



## Summertime Fun at The Inn

Childhood is precious and summer is one of the most sacred times of all. Structured schedules are replaced with vacations, camps and family barbecues. Interrupting childhood and summer freedom to treat a major medical condition can impede experiences that contribute to normal child development. Whether a two-day or two-month visit, The Inn strives to give children an opportunity to recapture the hope, enthusiasm, and sense of adventure that are essential parts of childhood.

If possible, families schedule NIH treatment when school is over, making summer The Inn's busiest season. With school out of session, summer months allow the flexibility to travel as an entire family and we see an increase in siblings at The Inn.

This summer is especially meaningful as we opened our new playground and park on May 22. This expanded outdoor space promotes both play and learning. In the coming months, families will attend Washington Nationals baseball games, tour

# INNspirations

The Children's Inn at NIH

## SUMMER 2013

### Mission Statement

The Children's Inn at NIH is a private, nonprofit residence for families and their children who are participating in pediatric research at the National Institutes of Health's Clinical Center. The Inn enhances the opportunities for groundbreaking medical discoveries by providing a free "place like home" that reduces the burdens of illness through a supportive environment including therapeutic, educational and recreational programming.

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DC monuments and take nature hikes. Family Dinners will include grilling and serving meals on the terrace. Our annual Camp INNcredible will bring traditional camp to life and gives parents time to work out, catch up on email or have coffee with fellow residents. Volunteers will engage kids in science experiments, theater and other activities that involve physical exercise. The Inn's Education Program Coordinator, Ronny Kempenich, ensures that teen counselors and kids have ample time to interact on their own, resembling a true camp experience where summer friendships quickly form.

The two-day Teen Retreat is another summer favorite, where activities build confidence and encourage interaction. Sibling Day gives siblings a firsthand look at the many procedures that their ill brothers and sisters endure. Siblings then enjoy group activities and are honored in a "Super Sib" award ceremony that includes an ice cream social.

Residents at the The Inn's Woodmont House also embrace the season with gardening and weekly cookouts. Summertime brings added fun to Woodmont's monthly Adventure Day, with more outdoor destinations and use of DC's Metrorail system.

Devoting all or part of summer to a child's daily medical treatment is not how most families envision their summer months. However, thanks to many contributors and volunteers, Inn residents can still have fun together as a family and not miss out on the joys of summer.



Residents enjoy an outing to a Washington Nationals baseball game—just one of the many fun activities planned this summer for Inn families.

# INNSpirational KIDS



Majida, Majed, and Atidal Taleb

## From Beirut to Bethesda: Teen Creates Her Own Beat

Music pumps through Majida Taleb's heart. The rhythms and beats have kept the 18-year-old Lebanese teen humming and hopeful through much of her challenging childhood. Her health troubles began as an infant. She repeatedly fell ill with ear infections and fevers. Majida was never afflicted by anything too serious, but there was always something, says her mother, Atidal.

At age six, doctors told Atidal and her husband, Majed, that their daughter might have leukemia. A blood test instead revealed another serious, life-threatening diagnosis: Job's Syndrome, a rare genetic immune disorder. Doctors told the family they had never seen a case before in Lebanon. For four years, Atidal traveled back and forth between her homeland of Canada and Lebanon, searching for a second opinion and successful treatment. Majida needed costly IV medicines every three months, but finding and affording the medicine wasn't easy.

On her 13th birthday, September 21, 2007, Majida was hospitalized for two months as doctors tried to contain a viral infection. "Doctors let her go [home] because they didn't think she would make it," Atidal said.

In 2011, after a decade of tests and theories in Lebanon and in Canada, the Talebs came to the US for the first time, leaving Majida's younger brother and sister behind with family. At the National Institutes of Health, she was diagnosed with Dock8 deficiency, a gene mutation, and was one of a few young adults to receive a bone marrow transplant. Atidal was quickly reassured as doctors at the NIH had seen cases like this before.

At The Inn and The Woodmont House, they feel at home. "You're not a stranger here," Atidal says. "Being at home is not just a bed to sleep in or a roof over your head, it's a feeling," she says. "Thank you for making us feel at home." Though she lost her hair from chemotherapy, Majida is feeling strong and able to pursue her love of music. Bach to Rock, a Bethesda music school, offered Majida free guitar lessons. On Sunday afternoons, she walked with her dad to the studio for lessons. To the enjoyment of staff at The Woodmont House, she often practiced the iconic American song "Sweet Home Alabama."

An avid cook, who recently spent three days preparing an elaborate, authentic Lebanese meal for Inn families and staff, Atidal delights in watching her daughter flourish. "She is beating the odds," she says.

## Susan Penfield Joins Children's Inn Board

The Children's Inn at NIH welcomes Susan Penfield, Executive Vice President at Booz Allen Hamilton, to the Board of Directors. Susan leads the firm's Civil Health business and has more than twenty years of strategy development and technology delivery experience. She is a specialist in the management and strategic use of information technology within the national health industry.

Susan has provided consulting services to every major federal health-related organization in the US and is a leader in health reform initiatives within both the federal and nonprofit communities. She holds a B.S. degree in Technology Management from Lock Haven University in Pennsylvania and a certificate in management from Northwestern's Kellogg School of Business.



# INNspirational EVENTS



Left to Right: Dr. Lee Helman, Scientific Director for Clinical Research, NIH and Chair, Children's Inn Board of Directors; Alysin and Avery Ayan; Zach Peters, Dr. Francis Collins, NIH Director; and Dr. Anthony Fauci, Director, National Institute of Allergy and Infectious Diseases, NIH.

## AFCEA Bethesda Gala: 15 Years Strong

On March 23rd, the Armed Forces Communications and Electronics Association (AFCEA) Bethesda Chapter celebrated its 15th anniversary of supporting The Inn at their annual "A Night for the Children" gala. Nearly 1,200 people, representing all areas of the federal information technology communities, gathered at the Washington Marriott Wardman Park in Washington, DC to generously contribute their time and financial support towards making a real difference in the lives of Inn families. Under the excellent leadership of Gala Chair, Diane Pearson, and Gala Vice Chair, Susan Penfield, the event raised \$840,000 for The Inn.

Inn resident, Zach Peters, 23, took the stage and impressed the crowd as he spoke confidently about the serious genetic illness, Congenital Adrenal Hyperplasia, that has been bringing him and his family from their home in Ohio to the NIH for the past 20 years. A bubbly and excited 8-year-old Inn resident from Florida, Avery Ayan, and her mother Alysin, joined him on stage. Alysin spoke of Avery's journey to find a name for the disease that caused her to become very ill shortly after birth in 2004. Last July, doctors at the National Institute of Allergy and Infectious Diseases diagnosed Avery with an extremely rare autoimmune disorder called RALD, a disease similar to leukemia.

The high-tech community delighted in a lively and enchanting evening emceed by Inn Board Member, Cokie Roberts, that included dancing, casino games, and silent and live auctions. This annual gala has become The Inn's single largest financial source over the last fifteen years thanks to the amazing efforts of AFCEA Bethesda and our generous sponsors, including: Diamond: Lockheed Martin; Platinum: Booz Allen Hamilton, Deloitte, Hygeia Solutions Partners; Gold: Microsoft, SRA International, Inc., Sapient; Silver: DMI, Hewlett-Packard, Northrop Grumman; VIP Reception: Delttek, Optum, RTI International; 15th Year Celebration: PricewaterhouseCoopers.

## Second Annual A WINNter Affair

The Inn's Young Ambassadors Council (YAC) knows the trick for beating the winter blues: throw a great party for a great cause! On February 23, the YAC hosted the 2nd annual A WINNter Affair gala, where nearly 300 young professionals danced the night away under the twinkling light display of House of Sweden in Washington, DC. The event raised more than \$30,000 to support The Inn's mission.

Young Ambassador Michael Dendas has a personal connection to The Inn - his cousin was a patient at the NIH many years ago and he stayed with her family at The Inn during her visits for treatment. Michael graciously offered to speak at A WINNter Affair, explaining why he believes in the work the YAC is doing and sharing his family's experience with The Inn. "The Council offers you a way to volunteer, with both time and money, to benefit one of the most amazing causes there is," Michael said. "The Inn offered my cousin an environment of compassion, understanding, and normalcy. If you visit The Inn yourself, I promise you will see its magic."

A WINNter Affair is just one of many initiatives organized by the Young Ambassadors Council. The YAC hosts multiple community outreach and fundraising events annually, along with quarterly volunteer projects that provide a unique opportunity for young adults to volunteer at The Inn alongside their peers. Visit [www.childrensinn.org/youngambassadors](http://www.childrensinn.org/youngambassadors) to learn more.



Michael Dendas with Young Ambassadors Council President and Inn Board Member Beth Maloney at the second annual WINNter Affair to benefit The Children's Inn at NIH.

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Inn residents of all ages enjoy the new Park and Playground.

## 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](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.

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## Inn Park and Playground Officially Open

When can we go out there? Can we really go inside the nest? Are those real giraffes?! These are just a few of the many questions overheard at The Inn since construction on the new Playground and Park commenced over a year ago. Kids staying at The Inn intently watched the progress from the large windows in the Playroom, longing for the day when the new space would be ready for play. On May 22nd, their wishes finally came true as The Inn celebrated the grand opening of its state-of-the-art Playground and Park. More than 300 friends came to view the new space and mingle with families, staff, board members and volunteers over shaved ice and live music.

The new Playground and Park is the result of years of planning, design and fundraising. Groups of supporters and volunteers were honored with a personal ribbon-cutting ceremony hosted by CEO Kathy Russell and several Inn Board Members. Honored groups in attendance included SAIC, KaBOOM!, MedImmune, The NIH Federal Credit Union, Liberty Tire, GovPlace, and many more.

Attendees marveled at the Playground's new features, which include a tree house, putting green, interactive music elements, spirit nest, garden kaleidoscope, kinetic giraffe sculptures, amphitheater and much more. Kids broke in the pathways on bikes and trikes and entertained the crowd with karaoke. It was a thrilling day for both the children and many grown-ups who worked diligently to turn a dream Playground and Park into reality.