



# OUTSTANDING GRASSROOTS VOLUNTEERS

{ *The Mikey Czech Foundation* }

“Hearing that felt like someone simultaneously hitting me in the stomach and in the back of the knees with a baseball bat,” recounts Steve. “I almost fainted.”

Only 150 to 200 children in the U.S. are diagnosed with a DIPG brain tumor like Mikey’s each year, so little research had been done on this lethal tumor, which grows in the brain stem and destroys the nerves that control eye and face muscles, breathing and swallowing. “The body gradually deteriorates, but the mind does not,” explains Steve.

Mikey participated in a clinical trial. Steroids caused a twenty-five-pound weight gain in three weeks, but the tumor began to shrink. He met Pope Benedict XVI and the Yankees. He started sixth grade at Saxe Middle School, where his older sister attended. Then, on September 7, 2008, nine months after his diagnosis, Mikey died.

The Czechs already had begun cementing their son’s legacy. Prior to his death, they founded The Mikey Czech Foundation to fund DIPG tumor research. Steve pledged a minimum of 10 percent of profits from his firm, Czech Asset Management. The foundation has raised over \$2 million and is funding a groundbreaking clinical trial at Harvard’s Dana-Farber Cancer Institute.

“They are doing biopsies,” says Jennifer. “This is huge.” Steve adds, “Kids’ lives will be prolonged and eventually they will be able to survive. That could happen in ten-plus years.”

Dana-Farber’s Dr. Kieran comments, “Thanks to the Czechs’ generosity and devotion to this cause, we are making great strides in coming up with more effective treatments for DIPG tumors.”

“What matters in life is not what you have,” says Steve, “it’s what you do with what you have.”

**IT WAS A SUNDAY, A NORMAL DAY EXCEPT THAT** it was energetic, baseball-loving Mikey Czech’s eleventh birthday. A normal day except that it was the day Steve Czech suggested his wife, Jennifer, take Mikey from their home in New Canaan to the ER at Norwalk Hospital. Mikey had been experiencing double vision and looking sideways at the TV. Steve headed to 10 o’clock mass.

By the afternoon, the Czechs were sitting in a somber office at Yale Children’s Hospital, where Mikey had been transferred by ambulance. The head of pediatric neurosurgery explained that the Czech’s only son had a rare and deadly type of brain tumor. He told them, “At best, he has three months to live. There’s nothing we can do.”