

News & Updates

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Partnerships Strengthen Research

In 2015, the first evidence-based <u>Psychosocial Standards of Care for Children and Their Families</u> was published in <u>Pediatric Blood & Cancer</u>. These Standards continue to be one of the top ten frequently downloaded articles through Wiley. Mattie Miracle had the vision for the creation of these Standards and it is thanks to the incredible leadership of <u>Dr. Lori Wiener</u> and the collaboration with over 80 healthcare professionals, that these historic Standards became a reality.

The Standards are designed to define what all 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. Since their publication and endorsement by 19 professional organizations, the current focus is to ensure that the Standards are implemented at treatment sites around the Country. To reach this goal, it was clear that the formation of a partnership, among researchers, clinicians, and well-respected patient and family advocacy groups, was necessary.

In 2022, the Standards implementation team received **a generous grant from** The Andrew McDonough B+ Foundation, and the innovative research study, Implementing the Standards Together: Engaging Parents and Providers in Psychosocial Care (**iSTEPPP**),

It's not just about the medicine!s**



16 Years of Service Video

was launched. <u>Dr. Anne Kazak</u>, is the principal investigator of this historic implementation study.

iSTEPPP highlights the benefits of the collaboration between researchers (Nemours Children's Health and The Center for Cancer Research, NIH) and national advocacy groups (Momcology and The Mattie Miracle Cancer Foundation), resulting 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.

Mattie Miracle is grateful for our partnership with The Andrew McDonough B+ Foundation and Momcology. These non-profits share Mattie Miracle's commitment to the implementation of the Standards of Care and value the use of evidence-based psychosocial support to enhance the quality of life of children with cancer and their families.

The peer-reviewed article entitled, Partnership with Patient Advocacy Organizations Improves Research Recruitment was published in March. The article highlights the critical importance of partnering with advocacy groups to elevate and incorporate the voices of children and families in research.

Click on the image to read the published article.



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Child Life Corner
with
Adina Levitan, CCLS

The Magic of Trick or Treating all Year Long

Very soon after the back-to-school sales end and there is a noticeable change in the weather, kids (and adults too!) start planning for a very exciting time of year: **Halloween**. Stores start advertising costumes, candy, decorations and a plethora of pumpkin farms and patches become the very best Sunday family trip. **However, for children with cancer, this time of year brings a completely different set of feelings to the surface**. Parents begin to ask questions about their child's safety while being immuno-compromised and following chemo schedules. Will an inpatient admission coincide with Halloween? Will a virus cause my child to need an emergency visit to the hospital and miss trick-or-treating? Will they feel well enough to pose for a photo in their costume, let alone go out collecting with their friends? What can I possibly do to help them feel like a child when they are fighting cancer?

Fortunately, child life specialists have been thinking about Halloween since the summer. In child life interest groups, blogs, and forums, child life specialists are collectively considering how to enhance the Halloween experience for patients and families. While traditional trick-ortreating, where children go from house to house collecting sweets and prizes, may not be possible, child life specialists have found a workaround: reverse trick-or-treating where children wait in their hospital rooms and doctors, nurses, therapists and child life specialists go from room to room, delivering tricks and treats directly to the patients. Of course, this is done in full costume! With special thanks to donors and the Spirit Halloween store, child life specialists are able to outfit patients in their costume of choice. Staff join in on the fun and scrubs are traded in for superhero costumes and fairy wings. Suddenly wearing a face mask is the cool thing to do and immuno-compromised children do not feel so different. Protective gowns and facemasks blend in with the costumes. Spooky decorations cover up the sterile walls and what once felt like a strange place feels more familiar.

For one day, child life specialists and hospital staff go all out to make Halloween a special day for children. As I reflect on the excitement of the day, I am reminded that while this one day is made to feel as normal and familiar as possible, it is hard to forget that once the costumes are put away, children are still in the hospital or returning to the clinic. When the treats are eaten, and the tricks are all tried, many children are left wondering, "now what?" Thankfully, Mattie Miracle has an answer to this question. With a nod to the orange pumpkins of Halloween, Mattie Miracle sponsors, stocks, and facilitates an almost daily dose of Halloween magic to children and families in the hospital with the Mattie Miracle Snack & Item Cart. This orange tool chest has been transformed into the ultimate reverse trick-or-treat event with drawers and shelves stocked full of favorites like chocolate and sour candy, granola bars and beef jerky, crackers, pretzels, drinks, toiletries, and so much more. This Cart is made possible through generous contributions from the community through Amazon wish lists, community collection drives, and personal donations. As the child life specialist pushing the Cart throughout the year, the magic never goes out. It's hard to put into words the way children's eyes light up when they see the Cart and the many different treats they can choose. Parents breathe a sigh of relief because, they have been unable to eat all day while caring of their child, and are grateful to be able to grab free snacks and the toiletries they may have forgotten to pack.

While Halloween holds an important and special place in the hearts of children and parents, Mattie Miracle recognizes that the **importance of magic for children with cancer is a year-round need** and the Snack & Item Cart delivers it daily to families.

Supporting Grieving Families

Mattie Miracle is proud to support the work of child life professionals. Though child life focuses on meeting the psychosocial needs of the pediatric population, the reality is all patients within a hospital setting can benefit from their supportive care. Case in point, recently Mattie Miracle's child life professional helped to support the family of an adult patient who was dying. The patient's heartbeat was recorded and this captured recording was offered as a tangible and meaningful keepsake for the family.



Reflections from the Child Life Team

When the child life team at Herman and Walter Samuelson Children's Hospital at Sinai (Baltimore, MD) heard about a stethoscope that could be used to record a heartbeat, they knew it was something that had to be obtained. While not the intended use, the Eko Stethoscope allows the Child Life team to record the heartbeat of a patient and transmit that recording to a legacy keepsake.

Most often, the Eko Stethoscope is used in the labor and delivery unit. The child life specialist is able to record the baby's heartbeat in the womb, prior to fetal demise. In these instances, the family is not going home with their child. What they can bring home is a recording of the beating heart to always remember and cherish their baby.

Other times, the stethoscope is used for patients in the NICU and inpatient units. Being able to hear their children's heartbeat after their passing plays a vital role in the grieving process.

The effective use of the Eko Stethoscope spread throughout the hospital. Most notably, child life was referred to an adult patient who was going to be removed from all life sustaining medical equipment. The family wanted a way to remember the man they loved so much. The stethoscope recorded the patient's heartbeat, and this recording was placed into a stuffed animal and given to the patient's son.

Candy & Snack Drive

It is candy and snack season! Please help us stock our **free Snack and Item Carts** at MedStar Georgetown University Hospital (Washington, DC), Children's Hospital at Sinai (Baltimore, MD), and The NIH Clinical Center (Bethesda, MD).

Our five 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. Hospitals have requested that candy remain in its original unopened vacuum sealed bags, with its manufacturer's expiration date. Therefore, the safest way to meet these requirements is to use an Amazon Wish List.

You can participate in our 15th annual Candy and Snack Drive from anywhere in the USA. Please view our Amazon Wish List, and we request all items be received by November 10, 2025.













Mattie Miracle Cancer Foundation is a GuideStar PLATINUM Participant Charity

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