A crowd gathered Sunday at Commissioner’s Park in Frankfort on perhaps the sunniest day of the year. Kids raced about with the colorful stains of candy on their lips and laughed hysterically in the inflatable bouncing pit. They were there because one little boy wasn’t.

The event was a kickoff picnic for the Caleb’s Crusaders Foundation, an organization established by Amanda Tokarski to help raise awareness and research money for a rare blood disorder called hemophagocytic lymphohistiocytosis (HLH). The disease claimed the life of Tokarski’s 4-year-old son Caleb in April.

“We’re here to get the word out, to get families involved and to let people know a little about HLH. It’s pretty uncommon, but the effects are devastating,” said Tokarski.

It all began for Caleb with what seemed like a persistent flu. They brought him to St. James Hospital in Olympia Fields to figure out why he couldn’t shake the flu. After some testing and uncertainty, they eventually diagnosed him with HLH, a disease that originates in the bone marrow and triggers an overactive immune system. There is no known cure for the disease.

The once rambunctious boy was robbed of his energy, he couldn’t keep food down and he broke out with what looked like a rash but turned out to be petechia, the bursting of blood vessels, that often signals serious illness in children.

“He just wasn’t himself. He was clearly sick. He had trouble sleeping, and he would toss and turn. All he wanted was to be comfortable, but he was miserable,” Tokarski said.

Soon he would be induced into a coma and started on a round of chemotherapy and steroids, but Caleb would never wake up again. He died April 12, one week after his fourth birthday.

The event was held not only to raise awareness of HLH, but also served as a reunion for those who loved Caleb.

“We want to honor his memory,” said Andrew Matas, Caleb’s uncle. “It means a lot to us to have our friends and family come together and remember Caleb and try to help us come full circle.”

Some came in support of the community as well as the cause.

“We’re here to support Amanda and her family. We want them to know we’re here for them. It’s also a great way to learn about HLH and help raise money so others won’t have to go through what Amanda did,” said Kris McGuire, a lifelong Frankfort resident.

For Caleb’s Crusaders this was just the beginning. They hope to hold a number of fundraisers throughout the coming year and to help provide dinners at Ronald McDonald House.

“All of the events will be family-oriented. That’s what we’re all about,” said Tokarski. “We want to have fun with the events as well, just like Caleb always did. He would have loved a day like today.”

Caption: Raising awareness: Amanda Tokarski (left) established the Caleb’s Crusaders Foundation after her son Caleb died of a rare blood disorder. She is joined at Sunday’s picnic by Caleb’s aunt and uncle, Amy and Levi Matas (right), and Andrew Matas, Caleb’s cousin. | A. Jay Wagner~For Sun-Times Media