

News & Updates

October 2022 | Volume 13 - Number 9

Upcoming Activities

October
[NCI Webinar](#)

November
[Candy & Item Drive](#)

December
[Annual Drive](#)



The Best Thing Ever

Mattie Miracle has been told that our four Snack & Item Carts are **THE BEST THING EVER!** Healthcare professionals and families caring for children with cancer or other life threatening illnesses have provided us with countless feedback since we started offering our Carts in 2011. **Our Carts service over 3,000 families a year and are considered a life saver by families who have little time to meet their own basic needs while caring and coping for a child with a serious illness.**

How can you help?

We rely on the kindness and generosity of our supporters to help keep these vital Carts stocked. Please purchase items through our [Amazon Wish List](#) or even start your own item drive for us in your community. All item donations make a difference.

What's being said about our Carts:

- "I can attest to the fact that my child knows the day of the week the Cart comes around and it is truly something he looks forward to. Being in the hospital for weeks at a time, there are only a few moments these kids look forward to and the Mattie Miracle Cart has achieved just that!" ~ *MedStar Georgetown*

About Us

Spreading Hope
Through
Psychosocial
Support SM

Learn

Support

Help Make The
Miracles Possible

Donate

CFC #59853

It's not just about
the medicine!SM

Hospital Parent

- "As I walk through the units with the Cart, it provides an opportunity for me to explain and offer my educational support services to those who may be struggling with school decisions." ~ *Christine Anninos, MedStar Georgetown Hospital Education Specialist*
- "The experience here has been so different from other hospitals, I mean look at this Cart... Mattie Miracle really loves families caring for children with cancer." ~ *Children's Hospital at Sinai Parent*

You can participate in our 12th annual Candy and Item Drive from anywhere in the USA. Please view our Amazon wish list, We ask that all items be received by **November 14, 2022**.



Spreading Hope Through Psychosocial Support. SM

Child Life Corner
with
Adina Levitan, CCLS



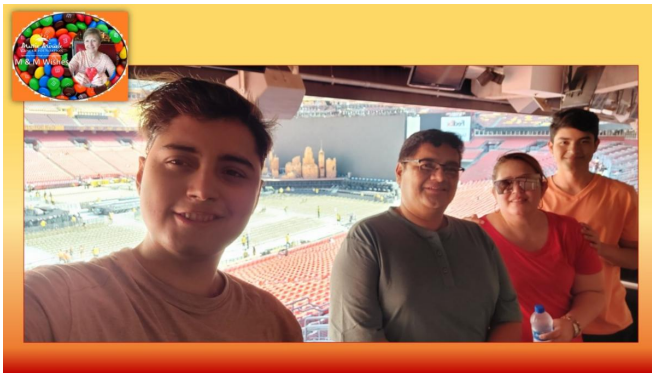
We welcome Child Life Corner to our newsletters. Each month you will hear from Mattie Miracle's Child Life Specialist, Adina Levitan. Adina will highlight topics, issues, and share stories from a child life professional's lens. Given the vital role child life plays in a child's medical and psychosocial journey, we are proud to feature this standing column.

Throughout a child's cancer treatment, there can be many bumps and setbacks. Each child is different and their ability to cope with each medical intervention can change from minute to minute. Most children thrive having a sense of routine and structure throughout their day. The same can be said for their cancer treatment. **As a child life specialist, my role is to empower and encourage my patients to develop coping tools to support their social and emotional needs during treatment and to learn and manage expectations.**

A common intervention for my patients is a port access. A port is a small device placed under the skin in the chest area. Not every patient will receive a port, but for those who do, it is a way to provide direct access to give medications, fluids, blood and blood products, and collect blood samples. A port is accessed by inserting a needle into the skin directly into the port. For my patients we work together to come up with a Port Access Plan. A successful plan includes pain management, comfort holds, if needed, distraction and positioning. The first port access usually sets the tone for the ones to follow. I walk my patients through the plan and help them to choose what they feel would help them cope best and what I assess would be most supportive.

Once we make the plan, I walk my patient through the port access, step by step. **When properly prepared and supported it is incredible to see the resiliency and coping that each patient displays.** When the port access is completed, I post-process with my patients. How did that feel? Was it better or worse than you expected? Do you feel that the plan we made worked for you? Do we need to make any changes? After my patient has reflected on the port access, I make a copy of the port plan to give to the family so that if their child ever needs a port access outside of their typical clinic visits, they feel empowered to share the plan with the team caring for their child. Developing a port plan requires a patient and family centered approach. The child needs to be involved in the preparation. The parent learns their role in how to support their child, the nursing team carries out the port plan, and the child life specialist prepares, supports and encourages the patient. Together, the child has a sense of what to expect and the team effectively supports the child's needs.

One of my patients, a five year old girl, required a port for her treatment. Leading up to her port being placed and receiving her diagnosis, she had received many IVs and blood draws. She was incredibly anxious and it was becoming more and more difficult for her to get needle pokes. When she finally got her port placed, I walked through exactly what to expect. She sat up, holding her mom's hand and playing on the iPad with me. When the port went in, she cried for only a second, and then went right back to playing on the iPad. **Her father expressed that he was so relieved with how easy it was for her. The whole family and medical team felt at ease that she would be able to receive her treatment without the same stress and anxiety she previously experienced.**



Making Wishes Come True

In 2021, Mattie Miracle launched its **M&M (Margy & Mattie) Wishes Program** in memory of our board member, Margy Jost. Margy was a steadfast supporter of children with cancer and devoted her life to this vital cause. In one year's time, Mattie Miracle has granted **\$12,000 to children and their families** to make their wishes come true. In many cases, families have reached out to us because they do not qualify for support through other organizations, either due to the child's age, at what stage the child is within treatment, or because the child was receiving end of life care.

This summer, Mattie Miracle learned about Caleb. **Caleb was 20-years-old** and was being treated at the NIH Clinical Center in Bethesda, MD. Caleb was diagnosed with Leukemia in his home country of Honduras. There were many procedural events that took place that were traumatic to him and to his family, including the lack of availability of pain medicine. He was sent from Honduras to Costa Rica for more treatment, and then to Florida where Caleb and his mother stayed for several months.

Due to continued disease progression, he was referred to NIH for CAR T therapy, as a hopeful bridge to transplantation. His medical journey remained complicated and complex. Despite pain, disease, fatigue and very aggressive treatment, Caleb took two courses online to learn coding and was studying German. He was described as "one of the most respectful, kindest young men the team had ever met." Caleb had not seen his brother or father for nine months while in treatment. There after, the NIH Clinical Center brought the family to United States with the hope that a family member would be a potential bone marrow match.

Caleb's favorite band was The Weeknd. The possibility of seeing the band and being together with his parents and brother before the family needed to return to Honduras was a dream come true. In fact, given the nature of Caleb's diagnosis, it was uncertain as to when the family would ever be together again. Due to being immunocompromised, Caleb's medical team would only allow him to attend the Weeknd concert if he and his family sat in box seats, away from others. This was when Mattie Miracle stepped in and granted Caleb the wish of **four box seats at FedEx field** to attend the concert in July.

Mattie Miracle is saddened to learn that Caleb died on September 6, 2022. Caleb will never be forgotten and he taught us an importance lesson that **granting wishes to children at all stages of their cancer journey is vitally important**. We thank our supporters for helping to make these M&M Wishes possible.

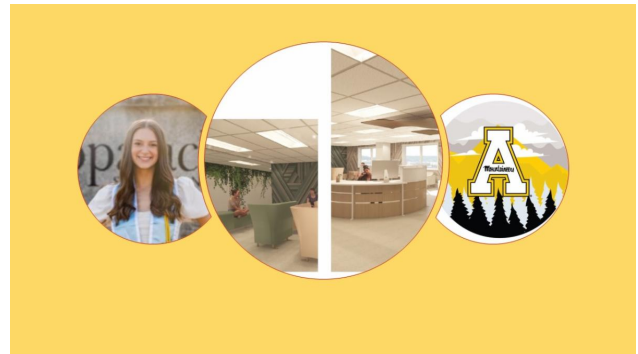
Message from Caleb

"I want to say a special thank you to Mattie Miracle's supporters and the help of Dr. Lori Wiener for making this amazing experience possible for my family and me. It's been a dream of mine since I arrived here in the States to go to the Weeknd concert. He is my favorite artist, and you are making this dream possible. It really moves my heart, for that I am extremely grateful!"

Message from Dr. Lori Wiener

*"I just wanted to thank you and Mattie Miracle for the incredible gift of the tickets for Caleb 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."*

Awareness through Design



Mattie Miracle has a long-standing connection with Faye Greenberg. She started volunteering with us when she was in high school. Earlier this year, she reached out to the Foundation because she was in her last semester of studying Interior Design at Appalachian State University in Boone, North Carolina. Faye was working on her **senior project** and wanted to incorporate some of Mattie Miracle's thoughts and ideas into the final presentation of her project. Faye's project was the design of a pediatric oncology center with a focus on the emotional and social health of children and their families.

At the completion of the senior project, Faye did an oral and visual presentation to classmates, professors, and professionals within the community. The 20-minute presentation included Faye's reasoning for choosing this project, an overview of Mattie Miracle, and highlighted Mattie Miracle's psychosocial input which guided Faye in her design strategies, design philosophy, pre-design research, and the development of the design.

Reflections from Faye Greenberg:

*"Pediatric hospitals must be designed as a family friendly environment that provides more spatial opportunities for family care. Short-stay options for children's families must be implemented in new designs of medical facilities, to provide families with a place to stay while their children are having treatment. **Overall, the emotional, social, and physical well-being of both children and their families***

must be the focus when it comes to designing health facilities. These facilities should radiate tranquility, hope, and serenity. I am grateful for Mattie Miracle's assistance, and I am proud to have received positive feedback on my project, as the reviewers were touched by my personal connection to the Foundation. I loved showcasing my passion for the integration of well-being in design, specifically for children with cancer and their families."

Click on "Check it Out" to see Faye's PowerPoint presentation for her senior project.



Mattie Miracle Cancer Foundation
www.mattiemiracle.com



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