



BRYON'S STORY

On Christmas Eve, December 2008, Bryon's daycare teacher mentioned that Bryon wasn't using his left hand much. Bryon's mom realized that she had been noticing this for several weeks, and brought him to the doctor.

The pediatrician's office scheduled an MRI for late January, but Bryon's strength deteriorated rapidly. He was brought to the CCMC Emergency Department on Saturday, January 9, 2009. The doctors showed his mom and dad the MRI images of the inside of Bryon's skull, complete with a tumor that appeared to be a third of his brain's size. Bryon was admitted to the hospital that night, surgery was scheduled for Monday to remove some of the tumor and to obtain tissue samples to help determine what the team was dealing with.

This surgical "resection" removed about 25% of the tumor mass, which was then given a name: Pilocytic astrocytoma of the optic chiasm. Chemotherapy infusions started immediately and Bryon was recovering well. He was released to go home and, although he was scheduled to go visit CCMC about three times a week for the coming year, it seemed like Bryon's family was going to be able to somehow manage their new life.



Unfortunately Bryon returned to CCMC after only two days, when the surgical incision site started to swell. The neurosurgeon had to put in a temporary drain to release the built-up fluid in Bryon's brain. When it didn't resolve, a plan was made to remove more of the tumor bulk in hopes of improving the cerebral spinal fluid circulation but this didn't work either. It became necessary to place a permanent drain, called an internal shunt, to divert the excess blocked fluid. Bryon didn't wake up after that surgery and the shunt didn't relieve the pressure either. They had to put another shunt in, and then another, and then another – and then do several revisions as well. Bryon's mid-brain was affected; a very crucial area to basic survival.

There was slow improvement over the next few months in the hospital and, in mid-May, Bryon was allowed to return home. He never recovered the ability to speak, or walk – or even crawl, and is fed through a tube directly into his stomach. Testing has determined that he suffers cortical blindness, and he has a tremor and muscle spasticity that prevents him from using communication devices.

And that rotten tumor has continued to grow, despite five different chemotherapy regimens over the past five years. In fact, Bryon has just started a course of eight, six-week long cycles of a four-drug combination called TPCV after taking a one month break from his last year of the chemotherapy drug Avastin. He continues to enjoy attending school when he is able, where he spends time both in a mainstream 2nd grade class environment and also in working with a physical therapist on range of motion and strengthening exercises, a speech pathologist on alternative means of communication, and doing grade-level academic work with a BESB (Board of Education Services for the Blind) teacher through multi-sensory learning methods. It is unlikely that Bryon will recover speech or mobility.



The miracle of it all is that Bryon is one of the happiest people you might ever meet. He leads a full and enchanted life, filled with amazing adventures, surrounded by countless loving fans and family members. He has swum with smiling dolphins and patted Beluga whales on their melons. He has felt the icy spray of Niagara Falls and also the warm sun from the deck of a ship cruising to the Bahamas. He also has cruised around the Statue of Liberty and felt the rush of wind across the Grand Canyon from the South rim. He has felt the cold crashing waves of the Pacific Ocean and the thundering of his adopted football team, the Bantams, crashing across the field to clinch their division championship. Bryon has waterskied with Leaps of Faith, participated in 5K races and Zumba-thons and he goes to summer camp in Maine and visits Disney World in the winter. He goes to concerts, and plays, and zoos, and circuses, and lectures, and is co-editor of the local Mineral and Gem Club. And everywhere Bryon goes, he finds friends and brings a smile to people's faces. He reminds us all to see the beauty in each day and to enjoy what is put before us.

