

The Community Counts

A monthly newsletter for Duke Pediatric Blood and Marrow Transplant patients, families and supporters



The volunteer-based Family Support Program is dedicated to caring for, serving, and lightening the burden of the Duke Pediatric Blood and Marrow Transplant Community through a comprehensive array of services and resources.

Apartments provide Hope to PBMT families

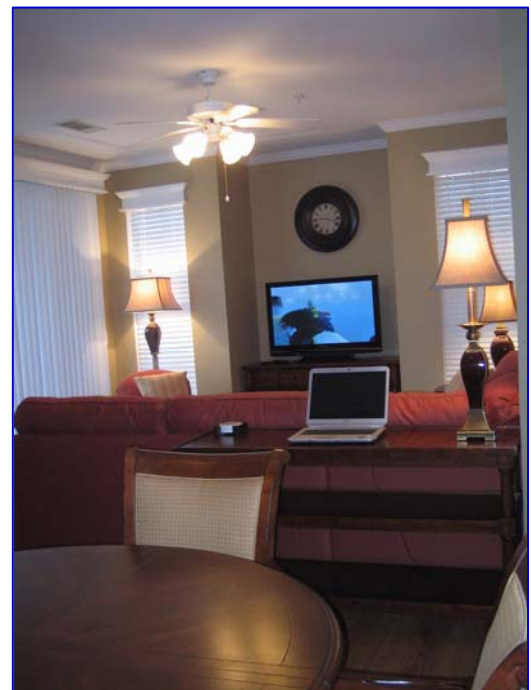
If there's anything that helps families to feel at home, it's having a comfortable place to live. The Evanosky Foundation is looking to do just that with the grand opening of their third "House of Hope" apartment for Duke PBMT families. This important initiative began in September 2008 when they opened their first apartment at Alexan Place apartments, about 10 minutes from Duke Medical Center. Priority is given to patients who have a Lysosomal Storage Disorder, which is a rare collection of diseases including (but not limited to) Metachromatic Leukodystrophy, Krabbe, Tay-Sachs, and Hurler's disease.

The goal of the House of Hope Initiative is to provide high-quality accommodations for PBMT patients, including amenities that enable a cleaner environment and furniture covered in a specially patented material that is both comfortable and can be easily disinfected! With 3 apartments already completed, the future looks bright for them to complete 6 apartments by July 2010.

A special thank you to the Hilliard Family Foundation, who provided funds for the renovation and furnishing of the 3rd House of Hope. We could not do this work without both of these family foundations!

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Some views of House of Hope 3, which was opened in July

New Kids on the block

“New Kids on the Block” features the patients on the 5200 unit who were admitted in the past month. It is our way to honor them and help the other families get to know them.



*Allison, age 13
Raleigh, NC*



*Amro, age 8
Raleigh, NC*



*Matthew, age 20
Candler, NC*



*Olivia, age 3
Dupont, WA*



*Shawn, age 1
Lakewood, WA*



*Amit, age 6
Kfar-saba, Israel*

Summer Vacation as a Rainbow Volunteer, by Emily S.

While many college students are busy taking trips to the beach to occupy their summer vacations, I, along with thirty-two other benevolent individuals, chose to dedicate part of our summer to the incredible children on 5200. I discovered the Rainbow Volunteer Program while shadowing Caroline Sweezy during my spring break in March. While touring the Connection Area, I saw a patient and a Rainbow Volunteer laughing and playing video games together. Upon leaving the hospital, I was curious to learn more about the program and searched the internet for further information. Within a few weeks, I was attending the orientation and anticipating my first session.

Every Monday afternoon, I am fortunate enough to spend three hours playing games and participating in Science Day activities with both the children and their parents. I do not choose to volunteer simply for college credit or to add a Duke placement to my resume; I do it because I absolutely love spending time with these kids. They constantly remind me to appreciate the small things and to never take life for granted. Their strength is both extraordinary and inspirational, and I look forward to spending as much time with them as possible. Though the last few weeks of summer are passing by quickly, my hope is to make them as enjoyable as possible for each patient I come in contact with. Being a Rainbow Volunteer has been an extremely rewarding opportunity and I am grateful to have been a part of such a remarkable program.



*Emily and Citlalli play some
Monopoly*

Aflac ducks

Once again this winter, visitors and staff in the PBMT unit or administrative offices could hear “Aflac! Aflac! Aflaaaaaac!” at any moment of the day. Not only were the cute plush ducks dressed in ski outfits ready to take on the cold weather, but they talked, too! More significant than the fact that they talk is that they also help raise a lot of money. For the third straight year, PBMT Family Support Program was chosen as the beneficiary of the “Aflac/Macy’s Holiday Duck Campaign,” receiving all profits from duck sales across the state of North Carolina.

Last month, the totals were tallied and a check for over \$15,000 was presented to the Family Support Program by Jill Denton, Regional Sales Coordinator of Aflac. In addition, Family Support sold over \$8,000 in ducks during a month-long sales campaign around the medical center and university, staffed by many of the local Aflac sales representatives of our area. So yes, while these ducks do make a great amount of noise, they also make a significant impact on the lives of PBMT families. The funds enable us to provide more services and support for transplant patients and families. We are truly overwhelmed by the success of the duck sales and are grateful to Aflac and North Carolina Macy’s stores for the continued support of PBMT. Thank you!



The 2008 Aflac ducks provided a great gift to Family Support

HeartBoxed



Above is an example of the personalized book that patients receive with messages and encouraging words

Family Support is very excited to introduce a new resource for our patients and families called HeartBoxed. HeartBoxed is a nonprofit organization created to tangibly encourage children and teens who require extended stays in the hospital. As you know, families going through a bone marrow transplant are in the hospital for an average of 55 days. They often have minimal physical support due to being away from home and are financially strained from all of the medical and living expenses. Beth Rose, the founder of HeartBoxed, hopes to lift the spirits of families going through difficult times such as these by offering support in a unique way.

Beth, a childhood cancer survivor herself, believes that “Having something, even if it is small, to look forward to each day can be both motivating and entertaining for a child, and this is the driving purpose of HeartBoxed.”

HeartBoxed reaches out to patients and families by creating age and gender appropriate boxes filled with gifts and activities to entertain and encourage patients through their transplant journey. Each box is personalized towards the interests of the patients referred to the organization. Most boxes have a countdown wall calendar, a personalized book, and a wrapped gift that coordinates with each day of the hospital stay. Other boxes, especially for teens, focus more on social interactions with friends (via webcams, laptops/internet, etc) and with more age-appropriate entertainment, such as Netflix. We are incredibly grateful to Beth and her husband, Shane, for opening their hearts and extending their support and resources to our program. We look forward to working with them as their organization continues to grow!

Christmas in July on 5200

Who says Christmas has to occur only in December? The patients and families on 5200 enjoyed a fun surprise when Santa stopped by the unit on his way to the beach for Christmas in July! He brought personalized gifts for each patient and their siblings and in Santa's special way he knew just the right thing to bring to everyone. As Santa visited from room to room it was clear that he was bringing Christmas joy to all with the many smiles & sounds of laughter that he left behind. A few patients asked Santa some clever questions. Rachel (4 yrs old) wanted to know what kind of snack she should leave for Santa when he visits her house in December and Santa said, "Oreo Cookies and a carrot for his reindeer!" This answer definitely made Rachel giggle! Jaden (6 yrs old) was wondering who was taking care of Santa's reindeer while he was on vacation



Olivia got some special surprises from Santa during Christmas in July

and Santa said, "The Elves of Course!" Santa has been missing his reindeer and elves and looks forward to seeing them again when he returns to the North Pole after his summertime beach trip!

The Family Support Program would like to thank the Me Fine Foundation and Elizabeth Diaz, their Program Coordinator, for arranging Santa's visit to 5200. The Me Fine Foundation is a non-profit organization dedicated to providing necessary resources and financial assistance to families of children being cared for at Duke Children's Hospital and the Children's Hospital at UNC. This was Me Fine's fourth visit to 5200 for Christmas in July. We appreciate their continued support to the patients and families in our program and look forward to working with them on special events in the future.

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Jaden got a new Hot Wheel to drive around 5200

Aloha on 5200

In July, 5200 was transported to the sunny beaches of Hawaii for Aloha Day! Colorful flowers, surfboards, tropical fish, sunglasses, and grass skirts were everywhere as everyone basked in the warm atmosphere. Beach-goers all donned beautiful leis and learned how to hula dance. Afterward, everyone settled down to play in the sand! Beach 5200 was certainly better than any other beach because we had all colors of sand - yellow, red, green, and blue! With the sand, beach-goers made beautiful sand art in fish-shaped and starfish-shaped vials! Also, with miniature sand kits (complete with miniature sand buckets, shovels, and seashells!) beach-goers were able to make incredible sand castles. All the while, everyone relaxed to songs with beautiful Hawaiian lyrics...

*Aloha e aloha e
'Ano 'ai ke aloha e
Aloha ae aloha e
A nu ay ki aloha e
There's no place I'd rather be
Then on my surfboard out at sea
Lingering in the ocean blue
And If I had one wish come true
I'd surf till the sun sets
Beyond the horizon*



Allison (right) and her mom shared time together decorating flowers with colorful sand



Rachel and her parents came ready for a luau

Scenes from PBMT



Baltej came by to visit the PBMT offices and ride the cart



Kadeja took a turn as the caller for Bingo



Aiden had a good time exploring the Connection



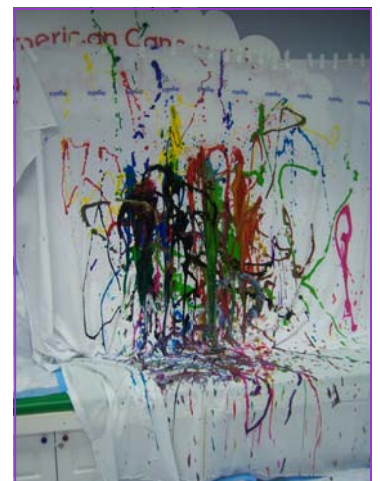
In Cellmates, Patients and families painted treasure boxes and then wrote encouraging messages to put in each other's boxes



Maddie and her sister came back to 5200 to put on a concert for Shawn and the other inpatient families



Rachel and Tray have a good time making up songs during Music Therapy



Kyle (above left) and several inpatients became artists during Cellmates and created a masterpiece doing syringe painting

Winner's Circle

We are grateful to all of the people who help support PBMT families through contributing their time, energy, and resources.

We would like to thank the following for their monetary donations:

- * Scott & Donna Larson *in honor of Alyssa Larson*
- * Marva Ramsey *in memory of Charles Cornell*
- * Alan and Joyce Siegel *in honor of Marilyn and Bill Paul's 50th wedding anniversary*
- * Melanie Taylor

We would like to thank the following for their in-kind donations:

- * Roy Cooper for his donation of 50 medals to reward kids through the Steps to Recovery Program
- * April Van Dyke for her donation of gifts from our Target.com wish list and gift cards
- * Kasey Fountain for her donation of books and toys from our Target.com wish list
- * Bill and Barbara Hyde for their donation of books, toys, and toiletry items
- * The Me Fine Foundation for hosting Christmas in July on 5200 and for their donation of phone cards
- * Karen and Danny Mercer for their donation of arts and crafts and Bingo prizes
- * The Saunders family for their donation of items from our Target.com wish list and toiletry items
- * Mary Catherine Wadsworth for her donation of McDonalds gift cards and pillows for patients.

Those who contributed to our Community Meals program last month:

- * All Saints United Methodist Church
- * Apex United Methodist Church
- * Ellen Tvrdy
- * Katie Swaney Foundation
- * Little Red Foundation
- * Macedonia Baptist Church
- * St. Luke's Episcopal Church
- * Trinity Ave Presbyterian Church

If we have inadvertently left you off our Winner's Circle, please let

New Super Stepper!

A new patient has walked her way in to the prestigious Super Steppers Club. Patients are able to earn their way into the club by walking a minimum of 250 laps while on 5200. In addition to being featured in Community Counts, we also give the patients a commemorative T-shirt with their picture on it. Throughout their journey to being a Super Stepper, patients get prizes as incentives to keep going and as a reward for their great efforts.

This month's Super Stepper inductee is Citlalli. Citlalli earned 105 feet by walking 525 laps. Congratulations to Citlalli and great job to all of our dedicated walkers!



Citlalli

Wish List

We are in need of the following items:

- * Phone Cards
- * Gift Cards: McDonald's, Chick-fil-A, Bojangles, Subway
- * We have specific toys, DVD's, books, and games listed on our Target.com and Barnes and Noble Wish Lists. You can access the Target list by going to www.tinyurl.com/targetlist. You can access the Barnes and Noble list by going to www.tinyurl.com/bnwishlist.

Thanks for your support!!

The Community Counts is a monthly newsletter produced by the Duke Pediatric Blood and Marrow Transplant Family Support Program, distributed free to patients, their families, volunteers, and staff.

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