



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

Spring
2019

www.nypedscbc.org

Join the Division of Pediatric Hematology, Oncology and Stem Cell Transplantation & The Children and Adolescent Cancer and Blood Diseases Center for our:

5th Annual Wellness & Survivorship Day

Sunday, May 5th
12:00-2:00pm

Macy Oval
Westchester Medical Center
100 Woods Road, Valhalla,
New York 10595



Join members of the staff of Maria Fareri Children's Hospital, a Member of the Westchester Medical Center Health Network, as we celebrate the wellness and survivorship of our pediatric cancer and stem cell transplant patients and their families.

Enjoy **food**, **carnival games** and **entertainment**.

Rain or shine.

RSVP to **Tara Giblin** at Tara.Giblin@WMCHHealth.org or **914.594.2179** by **April 29**.



Maria Fareri
Children's Hospital
Westchester Medical Center Health Network



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Food, games and entertainment

Join the Division of Pediatric Hematology, Oncology and Stem Cell Transplantation & The Children and Adolescent Center and Blood Diseases Center for our 5th annual Wellness & Survivorship Day on **Sunday, May 5th 2019 from 12:00 - 2:00pm** on the Macy Oval located next to the Maria Fareri's Children Hospital. This event will be held rain or shine. Please RSVP to Tara Giblin at Tara.Giblin@WMCHHealth.org or **914.594.2179** by **April 29th**

Survivorship Day 2018



5th Annual Wellness & Survivorship Day

The 5th Annual Wellness & Survivorship Day will be held this year on May 5th from 12PM-2PM. This special celebration brings together survivors, their families, and their care team for a lunch and carnival for all ages. In addition to classic carnival games, there is a DJ, bounce house, crafts, face painting and more! Come see your favorite doctors and nurses and meet other families for a relaxed afternoon of food and fun!

This year members from the newly formed Patient Family Advisory Council (PFAC) will be on hand. Please be sure to stop by their table with any questions or concerns or to say “Hello”.

Additionally if you are interested in joining PFAC please speak with a member.



“I find being a member of PFAC an extremely rewarding experience. I am happy to ‘pay it forward’ in being there for fellow families.”

- Celeste (PFAC member)

About the Wellness & Survivorship Clinic

Do you ever wonder why the infusion center is closed on Wednesdays?

It's because Wednesdays are reserved for specialty clinics, including the Wellness & Survivorship Clinic, which is held on the first and third Wednesday of every month! Patients are transitioned to this clinic when their follow-up care reaches yearly visits.

Survivors meet a team of providers including a doctor, nurse practitioner, social worker and neuropsychologist to understand their treatment history, learn how to monitor for potential late-occurring side effects of chemotherapy, radiation and surgery, and also screen for any social, psychological or cognitive difficulties the patient may be experiencing.

The focus of the clinic is on teaching patients and families about their past encouraging healthy habits for a long and fulfilling future. If you are a patient who is getting yearly checkups, talk to your oncologist about whether or not you are ready to come to the Wellness & Survivorship clinic!



KEY CONTACTS

DIRECTOR:

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CLINICAL PROGRAM COORDINATOR:

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SOCIAL WORK:

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Services provided:

Monitoring for and managing physical late effects

Addressing psychosocial needs of survivors and affected family members

Providing referrals to specialists and resources as indicated

Encouraging wellness and health promotion activities

Providing health education to survivors regarding their diagnoses, treatment exposures, and potential late effects

Assessing and providing intervention for educational and/or vocational needs

Assisting with financial and insurance issues

Guiding transition from pediatric to adult focused healthcare

Empowering survivors to advocate for their own healthcare needs

Facilitating survivorship research

Who's Who in Hem-Onc

In this issue we meet the coordinator for the wellness & survivorship program

Tara Giblin

Tara works with all newly off-therapy patients to provide them with a survivorship care plan, which summarizes their treatment and describes their plan of care. She also sees survivors in the late effects clinic, where her team aims to prevent and detect the long-term side effects of treatment.



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

Tara: I am a pediatric nurse practitioner, and wear many hats! My primary role is as the clinical coordinator for the wellness & survivorship program, but I am also the primary nurse practitioner for the pediatric neuro-oncology program, and I also coordinate our budding adolescent and young adult consult service.

PFAC: What is a typical day for you?

Tara: One thing I love about my job is that no day is the same! I might be found at the infusion center seeing patients getting chemo, or visiting a new diagnosis in the hospital, or at my desk preparing a survivorship care plan for someone who just finished therapy. On Wednesdays, I am usually found at Bradhurst seeing patients in the survivorship clinic with my team.

PFAC: Please tell us about the survivorship clinic

Tara: The clinic is a special place. It's interdisciplinary, so patients meet with me, Dr. Hochberg -the survivorship medical director, Rose Bartone -the social worker, and Dr. Suzanne Braniecki - our neuropsychologist who does cognitive evaluations. We also have help from Dr. Lila Pereira, our psychologist. Instead of your typical 20 minute follow-up visit that you do with your primary oncologist, our visits are about an hour and half.

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We go over the patient's treatment summary and care plan, we do a history and physical, and we do a lot of education to make sure the patient and family understand where they have been and where they are going. We want to make sure any lingering questions about a patient's diagnosis and treatment are answered, and that they are empowered to live their healthiest and happiest life.

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

Tara: After college, I got my masters in public health and did research at the US Centers for Disease Control and Prevention for a few years, but I really felt a pull to work directly with the people I was helping. So, I went back to school to become a nurse and then an NP, and my first NP job was in the pediatric heart transplant program at Columbia-Presbyterian, where I essentially took care of heart transplant survivors. They are also immunosuppressed to prevent organ rejection, so there is a lot of overlap with Hem/Onc. After many years in cardiology, I was ready for something new and came to MFCH in November 2015 to help build our survivorship program. It has been such a rewarding experience.

PFAC: What do you do in your spare time?

Tara: I'm a mom to two young children, so there is never a dull moment! My husband and I moved from NYC to CT right before I started this job, so I love working on home projects, and trying a new restaurant and catching up with friends is a favorite weekend activity. When I do get a rare moment to myself, I like to play the piano or curl up with a good book to unwind..



Tara with her family

Psycho-Social Corner

Getting through to the other side

When treatment ends, and after the initial anxiety of being on your own end, things should go back to normal, right?

After months of doctors appointments, scans, and hospital visits it can be difficult to figure out exactly what the new normal should be. Sometimes that transition goes smoothly, other times you struggle to find your footing then take off. While others may continue to struggle long after treatment has ended. When anyone has

been exposed to a situation where they feared for their own (or someone they love's) life, they have experienced a trauma. Many people are able to use the support of their friends and family to process and move on while others need support from their doctors or other healthcare professionals. Luckily, on our team we have the support you need if you think your child (or their sibling) is struggling with trauma related to their medical treatment

Keep an eye out for these signs:

Lack of appetite	Anger and irritability
Difficulty paying attention to teachers at school and to parents at home	Getting into fights at school or fighting more with siblings
Risky behaviors	Refusing to go to school
Bed-wetting or other regression in behavior	Withdrawal from friends or activities
Difficulty sleeping and nightmares	Interference with developmental milestones
Nervousness or jumpiness	Intrusive memories of what happened
Avoidance of scary situations	Play that includes recreating the event

Psycho-Social Corner

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At home you can consider these things to help your child:

- ▶ Learn about the common reactions that children have to traumatic events (much of the information in this write up is from The National Child Traumatic Stress Network - <http://nctsn.org>. We highly recommend you check out their website for more).
- ▶ Consult a qualified mental health professional if your child's distress continues for several weeks. Ask your child's school or medical team for an appropriate referral.
- ▶ Assure your child of his or her safety. Talk with him or her about what you've done to make him or her safe at home and what the school, doctors, and other adults are doing to keep your child safe.
- ▶ Reassure your child that he or she is not responsible. Children may blame themselves for events, even those completely out of their control.
- ▶ Allow your child to express his or her fears and fantasies verbally or through play. That is a normal part of the recovery process.
- ▶ Maintain regular home and school routines to support the process of recovery. If they are healthy enough, make sure your child continues going to school and stays in school.

Be patient. There is no correct timetable for healing. Some children will recover quickly. Other children recover more slowly. Try not to push him or her to "just get over it," and let him or her know that he or she should not feel guilty or bad about any of his or her feelings.

And of course, let us know if you have any questions. We are here to help and offer trauma-focused therapy to all patients and siblings.

Connect with us on Social Media



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