

## **News & Updates**

#### April 2025 | Volume 16 - Number 4

**Upcoming Activities** 

May 18
Virtual Awareness
Walk

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Through
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Miracles Possible

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Giving

It's not just about the medicine!™



## **Innovation Through Partnerships**

For 16 years, Mattie Miracle has been advocating for the importance of psychosocial care, because we believe that cancer care is NOT JUST about the medicine. We take pride in having had the vision to create the <u>Psychosocial Standards of Care</u>. These Standards are evidenced based and define what children with cancer and their families should receive to optimally support their psychosocial needs from diagnosis, throughout treatment, into survivorship or end of life and bereavement care. Thanks to the incredible leadership of <u>Dr. Lori Wiener</u> and over 80 healthcare professionals, these historical Standards were published in a top tier medical journal and they continue to be some of the most frequently downloaded articles through Wiley, a publishing company.

Mattie Miracle is committed to seeing the Psychosocial Standards of Care implemented at treatment sites around the Country and we realize the importance of collaborating with researchers, clinicians, and other well known and respected advocacy groups to make this vision a reality.

With the generosity of a grant from The Andrew McDonough B+Foundation, the innovative research study, Implementing the Standards Together: Engaging Parents and Providers in Psychosocial Care (iSTEPPP), was launched. Dr. Anne Kazak, is



15th Anniversary Video

the principal investigator of this historic implementation study.

iSTEPPP highlights the benefits of the collaboration of researchers (Nemours Children's Health and The Center for Cancer Research, NIH) and national advocacy groups (Momcology and The Mattie Miracle Cancer Foundation) which have resulted in intentional research that has the capacity for moving the implementation of the Psychosocial Standards of Care for Children with Cancer and their Families forward.

In March, a peer-reviewed article entitled, Benchmarks for Psychosocial Staffing in Pediatric Oncology: Implementing the Standards Together—Engaging Parents and Providers in Psychosocial Care (iSTEPPP) Study, was published. The article highlights the number and type of psychosocial staff at pediatric oncology programs in the United States as well as the challenges with the size and breadth of multidisciplinary teams needed to implement the Standards.

Click on the image to read the published article.



# Spreading Hope Through Psychosocial Support. sm

#### Come Walk with Us

On May 18th, Mattie Miracle will be hosting its 16th Awareness Walk. Being a virtual event enables our psychosocial message to reach far beyond our National Capital Area. The goal is to have participation from all 50 States and to raise \$50,000. Our Virtual Awareness Walk helps us generate funds to support Mattie Miracle's psychosocial programs and initiatives.

Walk with us on May 18th (10am to noon, in your time zone) and help us turn your neighborhood Mattie Miracle ORANGE!



Participating in our virtual walk is easy: All you have to do is WALK, SNAP, and POST from ANYWHERE!!!!

**WALK** and track your steps (on May 18th, from midnight to noon in your time zone) using a step counter/activity tracker.

**SNAP** photos and take videos showing your Mattie Miracle ORANGE spirit and share it on our Facebook, Twitter, and Instagram accounts. Be sure to use #MMCFWALK.

**POST** a photo of you with your total step count by noon (in your time zone) to Mattie Miracle's social media accounts or <u>email us</u>. Remember to use the hashtag #MMCFWALK.

Click on the shoe to register, purchase raffle tickets, and make a tax-deductible donation to the event, a walker, or a team.

# Top walkers have the chance to win:

1st Prize: \$100 gift card 2nd Prize: \$75 gift card 3rd Prize: \$50 gift card





Child Life Corner with Adina Levitan, CCLS

#### **Social Interaction is a Standard of Care**

It is well known that any amount of time spent in a hospital can be isolating. Many hospitals have restrictions on visitation, family members may have limited time to visit due to schedules, and certain conditions warrant extra precautions to prevent further illness. **Pediatric oncology patients** 

are among an especially vulnerable population due to their suppressed immune systems, a side effect of chemotherapy. Chemotherapy is designed to kill rapidly multiplying cancer cells but can often take healthy cells down as well. This is also why oncology patients lose their hair, as hair growth is the result of rapidly growing cells.

Many children's hospitals that focus on treating patients with cancer have specific units with rooms designed to keep their young patients safe from exposure to germs or other illnesses that could be devastating to their immunocompromised systems. These units may also feature negative pressure or isolation rooms that prevent the spread of infectious diseases from other patients or staff. All of this is to say, being a pediatric oncology patient admitted to the hospital can be incredibly isolating. This does not even account for the unknown number of days a child may spend in the hospital over the length of their treatment.

In the field of child life, our education and training are backed by the understanding of the developmental impact of illness and hospitalization. Teens and adolescents fall into Erik Erikson's stage of development called "Identity vs. Role Confusion." This is the stage where teens are developing their identity, often defining who they are based on their peer interactions. They begin to answer the question of "Who am I?" as they engage with their friends and social circles. They develop their interests based on peer groups and resolve moral dilemmas through friendships, social events, school, clubs, and groups. As you can imagine, a hospital isolation room is not exactly the place for building and developing friendships. However, a hospital isolation room can be a place where child life specialists facilitate peer interaction and social connection.

During the COVID-19 pandemic, when playrooms were shut down, all social interaction among patients were shut down as well. Patients were restricted to their own rooms and were rarely, if ever, allowed to walk the hallways. This meant that patients of similar ages or interests were separated by just a wall, unable to connect or engage. One of my patients, a teen boy with a passion for video games, had been isolated for weeks as he began treatment for leukemia. In the room next door was another teen boy admitted to treatment for bone cancer. The two teens, who may have organically developed a friendship in the playroom over a shared video game on the big screen TV, now had no way to even learn about one another's existence. That is, until I, as the child life specialist, began to make the introductions. With permission from both young men and their parents, I facilitated an exchange of phone numbers so the two patients could connect, discuss their shared love of video games, and hopefully find a way to cope together through their cancer diagnoses. The two patients continued this connection throughout their treatments.

Once we emerged from the restrictions of the pandemic, it was time to start connecting patients face to face again. The playroom, the clinic, even the waiting rooms became spaces where I could introduce patients to one another and open opportunities for connections. Our female teenage patients bonded over hair coverings, fashion, and friendship bracelets. I provided art materials for shared projects, and soon the hospital spaces were filled with giggles, music, and a sense of camaraderie.

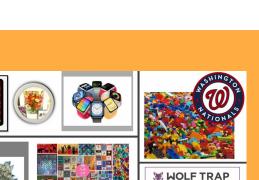
The role of child life addresses the psychosocial needs of patients in the hospital setting, focusing on the impact of illness and hospitalization at each developmental age and stage. This understanding is essential to treating patients from a whole-patient perspective, looking beyond just the diagnosis and treatment, and recognizing each patient as a person with an inherent need for social connection. Opportunities for social interaction is a Standard of Psychosocial Care that child life specialists operationalize every day with children with cancer. Mattie Miracle has funded child life services since 2011 and understands the importance of social connections, as illustrated in their tagline......Childhood Cancer is NOT Just about the Medicine.

Our 14th annual Item Drive, in honor of Mattie's 23rd birthday, was a success. The Foundation is grateful to all our supporters who donated countless toiletry items to stock our Snack & Item Carts 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).

Our Carts offer free items to over 2,500 families a year. We are honored to be able to provide psychosocial comfort and care through our five Snack & Item Carts, and we are grateful for the generosity of our supporters.

thank Lyon





### \$5 Raffle Tickets

Mattie Miracle's online raffle is open! **Tickets** are only \$5. We are featuring 10 wonderful items. All raffle proceeds go toward our fundraising goal, which enables us to support our programs and initiatives. Raffle winners will be announced on Mattie Miracle's Facebook page at 12:30pm EDT on May 18th. Items will be mailed to our winners.

#### **Great prizes, benefiting a great cause!**

- 1. Nats Tickets
- 2. The Ultimate Device Apple Watch
- 3. Apple iPad
- 4. Money Tree
- 5. Wolf Trap Tickets
- 6. Wine Club Membership & Tasting
- 7. Designer Quilt Creations
- 8. Capitals Collectible
- 9. Making an Impression
- 10. For the Lego Lover













MATTIE MIRACLE CANCER FOUNDATION | PO Box 6485 | Arlington, VA 22206 US

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