Mattie Miracle Cancer Foundation Board Member Interview

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NPS 300: Introduction to Nonprofits

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Mattie Miracle Cancer Foundation

The Mattie Miracle Cancer Foundation is a 501(c)3 public charity that was founded in memory of Mattie, a child who passed away from bone cancer at the age of 7. Their mission is to "increase childhood cancer awareness, education, advocacy, research and psychosocial support services to children, their families, and medical personnel" (Mattie Miracle, Psychosocial Support for Childhood Cancer, Arlington 2019). They take a strictly psychosocial standpoint, which involves improving the mental health of children and their families impacted by childhood cancer. This standpoint focuses on the treatment and awareness of the "social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from diagnosis through survivorship or bereavement" (Mattie Miracle, Psychosocial Support for Childhood Cancer, Arlington 2019). Psychosocial care has been found to decrease the patient's pain and help the treatments adhere.

I had the opportunity to interview Victoria Sardi-Brown, the Co-Founder, Chairman, and President of the Mattie Miracle Cancer Foundation. The first question I asked her was "What made you want to start the organization?" She stated that her child, Mattie, had died from cancer at a young age. He had a rare and aggressive form of cancer that caused him to experience an immense trauma. This experience made her realize that there is much more to cancer than just the disease itself. Mattie had suffered from depression, anxiety, and medical traumatic stress as a result of the disease and treatment received. Watching her son go through this mental trauma made her realize what she wanted the purpose and mission of the organization to be, completely psychosocial and support the emotional and mental needs of those impacted by childhood cancer.

I then proceeded to ask, “How does the organization achieve its goals?” Victoria said that they fund psychological research and give out donations and grants to families in need. Over 30,000 children with cancer and their families have been supported by the foundation (Mattie Miracle, Psychosocial Support for Childhood Cancer, Arlington 2019). They advocate on Capitol Hill to encourage legislation that recognizes the importance of psychosocial care. They also started a Child Life program fund to pay for the salaries of Child Life Specialists. The specialists come in and work one-on-one with the patients to make their experience more enjoyable and ease some of their stress. They provide individualized support and facilitate medical play to help ease some of the pain and fear that the children are experiencing. Victoria said the foundation also provides snack foods and candy to the children and their families, as well as toiletry items, and iPad holders to allow loved ones to stay connected during the Covid-19 pandemic.

Next, I asked, “What are the challenges and rewards of this work?” Victoria stated that the biggest reward is the overall impact the organization has made on the lives of the children and their families. She has received messages from families directly about the positive influence the foundation has had on them. She said it is a great feeling to know that they are helping people during the darkest moments of their lives and are making their days more manageable. She also stated that another reward is how they are changing the way people think about Childhood cancer on Capitol Hill. When presented with research and data funded by Mattie Miracle, legislators are starting to realize there is more to treatment than just medicine. They are developing standards of care that promote the social and emotional needs of the patient, not just the physical. These standards of care are impacting every child with cancer in the nation and are allowing cancer to be looked at more comprehensively (Sardi-Brown). We learned in class that 501(c)3 nonprofits cannot engage in “substantial lobbying” or participate in partisan political activity for or against a political candidate if they want to keep their tax exemption (Grobman, 2018). However, they can play a key role in influencing policy and legislation at the federal, state, and local levels (Rules of 501(c)(3) Nonprofit Lobbying). Mattie Miracle funds research and endorses legislation that promotes the psychosocial standards of care, which is an appropriate action for 501(c)3 nonprofits. Victoria then went on to describe some of the challenges she experiences working as the President of the organization. She said that there is an emotional toll that she encounters from focusing on childhood cancer every day. She stated she also can get overwhelmed as she is the one who does most of the fundraising, correspondence meetings, and administration. It can be a never-ending cycle she often finds herself needing a break to gather herself so she can continue to function and make a difference.

In light of the Covid-19 pandemic, I asked her what her predictions were for the future of her nonprofit. She stated that she believes there will always be a need for organizations that support childhood cancer, as it is so prominent. Most of the support families get comes from private philanthropy, not government funds (Sardi-Brown). With the world now experiencing the reality of isolation caused by the pandemic, she thinks it will allow for greater awareness of the experience of families who have a child with cancer. They are often stuck in the hospital caring for their loved ones and have decreased physical communication with the outside world (Sardi-Brown). This lack of communication causes increased stress and loneliness, which negatively impacts overall health. Mattie Miracle has been hosting virtual fundraisers and walks to connect with people from around the world. With greater awareness, Mattie Miracle hopes to continue their journey to fight the mental impact of childhood cancer and connect more families to their resources.

As a Health Services Administration major, I have researched the importance of providing mental health support in hospitals. There must be a patient-centered approach to care that addresses the emotional needs of individuals, not just focusing on the treatment of the disease itself. A "patient-provider partnership that considers treatment options based on a patient's unique concerns, preferences, and values" is needed to generate the best health outcomes (Solomon, 2018). Through the funding of Child Life Specialists, Mattie Miracle is allowing the children to engage in activities and routines that promote patient development and support the psychosocial issues experienced. In the future, I want to manage a hospital, and I will be sure to enforce practices that promote the overall well-being of the patient and implement guidelines like those developed by Mattie Miracle.

It is clear to see the impact that Mattie Miracle is making on the lives of thousands of children across the country. Not only are they directly impacting children through funding the salaries of Child Life Specialists and donation of supplies, but they are establishing standards of care and implementing guidelines that will continue to make a difference in the way doctors and nurses treat childhood cancer patients. With 43 children being diagnosed with cancer each day, heightened awareness and advocacy are necessary (Childhood Cancer Statistics: CureSearch, 2020). Increased connective technology and new treatment standards will allow nonprofits like Mattie Miracle to continue to assist children and families around the world.

References

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