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Addressing the Psychosocial Side of Childhood Cancer

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Battling childhood cancer is more than just surgeries, drugs and radiation. It can have a profoundly damaging psychologic impact on patients and their families.

Unfortunately, Victoria Sardi-Brown, Ph.D., LPC, co-founder, president and chairman of the Mattie Miracle Cancer Foundation learned this the hard way.

In the summer of 2008, her son, Mattie, was diagnosed with osteosarcoma that had four primary bone tumors. The six-year-old boy endured chemotherapy, two limb-salvaging surgeries, experimental immunotherapy, sternotomy and radiation. But after being off treatment for six weeks, his cancer metastasized and he died in Sept. 2009.

After seeing the psychologic impact the disease had on their son, Sardi-Brown and her husband, Peter Brown, started the Mattie Miracle Cancer Foundation in Nov. 2009, which is dedicated to addressing the psychological needs of children and families with childhood cancer, and also to educate health care providers on the psychosocial impact a diagnosis can have.

Before his passing, Mattie's surgeries left him so that he could not walk, run, play, get dressed or even go to the bathroom on his own.

"This was very frustrating and stressful for an active six-year old," Sardi-Brown said in an interview with *CURE*®. "So much so that within the first three months of treatment, Mattie was diagnosed with clinical depression, anxiety and medical posttraumatic stress disorder — issues which were not present prior to cancer."

Mattie was not alone in having those feelings. Sardi-Brown mentioned that 59 percent of children with cancer have a diagnosable health disorder as a result in their treatment, which often leads to frequent pain, isolation and other challenges. Sardi-Brown also mentioned that parents, caregivers and siblings of childhood cancer survivors are more likely to have mental health issues as well.

"Though medical treatment for children with cancer is standardized across the United States, there is significant variability in psychosocial services offered to children and their families at treatment centers," Sardi-Brown said. "Mattie Miracle's mission is to change this disparity in care."

The organization really started to pursue this goal in 2012, when it hosted the first Childhood Cancer Psychosocial Symposium on Capitol Hill. Here, lawmakers, researchers, parents and members of the health care community — including a panel of psychosocial oncology experts — met to develop psychosocial standards of care, which ensure that patients and their families have access to support from the time of diagnosis through survivorship or bereavement.

“Prior to Mattie Miracle voicing its vision for evidence-based standards, none existed. We are proud to have contributed to this crucial gap and are working with our core team of psychosocial researchers and payers to make the implementation of these ground-breaking standards a reality,” Sardi-Brown said.

Currently, 15 organizations have endorsed the standards of psychosocial care — titled *Standards for Psychosocial Care for Children With Cancer and Their Families* — but the organization’s goal is to have them endorsed and used regularly in cancer centers across the nation.

“To meet this goal, we believe it is important to unite researchers, payers, legislators and cancer advocates together to brainstorm implementation strategies,” Sardi-Brown said. “As Mattie Miracle always says, the standards are needed because ‘the psychosocial issues do not end when medical treatment does.’”