

## News & Updates

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### Upcoming Activities

**April**  
Toiletry Drive  
[Amazon Wish List](#)

**May 19**  
15th Annual  
Virtual Walk



## Capstone Collaboration

Mattie Miracle is honored to collaborate on a Capstone project with **Jackie Benjes**, a college senior, majoring in Education at Brown University. This project is a multifaceted body of work that serves as a culminating academic and intellectual experience.

### Reflections from Jackie

This semester I am focused on my Capstone project for my Education major. I had the opportunity to choose a topic I was passionate about and explore it extensively. **I chose to study the psychosocial needs of childhood cancer patients who are unable to be present in the classroom for long stretches of time.** I used my own experience as a cancer survivor as well as my experience as a camp counselor at an oncology camp in New Jersey as inspiration for the initial development of the project.

**When I was a senior in high school, in the midst of the pandemic, I was diagnosed with thyroid cancer.** I yearned for in-person connections and support, but I was unable to receive comfort in that form due to the need to keep myself as healthy as possible. However, my amazing friends (whom, to this day, we remain incredibly close) found other ways to ensure that I felt supported. They drew chalk messages on my driveway and collected videos for me to watch when I woke up from surgery. They conducted a card drive that included letters from almost everyone in my grade, and they sent cookies and flowers to my doorstep. One friend even came

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the medicine!<sup>SM</sup>**

to sit outside of my house and then called me on the phone so we could see each other through the window but still keep me safe from getting COVID-19. **This support is what got me through the hardest experience of my life, and it is the support that every child with cancer deserves. I was committed to creating a product that made this type of support accessible for educators to recreate and encourage within the classroom.**

Throughout the creation of this website, I was connected with some amazing individuals who graciously shared their experiences with cancer. Each interview allowed me to get one step closer to creating a website that would benefit children with cancer, their families, and educators. **Mattie Miracle's Co-Founder, Vicki, was one of the amazing connections who I had the privilege to speak with this year.** The head of Mattie's elementary school happened to be my roommate's father, and when I interviewed him about his experience working with students with cancer, he immediately offered to connect me with Vicki. Within just a few days of reaching out to Vicki, we had a Zoom call set up.

Talking with Vicki helped me immensely in developing this Capstone website. Her emphasis on the Psychosocial Standards of Care that Mattie Miracle funded directly connected with my Capstone work. The stories she shared about Mattie and her family's experiences working with the school helped the website progress. **Especially touching was learning how much Mattie loved when the head of his elementary school would come to the hospital and teach him magic. A lot of what the community had done for Mattie and his family were able to be generalized and added into the website so that these ideas can serve as inspiration for others.**

It is my hope that this website will create a more standardized approach that will allow for consistent support from schools to the child with cancer and their family. **I hope that this website will help educators have easy and accessible activities to do with their class so that the child is not forgotten after the first few months of treatment.** As the website continues to evolve and reach more people, I intend to continue to interview families touched by childhood cancer and add their stories to the website so that it can serve as a living, changing model for what educators and the school community might be able to do to support a child with cancer.

**If you wish to speak with me about your experience or comment on the website, it would be deeply appreciated. Please reach out to me at [jacquelyn\\_benjes@brown.edu](mailto:jacquelyn_benjes@brown.edu).** Thank you Mattie Miracle for the work that your Foundation does every day for kids with cancer, and thank you for providing me with an opportunity to share the SKCC (Supporting Kids with Cancer in the Classroom) website.

**Click on the image below to check out Jackie's website**



## 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.

### Hair Loss and the Cancer Journey

One of the more noticeable and often distressing effects of childhood cancer is hair loss. For some, this appearance altering result of chemotherapy symbolizes that this journey is “real.” **What I have found interesting is the meaning that many families associate with hair loss.** For the four-year-old girl with hair past her shoulders, her mother is mourning this loss of her childhood, her princess hair, and that cancer, more specifically the treatment of cancer, has entered their lives. For the twelve-year-old girl, this makes her “different” than her peers and she is scared about how her social relations will be impacted. For the teenager, this is a cool opportunity to do crazy things to his hair before shaving it off in defiance of his diagnosis. **Hair, and hair loss, are personal.**

As a child life specialist working with children with cancer, I anticipate this part of the treatment journey. Sometimes parents bring up the question before I do, recognizing the natural progression of treatment. **“How do we handle this for our child?”** That is the key point here: ‘for our child.’ **Each of the children I work with is unique, and so are their needs related to coping with hair loss.** It is at this point I can open the conversation of options, resources, and coping. For all my patients, I advise that each child and family are unique and whatever they choose is fine. Do you want to let your child's hair fall out on its own? Do you want to dye your child's hair? Add fairy hair? Maybe cut some of it into a fun hairstyle? That tends to be the most common choice regarding the first stage of hair loss. It is important to note that not all children will lose their hair completely. This is something to discuss with your child's doctor. Some of my patients have kept a loose ponytail or tufts of hair for a significant part of their journey.

Next, as treatment progresses, comes the question of complete hair loss. Do we shave it? Or let it fall out on its own? Anna, the patient I mentioned last month, kept her hair until it started getting matted due to the significant amount of time she was in bed. Eventually it was so uncomfortable she bravely told her mom to cut it off. No matter what the child and family choose, **hair loss is deeply personal and deeply symbolic of the meaning each family attaches to their cancer journey.**

Here is a list of books, resources and organizations I share with my patients and families to support their journey and coping with hair loss.

## Books

- [There's So Much More to Wear Than Hair](#) by Sarah Kravchuk
- [Princess Lily and the Hair Fairy: A book for children and their friends to help with losing hair due to being sick \(The Princess Lily Series\)](#) by Sarah Bankuti (Author), Kristina Dutton (Illustrator)
- [Anna Loses Her Hair](#)
- [My Hair Went on Vacation](#) by Paula Quinn (this book was written about alopecia but much of the content can relate to cancer hair loss as well)

## Wigs and Head Pieces

- [Headcovers Unlimited](#)
- [Pink Heart Funds](#)
- [Chemo Diva](#)
- [Locks of Love](#)
- [Children's Cancer Network](#)
- [Children with Hair Loss](#)
- [Wigs for Kids](#)

## Hats and Head Coverings

- [The Magic Yarn Project](#)
- [Love Your Melon](#)



## Coping with Grief

[Dr. Carolyn Phillips](#) (an assistant professor at The University of Texas at Austin, School of Nursing) is recruiting for a 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.

In January, Mattie Miracle received wonderful feedback from a bereaved mom who participated in this study. **She learned about the study from our newsletter and she is very thankful to have this special legacy item which captures her daughter's amazing life through a meaningful song.**

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 (child's age is <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.**



## We Need Your Help

In honor of Mattie's 22nd birthday, we will be hosting our **13th annual item drive**. All donated toiletries stock our Mattie Miracle Snack & Item Carts for pediatric families at MedStar Georgetown University Hospital (Washington, DC), Children's Hospital at Sinai (Baltimore, MD), and the Clinical Center at the National Institutes of Health (Bethesda, MD).



When living in a hospital 24 hours a day, seven days a week and caring for a child with cancer or other life-threatening illness, **receiving these items can feel like a gift.** Families often rush to the hospital when their children are ill and are unable to pack basic items that are needed for daily care. The Carts fulfill these basic psychosocial needs and **provide items free of charge to families.**

Check out our Amazon wish list below and help us keep our Mattie Miracle Carts stocked to support families caring for children with cancer. **Our Carts support over 2,500 families a year. We ask that all items be received by April 8, 2024.**

**Click on the image below for our Wish List.**





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