



# Annual Picnic Brings Music, Barbecue, Dancing to The Inn

The Inn recently held its annual picnic on our beautiful outdoor play park, hosting Inn families as well as supporters, members of our board of directors, trustees, committee members and staff. Guests enjoyed singing and dancing to live music performed by three-time Grammy-nominated singer-songwriter Brady Rymer and the Little Band That Could. Barbecue was served, and a Ben & Jerry's ice cream truck and a candy stand helped satisfy every guest's sweet tooth.

"The picnic was a lot of fun," said Sophia Hogas, 8, of Chesterfield, New Jersey, who has been staying at The Inn with her family since March to be close to her brother as he receives treatment for leukemia.

"I liked how they had the ice cream and candy," she added. "It was so delicious. I also



The Children's  
Inn at NIH

SUMMER 2017

# 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 for pediatric research and clinical care
- Provide a free family-centered "place like home"
- Reduce the burden of illness through therapeutic, educational and recreational activities

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loved the face painting. I normally don't go to a lot of parties, so it's nice to finally have my face painted!"

For her facial art, Sophia picked a rainbow design with black swirls. She also enjoyed the chance to have balloons shaped into animals and headgear for herself and her brother.

"My brother's favorite color is yellow, so I had a sword made in yellow for him, and a dog and hat, and we took them over to his room at the NIH Clinical Center," she said.

The balloon art was created by Kristin Graham of Rochester, Michigan, and her husband, Scott. Kristin, a clown and balloon artist by profession, and her family have been staying at The Inn since April while their eldest daughter, Jenna, 11, participates in a revolutionary trial for giant axonal neuropathy, a neurodegenerative disorder. Jenna spent time at the picnic with her sister, Hailee, 8, and other children residing at The Inn she's made friends with, including Sophia.

"I liked the ice cream and the music, and the balloons everywhere," Jenna said. "It was fun dancing!"

"Our annual picnic celebrates our families, supporters and staff," said Beth Maloney, a member of The Inn's board of directors. "It's fun to get together and see everyone enjoy themselves."

To see photos of the event, visit [www.flickr.com/photos/childrensinn/albums](http://www.flickr.com/photos/childrensinn/albums).



Inn residents and guests enjoy the annual picnic.



Lucy, 9, gets ready to be filmed for Discovery Channel's docuseries "First in Human."

## A Look Inside the NIH Clinical Center

How do medical breakthroughs happen at the National Institutes of Health's Clinical Center, the world's largest hospital dedicated to clinical research? Discovery Channel's docuseries "First in Human," set to air in early August, provides an exclusive behind-the-scenes look at the leading-edge research being conducted at the hospital, following patients as they participate in clinical trials in hopes of finding a new treatment and advancing science.

The three-part series highlights the journeys of four patients, including Lucy, 9, a pediatric patient and Children's Inn resident with a highly rare genetic disorder.

"The Children's Inn is honored to be part of this important documentary about the NIH, which shows how the NIH is on the forefront of the world's medical breakthroughs," says Jennie Lucca, CEO of The Children's Inn at NIH. "It's also exciting to see in this beautifully produced series how The Inn supports the important research happening at the NIH by providing 'a place like home' to pediatric patients and their families."

Filming for the series started in September 2015 and wrapped up in May 2016. While most of the filming took place in the laboratories and exam and hospital rooms of the Clinical Center, many hours of footage also were taken at The Children's Inn and on its large outdoor play park as the series followed pediatric patients like Lucy staying at The Inn.

The docuseries is narrated by Emmy®, Golden Globe® and Critics Choice®-winning actor Jim Parsons and directed by Emmy® winner John Hoffman, and is set to launch Aug. 10 at 9 p.m. EST. Two additional two-hour episodes will air Aug. 17 and Aug. 24. For more information, visit <http://childrensinn.org/first-in-human>. ★

## String Quartet Raises Funds for The Inn

Growing up, Natalie Hsieh, now 15, heard her father, Dr. Matthew Hsieh, a researcher at National Heart, Lung and Blood Institute, tell stories about his patients who traveled to Bethesda to find help for rare or critical illnesses at the NIH. Her father's stories and the family's friendship with long-time Inn board member Mark Raabe and his late wife, Jean, inspired Natalie to help NIH pediatric patients in her own way.

In late 2015, Natalie, a talented musician, and some of her friends formed a string quartet named Quadrivium, Latin for crossroads, to help others, especially the children and families of The Children's Inn, by sharing the joy of music with them.

The quartet has entertained Inn families during dinner and recently raised funds for The Inn by playing in downtown Frederick, Maryland, where a local business owner, whose young family member was an Inn resident, welcomed them to set up in front of her shop. To do even more to support The Inn, the quartet launched a fundraiser on crowdrise.com with the goal of raising \$1,000.

"It was really nice performing for the families at The Inn," Natalie said. "Everyone was having a great time, even though they were going through various treatments. I loved seeing the children be happy and enjoy themselves as a family."

Quadrivium hopes to perform quarterly at The Inn. To contribute to their fundraiser for The Inn, visit [www.crowdrise.com/QSQ4TheChildrensInn](http://www.crowdrise.com/QSQ4TheChildrensInn). ★



The Quadrivium string quartet played a concert for Children's Inn residents. Pictured here are members Spencer Tate, 17, Natalie Hsieh, 15, Phillip Lee, 15, and Katherine Kim, 15.





Jeff "Skunk" Baxter performs the national anthem alongside Inn residents at the 4th annual An Evening for Hope gala.

## A Record-Breaking An Evening for Hope

The 4th annual An Evening for Hope gala, held in April, netted a record \$927,000 for The Children's Inn. The sold-out event brought together 800 Children's Inn supporters, including NIH leadership, federal technology, health care and other industry leaders at The Ritz-Carlton, Tysons Corner, for food, drinks, live and silent auctions, and live entertainment.

Inn resident Shira Strongin, 18, of California spoke about the challenges of living with a life-threatening, undiagnosed illness. Thanks to caring NIH doctors and nurses, Shira has finally found hope for a diagnosis. Lori Sames, mother of Inn resident Hannah, 13, highlighted her daughter's diagnosis with a highly rare neurodegenerative disorder named giant axonal neuropathy, or GAN. Lori and her family launched an effort to mobilize the medical community to search for a lifesaving experimental treatment for Hannah and other GAN patients. Thanks to the NIH, which is conducting the clinical trial, Hannah is one of several GAN patients around the world to receive the revolutionary treatment. Mark Papier, father of Inn resident Dillon, also spoke to honor his late son, and NIH Director Dr. Francis Collins made heartfelt remarks. Guests also enjoyed an instrumental guitar rendition of the national anthem performed by Jeff "Skunk" Baxter, formerly of Steely Dan and The Doobie Brothers.

"We're so very grateful to our dedicated and generous supporters and sponsors who once again went above and beyond to help The Inn provide 'a place like home' to hundreds of children and families over the next year," Lucca said.

Thanks also go to top-tier sponsors Booz Allen Hamilton, CSRA and NETE as well as Allscripts, Deloitte, EagleBank, Leidos, Seven Bridges and Walgreens. ★

## Golf, Hula Skirts and Fun at the 10th Annual Golf INNvitational

The Inn's 10th annual Golf INNvitational, held at Lakewood Country Club in June, raised nearly \$150,000 for The Inn. Nearly 130 golfers played on the Rees Jones-designed course, enjoying a great day of golf complete with fun challenges and post-tournament festivities.

On hole three, golfers willing to don a hula skirt while teeing off got the chance to improve their score by driving from the forward tee. Jim Coleman Toyota sponsored two hole-in-one prizes, including a car. The 10th hole on the course featured a die-rolling game, giving winners yet another chance to move up to the forward tee.

The event concluded with a celebratory dinner and awards presentation at the club house. Inn board member Kristine Ribas shared her family's story of seeking help at the NIH for their daughter, Annie, who was suffering from pediatric Cushing's disease. Surgeons at the NIH successfully removed a hard to find tumor on Annie's pituitary gland that was the cause of her rare illness. During Annie's treatment, the Ribas family fell in love with The Children's Inn, leading Ribas to join The Inn's board of directors. Ryan Riel, an Inn board member and senior vice president at EagleBank, acted as emcee.

The event was sponsored by Booz Allen Hamilton; TerpSys; Capital One; CBRE; Duball, LLC; EagleBank; Fleischman Hillard; Genesis Security Systems; GHC Associates; Ketchum; Porter Novelli; Ventech; Washington Speakers Bureau; and BB&T. ★



Golfers enjoy a day out on the course at the 10th annual Golf INNvitational. Pictured from left to right: Scott Springmann (BB&T), Ed Woods (President, TerpSys), Kelly Woods (TerpSys) and Asha Kumar (TerpSys).



## Board of Directors

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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](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.

Follow us on:

## Fostering a Community of Runners in Support of The Inn, One Step at a Time

Whether you run or know runners, The Children's Inn #RunINN4Kids Marine Corps race teams offer opportunities for anyone to help make childhood possible for children and families facing the burden of illness.

By joining The Inn's marathon or 10K teams, which provide guaranteed entry into these highly coveted races, runners can meet their fitness goals while raising much-needed funds to support critical therapeutic, diversionary and educational programs The Inn offers families at no charge.

Runner or not, here's how you can support The Inn:

- Join The Inn's MCM 10K or marathon team and meet a \$600 fundraising challenge to benefit The Inn.
- Raise awareness of The Inn's race teams on your social and professional networks.
- Donate to one or several #RunINN4kids runners to help them meet their fundraising challenges.

Every step you take will go a long way in supporting The Children's Inn.



For details, visit the event website at [www.crowdrise.com/runINN4kids](http://www.crowdrise.com/runINN4kids) or contact Julie Ofrecio at [juliemae.ofrecio@nih.gov](mailto:juliemae.ofrecio@nih.gov) or 301-594-1625