

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.

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Love is in the air!



left: Dean and mom decorate cookies.
right: Katie shows off her heart mobile!



Parents gathered for a Valentine's day dinner provided by Carrabba's

Love is in the air on 5200! To celebrate Valentine's day, patients enjoyed an afternoon filled with laughter, cookie decorating and doing a heart-themed craft project. The Connection was full of decorations and the air was filled with the smell of freshly baked cookies.

Later in the day, the celebration continued with a magical night of delicious food, music, and great conversation for parents and caregivers. Family Support staff were the "servers" for the delicious meal (provided by Carrabba's Italian Grill) of chicken marsala, pasta, caesar salad, and bread; Foster's Market provided two scrumptious French silk chocolate pies for dessert. A big thank you to all who helped make this day special for families! Indeed, you could 'feel the love' on 5200!

"Welcome Spring" outpatient party

In February, PBMT outpatients and their families were invited to a spring themed event in the Children's Health Center hosted by Caroline Sweezy, Susan Trout, and Katie Vogel. Participants were able to choose from a variety of activities such as tissue paper flowers, leaf coloring, creating their life story with tree rings, bug treasure hunt, and more! Meredith (age 6) made creatures out of model magic and tissue paper flowers. Ryan (age 4) made his very own crayon castles. Rachel (age 3) enjoyed mixing colors as she created watercolor leaves. Dylan (age 14) stopped by for a while and brought his siblings with him to join in on the fun. David (age 21) stopped by to say hello to some of his outpatient friends while on a pass from the unit. While the patients were enjoying their time together, the parents and caregivers were able to enjoy some private fellowship and food next door. We look forward to providing more activities for our outpatient families in the future! Upcoming events include: March 16 – Treasure Egg Hunt; April 27 – Music with Tray; May 6 – Paperhand Puppet Intervention Show and Parade. All of these events will be held at Duke Gardens. More details to come!



Ryan plays with his crayon castles



Rachel makes watercolor leaves



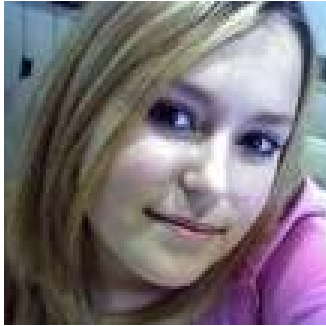
Meredith shows off her clay masterpieces



Dylan shares a moment with his siblings

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.



*Anna, age 14
Roanoke, VA*



*Henrique, age 8
Sao Paulo, Brazil*



*Cal, age 2
Norfolk, VA*



*Kalen, age 14
Matthews, NC*



*Kyra, age 6
Apex, NC*



*Olivia, age 3
Greensburg, PA*

March is Child Life month

Each year hospitals across the country take time in the month of March to honor a vital member of the health care team, the child life specialist. As many of you know, child life specialists are trained in child development and promote effective coping through play, preparation, education, and self-expression activities. They provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization. Understanding that a child's wellbeing depends on the support of the family, child life specialists provide information, support, and guidance to parents, siblings, and other family members. They also play a vital role in educating caregivers, administrators, and the general public about the needs of children under stress.

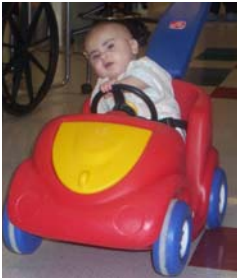
Our child life specialist, Allison Browne, is a valued member of the transplant team. In collaboration with our psychosocial team, she helps patients and families find ways to cope with the transplant process. We send out a big thank you to all of the child life specialists out there that make difficult experiences as positive as they can be for children and families.



Allison, 5200's Child Life Specialist, poses with Rachel on her 3rd birthday

Child Life Month will be celebrated at Duke the week of March 10th. To learn more about the child life profession please visit www.childlife.org.

Scenes from 5200



Joey is cruising in his red sports car



Andrea (left) and Elmer (right) share a moment together



Cal and his mom play the drum in music therapy



Katie (left) gets her hands dirty with Mary Margaret, our new Arts for Life instructor!

Honoring the decorating committee

For anyone who has been on 5200 in the past year, you know that the halls have been filled with beautiful art and decorations. The nursing staff participates in committees to help share some of the “extracurricular” work that needs to be done on the unit. One of those committees is the decorating committee, who has created beautiful themed artwork to help bring a sense of unity to the area.

Since part of the Family Support Program’s mission is to lighten the burden for families who are on 5200, we are grateful to the decorating committee who have enabled the transplant unit to become a more welcoming, nurturing space. In addition to the appropriate décor for all of the major holidays, some of the past themes have been camp-out, beach, Beatles tribute, penguins, and most recently, black history month. Thank you to all of the nurses, including decorating committee co-chairs Bobbie Caraher, Whitney Hendrickson, Stacey McDonald, and Amanda Miller for their special work!



Some of the amazing artwork that is hanging on 5200, courtesy of the decorating committee and their helpers!

Patient spotlight: Jose Andres

This month, our child life specialist, Allison, sat down with 12 year old patient, Jose Andres for an interview. She thought Jose Andres might be able to provide some insight about life on 5200...

Allison: *What was the work up like while you were getting ready for transplant?*

Jose Andres: Interesting. Not very long at all and once I got used to it...it was very easy.

Is life on 5200 different than you thought it would be?

Yes, I thought the transplant would be more like surgery...but it was just like a transfusion. And they gave me Benadryl which "knocked me out." I thought I would be in a larger room with more open space. I didn't think it would be so secluded.



Jose Andres shares about life on 5200

What was the hardest part of getting a bone marrow transplant?

The mucositis and getting hives. They were VERY uncomfortable. ATG = bad hives that hurt very badly.

What makes being up here easier for you?

BINGO!! Every week, it gives me something to look forward to...I love to play Bingo. I also love seeing my sister on the weekends and just having my family here for support.

Continued on page 4

Patient Spotlight (continued)

What is something you like about 5200?

Friends I've made and the babies on the unit! Seeing Joey makes me happy...he's my buddy. And, getting out to walk - even though it's hard with all of the meds that we're on.

What advice would you give to someone that is just starting to get ready to come to transplant?

Good mouth care is very important even though it's uncomfortable. Don't stop eating!! Don't worry...BE HAPPY!!

We've moved!

The Duke PBMT administrative offices have relocated! This includes our doctors, nurse practitioners and coordinators, insurance counselor, Family Support, and all of our administrative staff. We are now located at 1400 Morreene Road, just down Erwin Road from the hospital in the old Duke Credit Union. We will continue to get mail at our previous box number and address, so there's no need to change our address just yet! We're hoping that this is a temporary (6-12 months) move.

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:

- * New Horizon Church for providing a meal for 5200
- * The family of Gage Thompson for providing a meal for 5200
- * The Kearney family for providing discharge bags
- * Norma Powell for providing laundry bags
- * Bob Reeves for his donation of sports cards
- * Norma Ferrell and Marie Lloyd for providing massage for caregivers on 5200
- * Kellie Gates for cutting caregivers' hair on Salon Day
- * Carrabba's Italian Grill for donating dinner for Valentine's Day
- * Foster's Market for donating dessert for Valentine's Day
- * Courtney Hurd and Hendrick Pit Crews for Kids for the packages of Valentines for patients to give to each other
- * Amy McKenzie for her donation

Those who contributed to our Community Meals program last month:

- | | |
|--------------------------------|-----------------------------------|
| * Apex United Methodist Church | * Trinity Ave Presbyterian Church |
| * Little Red Foundation | * West Raleigh Exchange Club |
| * Macedonia Baptist Church | |

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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