

## *Baxley's Story*

Baxley was born happy, healthy and on time on 2/25/15. We had just celebrated his 4th birthday when we noticed the very first minor symptom 8 days before his story began. It all happened so fast.



**3.16.19** We had dinner and went to an arcade with our family. We went to bed that night and Bax woke us up with leg pain. It was out of the blue and pretty severe so we went to the ER. He had fallen asleep on the way there but we still went in and the doctors evaluated him. They thought maybe it was muscle spasms so they gave us ibuprofen and sent us home.

**3.17.19** The next day Bax was feeling better and played but he started experiencing pain and incontinence while going to the bathroom. That night he had bad leg pain again so back to the ER we went. When we got there, they did an Xray and ran



labs and everything appeared normal. They told us to follow up with our pediatrician in 2 days.

**3.19.19** Baxley was still having pain and trouble urinating so we went to the pediatrician. She wasn't our regular doctor but we had seen her 3 weeks prior for his 4 year old wellness visit so she was somewhat familiar with him. She lectured me on his diet and sent us



home to work on his “constipation issues”.



**3.21.19** Baxley was still in pain and having trouble urinating (sometimes-



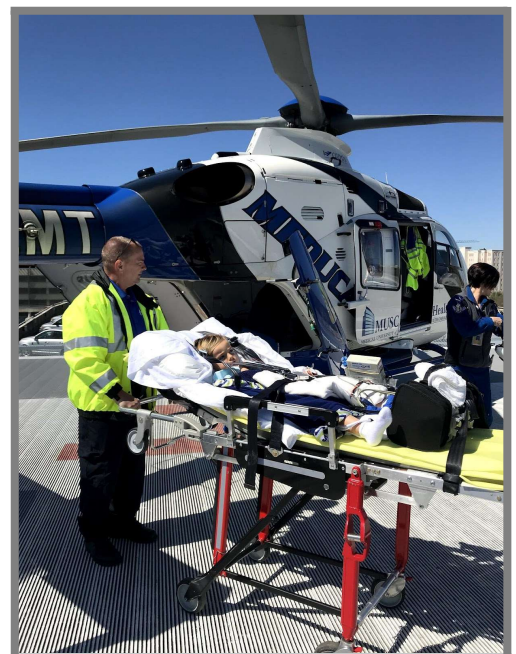
not every single time) so we went back to his pediatrician's office and requested to see a different doctor. We met a doctor that listened to my





concerns as we thought at that point it was a bowel obstruction so he scheduled a CT scan for the following morning. He would have sent us there ASAP but Baxley appeared fine in the office. That night he writhed in pain but we still waited for his appointment first thing in the morning.

**3.22.19** We got up early and went to check in for his CT scan. The pediatrician's office didn't do an insurance preauthorization so we headed to the ER instead. They noticed he was in bad shape so they drew labs and found out he was in kidney failure. They put in a foley catheter to relieve his bladder and we finally got the CT scan. There they informed us that they found a mass the size of a grapefruit in his abdomen. We were in a small hospital 2 hours away from a children's hospital with an oncology unit so we took a helicopter ride to MUSC in Charleston, SC.



**3.24.19** Baxley had an MRI and PET scan at MUSC to get better info on his tumor. It was 7cm and they found two small lung nodules and a little bit on his sacral ala bone so we knew at that point that it had spread.

**3.25.19** Baxley had a tumor biopsy and bone marrow aspirate to make sure the presumed cancer didn't spread to the bone marrow. Luckily we found out that it didn't but we still had a long road ahead. At this point we were waiting for pathology reports to come back so we could decide on a treatment plan.



**3.29.19** We have an official diagnosis- Stage 4 Group 4 Embryonal Rhabdomyosarcoma. Luckily it was still considered intermediate risk and he was eligible for a clinical trial. He had surgery to insert his power port for his chemotherapy. When transport arrived at our room with a wheelchair to take Baxley to surgery, he refused to go in it. At this point any kind

of choice he had was taken away so we tried to allow him to make any choice he could. He wanted to go naked in a

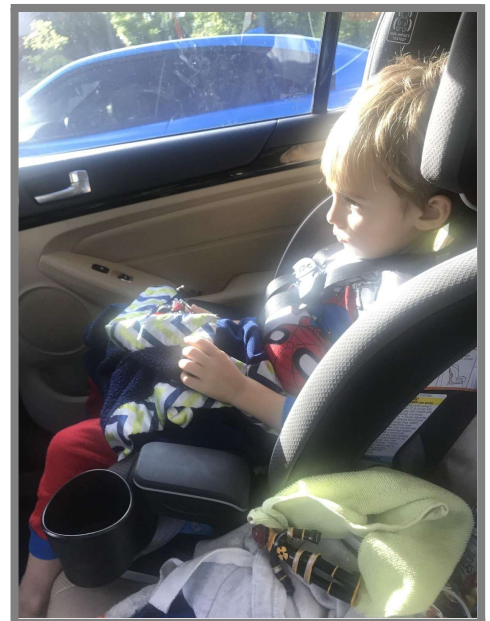
wagon and so he went to scans naked in a wagon- with a blanket on top.



**4.4.19** Baxley was accepted into a clinical trial and randomly selected to receive the trial drug so he began chemotherapy. We stayed inpatient because Baxley's tumor had been pressing on his bladder so long that it stopped working by itself so we had to learn how to intermittently catheterize him to allow him to urinate. This was absolutely the hardest part of his entire cancer

treatment. It's extremely difficult and traumatizing to do that to your own child. We had to learn to successfully "cath" our son before we were allowed to leave the hospital to go home.

**4.14.19** We finally got to leave the hospital after our 24 day hospital stay. Baxley's treatment plan was 67 weeks with weekly trips to Charleston (2.5 hours away from home) every Thursday. Every 3<sup>rd</sup> week we alternated between a 2 day or a 5 day







inpatient stay. One of my coworkers brought a collapsible wagon to us with gifts and offered to let us keep it. Baxley wanted to ride in it and it was so convenient to carry everything from the car all the way to clinic so we brought our wagon every time we had an appointment.

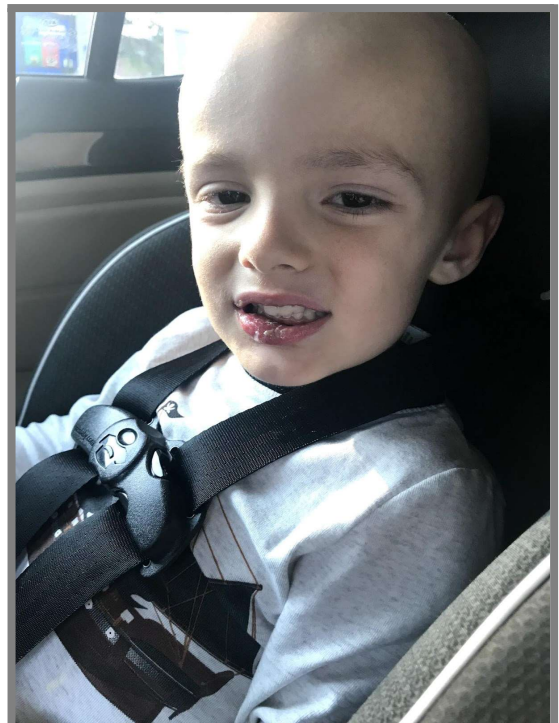
**4.28.19** Baxley's hair began falling out. We found out how lucky we were that he was a 4 year old boy going bald because he did not care and thought it was pretty cool that he got to get his head shaved. A wonderful nurse shaved what hair was left while we were inpatient.





**5.10.19** We were still “cathing” him to pee and it was grueling. He had regressed back to diapers since we didn’t have much control and sometimes we would find blood clots so we had to pack up and head to MUSC’s ER to be seen by their pediatric urologists.

**6.2.19** We ran into mucositis in Baxley’s mouth that made him drop weight drastically because he couldn’t eat. He had already lost so much weight from being in the hospital and being a picky 4 year old that we couldn’t afford for him to lose any more. There were talks about giving him a feeding tube or putting him on TPN IV nutrition but luckily he turned a corner and started eating before we had to resort to that.



**7.1.19** We began 33 proton radiation treatments in Jacksonville, FL spread out over 7 weeks. We stayed at the Ronald McDonald House there and every weekday we would head to



Proton radiation therapy at around 10am

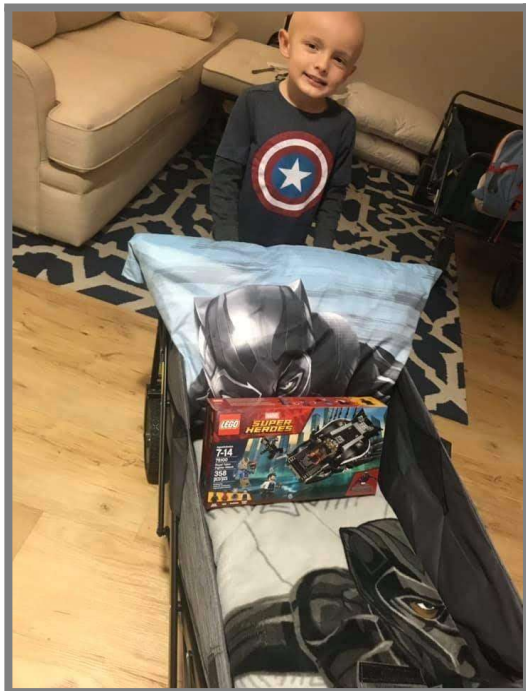
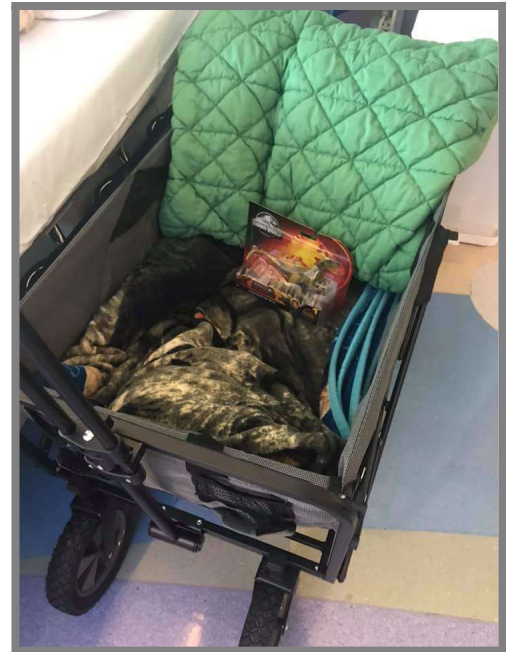
and he couldn't eat or drink anything before his appointment. He was sedated for every treatment because he needed to be extremely still for the entire 30 minutes of radiation.



**7.11.19** At this point we had talked about giving wagons to hospitals outfitted with IV poles so kids could cruise the halls in some cool wagons to and from scans. One day in May or June I was walking by the children's atrium at MUSC and I overheard an announcement that someone had donated 30ish wagons to the new children's hospital



that was about to open. I thought to myself, hmm... guess they may not need the wagons much after all. Some people had already donated money towards wagons but our concentration right now was killing cancer so it went on the backburner. I met Jaxen's mom Rowe at radiation and she asked to take a picture of Bax's wagon because it looked helpful and she wanted one too. We decided after that that we would give collapsible wagons to families and Jaxen was our first recipient.



**7.18.19** We stayed at the Ronald McDonald House for 7 weeks while Bax had radiation on the weekdays so we met a lot of families and formed amazing relationships. We connected and gave away 11 wagons in Jacksonville from 7/11/19 to 8/22/19.

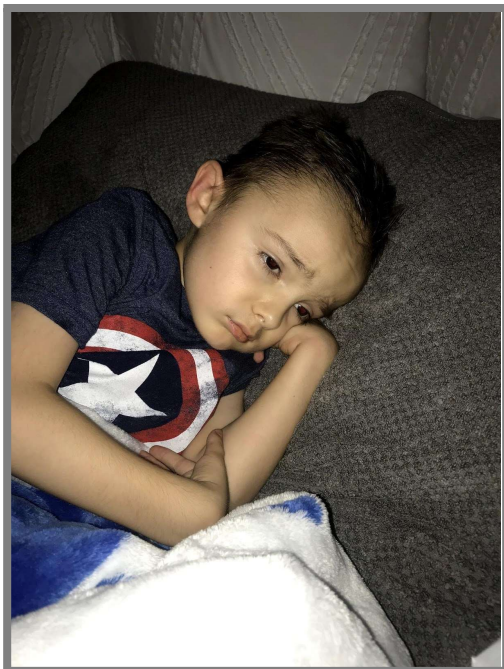
**9.27.19** We were gifted a playset in our backyard from RocSolid Foundation- an amazing nonprofit that builds playsets for cancer kids. It became free and easy physical therapy that Baxley desperately needed since he began experiencing intense neuropathy. He had been walking on his toes and refused to wear shoes. Being a recipient of so many kind and generous strangers gave us motivation to give back more.



**10.31.19** Halloween inpatient at the hospital. When Baxley was first diagnosed, I mapped out his entire treatment schedule to make sure we weren't in the hospital for holidays and thankfully we avoided most. We had scans and got good news that the residual tumor had decreased in size and was dead.



**11.22.19** Anytime Baxley got a fever of 100.4, it's an automatic visit to the local ER. We had a few local ER visits but most times his fever went down and his counts were high so we went back home. This time his counts were low so we took a midnight ambulance ride to MUSC. The ER was busy and so was the oncology floor so we didn't get much sleep that night but luckily we got to go home the next day.







**12.13.19** Christmas time at a children's hospital can actually be fun! We decorated cookies and the nurses helped us hide our elf "Tickle". Baxley's hair had already started growing back but it started falling out again triggering us and taking us back to the beginning.

Many kids on active treatment still have their hair and for me, it made them not look sick.

When a kid is bald or has hair missing, it's a constant visual reminder that they are pumped with poisons to kill the cancer.



**1.3.20** After 43 long weeks, we finally finished up our last



scheduled inpatient big chemo before Bax started the maintenance phase. Baxley was battling nausea that one medicine wasn't cutting it for anymore so they introduced IV ativan which made Bax super silly.



**1.26.20** Baxley began 10 radiation treatments to his lungs. Since we had to be in Charleston for a little over 2 weeks, we decided to make it fun so we rented an oceanfront condo and made it a “radiation vacation”. As strange as it sounds, this

was actually an “easy” part of treatment. Unfortunately radiation has more of an impact on side effects years down the line.



**2.25.20** Baxley turned 5 years old. We celebrated by gaming all day at his favorite place with lots of friends.



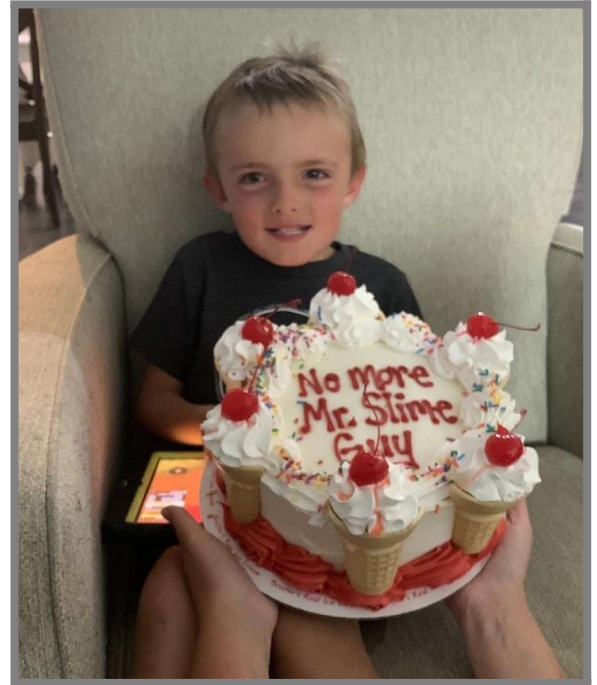
**3.26.20** Although we had been visiting the hospital weekly for almost 50 weeks, maintenance chemo meant less visits so this was our first visit back to the hospital since Covid 19 became a thing. We had already lived a quarantined life so not much changed for us but it was weird to see everyone else adapt to our lifestyle.



**6.25.20** There were a lot of weekly visits in between March to June but we finally reached Baxley's last IV chemo infusion. He still had to finish his oral chemo a few weeks after but this was a huge milestone.



**7.16.20** Baxley's last oral chemo so Baxley's done with treatment! He had named all of his oral medicines and his oral chemo was pretty gross so he nicknamed that one "Mr Slime Guy". We celebrated with family and close friends.



Some people don't realize that "end of treatment" doesn't mean the cancer journey is over. Baxley still has weekly physical and occupational therapy appointments and we follow up for scans often. We are still so fortunate that his

residual tumor is dead and considered “No Active Disease”.

What we didn't realize was that you're living in survival mode for those 67 weeks so you're living off of adrenaline and prayers. Once the chemo ended, something that was once a poison that sickened you to think of pumping through your child's veins suddenly became some sort of safety blanket that was ripped off like a band-aid. We tried our best to find the positives in every part of this cancer road but anxiety came in full force so we turned our fear into our mission to make Hug Your People as big as possible so we could help more kids. We had given away 28 wagons by the time Baxley finished treatment and now we want to make sure every kid that would like a wagon can get one. So we decided to hit the road to give a wagon to a kid in every single state.



Since August 1st 2021, we've camped in 24 states and counting and we've given wagons to kids in every state but 4- Maine, North Dakota, Alaska & Hawaii. Follow along with us as we continue to raise awareness for pediatric cancer, share stories of other cancer fighters and make memories living life after cancer.

Hugs.

*Suzanne*