



# With Your Help, The Inn's Main Wing and Common Areas Reopen

**A**fter eight months of closure, The Children's Inn's original building is finally back open. Thanks to you, children and families didn't miss out on activities, comfort or nutritious meals during this difficult time.

The Inn's main wing was forced to close in August 2018 after sustaining roof damage during ongoing renovation efforts. In mid-March 2019, the first families moved back into the original building. Inn staff, including Zilly, The Inn's therapy dog, have also returned to their permanent office spaces. Zilly is so happy to finally be back in her usual area behind the reception desk, where her bed, food bowls and toys make her feel right at home.



The **Children's Inn** at NIH

SPRING 2019

# INNspirations

## Support The Children's Inn

As we continue our mission to fully and consistently meet the needs of children and families participating in groundbreaking research at the National Institutes of Health, we ask for your support.

Your donation will:

- Contribute to the 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

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Chief Executive Officer: Jennie Lucca

Editor in Chief:  
Sonja Luecke, communications manager

Contributors:  
P. Jennifer Forester, Sonja Luecke, Bethany Cox, Fern Stone, Mysba Regis

Since the reopening, children have happily reclaimed The Inn's popular game room, mailboxes, breakfast bistro, education center and other communal areas. Family activities have resumed throughout all areas of The Inn, including the play room.

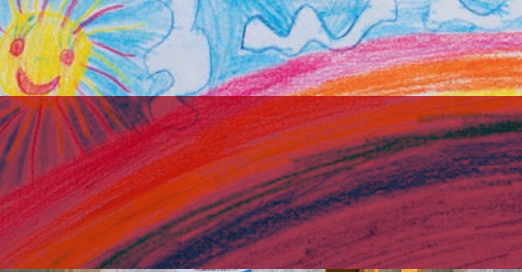
"Our children and families, our staff – and Zilly – are very excited that The Inn is nearly fully operational again," says Inn CEO Jennie Lucca. "Of course, we're about to embark on the long-awaited remodel of the E-Wing kitchen and dining area, which will require us to close the E-Wing for several months. But this will be a breeze in comparison to what we just went through – and the results will be stunning!"

Caring supporters like you made sure families had everything they needed when they were evacuated during the emergency closure's trying first days. With your help, families quickly moved into hotels, back into The Inn's E-wing or into comfortable and beautifully furnished apartments in the Bethesda Row area. You also made sure all of them could rely on entertaining activities, scrumptious meals and sustaining snacks, and that families living in the apartments could easily access the NIH Clinical Center and The Inn with the help of a private shuttle. Thank you for your ongoing support!

Read more about The Inn's partial eight-month closure and how you can continue to best help provide "a place like home" to seriously ill children at [childrensinn.org/roof](http://childrensinn.org/roof). ★



(From right) Thais, 7, Oliver, 6, and Kenzie, 6, enthusiastically participate in a monthly Happily Hungry cooking class taught by Danielle Cook Navidi and funded by The Mead Family Foundation.



**First photo:** Legislators and NIH leadership staff gather around Inn resident Abram, 8, (front center) of Missouri and his family as well as Inn CEO Jennie Lucca (third from right) during The Children's Inn's 2019 Congressional Networking Reception.

**Second photo:** Martina McBride performs in support of The Children's Inn at NIH thanks to the Rock and Roll for Children Foundation.



The Inn's E-Wing kitchen will be remodeled over the summer months. Materials and appliances used in the kitchen will be tested for potential installation throughout the building as part of The Inn's strategic plan #INN2025.

## Legislators Praise and Martina McBride Sings for The Inn

**Congressional Networking Reception:** Even before the official start of The Children's Inn's fourth annual Congressional Networking Reception, the Foyer of the Rayburn House Office Building was abuzz with legislators, NIH leaders and their respective staff, along with Children's Inn representatives. All were gathered to support The Children's Inn at NIH and the important role The Inn plays in advancing pediatric clinical research studies at the NIH.

Speakers included Children's Inn CEO Jennie Lucca; NIH Director Dr. Francis Collins; Sen. Roy Blunt, R.-Mo.; Rep. Tom Cole, R.-Okla.; Sen. Chris Van Hollen, D.-Md.; and Rep. Debbie Dingell, D.-Mich. Master of ceremonies was journalist and author Cokie Roberts, who also serves on The Children's Inn's board of directors.

Inn resident Abram, 8, of Missouri brought tears to the eyes of many when he described how The Inn's therapy dog, Zilly, helped him master painful injections and that the chance to throw the first pitch at a Nationals game as part of a Children's Inn outing was the best day of his life. View photos from the event online at [childrensinn.org/congressional2019](http://childrensinn.org/congressional2019)

**Rock and Roll for Children Foundation Concert:** Country star Martina McBride headlined The Rock and Roll for Children Foundation's fourth annual concert to benefit The Children's Inn at The Fillmore in Silver Spring in March. Hundreds of music fans attended the concert and silent auction that gave guests a chance to bid on trips and vacations, music memorabilia and raised more than \$50,000 for The Children's Inn.

"Martina McBride gave a beautiful performance," says Jennie Lucca, CEO of The Children's Inn at NIH. "We're so grateful to Jon Belinkie and Lou Marmon, founders of the Rock and Roll for Children Foundation, for continuing to support The Children's Inn through this great event to help more seriously ill children." Learn more about the event and view photos at [childrensinn.org/martina](http://childrensinn.org/martina) ★

## Keeping You in the Know: #INN2025 Update

**T**hanks to generous people like you, lodging, activities and meals are free for families and young adults staying at The Children's Inn while they are participating in groundbreaking clinical research studies at the NIH. With the help of our #INN2025 strategic plan, your support will accelerate The Inn's impact on medical discovery and care. Here's an update on #INN2025 progress:

After vetting master planners, The Inn has hired Gensler Architects to help create a more comfortable, technology-driven living environment that incorporates the best in hospitality and healthcare facility design for our children and families.

"Our goal is to make staying at The Inn as comfortable and easy for families as possible," says Cathy Morales, The Inn's chief program and services officer. "That includes using technology to stay ahead of maintenance issues, make our check-in process faster, provide a more individualized experience for families in their rooms and better meet families' unique medical needs by installing surface materials that are easy to clean."

Over the spring and summer months, The Inn will renovate its E-Wing kitchen and dining room. As part of the renovation, The Inn is installing new flooring and surface materials to test them for possible later installation throughout The Inn. The Inn will also test new kitchen appliances and make sure every family staying in the E-Wing has access to individual refrigerators. Stay in the know on these and other #INN2025 updates at [childrensinn.org/inn2025news](http://childrensinn.org/inn2025news). ★



Amber, 9, of California and her parents, Miguel and Leticia (right), along with The Inn's Stephanie Feinberg, admire Amber's portrait painted by Artist Jota Leal in honor of Rare Disease Day. Helping unveil the portrait is Beyond the Diagnosis Founder and CEO Patricia Elaine Weltin, who commissioned the portrait.

## Family of Amber, 9, Thanks You for Your Support at 2019 NIH Rare Disease Day

It's been a big year for Amber, 9, of California. In February, she celebrated the one-year anniversary of her gene therapy injection at the NIH Clinical Center and helped welcome first lady Melania Trump to The Children's Inn. On Feb. 28, she played a major role in highlighting the importance of gene therapy advancements in helping rare disease patients like herself as part of the 2019 NIH Rare Disease Day.

Born with giant axonal neuropathy (GAN), a highly rare disease that progressively limits her nerve and muscle functioning, Amber's family was elated to learn their daughter was eligible to participate in a gene therapy trial at the National Institute of Neurological Disorders and Stroke (NINDS). The potential for gene therapy to treat and even cure rare genetic diseases like Amber's is highly promising. But families like Amber's need support from donors like you and The Inn.

"I'm really grateful for The Children's Inn for helping us," Amber's dad, Miguel said. "I don't know that we could do this without The Inn's support."

Also as part of Rare Disease Day, Amber was chosen to have her portrait painted by Artist Jota Leal for "Beyond the Diagnosis," an exhibit of portraits of children with rare diseases painted by a group of volunteer artists for the Rare Disease United Foundation, which seeks to increase research and raise awareness of rare diseases. Amber's portrait will travel to various rare disease exhibits around the country in the years to come. For more information and photos, visit [childrensinn.org/rdd2019](http://childrensinn.org/rdd2019) ★



To honor the NIH pediatric patients who died from incurable diseases during the past year, NIH Clinical Center and Children's Inn staff hung feathers and lit candles in the children's memory as part of the NIH Clinical Center's 25th Annual Pediatric Remembrance Ceremony.

## NIH and Children's Inn Staff Hold 25th Annual Pediatric Remembrance Ceremony

The recent NIH Clinical Center's 25th Annual Pediatric Remembrance Ceremony, filled with singing, poetry readings, speeches and presentations, serves to remember, honor and grieve the losses of those NIH pediatric patients who died over the past year from incurable diseases.

Dr. Lori Wiener, co-director of the Behavioral Health Core and head of the Psychosocial Support and Research Program at the National Cancer Institute's Center for Cancer Research's Pediatric Oncology Branch, focused her keynote address on the importance of storytelling in learning about and addressing difficult topics. When she discovered a lack of stories about children dying from rare or incurable diseases geared toward children under 12, she set out to write one herself in an effort to help terminally ill children and their families with a story that they can relate to. Written with co-author Meaghann Weaver, a pediatric oncologist and former NCI fellow, Wiener shared "The Gift of Gerbert's Feathers," which tells the story of a brave but sick gosling and his family who come to terms with Gerbert's death. Read more about the ceremony online at [childrensinn.org/remembrance2019](http://childrensinn.org/remembrance2019) ★

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 and a cure possible tomorrow.



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7 West Drive  
Bethesda, Maryland 20814-1509  
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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](http://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.

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## First Lady Melania Trump Visits The Inn for the Second Time

The children, families, board of directors and staff of The Children's Inn were honored to welcome first lady Melania Trump for Valentine's Day for the second year in a row.

The first lady was greeted by Children's Inn CEO Jennie Lucca, NIH Director Dr. Francis Collins and Inn board chair and President of Palladian Partners Beth Maloney, along with Inn resident Amber, 9, of California.

Amber, who is being treated at the NIH for a rare neurodegenerative disorder called giant axonal neuropathy (GAN), had one burning question for Trump, "Do you remember me?"

Amber was overjoyed to hear Trump did remember her from last year's Valentine's Day visit. After talking briefly, Trump participated in Valentine's Day-themed activities with Inn children.

Amani, 13, of Kenya presented the first lady with a handmade MyIntent necklace with the words "hope" and "faith" inscribed. The words carry special meaning for Amani, who had been suffering from sickle cell disease his entire life and was preparing for a potentially curative bone marrow transplant at the NIH. Touched by Amani's kind gesture and moving story, Trump wished him well and invited him and his family to visit her at the White House once he's feeling better.

"All of us at The Inn are so grateful to the first lady," Lucca says. "She was so kind, asking our children how they were feeling, what their treatment is like, and she made our children feel so very special."

Read more about the first lady's visit at [childrensinn.org/flotus2019](http://childrensinn.org/flotus2019)



Children's Inn resident Amani, 13, of Kenya gets a hug from first lady Melania Trump during her second Valentine's day visit to The Inn. Over the past year, the first lady also invited Inn families to the White House for the Easter Egg Roll, Christmas tree lighting and the launch and anniversary of her Be Best campaign. See more photos online at [childrensinn.org/flotus2019](http://childrensinn.org/flotus2019)