



**Children and Adolescent
Cancer & Blood Diseases Center**

MARIA FARERI CHILDRENS HOSPITAL
WESTCHESTER MEDICAL CENTER
NEW YORK MEDICAL COLLEGE

Breakthrough personalized therapy through pioneering research



**Maria Fareri
Children's Hospital**

Westchester Medical Center Health Network

Patient Family Advisory Council (PFAC) Newsletter

www.nypedscbc.org

Summer
2019



Saturday, June 22nd

You are invited to our annual Day at the Farm, a fun, FREE event celebrating our oncology families on Saturday, June 22nd at the Land of Nod Winery in East Canaan, CT.

Bring your whole family and join in some fun for all ages, including hayrides, farm animals, fly-fishing lessons, lunch and wine tasting!

RSVP to Tara Giblin at 914-594-2179

Day at the Farm Info

LET'S GO ON
A HAYRIDE



What is the “Day at the Farm”?

It is a day to honor oncology families where children and adults alike will find something to enjoy:

- Take a hayride with fellow families around the farm
- Feed and pet the sheep and goats
- Learn how to Fly-Fish with Orvis Outdoor Guides
- Tour an old Maple Sugar Sugarhouse and the nearby Beckley Iron Furnace
- Taste wine from grapes grown in the vineyard (21 and over only)!

When & Where?

- Saturday, June 22nd from 10am-2pm
- It is in East Canaan, CT, about 1 hour and 45 minutes from the hospital, at **The Land of Nod Winery**, a family owned and operated vineyard and winery at 99 Lower Rd., East Canaan, CT 06018

What do I need to bring?

Just you and your family!
Lunch, drinks and snacks will be provided. Fly fishing gear will be provided as well.

And is there shade?

We will eat lunch under the outdoor party tent, but please make sure to wear sunblock and wear a hat as many of the activities are not shaded.

How do I RSVP?

RSVP to Tara Giblin at 914-594-2179. Please let us know how many in your family will be attending, how many are children, and if you have any special dietary restrictions or allergies.

More info can be found at:
www.landofnodwinery.com
or call 860-824-5225



The 5th Annual Wellness & Survivorship Day was a huge success!

Despite a rainy Spring day, we had nearly 30 families join us as well as many staff and friends! Reunion-goers enjoyed a delicious Cinco de Mayo taco bar, bounce house, cornhole, giant jenga, carnival games, crafts, face painting and a DJ. Cancer survivor Alex Katz gave an inspirational speech on his cancer journey, and everyone left with a gift!



Dr. Cairo & Alex Katz

WARRIORS FOR WARRIORS

Because no one fights alone

A Warrior to Warrior Story: John and Daniel

John Capalbo

► In the summer of 2011, while undergoing treatment for T-Cell Lymphoma, I met a former survivor and patient of Dr. Cairo's, Daniel Mitchell. At first I did not want to speak with anyone, which is a very common feeling that all patients seem to share. However, to this day I am extremely happy that I had the opportunity to not only meet and speak with Daniel but to form a lifelong friendship with him and his family.

► Daniel was a survivor of B-Cell Lymphoma, and like myself, his college career was interrupted because of his illness. In speaking with Daniel it helped me understand the confidence and strength that going through something like this helps build. This confidence and strength is something that a survivor will carry with them every day as they continue their life after treatment.

► As stated before, we are not just two survivors that shared an illness but we became two friends that continue to help each other and others. Sharing this type of bond allows for a friendship that most do not understand. To have someone I can go to that understands the difficulties of the treatment and continuing life after is a huge help. His family also was and still are great friends and were a big help to my family whenever they were going through a hard time with my treatment as well. Cancer effects everyone involved and to have Daniel and his family be there and be able to share and relate to our experience helped strengthen our battle that much more.

► Daniel and I try to take our experience and share it with others to show them the positive end result after their treatment. Through events such as ***Dribble for the Cure*** and private conversations with newly diagnosed patients, it helps others see the benefits of being in the care of someone like Dr. Mitchell Cairo and his team and also the power of strength in numbers. If it had not been for Dr. Cairo and connecting me and Daniel and his personal touch with being able to empathize with us as people and not just patients, my treatment would not have been as smooth.

► We will continue to strive for more connectivity among patients and families as they go through this difficult process. It made a difference for me and Daniel and I am confident that even if other patients do not understand the benefits of having a mentor during their treatment, they will surely understand it afterwards in the future. We are committed to being there for current patients and survivors of this battle.

Daniel Mitchell

- ▶ In summer of 2011, my oncologist Dr. Mitchell Cairo asked if I could help him out. An 18 year old patient of his was at Maria Fareri Children's Hospital in the midst of treatment for T-Cell Lymphoma and preparing for a Stem Cell Transplant from his sister to save his life.
- ▶ He was having a hard time and Dr. Cairo asked that I speak with him as a former patient and B-Cell Lymphoma survivor. I was excited and eager to help someone by talking about my experience and helping him know what to expect.
- ▶ When I met John Capalbo and his family, we immediately became friends. His family was so appreciative that I was willing to share my story and my experience. Not to mention, it helped boost their confidence that someone John's age had gone through treatment and is living their life with a stronger appreciation and more positive outlook on the future.
- ▶ Despite me helping John first and being a mentor to him, John has returned the favor many times over. Having a friend that understands the intricacies of cancer therapy and treatment is an incredible asset and I am fortunate to have a friend, not to mention another entire family, to lean on for support and encouragement.
- ▶ Over the years, my family and the Capalbo family have become very close through our shared experience of fighting cancer. We now share our experiences together as survivors and continue to give back to the organizations that helped save our lives. Both John and I have continually strived to advocate for the wonderful Maria Fareri Children's Hospital and the work of Dr. Mitchell Cairo at New York Medical College (NYMC) by staying involved.
- ▶ This September, John and I are putting together a fundraising Team for ***Dribble For the Cure*** at St. John's University - an event that raises money for the Pediatric Cancer Research Foundation - an organization whom Dr. Cairo and NYMC is a beneficiary conducting cutting edge Pediatric and AYA (Young Adult) cancer research that is saving lives and has saved lives of countless individuals including me and John.

“Continuing to be involved and helping mentor John has been a large part of my healing process despite being 10 years in remission.”



Who's Who in Hem-Onc

In this issue we meet nurse practitioner
Connie Leonick

Connie works mainly behind the scenes but you may run into her at clinic or in-patient.



PFAC: Connie, what is your role with the Hem-Onc team?

Connie: I am one of the Nurse Practitioners for the Division of Peds Hematology, Oncology, and Stem Cell Transplantation. I “job-share” with my colleague, Karen Wolownik, another nurse practitioner who I could not live without!

PFAC: What is a typical day for you?

Connie: Well, if there was ever a reason to say “LOL,” this would have to be it! I actually love that there is no “typical” day for me. My role leads me in many different directions each day. Many days I will attend morning rounds on the inpatient unit - I like to make sure that patients and their families know how important they are as part of our treatment team. I also enjoy providing educational updates for the staff. Our Division has access to so many cutting edge treatments for children with cancer and blood disorders. It is so important for each and every person involved in patient care to be an expert at what they do.

PFAC: What do you do in your spare time?

Connie: I am a planner. Whether it's figuring out what to make for dinner, or where to go for a day trip, or what color to paint the living room, I always seem to be googling something. Right now I can't wait to plan what I am going to plant in my yard for spring. If you have any ideas for my flowerboxes, feel free to let me know!

continued. . .

PFAC: How many years have you worked at MFCH? And what did you do prior?

Connie: In June, I will be celebrating my fifth anniversary at MFCH! The time has flown! Prior to this chapter, I was the nurse practitioner in Pediatric Immunology at the Cohen Children's Medical Center for 20 years! I treated children with immunological disorders, including HIV and AIDS. There was a remarkable improvement in prevention of mother-to-child transmission and treatment for kids with HIV/AIDS over those years. Prior to that, I was a pediatric oncology nurse and clinical nurse specialist at a cancer center in Manhattan for many years. So I have come full circle, now that I am back in the pediatric oncology world here at MFCH.

PFAC: What lead you to become an oncology NP?

Connie: When I first started my nursing career (by now you have a pretty good idea of how long I have been a nurse), I worked on a general pediatric unit at what was then the Schneider Children's Hospital. When the hospital decided to open a bone marrow transplant unit, a few of my nursing colleagues and I eagerly volunteered to help with the start-up of that unit. Just like many other specialties in the nursing and medical world, "oncology nurses" like myself just know that it is the right field for us to be in. I had taken care of so many children on the general peds unit with different types of cancer, so this was a logical choice for me. An opportunity arose at Memorial Hospital not long thereafter, and I plunged into the world of pediatric oncology. It is exciting to see the advances in treatment in this field. I focus on helping everyone to try to keep some normalcy in their lives - whatever that means.



Connie with, from left to right, Drs. Rosenblum, Stringel, Ozkaynak & McBride

Nutrition & Wellness

Focus on Food Safety



It is no surprise to hear that proper nutrition is important for good health. During treatment for cancer and blood disorders, many challenges arise that can affect your ability to maintain a healthy diet. While a registered dietician is an excellent source of information about your diet, your doctor or nurse practitioner can help to guide you in selecting foods and supplements that provide good sources of nutrition.

There are times when treatment can weaken the body's natural defenses. Certain foods may cause a bad reaction with some of the medications used in your treatment plan. Your health care team will advise you when it may be important to avoid certain foods.

One of the most essential things to remember when handling food is the importance of FOOD SAFETY. Here's a "TRUE OR FALSE" quiz that will test your knowledge about safe food handling:

1. _____ It is okay to thaw and marinate food on the kitchen counter if it is in a covered bowl
2. _____ Rinse fruits and vegetables well BEFORE peeling
3. _____ Check to see if meat is cooked by feeling it with the back of your hand
4. _____ Go directly home after shopping to put perishable food in the refrigerator or freezer
5. _____ Store grains such as rice or pasta below 40 degrees if you plan to re-use it
6. _____ Always rinse raw meat and poultry before cooking
7. _____ Wash sponges in the dishwasher or boil for 5 minutes to clean them
8. _____ It is okay to use the one-bounce rule when a favorite food item drops on the floor
9. _____ Handwashing is the most important way to prevent the spread of germs
10. _____ The Partnership for Food Safety Education offers information about safe food handling practices and has fun ideas for children regarding food safety on its website: www.fightbac.org

Answers on next page



Focus on Food Safety

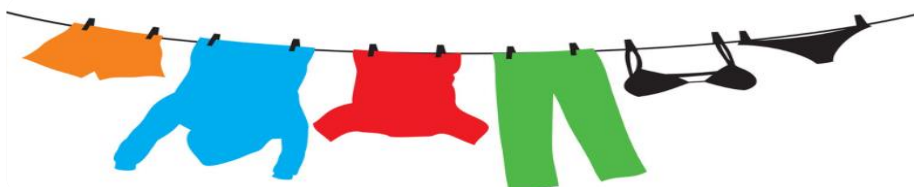
Questionnaire answers. . .

- 1. False** It is okay to thaw and marinate food on the kitchen counter if it is in a covered bowl. ***Food should be thawed in the refrigerator or microwave, and marinated in the refrigerator.***
- 2. True** Rinse fruits and vegetables well BEFORE peeling. ***Rinsing first prevents dirt and bacteria from being transferred onto the fruit or vegetable.***
- 3. False** Check to see if meat is cooked by feeling it with the back of your hand. ***Use a food thermometer to make sure meat is fully cooked.***
- 4. True** Go directly home after shopping to put perishable food in the refrigerator or freezer. ***If you need to make a stop, place perishable foods in an insulated bag/cooler with gel packs.***
- 5. True** Store grains such as rice or pasta below 40 degrees if you plan to re-use it. ***Grains may contain bacterial spores that may lead to food poisoning. Use within 24 hours.***
- 6. False** Always rinse raw meat and poultry before cooking. ***Rinsing meats before cooking can spread bacteria to the sink and countertop.***
- 7. True** Wash sponges in the dishwasher or boil for 5 minutes to clean them. ***Thoroughly sanitizing sponges reduces risk of bacterial contamination.***
- 8. False** It is okay to use the one-bounce rule when a favorite food item drops on the floor. ***You know the rule!***
- 9. True** Handwashing is the most important way to prevent the spread of germs. ***Singing or humming a favorite song for 20 seconds while washing with soapy water is fun.***
- 10. True** The Partnership for Food Safety Education offers information about safe food handling practices and has fun ideas for children regarding food safety on its website: www.fightbac.org ***Check out the website or call 202-220-0651 for more information.***

Did you know?

Pizza

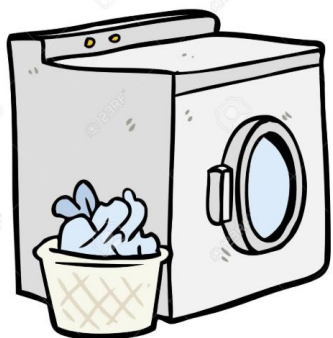
Every Thursday at the Infusion Center pizza is provided to patients and families courtesy of Giant Kids Foundation (GKF). GKF also supplies snacks, such as juice boxes and crackers, for infusion patients as well. GKF has generously donated each week since 2011.



Laundry

Every Tuesday there are volunteers that will do laundry for in-patient families. Please drop off your clothes directly with a volunteer or a volunteer will pick it up from your child's room. The laundry room is located on the 3rd floor of MFCH opposite the patient transport elevators. The laundry schedule is posted on the door. Another resource for laundry is the on-site Ronald McDonald House.

If you are not staying at the RMcDH you can still utilize their Day Program which includes use of the laundry rooms. You must first register for the Day Program in person with RMcDH by filling out their registration form which can be picked up at RMcDH (*Social work does not have these forms*) Please see the next page for the Day Program flyer.



@nypedscbc



The-Childhood-and-Adolescent-Cancer-Blood-Diseases-Center

WWW.NYPEDSCBC.ORG



Ronald
McDonald
House®
Greater Hudson Valley

Keeping Families Close®

Day Program

Respite Care

9am-8pm



Ronald McDonald House
Greater Hudson Valley

Ronald McDonald House of Hudson Valley provides a home environment for out-of-town families just steps away from the Maria Fareri Children's Hospital



[Click here to Visit Website](https://rmh-ghv.org/)

<https://rmh-ghv.org/>

What We Offer:

- Laundry
- Hot Meals and Snacks
- Fresh Coffee and Tea
- Playroom/Gameroom
- Rejuvenation Room

Who Can Use Our Program?

- Immediate families who have children aged 21 or younger being treated in Maria Fareri Children's Hospital or Blythdale Children's Hospital
- Monday-Friday, 9am-8pm only
- Identification is required for guests 18 years and older

If you have any questions, please stop by the house or call (914)-493-6455.

Connect with us on Social Media



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