



The Children's Inn at NIH

INN SPIRATIONS

A PLACE FOR HOPE

This Family Raced Against Time and the Coronavirus to Save Their Children

Racing against time to save their children's lives, Niclas and Jessica of Sweden weren't going to let a worldwide pandemic or international travel restrictions get in their way. Just one hour before the borders closed to foreign visitors, the couple and their three children - all of whom have a fatal, neurodegenerative disease - cleared immigration in New York to head to their ultimate destination: The Children's Inn and the National Institutes of Health.

Niclas and Jessica's world forever changed when they learned their son, Hampus, 5, had GM1 gangliosidosis, an ultrarare neurodegenerative disease for which no treatment exists. Five months later, the heartbroken family learned their twin girls, Julia and Isabella, 3, also had the disease.

Your support of The Children's Inn helps save lives. To make a gift, visit childrensinn.org/donate.



Jessica and Niclas hold their children, from left, Hampus, Julia and Isabella, prior to undergoing gene therapy. The family's remarkable story of determination and hope was recently featured in the Washington Post. Read it at childrensinn.org/wapo.

They found hope when Jessica came across an experimental gene therapy online. Getting their children admitted to the study became their single focus.

After finally arriving in Bethesda, Maryland, undergoing two weeks of isolation and multiple coronavirus tests, the children were cleared to prepare for the trial. In late April, the National Human Genome Research Institute at the NIH Clinical Center administered the experimental IV injection that provided all three children with healthy copies of their damaged gene. The hope is to coax their bodies into producing a crucial enzyme the children lack. If successful, the treatment could halt or possibly even reverse the children's progressive nerve cell death.

A week after receiving gene therapy, the family is back at The Children's Inn where they can finally relax. Their children love the indoor playroom, but when the weather is nice, they gravitate to The Inn's large outdoor playground. They also enjoy the catered meals. But most of all, they love spending time together as a family.

Although nobody can fully predict how the treatment will affect the children's health, for Niclas and Jessica, the gift of additional time with their children is what matters most.

The family thanks you for your support of The Children's Inn and NIH clinical research for giving them hope for the future. ★

A PLACE FOR FAMILY

You Help Save Lives and Make Childhood Possible During the Coronavirus Pandemic

Your continuous support and generosity help keep the families at The Children's Inn going during the unprecedented pandemic. The children and young adults who are staying at The Inn now need immediate treatment for serious, life-threatening conditions. For many of them, the coronavirus is especially dangerous.

But your support helps these children and families feel safe and cared for, even during the most trying times. Every meal you make possible, every dollar you give, every in-kind gift of books, arts and crafts supplies, face masks and non-perishable foods you have donated makes a difference.

Thanks to you, Princess, 8, of Nigeria can laugh during a virtual magic show while being treated for a difficult blood cancer. Because of you, Amri, 18, of Texas could continue to practice the marimba while recovering from a stem cell transplant for her life-threatening immune deficiency. Thanks to your support, every one of our wonderful moms at The Inn was treated to a gift basket and a special meal on Mother's Day. Thank you! ★

→ The children and families of The Inn are grateful for your support. To find the best way you can help now, visit childrensinn.org/emergency.



Above: Your support helped honor our moms this Mother's Day with gift boxes and special meals.

Left: Thanks to you, Inn children found joy hunting for eggs this Easter while baskets filled with sweet treats delighted their parents.



Families wear masks you donated and practice physical distancing throughout The Inn.



First lady Melania Trump sent the White House executive chef, pastry chef and ushers to hand-deliver specially prepared meals to encourage families and recognize staff.



Our families say "Thanks!" for your donations of non-perishable foods.

Official White House Photo by Andrea Hanks

SPRING 2020

A PLACE FOR COMMUNITY

Celebrity Chef José Andrés Joins You in Supporting Children's Inn Families

Celebrity Chef José Andrés is not only one of the world's best and most innovative chefs but also one of the most generous and effective humanitarians. Focused on helping prepare fresh and nutritious meals for people affected by the coronavirus crisis, Andrés and his nonprofit World Central Kitchen (WCK) have been providing breakfast and dinner to thousands, including Inn children and families since early April.

"Our families are grateful for the warm, nutritious meals," says Javin Smith, The Children's Inn's program operations manager. "It's a big relief for our families not to have to worry about shopping or cooking during this difficult time."

Chef Andrés has personally delivered meals to The Inn several times. During one of his visits, he met Pierina, 11, of Peru. Hearing she misses food from home, Chef Andrés treated her and The entire Inn to Peruvian-style arroz

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The kids are enjoying the food deliveries and their parents are too. It's nice to see them smiling as they share a family meal together.

con pollo – chicken with rice – one day before Pierina started a lengthy treatment for her rare disease.

"It means so much to our families to have José Andrés here in person and for him to do special things for individual children," Smith says. "We just cannot thank him enough!"

Inn staff also take meals to children staying inpatient at the NIH Clinical Center's pediatric unit.

"The kids are enjoying the food deliveries and their parents are too," says Gaynell Amaya, a research program assistant in 1NW Inpatient. "It's nice to see them smiling as they share a family meal together." ★



On behalf of Inn families, Chef José Andrés gets a thank-you kiss from Zilly, The Children's Inn's therapy dog, for providing daily breakfast and dinner through his nonprofit World Central Kitchen.

To make an even greater difference now, please use the return envelope or make a donation at childrensinn.org/donate. Thank you!



The **Children's Inn** at NIH

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OUR MISSION

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

PUBLISHED BY THE CHILDREN'S INN AT NIH

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INNspirations is going digital!

This is the last print edition of INNspirations! The newsletter will be electronic from here on. Check out the included flyer for more details.

Don't miss out! Sign up at childrensinn.org/innspirations to stay connected.



Donate Hope Today

Become a monthly donor to The Children's Inn now to help provide a safe haven for seriously ill children during this crisis. Visit childrensinn.org/donate to contribute today. Thank you!

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