

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.

The Caring Bridge

by Katie F

A lot of patients and families on 5200 have a Caring-bridge website that connects them to their loved ones back home. But what I have noticed in the short amount of time I have spent here is that these websites are just the beginning, the first few logs put down on the bridge we all travel across.

The way I see it, a patient and their family, friends and others are traveling over a huge, churning river and they have to build their bridge with love and support. Otherwise the water or the sea monster will swallow us whole!

Everybody's bridge is a little different, but they all work the same way – if you fall down, your bridge (support group) is there to catch you. My bridge started with my Caringbridge website. Then the first few people I met on my visit to 5200 made a second plank and the support from my school, another plank. My family is the entire framework of the bridge. My doctors and nurses form another plank and each and every day makes my bridge a little stronger.

I also have to say that this is the best pediatric floor I've ever been on. We have activities and the nurses are always a ton of fun. Everyone always has something to make somebody else smile. It is a big part of my Caring Bridge.



Guest columnist Katie takes a break from writing for a picture!

CellMates makes a return to 5200

We are happy to announce that the CellMates support group will be coming back to 5200 beginning in February. With the help of additional staff and support we are able to add this group into our ongoing activity calendar.

CellMates was created in 1997 as a program that allows patients to come together and support one another before, during, and after blood and marrow transplant treatment. The name "CellMates" has dual meaning - patients are companions on this journey as they wait for new cells, and, isolated to a common location.

CellMates is an opportunity for patients to express what they are experiencing through art, games, and activities. Siblings and patients of all ages are invited, but each child must be able to participate independently. This is a "For Kids Only" group! It will be held on Thursdays at 2 pm, conveniently at the same time that our social workers are meeting with parents and caregivers during the "Snack and Chat" time. CellMates will be facilitated by Caroline Sweezy (Program Coordinator for PBMT patients) and Allison Browne (Child Life Specialist). Please don't hesitate to ask them for more information if you have questions.

Please stop by the Connection to take a look at our CellMates scrapbook so you can see some of the exciting and fun things we will be doing!

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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.



*Andrea, age 4 mo.
Lajas, Puerto Rico*



*Brad, age 5
Newland, NC*



*Cali, age 1
Lillington, NC*



*Dean, age 3
Charlotte, NC*



*Jose, age 12
Chesapeake, VA*



*Nicholas, age 4
Dallas, NC*

Two more patients join Super Steppers club!

Two more patients have walked their way into the Super Steppers Club, which means that they walked 250 laps on the 5200 unit. For every 5 laps that a patient walks, they earn a plastic footprint, and earn a tshirt with their picture on it when they reach the 50 footprint mark. This month's inductees are Katie and Meredith. Katie has earned 63 footprints so far (315 laps), while Meredith earned 67 footprints (335 laps) prior to being discharged. It's a big accomplishment to do what these two brave girls have done. Great job to all of our walkers - keep up the hard work!!



*Katie (above)
and Meredith
(below) show
off their
footprints*



Update on volunteers

Last month, we trained a new class of 15 Best Buddies, who are matched one on one with a patient and his/her family throughout their time in Durham. The Best Buddy program has been one of the cornerstones of the PBMT Family Support Program since 1997.

Our Rainbow Volunteer program is also back up to full capacity as 6 new volunteers trained in January, and will join the 18 returning volunteers to fill the schedule. This program provides PBMT families an array of support on 5200: bedside activities with the kids, respite for caregivers, and assist with general Connection upkeep. Rainbow Volunteers are available on the unit in three hour shifts, from 12 to 9 pm, every day. They are recognizable by the white t-shirts that say PBMT Rainbow Volunteer on the back.

We are grateful to all of the PBMT staff and Duke professionals who volunteered their time to prepare our volunteers for their experiences on the PBMT unit! Please welcome our new volunteers when you see them!

Scenes from 5200



Joey digs in to his 1st birthday cake!



"Big David" and "Little David" are good buddies



Alivia and her mom display their masterpiece



Cali and her mom share a piece of cake



Rachel opens up a gift at her 3rd birthday party



left: Caitlin displays her new bingo prize

right: Brad shows off his slime



Crystal and Caitlin get their hair done during "Salon Day" on 5200

Massage chair donated for weekly relief to caregivers

Massage therapy has been available to caregivers for almost 2.5 years, providing them 15 minute massages to help ease some of the tension they hold in their shoulders, neck, and back. Recently, one of our "former" massage therapists, Candy Walter, wrote a grant application to the North Carolina chapter of the American Massage Therapy Association (AMTA) for funds to acquire a massage chair for the 5200 unit. It eliminates the need for Norma and Marie, our current Massage Therapists, to haul their personal chairs into the hospital and up to the 5200 unit. It was an extraordinary gesture on Candy's part to continue to think of us, and we are grateful for the energy and time she put into it! Norma and Marie are too as it makes their job a little bit easier. Thank you to Candy and the AMTA!



Marie provides massage using the new chair

Discharge bags find a new home

Upon discharge from the hospital, each patient receives a "discharge bag" - a collection of items which will be helpful to them in the outpatient setting. Paper towels, antibacterial gel, a digital thermometer, an insulated cooler and other items are included in this bag. For the past several months, Paula Haste has been responsible for the shopping, assembly, and delivery of the bags. For personal reasons, she needed to pass the torch to another group to take responsibility of the bags. We are grateful that the Kearney family has volunteered to fulfill this task - so Steve, Lori and their two kids, Cade and Delaney, will now be the "owners" of this project. Thank you to Paula for doing this for us in the past and also the Kearney family for their 'yes' to this task. We are grateful for all of you!



The Kearney family prepares discharge bags for patients

New Rainbow of Heroes Website launched!

We are excited to announce the launch of our new website for the Rainbow of Heroes Walk, PBMT Family Support Program's annual fundraising event. Now in its 8th year, the Walk is held the first Saturday in May and is open to PBMT families, friends, staff and supporters. We hope that the new website will provide more information and answer any questions one might have. Stay tuned for more information about the upcoming Walk. In the meantime, we encourage you to visit our website at www.rainbowofheroeswalk.org. Hope to see you on May 3rd!

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:

- * Sara Brandeleone for donating two Playstation 2 games
- * Duke Hospital Auxiliary for the "In Case You Forgot Basket" toiletry items
- * Norma Ferrell and Marie Lloyd for providing weekly massage
- * Kellie Gates for cutting caregivers' hair on Salon Day
- * Amy Goodreau, Jim Allen, and Elizabeth Carver for providing gift cards
- * Edward Harris for donating CD's
- * Lillie Merritt for the beautiful laundry bags
- * Kathy Michael for donating a printer and "Lost: Season 3" on DVD.
- * Tri Phi Mu Alumni Chapter of the Phi Mu Fraternity for the donation of toys
- * Warners Chapel Church of Christ Youth Group, Clemmons, NC for the donation of toys and art materials

The individuals and organizations who made monetary donations:

- * Matthew Aufman and Carin Cornish
- * Miriam Donohue
- * Charles and Robin Eisenbeis
- * Cade and Delaney Kearney
- * Jean Kluttz
- * Tom and Donna Neff
- * Mark and Kathleen Rumbles
- * Michael and Jenny Sledge
- * Amy Sturtevant
- * Chris Sundberg
- * James and Jeri Young

Those who made gifts through our Target.com Wish list:

- * Frederick
- * Yancy Gallego
- * Samantha Pino

Those who contributed to our Community Meals program last month:

- * Apex United Methodist Church
- * Little Red Foundation
- * Macedonia Baptist Church
- * St. Luke's Episcopal Church
- * Trinity Ave Presbyterian Church
- * West Raleigh Exchange Club

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

Wish List

We are in need of the following items:

- * Photo paper
- * Gift cards: Wal-Mart, Food Lion, and BP gas cards
- * Playing cards
- * We have specific toys, DVD's, and games listed on our Target.com Wish List. Enter "Duke PBMT" (first name) "Family Support" (last name)" in the "Find a Wish List" search engine and go from there.

Many 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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www.cancer.duke.edu/PBMT/support/family.asp

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