

News & Updates

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Grand Unveiling at NIH

We are proud to offer **four Snack & Items Carts** in the Washington, DC region. Our Carts are housed within hospitals and serve families who are caring for a child with cancer or other life threatening illness. The Carts provide nutritional snacks, candy, drinks, toiletries, and comfort items to family caregivers.

On May 5, the co-founders of Mattie Miracle celebrated the official unveiling of our **Wellness on Wheels** Cart at the Clinical Center of the **National Institutes of Health (NIH)**, Bethesda, MD. Greetings at the ceremony were provided by [Dr. Lori Wiener](#), [Dr. James Gilman](#), and Mattie Miracle's co-founders. We invite you to see the short video clip of Luciano (a patient from Peru) unveiling our cart to the audience. Mattie Miracle is honored to provide families with this vital psychosocial support while their children are participating in a NIH clinical trial.

Currently there are around 1,600 clinical research studies in progress at the NIH Clinical Center. About half are studies of the natural history of disease, especially rare diseases, which often are not studied anywhere else. Most other studies are clinical trials, which often are the first tests of new drugs and therapies in people. Of the 1,600 active protocols at the NIH Clinical Center 35% include children.

[Click on the image below to see Luciano unveiling our Cart.](#)



It's not just about
the medicine!SM

Spreading Hope Through Psychosocial Support. SM



7 Wishes Granted

In 2021, the Mattie Miracle Cancer Foundation established the **M&M** ("Margy & Mattie") **Wishes program** in memory of our board member, Margy Jost. Margy was a fierce childhood cancer advocate who devoted her life to helping children with cancer. Margy was passionate about

providing grants to families to help create memories outside of the hospital experience. M&M Wishes offers families a **grant of up to \$1,000** to support a fun family activity, trip, or a wish list item for a child with cancer.

We are proud to announce that **7 M&M Wishes have been granted** to children with cancer and more are on the way. Our grants have supported:

- Great Wolf Lodge getaway
- Disneyland vacation
- VR goggles
- Video games
- Gift cards
- Xbox & Xbox gift cards
- Adaptive sports camp

This is Jamie's story, one of our M&M Wish recipients:

Jamie's journey started in December 2019 when he injured himself in gym class. X-rays showed a small mass in his tibia just below his right knee. Biopsy results came back inconclusive. Then the COVID pandemic hit the world. At his next check-up the mass quadrupled in size. In the summer of 2020, Jamie was officially diagnosed with a high-grade osteosarcoma which led us to the wonderful team at Children's Hospital at Sinai. There he was treated right away with methotrexate doxorubicin cisplatin (MAP), then ifosfamide etoposide (IE), later regorafenib, and now cyclophosphamide topotecan cabozantinib. His osteosarcoma has shown to be chemo-resistant, reoccurring, and metastatic. It is currently in several of his other bones and lungs. Also along the way, he had eight surgeries to include an above knee amputation and a feeding tube. We recently discovered he has a TP53 gene mutation known as Li-Fraumeni syndrome putting him at high risk for developing other cancers. Jamie successfully completed 6 weeks of clinical trials in Boston which combined traditional chemotherapy and inhibitors to be continued off protocol at Sinai with the addition of radiation. He is enrolled in several research clinical trials to help further study childhood cancer, osteosarcoma, and TP53 gene mutations.

Jamie has grown into maturity and wisdom. He remains mostly stoic yet positive. He places high value in family and friends. He regularly connects with his cousins and friends via online

computer games and iPhone group chats. He uses computer games as his escape and way to keep some normalcy. Right now he is taking a break from school but looks forward to going back and re-enrolling in his high school robotics club and pre-med program. His favorite subject is biology and he will be learning how to drive this year! Jamie has many things to look forward to and a lot of fight left in him.

Grants for Therapy

On September 9, 2021, Mattie Miracle participated in Thrivent's Take the Plunge, a non-profit Shark Tank. Thanks to the hundreds of votes we received from supporters and generous donations, we were granted \$10,000 to start a new initiative. Our new **therapy support program**, grants children with cancer up to **\$1,000** for therapy sessions with a licensed mental health provider within their community.

Families of children with cancer are typically referred within the community to professionals who can help support their psychosocial needs and concerns. Families face a host of mental health issues as a result of a childhood cancer diagnosis, such as depression, anxiety, medical traumatic stress, substance abuse, and eating disorders. **Yet it is challenging for families to access such support because of financial difficulties.**

We are honored to award our **first grant to Elliott**. Elliott is 9 years old and is being treated for Medulloblastoma in Michigan. Elliott's mom reflects on her family's journey and it is clear that childhood cancer IS NOT JUST ABOUT THE MEDICINE.

Reflections from Elliott's mom:

Our small family has been profoundly changed by Elliot's cancer diagnosis. He was diagnosed unexpectedly in January of 2020, and I resigned my position at work to be with him in the hospital. Cancer and cancer treatment altered us all. We have all described feeling like our essential "self" got rearranged, like someone messed with our DNA and we are altered, and we look the same but feel completely different. We have all wanted to use therapy to explore the tender edges of that change. All of us have different PTSD symptoms (intrusive thoughts, nightmares, increased hyperarousal, dissociation, etc.) in addition to some increased anxiety and depression.





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