



The Inn Makes Learning Fun

Homework assignments for a child who's just finished a long day of medical treatments might be overwhelming. But, offer entertaining, interactive educational sessions and you'll discover The Inn's secret for making learning fun and appealing for its residents. Of the more than 1,500 seriously-ill children who visit The Inn each year, 1,000 of them are school-age and miss many days of school when at the NIH for treatment. The Inn's Education and Instructional Support Program is critical to helping these children stay on track with their school projects while they're away from home. We even assist siblings and help international residents brush up on their English.

During the school year, we keep kids' skills sharp in a variety of ways. At Study4Fun, The Inn's Education Coordinator offers homework help and tutoring in a wide variety of subjects. Each year we provide over 300 hours of tutoring, ensuring residents get the individualized assistance they need. For our ExploreINN program, students enrolled in the



The **Children's
Inn** at NIH

FALL 2016

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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NIH's Post-Bac program (college graduates gaining research experience in NIH labs) lead entertaining hands-on experiments with residents, bringing to life a host of STEM topics like chemistry and engineering.

Our AdventureINN program takes residents and families off-campus for interactive learning. Destinations for The Inn's educational field trips have included DC monuments, the National Zoo, and many museums. Thanks to our partnership with NASA, a recent trip to the NASA Goddard Visitor Center allowed participants to get some hands-on robotics experience and learn about space missions, magnetic fields and the ozone layer.

The learning continues June-August at CampINNcredible, The Inn's daily "summer camp." Many of our residents have never attended a traditional camp, so they enjoy the mix of theme-based activities and off-site field trips led by volunteer counselors and staff.

Seriously-ill children often can't participate in the enriching opportunities enjoyed by their healthy peers. To address this need, we introduced an INNrichment Fund this summer. This application-based "scholarship" enables residents to apply for funding for activities that support their recovery and enrich their lives, but which their family might not be able to afford. We recently awarded five worthy applicants, supporting therapeutic horseback riding, art classes, and college tuition.

The generous support of our donors and friends enables our Education Program to make a big impact on a child's daily life at The Inn and their return back home.



Inn resident Jordan from South Africa enjoying his time at the Goddard Visitor Center, an AdventureINN program.



Reem can be found having fun in almost every corner of The Inn!

Finding Comfort Half a World From Home

A bright green flash whizzes by one of the activity rooms at The Children's Inn. If you look quickly, you'll catch beautiful dark brown curls flowing from 7-year-old Reem. She's a friendly and active girl who darts in and out of doors looking for fun and someone to play with.

It is hard to believe that this young and energetic child has a very serious disease: severe aplastic anemia. Decades ago, before current medical advances made possible by research, this diagnosis was ominous, with a low survival rate.

Today, according to Dr. Neal Young, an NIH scientist who pioneered treatment of aplastic anemia and is Reem's NIH physician, a large majority of people with this disorder do fine with immunosuppression, which is standard treatment.

At the NIH, Reem is participating in a clinical trial at the National Heart, Lung, and Blood Institute that combines immunosuppression with a drug that stimulates stem cells in her bone marrow to re-grow themselves and also make red cells, white cells, and platelets. The goal is to no longer need transfusions and not be susceptible to infection.

In July 2016, Reem and her mother Noura traveled from Cairo, Egypt, to obtain the experimental therapy, which is unavailable in her home country. It is the first US visit for both, and they will stay until early 2017.

Reem, an outdoorsy child, loves The Inn's garden, Zilly the therapy dog, and outings to nearby attractions like the National Zoo and Nationals baseball games. Being with a very active Reem all day, every day can be tiring for Noura, but The Inn's many programs and services keep Reem engaged. Noura is ever grateful for The Inn's staff and volunteers who look after their well-being. "I have trust in her doctors here and a lot of hope. The Inn is such a caring place," she says.



Become a member of The Innkeepers Society and make a difference for the thousands of children and families who need The Inn during some of the most difficult times of their lives.

Creating Your Legacy

Over the years, The Children's Inn has received significant resources from generous individuals who decided to make a legacy gift by bequest to support our mission of providing "A Place Like Home" for seriously ill children and their families who have come to the NIH seeking a diagnosis, treatment or a cure.

Many of these donors told us that they made their bequests to The Inn because they wanted to know that their legacy would help others and ensure that Inn children and families would always have the support they need during a difficult time in their lives. These donors range from long-time annual donors to first time donors who make their first, and perhaps only, gift to The Inn through a bequest.

If you are thinking about your legacy and considering a gift to The Inn through your estate plan, or would like more information about The Innkeepers Society, please contact Anna B. Tate, Assistant Director of Leadership and Legacy Giving, at 301-451-3464 or tateab@mail.nih.gov.

The Innkeepers Society honors those visionary donors who have included The Children's Inn in their wills or estate plans. The Society's goal is to help fulfill The Inn's mission of providing "A Place Like Home" for the more than 1,500 seriously ill children and their families who stay at The Inn each year.



ICF Senior Vice President Todd Pantezzi

ICF: Important Partners with The Inn

ICF is one of the top contractors at the National Institutes of Health (NIH), providing scientific management, biomedical information, communications, and information technology services. ICF supports programs such as Smokefree.gov and Cancer.gov for the National Cancer Institute, AIDSinfo for the National Library of Medicine, and the National Eye Health and Education Program for the National Eye Institute. Supporting The Children's Inn for more than 10 years, ICF understands the essential role that The Inn plays as a partner in research and discovery with the NIH. ICF's commitment is reinforced when the company's many volunteers come to The Inn to host family dinners.

The ICF team who works closely with The Inn includes Senior Vice President Todd Pantezzi, who is chairing The Inn's annual *An Evening for Hope* gala for the second year. With Todd's leadership, the gala committee aspires to set a new record in 2017 by raising more than \$1,000,000 to support The Inn.

"Chairing *An Evening for Hope* is important to me on the most personal of levels. Having lost a son to cancer, and enduring a similar journey as the children and families who count on The Inn, the gala enables me to honor his memory while contributing to the advancement of biomedical research that benefits all children and adults," says Todd. "The Inn's existence enables the scientists to attract more patients to participate in the NIH's research, leading to treatments that eventually become available to all. ICF stands behind this commitment by supporting my time and efforts as chair of the gala, and our people show their commitment by volunteering their time and effort at The Inn."

Inn Board Welcomes Scott Vogel

If there's anyone who truly understands the value of The Inn, it's incoming board member Scott Vogel. Scott first visited the NIH at just six months old, when his family learned he had a rare immune deficiency known as Chronic Granulomatous Disease (CGD). At age eight, he contracted a life-threatening fungal pneumonia that stumped his New York doctors. Not until his father, Bob, discharged him from the hospital, rented oxygen tanks and drove him to the NIH, did he finally recover from the infection. According to Bob, that visit—Scott's first long-term stay at The Inn—saved his life.

With more than 260 nights at The Inn under his belt, Scott brings a unique perspective to the board. He has stayed at The Inn every year since 1990, once for nearly four months, and has grown up along with The Inn. As a teen, Scott spoke at the ribbon-cutting for our 2004 expansion, and in 2015 was a featured speaker at our 25th Anniversary Hope Gala.

Scott is in the process of becoming the proprietor of a restaurant and piano bar in Maine called The Front Porch. He formerly was a sales director for PatientPop Inc., an Athena backed marketing software solution for healthcare providers. He also brings three years' experience managing ticket sales for the Maine Red Claws, a Boston Celtics affiliate in the NBA Development League. Scott earned his bachelor's degree from the University of Southern Maine and formerly volunteered for The Maine Children's Cancer Program. In his free time, he likes to play hockey and go kayaking, stand-up paddle boarding, and sailing. Scott continues a Vogel family tradition, as his father Bob served on our board from 2005-2016. Welcome, Scott!



"Whether I've seen them a hundred times or for the first time, it's family," says new Board Member, Scott Vogel, of the long-term relationships he's developed at The Inn.

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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:



Children's Inn residents with Nationals mascot Screech.

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An Unforgettable Night at the Ball Park

This year marks the fifth year that Washington Area Toyota Dealers have supported The Children's Inn through their K's for Kids Program. The program is very near and dear to our hearts because Inn families who come to the National Institutes of Health (NIH) to participate in research from all over the world are able to experience, sometimes for the first time, a trip to Nationals Park to watch a baseball game.

Families don't just get to watch the game—they get the VIP treatment. On September 29, Inn families were invited to attend batting practice, meet Nationals star pitcher Stephen Strasburg, go onto the field before the game for the starting lineup, and Inn resident Janelle was chosen to throw the first pitch.

For children and families who don't know what tomorrow will bring, this VIP experience is one that they cherish. "Dillon looks forward to this event every year. He's a huge Nationals fan and, for one night, he's able to forget about all the tests, treatments, and complications that come with his disease. Dillon gets such joy from this event as baseball is the best medicine for him," says Daryl Papier, Dillion's mom.

For every strikeout during the season, Washington Area Toyota Dealers donated \$37 to The Inn. This year, they presented a check for \$50,000 to The Inn. "The K's for Kids program is the perfect opportunity to give back. Toyota strives to be a positive influence and part of the fabric of the Washington community. We were very delighted to continue our relationship with The Children's Inn at NIH this season," says Mark Shwetz of the Washington Area Toyota Dealers.

Thanks to this generous donation, The Inn will continue providing free lodging and support services to families journeying into the unknown—pioneers whose participation in medical trials at the NIH can change the story for children around the world.