

Jeff Kramer & The Chondrosarcoma Foundation



Jeff Kramer's life was forever altered by the loss of his daughter, Shayna. Yet, her memory—a testament to her strength, kindness, and unwavering spirit—inspired him to establish the Chondrosarcoma Foundation.

In 2016, Jeff Kramer's daughter Shayna was diagnosed with the rare bone cancer chondrosarcoma after an initial misdiagnosis of a spinal disorder. Despite undergoing extensive treatment, including two major surgeries and radiation therapy, Shayna's cancer ultimately metastasized, and she passed away in 2019 at the age of 28.

Even before her diagnosis, Shayna dedicated her life to advocating for others. She worked with children with special needs, and upon learning of her disease, she was eager to help other patients and began advocating for the cause. Determined to honor his daughter, Kramer founded the Chondrosarcoma Foundation in 2020. The foundation's mission is to raise awareness of this ultra-rare cancer and drive progress in research and treatment.

A Rare Disease, A Silent Struggle

Chondrosarcoma is estimated to affect only around 5,000 people globally each year, and Kramer emphasized the challenges in diagnosing the disease early. Patients often experience gradually worsening pain for over a year before seeking medical care, by which point the cancer may have progressed further. Earlier detection, correct diagnosis, and treatment can make a significant difference in outcome. As Shayna was initially misdiagnosed with spinal issues, she received incorrect treatment, causing her more pain while her cancer continued to progress untreated. The foundation is working on creating guides to educate both patients and physicians about recognizing the signs and types of chondrosarcoma, to aid in early diagnosis and determine the appropriate treatment approach.

A Data-Driven Approach to Improving Patient Lives

A key initiative of the foundation is its patient registry, developed in collaboration with the National Organization for Rare Disorders (NORD). This registry captures data from both living and deceased patients, allowing their stories to continue inspiring and helping others. The foundation plans to enhance the registry by tokenizing the data, thus enabling the comparison and analysis of patient medical records and claims data to identify opportunities for earlier diagnosis.

Through the registry data, the foundation has also found that the quality of life for chondrosarcoma patients is low, even when compared to other cancer patients. To address this issue, they are working to create a virtual dialogue around topics such as mental health (anxiety, depression, etc.), stress, and how to improve the quality of life for those with the disease. Additionally, the foundation is working to create support groups both for patients and for the families of those with chondrosarcoma. Through these efforts, Shayna's positivity and belief in connecting to the community continue to make a powerful difference.

A Vision for the Future

The Chondrosarcoma Foundation continues Shayna's legacy of helping others, and envisions a future where patients have access to timely diagnosis, effective treatment, and a better quality of life. As part of this mission, the foundation is driving the establishment of a specialized treatment center to advance research into new treatment approaches.

To learn more about chondrosarcoma, please visit <https://csfshayna.org/>, email info@csfshayna.org, and/or visit the Chondrosarcoma CS Foundation Support Facebook page at <https://www.facebook.com/groups/1213169615757418>.