

Thrivent's Take the Plunge – September 9, 2021

Good evening and thank you for the wonderful introduction. As you just heard, I am Victoria Sardi-Brown and I am the co-founder and president of the Mattie Miracle Cancer Foundation, which is based in Arlington, VA. Mattie Miracle is honored to be selected as a Thrivent finalist, to share this virtual stage with four other amazing non-profits, and to have the opportunity to interact with the Thrivent network and Daymond John.

On July 23, 2008, my life changed forever. On that day, I heard the four words NO PARENT ever wants or hopes to hear, and they are.... YOUR CHILD HAS CANCER. My son Mattie was only six years old when he was diagnosed with a rare form of bone cancer. After 14 months of aggressive treatments and surgeries, Mattie died in my arms on September 8, 2009. Yesterday was the 12th anniversary of his death.

As you can imagine, after we lost our only child to cancer, we were devastated, lost, and hopeless. Yet Mattie's death had to serve some sort of purpose. So, two months after he died, my husband and I created the Mattie Miracle Cancer Foundation. Mattie taught us two things that guide the work of the Foundation: 1) childhood cancer is a family disease and 2) childhood cancer is not just about the medicine.

There are 16,000 children diagnosed every year with cancer. September is childhood cancer awareness month, and I am sure you have heard about the need for better cures and funding for medical research. However, what isn't always highlighted, but is equally as important, are the devastating long term psychological, social, and emotional issues, that result from the medical treatment for both the child and the entire family. In fact, 60% of children with cancer are reported to have a diagnosable mental health issue because of treatment. Psychosocial support, provided to children and their families, has been shown to manage symptoms, alleviate pain and fatigue, and increase quality of life, but it is well documented that this support isn't always adequately provided to address the concerns of patients, siblings, and parents.

Mattie Miracle is the only national non-profit dedicated to psychosocial awareness, advocacy, support, and research of childhood cancer. To date we have raised \$1M to support the cause. Annually, Mattie Miracle provides direct support to 1,500 children with cancer and 2,500 families, through our endowed child life programs, M&M family grants, and hospital snack and item carts. In addition to delivering locally based support, the Foundation had the vision and funded a three year long international project, with the help of an amazing team of health care professionals, to develop the very first evidence based Psychosocial Standards of Care. It is thanks to our advocacy that these Standards exist. The Standards are historic and were

published in 2015, in a top tier medical journal. These Standards are designed to ensure that children with cancer and their families have access to optimal psychosocial care throughout their cancer journey at every treatment site in the country.

Mattie Miracle is passionate about ensuring that psychosocial care is part of comprehensive cancer care and if we should win the \$10,000 grand prize, this will enable us to start a new initiative, a psychosocial referral and resource program. This program would enable us to connect families coping with childhood cancer to qualified mental health providers in the Northern Virginia community and pay up to six therapy sessions per family. Such an initiative is vital because of four reasons:

- 1) It doesn't exist today. Hospitals treat only patients, all be it inconsistently, but that is insufficient as siblings, parents, and the entire family are all affected by a childhood cancer diagnosis. They have real mental health needs that arise, which many times go unaddressed.
- 2) Insurance coverage is all over the map or does not even include behavioral health coverage.
- 3) The mental health care and expertise for this population needs to be very tailored to address their unique needs and concerns and not every provider has experience working with this population.
- 4) Since there is no recognized referral and resource program currently available, families expend energy that they do not have trying to find mental health support and typically pay out of pocket to receive it. But this adds to the financial hardship families face during cancer treatment, and research shows that financial hardship impacts mental health and well-being of the family.

So, in summary, even if we had an 100% medical cure rate for childhood cancer there would still be devastating long-term psychosocial issues for children and their families that AS OF TODAY go <u>under</u> or <u>unaddressed</u>. Mattie Miracle believes that our children deserve better, they are our future, and as Margaret Mead always said, never doubt that a small group of thoughtful, committed citizens (like yourselves) can change the world; indeed, it's the only thing that ever has. Thank you for tuning in tonight, please vote for Mattie Miracle, and help us address these important psychosocial needs of children with cancer and their families.

Clips from the event:

https://youtu.be/vH4esM0UmCE

https://youtu.be/ADjT6CCb7AU

https://youtu.be/UrgqALfdQp8