

News & Updates

February 2023 | Volume 14 - Number 2

Upcoming Activities

February 14,
2023

Keynote Address
Jamaica
Psychosocial
Cancer Care
Stakeholders
Zoom Meeting

April, 2023

12th Annual
Toiletry Drive

[Wish List](#)

May 21, 2023

14th Annual
[Virtual Walk](#)

About Us

Spreading Hope
Through
Psychosocial
Support SM

[Learn](#)

Support



United to Improve Care

Mattie Miracle announced in November of 2022, that **The Andrew McDonough B+ Foundation** awarded the **Standards Research Team** a \$115,000 grant to pursue a large-scale implementation study of the Psychosocial Standards of Care. The team conducting this study represents a strong partnership between family advocacy groups (Mattie Miracle Cancer Foundation, [Momcology](#)) and researchers ([Dr. Anne Kazak](#), [Dr. Kimberly Canter](#), [Michele Scialla](#), [Dr. Emily Pariseau](#), [Dr. Kamyar Arasteh](#) and [Dr. Lori Wiener](#)) who are leaders in the development, testing and implementation of psychosocial care in pediatrics.

We are honored that Momcology has partnered with us to become an integral member of the Standards Research Team. Momcology is a national 501c3 committed to empowering and healing pediatric cancer families through the resource of peer support. Momcology's national platforms allow parents to connect with each other from anywhere and at any time of day. Their modern and accessible social media platforms enable parents to find important lines of support across the world with just a few keystrokes. Currently **they connect over 200 families a month to their secure, moderated and guideline-based online support.**

For the [Psychosocial Standards of Care](#) to become operationalized,

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Giving

It's not just about
the medicine!SM

the support of pediatric patients and their families is crucial. Having the opportunity to engage family caregivers in a meaningful discussion about the Psychosocial Standards of Care, seeking their feedback on the Standards, and identifying the importance of specific Standards, are necessary in order to successfully move towards the implementation of the Standards. **Given Momcology's extensive membership network of family caregivers, their solid and trustworthy reputation within the childhood cancer community, and their commitment to evidence based psychosocial care, Mattie Miracle feels they are an asset to the implementation of the Psychosocial Standards of Care.**

Reflections from Kim Buff (Founder & Executive Director of Momcology):

Momcology is honored to be a new partner in the implementation process of The Standards of Psychosocial Care. **For many years, Momcology has leaned on the guidance of The Standards in the creation and delivery of caregiver-based programs.** Being tapped by the Mattie Miracle Cancer Foundation to be involved in this research process with the goal of making evidence-based psychosocial interventions more accessible to children and families is a responsibility we are enthusiastic and eager to pursue.

Momcology's direct connection to patient families and our ancillary mission of utilizing the patient family experience to accelerate all aspects of research and care is a perfect fit for helping to identify the most urgent psychosocial needs families face and the opportunity to create sustainable solutions.

It is common practice to hear that those closest to the problem are often also closest to the solution. We look forward to engaging the full breadth of the Momcology community's expertise and experience to analyze and innovate what true wrap-around care means for families facing childhood cancer.

Psychosocial support from the time of diagnosis is critical to the pediatric cancer care journey. **Being a conduit to the caregiver community has taught us repeatedly that there is a great unmet need in ongoing and accessible psychosocial support for children and families.** We believe a protocol in psychosocial wellbeing has the opportunity to be just as important in the trajectory of life after diagnosis as a medical one.

Vicki and Peter Brown, 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 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 and care.

Spreading Hope Through Psychosocial Support. SM



We Love Innovation

Mattie Miracle is committed to the implementation of the Psychosocial Standards of Care for Children with Cancer and their Families at every treatment site in the country. These evidence-based Standards define what children with cancer and their families **must receive to effectively support their psychosocial needs** from the time of diagnosis, through survivorship, or end of life and bereavement care.

On February 14 (Valentine's Day), Mattie Miracle is providing **\$42,000** in research funding to the American Psychosocial Oncology Society (APOS). **The funds directly support innovative grants that will assist in the implementation of the Psychosocial Standards of Care.** Mattie Miracle is honored to house our implementation grants at APOS and to have APOS as our professional partner.

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.

Holidays in the Hospital

Although the major winter holidays are behind us, it's very clear to see that the passage of time is marked by the various holidays celebrated throughout the year. Holidays hold a special place in each of our hearts as we associate the holidays with special traditions, food, and gatherings with family and friends. For children in the hospital, **the holidays are a way to break up the monotony of the hospital routine: vitals taken, blood work, medication, testing and scans, beeps of machines, and unfamiliar faces. However, they can also be a time marked with sadness due to being in the hospital and not at home celebrating.** Child Life Specialists mark the holidays through special events, goodies, and giveaways to change up the routine and recognize the importance of these holidays in each child's life.

The winter holidays are usually filled with a lot of strong emotions. A couple of years ago I came into the hospital on December 24th and was greeted by my nurses informing me that there was a new patient on the unit with a potential diagnosis of leukemia. As I dug a little

more, I learned that this family celebrated Christmas. I could only imagine the conflicting feelings of a potential cancer diagnosis colliding with Christmas. This of course motivated me to ensure that this child's Christmas was not clouded by his diagnosis. I made sure he had decorations in his room, a pile of presents and as much Christmas cheer as I could fit into his hospital room. Thankfully his family was able to be in the hospital to celebrate with him.

One way that we celebrate is by packing huge bags of gifts for each patient and their siblings. In the days leading up to Christmas, we ensure that our inpatient children have gifts to take home. **Being in the hospital before Christmas often means that parents may not get to shop or wrap presents. Child Life Specialists recognize this can be a stressor and with the help of incredibly generous community donors and partners, we are able to ensure that parents have gifts for their children.** These same donations stock our programs year-round. On Christmas Eve, after the Child Life Team has packed bags for all the patients who are on the unit, we then leave these bags with the nurses to place outside the patients' doors so when they wake up their presents are awaiting them, dropped off just like Santa does.

Another patient of mine is frequently admitted to the hospital each year around Christmas time. There is always this moment where we hold our breaths, wondering if he will be discharged in time to open presents with his siblings. It was pretty emotional when his mother got the 'all clear' from the medical team that he could go home in time for Christmas Eve. **With a wagon loaded with presents for his family, I rolled him out of the hospital to his car.** His mom was so grateful and so happy to be able to go home.

Child Life Specialists also find ways to mark the little holidays throughout the calendar year. National "fill-in-the-blank" day calls for decorations, goodies and maybe a cupcake or two. **These surprise celebrations mean that not every day has to look like the day before. This gives kids a chance to see themselves outside of the hospital and more like a regular kid. These are the special moments that parents photograph and treasure.**

Supporting Non-Profits

In the Fall of 2022, the co-founders of Zach's Bridge, reached out to the Mattie Miracle Cancer Foundation. **Zach was their only child and after a courageous journey against Osteosarcoma, Zach died in November of 2021**, at the age of 16. Zach's Bridge was created in his memory.

Zach's family experienced a gap in support while facing advanced pediatric cancer and found it close to impossible to find a peer willing and able to lend support. Zach's Bridge helps families navigate advanced pediatric cancer through peer support. **Their goal is**



Reflections from Jon Wall (Co-Founder & President of Zach's Bridge):

"When we started exploring ways to help the next pediatric cancer family, we saw that there were many organizations that provided research funding, and others that provided family support largely at the start of the diagnosis or after the death of a child. But organizations that help a family with connection, guidance and support from the time of a terminal diagnosis didn't really exist. When Zach was in the late stages of his journey, we had looked for peers who had gone through what we did and it was almost impossible to find them. It's such an overwhelming time as a parent

to ease the journey and give the entire family comfort and time to focus on what truly matters to them.

Mattie Miracle is honored to serve on the Zach's Bridge Advisory Council, to be a part of Zach's legacy work, and to help other families cope when a medical cure for their child is not possible.

and while there are actually a broad range of resources available, when faced with the end of your child's life, it can be hard to find, understand and use them. **So we decided to put together a service that connects families with an experienced, bereaved, trained peer who can provide connection, thoughtful conversation, guidance and access to curated resources.** We do this because we want to ease this journey and give the entire family comfort and time to focus on what truly matters to them."

Reflections from Jenn Wall (Co-Founder & Executive Director of Zach's Bridge):

"As we explored how to do this, Mattie Miracle came up a few times in conversations and it seemed like it was very connected to the idea that was forming around Zach's Bridge, and one of the only organizations that really focused on the psychosocial impact on the child. Once we connected with Vicki and Peter, it was immediately clear that we both had similar viewpoints and that Mattie Miracle had done a spectacular job building awareness and providing resources to help children and families facing pediatric cancer. **We knew very quickly that based on our common experience of losing a child to cancer, and the thoughtfulness and experience that Peter and Vicki could offer, that we wanted them to help both guide the development of Zach's Bridge, as well as assist future families.** Therefore, we asked Vicki and Peter to join our advisory council and we are so grateful they accepted our invitation."

Help Keep our Carts Rolling

In honor of Mattie's 21st birthday, we will be hosting our **12th 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 who is battling 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.**



Click on the image below for our Wish List.

You can participate in our item drive from anywhere in the USA. 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 10, 2023.



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