

# the Star

The Children's Inn at NIH

LEAVES ARE falling  
AUTUMN IS calling

Family Newsletter



Fall 2018

## MoveINN Forward

Alma Chavez, Resident Services Manager

The Children's Inn is working hard to meet your needs during this unusual time. Following the structural incident on August 21 when 45 families were evacuated and safely relocated to local hotels, we have regained access to 23 of our E-wing rooms, while maintaining five community apartments. In addition to these rooms, we also temporarily acquired 10 community apartments at The Brody Apartments. The Children's Inn staff, volunteers and friends worked tirelessly to move furniture and other home essentials to the newly-leased community apartments, which allowed families to be able to move in on August 31.

Our partnership with these apartments, located in downtown Bethesda with access to local transportation, restaurants and shops, has been a tremendous support during this difficult time. The apartment staff have been extremely welcoming to our families and supportive to The Children's Inn staff as we continue our efforts to make The Inn and the apartments feel as much as "a place like home" as possible for you.

Construction to fix the roof is expected to take several months. During our ongoing repairs, families will continue to stay at The Inn or our community apartments, pending occupancy. Resident Services continues to process reservations as usual. Despite our limited space, meals, activities and trips continue to be offered for you. We are grateful to all the donors and volunteers who continue to support us during this time, and we greatly appreciate your smiles, resilience and cooperation throughout this challenging time. Please let us know how we can best serve you by reaching out to our Resident Services Team. Thank you for bearing with us!



*The Brody  
Apartments in  
Bethesda, MD*

### Zilly's Corner

Woof, woof! Hi, Friends! I don't know about you, but I had a great summer. It sure was hot, but I had so much fun going to The Inn's summer concerts and even had a chalk artist draw a picture of me on the playground! I have even been hard at work supervising some of the building construction. I also am looking forward to the cooler weather ahead. We have a lot of fun activities planned for the fall, including a trip to the pumpkin patch, a fall fest party and a celebrity chef visit. I especially can't wait to go trick or treating at The Inn! Hmm, that reminds me, I still need to figure out what my Halloween costume is going to be this year! Please feel free to stop by our front desk and drop off some fun, costume suggestions. Nothing too scary!!



## Respite Weekend 2018: Baltimore

Javin Smith, Program Operations Manager

Each year, The Children's Inn at NIH has the opportunity to take up to ten families on an all-inclusive, two-day, one-night mini vacation. This weekend getaway is made possible through the generous support of the Children's Cancer Foundation. This respite provides families the opportunity to meet other families and spend quality time together. Past trips have been to the National Harbor and Old Town Alexandria, Virginia.

In September, eight families enjoyed a special trip to the Inner Harbor in Baltimore, Maryland. The weekend began by stopping at the local Giant Grocery Store in Bethesda where families met Children's Cancer Foundation representatives and received bags full of snacks and drinks for the getaway. The next activity challenged everyone's ability to think on their feet as they were locked in an Escape Room and had to solve clues in a push to freedom. While it was a lot of fun, the rooms proved to be a bit too challenging and no one escaped! There's always next time. After lunch, families headed to their hotel in Baltimore's Inner Harbor. After relaxing for a bit, families participated in a behind-the-scenes tour of the National Aquarium, spending time with sharks, a 400 lb. sea turtle and an immersive adventure in the Australian Outback. The evening concluded with dinner at BRIO Italian Grille, followed by ice cream and a walk around the harbor.

The next morning, despite the rain, families braved the elements to tour the USS Constellation. The tour gave a fascinating look at what life was like on the ship in the 1800s. Families learned that you did not want to be one of the powder boys that carried gun powder between the cannons! The weekend culminated with lunch at the Cheesecake Factory, with cheesecake to-go, before boarding the bus back to The Inn. Respite Weekend was truly a fun and eventful adventure for everyone!



*Faith Anne and Mom on  
The USS Constellation*

## ACTivitiEs

**Art & Collage:** Make unique artistic collages using a variety of designed paper, stickers, letters, and fun scissors.

**BINGO:** Come eat Georgetown Cupcake's famous goodies and play BINGO to win great toys and prizes. Fun for the whole family!

**Family Dinner:** Enjoy a meal provided by our friends in the community, meet new families and catch up with friends in the E Dining Room.

**Family Night:** Bring the whole family along for a night of fun activities and community-building time with fellow residents.

**Grocery Store Run:** Sign up at the front desk for weekly grocery shopping trips to Giant or Shoppers.

**Open Play:** Drop your kids off for an hour of Inn staff-supervised fun play on the sport court or Multipurpose Room.

**Caregiver Gathering:** Join other parents and caregivers for music and conversation, build friendships and share support.

**Seated Massage:** Enjoy a 15-minute seated massage Tuesday evenings by licensed masseuse Erasmo in the Teen & Young Adult Lounge

**Spiritual Support:** Talk to NIH Chaplain interns at The Inn Monday and Wednesday evenings. Ask our Resident Services staff for information on places of worship and services held at the Clinical Center.

**Teen Night:** Fun just for teens. Meet new friends; enjoy a group game or project and meaningful conversation with peers and program leaders.

**Young Adult Night Out (YANO):** Young adults ages 18-30 enjoy a night out for dinner or an activity with their peers at a local restaurant. The outing is sponsored by The Children's Inn.

## A Place Like Home with People Like Family

Connie, Children's Inn Mom

They say it takes a village to raise a child. Few people realize how important this village becomes when the child is diagnosed with a rare, life threatening disease. In August of 2014, our youngest daughter, Meghan, was diagnosed with a life-threatening, rare genetic immune disorder called DOCK8 deficiency. The disease had only been discovered five years prior, and there were very few known cases worldwide. Since the research team of brilliant scientists who identified the disease is located at NIH, it made the most sense for us to receive care there. During our first NIH visit, our son, Lliam, was found to also have DOCK8 deficiency. For the past four years ago, the Children's Inn at NIH has been our "home" for every clinical visit; including the entire time of Meghan's bone marrow pre-transplant work-up, nearly two months of in-patient hospitalization, and during post-transplant out-patient observation period. This is when we needed our village the most.

Managing responsibilities back at home in New York while caring for Meghan at NIH can get very overwhelming. During this incredibly difficult time, family and friends have come to our assistance back at home, as did the staff and volunteers of The Children's Inn. During Meghan's hospitalization, The Children's Inn provided a place for my husband and other children to stay so they were able to visit to help support Meg through her recovery period. Meghan has always enjoyed staying at The Children's Inn as part of our past clinical visits because of all the wonderful surprises and activities that the very special staff and volunteers provide, so she was very much looking forward to being discharged and staying the rest of the summer at The Inn. Unfortunately, just prior to her discharge, Meghan was placed on isolation. The thought of prolonging Meg's hospitalization for another three weeks was crushingly devastating.

During this difficult time, The Children's Inn was there to offer another "place like home" in downtown Bethesda at the beautiful Brody Apartments. The apartments truly allowed Meg to comfortably recover and feel the accomplishment of discharge. Our apartment is fully furnished, well planned and well stocked. We couldn't have needed or wanted for anything while staying at the apartment because they had already anticipated all of our needs and made sure they were met. By carefully placing us in this beautiful place for Meg to recover was as if we were being told, "You are part of our family; we always have your back, and especially at your greatest time of need, we are not going to let you fall." As if providing this wonderful space weren't enough, it was also made clear to us that we shouldn't feel isolated or disconnected from The Inn community. We were provided a liaison from The Inn, Alma, with whom we were encouraged to communicate any needs or concerns. Once off isolation, Meghan was encouraged to come back to The Inn for any and all fun activities that she would like to participate in. We have spent approximately seven weeks living comfortably at The Brody apartment. It is a short drive to the Clinical Center, so there was never an issue getting to and from appointments. Exploring the city of Bethesda on foot provided Meg with much needed exercise after her long hospitalization. We were encouraged to come for family dinners whenever possible. The Children's Inn continued to provide a grocery gift card each week, and Giant is located at a short walking distance from the apartment. I enjoyed cooking for my family each night and we were able to sit down comfortably and eat dinner as we would at The Inn. My personal favorite amenity of the apartment was the rooftop penthouse. This is a beautiful common space where I spent many evenings watching gorgeous sunsets.

My family and I couldn't be more thankful to The Children's Inn for all their thoughtfulness and caring in providing Meg's recovery space. In the words of my oldest daughter and Meg's bone marrow donor, Brooke: "When we were first made aware of Meghan's possible genetic disorder, I didn't want to accept it, so I just didn't think about it. I didn't think it would be a bearable experience."

*Continued on next page*

## LaUGHTer



## A Place Like Home *(continued)*

When we arrived in Maryland, I was very surprised upon entering The Children's Inn. Not only was it a cozy place to stay while seeking treatment for my now two newly DOCK8 diagnosed siblings, but it was entertaining and full of life. Nearly every day was jam-packed with activities and events that families could attend in-between and after many taxing hospital appointments. The Children's Inn had completely changed the experiences my family had at the NIH. When we had moved into a charming apartment in Bethesda, I didn't want to part with the experiences we were having at The Inn, however, when we did move in, there were many great things to do around Bethesda. The nearby stores remind me of a town near home on Long Island that we like to visit. With all that we had going on during this time in our lives, our experience was made enjoyable."

In Meg's own words, "My family and I are extremely thankful that The Children's Inn gave us the opportunity to stay at the Brody Apartments because it allows us to be placed in an environment that's more comforting than a hospital room. It allows us to get out and about more often, and there's a shopping center down the street so we don't have to go too far for groceries. The rooftop view of the city is beautiful, especially at night. Many times, me and my mom find ourselves on the roof, stargazing. I am grateful that The Children's Inn has allowed us to stay here for the tail end of the summer."

## Unbe-leafable Education this Fall

Javin Smith, Program Operations Manager

School is back in session, which means that Education Programs are in full swing! Even though we are excited that school has started, we recognize the amazing summer we had! Camp INNcredible and the INN Squad Teen Program were the highlights for the families who visited. We traveled to other countries, learned about outer space and plunged beneath the depths of the ocean to study marine life. The INN Squad provided activities specifically for teens, including a Starbucks Run and pasta making. Camp also included great trips to The Smithsonian Folklife Festival and Great Falls. Camp INNcredible culminated with our Summer Finale Party!

This Fall we are excited for all the activities that are planned! Study4Fun resumes on Mondays and Wednesdays from 3:30 p.m. - 4:30 p.m. This is an opportunity for caregivers to drop off their children for help with school work. Just like real super heroes, we will be putting on our capes and exploring Comic Book heroes for Snack and Discover. Another education program to look for is ExploreINN. This is an afternoon dedicated to STEM activities. As with any of our programs, our goal is to keep kids engaged and learning while they are here at The Inn.

We also have fun trips to look forward to. Beginning in October, we will head to the Washington monuments, where families get to stroll through history. To get our full fall fix (say that 10 times fast), we will head to Butler's Orchard to learn about farms and pick our own pumpkins. As the leaves change, there are always fun activities to do!

Whether you are visiting The Inn this fall for a day or a month and would like to learn more about the educational services available, please email Javin, The Inn's Program Operations Manager, at [javin.smith@nih.gov](mailto:javin.smith@nih.gov). You can also stop by the Multipurpose Room when you get here. We love having visitors and making new friends!

## ProGRAms

**AdventureINN** provides opportunities for the entire family to take field trips to Washington or other places in Maryland and Northern Virginia. Come explore museums, monuments and cultural activities. Our educational field trips take place once a month.

**English Classes** provide an opportunity for all non-English speaking adults and children to learn, improve or maintain English-language skills. Classes are tailored to meet the needs of each individual.

**ExploreINN** is The Inn's science program that provides hands-on learning experiences for our school-aged residents. This program is often sponsored by scientists from the NIH or by other members of the community and has included experiments such as testing for acids and bases, exploring DNA, making homemade glue and much more. ExploreINN is typically held twice a month.

**Snack & Discover** is a time for children of all ages to bring their homework to the Learning Center and receive support from a certified teacher. If children don't have homework, they can play educational games or do fun activities. Snack & Discover occurs once or twice a week.

**Study4Fun** is a time when parents are encouraged to drop off their children in the Learning Center to do homework, read or play games. No need to preregister: just drop in any time between 3:30-4:30 p.m. on Mondays and Wednesdays.

