with higher speeds and added additional hot spots around the facility
- Upgraded Woodmont House security system software
- Upgraded Kids' Computer Room with wall mounted wireless computers
- Upgraded Game Room with latest gaming systems

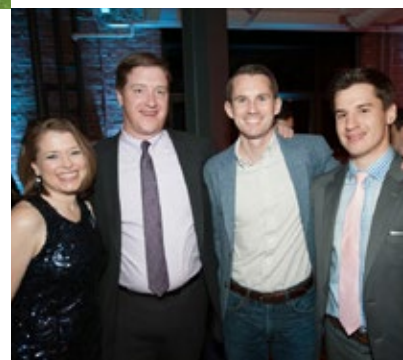


finance

- Completed first full year of long-term investments with new investment manager
- Successfully completed fiscal year 2013 audit with an unqualified opinion and no management letter
- Worked with Human Resources & Business Operations to revise contract policy and implement a process to perform background checks on on-site contractors

Above left: Ruthven Siblings in the Renovated Kids' Computer Room

Above right: Papier Family at An Evening for Hope
Below: A WINNter Affair 2014



development and communications

Fundraising

- Raised more than \$9.6 million in charitable contributions
- Secured a \$5,000,000 gift from The Merck Foundation to support The Woodmont House
- Held the first annual **An Evening For Hope** gala, raising more than \$760,000
- Increased the number of gifts by 30.2% and number of donors by 26.9% over the previous year
- Achieved a 38% increase in net income from **A WINNter Affair** from the previous year

Communications

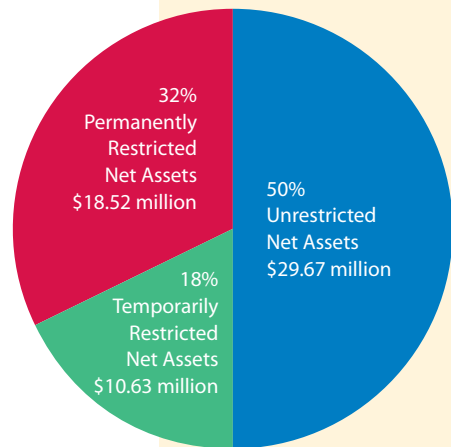
- Updated the mission and vision statements
- Unveiled a new corporate and 25th anniversary logo for 2015
- Began major redesign of website with launch by early 2015
- Continued to grow The Inn's online presence

financial overview

2013-2014

Net Assets as of June 30, 2014: \$58.82 million

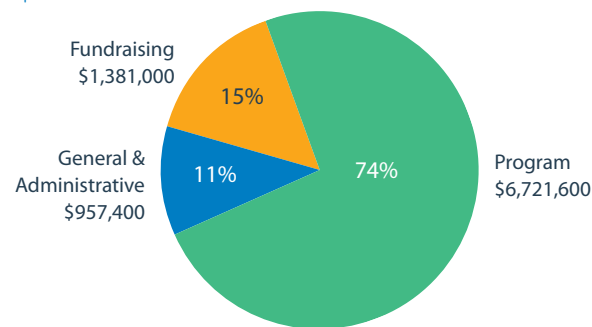
Total Income for FY2014=\$19.24 million (including in-kind contributions of \$3.62 million)



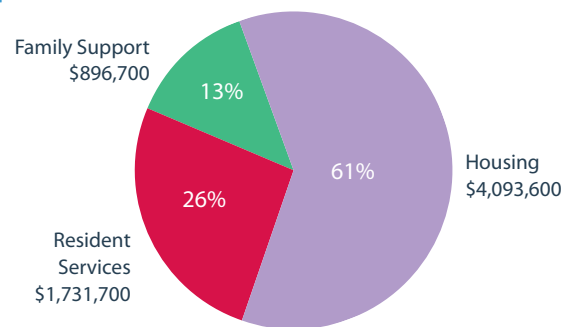
The Children's Inn at NIH and The Woodmont House are a haven of hope for up to 64 families each day, from across the country and around the world, seeking help for their children's medical conditions and hoping for a cure while participating in research studies at the National Institutes of Health—the nation's premier biomedical research center.

More than 12,500 children and their families, from 50 states and 86 countries, have stayed at The Inn since it opened in 1990. The Inn continues to enhance programs and services for residents that fulfill our mission of keeping the family together during a child's illness and providing a healing environment through mutual support.

Total FY2014 Operating Expense: \$9.06 million



Programming Expense Breakdown: \$6.72 million



Source: Audited financial statements as of June 30, 2014; Available upon request. The Children's Inn holds the Better Business Bureau seal of approval and is recognized by Charity Navigator, indicating that we fulfill our mission in a fiscally responsible way. These exceptional designations demonstrate to supporters that we are worthy of their trust.



me time



cuddle time



makenna harrod

Four-year-old Makenna Harrod, of Louisville, Kentucky, has a bright and bubbly personality that lights up any room. Her father, Larry “DJ” Harrod, describes her as “spunky” with a big imagination. With such a positive outlook on life, you would never imagine that seemingly always cheerful Makenna suffers from an extremely rare inflammatory disorder called Blau Syndrome, which affects her skin, joints and eyes. Discovered when she was just two months old, Makenna has been seeking treatment at the National Institutes of Health (NIH) most of her life.

“We found a rash on her chest when she was just a baby,” DJ, says. “When we took her in to see her primary care physician, he said it was eczema.” However, Makenna’s parents were not convinced by the doctor’s hasty diagnosis, so they consulted a dermatologist to get a biopsy. At that point, symptoms worsened leading to swollen hands and various skin bumps. Ultimately, Makenna was taken to see a specialist at St. Louis Children’s Hospital-Washington University, where, according to DJ, the doctor immediately knew what was wrong with Makenna. Soon after, the family was connected to doctors at the NIH and Makenna was enrolled in a protocol at the National Human Genome Research Institute (NHGRI).

When receiving treatment at the NIH, Makenna and her family stay at The Children’s Inn. Makenna’s first visit was in 2011 with her mother, Mary, DJ, and seven-year-old brother, Ian. “At first, we didn’t know what to expect and we were pretty nervous,” DJ says. But, after getting acquainted with The Inn’s facility and programs, “...we got comfortable and felt at home,” he says.

Makenna and her brother have established their favorite go-to spots at The Inn. You can typically find Makenna in either the Playroom or outside on the Playground. In the mornings, she is one of the first to check her mailbox to discover what thoughtful treasure awaits her. Ian enjoys the Game Room and all the different video game consoles at The Inn. When he isn’t able to come along, “Ian gets jealous when Makenna gets to come to The Inn,” says DJ.

With visits as frequent as every three months, Makenna and her family have made The Inn their second home. “We’ve been here for almost every holiday, including Thanksgiving and Christmas, and every season,” says DJ. “We’ve met so many different people from different cultures, and different walks of life.” With all the pressure and stress associated with having a seriously ill child, the Harrods have found comfort at The Inn. “Everything we’ve ever needed, we’ve gotten [here],” he says.



play time



bryce
greenwell



Bryce Greenwell of Murfreesboro, Tennessee is a six-year-old boy who likes building with Legos, watching Disney shows, and playing with his baby brother, Vance, 19 months. It took doctors several months to figure out that his symptoms—an unusual rash, joint pain and fever—were signs of Acute Lymphoblastic Leukemia (ALL).

Diagnosed last December, doctors in Tennessee recommended considering a bone marrow transplant, but when Bryce's cancer didn't respond to standard chemotherapy, his parents learned about a clinical trial at the National Cancer Institute (NCI) at the National Institutes of Health called T-cell therapy. This type of treatment utilizes the body's immune system to kill cancer cells and entails taking some of Bryce's T-cells, altering them in the lab, and reinserting them back into his body. The goal was that the altered T-cells would fight off the remaining cancer so that Bryce could then receive a bone marrow transplant.

While receiving treatment at the NIH, the family stayed at The Children's Inn. Bryce's mom, Jenny, says that at The Inn, Bryce was excited to play with kids of the same age and he particularly enjoyed the Playroom and BINGO nights. She and her husband, Dustin, were pleased with how "awesome" it was at The Inn. "Everyone was so helpful and nice," she says.

During their stay at The Inn, Bryce's mom says he "wore himself out" the first three days playing in the Playroom and on the Playground with the friends he met. He also enjoyed spending time with Vi, The Inn's therapy dog. Before coming to the NIH, Bryce, an avid dog-lover, took part in a study to see if therapy dogs could help reduce stress for pediatric cancer patients



and their parents. Jenny says that his weekly visits with Swoosh, a Pomeranian therapy dog, definitely eased some of Bryce's anxiety around the discomfort of chemotherapy treatments and spinal taps. The Greenwell family has two dogs of their own, Roxy and Brunni—otherwise known as Fox and Hound.

About a month and a half after leaving The Inn, Jenny and Dustin reported that Bryce was able to receive his bone-marrow transplant. It went so well that he was discharged only four weeks after the procedure. Now that Bryce is feeling better, the family is looking forward to boating at a nearby lake, as well as going to the Smokey Mountains vacation area of the state to play arcade games and ride go-carts. They are grateful for all the support they received while at The Inn and from their friends and family. "Bryce is our superhero," says Jenny. "He makes us want to be stronger."

snack time



sydney
coore

Sydney Coore, six, can't help giggling while preparing the perfect peanut butter and jelly sandwich in one of the two newly remodeled kitchens at The Children's Inn at NIH. For this pint-sized chef, PB&J is child's play when it comes to the kitchen. Perched on top of a stool in order to reach the counter, this vivacious and animated young girl happily recounts her favorite foods to prepare with her big brother, Ethan, eight. At their home in Bronx, NY, Sydney and Ethan enjoy helping in the daily preparation of their family's meals. For the Coore family, which also includes mom, Nicole, and dad, Sekou, spending time in the kitchen is a way to relax, unwind, and enjoy time together after a long day.

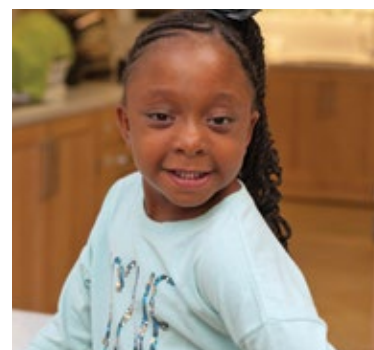
The last six years have held many long days for Sydney's family. Nicole and Sekou knew something was wrong with their new baby immediately after her birth. She was unable to breathe on her own and required assistance to eat. Over the next three years, Sydney faced many trips to the hospital due to chronic high fevers and bouts of pneumonia. Unable to establish a diagnosis and an effective treatment plan, Sydney's pulmonologist referred her to a doctor at the National Institute of Allergy and Infectious Diseases (NIAID) at the National Institutes of Health. The Coore family made their first trip to the NIH in 2011 when Sydney was three. During this trip, Sydney was diagnosed



with Hyperimmunoglobulin E Syndrome, also known as Job's Syndrome. Common symptoms of Job's Syndrome include bone and tooth defects, eczema, skin abscesses and infection, and repeated sinus and lung infections. Due to Sydney's weakened immune system, she developed a MRSA infection. Sydney spent the next two trips to the NIH in isolation at the Clinical Center so her doctors could treat the infection while also working to strengthen her fragile immune system with antibiotics, antifungal and antiviral medications. Due to these effective medical therapies, Sydney's health is greatly improved today.

From playing on the Playground, to participating in many of the programs and activities offered each day, this active family appreciates that The Inn allows them to be together in a relaxing, kid-friendly, and family-focused environment. Nicole and Sekou also enjoy the opportunity to create friendships with families from all over the world.

When Sydney is at home, she enjoys helping with household chores including cleaning, sweeping the floors, and of course, cooking. She also enjoys riding her bike around the neighborhood with Ethan, playing with her favorite dolls, and "anything girly," according to her parents. Sydney began a new challenge this year—first grade at a brand new school, which should be a fun experience for this social butterfly.



silly time



kayla & cody ruthven

Cody and Kayla Ruthven, siblings from Lexington, Texas live with Niemann-Pick Type C disease (NPC), yet are filled with optimism and a love for life. Whether it's high fiving other residents, or sharing jokes and stories with Children's Inn staff, these two upbeat teenagers leave an unforgettable impression everywhere they go. However, the Ruthven family traveled a long and difficult road before arriving at the NIH.

When Cody was three, Dena and Scott Ruthven took their son to the doctor for a routine check up. After noticing Cody had an enlarged spleen, further testing showed that he had an unidentifiable genetic disease. Doctors weren't sure that any physical manifestations would ever occur due to the diagnosis. "As Cody got older and when Kayla was born, we noticed that they walked a little differently, and even talked a little differently, than other children, but we didn't think anything of it," Dena explains. Nothing came of the diagnosis for several years.

By 2009, both Cody and Kayla were experiencing mobility loss, speech impediments, and learning disabilities and the family needed answers. After two years of searching, the Ruthven's saw an optometrist who was familiar with NPC. Cody and Kayla could not roll their eyes up or down to see, common in NPC patients. The family was sent to a pediatric genetic neurologist at Vanderbilt University Hospital in Nashville, Tennessee.

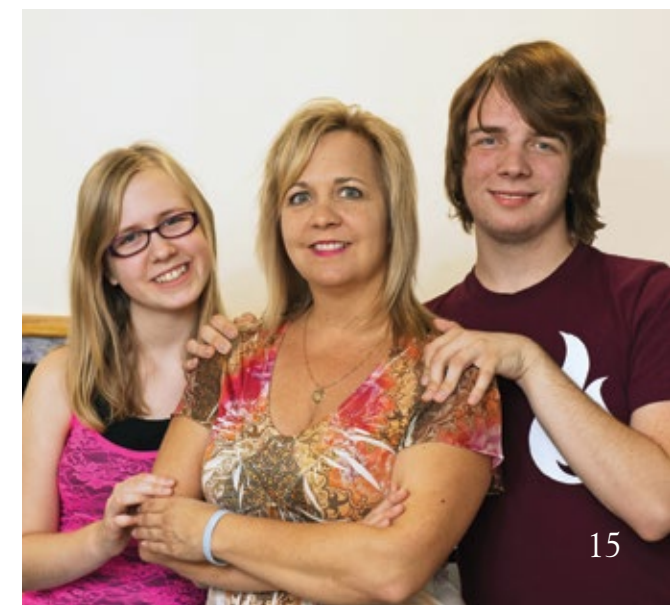
Once Cody and Kayla arrived at Vanderbilt, an extensive medical family history investigation was completed, along with several tests on Cody. On January 28, 2011 Cody was officially diagnosed with NPC and Kayla shortly after. NPC is an extremely rare Neurological Disease that causes progressive deterioration of the

nervous system. Currently there are less than 500 diagnosed cases worldwide and there is no cure.

Cody, now 18, and Kayla, 14, first came to The Children's Inn in January 2014 when they began participating in a clinical trial with a handful of other NPC pediatric patients through the National Institute of Child Health and Human Development (NICHD). Since beginning the trial, Dena and Scott have noticed slow progress in both of their children.

They now stay at The Inn one week each month and have built a sense of community with staff and other residents. The entire family loves The Inn. Kayla can be found painting in the Arts & Crafts Studio and Cody is usually socializing with staff and other teenage residents. Dena and Scott can be found in the kitchen, trying their best to share with and support international families.

"The Children's Inn is our getaway, a place where we are taken care of outside of the medical world. And the NIH, it means hope. We are grateful for both," says Dena. "This is where we are supposed to be."



dinner time



joshua sobers- henry

Last fall, sixteen-year-old Joshua Sobers-Henry was dividing his time between the demands of high school, cooking for his family, and training to be a goalie for the Barbados national soccer team. With such a rigorous schedule, it wasn't a surprise that Josh began taking extra long naps after school. When he started having severe headaches, fatigue, and shortness of breath, he tried to hide his symptoms because he didn't want anything to get in the way of the prospect of making the soccer team. But when the symptoms worsened and his tongue and fingertips turned white, his mother, Carolann, rushed him to the hospital.

After a series of blood tests, doctors told them that Joshua had very little platelets or blood cells. Unfortunately, the hospital in Barbados lacked the equipment to determine the cause of his anemia. Doctors at Queen Elizabeth Hospital sent Joshua's blood cells to the US to be tested, and they soon received a diagnosis of severe aplastic anemia. Aplastic anemia is a rare blood disorder in which the body's bone marrow doesn't make enough new blood cells. Josh was admitted to the hospital in Barbados where he was given daily blood transfusions, which can help relieve the symptoms, but are not a permanent treatment. To have a chance at successfully overcoming the disease, Josh needed to have a stem-cell transplant.

In January of 2014, Josh and Carolann came to the National Institutes of Health for the lengthy transplant process at the National Heart, Lung, and Blood Institute (NHLBI). They kept in touch with Josh's dad, Richard, and brother Ocean, 18, and sister Skye, 12, through Facebook and regular Skype sessions. Josh's family owns a cooking shop at home so they were happy to find a Caribbean market in downtown Washington



so that they could make and share some of their favorite dishes with other families at The Inn. "The Cultural Family Night allowed me to keep a sense of normalcy as an aspiring chef—that's something I'd do in Barbados," says Josh.

After his transplant, Josh needed to stay near the NIH for several months. The family transitioned to The Inn's Woodmont House, which enabled them to have more independence, while still having the opportunity to participate in activities that were offered by The Inn. The family also took a week-long Caribbean cruise this summer, sponsored by the Make-a-Wish Foundation. Josh was excited to have the opportunity to cook in the galley with the ship's chef and receive an official chef's hat and jacket (pictured wearing above.)

Josh and his mom feel that the doctors at the NIH left no questions unanswered. "I don't have to worry. They're helping me, but I'm helping someone else because of the research. It's pretty cool," says Josh.

donors 2013-14

The Children's Inn at NIH is deeply grateful to the generous donors who gave gifts of cash and pledges between July 1, 2013 and June 30, 2014. The following list recognizes cash gifts of \$250 or more, as well as The Innkeeper's Society and our Northern Stars supporters. (The Inn also appreciates the many in-kind gifts and services that we receive throughout the year.) Every effort has been made to ensure the accuracy of our records. Please contact Lucy Merkley at seagraveslf@mail.nih.gov or 301-451-9455 if we need to make a correction.

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TerpSys Ed & Kelly Woods

Rockville-based technology company TerpSys, led by President and CEO Edward Woods, encourages employees to be leaders in the community through the generous giving of time, talent, and treasure. So when a friend of a TerpSys employee stayed at The Children's Inn in the early 2000's while receiving cancer treatment at the National Institutes of

Health, the company wanted to help. TerpSys made a donation to The Inn and started sending groups of employees to volunteer to make dinner for Inn residents. It was the beginning of a new partnership.

"When you get involved with The Inn, you have an overwhelming sense of concern for the kids and their families, since they are going through an incredibly tough time," says Ed. "It means a lot to us as a company to provide a small bit of comfort to their day."

TerpSys serves as a lead sponsor of The Inn's annual Golf INNvitational, and the Woods family generously donates a foursome so that an Inn family can participate each year. "My hope is to give these families a brief respite for the day," he says. "To me, it's the most rewarding thing that I do in support of The Inn."

Ed's wife, Kelly, was so inspired after talking to an Inn volunteer at the golf tournament that she signed up to become a kitchen assistant volunteer, stocking the pantry with food and keeping things organized so that Inn families can prepare their meals easily. "I am amazed at how many people it takes to run The Inn and it takes the entire team to make all of it work. I was looking to be part of a team and that's what I enjoy the most about my experience," says Kelly.

"We've been blessed to be able to support The Inn in many ways," says Ed. "It just shows how special we think The Children's Inn is."



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Estate of Marnet Whittington

The Children's Inn is pleased to announce a generous gift of \$100,000 from the Estate of Marnet Whittington to The Inn's Endowment Fund, which will support in perpetuity an array of programs, services and activities provided for Inn families.

Ms. Whittington, a retired program analyst with the U.S. Department of Agriculture, passed away

on November 21, 2013, in Bethesda. Born in Washington, DC, she was a resident of Kensington and learned about The Inn's good work from her brother, the late Milton "Buddy" Whittington, Jr. and her sister-in-law, Peggy Whittington, both retired NIH employees and long-time supporters of The Inn.

"Marnet would be so pleased to see her gift doing good things for children and families from all around the world," Peggy says. "We often talked about The Inn and how it is such a special place." Peggy and Buddy were early supporters of both The Children's Inn and Special Love, a nonprofit organization that offers camps and other support for children with cancer.

Charitable bequests, like Marnet's, are the simplest and most popular form of estate gift and can provide valuable resources to support The Inn's mission. Donors who make estate commitments to The Inn may join The Innkeeper's Society, a special recognition program for individuals who have notified us that they have made provisions for The Inn through a bequest, life insurance policy or charitable trust.

For more information about The Innkeeper's Society or these types of gifts, please contact Anna Tate, Assistant Director of Major & Planned Gifts, at 301-451-3464 or tateab@mail.nih.gov.

The Inn is deeply grateful to the entire Whittington family for their generous support over so many years.



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Rapp Family

Ray and Dorothy Rapp of Mars Hill, North Carolina are generous supporters of The Children's Inn. Their connection with The Inn began in 2010 when their son, Aaron, was referred to the National Institutes of Health after having mysterious episodes of high fever and debilitating periods of weakness.

"We had taken him to every specialist in North Carolina and the doctors there told us 'it was a head-scratcher,'" says Ray. Aaron had lost a significant amount of weight, could not walk on his own and his parents feared that they were losing him. "It was one of the scariest times in our lives," says Dorothy.

It took several visits to the NIH, and dozens of examinations and tests, but the doctors were finally able to make a diagnosis of Addison's disease, a rare, chronic disorder that occurs when the body produces insufficient amounts of certain hormones produced by the adrenal glands. People with Addison's disease can lead normal lives as long as they take their medication.

The Rapps credit the NIH for saving their son's life and are grateful for the care and support they received at The Children's Inn. "We feel strongly that when we got to the NIH, we encountered angels—the people at The Inn, the team of doctors, the social workers, as well as the security guards, receptionists and bus drivers who were also so very kind... we were embraced and taken care of by some of the most special people on earth," says Ray.

Today Aaron is doing well. He is currently pursuing a Masters degree in Applied Math at Western Carolina University and is planning to pursue a Doctorate degree.

"We were touched so deeply by the brilliant minds and beautiful souls we encountered at NIH and The Inn—there are no words to describe how indebted we are to all of them," says Dorothy.



Meredith Balenske

Meredith Balenske has a busy career as Director of Communications for Revolution, a local venture capital firm founded by AOL cofounder Steve Case, but she still makes time for philanthropic endeavors, especially supporting The Children's Inn. "It is important to me to be involved with an organization where I can see my impact," she says.

"I'm inspired by the amazing amount of support The Inn provides to families who are enduring stressful, painful, and scary situations."

As one of the founding members of The Inn's Young Ambassadors Council (YAC), Meredith is also the founder and chair of A WINNter Affair, an annual fundraising event for young professionals in the DC area, that has raised over \$100,000 for The Inn since its inception in 2012. "When we started A WINNter Affair, I was given the flexibility to build it from scratch," says Meredith, whose role includes finding a venue, caterer, and entertainment, managing a communication and ticket sales strategy, and helping secure corporate sponsors. "It's rewarding and exciting to see hundreds of people enjoying the party, dancing, and raising money for The Inn year after year."

Originally from Annapolis, Maryland, Meredith currently resides in Georgetown in Washington, DC, where she enjoys running, cooking, and playing with her French Bulldog, Dooley. As an active member of the YAC, she works on A WINNter Affair year-round. "The best thing about being three years into the event is working with the partners and sponsors," she says. "Every year we grow together and learn how to make the event better."



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Sarah Cuneo

Initially hired as a Children's Inn welcome desk volunteer for a once a week shift, Sarah Cuneo eagerly increased her hours to three days a week after discovering the need for help in The Inn's three kitchens and food storage area.

It was apparent that our food donation process needed to be re-organized and it was an extremely

time consuming process. Sarah, determined to improve and streamline the process, took charge of the project, coming in for several weeks, sometimes staying for eight hours at a time. "She sees a need and gets things done. She is well loved by her co-volunteers and the staff," says Laura King, Senior Director of Volunteers and Community Outreach.

In addition to her volunteer duties at The Inn, Sarah can be found shuttling her nine-year-old twin daughters, Chelsea and Jenna, around Bethesda or at her vacation home in Deep Creek Lake in Western Maryland. In 2011, Sarah resigned from her position as a healthcare administrator at a same day surgery center to be a stay-at-home-mom. "That was the year The Children's Inn became a part of my life and more importantly, my family's life," she says.

Sarah and her husband, Brian, instill the importance of giving to others in their daughters. For their sixth birthday, the twins had a party and decided to donate their presents to a charity of their choice. Chelsea chose an animal shelter that year and Jenna chose The Inn. "I had always been intrigued by The Inn's mission and saw this as my opportunity to get involved. Since then, my daughters have brought their presents to The Inn and absolutely love it," says Sarah.

Sarah was the youngest of nine children. Her father was a cardiovascular surgeon involved with various NIH protocols and her mother was a lifetime volunteer at the hospital where her father worked and was honored for her years of service and dedication. It's no surprise that Sarah followed in her mother's footsteps, motivated to give back to the community.

"I am amazed that the families have so much strength and wonder if I could ever be as strong as they are. They ask for so little and are grateful for so much. I enjoy being able to answer their questions, provide them with their favorite snack or just listen to their stories," she says.



THE INNKEEPERS SOCIETY Recognition of Planned Gift/Estate Gift Donors

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Heather Mansfield and Charles Lewis, In memory of Norman D. Mansfield
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Maureen and Thomas Patton, In memory of our son, Andrew Thomas Patton
Richard M. Ralston

* Deceased

The Children's Inn at NIH deeply values all contributions, as they help to sustain our mission. To protect the privacy of our donors and their special relationship with The Inn, we maintain the following: We do not trade, sell, or rent our donor lists with other organizations. We offer donors the option to be recognized anonymously. Donors may request to be removed from our solicitation list and/or our mailing list.

For more information, contact Fern Jennifer Stone, *Chief Development & Communications Officer*, at 301-451-9453 or stonefj@mail.nih.gov.

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Editor-in-Chief: Julie Hykes Herman
Contributors: Katelyn Baughan, Dorleen Dove, Dorie Hightower, Julie Ofrecio, Lauren Stabert, Eva M. Starrak, Anna B. Tate, Taylor Watson
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The Children's Inn at NIH

7 West Drive, Bethesda, MD 20814-1509
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Chef Spike Mendelsohn baking pizzas at The Inn.