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The B+ Foundation gives us a lot to "Be Positive" About!

Mattie Miracle met Joe McDonough, the Founder of The Andrew McDonough B+ Foundation in March of 2012, when he and his daughter, Ali, attended Mattie Miracle's Psychosocial Symposium for Childhood Cancer on Capitol Hill. The Symposium launched a three year long international research project to develop the first Psychosocial Standards of Care. The Standards were published in a special supplement of *Pediatric Blood & Cancer* in 2015. These historic 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. Soon after the Standards were published, **The B+ Foundation became one of the first professional endorsers of the Standards, signaling their commitment to evidence based psychosocial care.**

The Andrew McDonough B+ Foundation is named in memory of Andrew McDonough. Andrew battled leukemia, septic shock, and complications of childhood cancer for 167 days before passing away on July 14, 2007, at the age of 14. **Andrew's B+ blood type became his family's and friends' motto throughout his fight against childhood cancer – to "Be Positive."** The B+ Foundation is the largest provider

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

of financial assistance to families of kids with cancer in the US, helping over 4,000 families this year and have proudly provided funding to over 150 critical, cutting-edge childhood cancer research projects at top institutions globally.

Mattie Miracle is committed to seeing the Psychosocial Standards of Care operationalized at every cancer center in the Country. However, to achieve this goal, implementation research must be conducted to 1) assess the extent childhood cancer programs in the United States are delivering care consistent with the Standards, 2) capture the voice of family caregivers to determine which Standards of Care should be prioritized for implementation, and 3) identify barriers and facilitators of implementing the prioritized Standards.

To conduct a large-scale implementation study of this kind, requires significant funding. Mattie Miracle is thrilled to announce that The B+ Foundation has generously awarded the Standards Research Team a \$115,000 grant to pursue this cutting-edge research. 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](#), [Dr. Lori Wiener](#)) who are leaders in the development, testing and implementation of psychosocial care in pediatrics.

Victoria Sardi-Brown (Mattie Miracle Co-Founder and President) stated, "We are grateful to Joe McDonough and The B+ Foundation for their long-standing commitment to The Psychosocial Standards of Care. When it came time to seek funding for this groundbreaking implementation research study, Mattie Miracle chose to partner with The B+ Foundation. The B+ Foundation is a leader in the childhood cancer advocacy community, they generously support cutting edge research, and they have been an integral part of the Standards of Care development journey since 2012. I am confident with B+ Foundation's financial support that the Standards will continue to guide and to support the psychosocial care of children with cancer and their families."

Joe McDonough (The Andrew McDonough B+ Foundation Founder) stated, "There is no disputing the significant physical challenges that a child with cancer faces, but far too many people don't 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 Vicki and Peter Brown for being the catalysts. The Andrew McDonough B+ Foundation is proud to be a partner in their efforts."

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.

What is a child life specialist?

Children's hospitals are a special place within our healthcare system. Hallways are filled with thoughtful and playful artwork. Rooms are decorated in uplifting themes and equipped with familiar items to kids like gaming systems to help pass the time during hospitalization. Advances in medicine and psychology have shown us that children are not just "little adults." **Pediatric patients require special accommodations to ensure optimal healing: preparation for procedures and interventions, parental presence during procedures, extended visiting hours for siblings and visitors and spaces for play and exploration.** Staff, such as nurses, doctors, and social workers, are trained with understanding the nuances and needs of pediatric patients. Within the interdisciplinary team treating each child is an even smaller team of professionals, specifically trained to encourage the best psychosocial outcomes for children during hospitalization. **Child life specialists are healthcare professionals with specific education and training to help children and families navigate hospitalization with the intentional goals of reducing stress, anxiety, trauma, and encouraging typical development and promoting overall positive coping.** This sounds important, but what does this look like exactly?

When I introduce myself to patients and families, from the first interaction they can often tell that I am different from the nurses and doctors. I usually walk into rooms with a toy, a bag of goodies or a teaching tool, like a book or doll, designed to help a child understand what is happening to their body and why they are in the hospital. My usual introduction sounds something like this: "Hi, my name is Adina, I am a child life specialist. My role in the hospital is like a hospital teacher and a hospital coach. I am here to explain what is happening, answer your questions and help you with anything that may be tough for you. Can you tell me why you are here?" Through questions assessing children's understanding of why they are in the hospital I can clarify misconceptions about what is happening: 'Yes, you will need to have blood taken, no, we are not going to take all of your blood.' More often than not, children do better when they have a clear explanation of what is going to happen. A scary place only becomes scarier when a child has no idea what is happening or what to expect. **My role is to ensure that there are no surprises when it comes to their medical care and that children are active participants in knowing what helps them cope best with difficult or painful procedures.**

When staff and visitors see me working with children, they will often see me with an array of toys, play items, bubbles, and other fun looking items. These are chosen with the intention of helping children cope and understand their medical experience. I am not simply there to play, although this is a large part of what I do. **To become a child life specialist, one must complete specific coursework at a bachelor's level, although many pursue a master's degree. One must complete a minimum of 100 hours of volunteering in a child life program, and often hundreds of more hours are actually accrued. Aspiring child life specialists have the option to complete a child life practicum, which is an observational experience and finally, a mandatory child life internship, totaling over 600 hours.** These experiences all build upon one another, giving aspiring child life specialists a hands-on opportunity to work with children and families in the hospital and understand the nuances impacting children in the hospital setting. Child life specialists are unique to the healthcare system as we are often only found within children's hospitals, making us a smaller and lesser-known profession. However, **Speak to any family who**

has worked with a child life specialist, and they will likely tell you about the large impact we made on their child's hospital experience.



Thanks to You

On November 2, 2022, **Mattie Miracle celebrated its 13th birthday!** Since 2009, we are the only national non-profit dedicated to psychosocial support, awareness, advocacy, and funding innovative psychosocial research for childhood cancer. We are grateful to our sponsors and supporters for making the Mattie Miracles possible. Together we have:

- Raised over \$1M for childhood cancer
- Supported 35,000 children with cancer and their families
- Delivered 26,000 snacks to in-patient families
- Funded 5 child life specialists
- Awarded 10 M&M Wishes
- Funded 2 psychosocial therapy grants to children with cancer
- Awarded \$130,000 in psychosocial research grants
- Published the first evidence-based Psychosocial Standards of Care

10th M&M Wish Granted



In September, Mattie Miracle received a request for a M&M (Margy & Mattie) Wish to be granted to a **21-year-old named Julian**. Julian's aunt said that due to his age, Julian would not qualify for support from other organizations supporting children with cancer. Julian's social worker explained that Julian was diagnosed with Desmoplastic Small Round Cell Tumor (DSRCT) in November 2021, but sadly has not responded to standard treatment. Therefore, Julian will be starting a clinical trial at an institution in Washington, DC. Julian's social worker stated that, "Julian is cared for by his mother, who is a single working mom and because she has missed so much work to care for Julian and to bring him in to frequent medical appointments, she has missed a lot of work resulting in a significant reduction in her income, causing her to struggle to keep up with basic monthly expenses."

Julian has been a huge New England Patriots football fan since he was in elementary school. It has been his dream to see a live game at the Gillette Stadium in Foxborough, MA. When Mattie Miracle received this Wish request, we mobilized forces and contacted Margy's family, who plays an instrumental role in our M&M Wishes program. Margy was a fierce childhood cancer advocate and a

Mattie Miracle board member. In her memory, Mattie Miracle continues her legacy work by granting wishes to children and teens with cancer.

Mattie Miracle awarded Julian **\$2,200 to make his wish come true**. We provided four seats to the Bears vs Patriots game on October 24th, and we included a special message for Julian and his family on the stadium jumbotron which read, "Shout out to Julian & his family, battling cancer! Love M&M Wishes." The Patriots also arranged for the family to walk on the field, meet players, as well as try on real Super Bowl rings. Julian's mom said, "I'm blown away at how quickly Mattie Miracle got everything done. Time is so precious, but not everyone feels the urgency we do." **Mattie Miracle understands that wishes must be granted around a family's timing and needs, and we work hard to ensure that children and teens who may not qualify for wishes through other organizations have a chance at making their dreams come true.**

Reflections from Julian's Mom

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! I will make sure to capture it all and send photos. **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.**

Reflections from Julian's Aunt

I am going to try to put into words what I just experienced when Julian's mom told him about the trip to see the Patriots play on October 24th. First was disbelief, then excitement and then tears! He said, "Seriously?! I'm going to Gillette Stadium?! OMG, IM GOING TO GILLETTE STADIUM!!!" Then he got to deliver the news to his brothers, where they all screamed for joy and started talking about football and googling everything they could about Gillette Stadium and every fact you can imagine! It gave me goosebumps and made us all misty eyed! I wish we could have got it on camera, but we didn't even think about it at the time. However, there will be tons of pictures and videos at the game and everything in between! **I wish I could express to you our gratitude for the gift that you just gave Julian. Your kindness will never be forgotten!**



Supporting Miracles

During this season of Thanksgiving, **we are grateful for you**. Thanks to our incredible supporters, our 12th Annual Candy & Snack Drive was bigger and better than ever. Boxes of items from our on-line Wish List flooded the Foundation.

In 2020, due to COVID-19, Mattie Miracle migrated away from a live Candy & Snack drive to an all-virtual format. This was a difficult decision, especially since our Fall Drive had great community energy, spirit, and participation. **We were concerned that the virtual format would greatly impact the success of the Drive. However, we have learned never to underestimate your loyalty and generosity.**

All donated items will help to stock our Snack

& Item Carts at MedStar Georgetown University Hospital (Washington, DC), Children's Hospital at Sinai (Baltimore, MD), and the NIH Clinical Center (Bethesda, MD). Our supporters clearly understand how vital our Snack & Item Carts are to the **3,000 families** we serve annually who are caring for children with cancer and other life-threatening illnesses.

Mattie Miracle Cancer Foundation
www.mattiemiracle.com



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