

# Noah's Story



Noah was a perfectly healthy baby for the first six months of his life... or so we thought. After five days of what we thought was a stomach bug, a trip to the emergency room led us to a GI appointment to explore Noah's symptoms. After receiving fluids and still showing no progress, doctors at Children's Hospital of Pittsburgh decided to consult with Neurology and a CT scan was done. On January 5, 2017, we got the horrifying news that Noah had a golf ball sized brain tumor and hydrocephalus due to the build up of fluid in his brain. He was immediately rushed to the pediatric intensive care unit where an emergency surgery was done to place an External Ventricular Drain to relieve the pressure build up in his brain.

On January 10, 2017, Noah had a nine-hour brain surgery to remove as much of the tumor as the surgeons felt they could safely remove without putting Noah's life in jeopardy or causing any long-term side effects. They were able to get about 50% of the tumor. We were told Noah had grade two Ependymoma, which is a malignant brain tumor that grows from the central nervous system. This form of cancer is very rare with about 200 children a year in the United States receiving diagnosis.

Five days from his initial surgery, on January 15, 2017, Noah exhibited concerning symptoms and a CT scan indicated bleeding in his brain. He was rushed into his second brain surgery where they were able to remove 25-30% more of the tumor and clean up the bleeding. A large piece of his skull was removed during the surgery and left out to allow for any swelling to have room without causing hydrocephalus. A few days later, Noah's EVD was removed and his body proved to be able to drain the Cerebrospinal fluid on its own.



After about a month of recovery and putting plans into place, Noah began three rounds of a high dose chemotherapy regimen. Over the next nine weeks, Noah had numerous complications, including fevers, low blood counts, infection, surgeries, and was admitted to the hospital for close to six out of the nine weeks of chemo. Those three rounds of chemo were not only excruciating to watch, but shaped our family's decision for the next steps in our son's treatment. Following chemotherapy, Noah's MRI showed that his tumor had slightly shrunk. Our family traveled to Children's Hospital of Philadelphia for a full second opinion following chemotherapy. He received 30 rounds of Proton Beam Radiation, a type of radiation that is found to be safer for young children that have developing brains. He was ten-months-old.

On November 10, 2017, our family heard the words that every family fighting this battle wants to hear, "Noah is cancer-free."

Unfortunately, on May 18, 2018 we were faced with the enemy again. A mass growing on the original tumor bed was spotted on an MRI. Children's Hospital of Pittsburgh informed us that Noah's cancer had spread to his spine as well as the new tumor in the brain and the neurosurgeons in Pittsburgh felt that taking out the mass in his brain would not change the prognosis that Noah had less than a 20% chance of surviving the next five years. Our family was not going to sit back and give up.



After sending images, reports, etc. to Children's Hospital of Philadelphia (where Noah finished up his proton radiation in June last year), the doctors felt that removing the tumor in his brain will give him the possible chance of fighting this cancer and are not fully convinced of the disease in Noah's spine. Our family will be in Philadelphia for brain surgery, a spinal tap, and treatment.