

News & Updates

October 2021 | Volume 12 - Number 8

Upcoming Activities

November 2021
Fall Candy Drive

March 2022 Symposium at APOS Conference

May 15, 2022 13th Annual Virtual Walk

About Us

Spreading Hope Through Psychosocial Support SM

Learn

Support

Help Make The Miracles Possible

Donate



Wellness on Wheels

Mattie Miracle has great news! We will be launching a Snack and Item Cart at the **National Institutes of Health** (NIH). This will be our **third Cart** that we fund and operate in the National Capital Area. Our Carts offer free candy, snacks, and other items to families in the hospital who are caring for a child with cancer and other life threatening illnesses. The NIH Cart will be called, **Wellness on Wheels**, and will provide an expanded offering of comfort items such as blankets, robes and slippers to help support families who are far from home while their child is participating in a 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. What researchers learn by studying rare diseases often adds to the basic understanding of common diseases. Most other studies are clinical trials, which often are the first tests of new drugs and therapies in people. The clinical trials at the NIH Clinical Center are predominantly Phase I and Phase II, often first-in-human to test safety and efficacy.

The NIH Clinical Center enrolled 5,390 new patients in 2020 with 3,120 inpatient admissions. This resulted in an average hospital stay of 10.6 days. As a research facility, only patients with the precise kind or stage of illness under investigation are admitted for treatment. Of the 1,600 active protocols at the NIH Clinical Center 35% include

CFC #59853

Giving

children and 14 NIH Institutes admit children. In general, Pediatrics accounts for approximately 13% of Clinical Center patient activity.

We welcome 'Wellness on Wheels,' to the Mattie Miracle family of services and we invite our supporters to help us launch this Cart by donating needed items from our **Amazon Wish List**. It is thanks to you that we have been able to operate our Snack and Item Carts successfully since 2011.

Click on the wellness apple to help stock our Carts!



It's Not Just About the Medicine sm



Board Legacy

On March 28, 2021, Mattie Miracle lost an amazing board member and supporter, Margy Jost, to ovarian cancer. Margy understood and shared Mattie Miracle's philosophy that childhood cancer is NOT just about the medicine. Margy devoted her life as the "Play Lady," helping hundreds of children with cancer cope with their diagnosis, the effects of treatment, and advocated for comprehensive cancer care (which included psychosocial support) for all her pediatric patients and their families. In addition to her clinical work, she also ran a successful non-profit, Growing Hope, for twenty years, and raised over \$1M for the cause.

Mattie Miracle is honored to continue Margy's legacy by inviting her daughter, **Kristy Jones**, to serve on our Board of Directors. Kristy is no stranger to healthcare, as she has devoted her life to helping children as a licensed physical therapist. Kristy was also an active supporter of Growing Hope and learned to be an advocate for the cause through one of the best mentors we know, her mom, Margy.

The Foundation is honored to welcome Kristy to our leadership and together we will run **M & M** (Margy & Mattie) **Wishes**. This program will continue Margy's legacy by providing family grants up to \$1,000 to support a fun family activity, trip, or a wish list item for a child with

cancer.

To learn more about Kristy, please read more.

Read More

Funding Innovation

Mattie Miracle awarded a research grant to <u>Dr. Alexandra Psihogios</u> through the <u>American Psychosocial Oncology Society</u>. The grant funded a pilot study to explore the feasibility and acceptability of implementing text-based assessments of oral chemotherapy adherence in adolescents and young adults with leukemia. The Foundation is honored that this innovative work was **recently published** in *Pediatric Blood & Cancer*, a top-tier medical journal.

Non-adherence to treatment is a pervasive issue, particularly among adolescents and young adults, and this results in devastating health consequences and significant health care costs. Routine assessment of treatment adherence is one of the 15 evidence-based Psychosocial Standards of Care. We invite you to read Dr. Psihogios' study and learn more about the benefits of daily text-based surveys as a feasible and acceptable method for delivering medication adherence.

Read More









We Need Your Help

Please donate candy and other snack items, so that we can continue to stock our <u>free Snack and Item Carts</u> at hospitals. These Carts are considered a life saver by families who are caring for a child with cancer or other life threatening illnesses. Our hospital Carts service **2,500 families** a year.

After a decade of successful in-person Candy Drives, we have made the difficult decision to transition to an all virtual event. Hospitals have requested that candy remain in its unopened vacuum sealed bags, with its manufacturer's

expiration date. Therefore, the safest way to meet these requirements is to use an Amazon Item Wish List.

You can participate in our Candy and Item drive from anywhere in the USA. Please view our Amazon wish list, We ask that all items be received by November 15, 2021.

Wish List

Mattie Miracle Cancer Foundation www.mattiemiracle.com











