



Shirley Howard and The Children's Cancer Foundation: Special Friends of The Inn

A cherished friend of The Children's Inn since its founding, philanthropist Shirley Howard is still going strong at 84. As president of The Children's Cancer Foundation (CCF), the organization she began 25 years ago with her late husband Bill, she remains hard-working and committed to raising funds for pediatric oncology research. She also is a champion and loyal donor to facilities like The Inn, that improve the quality-of-life for young patients and their families.

In 1990, Shirley's first gift on behalf of the CCF was instrumental in completing construction of The Inn. Since that time, her legendary generosity, and that of her Founda-

INNspirations

The Children's Inn at NIH

FALL 2008

Profile on Heidi Peck	2
Congressional Gala Honors Debbie Dingell	3
Sprint NASCAR Visits The Inn	3
Board of Directors	4
Honorary Gifts	4
Memorial Gifts	5
Holiday Donation Deadlines	5
Molly Matthews, New Board Chair	6
Thoughtful Giving	6
Inn Opens Sport Court	7
Golf INNvitational 2009	7
CFC in Progress	8
Holiday Cards Now Available	8

Mission Statement

The Children's Inn at NIH is a private, non-profit, family-centered residence for pediatric outpatients at the National Institutes of Health and their families. Its purposes are to keep children together with their families during serious illness, reduce their stress, and facilitate their healing through mutual support. The Inn relies on private contributions for its operating funds.

tion, have ensured that The Inn's facilities are as up-to-date, reassuring and comfortable as possible for residents—with donations totaling approximately \$1.5 million.

This year alone, Shirley and the CCF have contributed funds to complete a trio of much needed projects. First is the newly finished renovation of The Inn's front office area, the heart and soul of services to Inn families. This more open and accessible lobby will be named "The Children's Cancer Foundation and Shirley Howard Welcome Desk," to represent the loving spirit behind it.

Thanks to Shirley and her Foundation, plans are also well underway for a new reflection space, designed to help residents find a place to relax, reflect and renew themselves. Their third underwriting this year enabled The Inn to purchase a minivan to better serve residents' transportation needs.

Shirley has had her share of challenges in her own life. In 1983, just as she and Bill established The Children's Cancer Foundation, he suffered brain damage while undergoing surgery. Just 65 at the time, Bill lived another 13 years, before his death in 1997. Through all the difficulties, Shirley "worked like crazy," she says, fundraising for the Foundation and determined "to do good," she explains.

Born and raised in Maryland, Shirley Howard has lived for 46 years in the same Baltimore area home, which remains the site of the CCF's office. She is delighted that her daughter, Diane Perry, was recently named the Foundation's new executive director, and will ensure continued success in the future.

"The Inn is a friendly, warm and loving place—I adore it," Shirley says. "We will always be there for The Children's Inn."



INNspirational KIDS



“Music is a significant part of my life,” says Heidi. “I plan to go to college to pursue my passion for music.”

Heidi Peck: The Healing Power of Music

After a trip to the doctors for what her parents believed was a common ear infection, Inn resident Heidi Peck was diagnosed with Autosomal Recessive Polycystic Kidney Disease (ARPKD). Suddenly, at 6 months of age, she was fighting for her life as she went into congestive heart failure.

Heidi's mother, Debi, says that when Heidi was diagnosed, the doctors did not give their family hope that she would survive beyond her toddler years. “We were told almost 50 percent die at birth, or shortly thereafter, and that getting through the first 18 months would be critical to Heidi's survival,” says Debi. But the Peck family never gave up hope and Heidi didn't stop fighting.

ARPKD is a rare genetic disorder that occurs in approximately 1 in 20,000 individuals, according to the PKD foundation. In ARPKD patients, small cysts form and soak up fluids in the kidneys causing them to enlarge, thus taking away room in the abdomen for other organs to grow and function normally.

With each birthday, Heidi grew stronger, distancing herself from the possible mortality of the disease. Along with routine visits to her local doctors, Heidi began participating in an ARPKD research study at the National Institutes of Health in 2005, under the direction of Dr. William Gahl, Clinical Director of the National Human Genome Research Institute.

Giving Heidi a normal childhood, despite all the medical problems she faced, was a high priority to her parents. In fifth grade, they encouraged Heidi to start playing an instrument. “My cousin played the flute,” Heidi says. “There was just something about it that drew me in.” Now, Heidi can't imagine her life without it.

The flute has become her constant companion and even helps combat the disease that continues to threaten her life. Playing the flute has required Heidi to exercise her lungs on a daily basis. In fact, a recent trip to the NIH revealed that her lung capacity is above normal due in part to her flute playing. Her parents credit music as her stabilizing force, allowing her to excel against all odds.

In her younger teen years, Heidi earned college credits by receiving the Val P. Hattemer Endowment award, which gives scholarships to high school students who are members of the youth wind ensemble at Sinclair Community College. In both 2007 and 2008, Heidi earned scholarships to Northwest Nazarene University for winning in the instrumental solo category at the Nazarene Northwest Region Main Event. Heidi is a member of the Treasure Valley Youth Symphony (affiliated with the Boise Philharmonic) and maintained “first chair” for the Boise State University all-honors high school band, all while continuing to fight her disease.

Last year Heidi's family, along with the ARPKD/CHF Alliance, held a benefit concert raising \$2,500 for ARPKD research. Heidi says that her true passion is sharing her love of music with others. During her most recent visit to NIH, the angelic strains of her beautiful music could be heard throughout The Children's Inn, as she practiced to perform in the NIH Clinical Center lobby over the lunch hour. “It brings me joy to play for people,” Heidi says. “I hope to continue to do so for the rest of my life.”



INNspirational EVENTS



L-R: Carmala Walgren, Chris Downey, Dr. Philip Pizzo, Cokie Roberts, Debbie Dingell, and Gordon Peterson

20th Annual Congressional Gala Honors Debbie Dingell

On June 25, 2008 under the historic archways of the National Building Museum, more than 530 guests attended the 20th Annual Congressional Gala to honor Debbie Dingell, vice chair of The Children's Inn board of directors. The evening raised more than \$734,300 to support The Inn.

Gordon Peterson, anchor for WJLA-TV, served as Master of Ceremonies, as he did at the first Gala, along with Mistress of Ceremonies Cokie Roberts, Inn board member, senior news analyst, NPR and political commentator, ABC News. Presentations were made to Merck & Co, PhRMA and Viacom for their generous sponsorships. A special recognition was made to Mark Raabe, Inn board member and consultant, Merck & Co, who was instrumental in the founding and continuing success of The Inn.

Debbie's connection to The Inn began in 1987 when "The Friends of The Children's Inn" was founded to meet the challenge of designing a home for the families whose children were undergoing treatment at the NIH. The Gala was created with Debbie as Gala Chair. It is thanks to the energy and determination of the original "Friends" that The Inn opened its doors in 1990. Since the opening, Debbie has served on The Inn's board of directors and has been among our leading advocates.

The evening was particularly meaningful since many of the original founders were present including: Dr. Philip Pizzo, The Honorable Billy Tauzin and Cecile Tauzin, Michael Berman, The Honorable Doug Walgren and Carmala Walgren and Chris Downey.

"The concept of a Children's Inn at NIH was a dream for nearly a decade before it came to fruition," said Dr. Pizzo, now dean of the Stanford University Medical School, who at the time was chief of pediatrics for the National Cancer Institute. "It would have likely remained a dream without the engagement, dedication and support of Debbie Dingell and her congressional spouse colleagues. Together they opened doors that were inaccessible and created a community of support rather than one of resistance."

A video was played honoring Debbie's many contributions to The Inn, followed by two original songs performed by political satirist, Mark Russell.



L-R: Dr. Philip Pizzo, Kathy Russell, Inn CEO and The Honorable Nancy Pelosi, Speaker of the House

Sprint/NASCAR Visits The Inn

On August 18 and 19, 175 Inn residents and their families had the opportunity to see what it takes to be a NASCAR Sprint Cup Series driver. Thanks to the Sprint Racing Experience, four state-of-the-art full motion simulators arrived in a 53-foot tractor-trailer. You could feel the excitement in the air from our children and families for days. Our partners at Comcast SportsNet participated in this fun event. Comcast commentator and local NASCAR driver, Donnie Neuenberger, made a pit stop, taking photos with Inn families, signing autographs and filming his "Behind the Wheel" with Donnie Neuenberger feature with an Inn family. Dominic Mediate, midfielder for DC United, also stopped by to greet Inn residents. Our deepest appreciation to Sprint!



Donnie Neuenberger interviews Inn resident Tony Grayson for his "Behind the Wheel" segment.

INNspirational PEOPLE



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Honorary Gifts

Birthdays, anniversaries, graduations and retirements are just some of the special occasions celebrated with gifts to The Inn. The following gifts received from May 1 through August 31, 2008 are in honor of:

David Allentuck's Birthday
 Dr. Michael April's Birthday
 Isaac Barchus
 Pat and Grif Bates' Anniversary
 Dr. Mary Bell's Retirement
 Joseph Bishow
 Dr. Jaimebrahim's Retirement
 Phyllis Burka's Birthday
 Sandy and Andy Busch
 Dr. David Castle
 Dr. Ken Chase's Birthday
 Julia Coventry's Bat Mitzvah
 Cox/Wallace Family Get Together
 Cindy Crane's Graduation
 Craig Charleston Crossley's High School Graduation
 Carol Dahlberg's Retirement
 Thelma Daub's Birthday
 Mr. and Mrs. Sarkis Demirji's Anniversary
 Maci Dickerson
 Debbie Dingell
 Joseph Eanet
 Henry Eisenberg
 Sara Feldman's Birthday
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 Mollie Fletcher's Retirement
 The Foster Family
 James Glassman
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 Shirin and Jeffrey Goldberg's Birthdays
 Myron and Natalie Goldberg's Anniversary
 Sheldon and Joan Goldstein's Anniversary
 Seth Gordon
 Alyson Hale's Birthday

Birth of Annabelle Avery Hanscom
 Dr. Hershel Hausman
 Norman Heim
 Stephen Katz's Birthday
 Dr. Richard and Barbara Kaufman
 Mr. and Mrs. Tave Kaufman's Anniversary
 Michael Kay's Birthday
 Kensington Parkwood Elementary Faculty & Staff
 Bill Kleiner's Birthday
 Mike Klonsky's Birthday
 Marvin Kotz's Birthday
 Meagan Frances Leach's First Communion
 Carol Lederer's Birthday
 Sylvia Lipps' Birthday
 Charles Markison's Birthday
 Ruth Rosner Marks' Birthday
 Brenda and Gerry Meyer's Anniversary
 Sima Minton
 Allison Mostow's Birthday
 Molly Mostow's 1st Birthday
 Bob Moyer
 NIH - Environmental Protection Branch
 NLM AFP Class of 2007-08
 Helen Olson
 Alex Parker's Birthday
 David Parker's Birthday
 Ronald and Anne Pomykala's Anniversary
 Daniel Joseph Portelli
 Ruth Rheingold's Birthday
 Ellen Rigterink's Birthday
 Paul and Ellen Rigterink's Retirements
 Emily Rogers' Bat Mitzvah
 Kitty Salasin's Birthday
 Sonia Santani
 Ian Schapiro's Bar Mitzvah
 Danielle Schapiro's Bat Mitzvah
 Dr. and Mrs. Robert Scheon
 Mr. and Mrs. Vincent Sigillito's Anniversary
 Keri Singer's Bat Mitzvah
 Andrew Smith's Bar Mitzvah
 Senator Arlen Specter
 Samantha Leah Springer

Ralph Stein
 Michael Stevens
 Sauren Stone's 10th Birthday
 Janet Turim's Birthday
 Yogini Patel and Stuart Wallace's Marriage
 Madison Morgan Wayne's Bat Mitzvah
 Frank Weisel's Birthday
 Mr. and Mrs. Frank Weisel's Anniversary
 Lori Weisel's Birthday
 Mr. and Mrs. Michael Weisel's Anniversary
 Wendy Wilson's Birthday
 Homer Wolf's Birthday
 Mr. and Mrs. Jeff Zachem's Anniversary
 Al and Fran Zionts' 50th Anniversary
 Marty Zober's Birthday



Memorial Gifts

The Inn receives thoughtful contributions in memory of relatives and friends who have passed away. We join in honoring gifts received from May 1 through August 31, 2008 in memory of:

David Abraham
 Kevin Acevedo Ramos
 Joseph Albert
 Celeste Angel
 Eli Arenberg
 The mother of Soraya Azarsa
 Lurline Babbitt
 Robin Spear Bartone
 Kathleen Anne Beard
 Michael Bellesky
 Philip Berger, Sr.
 Maurice Berk
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 The grandson of Phil Wahlberg
 Edgar John Walker, Jr.
 Patricia Walton
 Richard Warfield
 Moe Weisinger
 Sylvia G. Weiss and Joseph Weiss
 Ruth Amy Weissmeyer
 Capt. Edward Willever, USN (Ret)
 Kathleen Hensley Woods
 Charlie Workman
 Louise Zimmerman
 Edith Zober
 Bertha Miller Zukerman
 Helen Zuppas

Holiday Donation Deadlines:

Financial gifts to The Inn-
 Must be received by
December 12 to be
 acknowledged by the
 holiday.

In-kind gifts to The Inn-
 The needs of our families have
 changed and, at this time, we
 are no longer accepting toys.
 Please visit our website at
www.childrensinn.org for more
 information and to view our
 holiday wish list. **December
 14** is the last day for holiday
 in-kind donations to The Inn.

New Board Chair, Molly Matthews

The Children's Inn announces the appointment of Molly Mahoney Matthews as the new chair of the board of directors. For as long as she can remember, Molly has had ties to NIH. Her company, Matthews Media Group, has recruited patients to the NIH Clinical Center for NCI, NHLBI and other institutes since 1987. Twenty years ago, her mother participated in a research study for breast cancer and much earlier in her life, Molly volunteered in the blood bank when she was 16 years old. It was not until Philip Pizzo, M.D. approached her to share his vision for the public private partnership that she became interested in what would soon become The Children's Inn. "I was initially involved with pediatric cancer patients and then when the AIDS epidemic arrived, the need for a home away from home became even greater," says Molly. "It has been a real privilege to watch our ability to respond unfold over two decades." Molly worked on several pro-bono communications projects for The Inn after it opened in 1990. "We produced a video that we sent to families before they arrived so they would know what to expect." "The Inn functions beautifully with the hard work and leadership of the staff and volunteers. As chair, I hope to challenge each board member to find an area to focus on, one goal that each person will identify and champion," Molly says. Molly began her professional career as a teacher and, after earning a master's degree in Health Communication, worked for Porter, Novelli and Associates and as Director of Public Education at Children's National Medical Center in Washington, D.C. She is a published author and has taught several courses at the University of Maryland and George Washington University. Molly also serves on the Board of Trustees at St. Mary's College, the state's public honors college. She enjoys her recent empty nest, running her new business, Finding Cures, Inc., travel and is currently writing a memoir. She and her husband have four children and two grandchildren.



Thoughtful Giving

We would like to extend our appreciation to the following friends who have generously donated \$1,000 or more to The Inn between May 1 and August 31, 2008. We are honored to distinguish them by giving levels:

STARS (\$100,000+)

AFCEA - Bethesda Chapter
Merck Company Foundation
Pharmaceutical Research & Manufacturers of America

EXECUTIVE CIRCLE (\$25,000+)

Estate of Andrew Thomas Patton

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The Andre Sobel River of Life Foundation
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NACDS Foundation
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Inn board member, Linda K. Berdine and Children's Inn residents open the Sport Court during the ribbon cutting ceremony.



Children's Inn Opens Sport Court

Since joining The Inn's board of directors three years ago, business leader Linda K. Berdine has consistently found new ways to give.

Linda, who heads her own award-winning company, G&B Solutions Inc., has recruited and inspired members of the business, banking, and technology community to support The Inn. As an officer of the board of directors for the Bethesda Chapter of AFCEA (Armed Forces, Communications and Electronics Association), Linda launched the annual "Night for The Children" gala, an event that celebrated its 10th anniversary this spring. To date, this group has contributed more than \$2.5 million to benefit seriously ill children and their families at The Inn. This year, the AFCEA group established the AFCEA Bethesda Endowment, a long-lasting gift to The Inn.

Linda continues to increase her support and comfort to families at The Inn. Her most recent gift affects families personally and directly, each day. The new and already popular Sport Court opened in September, with Linda on hand for the dedication ceremony. Through her gracious donation, families can play a variety of sports from volleyball to tennis, basketball, badminton and roller hockey—much-needed activities after a long day of tests and treatments at the NIH Clinical Center.

During the opening ceremony of the Sport Court to Inn families, Rev. Amy Lewis, The Inn's Spiritual Wellness Coordinator, delivered a blessing encouraging everyone who plays on the court to recognize all it offers: "May all who play here experience the exertion of increased confidence to meet a new day of challenges; May all who play here—who come with burdens—leave with a renewed sense of energy and hope; May all who play here be encouraged by finding The Children's Inn Sport Court to be a place where every team has a multitude of fans and every person is a champion."

The key to Linda's success is not only her ability to keep pace with the rapidly changing technology industry, but to cultivate a corporate commitment to the community.

"I deeply believe in the power of giving back," Linda says. "The Children's Inn puts children on a brighter path. It touches me on a personal level."



Linda K. Berdine

FRIENDS (cont.)

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- St. John's Episcopal School
- Suburban Hospital
- Sunoco, Inc.
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- Toyota Motor North America
- Universal Music Group
- Van Scoyoc Associates
- Whole Foods Market



SAVE THE DATE!

Monday, June 1, 2009

Lakewood Country Club, Rockville, Maryland

For more information, please contact Fern Jennifer Stone at 301-451-9453

INNspirational KIDS



2008 Combined Federal Campaign (CFC)

We are pleased to announce our inclusion in the 2008 Combined Federal Campaign (CFC). A vital source of operating income for The Inn, contributions through the CFC are used to help create a healing environment and enriching experiences for each of our residents. If you, or someone you know, are interested in supporting The Children's Inn through the Combined Federal Campaign, our charity number is 10324. For any inquiries regarding the many ways CFC giving benefits The Inn, or how you can participate, please contact Courtney Phillips at phillipscp@mail.nih.gov or 301-451-9461.

Children's Inn residents have fun displaying our CFC number: **#10324**

Holiday Cards Support The Inn

Once again this year, we proudly share our special holiday cards with you—cards showcasing the artwork created by children who have stayed at The Inn. After a long day of treatment at the NIH Clinical Center, children and their families decorated these fun cookies with the guidance of Meaghan Mountford, author of *Cookie Sensations*. Orders must be received by December 5 to have them in time for the holidays. Visit our website at www.childrensinn.org to download an order form or contact Julie Hykes at jhykes@mail.nih.gov or 301-451-2878.



INNspirations

Published by The Children's Inn at NIH

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