



A Refreshed Season at The Inn

Your support is helping us better serve our courageous kids and families this summer by refreshing some of the most-used communal spaces at The Inn.

Our lobby is the first stop for travel-weary families who arrive from afar, and serves as every visitor's first impression of The Inn. To better welcome our residents and guests, we undertook a refreshing update of this space and its adjacent living room. Beautiful new sofas and modern armchairs now provide a more comfortable, inviting space for our families to gather and relax. The new tables even have built-in charging stations, so no guest will ever miss an important call or text. We're taking care of the small things so our families can focus on the big ones.

Whether it's 6:00 a.m., noon, or midnight, you're likely to find an Inn resident working out – and de-stressing – in our Exercise Room. We just completed an incredible transformation of this essential and popular amenity for our residents, and, as one parent

INNspirations

SUMMER 2016

The Children's
Inn at NIH

Mission Statement

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

We will:

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

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told us, "it's nothing less than amazing." Made possible by The Philip L. Graham Fund, this beautifully renovated space features the latest cardio and strength-training equipment, and offers residents uplifting thoughts via a wall mural composed of inspirational words like courage, bravery, and perseverance.

Another exciting renovation project currently underway will give The Inn's teens and young adults (more than 800 visit us per year) a much-improved place to "hang out" and seek support from their peers. Designed with input from the teens and young adults themselves, and supported through the kind generosity of The Neall Family Charitable Foundation, The Inn's revamped Teen/Young Adult Lounge will feature new flooring, fun furniture, and interactive media. It's easy to imagine The Inn's coolest residents enjoying this newly-modernized space of their own (no parents or younger siblings allowed!)

On behalf of all our residents who call The Inn home – whether for a day, a month, or more – thank you for your support. Your generosity helps to make childhood possible for kids and young adults who've already lived through more than most, and we are grateful for your gifts, big and small. By providing this one-of-a kind home at no cost to the families participating in pediatric clinical trials at the NIH, you are our partner in hope and the NIH's partner in discovery.



The Inn's newly renovated Exercise Room, complete with an inspiration wall mural.



“...the two of them together make a dynamic duo and have resolved to do whatever it takes to cure this debilitating disease,” says Dr. Richard Childs, of Michelle and Sophia Trujillo.

A Dynamic Duo

After a routine check-up at the doctor, Michelle Trujillo learned that her five-year-old daughter, Sophia, had a dangerously low red blood cell count. Not certain about a diagnosis, she was told to quickly pack her bags and head to the hospital.

Several tests revealed that Sophia had severe aplastic anemia, a rare and serious blood disorder in which the body's bone marrow doesn't make enough new blood cells. Sophia had the worst kind of aplastic anemia, rendering her completely dependent on transfusions to survive, with no immune system to protect her from infections.

Michelle spent months trying to find a match for Sophia to receive a blood and marrow stem cell transplant. Unable to find a relative or unrelated donor who was a tissue match, Sophia and Michelle traveled from their home in Chicago to the National Institutes of Health (NIH) to participate in an experimental protocol. She was treated using a combination of two stem cell sources; mis-matched umbilical cord blood stem cells combined with mis-matched stem cells from her mother.

“Historically, treatment-refractory patients like Sophia would die from their disease,” says Dr. Richard Childs, Sophia's NIH physician and the Clinical Director for the National Heart, Lung, and Blood Institute (NHLBI). “New medical therapies and transplants for aplastic anemia developed by doctors at the NHLBI can now effectively treat and cure the majority of patients. In particular, mismatched transplants are now much safer.”

As a single mom who had to leave her job to take care of her seriously ill child, Michelle still maintains a positive outlook. “It's been challenging to pick-up and leave our life in Chicago, but faith keeps me going,” she says. The two have stayed at The Inn for nine months. “I had to let go of my natural urge to be in control. You cannot plan when your child has a rare disease.”

Sophia, now seven, enjoys all of the friends she has made at The Inn, playing with Zilly the therapy dog, and going on fun field trips. “The Inn is our home and the staff has become like family,” says Michelle. “We wouldn't be here if it weren't for The Inn.”

NCATS Director Shares Latest Advances

On June 9, members of our newly launched Leadership Circle came together at the home of gracious hosts, Lois and Les Alperstein, to celebrate another year of generous and compassionate support of The Inn and to learn about the most recent advances in translational science at the National Institutes of Health (NIH).

Throughout the evening, guests connected with one another over their shared passion for The Inn and mutual interest in the leading-edge research currently happening at the NIH. Special thanks to Dr. Christopher Austin, Director of the National Center for Advancing Translational Science (NCATS), who shared new advances in translational science and explained how The Inn impacts his work. But it was Aaron Waddle, proud father of Inn resident Iley, 8, who was the highlight of the evening with an emotional speech about what staying at The Inn has meant to his entire family.

The Leadership Circle recognizes a community of donors who work tirelessly to make sure childhood is possible for every courageous child that walks through our doors. This special night acknowledged and connected them to the families we serve and the clinicians who are making a profound difference in childhood illness.



Inn resident Iley Waddle, from Tennessee, surrounded by her grandparents, parents and older sister.



Inn resident Connor O'Brien (front right) was the featured speaker at the 3rd Annual *An Evening for Hope* gala. Connor is pictured above with brother Cayden, mom Tammy, and dad Mike.

A Record-breaking "Evening for Hope"

On May 7, Inn supporters gathered for the 3rd Annual *An Evening for Hope* gala at The Ritz-Carlton in Tysons Corner, Virginia. The event, which sold out for the first time ever, brought together close to 800 guests from the federal information technology and health industry community for an evening filled with food, wine, silent and live auctions, and ample entertainment, all to benefit The Children's Inn at NIH. Jeff "Skunk" Baxter, featured guitarist of Steely Dan and The Doobie Brothers, kicked off the night with a rocking rendition of The Star Spangled Banner, followed by 13-year-old Inn resident and aspiring "spy" Connor O'Brien, who gave guests a comedic and enlightening account of his time at The Inn. Despite his lifelong hospital visits, multiple brain surgeries and ongoing treatments, Connor has a positive outlook on life and an amazing sense of humor. He finds time to play the piano, study Latin and take care of his dog, Kali, a loyal Bull Mastiff. He's also a big fan of The Inn's therapy dog Zilly. Guests heard from master of ceremonies Fox News correspondent James Rosen and NIH Director Dr. Francis Collins. The night was capped off by a performance from the political satirist group The Capitol Steps. At the end of the evening, event chair Todd Pantezzi, Senior Vice President, ICF International, announced a record-breaking net fundraising total of \$892,500, which will be used to help The Children's Inn continue to take care of the little things so families can focus on the big ones. Special thanks to our top-tier event sponsors: Hewlett Packard Enterprise, Lockheed Martin, Booz Allen Hamilton, CSRA, Deloitte, ASMR/Accenture, EagleBank Foundation, Amazon Web Services, Walgreens, ICF International, Unissant, immixGroup, Sapient Government Services, and PwC.

Golfing on Par for The Children's Inn

The 9th Annual Golf INNvitational was held on June 6 at Lakewood Country Club in Rockville, MD. It was a picturesque day for the more than 100 golfers who participated in The Inn's annual tournament. Since its inception, the INNvitational has raised more than \$1 million to support The Inn's mission and support programs. The honorary guests for the evening were Inn resident Dillon Papier and his mom, Darrile, and dad, Mark. During the dinner reception, Mark shared his family's personal story of staying at The Inn while finding a treatment for Dillon's rare disease, Neimann-Pick type C. The Inn expresses its gratitude to Platinum Sponsor Booz Allen Hamilton and Gold Sponsor TerpSys. Save the date for the hallmark 10th Annual Golf INNvitational: Monday, June 4, 2017 at Lakewood Country Club.

In addition to the INNvitational, several local golf outings this spring also benefited The Inn. On April 25, Passion Food Hospitality hosted the ComPassion Golf Tournament at Reston National Golf Course in Reston, VA, which benefited The Inn for the sixth year in a row. On May 13, GovPlace hosted the 8th Annual Federal IT Golf Tournament at Westfields Golf Club in Clifton, VA. And while they didn't play golf, employees at ProShares have found an equally fun way to support the children and families of The Inn by hosting their annual Casino Night, for the seventh year in a row, on May 11. The Children's Inn is proud to be partners with these local companies and expresses its utmost gratitude for their continued support.



TerpSys, led by President Ed Woods, generously sponsored a foursome at the 9th Annual Golf INNvitational for the family of Inn resident Dillon Papier. Pictured above: Joel Papier (far left), Mark Papier (far right) and fellow golfers and Inn supporters, Trillium & Ben Rose (center).



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The Children's Inn at NIH

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There are many ways to support The Children's Inn, such as food drives and the Thoughtful Treasures mailbox 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."

Follow us on:

Be a Part of our Team at the Marine Corps Marathon and 10K

For the second year in a row, The Children's Inn is a charity partner for the Marine Corps Marathon and 10K. Supporters can run on behalf of The Inn to raise funds and awareness through the marathon or 10K race, which will be held on Sunday, October 30 in Washington, DC. In its inaugural year, more than 50 runners joined The Inn's team, including CEO Jennie Lucca, board members, staff, and NIH supporters. Their combined efforts raised nearly \$70,000 to support The Inn's mission and programs.

The Inn hopes to double the number of runners this year with 50 slots each for the marathon and the 10K race available. With a certified running coach on board to support the runners' training, The Children's Inn race team is a unique opportunity to foster a community of Inn ambassadors, garner awareness and encourage fundraising. Whether you are a beginner or veteran runner, the flat race course for both the marathon and 10K make it an attainable running feat for anyone with an interest.

Registration is still available. For complete details, visit the event website at www.childrensinn.org/marinecorps. Contact Julie Ofrecio at juliemae.ofrecio@nih.gov or 301-594-1625 with any questions.

