

## News & Updates

March 2024 | Volume 15 - Number 3

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Through  
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Help Make The  
Miracles Possible

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**CFC #59853**

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## 15 Years of Walking

On May 19, Mattie Miracle will be hosting its 15th Annual Awareness Walk. This is a long standing tradition, with origins that tie back to Mattie Brown's amazing support community. Specifically, in May of 2009, Mattie's support community organized and hosted the "**Mattie March.**" The Mattie March was an outdoor event, held on the track of his school, to honor Mattie and to show him that his friends and family loved him and rallied around his recovery.

The Mattie March was so successful and meaningful, that the Mattie Miracle Cancer Foundation decided to continue the tradition by hosting its Awareness Walk each May. **The Walk is designed to spread awareness of the importance of psychosocial care in cancer treatment and to raise funds to support our work.** In 2020, our Awareness Walk became a virtual event. Now supporters from all over the country are walking, sharing our mission and story, and helping us raise funds for our initiatives and services.

We thank our Mattie Miracle sponsors and supporters for uniting behind our mission for the last 15 years. Together we have made many psychosocial miracles possible for children with cancer and their families. Join us on May 19, and help us celebrate our 15 years of service. Walk proceeds support our **Child Life Programs**, **Innovative Psychosocial Research Grants**, **M&M Wishes**, and **Therapy Support Grants**.

- We are making progress, and gains that definitely would not have happened without Mattie Miracle being the glue that brings us together around these important projects and milestones in our quest for psychosocial care for children with cancer and their families. ~ **Dr. Anne Kazak** (Co-Director of the Nemours Center for Healthcare Delivery Science)
- The Standards were designed to ensure that all children with cancer and their families have access to optimal psychosocial care from the time of diagnosis, throughout treatment, into survivorship or end of life and bereavement care. *Pediatric Blood & Cancer* commends the vast number of healthcare providers who worked tirelessly to develop the Standards of Care and to the co-founders of Mattie Miracle who turned the tragedy of the death of their son, Mattie, into his legacy that will help countless children with cancer and their families. *Pediatric Blood & Cancer* is honored to be the publication home of the Psychosocial Standards of Care. ~ **Dr. Peter Newburger** (Editor-in-chief of *Pediatric Blood & Cancer*)
- On behalf of the American Psychosocial Oncology Society (APOS) Board of Directors, we are thrilled to announce Mattie Miracle as our first Honorary Community Partner! We are so grateful for your continued support and significant contributions and look forward to continuing our relationship for many years to come. Thank you for your longstanding commitment to the mission, vision, and values of APOS. We are so honored to extend this first honorary community partner to you and the Mattie Miracle Cancer Foundation. It is through continued great partnering with advocates such as the co-founders of Mattie Miracle that we will continue to make a difference! We are truly grateful that you have chosen APOS as your partner organization and for all the work you continue to do to honor the importance of psychosocial/psychological care for patients and their families. ~ **Dr. Elizabeth Archer-Nanda** (APOS 2022 President)
- There is no disputing the significant physical challenges that a child with cancer faces, but far too many people do not realize the profound emotional challenges that the children – and their families – face. We have tremendous admiration for Mattie Miracle for advancing the need for and then creation and implementation of the Psychosocial Standards of Care. While there have been many people involved in the Standards, I will always thank Mattie Miracle's co-founders for being the catalysts. The Andrew McDonough B+ Foundation is proud to be a partner in their efforts. ~ **Joe McDonough** (Founder, The Andrew McDonough B+ Foundation)
- The co-founders of Mattie Miracle have been thought leaders in psychosocial support for over a decade. We believe there is a great opportunity to access the patient-family experience to influence psychosocial research like never before. We are proud that Momcology's community and network is now being valued in this important role in the ongoing advancement of knowledge, care, and the implementation of the Psychosocial Standards of Care. ~ **Kim Buff** (Founder & Executive Director, Momcology)
- The Mattie Miracle Cancer Foundation is, personally, a cause that is near and dear to my heart. I have witnessed the impact the Foundation has had on both families and care providers who together battle childhood cancer every single day...and I am truly inspired. Reaching this anniversary is no small feat! They truly make a difference in the lives of others. ~ **Todd Schuerhoff** (TeraThink VP - Homeland Security/Digital Transformation)
- Thankfully, Mattie Miracle's child life specialist was at the hospital and able to help my patient and her mom through the medical procedure, making the procedure go much more smoothly and safely for everyone involved. I honestly do not know what/how we would have done it without her! ~ **Kat Clark** (PICU Nurse, MedStar Georgetown)
- Thank you will NEVER cover it! Not ever! Julian has been a Patriots fan since elementary school. We are a big football family (Julian is number 3

out of 8 siblings). He has been taking on the whole family for years, rallying for his team. Since the news of your blessing, we don't go 15 minutes without hearing something about our trip to Gillette Stadium. He's been wanting this his whole life. Because he is 21 years old, I didn't think a blessing like this was possible. Financially, I could NEVER pull something like this off. Christmas came early and I CAN NOT WAIT to see his little face on game day! Gifting him HIS LITERAL DREAM goes beyond charity. It's confirmation that my son's life has value and that he deserves to live the BEST LIFE. ~ **Julian's mom** (M&M Wish Recipient)

- I really want to say thank you from the bottom of our hearts. This Christmas is going to be different than any of us have had before, but what we will always remember is being able to choose our new tree together. Every year when we get the tree out to celebrate our favorite holiday, we will remember that the reason we were able to have such a beautiful tree is because of the generosity of Mattie Miracle and the big heart of our Ashton. Your generosity has touched our lives forever, and I will never forget the smiles that you have already brought to Ashton, they mean everything these days. ~ **Ashton's mom** (M&M Wish Recipient)
- I want to let you know how much our parents appreciate your generosity with the Mattie Miracle Snack & Item Cart. So many of our families arrive with little or no resources to provide their own food. They haven't had time to prepare for hospital-life. Sometimes, parents are too embarrassed to mention their dire financial situation. Recently, until the nursing staff realized what was happening, a new mom's only "nutrition" was from the Snack Cart offerings. It's nice to see the smiles and genuine thankfulness from our parents when that familiar Snack Cart rolls around. It is one of the only continuities that our families can count on. It provides great joy to our families, which, in turn, provides great joy to our nursing and medical staff. Thank you from the bottom of our hearts. ~ **Lyn Knowles** (Clinical Manager, MedStar Georgetown)
- I want to thank Mattie Miracle for the incredible gift of concert tickets for my patient and his family. He died today (September 6, 2022), surrounded by his family. He told all of us that the concert was one of the best days of his life. You helped make this happen. ~ **Dr. Lori Wiener** (NIH, co-director of the Behavioral Health Core)

**Click on the image below to participate and support our 15th Annual Walk!**



Spreading Hope Through Psychosocial Support. SM

**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.

### March is Child Life Month

March is Child Life Month! This is often marked as a time to celebrate and uplift child life specialists for the work they do to support children and families in the hospitals. Normally, I would share posts and stories highlighting how we use play as an intervention, develop coping plans with patients and provide normalization to families, like events and parties. However, this month **I would like to highlight a different side of child life, one that we do not usually bring up in our “elevator speech.”**

Specifically in the world of oncology, child life specialists always have an awareness in their minds about the **precarious nature of a cancer diagnosis. Patients can be doing so well on their treatment plan and then a single blood test can show something concerning.** This was the case for one of my patients, Gina. Gina came to our hospital as a timid shy pre-teen who was always happy to color and do art together and I used this as a way to connect with her through therapeutic activities. After several months of treatment, Gina had been doing well, emotionally and medically. Her hair had grown in soft and fuzzy and she adorned it with cute headbands. She was more relaxed and talkative, and we had developed a great rapport. She was sitting in the clinic doing homework while the lab processed her routine bloodwork. This was when her doctor came out to the nurses' station to share the unfortunate news that it appeared Gina's cancer, although she was in active treatment, had returned. Very quickly, as a team, we had to address how to support Gina's mother and Gina when we shared the news. We informed Gina's mother who was understandably devastated but also incredibly overwhelmed with how to inform her daughter. As a group, her doctor, myself, and her mother, we returned to her clinic room, and we spoke with Gina, who expressed that she understood her cancer was back. Over the next few weeks, Gina transitioned to a new hospital to continue aggressive treatment. I visited her several weeks into treatment when, sadly, she was intubated, unable to breathe on her own, and her family had to decide about the path forward. Ultimately, Gina's body succumbed to cancer, and she died with her family around her.

**This is the side of child life that we do not readily bring up: the side of child life that deals with death, dying, end of life, bereavement, and grief.** I rarely discuss how I spoke with an 18-year-old patient about his last wishes and what he wanted following his death, for his possessions, his burial and celebration of life. I hardly ever bring up the hand molds and handprints I made with a patient in her hospital room just hours after her death, following years of battling cancer. I don't bring up the difficult discussions I have with parents about how to have the conversation about dying. Yet, this is a huge component of the work we do. **We provide children and families with the language to use to address death and dying. We provide opportunities for memory making and legacy building. We discuss last wishes and how patients want to be remembered. We hold the hands of our patients and families as they die. We attend remembrance ceremonies and funerals.**

This child life month, I want to highlight the work of child life specialists, the side of our work that is typically not discussed and therefore may not be noticed. I want to bring awareness to the importance of child life specialists in supporting children and families during these intense periods of grief and pain.

**Death and dying are difficult topics to discuss. Below are some valuable resources for addressing these conversations with children.**

**Coming Soon: What Happens When Someone I Love Can't Get Better** (for End of Life) by Sara Olsher and Jenni Rogers, MS, CCLS, CTRS

**The ABCs of Grief** by Jessica Correnti, MS, CCLS

**When Someone Dies** by Laura Cameron, CCLS

**Voicing My Choices: A Planning Guide for Adolescents and Young Adults**

**When Dinosaurs Die: A Guide to Understanding Death** by Laurie Krasny Brown, Marc Brown

**The Invisible String** by Patrice Karst

**Fire in My Heart, Ice in My Veins: A Guided Grief Journal for Teenagers and Young Adults** by Enid Samuel Traisman



## Implementing Psychosocial Standards Together: Engaging Parents and Providers in Psychosocial Care (iSTEPPP)

The 15 Psychosocial Standards of Care for Childhood Cancer were published in late 2015 with evidence from systematic reviews that justify the need for comprehensive psychosocial care in pediatric cancer. However, **it is not known to what extent pediatric cancer programs in the United States (U.S.) are delivering care consistent with the Standards.** This information is important to assure that evidence-based care is delivered. But it is also critical to know because implementation is difficult and learning more about centers' experiences can inform next steps.

The iSTEPPP project is funded by a research grant from the Andrew McDonough B+ Foundation. We are assessing the status of pediatric cancer care consistent with the Standards, from the perspective of healthcare providers and families. **This is the first time families have been provided an opportunity to report on what Standards are most important to them.** The team conducting this study represents a

**Submitted on behalf of the iSTEPPP Research Team:**

Anne Kazak, Ph.D.,  
Michele Scialla, MSN,

Kimberly Canter, Ph.D., and  
Emily Pariseau, Ph.D.,  
Nemours Children's Health

Lori Wiener, Ph.D.,  
National Cancer Institute

Kim Buff, Momcology

Victoria Sardi-Brown, Ph.D.,  
The Mattie Miracle Cancer  
Foundation

strong partnership between family advocacy groups (Mattie Miracle Cancer Foundation, [Momcology](#)) and researchers who are leaders in the development, testing and implementation of psychosocial care in pediatrics.

iSTEPPP is a mixed methods study that began with a national quantitative survey of 200+ cancer programs (in the Children's Oncology Group) across the United States. Healthcare professionals and a sample of caregivers from families across the country will provide data on the importance of specific Standards and insights into the facilitators and the challenges associated with moving towards successful implementation of the Standards. **We are very pleased that a comparable study is planned for Australia this year (iSTEPPP-AU), led by Maria McCarthy, Ph.D.**

The data collected will inform future research focused on implementation strategies for five of the Standards identified as most important.

## Upcoming Activities

### 13th Annual Item Drive



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

### Walk with Us on May 19th



Our Virtual Awareness Walk will be held on **Sunday, May 19, from 10am to Noon** (in your time zone). You can participate wherever you are and help us turn your community **ORANGE!**

Our Annual Awareness Walk raises **90% of the funds** we need to directly support our psychosocial programs and initiatives which help children with cancer and their families.

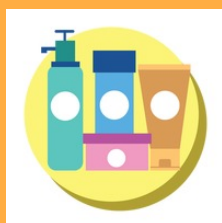
**Date:** Sunday, May 19th

**Time:** 10am to 12pm (in your time zone)

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.**



**Where:** Mattie Miracle Facebook Page

**GOAL:** Awareness Event and to raise over \$100,000

**Great prizes for walkers with the greatest number of steps!**

**Click on the Mattie Miracle sun to register, purchase raffle tickets, and donate to our Awareness Walk.**



Mattie Miracle Cancer Foundation  
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