



# Q&A With New Inn CEO

**J**ennie Lucca assumed the role of CEO of The Children’s Inn on January 9. She has served in a leadership capacity at The Inn for more than 11 years, overseeing resident services and facilities needs in support of our children and their families. We recently talked to her about her goals and priorities for The Inn:

**Q:** What are your main goals over the next few months?

**A:** I’m fortunate to be taking over the reins of an organization that is functioning at the most optimal level that it has in its 25-year history. I see my job as ensuring that we continue this trajectory of excellence as well as exploring ways that we can be even more innovative in bringing the best programs and services to our families. Another goal is to raise awareness about the dual mission that we have of supporting families and advancing medical research. The Inn has had a significant impact on treatments for major illnesses like AIDS and pediatric cancers. I want people to know that when you



# INNspirations

SPRING 2015

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 ground-breaking 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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support our organization you are helping us to make an impact worldwide.

**Q:** Are there programs or services that you would like to add?

**A:** A priority of mine is to strengthen and enrich the experiences of Inn families. I think that making the rooms more comfortable and cozy, more home-like, this is where we can help families. When a family walks through our doors, I want them to feel this great sense of respite, knowing that they can focus on the medical piece and that our staff and volunteers will completely support their day-to-day needs. Also our isolation project, which included renovating a few rooms at The Inn and Woodmont for children with antibiotic resistant infection, is a key priority at a national level and a priority for us as well, working in concert with the NIH to support their evolving needs. Our pilot was highly successful and the next step is to explore the possibility of having some apartments in the area for families who are on isolation for a longer period of time, so that program will grow. Another priority of mine is to plan for The Inn’s funding needs in the future to ensure that we have the resources to continue to be successful and leading-edge. Our Young Ambassadors Council is an example of how we do that, because those young adults are our future leaders.

**Q:** What do you value most about The Inn’s values and culture?

**A:** I can say with great honesty that every person connected to this organization is passionate about the mission and that is what makes our culture so special. It’s a very caring culture of making every single decision with the children and their families in mind.





# INNspirational PEOPLE



Inn resident Jordan Neal riding the DC Metro for the first time.

## Meet Inn Resident Jordan Neal

Twenty-one-year-old Jordan Neal came to the National Institutes of Health (NIH) for the first time this January and was given a new diagnosis—and new hope—for a more effective treatment for his immunodeficiency disease. Doctors at the NIH had only recently identified his rare, genetic immunodeficiency called PASLI disease.

Jordan had been undergoing treatment for Common Variable Immunodeficiency (CVID) since he was four. The treatment for CVID involved monthly infusions of immunoglobulin—a blood product that contains antibodies that are important for a functioning immune system—as well as heavy doses of antibiotics and steroids. “We had been living under the CVID cloud all this time,” said Jordan’s dad, Mike. “It’s a blessing to get a diagnosis that gives us better options.”

When Jordan was a toddler, he had recurrent infections so his parents took him to several specialists near their home in Louisiana. Doctors told Mike and his wife, Kerri, that Jordan had only about 10% of a normal immune system. He not only had reduced lung function, but also had an enlarged spleen and lymph nodes.

The family moved to Ft. Collins, Colorado so that Jordan could be treated at Denver’s National Jewish Hospital, which has a national reputation for treating respiratory diseases. After reviewing multiple blood tests, biopsies, CT scans and MRI’s, his doctor there recommended that Jordan take part in a genetic study at the NIH to better pinpoint his medical condition.

Jordan and his dad will return to the NIH later this year. “The Children’s Inn staff is so professional, inviting, and provided not only financial relief but an ‘at home’ feeling as well during our stay,” said Mike. Jordan and his parents are optimistic that the new diagnosis and treatment will be successful. Jordan grew up hunting and fishing with his dad. Being outdoors is his passion. He is enrolled at a local community college and plans to become a Wildlife and Fisheries Agent when he graduates.

## Inn Announces STEM Initiative

The Inn’s Education Program announces a series of new offerings focusing on science, technology, engineering and math (STEM) programs. “Because of their participation in research clinical trials, our children are keenly aware of the importance of science, technology and STEM education. It’s a part of their daily lives,” says Ronny Kempenich, The Inn’s Education Program Coordinator. “We understand that STEM education is vital to the future of these children and future generations.”

The Inn’s STEM programs and activities include: tutoring, one-on-one homework support in science and math, technology support for children with special education needs, Study4Fun (a twice-weekly education program), and ExploreINN (a twice-monthly program offering children fun, hands-on science and math activities).

Last summer, The Inn also began a partnership with NASA. Dorian Janney, an Education Specialist with the Global Precipitation Measurement (GPM) Project, visits each month to lead space-related science activities with residents. Through this new partnership, The Inn has been able to expand our science and technology programming, such as a fun activity led recently by NASA Astronaut Col. Mike Hopkins.

The Inn wishes to acknowledge Battelle, one of our generous corporate partners, for their financial support of the STEM educational programming.



Residents taking part in fun science-related programming at The Inn.



# INNspirational EVENTS



Inn CEO Jennie Lucca spoke at Rare Disease Day at the NIH on February 27.

## Rare Disease Day at the NIH

Rare Disease Day was observed at the National Institutes of Health on Friday, February 27 with a day-long conference focusing on research advances, the development of new diagnostics and treatments, advocacy, and new collaborative models to facilitate interactions among government, industry, academia, and patient advocates. The day was established in 2008 to raise awareness about rare diseases, the challenges encountered by those affected, and the importance of research to develop diagnostics and treatments. Because roughly 80 percent of rare diseases are genetic in origin, it is estimated that about half of all rare diseases affect children.

Although each rare disease affects fewer than 200,000 Americans, in total, these illnesses touch an estimated 30 million people. Rare diseases can be chronic, progressive, debilitating, and life-threatening, and the people affected face challenges such as delays in diagnosis or misdiagnosis, and the psychological burden and lack of support services. Treatments for rare diseases can be financially prohibitive or unavailable.

The majority of children who stay at The Inn are dealing with a rare disease or difficult-to-treat forms of other diseases. Jennie Lucca, Inn CEO, spoke to the attendees at the Masur Auditorium about the role that The Inn plays in supporting rare disease research. "The Children's Inn empowers the work of the NIH clinicians and researchers who work tirelessly to improve the quality of life for our children," she said. "The clinical trials in which these brave kids participate provide new information and knowledge to the scientific community for the benefit of generations of children to come."

Other presenters at Rare Disease Day included Congressman Leonard Lance, co-chair of the Rare Disease Caucus; NIH Director Francis S. Collins, MD, PhD; The National Center for Advancing Translational Sciences (NCATS) Director Christopher P. Austin, MD; and NIH Clinical Center Director John I. Gallin, MD.

## 4th Annual A WINNter Affair a Success

The 4th annual A WINNter Affair, held at the Ronald Reagan Building in Washington, DC on February 21, was another successful event hosted by The Inn's Young Ambassadors Council (YAC). Despite harsh weather conditions, 200 young professionals attended, enjoying cocktails, hors d'oeuvres and dancing in support of The Inn. Trade Center Management Associates donated the event space, catering and refreshments. DJ Neekola provided the up-beat music, which brought guests to the dance floor.

Through generous donations from many local companies and businesses, the evening included a San Francisco get-away raffle package and a wide variety of prizes in its first ever silent-auction. Prize winners went home with concert tickets, DC sports tickets, dining experiences, local outings and much more. At the end of the night, the YAC raised \$60,000 for sick children and families who call The Inn "a place like home" while undergoing treatment at the National Institutes of Health. This evening marked the council's most successful gala to date.

Founded in 2011, the YAC is a volunteer council of young professionals in their 20s, 30s, and 40s who work together to spread The Inn's mission through fundraising, social events, volunteer projects, and community outreach initiatives. The WINNter Affair is just one of the many ways that the YAC supports The Inn. Learn more about upcoming events and projects at [www.childrensinn.org](http://www.childrensinn.org).



Members of The Inn's Young Ambassadors Council at the fourth annual A WINNter Affair gala on February 21.



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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:

## Run for The Children's Inn at the 2015 Marine Corps Marathon and MCM 10K

As part of The Inn's 25th anniversary celebration this year, we are fielding running teams for the 2015 Marine Corps Marathon and the Marine Corps 10K. Join our team to make a difference in the lives of seriously ill children and their families.

All Children's Inn Marathon and MCM 10K runners will receive:

- Personalized fundraising page and online tools to make fundraising easy
- Training tips and support from The Children's Inn
- Children's Inn team race jersey
- Opportunity to win fundraising prizes
- Invitation to visit The Children's Inn for a pre-race pasta dinner and to see firsthand the impact your fundraising is making.

For complete details or to register, visit [www.childrensinn.org](http://www.childrensinn.org).

