

September 25th: Bryce's Story, written by his mom, Tiffany

September is pediatric cancer awareness month. We are now two years into Bryce's diagnosis. There are still days I feel like I had the wind knocked out of me. There are still days that I sit alone and cry. There are still days I just mentally shut down. No one sees me having those days except for those closest to me.

Never have I ever pictured my life where I am. When I lost my Poppop, who was my best friend, it was the worst possible thing that I could have imagined. When I lost my dad to cancer at 50, it was gut-wrenching and I felt like I couldn't move forward. Then it happened, my "new" worst...Bryce was rushed to the hospital when a mass was felt.

The story: Coughing turned to exhaustion, which turned into not eating, which turned into cancer. For two months, I fought to find what was wrong with my boy. Whooping cough? Nope. Virus? Nope. Bacterial infection? Nope. Finally a doctor physically felt the mass and sent us to the hospital where Chris met us. As the ultrasound ended, we were not given any info but the technician walked out and walked back in with a phone and asked me to speak to our doctor. "Several masses were found. We are not sure what we are dealing with but please prepare yourself for whatever may come your way. We need to admit Bryce immediately and figure out the course from there."

We laugh and joke through everything. I will never, ever forget sitting in the waiting room, waiting for them to take Bryce back for a CT scan. Chris excused himself and, two minutes later, I heard him gut-wrenchingly sobbing. I told Bryce I was running to the bathroom quick (knowing he heard his dad), ran in the hall, and needed to look Chris in the face and tell him to pull it together. His child was scared and could hear him. I never saw Chris cry before. Sure, tears when my Poppop and dad passed. Happy tears when we got married and had our kids. But those were tears. Over the course of the next two years, we flip flopped those roles. He'd tell me to pull myself together many times. After that though, I cannot remember us crying in front of Bryce again.

What came next: an unsuccessful invasive surgery at LVHN the day before his 13th birthday, a week at LVHN, a call saying it was benign...and then an oncology meeting two days later saying it was Gastrointestinal Stroma Tumor (GIST)...malignant and very rare and not able to be treated at LVHN. Then home with a child that looked pregnant at that point, calls and meetings and testing. Being told surgery was not possible to being told if they didn't try surgery he would die. Sitting in that waiting room for almost 9 hours at Children's Hospital of Philadelphia and then being told he made it through surgery but had three inoperable tumors remaining...but would live to see more days. Trips to CHOP regularly still. People we knew dropping out of the picture but people we didn't know stepping into the picture.

I still research. GIST itself can be fairly common in people of a certain age. After testing, we discovered that Bryce was harboring a more rare form of GIST, Wildtype. He has SDHA GIST. There are several types. His is non-responsive to any possible treatments. Surgery is his only course of treatment. We've been to Boston. We've participated in a clinic at the National Institute of Health. I still research and listen. I'm now a PA East advisor for The Life Raft Group, which helps bring awareness to others and support those in diagnosis.

Bryce now is missing almost half of his stomach. He deals with dumping syndrome and at times, intense pain. Exhaustion plagues him regularly. He says he has pain every day but he's learned to cope now. Certain days he cannot cope and he cannot hide it.

This is a forever diagnosis. Never will he be in remission. Never will we know life again without cancer. It is a beast that's infested our lives.

We have learned through genetic testing that both Chris and Arianna are SDHA-deficient, which caused Bryce's tumors and cancer. Both are under the care of doctors and monitored regularly. We deal with unknowns regularly. Bryce gets sick and we freak out and want to rush him to CHOP for scans. Just three days ago, I found a lump in Arianna's throat when she was struggling to swallow. Chris asked me to rush her to the doctor in case it was GIST...I called and described it, and they diagnosed her with tonsil stones over the phone. Arianna was sick a few months ago and begged me

for scans to make sure she was not growing cancer. How do you process all this, especially as kids?

I found a paper in a notebook the other day. Cameron was in 6th grade and journaling in class. I sat on the floor in tears. "I don't want my brother to die." "I don't want to go to school. I just want to be at the hospital." "My birthday is always my favorite but this year, I woke up and my mom and dad and brother weren't there and I was sad. I got to miss school though with my sister and go to the hospital." (We were at chop for a month that surgery.)

Bryce's cancer has metastasized to his liver. He remains under a watchful eye. PET scans, MRIs, blood work, oncology visits are all a part of our routines. Chris and Ari get PET scans and MRIs and blood work themselves and meet with oncologists, too.

Insurances make my life hell. People can be complete jerks in every facet of life but others can shine on you and hold you up. Organizations such as Pediatric Cancer Foundation of the Lehigh Valley, Moment Of Peace Adventures, Dream Come True of the Lehigh Valley and so many more have helped us through this and have provided us with the most important thing ever...memories!

Many tough days and tough decisions lay ahead of us. My kids will need to decide on having their own kids since it's genetic. Insurances are forever more an issue. No life insurance. No freedom from doctors. We have each other though, and over the past two years, our family has strengthened and our sense of humor has darkened. Our hearts have grown. Our experiences broadened. We live life to the fullest every single day. I beg everyone I know to do the same. Tomorrow is never guaranteed in anyone's life.