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## News & Updates

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October 2023 | Volume 14 - Number 9

### Upcoming Activities

**November**  
Candy & Snack  
Drive  
[Amazon Wish List](#)

**December**  
Annual Fund  
Campaign

**About Us**  
Spreading Hope  
Through  
Psychosocial  
Support <sup>SM</sup>

[Learn](#)

**Support**  
Help Make The  
Miracles Possible

[Donate](#)

**CFC #59853**

[Giving](#)

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## International Webinar

On September 29, Mattie Miracle was a featured speaker at a conference webinar hosted by the [International Psycho-Oncology Society](#) (IPOS) entitled, Legacy Making Across the Lifespan. This 90-minute presentation focused on the creation of legacies as an essential aspect of coping and meaning-making. **Legacy making is defined as what one leaves behind and how one hopes to be remembered after death.** The webinar discussed legacy making across the lifespan, with examples highlighting art, music, and writing of personal stories capturing the lived experiences of family members.

There are 15,000 children diagnosed with cancer in the United States each year, resulting in around 40,000 children receiving cancer treatment (Siegel et al., 2017). **Children with cancer experience substantial suffering and decreased quality of life throughout their cancer journey, including physical symptoms, emotional, and social distress** (Levine et al., 2017). Legacy making may play a significant role in quality of life during illness and at end of life (Foster et al., 2012).

Legacy activities include memory books, songwriting, photographs, and videos (Robb et al., 2014). **Legacy making has been explored with both adults and children and it is shown to increase sense of dignity, purpose, meaning, and will to live, while decreasing**

**It's not just about  
the medicine!<sup>SM</sup>**

**suffering and depressive symptoms** (Chochinov et al., 2005). Many children's hospitals offer legacy making activities to their pediatric patients and their family members. Hospital staff have reported that legacy activities helped children cope and communicate and the benefits also extended to family members. Legacy making enables family members to cope, communicate, and continue bonds in the case of their child's death (Foster et al., 2012).

Mattie Miracle's President shared her lived experience on this webinar. For Mattie Miracle's co-founders, the awareness of legacy making occurred after Mattie died. Specifically, the co-founders learned about the topic while they attended a palliative care conference. The takeaway message from the conference was at end of life, the family (with input from their child) should capture wishes, how the child would like to be remembered and memorialized. But what happens if this does not occur? After all there are many barriers to legacy making, such as timing or sensitivity to discuss these topics with children and their families.

Instead of looking at legacy work as something that is passed down from the person dying to those left behind, **Mattie Miracle views legacy making as the life story families create together throughout the entire cancer journey.** None of us possess a crystal ball, and therefore, we have no idea of a child's disease outcome. Therefore, we believe that legacy making is about the living and for the living. We invite families and clinicians to think more holistically about legacy making. **For children with cancer and their families, memories and how a child wishes to be remembered may not come from prescriptive exercises but instead by examining the child's life, activities, and creations.**

### Resources to Consider



[Legacy Intervention](#)

[Digital Story Telling](#)

[A Quest for Meaning](#)

Spreading Hope Through Psychosocial Support. <sup>SM</sup>

## Funding Child Life

In July 2018, Mattie Miracle endowed its second Child Life Program Fund. **To date we have donated over \$250,000 to**

**Children's Hospital at Sinai** (Baltimore, MD). This fund pays for the full-time salary of a child life specialist. We are honored to introduce our supporters to Emily Nosek. **Emily is the 6th Child Life Specialist funded by Mattie Miracle since 2011.** Our Child Life positions serve around 1,500 children and families a year.



Mattie Miracle is committed to funding access to Child Life services for children with cancer. A Child Life Specialist has the necessary skills and abilities to make a very frightening and stressful medical experience more manageable. In fact, we believe Child Life services are just as important as the medical treatment.



## Reflections from Emily

I am the Mattie Miracle Child Life Specialist at Sinai Hospital in Baltimore, Maryland. I am very excited and honored to have the opportunity to represent Mattie Miracle as I provide child life and psychosocial services to patients and their families in the hematology/oncology clinic.

I first learned about child life when I was in high school. My mother was a pediatric nurse at Mt. Washington Pediatric Hospital (MWPB) in Baltimore. She brought home a brochure that explained their child life program and the role of a child life specialist. I knew I wanted to work with children, but also wanted to work in a unique and challenging setting other than a daycare. After shadowing a child life specialist at MWPB **I fell in love with the job and knew I wanted to pursue a career as a child life specialist.**

I started volunteering at MWPB, then moved to a child life assistant role before completing my child life internship. Prior to my internship, I completed my practicum at the Children's Hospital of Philadelphia (CHOP) in their pediatric proton therapy center. It was there that I observed and shadowed a child life specialist. During my time at CHOP, **I worked with the oncology patients in the waiting room before they went to receive their treatment and I immediately knew this was the population I wanted to work with and support.**

I remember working with a teenage girl who was telling me about her diagnosis and how she had to stop playing soccer due to her treatment plan and how her summer had been ruined. It broke my heart. I thought, what can I do to best support her? How can I make this better for her? It was challenging and I knew it would be a hard population to work with, but I am dedicated to helping patients like her in my career.

I started my career as a child life specialist at the HSC Pediatric Center in Washington, DC. At this pediatric rehabilitation hospital, I provided activities and interventions to help patients cope with their hospitalization while also meeting their developmental, emotional and educational needs. I worked with a variety of diagnoses, oncology being one of them. It was inspiring to see the strength and determination of children during their physical and occupational therapy sessions.

**After three years at HSC, I knew I wanted to work only with the oncology population. I then applied to work at MD Anderson Cancer Center in Houston, TX as a child life specialist,**

specifically to work with their Adolescent and Young Adult (AYA) population, working at their camps, and learning more about the different types of cancer. I developed close relationships with my patients and their families during that time. They taught me a great deal and they helped me grow within my career as a child life specialist.

I decided to return to the East Coast to be closer to family and **I am honored to be Mattie Miracle's full-time child life specialist at Sinai Hospital, working in the hematology/oncology clinic. I am very grateful for this opportunity, and I am committed to enhancing the quality of life of children with cancer and their families.**

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## 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.

### ~~~~~ The Art of Supportive Care

Part of any treatment for pediatric cancer is intensive chemotherapy designed to wipe out the bad cancer cells. Unfortunately, this can also take out good cells that fight infection and viruses at the same time. **This means that many children with cancer have their immune system wiped out, making them incredibly susceptible to viruses and infections which can be incredibly dangerous.** Anytime children with cancer have a fever they are instructed to go right to the hospital for an immediate infusion of antibiotics to prevent anything more serious from occurring. Furthermore, because chemotherapy wipes out the immune system, pediatric cancer patients must redo their childhood vaccines after treatment. **Therefore children with cancer are at a higher risk for illness during treatment. That means that exposure to a cough or cold from a friend or family member can mean immediate hospitalization.** This is why vaccines for the greater population are important to protect children with cancer. As we are approaching flu season, there are several ways that parents can support their child in getting a vaccine. Child life specialists support children receiving vaccines and shots in many different settings and offer support and resources to make it as calm as possible.

1. Preparation - when your children are scheduled for a vaccine, it is important to prepare them prior to their appointment. Younger children, like toddlers and preschool-age students, should be told the day of their vaccine. Older school-age children can be told the day before. Talk with your child about what to expect and come up with a coping plan together.
2. Comfort holds - Vaccine clinics, or even the doctor's office, typically move quickly. This means that having a plan to best support your child is helpful when things are moving quickly. Comfort holds are a supportive way to hold your child safely during a vaccine. **[Click here](#)** for a great resource to become familiar with comfort holds.



3. Coping plan - every child is different and therefore coping needs are different. Some kids may want to look at the syringe while they get a vaccine while others may want to look away. Consider bringing comfort items like a stuffie or blanket for reassurance, and fidgets or an iPad for distraction during the vaccine. Having something prepared ahead of time ensures that the vaccine can occur in a timely manner with as little stress to the child as possible. Sometimes the anticipation of the poke can be more frightening than the poke itself.
4. Pain management - There are several pain management options that can be used by parents in any vaccine clinic setting. For example, using an ice pack to numb the skin prior to the vaccine, or using a Buzzy or other small vibrating device next to the site of the vaccine. Ask the person administering the vaccine where to hold the Buzzy near the poke. The Buzzy vibrations trick the nerves into focusing on the vibrations instead of the poke. Also, if your child is incredibly anxious, ask your pediatrician about numbing cream. This may require a prescription, but it is incredibly effective at numbing the skin, so the child does not feel the poke.
5. Positive reinforcement - Whether the vaccine was administered smoothly or not, it is important to acknowledge your children's positive coping skills. Did they sit still even if they cried? Did they take deep breaths? Did they utilize their coping plan? Praise and acknowledge the things your children did well and reinforce the tools that helped them.

Vaccines and pokes are a routine part of life. However, for the child with cancer, the aftermath of treatment means that the child has endured hundreds, if not thousands of shots and pokes, and once treatment is complete, they are still not done! For some children, they have adapted to their treatment and feel confident in having their port accessed regularly, but a port cannot be used for vaccines. This means reassessing their coping needs and preparing them for revaccination pokes. For my patients, this means introducing a new coping plan, offering new pain management options, and developing a new distraction plan. Despite those hundreds of pokes received during treatment, not every poke is the same. **Even if a child with cancer has had their port accessed with ease does not always mean the next poke will be as easy. Child life specialists understand that coping is fluid and support needs to be constant.**



## 13th Annual Fall Drive

We need your help! Please donate candy and snack items, so that we can continue to stock our free Snack and Item Carts at hospitals.

Our four Carts are considered a life saver by families who are caring for a child with cancer or another life threatening illness. **Our hospital Carts support 2,500 families a year.** After a decade of successful in-person Candy Drives, in 2020, we made the difficult decision to transition to an all-virtual event.

Hospitals have requested that candy remain in its original vacuum sealed bags, with its manufacturer's expiration date. Therefore, the safest way to meet these requirements is to use an Amazon Item Wish List.

You can participate in our 13th annual Candy and Snack Drive from anywhere in the USA. Please view our Amazon wish list, and we request all items be received by November 13, 2023.



Mattie Miracle Cancer Foundation is a GuideStar PLATINUM Participant Charity



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