



The Healing Power of Research

No parent ever wants to hear the words, “your child has cancer.” However, today the majority of children with cancer are cured. In fact, in the last 50 years, the overall survival rate for children’s cancer has increased from 10% to almost 90%. And not only are today’s modern medicines more effective, they have fewer side effects, too.

For decades, children and adults have traveled to the NIH Clinical Center in Bethesda, Maryland, to volunteer for clinical research studies. Patients who come to the Clinical Center have a wide range of diseases, including cancer, genetic disorders, and autoimmune conditions.

“When patients first come here, they are often seeing a world expert in their disease and have had frustrating experiences with repeatedly seeing doctors who have never heard of their disease,” says physician scientist Dr. Deborah Merke, Chief of Pediatric Services at the NIH Clinical Center.



The **Children's
Inn** at NIH

SPRING 2018

INNspirations

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 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

Published by:
The Children’s Inn at NIH

Chief Executive Officer: Jennie Lucca

Editor in Chief:
Lindsey Perreault, *Development and Communications Coordinator*

Contributors:
Abby Case, Allison Davis, P. Jennifer Forester, Meredith Keller, Sonja Luecke

But for many, NIH is a long way from home, and so The Children’s Inn is an important part of this winning team. The Inn provides a safe, comforting, and fun environment for children and their parents who have a lot to worry about. Staying at The Inn can melt away those worries and also supply love and support from other families facing the same challenges.

“Children really enjoy staying at The Inn,” says Merke. “It is a wonderful place to relax after a stressful day seeing doctors, having studies done, and receiving medical treatment.”

Yet, treatments don’t work in everyone, and that is why continued research is a must. Inn residents include kids with cancer whose treatment stopped working, and doctors are looking for new options. Some children have immune diseases so rare they affect only a few people in the world. NIH scientists can custom-design treatments based on cutting-edge molecular approaches like genome sequencing.

Every day, children and their families from all over the world are partners in hope with NIH and The Children’s Inn to solve mysteries about what makes us sick and help all people live happy, healthy lives. ★



The Children’s Inn supports families enrolled in pediatric clinical trials at NIH.



INNspirational PEOPLE



Tej Neaz Powell, 20, a student at Virginia Commonwealth University, received life-saving treatment for sickle cell anemia at the NIH and spent several months at The Children's Inn. He is pictured here with Inn resident, Sashay.



Inn families met Members of Congress at the 29th annual congressional reception.

Inn Resident Shares What It's Like To Live With Sickle Cell Anemia

I didn't really realize I was different from other people until I had one of my many pain crises in middle school. The immense pain and the realization that nobody else understood what I was going through made my disease sink in.

Sickle cell anemia is a hereditary disease that causes misshapen red blood cells that clog easily, cutting off the oxygen supply to vital organs, which is not only excruciatingly and unimaginably painful but also can be fatal.

I was diagnosed at birth. As a young child, my disease wasn't nearly as debilitating. But as I grew, I began experiencing pain after physical activity, and I couldn't do things other kids took for granted.

My first year of college, I was told I needed a bone marrow transplant to survive. Luckily, my younger brother was a perfect donor match for me, and the NIH accepted me into a clinical trial for sickle cell patients with donors.

In summer of 2017, I received my transplant, and although I had been terrified of this invasive procedure, I was lucky and tolerated it well. My family and I spent several months at The Children's Inn during my recovery. I met wonderful children and young people there who were battling rare diseases and were going through experiences similar to mine.

I am grateful to my closest friends and family, the NIH, The Children's Inn and its supporters for being there for me. My goal is to become a doctor. I hope that one day, I will be able to help children going through similar experiences to mine. ★

Inn Celebrates 29 Years of Bipartisan Support

The Children's Inn at NIH held its 2018 congressional reception in January to celebrate 29 years of bipartisan support for the organization alongside 20 lawmakers and senior staff from both parties, NIH leaders and scientists, and corporate executives.

"This was a truly wonderful event that united a core group of bipartisan supporters who are crucial to helping advance medical science at the NIH and supporting the brave children and families who enter clinical trials to help bring about medical advancements that benefit all of mankind," said Jennie Lucca, CEO.

"When it comes to the NIH, people put partisanship aside," said Senator Chris Van Hollen, D-Md.

On behalf of The Children's Inn, Inn Trustee and Congresswoman Debbie Dingell, D-Mich., and Inn resident Avery Ponzar, 9, of Missouri presented The Inn's champion award to Congresswoman Doris Matsui, D-Calif., for her tireless support of The Inn and for attending every single one of The Inn's congressional events.

NPR political commentator and Children's Inn board member Cokie Roberts served as mistress of ceremonies. The event was co-chaired by Senator Roy Blunt, R-Mo.; Senator Chris Van Hollen, D-Md.; Congressman Tom Cole, R-Okla., who could not attend the event; and Congresswoman Debbie Dingell, D-Mich. NIH Director Dr. Francis Collins and his wife, Diane Baker, a member of The Inn's board of directors, also spoke at the event.

"Days are long in the clinical center, there are tests that have to be done, painful procedures that your children may have to go through, and parents desperately hope for an oasis in the middle of all this. And that's what the Children's Inn is," said Dr. Collins. ★



Caregivers from Massachusetts, the Dominican Republic, and Honduras enjoy dinner together at Caregiver Night INN, The Children's Inn's newest program.

Supporting Caregivers In New Ways

The Children's Inn recently held its second Caregiver Night INN program. At this quarterly event, caregivers get the chance to enjoy some much-needed respite. While Inn staff and volunteers keep their children entertained with fun activities, caregivers enjoy a relaxing evening filled with therapeutic activities tailored just for them.

In January, parents and caregivers were joined by Inn volunteers and staff for an appetizer cooking class and virtual reality activity. Dinner was provided and served by volunteers from Booz Allen Hamilton. Afterwards, caregivers enjoyed a "Terrarium and Sip" activity where they crafted edible succulents out of chocolate, fondant, and other food while they sipped coffee or tea and enjoyed dessert.

Javin Smith, education program manager at The Inn, said, "For parents and caregivers that spend most of their time concerned about the needs of their children, this 'night in' event was a way that the Inn could celebrate the caregivers, so they could participate in activities and a dinner created especially for them."

While the caregivers enjoyed a night together, their children were busy with a cooking project, art activities, and a scavenger hunt. Activities were led by Booz Allen volunteers, who also provided a pizza dinner and dessert. An activity by the Mad Science group rounded out the evening, including scientific demonstrations and a glow in the dark slime activity. We look forward to hosting the next Caregiver Night INN this summer. ★

Teen Ambassador Raises \$525 For The Inn

Samantha Cohen, a seventh grader at Tilden Middle School in Rockville, Maryland, recently raised \$525 for The Inn by selling old-fashioned gourmet lollipops.

Samantha learned about The Inn years ago from her parents, Debra and Anton Cohen, who have been Inn donors for several years. Her father also serves on The Inn's finance committee. As a seventh grader, Samantha joined The Inn's Teen Ambassador Program, a group of middle and high school students who support the mission of The Children's Inn through volunteering, fundraising and serving as junior board members, and was inspired to launch her own fundraiser to benefit Inn residents.

Samantha started selling See's Candies by going door to door in her neighborhood, and sold a good number at a local elementary school picnic. Even though her dad offered to help with her fundraiser, Samantha was adamant about completing it on her own.

Meghan Arbegast, community outreach and volunteer program coordinator at The Inn, was impressed with Samantha's initiative.

"Middle and high schoolers are so busy with their studies and extracurricular activities, yet teens like Samantha are still dedicating time to help others and learn about nonprofit fundraising," Arbegast said. "She exemplifies the passion and skills we try to instill in young people through our Teen Ambassadors Program, and we're very grateful to her and her family for all they do for The Inn year after year."

The Cohen family recently returned to The Inn to volunteer at The Inn's holiday gift shop, organizing gifts for kids to pick out for their family members. Samantha also organized a winter coat drive at her former elementary school and volunteered on the Martin Luther King, Jr. Day of Service at the Bethesda Marriott with other Teen Ambassadors. ★



Teen Ambassador Samantha Cohen sold lollipops to raise more than \$500 for The Children's Inn.

Are you or someone you know a runner? Join Team #RunINN4Kids for the Marine Corps Marathon & 10K! For additional details, visit www.childrensinn.org/marinecorps



Board of Directors

Timothy J. Atkin, *Chair*
Beth Maloney, *Vice Chair*
Cokie Roberts, *Secretary*
Matt Bell, PhD, *Treasurer*

Lois Alperstein
Diane Baker
Robert J. Filippone, PhD
Christine Grady, MSN, PhD
Neal Katyal, JD
Brian Kelly
Jill Olmstead
Susan Penfield
Kristine Ribas
Ryan A. Riel
Constantine Stratakis, MD
Porter Shifflett
Scott Vogel
Daniel L. Weaver, CPA
Kelvin K. Womack

Jennie Lucca, *Chief Executive Officer*

The Children's Inn at NIH

7 West Drive
Bethesda, Maryland 20814-1509
301-496-5672 phone
www.childrensinn.org

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: 

Rock and Roll Concert Benefits The Inn

The Rock and Roll for Children Foundation (RRFC) planned another successful fundraising event that raised \$50,000 for The Inn! On March 17, 2018, music lovers of all ages came together to "rock out" at The Fillmore in downtown Silver Spring, MD to once again support children battling life-threatening illnesses at the NIH.

The concert was headlined by double platinum award-winning singer Ann Wilson of Heart and her performance featured songs from throughout her career and incredible covers of rock classics. Not only were guests treated to an amazing night of music, but they were also able to bid on live and silent auction items that included musical memorabilia autographed by Bruce Springsteen, Eric Clapton, Paul McCartney, Billy Joel, Bob Dylan, The Rolling Stones, Taylor Swift, and more.

RRFC has another annual tradition. Every year, the Friday before their main stage concert, RRFC brings in artists to play a private concert at The Inn. This year it was such a treat to have award-winning artist and composer Snuffy Walden and singer/songwriter Sara Niemietz perform for the entire staff and families.

RRFC is an all-volunteer lead organization that is devoted to raising money to improve the lives of critically ill children and their families. Their efforts have raised over \$200,000 for The Inn and we think they rock! 



Ann Wilson, former frontwoman of Heart, was the headliner for the Rock and Roll for Children Foundation's annual concert to benefit The Inn.