



Inn Family Wins Contest— Goes to Disney World

As part of our 25th Anniversary celebration last year, Inn families were invited to submit a photo and caption through Instagram describing their experience staying at The Inn. The photo with the most votes won a four-day family trip to Walt Disney World in Orlando, Florida. With 3,442 votes in less than a month's time, Sophie Kinard was the winner of the contest. It was clear that Sophie, a teenager with Muscular Dystrophy, had a lot of friends and family rooting for her.

Sophie's mom, Dusty, submitted a photo of Sophie at The Inn with the following caption: "Sophie Kinard is a thirteen year-old girl with Muscular Dystrophy. She is in the new study for the Omigapil drug that we are so hopeful about. Muscular Dystrophy has robbed her of everything that gave her freedom. The Children's Inn has helped us feel at



The **Children's
Inn at NIH**

SPRING 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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home after exhausting days in the clinic. Thank you Children's Inn!"

Dusty and Sophie traveled to the NIH from their home in Ashland, Kentucky for the first time last December. Sophie is participating in a clinical trial at the National Institute of Neurological Disorders and Stroke (NINDS).

Sophie, her parents, and two siblings were very excited about their trip to Disney World in February. Sophie's parents waited until the last minute to surprise their three kids with the trip, although Sophie was suspicious when she caught her parents packing the car the night before.

"Honestly, it's hard for our family to go on vacation because it's so expensive. Having the whole trip paid for made it easy. We were able to enjoy sit-down meals and not have to leave the park to go somewhere else, which is difficult with Sophie's wheelchair...we were able to relax and not stress about expenses," said Dusty.

Sophie's favorite parts of the trip were the Splash Mountain water ride and eating dinner at the Sci-Fi Dine-In Theater Restaurant. She wore her mouse ears the entire time.

Thank you to our contest sponsors CSRA and Marriott Orlando World Center. CSRA donated funds for the family's airfare, Disney park tickets, and other expenses, and Marriott Orlando World Center donated a four night's stay at their resort, which has multiple pools, two 200-foot winding waterslides, a 90-foot speed slide, and kid's splash park.



Inn Resident Sophie Kinard



INNSpirational PEOPLE



Seth, Eli, and Julie Palmer

Inn Resident Brings Joy to Others

Six months after turning two, Eli Palmer still wasn't walking, and his parents, Julie and Seth, had begun to worry. But they figured their fourth child was growing at his own pace and would soon catch up.

Unfortunately he didn't, and a few weeks later, a doctor told his parents that their toddler had a congenital myopathy – in other words, Eli had been born with a lifelong muscle disorder. As time passed, more doctors gave it a name: central core disease, a rare condition that weakens Eli's muscles but that probably won't worsen over time.

Yet today, you wouldn't know that Eli has a health problem. At 11, not only does he walk normally but he races up and down the soccer field and enjoys sledding during long Michigan winters back home with his family. By all accounts, Eli is a healthy and popular sixth-grader. "He's the guy everyone wants to hang out with," says Julie.

However, Eli's condition makes his muscles ache, and he's frequently in pain. He is participating in a clinical trial at the National Institute of Nursing Research at the National Institutes of Health to test a treatment for his condition. While there, Eli, his parents, and their five other children experience a "joy-filled, magical place" when staying at The Children's Inn.

During their recent stay at The Inn, a highlight was meeting One Direction—or at least extremely lifelike versions of members of the popular UK band. Madame Tussauds DC unveiled their new wax figurines for the first time in the DC metro area at The Inn.

Eli frequently brings joy to others. Julie recalls a time when her son's optimism had a profound outcome. "He's my inspiration," said a member of the family's church who had battled addiction for a decade. Since meeting Eli eight years ago, she's still sober. He's just the kind of child that makes a difference in the lives of others. Read much more about Eli's journey on The Inn's blog at: childrensinn.org, under News & Events.

Daniel L. Weaver, CPA Joins Inn Board

Daniel L. Weaver, CPA, Vice President, with Councilor, Buchanan & Mitchell, P.C. (CBM) has joined the Board of Directors of The Children's Inn at NIH.

Dan is the Chairman of the Not-for-Profit Service Group at CBM. His years of experience include audits, reviews, tax preparation, and research and planning services, primarily in the not-for-profit industry.

"I am delighted that we have added an audit and tax expert with a robust background in the nonprofit industry to The Children's Inn Board," says Jennie Lucca, Inn CEO. "I know Dan will further strengthen our exemplary Board of Directors."

Dan also has a very personal connection to The Inn and the National Institutes of Health. His step-brother, Bobby, was born with a form of mucopolysaccharidoses (MPS) called Hurler-Scheie. In the 1980s, before The Inn was built, Dan remembers his parents bringing Bobby to the NIH for experimental procedures. "Unfortunately, Bobby died when he was 20 years old, but I know he and my parents would have benefitted greatly from The Inn if it had existed at that time," says Dan.

Dan received his Bachelor of Science in Business Management from Bucknell University and is a Certified Nonprofit Accounting Professional (CNAP) Instructor. He lives in Silver Spring, MD with his wife, Rebecca, and their two children.





Eleven year-old Inn resident Meredith Hobbs is excited to show off the Thoughtful Treasures she received during her recent stay.

MedImmune Makes Special Contribution to Help Inn Families

In December, MedImmune, the Gaithersburg-based biologics subsidiary of AstraZeneca, made a \$100,000 grant to The Children's Inn to support two initiatives that directly affect the daily lives of our residents: the Grocery Gift Card and Thoughtful Treasures programs. Since 2008, MedImmune has been a generous corporate partner with The Inn.

"We are pleased to make this contribution to The Children's Inn," says Matthew Bell, Chief Operating Officer at MedImmune and an Inn board member. "The grant for these two programs directly aligns with our core values of making a meaningful and sustainable difference in patients' lives."

The Grocery Gift Card and Thoughtful Treasures programs are both part of The Inn's Family Support Services, which provide therapeutic, educational and diversionary programs for the more than 1,500 seriously ill children and their families who stay at The Inn each year. Many families need a little extra financial assistance with purchasing groceries and fresh foods that they prepare at The Inn. Last year, The Inn provided more than \$60,000 in grocery gift cards to residents.

Thoughtful Treasures is a unique Inn program that provides small gifts in the child's mailbox each night, including siblings, so they have a fun surprise to look forward to every morning during their stay at The Inn.

"MedImmune has been an exceptional partner with The Inn," says Jennie Lucca, Inn CEO. "Matt [Bell] has provided strong leadership and expertise to our Board, and other MedImmune employees have volunteered in many ways over the years to help our residents. This most recent grant will provide direct assistance to our families who need a little extra help with groceries and will brighten the children's day when they open their mailboxes. We are truly fortunate to have such a generous, innovative corporate partner."

5th Annual A WINNter Affair a Success

The 5th Annual A WINNter Affair gala, held on Saturday, February 20th, was an eventful evening of cocktails, hors d'oeuvres and dancing to help raise awareness and funds for The Children's Inn mission and critical support programs. The Inn's Young Ambassadors Council (YAC) welcomed over 400 young professionals from the greater DC Metropolitan area to the Pavilion at the Ronald Reagan Building for a sold out event. Trade Center Management Associates once again donated the event space, catering and refreshments. DJ Phlipz brought guests to the dance floor all night long.

This year, the event included a mixologists competition—DC's premiere mixologists competed for the best Caribbean-style cocktail. Guests voted on their favorite handcrafted drink and crowned mixologists Babak Pakravan of Penn Commons restaurant the victor. Participating competitors donated their ingredients and also included mixologists from Jack Rose Dining Saloon, SILVER, Tico, Hank's Oyster Bar and McClellan's Retreat.

The event raised over \$80,000, the most in its history, to support sick children and families who call The Inn home during treatments at the NIH. The Inn extends its utmost gratitude to corporate sponsors: Palladian Partners, PwC, Eagle Bank, Home Depot, Newmark Grubb Knight Frank, DPR Construction, RMF Engineering, Streetsense and the Lyle Family. Learn more about the YAC: www.childrensinn.org/youngambassadors.



The 2015-2016 Children's Inn Young Ambassadors Council



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The Children's Inn at NIH

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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 to Support The Inn

Thanks to the Rock and Roll for Children Foundation, legendary performers John Popper of Blues Traveler, Christine Ohlman of the Saturday Night Live Band, Ricky Byrd of Joan Jett and the Blackhearts, and many more, for coming together on March 12 to support the children and families who stay at The Inn.

This annual rock event has become a beloved Bethesda tradition for those who are nostalgic for the era of the Beatles and Woodstock. This year, guests came to the Bethesda Blues and Jazz Supper Club, where they sang, danced, and most importantly, enjoyed some great Rock 'N Roll. Throughout the evening, guests bid on silent auction items including trips, signed memorabilia, and one-of-a-kind experiences. The Rock and Roll For Children Foundation once again was able to make a generous contribution to The Children's Inn.

The success of this event would not be possible without the organization's founder, Jon Bellinke. After witnessing the struggles of families caring for a sick child, it was his vision to create a fundraising event that brought together musicians from some of the most famous bands in the world. Twelve years later, the foundation has raised \$500,000 for charities supporting children in need. It is with much gratitude that we thank the Rock and Roll for Children Foundation and Jon Bellinke for their continued support of The Inn!



Standing Left to Right: Jon Bellinke, Inn CEO Jennie Lucca & Ricky Byrd
Sitting: John Popper