

# The Inn To Celebrate 25th Anniversary

he Children's Inn at NIH will mark its 25th anniversary on June 21, 2015 and the countdown to that historic day is beginning. We are looking forward to a year of celebration, retrospectives and special events leading up to the big day.

When the founders of The Children's Inn first envisioned this project, it was a revolutionary concept. Merging public and private resources to establish The Inn took hard work, dedication and commitment. Their dream became a reality in June 1990 when the opening ceremonies were held with President and Mrs. George H.W. Bush and many other dignitaries present for the ribbon cutting. Now, almost a quarter century later, President George H.W. Bush and his wife, Barbara are delighted to serve as the honorary chairpersons for the 25th anniversary of The Children's Inn.

# rat The Children's Inn at NIH

#### **SUMMER 2014**

#### 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.

- Respond to evolving family support needs from pediatric research and clinical care
- Provide a free family-centered "place like
- Reduce the burden of illness through therapeutic, educational and recreational programming

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Since 1990, The Inn has provided more than 12,500 children and families from all 50 states and more than 80 countries with emotional and social support while they are receiving treatment at the NIH. Along the way, we have added a new wing, expanded our recreational and therapeutic programs, opened The Woodmont House, adjacent to the NIH campus, and even welcomed Vi Mars, our therapy dog.

We are planning a variety of activities and events to celebrate and commemorate the 25th anniversary kicking off with an opening reception in our newly remodeled kitchens where



The Children's Inn at NIH is counting down to its 25th anniversary on June 21, 2015.

we will sample hors d'oeuvres made by celebrity DC-area chefs. The Congressional Gala in September and publication of a "Hope" book of art, poems and short stories by Inn residents will follow. We are excited for our second annual "An Evening for Hope" gala next spring, for which Bloomingdales at Tysons Corner has already committed to donating a portion of sales for a weekend prior to the event. We are planning to reach out to national media and the year will culminate with a very meaningful anniversary reunion for residents and Inn friends next June.

The Children's Inn vision and mission statements have been updated, effective July 1, 2014—stay tuned for more details as the year unfolds. We are looking forward to an exciting anniversary year!



Manuel, Daniel and Dana Iniquez

# Meet Inn Residents: The Iniguez Family

Six-year-old Daniel Iniguez of Ontario, California has been coming to The Inn twice a year for the past four years so that researchers can follow him to better understand and treat his neurofibromatosis type 1 (NF1). NF1 is a genetic disorder in which patients are at increased risk of developing tumors (usually non-cancerous) of the nervous system, which affects essentially every organ system.

When Daniel was only nine months old, his mom, Dana Iniguez, noticed that he had unusual "cafe-au-lait spots," a symptom of NF1. Doctors in California diagnosed Daniel with a brain tumor and after many more tests and visits to top specialists, the Iniguez's were referred to the NIH.

When Daniel comes to the NIH, his mom says that he tells people matter of factly, "I'm taking an airplane to The Children's Inn." Although they leave his two brothers, Joey, 13, and Anthony, 4, his sister Natalie, 11, and two dogs named "Chance" and "Bones" at home, "Daniel is ecstatic about coming to The Inn," says Dana. "His absolute favorite thing is the 'treasure' he finds in his mailbox at The Inn every day and he absolutely adores the Playground. The fact that he loves to come to The Inn is one thing off our plates."

The disorder is causing Daniel to lose some of his eyesight and muscle tone, and he is now in a wheelchair much of the time. He is excited about the possibility of soon getting a service dog.

Dana and her husband, Manuel certainly have a full plate—in addition to Daniel, their older son has autism and their daughter has Tourette's syndrome. They find solace in talking with other parents at The Inn. "Our struggles are all the same—it is a different feeling to know someone really understands what you are going through," says Dana. And although Daniel's case is progressing faster than average, his mom says, "I know that Daniel has the best [here] that I can do for him."



## The Inn's Board Welcomes Matt Bell

Matt Bell, PhD, Chief Operating Officer, MedImmune, has joined The Children's Inn Board of Directors. Prior to his work at MedImmune, Matt worked in a number of different R&D roles at Wyeth, PA and at Cambridge Pharma Consultancy in New York. He moved to the Maryland area in 2010.

Matt graduated with a degree in Natural Sciences from the University of Cambridge, England and completed his post-graduate studies in the drug discovery laboratories of Parke Davis Neuroscience.

As someone who has worked his entire career in the life sciences, Matt is excited to be joining The Children's Inn Board of Directors to connect more directly to patients who can benefit from advances in healthcare and clinical practice.

Matt lives in Gaithersburg, MD with his wife and two young sons.

# **INNspirational**



The Papier family: Darrile, Dillon and Mark, attended An Evening for Hope where Mark spoke about Dillon's illness and how the support they receive at The Inn makes their situation easier.

# Recent Events Make a Big Difference

hank you to our long-time friends at the AFCEA Bethesda Chapter, who raised \$275,000 for The Children's Inn at the 16th annual "A Night for the Children" gala held on March 22 at The Marriott Wardman Park in Washington, DC. Stephanie Hill, President of Lockheed Martin's Information Systems & Global Solutions, served as Chair of the black-tie event. Guests from the high-tech community delighted in a lively and enchanting evening of dinner, dancing, casino games, and a silent and live auction.

On April 5, The Children's Inn celebrated its inaugural fundraising benefit, "An Evening for Hope," at The Ritz-Carlton in Tyson's Corner, VA. More than 700 health industry supporters, high-level corporate executives, and entrepreneurs who represent all areas of the federal information technology community attended the event. Under the excellent leadership of Robert Guerra, a long-time supporter of The Inn, and Kelvin Womack, Vice Chair of The Inn's Board of Directors, the event raised \$740,000 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.

The Inn hosted its 7th annual Children's INNvitational at Lakewood Country Club in Rockville, MD on June 2. Over the past seven years, the golf outing has raised more than \$1 million for seriously ill children and their families to stay at The Inn. Thanks to the many individuals and sponsors that made it possible, including Platinum Sponsor Booz Allen Hamilton and Diamond Sponsor TerpSys. Save the date for next year's tournament: June 1, 2015.

The INNvitational wasn't the only golf outing this spring. On April 28, Passion Food Hospitality hosted the ComPassion Golf Tournament benefiting The Inn for the fourth year in a row. On May 3, GovPlace hosted the 7th annual Federal IT Golf Tournament, raising \$60,000 for The Inn. And while they didn't play golf, employees at ProShares raised \$27,215 for The Inn at their annual employee Casino Night on May 15.



Spin for The Inn at Equinox in Bethesda was a success.

## Fitness Fundraisers for The Inn

Inn supporters are embracing fitness as a fun, new way to raise awareness—and funds— I for The Children's Inn at NIH. On May 3, 2014, a group of volunteers led by The Inn's Young Ambassadors Council (YAC) hosted the inaugural "Spin for The Inn!" fundraiser at Equinox in Bethesda, MD. Forty cyclists participated in a vigorous 45-minute spin class, with an emphasis on breath work, cadence and mind-body awareness. Most importantly, before the event started, the riders asked friends, family and colleagues to join them in supporting The Inn by donating to their personal fundraising web pages. Collectively, the group raised \$3,155 for The Inn!

Equinox donated the event space, equipment and the instructor's time, and generously agreed to award the event's top fundraiser with a free month of membership. "It was a great workout and a unique way to support a cause I'm passionate about," said Ariel Beck, who participated in the event and raised almost \$300 for The Inn.

The YAC is already building on the success of Spin for The Inn with other exerciserelated events this spring and summer, including a Barre Body® class held on May 31 and a yoga class that's being planned for July. Check The Inn's website to sign up for these events as they are posted.



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The Inn's recently renovated Children's Computer Room.

#### 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 and click on Get INNvolved to learn more about how you can help the many children and families who call The Inn home.



# Children's Computer Room Renovated

The Children's Computer Room on the second floor of The Inn, adjacent to the Bistro and family den, is a popular spot for residents. Recently redesigned and renovated to better support the growing technology needs of our residents, this updated space is where children of all ages can play educational and fun computer games, keep in touch with friends and family back home via email, Facebook and instant messaging, and meet other kids facing similar medical challenges. Thanks to our generous friends at The Children's Cancer Foundation (CCF), this room has a fresh and modern look, with two wall mounted Apple iMacs and three contemporary computer desk stations. A wide border of Van Gogh graphics encompasses the room, adding some color and flare. Parents can keep an eye on their children as they work on their laptop or iPad at the work desk and charge station. It was an exciting project for The Inn's facilities and resident services team and we extend our gratitude to the CCF for giving us this opportunity. The CCF provides grants not only to The Inn, but also to many other organizations contributing to research and treatment of cancers that affect children and facilities that help to improve the quality of life of pediatric patients and their families. It is because of their contribution that The Inn has been able to create a much more comfortable and inviting space where residents can stay connected.