

## **INNriching Residents' Lives**

or years, Colton Clifford's mom prayed for her son to begin speaking. Born with a rare developmental disorder, Colton answered his mom's prayer by uttering his first word during a therapeutic horseback riding class.

"His first word was, 'Go!" his mom remembers.

Colton has Smith-Lemli-Opitz syndrome, a developmental disorder caused by his body's genetic inability to make cholesterol. While the disorder affects children differently, in Colton, it causes sensory issues as well as difficulty communicating, a short body stature and limp muscle tone, along with other issues. Colton also has a secondary diagnosis of autism.

But thanks to financial assistance from The Inn's INNrichment Fund, Colton, 7, of Edwardsville, Illinois, is one of 20 Inn children and young adults able to benefit from specialized therapies or academic programs that help them achieve developmental or educational goals, including college degrees, they wouldn't otherwise be able to afford.

# The Children's Inn at NIH

### **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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Colton had tried a variety of therapies in the past, including therapeutic horseback riding, behavioral therapy and therapy for children on the autism spectrum. Insurance now helps the family pay for speech, occupational and physical therapy – but not therapeutic horseback riding. Without assistance from the INNrichment Fund, Colton's family wouldn't be able to afford therapeutic horseback riding classes, which cost \$45 per class, even though that's where Colton's mom has seen her son make some of his greatest advancements in speech and enunciation, developing social skills and improved posture.



Inn resident Colton, 7, benefits from therapeutic horseback riding paid for with the help of the INNrichment Fund. To help support The Inn's INNrichment Fund and other activities benefiting children, make a donation at www.childrensinn.org.

"I had prayed for this boy to be able to talk, to be able to say his needs and wants," his mom says. "Through horseback riding, his communication skills continue to improve, and he now speaks a lot more. He now goes on and on about the horse, and it's also helped him connect with other children because it gives him something to talk to them about."

Your support of The Inn enables The INNrichment Fund to help eight young adults afford college classes and 13 children benefit from a variety of therapeutic and academic activities, including computer classes, English lessons, art classes, job certification classes, piano lessons, a summer medical academic program, gymnastics and SAT preparation.



Volunteers from Uber spent a day assembling grab-and-go lunches for families. The lunch program provides a new service opportunity for volunteer groups.



Inn resident Dahd, 13, asks Nationals centerfielder Andrew Stevenson for an autograph after throwing the first pitch at the annual K's for Kids night sponsored by Washington Area Toyota Dealers.

### Inn Launches Lunch Program Trial

When a child is ill, a favorite snack or meal can make a big difference. That's why, in addition to providing breakfast every morning and dinner most nights, The Inn has launched a three-month trial to serve free lunch to Inn residents.

The Inn's stocked breakfast bistro serves as Inn residents' first stop of the day before heading to the Clinical Center for a long day of tests and appointments. And nearly every evening, families arrive "home" to The Inn from the Clinical Center to a family dinner hosted by one of The Inn's many volunteer groups. Recent resident surveys have shown that providing a midday meal would significantly ease families' hectic schedules, which leave little free time to prepare a meal between a long list of medical appointments. The financial stress of caring for a seriously ill child also leaves many families with few resources to spend on meals at the hospital cafeteria.

The Inn's lunch program pilot serves sandwiches, fruit, chips and drinks Mondays through Wednesdays, along with a variety of snack options other days. Thanks to in-kind donations from Papa John's and Mamma Lucia, residents also enjoy pizza twice a month.

The Inn sends a big thank you to our generous lunch program community partners who allow The Inn to take care of the little things so our families can focus on the big ones!

If you know of a business interested in donating to our lunch program, please contact Anne Mandeville at anne.mandeville@nih.gov or at 301-451-9461.

### Fun Summer Activities Delight Families

This summer, The Inn's corporate, community and individual supporters created unforgettable memories for Inn residents. Volunteers at Circle of Hope, a local therapeutic horseback riding program, regularly worked with Inn families this summer, teaching them how to ride and/or groom a horse, decorate horseshoes and more. Interaction with horses is not only fun, it's also been shown to have therapeutic benefits that ease children's physical, mental and developmental issues.

Washington Area Toyota Dealers raised more than \$50,000 for The Inn, donating \$37 for every strikeout thrown by a Washington Nationals pitcher. The group also generously donated many ballgame tickets, invited Inn families to batting practice and introduced residents to one of the team's racing presidents. Inn resident Dahd Cannon, 13, of Great Bend, Kansas, threw the first pitch at a recent game, receiving high praise from Nats player Andrew Stevenson for throwing the best first pitch all season.

Inn families tested out their sea legs by sailing on a 60-foot schooner captained by Aram Nersesian, owner of Schooner Heron Charters. Captain Aram enthusiastically hosts monthly Chesapeake getaways for Inn families, helping them create treasured memories. Inn residents also enjoyed a day at St. Mary's Yacht Club thanks to the generosity of club members.

D.C. United defender Sean Franklin and goalkeeper Eric Klenofsky delighted The Inn's many young soccer fans when they held a mini soccer clinic during their special appearance at Camp INNcredible. And in early September, Dulles Golf Center & Sports Park hosted Inn families for a great day of mini golf, batting practice, basketball and even panning for gemstones.

To view photos of summer activities, visit The Inn's gallery on Flickr.com. 🔶

### INNspirational EVENTS



Young adults learn to paint during a night out. The Inn's new on-campus residence will provide housing and supportive programming to residents ages 18-30 years old.



You can support Inn residents with a legacy gift to The Inn. For more information about legacy gifts, please call or email Anna Tate, assistant director of leadership and legacy giving, at 301-451-3464 or at anna.tate@nih.gov.

### New On-Campus Residence to Offer Extra Support for Young Adults

Thanks to newly available space at the NIH, The Children's Inn will enhance its services to young adults in the near future by opening a second residence located on the NIH campus.

Last year, The Inn began serving residents up to age 30, and this age expansion prompted a focused assessment to help ensure The Inn is meeting the unique needs and challenges of its young adult residents.

"Many of our young adult residents have had to make their health the focus of their lives, putting aside education, professional ambitions and family aspirations," says Cathy Morales, The Inn's chief program and services officer. "As a result, they are not as prepared for independent living. Our goal is to help them get there by offering ageappropriate housing, activities and programming."

The Inn's new housing for young adults will arise from the renovation of the old: a 1940s-era brick duplex that sits just across the street from The Inn on the NIH campus. Its close proximity to both The Inn and the Clinical Center makes its location ideal, and its renovation will create age-appropriate housing for The Inn's 18-30-year-old residents.

With new on-campus housing on the horizon, The Inn plans to sell The Woodmont House, its off-campus housing facility near downtown Bethesda.

"Our housing task force provided strong data showing our residents will be better served by on-campus housing," says Jennie Lucca, CEO of The Children's Inn. "Like The Woodmont House, the new young adult residence also will serve other, younger residents whenever The Inn is full."

### What's Your Legacy?

alita Palekar, Ph.D., had a plan. As a long-time scientific review administrator with the National Cancer Institute, Dr. Palekar knew she wanted to leave a portion of her estate to The Children's Inn to benefit future NIH patients.

Dr. Palekar, who passed away in March 2017, used a variety of simple charitable gift vehicles to make her gifts and establish her legacy at The Inn. These channels included her designating The Inn as a beneficiary of her life insurance policy, Individual Retirement Account (IRA) and 401(k) plan, as well as leaving The Inn a percentage of her residuary estate.

These combined gifts provide a meaningful legacy in tribute to Dr. Palekar and in support of The Inn's endowment fund, which will provide valuable resources in perpetuity for The Inn's family support programs and services.

There are many ways to give to The Children's Inn that can fulfill your philanthropic wishes:

•A future gift through your will or trust (bequest), or by beneficiary designation (e.g. life insurance, IRA or pension plan).

•An outright gift during your lifetime of appreciated stocks, real estate, IRA distribution or through your donor-advised fund or family foundation.



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There are many ways to support The Children's Inn, such as food drives and the Thoughtful Treasures mailbox program or by making a donation. 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:

### Support our Marine Corps Marathon and 10K Team's Fundraising Efforts



The Inn's Marine Corps Marathon and 10K #RunINN4Kids team has 40 runners so far. You can make a difference for our residents by supporting the team at http://www.crowdrise.com/runINN4kids.