

Bereavement Family Support

The day after her son Cory would have celebrated his 19th birthday, Teresa Gaudet, from Massachusetts, received a gift in the mail from The Children's Inn. The pillar candle had a blue ribbon attached to a silver plate with the inscription: "Your light shines on." The gesture was more than symbolic for the Gaudets, who spent time at The Inn from December 2011 to March 2012 while Cory was treated at the National Cancer Institute for a rare brain cancer.

"We always felt so welcomed at The Inn," Teresa says. "It was like being in our own house. They went above and beyond." Knowing that The Inn was still thinking of the family a year later was comforting, she adds. "That is so important to any family that loses a child."

The small remembrance gift was part of The Inn's Bereavement Family Support Program, a grant-funded program that offers year-long support to families who have



INNspirations

The Children's Inn at NIH

FALL 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.

INNspirations

Published by The Children's Inn at NIH

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experienced a loss, and also offers guidance and training to Inn staff and volunteers.

"We want families to know that we remember and honor their child," says Ryan Whited, The Inn's Family Program Manager. As a certified Child Life Specialist, Ryan is trained to help families cope with the challenges of caring for a seriously ill child and support them through their grief if needed. Ryan stays in touch with families to be sure they receive support and resources throughout the first year after a loss.

The Inn's bereavement support includes sending books, brochures and resources for handling grief, geared towards the entire family, and phone calls to listen and offer encouragement. Ryan works closely with colleagues at the NIH Spiritual Care Department and counseling staff in case additional follow-up outreach is needed.

The program serves almost 100 families each year and is funded through a grant from the Jeff Gordon Children's Foundation. In addition, the program supports Inn staff and volunteers through quarterly grief management gatherings, and an annual Remembrance Service at the NIH Clinical Center.

The poignant annual Remembrance Service, held in the Clinical Center Chapel, includes speakers, music by NIH doctors and staff and a photo slideshow of every child who passed away that year. Photos continue to be displayed at The Inn throughout the year on a flat screen television in The Inn's upper living room.

"Receiving this candle was so special," Teresa posted on The Inn's Facebook page, prompting other families to write with gratitude about their visits to The Inn. "Cory's light does shine on."



The Inn's bereavement program offers a year of support to families after they have experienced a loss.



INNspirational PEOPLE



Inn resident Hope Vivian enjoys her monthly trips to The Inn, where she can get away from some of the stresses of college and catch up with Inn friends she's made during past visits.

Meet Inn Resident Hope Vivian

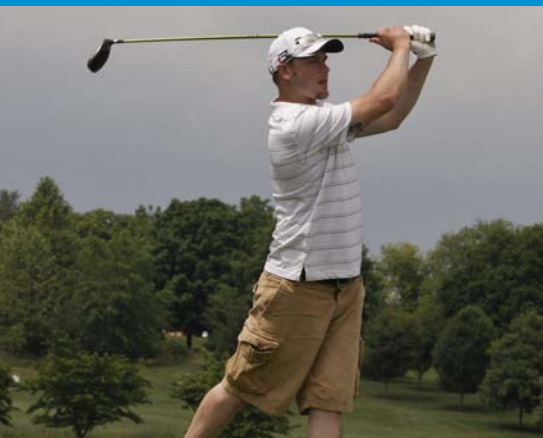
Although she usually travels to The Inn alone, 19-year-old Hope Vivian from Fort Collins, Colorado, has no trouble making friends with other residents. Hope has been coming to The Inn once a month since February 2013 to take part in a research study at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health (NIH). However, she has been involved with the NIH for three years.

When Hope was 16, her younger sister Hannah, then 12, was diagnosed with Behcet's Disease—an autoimmune disease in which the immune system attacks the body, often causing ulcers. It took a year for Hannah to be diagnosed, but when Hope started presenting similar symptoms a few months later, she was quickly diagnosed with the same disease. Soon after, both sisters began taking part in a natural history study at the NIH. There is no known singular cause of the disease, but Hope and Hannah brought an interesting genetic perspective to the study, since the disease is usually seen outside of the U.S., often in the Middle East.

After repeated hospital stays back home and trying three different medications with no success, Hope began participating in a different study at the NIH earlier this year. She is one of five patients enrolled in the study, which lasts a year and involves a trial of the immunosuppressive drug Anakinra. Hope takes two shots of Anakinra a day, and it is the only medication that she has responded to. "This is the best I've been doing in two years," she says.

Although her sister has the same diagnosis, the two have very different experiences with the disease. Hannah's ulcer outbreaks occur two to three times a year and always present the same symptoms. While her outbreaks are severe, resulting in several-day hospital stays for Hannah each time, her treatment is sufficient and doctors do not believe she needs an immunosuppressive medication. Hope's symptoms, however, are never uniform and her outbreaks occur more frequently.

Hope is grateful for her involvement with the NIH. "It has inspired me," she says. "I get the chance to help other Behcet's patients and my sister." Hope is a molecular biology major at the University of Colorado and plans to go to medical school after college.



Inn resident Dewayne Johns enjoyed a great day away from the hospital, on the links at the Sixth Annual Children's Golf INNvitational.

Sixth Annual Children's INNvitational

The Sixth Annual Golf INNvitational hosted 127 golfers at Lakewood Country Club in Rockville, MD on Monday, June 3. Golfers enjoyed lunch on the terrace before playing a full round of golf, followed by a cocktail reception, dinner, awards ceremony, and silent and live auctions. Thanks to the generous support of Diamond Sponsor TerpSys, Inn residents Dewayne Johns and Paul Patterson from Pennsylvania were able to participate in the day's activities.

Special thanks to the planning committee, all volunteers, and the generous sponsors who made the tournament possible: Booz Allen Hamilton, TerpSys, CA Technologies, GlobalNet Services, Inc., Ketchum, Porter Novelli, Russ Reid, Fleishman-Hillard, Washington Speakers Bureau, Grey Goose, The Hill Group, and Red River. Save the date for the seventh annual INNvitational on June 2, 2014. For more information, contact Lauren Stabert at lauren.stabert@nih.gov.



Thursday morning Welcome Desk volunteers Randi Evans (left) and Helen Wing (right) have enjoyed working together for the past decade to help Children's Inn families.

Volunteers Get More Than They Give

For nearly a decade, Helen Wing and Randi Evans have been “working” the Welcome Desk shift at The Children's Inn at NIH every Thursday morning. The cheery and cheeky duo greets families as they enter The Inn. With their wry sense of humor and bickering style, the two women keep Inn staff, families—and themselves—laughing their way through tough times.

Randi, 75, originally from Norway, has learned her way around the area and is quick with a travel tip for navigating DC. “Count the syllables in the street names,” Randi informs her sidekick Helen. “Van Ness Street, two syllables, is closer to downtown DC than Chesapeake, three syllables,” she adds. “Is that some kind of Norwegian folklore?” Helen, 73, teases, in her strong Brooklyn drawl.

“We're like the Bickersons,” Helen explains to a mom at the front desk, referring to the 1950s radio show. “You're too young to remember that show,” Helen tells the mom, who is staying at The Inn while her seriously ill son receives cancer treatments at the National Cancer Institute. “That's before my time too,” Randi chimes in. “You always lie,” Helen laughs. “Well, it was before I came to this country,” Randi replies. The two of them chuckle and so does the mom.

Randi and Helen are among a group of more than 200 dedicated volunteers at The Inn. Randi found The Inn a decade ago and has been working with Helen ever since. “After my husband died, I needed a reason to get up in the morning,” she says. Randi, who owned “Randi's Bouquet,” a florist in Rockville, is retired and lives in Bethesda.

“The kids and families are so inspiring,” says Helen, who worked in retail and lives in Potomac. “Yes, the kids are ill, but they make us feel better,” Randi says. “They're so resilient.” Randi then turned to Helen with a serious face and added, “Wow, that was a big word for me.” Helen nodded, “Yes and you used it correctly.” And they're chuckling with families who are on their way to treatment.



Runners participate in the Shulman Rogers 5K race to benefit The Inn. The race was part of the company's year of giving back anniversary celebration.

Shulman Rogers: A Year of Giving Back

Potomac-based law firm Shulman, Rogers, Gandal, Pordy & Ecker commemorated forty years of continuous growth by kicking off an entire year of giving back to the same community where the company prospered. Team members chose several area nonprofits to benefit from monthly philanthropic initiatives, and over the course of twelve months, the 95-attorney firm held a blood drive, constructed housing for the homeless, planned a bowl-a-thon, served meals in a soup kitchen, and much more. On April 6, the “season finale” of the firm's yearlong campaign, was a USATF-certified 5K race benefiting The Children's Inn. Nearly 200 runners competed and \$34,000 was donated to The Inn. In addition to the race, the company organized a short Children's Fun Run and public celebration in front of the Park Potomac building where the Shulman Rogers office is located. DC-area radio station Hot 99.5 FM played music and made announcements, and prizes were awarded to the top finishers. Several Children's Inn staff members ran in the race, taking advantage of the opportunity to exercise while raising funds and awareness of The Inn's mission and programs. Thanks to Shulman Rogers, the race sponsors, and the many employees and volunteers who made the event possible.



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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.

The Children's Inn at NIH

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Special Thanks from The Inn

The Children's Inn at NIH is deeply grateful to the more than 4,300 donors who gave \$5,127,604 in fiscal year 2013 to help provide "A Place Like Home" for the more than 1,500 families who stay here each year. These gifts supported the more than 900 programs and activities available for residents, as well as the new Playground and Park, kitchen and dining area renovations, and many other priority needs. Select major gifts received between April 1 and June 30, 2013 were:

- Neall Family Charitable Foundation - \$40,000 for the new Playground
- Pindaros Foundation/P. Roy and Diana Vagelos - \$100,000 for The Roy and Diana Vagelos IsolateINN Pilot Project
- Mead Family Foundation - \$20,000 for general operating and nutrition program support
- Proshare Advisors, LLC-Casino Night - \$27,838 for general operating
- Estate of Ethel Woodruff Rulloda - \$58,402 for the Endowment Fund
- AFCEA-Bethesda - \$820,000 for the new Playground and area of most need
- GovPlace-Golf Tournament - \$36,609 for the new Playground

Do you work for a Matching Gift Company? Many companies, large and small, match charitable donations made by employees and their spouses. Check with your company's HR or Administrative Office to determine eligibility and you just might be able to increase the value of your gift to The Inn. Some companies who match their employees' gifts are ExxonMobil, Microsoft, GE, SAP, Johnson & Johnson, Boeing, Merck, Sanofi, and Bank of America, to name a few.