

Maryland Senate,

I am writing to show my support for SB51/HB775 – the establishment of a Pediatric Cancer Fund in the state of Maryland.

According to cancer.gov, there are an estimated 5 children per week in Maryland diagnosed with pediatric cancer. On March 28, 2014, just shy of his fifth birthday, my son Sullivan “Sully” became one of them. Sully was diagnosed with Stage IV neuroblastoma. At the time of diagnosis, Sully had an 11 cm tumor between his stomach and spine. The bones in his skull, shoulders, hips, femurs, and knees all contained cancer cells and 95% of his bone marrow was made up of cancer cells. After consulting with several different hospitals, we learned there is no standard treatment for neuroblastoma. Every child is put into a clinical trial. Within a week of diagnosis Sully was enrolled in a trial and started chemo. Over the next five and a half years Sully endured:

5 surgeries

29 rounds of chemotherapy (each round lasting one to three weeks)

5 rounds of immunotherapy

8 rounds of immunotherapy combined with chemotherapy

3 rounds of MiBG therapy (targeted internal radiation that made him so radioactive we could not touch him or approach him without protective equipment and a metal shield for multiple days)

1 month of daily photon radiation

1 month of daily proton radiation (to his skull, his head was covered with a hard plastic mask that was screwed down to the table every day)

A stem cell transplant that kept him in the hospital for the entirety of the month of December in 2015

Over 150 nights in the hospital

2 life threatening reactions to medication

More blood and platelet transfusions than I can count

Innumerable trips to the ER for any fever

2 relapses

In total Sully spent 1667 days in treatment.

Thankfully, after all that, something stuck. Sully is now cancer free and a 7th grade student at St. Anne’s School of Annapolis. We are so grateful Sully is alive. Sully would tell you he is a “statistical anomaly” and he’s right. At the same time, we are living with the fallout from his toxic treatment every single day. Sully’s team includes:

Oncology – he has follow-ups every few months and when strange symptoms pop up, which they often do, our oncologist is still my first call.

Endocrinology – Radiation destroyed Sully’s thyroid, so he must be on medication for the rest of his life. He did not grow for a year and a half during treatment so we may need to supplement

him with human growth hormone. Sully, like most cancer kids, will not be able to have biological children because of the toxicity of his treatments.

Orthopedics – Radiation stunted the growth of one of his legs so he will need to have extensive surgery to correct that disparity which also causes a curve in his spine.

ENT – radiation scarred his lung sacs, so he is unable to properly take a deep breath. That gets to be a burden when you are an active kid who wants to keep up with your friends.

Gastroenterology – Sully’s liver and kidneys were so overburdened by the toxicity of his treatment that he now has fatty liver disease and non-alcoholic liver cirrhosis.

Audiology – chemo caused high frequency hearing loss.

Cardiology – Sully’s heart was damaged by chemo.

We learned so much through all of this. Unfortunately, some of the things we learned were that only 4% of federal cancer research dollars are spent on all childhood cancers combined and that most states, Maryland included, don’t do anything about childhood cancer. That needs to change. We need your help to change it.

We ask that you vote in favor of the establishment of a Pediatric Cancer Fund for the state of Maryland.

Sincerely,

Amy and Sully Shields
Edgewater, MD