



**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

Fall 2019

[www.nypedscbc.org](http://www.nypedscbc.org)



**ST. JOHN'S**  
**BASKETBALL**  
PRESENTS:

**SATURDAY, SEPTEMBER 21, 2019**

10:00 AM at St. John's University  
Carnesecca Arena



9TH ANNUAL

**DRIBBLE**  
**FOR THE CURE**

SEPTEMBER  
IS CHILDHOOD  
CANCER  
AWARENESS  
MONTH.



JOIN US  
TO FIND  
A CURE!

REGISTER ONLINE AT  
[WWW.DRIBBLEFORTHECURE.COM](http://WWW.DRIBBLEFORTHECURE.COM)



## Dribble for the Cure

The 9<sup>th</sup> annual Dribble for the Cure will take place on **Saturday, September 21<sup>st</sup>, 2019** beginning at **10:00am** at St. John's University in Queens, NY. This event will be held rain or shine.



# St. John's University

Carnesecca Arena, 8000 Utopia Pkwy, Jamaica, NY 11432

## EVENT SCHEDULE

10:00 AM – Registration and Festivities Open

11:30 AM – Welcome Ceremony

11:45 AM – Dribble for the Cure begins

12:15 PM – Awards and Autographs

- ▶ The 9th annual Dribble for the Cure, which has raised more than \$500,000, will take place **Saturday, September 21** on the St. John's University campus. The Red Storm men's and women's basketball teams and the Pediatric Cancer Research Foundation (PCRF) will once again join forces in the fight against pediatric cancer.
- ▶ The Dribble event will kick-off at 10:00 a.m. with a festival featuring the St. John's cheerleaders and band, games and refreshments. Each participant will bring a basketball (or buy a basketball on site) for the mile long dribble course winding through the St. John's Queens campus and ending at Carnesecca Arena. Finish line festivities are slated to begin at 12:15 p.m., giving participants a unique opportunity to meet for autographs and pictures with the men's and women's basketball teams.
- ▶ Each participant will be asked to collect donations for their "Dribble" and will be eligible for prizes based on the amount of pledge money turned in by the date of the event. In addition, each participant will receive a Dribble for the Cure t-shirt and souvenir bag.
- ▶ Proceeds raised from this event will be directed to the Pediatric Cancer Research Foundation in support of the Pediatric Cancer Research Laboratory at New York Medical College. The PCRF Laboratory is directed by Mitchell S. Cairo, M.D., also director of the Children and Adolescent Cancer and Blood Diseases Center at Maria Fareri Children's Hospital.



# DRIBBLE WITH THE ST. JOHN'S RED STORM!

**SATURDAY, SEPTEMBER 21, 2019**

**10 AM • ST. JOHN'S UNIVERSITY • CARNESECCA ARENA**



**REGISTER ONLINE • FORM A TEAM • JOIN A TEAM**

Join the Red Storm men's and women's basketball teams along with Coach Mike Anderson and Coach Joe Tartamella as they team up with the Pediatric Cancer Research Foundation for the 9th Annual St. John's Dribble for the Cure.

The mission of Dribble for the Cure is to engage youth and the community in the fight against pediatric cancer.

**YOU CAN HELP!** By forming a Dribble Team, you can raise money that will help doctors find a cure for pediatric cancer and help save the lives of children.

All proceeds from this event will be directed to the PCRF Laboratory directed by Mitchell S. Cairo, M.D. at the Maria Fayeri Children's Hospital and New York Medical College.

**WWW.DRIBBLEFORTHECURE.COM**

**OR FOR MORE INFO CALL 800.354.7273**



ENJOY  
PRE-DRIBBLE  
FESTIVITIES!

JOIN  
THE FIGHT  
FOR A CURE!  
REGISTER  
ONLINE



“This is an outstanding opportunity to support cutting edge Pediatric Cancer Research at New York Medical College, support children and families with cancer and provide community service,”

- Dr. Mitchell Cairo, M.D.



# Supporting Your Child's Education

*Needs Upon Returning to School. . .*



Continuing to be part of the school community throughout treatment is important, even though many days it may be the least of your concerns given everything else your child is enduring. However, for many children, school is a safe place to build and maintain friendships. It may be a nice break for them from the world of cancer. Going back to school is also a sign of normalcy.

There are multiple school options during the course of treatment. Your treatment team will help you determine which is best for your child during the different stages of treatment.

Some options include:

- ▶ Homebound instruction
- ▶ Attending a hospital or clinic-based school
- ▶ Attending the child's school
- ▶ Receiving additional supports through a 504 Plan or an Individualized Education Plan (IEP)



# Supporting Your Child's Education

*Continued. . .*

If your child is able to return to school please schedule a meeting with the school principal, nurse, teacher, school psychologist and social worker to create a reentry plan for your child.

## Re-entry to school plan

Bring a note from the oncologist, and any other specialists your child sees, indicating your child's diagnosis, any expected changes in your child's routine/school attendance, and possible side effects of treatment.

List medications your child is taking. If any need to be given in school, a note must be provided to the school nurse.

Special precautions need to be indicated - extra sanitizing of the classroom, school needs to inform you of highly contagious illnesses they may have been exposed to (*i.e. If another student develops chicken pox or other illness that might be problematic for your child.*)

Create a plan for managing side effects (fatigue, pain, nausea, difficulty navigating the building, loss of hair.)

Inform the school of what to do if your child has a fever.

Create a plan to address social/emotional needs of your child.

Create a plan to properly address the questions, concerns, and curiosities of the other children in the classroom or school.

This meeting is also the time to discuss best next steps to support your child's educational needs and possible accommodations. **Your child may be eligible for a 504 plan or an Individualized Education Plan (IEP).**

# Supporting Your Child's Education

## *What is a 504 Plan or an IEP?*

- ▶ Both are plans developed by the school and you, the parents, to help address and meet the individual needs of your child based on the impact they have on your child's education.
- ▶ A 504 plan is an accommodation plan, provided through general education, that allows for changes to the learning environment that enable your child to access his/her education along with his/her peers. A 504 plan can be provided for any child with any type of disability that limits a major life activity (learning, reading, walking, breathing, communicating, thinking, etc.) and interferes with your child's ability to learn in the general education classroom.
- ▶ An IEP provides individualized special education and, if needed, related services (speech, occupational therapy, physical therapy, counseling) to meet your child's specific needs. In order to receive an IEP, your child must qualify, under IDEA, as having one or more of the 13 disabilities listed in the law. In order to determine qualification for an IEP, the school, at no cost to your family, must conduct a thorough psychoeducational evaluation, along with other evaluations. However, speak to your treatment team about having your child receive a neuropsychological evaluation conducted by a neuropsychologist who is familiar with evaluating children undergoing treatment.
- ▶ Returning to school can be very overwhelming for both you and your child. Reach out to your treatment team for support. Families who have made this transition already are also a great resource. Remaining in constant communication with your child's teacher and other school personnel (especially the nurse) will help guide you on how best to support your child while he/she is in school.



# One Parent's Advice. . .

## *Take Notes & Keep Track*

Growing up my mother always taught me the importance of writing things down and keeping track. *How else am I to remember important dates and "to do" lists?* Several days after my world was turned upside down with my son's cancer diagnosis I realized I needed to get organized. I needed to keep track of what was happening on a daily basis. Armed with a spiral notebook and calendar I proceeded to keep a daily journal of pertinent info. . .fever, BMs, medicines. Anything that I felt was relevant to my son's status at that time I wrote down.



**A monthly calendar** is helpful in keeping track of appointments, start and end of new medicines, duration of fevers, etc.

As my son received a stem cell transplant it was good to visualize exactly where he was for certain milestones such as Day 100 post-transplant.

**Write down questions** - Keep either a section in your notebook or a separate notebook for jotting down questions - this will help you remember what to ask when the attending doctor rounds or at your next check-up.

**Keep lists & charts** - For e.g. I kept lists of my son's IGG readings and corresponding IVIG infusion dates.



**And please don't feel that you need to write everything down!** Don't let your record-keeping burden you. . .the doctors and nurses that take care of your child are already thoroughly documenting your child's treatment. Your notes should merely serve as a reminder to yourself and a refresher when going over your child's status.

# September is Childhood Cancer Awareness Month

September and the fall season bring Childhood Cancer awareness to the forefront. September is also specifically an awareness month for Lymphoma, Leukemia & Hodgkin Lymphoma



Childhood Cancer



Lymphoma

EVERY DAY,   
**43 KIDS**   
ARE DIAGNOSED   
WITH CANCER IN THE U.S. 



**1 IN 4**  
ELEMENTARY SCHOOLS  
has a child with  
**CANCER**



Hodgkin  
Lymphoma

the average  
HIGH SCHOOL HAS

**2**  
STUDENTS  
WHO ARE CURRENT OR  
FORMER CANCER PATIENTS



Leukemia

**CANCER IS THE  
#1 CAUSE OF  
DISEASE-RELATED DEATH IN  
CHILDREN**  
under the age of 15  
in the  
**UNITED STATES**

IN 2014

approximately

**\$8 BILLION**

of government  
annual funding is set  
aside for all types of  
cancer research.



**BECAUSE OF  
RESEARCH**

THE CANCER DEATH RATE  
HAS DROPPED MORE  
DRAMATICALLY FOR  
CHILDREN THAN FOR ANY  
OTHER AGE GROUP.

BUT,

**LESS THAN 4%**

goes towards  
**CHILDHOOD CANCER  
RESEARCH.**