



# GREYSON

Greyson was diagnosed with neurofibromatosis 1 (NF) before birth. It can cause tumors, typically benign, to grow on nerves throughout the body. His father died from a tumor in his intestine in February 2017.

Greyson really had no issues other than ADHD until he was 10 years old. In May 2018, when Greyson was 10 years old, he had a seizure for the first time and a brain scan revealed a tumor. It was believed to be an NF tumor, which are typically very slow growing.

Over the summer, his seizures increased in frequency. And his short-term memory stopped working (he could remember everything that had happened prior to May or June but nothing after that. He couldn't even remember things that happened a couple minutes ago. He would ask the same questions repeatedly every day). By August, it was decided that he needed epilepsy surgery to remove the area of the brain causing the seizures because he was having nearly 100 seizures a day on medication. They also obtained tissue samples of the tumor for testing during the epilepsy surgery process. At first it still appeared to be a low-grade astrocytoma, but he also had a genetic mutation that would indicate a very aggressive cancer in a non-NF patient, so we weren't sure what to expect. He was starting to have right side weakness from the tumor also.

In late September 2018, he started the typical chemotherapy for NF brain tumors, which involved chemo almost every week for a year. In November and December, he had some brain bleeds that caused setbacks. At this point, he was almost exclusively in a wheelchair other than very short distances around the house. In January 2019, he needed a shunt placed in his brain because the fluids weren't draining properly. He needed 2 additional surgeries to adjust the shunt to get the fluids draining well enough. At the end of February 2019, he was brought into the ER at Children's Hospital again because of decreasing ability to walk and function. A brain scan showed that the tumor was continuing to grow.

At that point, we were informed that it was a high-grade tumor and he was terminal. His family had to decide how much treatment we wanted to do to prolong his life. We chose to do 6 weeks of daily radiation with the hopes that he could come home and have some quality time with the family before declining.

He came home in early April on hospice care. He was mostly confined to a bed at that point and slept most of the time. By the end of April, his seizures were increasing again, and his decline was clearly starting again. He died at home on June 28th, 2019 at the age of 11.



**EVERY 2 minutes** a child is diagnosed with cancer.

**More than 40,000** children are in cancer treatment each year. **More than 15,000** children & teens will be diagnosed this year in the U.S.

**95% of kids** who win the fight against cancer, have other life-long side effects from the cancer and/or its treatment.

**Since 1980, ONLY 3 drugs** have been specifically approved & less than 10 drugs have been developed for use in children.

**4% of government cancer research** goes to childhood cancer.

## WAYS TO SUPPORT

[www.womenformacc.org](http://www.womenformacc.org)

Women for MACC brings hope to families through research & awareness to end childhood cancer and related blood disorders. Your support of Women for MACC will benefit ongoing critical childhood cancer and related blood disorders research made possible through the MACC Fund.