

News & Updates

September 2023 | Volume 14 - Number 8

Upcoming Activities

September 29 Legacy Making Live Webinar IPOS Conference

November Candy & Snack Drive Amazon Wish List

> **December** Annual Fund Campaign

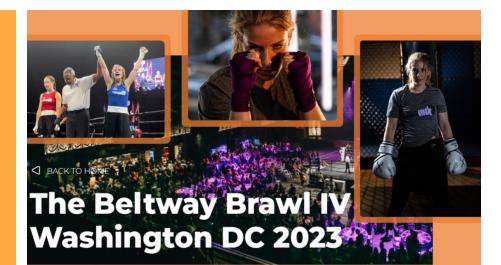
About Us Spreading Hope Through Psychosocial Support SM



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Fighting for Miracles

On September 13, <u>Jennifer Markowitz</u> participated in the Beltway Brawl, held at the Anthem in Washington, DC. This charitable boxing event was sponsored by Haymakers for Hope.

Haymakers for Hope is an official 501(c)(3) charity organization that gives participants the opportunity to fight back against cancer. They help participants train for — and compete in — a sanctioned charity boxing event to raise funds for cancer research, care, awareness, and survivorship. To prepare for each event, the organization combines the efforts of local boxing gyms and volunteers, and they match participants up with someone of a similar experience level (even if that experience level is "none"). At the end of this journey, participants will compete in front of thousands of supporters, and win or lose they will step into and out of the ring as a champion.

Jen is a pediatric speech language pathologist at MedStar Georgetown University Hospital in Washington, DC. She selected Mattie Miracle to be the recipient of the proceeds she raised from her incredible efforts. **Congratulations Jen! She not only won her boxing match but Jen raised over \$15,000 for Mattie Miracle!**

Cancer is a personal cause for Jen as her grandfather died from stomach cancer and her mom is a breast cancer survivor. Jen shared these reflections, Giving

It's not just about the medicine!™ "I still remember visiting my grandfather in the hospital. I remember his face...the way it always was. Children have an uncanny ability to see beauty in painful situations. I also witnessed my mom navigate surgeries, chemotherapy, and radiation, while making sure my brother and I experienced comfort and love that only a mother can provide. My mom taught me to persevere through all things and through this she taught me about unconditional love. I chose to support Mattie Miracle because I believe in its psychosocial mission. It is vitally important to fight for the families (parents, siblings, relatives) standing alongside their loved ones on their cancer journey, and Mattie Miracle is a champion of this supportive care."



Spreading Hope Through Psychosocial Support. sm



It's not just about the medicine!™

- The <u>Psychosocial Standards of Care</u> provide evidence-based information on the emotional and social support needed to optimize the quality of life for children with cancer and their families (Wiener et al., 2015).
- Optimal cancer treatment must include psychosocial care (Institute of Medicine, 2008).
- Depression and other psychosocial concerns can affect adherence to treatment (Institute of Medicine, 2008).
- 4. Psychosocial care has been shown to yield **better management of pain and fatigue** (Jacobsen et al., 2012).
- 5. **Treating the pain, symptoms, and stress** of cancer enhances quality of life and is as important as treating the disease (Institute of Medicine, 2015).
- Siblings of children with cancer are at risk for developing anxiety, depression, and posttraumatic stress disorder (Alderfer et al., 2003).
- 7. Childhood cancer survivors reported medication use for **anxiety and**

depression at rates nearly two times those reported by the general public (Hawkins et al., 2017).

- 8. Symptoms of **post-traumatic stress** disorder are well documented for parents whose children have completed cancer treatment (Kazak et al., 2004).
- 9. **Financial hardship** during childhood cancer treatment negatively impacts family well-being (Bona et al., 2014).
- 10. The **death of a child** to cancer frequently results in depression, anxiety, loss of appetite, sleep disturbances, and fatigue (Alam et al., 2012).

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.

September is NOT just about School

By this point in the year, school has officially begun. New pencils have been sharpened, school supplies have been unpacked and learning is in full swing. **However, there are some classes that may have an empty desk.** There is a name on the roster that hasn't been marked "present." I feel strongly that **it is no coincidence that Childhood Cancer Awareness Month is in September, as we are most acutely aware of children during the month they return to school.**

Every year 17,000 children are diagnosed with cancer. This comes out to roughly 47 children diagnosed every day with cancer or approximately two classrooms filled with children. These statistics paint a very real picture of childhood cancer and how it shouldn't be surprising that kids across America may have a classmate, sibling, friend, or teammate battling cancer.

As a child life specialist, the work that I do is typically limited to the hospital setting. I see pediatric patients diagnosed with cancer in the outpatient clinic for their routine blood work and chemotherapy infusions or when they are inpatient for neutropenic fever, extended chemotherapy, or other more intense treatment needs. However, **the scope of my work is to support the ever-changing psychosocial needs of my patients, particularly addressing the needs that have been disrupted due to cancer.** At the start of a new diagnosis, parents will often ask how to explain this to their child's teacher or classmates. What was just "feeling achy" has turned into week long absences, and their empty chair serves as a stark reminder of what has become a true nightmare. This is where the concept of "**school reintegration**" is introduced. This is an ongoing discussion between me, the parents, the child, and the school about how to best support the patient and their classmates who are also affected by their friend's illness.

Once the diagnostic scans and tests have been completed and a treatment protocol has begun, parents have the space to think about how to address their child and their schooling. This is where I introduce my good friend, the monkey! <u>Monkey in My Chair</u> is a wonderful resource to help connect the child with cancer with their classmates. The Monkey is a child-sized stuffie that sits in the child's desk at school as a reminder to the class about their friend with cancer. The Monkey comes with a photo album so friends can take photos with the Monkey to share with their friend in the hospital, as well as a journal for them to share stories and notes. The kit also includes a handbook for teachers of talking points to discuss cancer in an age-appropriate way. This is a resource I share with parents and schools, and it provides a tangible way to mitigate a very real and potentially scary conversation.

The Monkey is helpful when the child is not attending school and wants to remain connected, however, once the child is ready to return to school, I will once again open up a conversation about how the child wants to reintegrate into the classroom. There certainly have been many physical changes due to treatment, such as hair loss or limb loss. There may also be emotional changes, such as anxiety or depression, all of which are very real side effects of childhood cancer. With the child, I will come up with a plan about speaking to the class and explaining their friend's cancer journey. The classmate with cancer may attend this discussion or not, however, my role is be their advocate while also acting as a resource for the classmates.

September is Childhood Cancer Awareness Month. Cancer remains the #1 leading cause of death (by disease) in children in America. Those who do survive struggle with the emotional and physical side effects, usually for the rest of their lives. The work of the Mattie Miracle Cancer Foundation is vital in reducing the damaging psychosocial effects of cancer and I have seen first hand how their services enable children and families to have a better quality of life.



M&M Wishes

In 2021, Mattie Miracle launched its M&M (Margy & Mattie) Wishes Program in memory of our board member, Margy Jost. Margy was a fierce childhood cancer advocate who devoted her life to helping children with cancer. Margy was passionate about providing grants to families to help create memories outside of the hospital experience. **M&M Wishes offers families a grant of up to \$1,000** to support a fun activity, trip, or a wish list item for a child with cancer.



Therapy Grants

In 2021, Mattie Miracle participated in <u>Thrivent's Take the Plunge</u>, a nonprofit Shark Tank. Thanks to the hundreds of votes we received from supporters and generous donations we were granted \$10,000 to start a new initiative.

Our therapy support program grants children with cancer up to \$1,000 for therapy sessions with a licensed mental health provider within their To date, Mattie Miracle has granted **\$17,000 worth of M&M Wishes** to children and their families. In many cases, **families have reached out to us because they do not qualify for support through other organizations**, either due to the child's age, the stage the child is within treatment, or because the child was receiving end of life care. Mattie Miracle understands that wishes must be granted around a family's timing and needs, and we work hard to ensure that children and teens have a chance at making their dreams come true.

Check out our application and we look forward to the opportunity to coordinate M&M Wishes with families and their care teams.



community. Families face a host of mental health issues as a result of a childhood cancer diagnosis, such as depression, anxiety, medical traumatic stress, substance abuse, and eating disorders. Yet frequently families of children with cancer are referred out of the hospital system and into the community for support, in order for them to manage and cope with their psychosocial needs and concerns. The problem with this is it is **very challenging for families to access such support because of financial difficulties.**

Our grant program steps in to ensure that families are able to obtain mental health assistance in the community, because we understand that childhood cancer is not just about the medicine. We invite families and their social workers to reach out to us about these support grants and we welcome you to download our application.





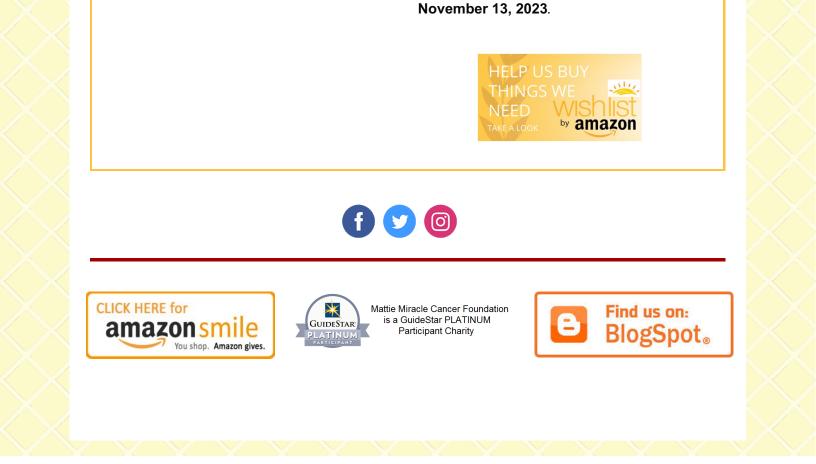
13th Annual Fall Drive

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 other 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



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