



Easing Burdens for Inn Families Making Experiences More Meaningful

At The Children's Inn, we constantly strive to find new ways to make families' stays with us even more meaningful through family programming and other supportive services in an effort to provide the best possible "Place Like Home." Long-time Inn supporter Booz Allen Hamilton recently partnered with us on this initiative and offered their expertise in researching and analyzing families' experiences and wishes, and devising a tailored solution - all on a pro-bono basis for The Inn.

Booz Allen's design thinking approach began with a detailed qualitative research phase during which the company's staff interviewed residents, volunteers and staff. Analysis of the collected data showed families wanted clear, concise and simple communication from The Inn prior to their first visit, among other things.



The **Children's
Inn** at NIH

SPRING 2017

INNspirations

Mission Statement

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 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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Until now, The Inn has been sending a robust welcome packet to every family two weeks prior to their first stay with us. But feedback from Booz Allen showed families often didn't have time to go through the welcome pack. As an alternative, Booz Allen suggested devising a mobile-friendly website that includes a condensed version of the welcome pack. We're excited to bring this new tool to our families this summer.

Here's what it will entail:

Trip planning: Information on what to pack, how to

check in, how to get to The Inn and where to park;

Info and services: Inn rules, services and family pro-

gramming; Life at The Inn: Meals and shopping, fitness and activities, NIH shuttle and Metro information;

Getting around: What's where at The Inn and the NIH, information on local stores, local buses and Metro, NIH shuttles and taxis, exploring the capital and surrounding areas;

Chat bot: Families can ask questions about The Inn and get detailed answers from an avatar version of our therapy dog Zilly.

"We're so grateful to Booz Allen for their initiative and generosity in lending us their team and expertise to help the more than 1,500 families and children we serve every year have even more meaningful experiences at The Inn," says Jennie Lucca, Inn CEO. "We very much look forward to the release of the digital welcome site, and we think our families will love using it!" ★



Hi! I'm Zilly, The Inn's therapy dog. How may I assist you?



INNspirational PEOPLE



Inn resident Chris Petty spoke at the 2017 NIH Rare Disease Day and brought the audience of researchers and patient advocates to laughter and tears.

Inn Resident Receives Standing Ovation

Chris Petty, 26, from Mesa, Arizona, has stayed at The Inn more than 30 times and spent several months inpatient at the NIH Clinical Center. He recently told his personal story battling a rare illness at the 2017 NIH Rare Disease Day.

Toward the end of his senior year of high school, Chris started getting headaches and began passing out. An MRI revealed a quarter-size mass in his brain, which turned out to be a nocardia bacterial infection. Chris had brain surgery and received steroids and antibiotics to fight the infection. But the abscess returned. Stumped why a healthy young man would get an illness that normally affects people with immunodeficiency, he was referred to the NIH's National Institute of Allergy and Infectious Diseases for evaluation and further treatment.

At the NIH, doctors discovered what looked like additional infection on his spine, but surgery revealed it was inflammation, most of which could not be removed. Chris now is battling what doctors think is a rare reaction of his immune system, causing inflammation in his spine. The inflammation has periodically robbed him of sensation in his legs and lower body, confining him to a wheelchair. During Rare Disease Day, Chris shared his story and also shared ten things that are helping him cope, including: books and the caring NIH librarians, good food, family dinners and activities at The Inn, the support of family and friends, humor, kindness and people who care, knowing other people have tougher illnesses but keep a great attitude anyway, and the support of Inn staff. Chris received a well-deserved standing ovation for his speech. ★

The Critical Importance of "A Place Like Home"

Sarah Allen and Tim Powderly of Arlington, Virginia, know all too well the stress and anxiety of having an ill child. Their son Evan, 7, was born with a rare eye condition called a coloboma, in which the eye's structure is incomplete. A coloboma often causes blindness at birth and can be linked to other serious syndromes. After the diagnosis, Sarah and Tim were surprised to discover that there was little information to be found.

They eventually learned about the work of Brian P. Brooks, MD, PhD, Chief of the Unit of Genetic and Developmental Eye Disease at the National Eye Institute. "We were thrilled to learn that the world's leading, and pretty much only, coloboma expert was just up the street from us at the NIH," Sarah says.

At 18 months old, Evan spent two days at the NIH participating in a genetic study. Sarah and Tim were impressed with the care and support they received from Dr. Brooks and his team. They feel fortunate that today Evan's vision is largely fine and he suffers no related syndrome.

Sarah and Tim realize the critical importance of "A Place Like Home" for families going through difficult times. Although they never stayed at The Inn, Sarah says, "We support The Inn because our hearts break for the families that come [to the NIH] with really sick children seeking both care and answers. We also support The Inn because it's so important to our family that people from all over the world [can come to the NIH] to participate in Dr. Brooks' coloboma study, so that Evan's children might have a higher probability of not being born visually impaired." ★



The Children's Inn is deeply grateful to Sarah Allen and Tim Powderly, parents of Evan pictured above, for their annual support. We welcome them as new members of the Leadership Circle, a recognition program for individual donors who make gifts of \$1,000 or more annually.



The newly renovated Breakfast Bistro provides families not only the food they need to fuel their day, but the companionship that feeds their souls.

Newly Renovated Breakfast Bistro Fueling the Day and Feeding the Soul

Mornings at The Children's Inn start early for families. With medical appointments as early as 7:00 a.m., some residents are on their way to the Clinical Center before the sun rises. To help make mornings less hectic, The Inn offers a variety of healthy breakfast foods and beverages in our Breakfast Bistro, a comfortable, sunlit community space where families fuel up for the day. Bagels, muffins, yogurt, fruit and other snacks are available, along with plenty of coffee, tea, milk and juice.

Thanks to the generosity of donors Tom and Kathleen Fingleton and others, the Bistro was recently renovated. New dining tables and chairs, sofas, and new flooring, wall units, and light fixtures have transformed the Bistro into an inviting, comfortable space, staffed every morning by volunteers who arrive early to ensure it's fully stocked.

On a recent morning, four children—strangers before their visit to The Inn—were making fast friends over breakfast. One girl described the fun “treasure” she had found in her mailbox that morning. One boy started an informal poll—who brushed their teeth this morning?—while another young girl's compassion shined as she reassured another child, “the bloodwork isn't that bad.”

Parents and caregivers make connections over meals here too: they compare clinic visits, discuss travel plans, and exchange contact information. Even families who don't have time to linger appreciate the Bistro, where they can fill a backpack with items “to go.” Every family who walks through our doors faces unimaginable challenges and The Inn strives to support them in every way possible. ★



The Children's Inn 2016-2017
Young Ambassadors Council

A WINNter Affair Wonderland 6th Annual Junior Gala Raises More Than \$100,000

For the second year in a row, The Children's Inn Young Ambassadors Council (YAC) hosted a sold out A WINNter Affair at the Pavilion at the Ronald Reagan Building. Over 400 young professionals from the Corporate, IT, non-profit and government sectors donned cocktail attire to support the more than 1,300 programs and services The Inn offers each year. Guests enjoyed heavy hors d'oeuvres, open bar, silent-auction, and dancing. The Inn would like to thank Trade Center Management Associates (TCMA) for sponsoring the venue and catering for the past three years for this event.

A WINNter Affair is the YAC's perennial event, led by a volunteer council of young professionals in hopes of cultivating a new generation of Inn supporters. This year's event co-chairs, brothers Mike and Zach Dendas, whose cousin was a former Inn resident who sadly passed away from her illness, spearheaded the planning alongside the 13-person council through corporate and donor outreach, logistics planning, and ticket sales.

The Inn would like to extend its gratitude to this years sponsors: Palladian Partners, PwC, EagleBank, The Home Depot, TCMA, Booz Allen Hamilton, CSRA, Generations Visa Service, Asymmetrik, DPR Construction, The Lyle Family, The Shelk Fischer Family Foundation, and Cvent. In addition to A WINNter Affair, the council hosts a number of external events to foster awareness and raise funds on behalf of The Inn. For more information about the council, visit www.childrensinn.org/youngambassadors. ★

Are you or someone you know a runner? Join The Children's Inn Marine Corps Marathon #RunINN4Kids team today! Visit www.childrensinn.org for details.



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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 home.

Follow us on: 

Rocking and Rolling for the Children Steven Van Zandt Supports Inn Families

The evening of March 18, 2017 was a night like no other! The Rock and Roll for Children Foundation (RRFC) once again brought together avid music lovers in support of The Children's Inn and it was a concert for the ages.

Held at The Filmore in downtown Silver Spring, Maryland, guests were treated to music by legendary performers from some of the greatest bands in history. It was thrilling to see Little Steven and the Disciples of Soul, featuring GRAMMY award winner Steven Van Zandt, the Rock and Roll for Children All Star Band, and The Peacemakers up close and personal. Throughout the night, guests also competed for one-of-a-kind experiences, jewelry, and signed memorabilia during the silent and live auctions. RRFC's hard work, time, and commitment to the event paid off and it's the families at The Inn who will benefit from their generosity.

RRFC is an all volunteer-led organization that is devoted to raising money to improve the lives of critically ill children and their families. Created by Jon Belinkie, the foundation has raised more than \$500,000 for charity since its inception. The Inn is grateful for the generosity of RRFC—they truly have become our rock stars! ★



Little Steven and the Disciples of Soul, featuring Steven Van Zandt, was the headliner for the Rock and Roll for Children Foundations' annual concert to benefit The Inn.