



# The Inn Welcomes Zilly

Studies show that having a furry companion can lead to several positive emotional and physical benefits. After The Inn's previous therapy dog, Vi, retired, a 'BARK Committee' was formed to make the very important decision of recruiting a new four-legged friend. We're excited to announce that an adorable one-year-old Labradoodle arrived at The Inn in mid-January and, after a successful trial period, we've determined that she is the perfect fit for us!

Zilly is a multi-generational Australian Labradoodle, a breed that is known to be hypoallergenic, friendly, energetic, and good with families and children. Her breeder had noticed her gentle and calm temperament from a young age and, because of these special characteristics, wanted to place her as an aid/therapy dog. Her duties at The Inn include playing games of fetch, performing tricks, enjoying petting and belly rubs, and spending time with Inn residents during our many programs and activities.

## INNspirations

SUMMER 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 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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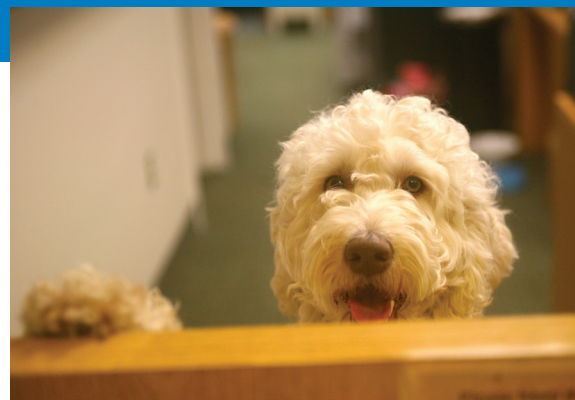
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"Zilly brings so much comfort, security and just plain fun to our special families," says Jennie Lucca, The Inn's CEO. "She is definitely an extrovert and gets her energy from being around the kids. She has a lovable personality and it's great to watch children playing fetch with her or getting down on all fours and cuddling with Zilly," Jennie adds.

Al Marx, the owner of Obedience Works, LLC, has generously volunteered his time to help train our new therapy dog, visiting The Inn once a week for a session with Zilly and several staff members. Volunteers and staff members reinforce Al's training with Zilly four times a day on weekdays. Ongoing training will include passing the Canine Good Citizen test, followed by the National Capital Therapy Dog test—which will enable Zilly to visit patients at the NIH Clinical Center. Zilly is now 16-months-old and most therapy dogs become certified at 2-3 years of age.

A Better Pet LLC provided Zilly's training foundation and placement guidance at The Inn and Zilly is groomed at Groomingville in Rockville, MD. The Inn's therapy dog program is made possible by the support of Tom and Mimi Nordlinger and the Gwyn and Nancy Ackland Memorial Fund at the Montgomery County Community Foundation through trustees Steve and Louisa Hollman. Welcome, Zilly! We look forward to many years of you bringing smiles to the faces of Inn children and adults alike.



**Hi! My name is Zilly and I'm the new therapy dog at The Children's Inn. Stop by to see me when you're here!**



Hedieh and Pari share their thankfulness for what The Inn has provided for them.

## Making Friends From Half a World Apart

**H**edieh Hajesmaeili is an energetic 10-year-old from Tehran, Iran. It's hard to miss her sense of style as she models something new every time she passes The Inn's front desk. Her family came to the NIH in November so she could receive treatment for DOCK8 immune deficiency. This hereditary disease can cause recurrent ear and sinus infections, pneumonia, allergies, asthma, eczema, viral skin infections, and can also lead to cancer. The family already lost one daughter to the same illness in Iran because they were originally unable to diagnose this rare condition.

With a great deal of anxiety, Hedieh and her mother, Pari traveled to the NIH in hopes of a cure. "I was coming to an unfamiliar environment where I did not know how to communicate and didn't know anyone," says Pari. "I was very worried about the surgery she needed and what would happen after, and what our fate would be."

Doctors here recommended that Hedieh undergo a stem cell transplant to establish a new immune system. Prior to the procedure, the family stayed in one of The Inn's isolation rooms because Hedieh carried an antibiotic resistant virus. Although they were initially restricted to that room, Hedieh and Pari looked forward to the evenings when they could spend time talking with an overnight staff member who spoke Farsi.

Pari tears up as she recalls how lonely she initially felt but how the welcoming staff made her feel like The Inn was her second home. During the Christmas season, Hedieh was excited to receive many gifts and to have a special visit from Santa. After New Year's, Hedieh father, Ali Akbar was able to come and join his wife and daughter, and the family was able to take trips into the community together.

After her transplant, Hedieh and her mom were able to take advantage of the many trips and activities offered at The Inn. "I love playing with Zilly and swinging on the playground," Hedieh exclaims in English, as she has become quite fluent thanks to help from Ronny, The Inn's full-time teacher.

"One of the most amazing things about staying here has been connecting with other families from different parts of the world and the States," says Pari. She became close friends with a mother from the Dominican Republic, as they cooked and laughed together in The Inn's kitchen. "Even though our countries are half a world apart, we are mothers who walk the same path; we understand each other through love."

## Holly Gibbons: New YAC President

**I**n May, The Children's Inn welcomed Holly Aprea Gibbons as the new President of its Young Ambassador Council (YAC). Holly earned her Bachelor of Arts in Political Science at American University in Washington, DC, and her Masters in Public Policy from the University of Minnesota's Humphrey School of Public Affairs. She has worked in the health policy and government relations fields for more than fifteen years, focusing on tobacco prevention policy and cancer research. Holly is a Program Analyst in the National Cancer Institute's Office of Government and Congressional Relations.

Holly has been volunteering at The Inn since becoming a part of the NIH community and she looks forward to continuing to support its mission as President of the YAC. When not working or volunteering on the NIH campus, Holly enjoys running with her husband, Steve, and her son, Abe, exploring DC's parks, and spending time at the beach with her family in Massachusetts.



Holly Aprea Gibbons, YAC President

## 25th Anniversary Update

**25**  
YEARS  
1990–2015

### At the Intersection of Hope & Science: 25 Years of Advancing Medical Discoveries

The Children's Inn celebrated its 25th anniversary with a symposium at Masur Auditorium in the NIH Clinical Center on June 18. This thought-provoking and emotional event highlighted The Inn's contribution to pediatric research and how those discoveries have benefited people the world over.

Dr. Francis Collins, NIH Director, described the partnership between the NIH Clinical Center and The Inn: "In those past 25 years, our nation has made impressive gains in health and longevity. It is progress that has been hard-won and that requires an amazing village of scientists and clinicians of all sorts, along with patients and families all working together."

"Before The Inn existed, it was really awful in many ways," said Dr. John Gallin, Director of the NIH Clinical Center. "Families were sleeping in the waiting room or in their cars. They came here at their own expense and families were frequently split up. As a result, divorce was very common as well." Gallin recalled hearing Dr. Phillip Pizzo's vision of creating an inn for pediatric patients and their families and his astonishment that Dr. Pizzo, along with a group of Congressional spouses and the generosity of Merck were able to make the dream a reality.

Jennie Lucca, Inn CEO, spoke about the anxiety and fear that families often experience when they arrive. "They leave their homes, their jobs and their support systems to come to the NIH to be seen by clinicians who have made it their life's work to study their child's disease, and what they discover when they arrive at The Inn are all the things we do to provide a complete sense of respite to make sure that families feel safe and cared for."

Ben Banks, who stayed at The Inn in the mid-90s, described his experience coming here as an HIV-positive teenager. Now 36, he had unknowingly received contaminated blood during surgery for pediatric cancer. Little was known then about how HIV/AIDS affected children, but most patients were not expected to survive for more than two years. Ben's mother enrolled him in a clinical trial at the NIH, and he has not only been healthy, but has gone on to complete a master's degree in public health, get married, and with some medical intervention, he and his wife Kasiah were able to have a biological HIV-free child. "The Inn provided me with hope for the future and medicine has made it possible for me to have a family," Ben said.

Dr. Lauren Wood of the National Cancer Institute and a member of The Inn's Board of Directors led a panel discussion with three NIH physicians and their young patients. The physicians included: Dr. Steven Holland, National Institute of Allergy and Infection Diseases, Dr. Crystal Mackall, National Cancer Institute, and Dr. Raphaela Goldbach-Mansky, National Institute of Arthritis and Musculoskeletal and Skin Diseases. The patients who spoke were Robert Harding, 25, from New Jersey, Amanda Lee, 20, from Massachusetts, and Isaac Barchus, age 11, from Nebraska, along with his mother, Kathe.

"This fireside chat has been 25 years in the making," said Dr. Wood. "It's been born out of a purity of passion and commitment to see not only the science move forward, but to make a difference in the lives of patients and their families as well as the global populations that are affected with those diseases," she said.

*continued on page 4*



Dr. Francis Collins, NIH Director, described the unique and important partnership between the NIH Clinical Center and The Inn.



Inn resident Isaac Barchus and his physician, Dr. Raphaela Goldbach-Mansky, were part of a lively panel discussion.

## 25th Anniversary Update

### The Inn's 25th Anniversary Year Filled with Special Celebrations

It has been an eventful year as we celebrate the 25th Anniversary of The Children's Inn! Festivities kicked off last September at the KitchINN Grand Opening—an enjoyable event that highlighted our newly remodeled kitchens with sampled hors d'oeuvres made by DC-area celebrity chefs—and have continued up to our first-ever Symposium: “At the Intersection of Hope and Science,” highlighting the past 25 years of pediatric research and The Inn's role in supporting that research. NIH physicians and Inn families shared their remarkable stories and the fascinating scientific advances that have been made in treatment of their diseases (see Symposium story on page 3).

Amidst the many celebrations and wide array of activities this year, a very special event took place at The Inn on June 4 for staff, board members, residents, volunteers and supporters at our 25th Anniversary Picnic. It was a fun-filled evening with music by DJ Beauty and the Beatz, a mouth watering BBQ dinner, riveting acrobatics by Radiant Hoops, and special speakers including former Inn CEO Kathy Russell and long-time board member Holly Parker. Former Inn resident Lucia Cruz, 33, shared her memories from when she was just a little girl seeking treatment at the NIH before The Inn existed and then finally being able to spend time here between her treatments after it was built. We had the opportunity to honor individuals and community partners who have supported The Inn throughout our 25-year history, including volunteers who have been with The Inn since first opening our doors in 1990 and local car dealership Chevy Chase Acura, who has continuously supported The Inn's hallmark Come Back to Bethesda Car, Truck and Motorcycle Show fundraising event. Thank you to the Richard and Audrey Mandell family for their gift to support this important and special event.


The culmination of anniversary celebrations will take place at our annual Congressional Gala on October 8 and with our participation in the Marine Corps Marathon on October 25. We are extremely grateful for the overwhelming support of sponsors and local community groups who have made all of these celebrations possible.

Major medical advances have been discovered in the last quarter century and with the help of our supporters, we will continue to be a partner with the NIH in medical discovery and care for 25 more years of hope and healing at The Children's Inn.

### 25 Years of Advancing Medical Discoveries (continued)

Dr. Collins ended the afternoon with a discussion about the future of medical research and The Inn's role in supporting and facilitating that research. “It's a special kind of partnership,” he said. “Nobody who has had their life touched by being involved in this, whether as a volunteer, as a physician taking care of patients, or as a child or a family who stays there [at The Inn] leaves without being touched by that experience.”

The Inn wishes to thank our generous sponsors for supporting the 25th anniversary symposium: PWC, Booz Allen Hamilton and The Hill Group.



Radiant Hoops entertained the 25th Anniversary Picnic attendees with an exciting aerial arts performance.

*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.*



Inn resident Keller Lai's father, Lothar, was one of the speakers at the 2nd Annual *An Evening for Hope* gala.



Robert Filippone (left) and Brian Kelly (right) join the Board of Directors at The Inn.

## 2nd Annual An Evening for Hope and 8th Annual Golf INNvitational A Success

The Children's Inn had a busy spring season with two very successful fundraising events. On May 2, Inn supporters gathered for the 2nd Annual *An Evening for Hope* gala at The Ritz-Carlton in Tysons Corner, Virginia. More than 750 guests enjoyed delicious food, great wine, and silent and live auctions to benefit The Inn. Budding pop star Aishlinn Kivlighn kicked off the evening with a beautiful rendition of the National Anthem and the night was capped off by inspirational stories from Inn residents and a witty performance from political satirist The Capitol Steps. Under the excellent leadership of Event Chair, Robert Guerra, a long-time supporter of The Inn, and Inn Board Chair, Kelvin Womack, the evening raised more than \$700,000 in support of The Inn and its mission to provide "a place like home" for families with children treated at the National Institutes of Health.

On Monday, June 1, enthused golfers spent the day at Lakewood Country Club in Rockville, Maryland for the 8th Annual Golf INNvitational. The event provided golfers the opportunity to enjoy a round of golf at the championship Lakewood golf course, followed by a reception with light fare, awards, and live and silent auctions. Inn resident Scott Vogel, 25, spent the day golfing and shared his inspiring story with guests during the evening reception. Over the past eight years, the golf outing has raised more than \$1 million for seriously ill children and their families at The Inn. We extend our gratitude to the many individuals and sponsors who made this year's INNvitational possible, including Platinum Sponsor Booz Allen Hamilton and Gold Sponsor TerpSys. Save the date for next year's tournament: Monday, June 6, 2016.

## New Members Join Board of Directors

The Children's Inn at NIH welcomes Bob Filippone and Brian Kelly to its Board of Directors. Bob Filippone is currently the Vice President, U.S. Policy and Government Relations at Merck. He and his team represent Merck in Washington, DC and are responsible for U.S. policy development and legislative advocacy on Merck's key federal issues. They also oversee the administration of the Merck PAC and the company's grassroots program. Bob holds a PhD and a Master's degree in international relations from the Fletcher School of Law and Diplomacy at Tufts University, and Bachelor's and Master's degrees in engineering from Worcester Polytechnic Institute. He is married to Desiree Geneva Filippone and they have two sons and a daughter.

Brian Kelly, Editor and Chief Content Officer, is a member of U.S. News & World Report's executive committee, with primary responsibility for all the company's content, which includes the websites usnews.com and rankingsandreviews.com, print and e-book guides on education and health care, and a conference and events business. He has led the transformation of U.S. News from a traditional print news magazine to a largely digital publishing company. Under his leadership, usnews.com has gained an audience of more than 30 million monthly users. He is a Vice President of the Economic Club of Washington and a former board member of the World Affairs Council of DC. Brian holds a Bachelor's degree in economics from Georgetown University. He is married to Pat Wingert and the couple have three children.



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Cathy Morales and Brian Dowell have joined The Children's Inn leadership team.

## The Children's Inn at NIH

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## Meet Cathy Morales and Brian Dowell

We are happy to welcome Cathy Morales and Brian Dowell to The Inn's leadership team. As The Inn's Chief Program and Services Officer, Cathy oversees the management of resident services, family programs, the facilities, volunteers and community outreach programs. Previously, Cathy served as the National Program Director for the National REACH Coalition, where she was responsible for the development and implementation of REACH's organizational and programmatic goals. She brings experience from her work in other nonprofit organizations that focus on improving health outcomes for vulnerable populations. Cathy was born and raised in Kingston, Jamaica and currently lives in Washington, DC. She earned a Bachelor of Science degree in Human Services from Lesley College in Cambridge, MA, and a Masters of Business Administration from Northeastern University in Boston, and was awarded a Certificate of Recognition from Boston University's School of Public Health.

Brian Dowell, Director of Facilities & Construction Management, is responsible for leading, planning, coordinating and managing facility and construction functions at The Inn and The Woodmont House. He most recently served as a Project Director for Capital and Construction Solutions with MedAssets, and prior to that was a Health Care Construction Program Manager with Monteith Construction-developing and managing healthcare construction for a number of medical and hospital facilities. Brian was born and raised in Howard County, Maryland and has recently returned to the Washington metro area after living in North Carolina for a decade.

Brian earned a Bachelor of Science degree in Civil Engineering from Virginia Tech and a Masters of Business Administration from the University of North Carolina at Wilmington. He holds a Project Management Professional (PMP) certification.