

News & Updates

December 2022 | Volume 13 - Number 11

Upcoming Activities

April, 2023 12th Annual Toiletry Drive (Wish List Coming Soon)

May 21, 2023 14th Annual Virtual Walk

About Us Spreading Hope Through Psychosocial Support SM

Learn

Support Help Make The Miracles Possible

Donate

CFC #59853



Our Wish for You

We wish you a happy holiday season and the best of health and happiness in 2023. You play a vital role in our success and help to make the Mattie Miracles possible. We appreciate your continued contributions, your loyalty to the Foundation, and your commitment to our psychosocial mission. Thanks to you we are the only national non-profit, dedicated to PSYCHOSOCIAL awareness, advocacy, support, and research of childhood cancer.

Over the last 13 years, together we have:

- 1. Raised over \$1M to fund our psychosocial programs
- 2. Supported 35,000 children with cancer
- 3. Funded 5 child life specialists
- 4. Awarded \$130,000 in psychosocial research grants
- 5. Published the first evidence based <u>Psychosocial Standards of</u> <u>Care</u>
- 6. Sponsored the publication of the <u>Matrix and Guidelines</u> to help implement the Psychosocial Standards of Care
- 7. Awarded 10 M&M Wishes
- 8. Funded 2 Therapy Support Grants
- 9. Delivered 26,000 snacks to in-patient families
- 10. Donated millions of pieces of candy and toiletry items to families



It's not just about the medicine!™

11. Introduced House Resolution 262

12. Added Psychosocial Language to the <u>STAR Act</u> (signed into law June 2018)

Please contribute to our Annual Drive by clicking on the gift box. Your **tax-deductible donations** make the Mattie Miracles possible.

Click the Present to Donate Now!



Spreading Hope Through Psychosocial Support. 5M

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.

Supporting the Entire Family

In previous newsletters, I have discussed the role of a Child Life Specialist, how we support children in the hospital and how to become a Child Life Specialist. As the name indicates, a majority of our role is focused on children and their needs in the hospital. Our training includes extensive child development knowledge and experience working with children in different settings. Yet, when children come to the hospital, they come as a unit with their caregivers, perhaps siblings, and even extended family who make up their support network.

When Child Life Specialists introduce services to a patient in a hospital room or treatment center, we are speaking to the whole family. In fact, we rely on parents and caregivers to help us learn about their children and their needs, their likes and dislikes, their previous hospital experiences, and their overall coping. I have often described a Child Life Specialist as the glue of a children's hospital. We relay information from physicians and nurses to families in a way that children can understand developmentally and that parents can digest when they are facing their worst nightmare. We prepare the parents for their children's procedures just as much as we do the children themselves. When I prepare patients for procedures, I am always involving the parents in how they can best support their children. This may be how they sit with their child in a position of comfort which is a specific way of holding their child that makes the child feel

secure and safe and allows for procedures to take place with extra support. Or, I may be reminding a terrified parent that their child will reflect mom or dad's emotions and reactions. A calm parent usually means a calmer child, and often this is a struggle for parents as they are watching their child suffer or in pain. This is why coping plans are developed with the child to include the parents so that everyone feels supported and prepared.

Beyond the hospital, Child Life Specialists aim to give parents and caregivers the tools and resources to support their child at home. When children need to take medication or receive treatment at home, Child Life Specialists may provide parents with an incentive plan for their children to follow in which they complete their treatment needs at home and receive a prize or reward when they return to the hospital. Child Life Specialists partner with parents to ensure their child is receiving optimal support in the hospital and at home and parents are receiving support as well.

The child's support team may also include siblings. Child Life Specialists provide support to siblings as well in understanding their brother or sister's diagnosis, explaining how they can help and even more so, how they can take care of themselves when they are struggling with their sibling's illness.

To highlight the importance of the family system, I want to share a story about a patient I worked with and how I involved his family in his care. Matt (name has been changed) is a 5year-old boy receiving treatment for Leukemia. Due to a fever, he had to be admitted to the hospital. He was already small for his age and since he felt sick, he was having a hard time eating enough to keep up his weight. His doctors decided the best course of treatment for him to be able to gain weight and get stronger was to place a Nasogastric Tube (NG) in his nose to get calories directly into his stomach. He had this before and I knew it would be difficult for him. I spoke with his mom about his past experience getting an NG tube and shared what I felt would be the best way to get this done. One, he would sit with his mom on her lap. Two, his sister, who was always present and looking out for him, would be in the room holding his hand. Three, I would be talking him through the NG tube placement and holding his iPad so he could watch his favorite show. Since I knew he would get very upset with this procedure, I prepared his sister as well for what to expect to ensure she felt she could stay in the room. I reminded her how important it was for her to stay calm and she understood. Overall, the patient did well with the procedure and the family felt prepared and supported and in turn, the patient felt supported. This is why Child Life Specialists involve the entire family unit in the patient's care.



Highlights from 2022

As 2022 draws to a close, we reflect on **this year's highlights and accomplishments**. Together, with your support, we have made many Mattie Miracles possible.

- 1. Endowed the Mattie Miracle Child Life Program Fund, by donating \$53,000 to support a full-time child life specialist position.
- 2. Funded Psychosocial Standards of Care implementation <u>research grants</u>, totaling \$130,000 across 21 studies.
- Launched a non-profit research partnership with <u>The Andrew McDonough B+</u> <u>Foundation</u> and <u>Momcology</u>. We are grateful to the B+ Foundation for their \$115,000 grant to conduct innovative implementation research with the Psychosocial Standards of Care.
- 4. Operated the Mattie Miracle Free Snack & Item Carts for in-patient pediatric families at the MedStar Georgetown University Hospital (Washington, DC) and at Children's Hospital at Sinai (Baltimore, MD). These carts serviced over 2,500 families this year.
- 5. Launched a new Snack and Item Cart at the National Institutes of Health's Clinical Center (Rockville, MD).
- 6. Held the virtual <u>13th Annual Walk</u>, generating \$144,500 and with walkers from 41 states and six countries.
- 7. Created the <u>M&M Wishes Program</u> in memory of our board member, Margy Jost. This program awarded 10 family grants this year, ranging from \$600 to \$2,220. These grants support a fun family activity, trip, or a wish list item for a child with cancer.
- 8. Funded **two therapy support grants** for children with cancer. Each \$1,000 grant covered the cost of psychological services within the community.
- 9. Partnered with the American Psychological Association's Division 54 to launch a **successful social media campaign** about the importance of psychosocial issues and care during Childhood Cancer Awareness Month.
- 10. Coordinated **two annual community item drives** (candy, snacks, and toiletries) to help stock our hospital Snack & Item carts.

We Love Our Supporters

Thank you for standing behind our mission to assist children with cancer and their families for 13 years.

Mattie Miracle has **no paid staff** and therefore all contributions go directly to our programs and initiatives.

Please make a **tax-deductible contribution** today. Your contribution will help us meet the psychosocial needs of children with cancer and their families, as well as implement the Psychosocial Standards of Care, so that every child with cancer has access to optimal psychological and social support.

Best wishes this holiday season and thank you for your continued support!







Mattie Miracle Cancer Foundation www.mattiemiracle.com





Mattie Miracle Cancer Foundation is a GuideStar PLATINUM Participant Charity

