

News & Updates

July 2023 | Volume 14 - Number 7

Upcoming Activities

September 13
Haymakers for Hope
[Learn More](#)

November
Candy & Item Drive

December
Annual Fund Campaign



Made Possible By



It's Not Just About the Medicine

Mattie Miracle operates **four Snack & Item Carts** which are housed at hospitals within the National Capital Area. Our Carts serve over **2,500 families a year** who are caring for a child with cancer or other life-threatening illness. **The Carts provide nutritional snacks, candy, drinks, toiletries, and comfort items to family caregivers.**

In October of 2021, Mattie Miracle launched a Snack and Item Cart, called **Wellness on Wheels**, at the National Institutes of Health's (NIH) Clinical Center (Bethesda, MD). As a research facility, only patients with the precise kind or stage of illness under investigation are admitted for treatment. Of the 1,600 active protocols at the NIH Clinical Center 35% include children and pediatrics accounts for approximately 13% of Clinical Center patient activity.

As with all our Carts, Wellness on Wheels helps to meet the basic psychosocial needs of families, so that they can remain at their child's bedside and support their child through medical treatment. The Carts are considered a lifesaver and some families have told us that the Carts brighten their very long days in the hospital.

Mattie Miracle is grateful to our supporters who donate countless items to our Carts during our annual Item Drives. It is thanks to you that we can keep our Carts stocked. In addition to donated items, the

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Foundation also annually funds each of our Carts in order to meet the specific needs of the hospitals we serve. This June, Mattie Miracle **donated over \$2,000 worth of items** to the Wellness on Wheels Cart.

It's not just about the medicine!SM

Childhood Cancer is Not Just About the MedicineSM, and we are honored that our Snack & Item Carts can directly meet the psychosocial needs of children with cancer and their families.

Spreading Hope Through Psychosocial Support. SM



Skating Miracles

We congratulate **Susan Rotherham**, a junior at Meridian High School in Falls Church, VA for **raising \$1,600** at her Skate Night Fundraiser held on May 19. We are thrilled that our psychosocial mission resonates with Susan and that she selected to raise funds for Mattie Miracle two years in a row.

Susan is an ice hockey player at her school and is passionate about combining her love for skating with raising funds for childhood cancer. Susan surpassed her fundraising goal and successfully spread awareness of childhood cancer to her community.

Child Life Corner with Adina Levitan, CCLS



We welcome Child Life Corner to our newsletters. Each month you will hear from Mattie Miracle's Child Life Specialist, Adina Levitan. Adina will highlight topics, issues, and share stories from a child life professional's lens. Given the vital role child life plays in a child's medical and psychosocial journey, we are proud to feature this standing column.

Managing a Cancer Diagnosis

Upon **hearing the words "your child has cancer,"** several thoughts begin spinning around a parent's head. What treatment options are there? What procedures come next? How will I explain this to my child? It can be incredibly daunting and terrifying to say the words "cancer" out loud, and especially to a child. Perhaps they have heard this word before in connection with a family member or someone in the community. Or maybe they have never heard it and

the child's parents now are struggling with how to communicate the severity of this illness without scaring their child. Do I say they are sick? But this is not sick like a cold... and I know the medicine will make them feel awful yet somehow it is making them better. How will they understand that? **Every age and developmental stage will understand aspects of illness differently therefore knowing the tools available is critical for imparting honest, age-appropriate information.** Child life specialists utilize bibliotherapy, books for a therapeutic purpose, to educate, prepare and help children understand what is happening inside their bodies. Below is a list of resources that I found helpful for explaining a diagnosis of cancer to preschool and school-age children as well as resources for parents to utilize at home.

At the top of the list of concerns for many parents is how to explain hair loss to children. This is almost immediately the sign of a child with cancer and for young children can make them feel different than their peers. **There's So Much More to Wear than Hair** by Sarah Kravchuk is an uplifting book that helps children identify creative head-covering options and opens the imagination to alternative kinds of hair (Spaghetti hair sounds fun!). This book can be used to start the conversation of how children want to cover their heads, or not. Do they want to wear hats, bandanas, headbands, or a wig? Do they want to dye their hair a fun color before it falls out? Will they cut or shave their hair or let it fall out on its own? These are the questions I help my patients and their families work through as treatment progresses.

Diagnosis teaching is essential to helping children understand what is happening inside their body, why they need certain medicine and to be in the hospital. **Blood Soup** by Jessica Wilfore and Tryandi Moch is an interactive teaching book that explains the four parts of blood which can be used to explain how leukemia affects the body and how chemotherapy fights cancer. I often use this activity with art supplies or candy and create a fun sensory or tasty treat together while learning about leukemia.

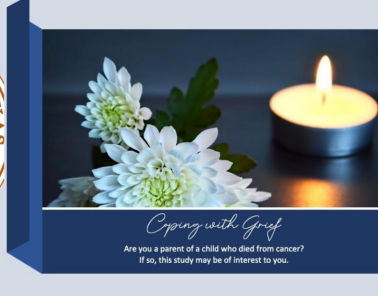
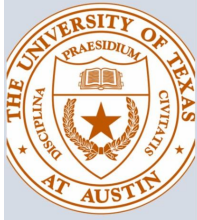
The Donut That Roared: A Child's Guide to Surviving an MRI by Joan Yordy Brasher with Jackson Grant is written from the perspective of a child who has a brain tumor and his impression of what an MRI machine looked like: a donut! An MRI machine is utilized for many different types of cancer and is an important, and oftentimes, intimidating diagnostic tool. This book is a great way to open children's imagination about what they think an MRI machine looks like and what coping tools they can utilize to be successful at their scan.

While not specific to cancer, **Caroline's Infusion Day** by Kelly Brennan can be adapted for a child undergoing chemotherapy and realistically depicts what a chemo infusion day will look like, how to prepare, and what to expect throughout the day. Caroline also shares her coping tools for pokes, nausea, and getting through a long clinic day.

Child life specialists utilize bibliotherapy to support pediatric patients with cancer and their families as books are a tangible resource that are familiar to children. Realistic drawings and descriptions allow families to learn about their child's diagnosis, what to expect throughout treatment and how to cope during a difficult time. Many of these books are written by children who went through treatment or by their parents from their child's perspective.

Here are a few additional books that I utilized with my patients and families:

- *When a Kid Like Me Fights Cancer* by Catherine Stier
- *Someone I love has Cancer* by Sara Olsher
- *The Great Katie Kate Tackles Questions About Cancer* by M. Maitand Deland and Jennifer Zivoin
- *My Chemo Fairy* by Heather Pastrick and Stephanie Parker
- *Princess Lily Earns her Beads* by Sarah Bankuti
- *Princess Lily and the Hair Fairy* by Sarah Bankuti



Dr. Carolyn Phillips (an assistant professor at The University of Texas at Austin, School of Nursing) is recruiting for a new research study evaluating the use of **“Storytelling Through Music”** to help parents who have lost a child to cancer, tell their stories, and create a personalized legacy song.

Last month the research team began enrolling parents to the study. They are hoping to have the study completed in the next year and to enroll 30 people. **The study eligibility criteria are:**

1. >18 years old;
2. ability to read and speak English;
3. bereaved parent of a child who died from cancer (ages <39 years);
4. child’s death >6 months and <5 years prior to study initiation;
5. access to internet and computer.

To learn more about the study and to share this research opportunity with other bereaved parents, please download this flyer.



Mattie Miracle Cancer Foundation is a GuideStar PLATINUM Participant Charity



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