



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

Winter
2019

www.nypedscbc.org

The Patient and Family Advisory Council is a committee initiated in 2017 that partners family members with Division staff to identify ways to improve the patient experience and ensure family-centered care. Members of families both actively in treatment as well as those who have completed their therapies use their experiences to develop innovative processes and contribute to the Center's goal of providing state-of-the-art compassionate care.



If you have a desire to share your suggestions or experiences and participate in initiatives that will impact the lives of the families battling cancer and blood disorders, contact us today. You do not need to be a PFAC member to share your input, however, we always welcome new applicants!

Families helping families. . . Patients helping patients

PFAC recently established the *Warriors for Warriors* program to assist patients and their families in navigating the unfamiliar world of cancer and blood disorders. Former patients, parents and siblings provide support to newly diagnosed patients and their family members. Whether it is a quick “how are you doing?” text, a chat on the phone, a visit to the Maria Fareri Children’s Hospital or the Infusion Center, volunteer patients and families are there to lend a helping hand, attentive ear and warm hug because they have been there and know the journey firsthand.

To be paired with a Warrior contact your Social Worker:

Rose_Bartone@nymc.edu
(914) 594-2159

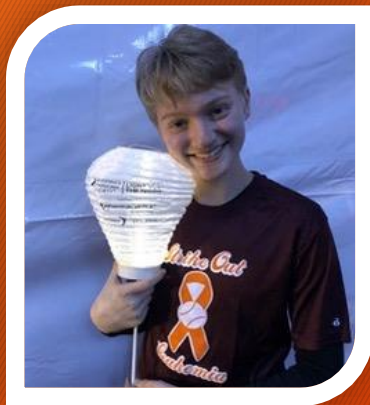
Barbara_McLain@nymc.edu
(914) 594-2160



To volunteer as a Warrior contact:

Dr. Jessica Hochberg
Jessica.Hochberg@wmchealth.org

Dr. Lila Pereira
(914) 493-7997



Charlie

“Once I was diagnosed with cancer, I had so many questions. Talking to someone who had gone through a similar experience really helped me.”



Lila

“I have seen my own patients feel great comfort when connecting with true peers who really understand what they are going through.”



Dan

“As a cancer survivor, any advice I could give through my experience to someone who didn't know what to expect was so important.”

Research suggests that peer support is one of the most important resources patients and family have when facing a cancer diagnosis. Even beyond what research says, I have seen my own patients feel great comfort when connecting with true peers who really understand what they are going through. Sometimes we shy away from that connection because it can feel scary to be close to someone who is going through so much and reminding us of our own struggles, but time and time again I hear that families always wish they had connected with someone who really “got it” earlier in the course of their treatment.

Lila Pereira, PhD
Postdoctoral Pediatric Psychology Fellow
Pediatric Hematology/Oncology/SCT
New York Medical College
Maria Fareri Children's Hospital



Daniel's Story

As a cancer survivor, once I went into remission I felt like I had an obligation to give back. Any advice I could give through my experience to someone who didn't know what to expect or someone who just needed a person their age to relate to or a friend who could truly understand what they were going through was so important.

Not only did this hopefully help in their recovery process but it helped in mine. I encourage anyone who has completed treatment to try and help someone - you don't realize the power you hold and how much you could improve someone's outlook and well being while going through treatment.

As amazing as doctors, nurses, researchers, family & friends are able to help, there is nothing that compares with talking to someone who has personally been there before. Someone who will be honest with you because they truly know what its like to go through treatment.

When I was undergoing treatment, a survivor named Chris would frequently stop by my hospital room to visit me. We developed a special relationship and he helped get me through some of my worst days. That is something I will never forget and I will continue to pay it forward.

One Parent's Advice. . .

Making Connections

I never felt so alone as I did when an emergency room doctor told my husband Pat and I that our son Sean had cancer. I soon found out that I was not alone. . .

CONNECT WITH THE PEOPLE AROUND YOU

No one knows better than I do how hard it is to talk to strangers about the worst thing in your life, but trust me when I say you should try. It is so important to make connections with other parents at clinic or in the hospital.

What's That? Look around the clinic. There are many treatments happening at the same time and you can learn a lot from the person sitting next to you. For example, we spent our first month home pumping Sean's medication through an archaic machine that resembled a small backpack. We cleared lines, tapped out air bubbles and spent hours on the phone with our service. It was very, very frustrating. Then one day at clinic, I looked over and saw another patient with a clear plastic ball that was pre-filled with medication. The boy popped the ball out of his pocket, hooked it up to his port and was off and running. I simply asked "What's that?" and the next month, we had our own ball of medicine and life got a little easier.

You Went Where? I also learned about opportunities, such as camps, for my son and my family through other families at the clinic. The Hole in Wall Camp in Ashford Connecticut, Double H Ranch in the Adirondacks and Camp Sunshine in Lake Sebago, Maine dedicate summers to cancer kids and their families. We went. We danced. We sang. We even "shook our fluffy tails" together with other families just like us. Thanks to Paul Newman's charities, Sean went to camp every summer for the last six years. He loved every minute of camp and still keeps in touch with his newfound friends today.



continued. . .

One Parent's Advice. . .

Making Connections

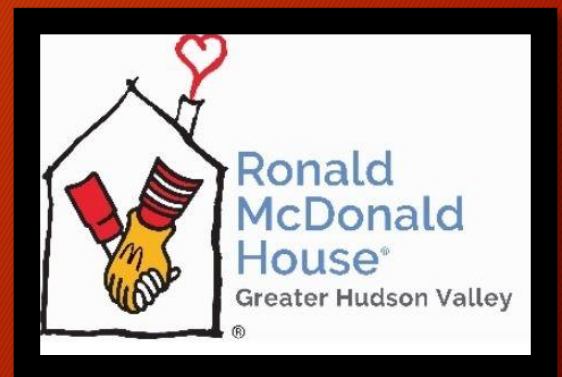
Who's That? Finally, I learned about the professionals that were in the hospital eager to help us. The Child Life Department at MFCH is amazing! These men and women provide creative programming, workshops, DVDs, games and other creature comforts to the children of the hospital. Even though we were inpatient we had a pretty great Christmas thanks to Lauren in Child Life. At the hospital there is also a masseuse available to patients, as well as parents. (*We love you Meg!*). And thanks to the Ronald McDonald House, I enjoyed reflexology once a week and a great holiday party every year.



The Child Life and Creative Arts Therapy Department helps you and your child adjust to and understand hospitalization, illness, injury, and treatment. The Child Life team is comprised of Certified Child Life Specialists, a Board Certified Music Therapist and a Board Certified Art Therapist, all of whom are professionals with advanced training in areas related to working with children and families in medical settings.

The Ronald McDonald House of the Greater Hudson Valley Located on the campus of the Westchester Medical Center is just steps away from the Maria Fareri Children's Hospital.

Telephone: (914) 493-6455
Email: info@rmhghv.org



I know better than anyone how hard it is to talk to others about what was happening to my family. My husband Pat is much better at it than I am. I was out of my comfort zone, but in the end, it was worth putting myself out there to connect with others.

- Michele

Psycho-Social Corner

If you've made it this far into the newsletter, you've already read my thoughts and what the research says around the importance of peer support. So rather than tell you about one study or another, I will tell you a couple of stories that I hope exemplifies how important peer support is and the interesting ways to connect with others when you need it most.

“Camp saved me. It turned me from a really angry kid into someone who could talk about what was going on with them and want to use that to help others.”

In graduate school, I began volunteering for Camp Okizu (the California equivalent of Camp Sunshine and Hole in the Wall Gang). The wonderful place was recommended to me by a dissertation committee member who conducted a lot of research around the importance of camps, respite, and peer support for families facing pediatric cancer. I thought I would volunteer, solidify my interest in Pediatric Hematology/Oncology, and do something fun for a week. What I didn't realize was how much I would actually learn about the importance of relationships with people who really get it.

I've seen campers who became counselors and volunteer for the same week every year to support both their fellow counselors and campers as they grow up. I've also seen counselors who became friends in elementary school at camp and continue to keep in touch well into their 30s. These relationships lasted through medical challenges and life milestones creating an extended family that encompasses more than just a diagnosis and translates into how life evolves after the hospital. A SIBS (short for Special and Important Brothers and Sisters) camper turned counselor told me,

“Camp saved me. It turned me from a really angry kid into someone who could talk about what was going on with them and want to use that to help others.”

continued. . .



Psycho-Social Corner

Momcology

info@momcology.org

<https://momcology.org/>

Stupid Cancer

(212) 619-1040

<https://stupidcancer.org/>

Gilda's Club

(914) 644-8844

<http://gildasclubwestchester.org/>

As for what drew me to a place like Okizu, prior to starting graduate school I watched a friend of mine struggle with a sister's cancer diagnosis. On her 23rd birthday she received her diagnosis and went immediately into the transplant process. With her life put on hold, her only access to the outside world was occasional visitors, the letters we sent, and her Facebook account. She loved being sent text messages of our pets, but we never talked about what was going on; and at the time I didn't know how to ask her. I often think about her sitting alone in her hospital room and talk with her sister frequently about the work I do here, trying to ensure that we do things differently here. Her friends (and the internet) were her lifeline throughout everything she went through, but I think

if she had someone who had “been there and done that” she could have talked about more than just cute kitten pictures.

Even if our new Warrior for Warriors program isn't for you, there are so many ways to get the support you need. Join our parents group, check out Gilda's Club, look into the Facebook group a lot of our moms are on, visit Momcology.com or Stupid Cancer, write a blog, say hi to someone you see a lot in the waiting room, or even check out a family weekend at one of the local camps. Your social worker will know how to get you there. Relationships change after a diagnosis often because people don't know what to say, but what if there was someone who understood when you needed to talk and when you didn't? That's what peer support is really about. The shared understanding that sometimes this is really hard and sometimes (as my Okizu friend Tajar says) you just want to “dance in the moonlight on your toes.”

Lila Pereira, PhD

Postdoctoral Pediatric Psychology Fellow
Pediatric Hematology/Oncology/SCT

Connect with us on Social Media



Children and Adolescent Cancer & Blood Diseases Center

MARIA FARERI CHILDRENS HOSPITAL
WESTCHESTER MEDICAL CENTER
NEW YORK MEDICAL COLLEGE

Breakthrough personalized therapy through pioneering research

Be sure to check out our website!

WWW.NYPEDSCBC.ORG



Facebook:

Like us at The-Childhood-and-Adolescent-Cancer-Blood-Diseases-Center



Instagram:

Follow us at @nypedscbc



Twitter:

Follow us at @nypedscbc