In January of 2023, our hearts were shattered with the words that no parent wants to hear - “I’m sorry, your son has cancer”. From that moment on, our lives completely changed. Owen, then 15 months old, was diagnosed with Stage 4, High Risk, Metastatic Neuroblastoma. The cancer originated from his right adrenal gland, but ultimately spread to bones and bone marrow. We noticed something was “off” when Owen was refusing to walk. This prompted medical investigation with X-rays of his pelvis. At this point, we were told it was Osteomyelitis, a common, but painful bone infection that can be rather common in kids Owen’s age. We were treated for a few days in the hospital and then sent home on oral antibiotics. As one week passed, we saw little to no improvement but we were assured that it is quite the healing process. The second week went by, and Owen began refusing to walk again. We rushed him back to the ER where a repeat x-ray was taken and that’s when they found a fracture in his femur.

The look on the doctor’s face when he came in to tell us about the fracture, was a look we will never forget. Our hearts sunk, because we could feel that something bigger was going on. We were transferred out of the ER and admitted for a stay while they investigated further. Owen, at the time, had very elevated liver levels. So to rule out any viral liver infections, they ordered a liver ultrasound. This is when they made an incidental discovery, a 5cm mass next to the liver on the adrenal gland.

A mass on the adrenal gland is a tell tale sign of Neuroblastoma. We were quickly transferred to the oncology unit, and that is when all of the in depth testing started. Within a couple of days, Owen was sedated for a spica cast placement for his broken femur, different sets of scans, a needle biopsy of the mass and a single lumen port placement into his chest for his chemotherapy regimen that he would soon begin. We were broken, we were numb, we were scared. Full of all of these emotions, we never wavered from researching until early hours in the morning, grasping for all information we could possibly find to learn about this “new life” we were thrown into. As our results of scans and biopsies began to come back, we learned more about Owen’s risk factor. His biopsy results came back with a pathology of MYCN amplified and ALK amplified, two things we prayed were not on that result paper. It felt like blow after blow when we were there getting all of this information. We took these results and furthered our research. What we read was horrifying. Statistics and a prognosis as low as 4% for a child with these pathologies within their disease. The in depth research that we stayed up every night doing, was something we believe to this day, helped us become the advocates that we are for our son. As a cancer parent, you never realize how many treatment decisions are actually up to the parents until you’re in this nightmare. We were quickly making life saving treatment decisions for Owen.

We sat down with Owen’s home oncologist and went over the treatment protocol for High Risk Neuroblastoma which includes the following: Five rounds of high dose chemotherapy, tumor resection surgery, two stem cell transplants, and 6 rounds of immunotherapy. This protocol would be the next 18 months of our lives. We agreed to start this protocol and as soon as Owen's port was placed, we began his first round of chemotherapy. We were terrified it would hurt him going into his body, scared of the lasting side effects it would have on his tiny being, but we had to stop this deadly disease. Upon starting our first round of chemotherapy, Owen was Covid positive. This heightened our concerns even more to be giving such an immune depleting drug, while positive for an aggressive virus, but we had to push forward. He overcame his Covid diagnosis along with his first round of chemotherapy. From that point forward we had no clue this would be the start to what would seem like, non-stop lung issues. Going into round two of chemotherapy he was then positive for viral pneumonia from the Covid virus leaving all of the leftover junk in his lungs. Since Owen was in a spica cast for his broken femur, he couldn't walk around and mobilize fluid out of his lungs. Regardless of this secondary diagnosis, we proceeded with his cancer treatment. He began his special inhibitor that targeted his ALK mutation. The drug is known as Lorlatinib. This medication would come to be our son's saving grace. This inhibitor basically gave his chemotherapy the extra boost it needed to kill all over the over expression of ALK he had in his cancer. This was something very important because ALK is known to be unforgiving and aggressive.

We soon passed through round three of chemotherapy, at this point Owen had yet another respiratory illness - Rhinovirus. Although this round was different because he got his spica cast removed and immediately began walking! He conquered this huge obstacle like no other! It felt like we finally saw Owen begin to light up when he got his mobility back. Him not being able to walk was an emotional struggle for all of us. A few weeks later, we proceeded with round 4 and straight into scans to map out his resection surgery. This CT scan was the first scan he had gotten since diagnosis. We were both extremely nervous and cautiously optimistic to get the results. These results would give us an idea as to how well Owen was responding to his treatment regimen. The results came in shortly after the scan and we had gotten the news Owen had a complete response to treatment and his tumor went from the size of a lime to a single peanut out of the shell! We were thrilled! This felt like the first positive news we had received, and it sure boosted our spirits quite a bit! So on to surgery we went. Resection surgery came with risks such as: losing his kidney, infection, bleeding concerns and in rare cases - death. We reassured ourselves that Owen was in great hands with arguably one of the best Neuroblastoma surgeons in the country. Surgery was in May of 2023. We were told to expect about a one week stay in the hospital following his surgery for recovery. Owen's surgery was about six hours long and after the surgeon completed the surgery, she came out to inform us that the resection was successful and she was able to remove 100% of the residual mass and Owen did not lose his kidney! Once he was settled in the post op unit, we got to go back and see him. He was out of it and barely awake. It was painful seeing him attached to all of this support, not alert or aware of what just happened. He had an epidural in his back to keep his stomach numb, and he was on a higher dose pain regimen. We were unable to pick him up or hold him and that was really hard because all we wanted to do was hold our baby. Days went on in recovery and Owen slowly began to regain his walking following this major surgery. By day 7 post op, we got the approval that we were good to be discharged and sent home! He did it! He had overcome yet another massive part of the treatment regimen!

We were home for a couple weeks and then we went back into our home hospital for Owen's final round of induction chemotherapy, round five. He completed this and now moved onto the prepping for the part of treatment all parents question and dread - tandem stem cell transplants. The risks that come with this portion of treatment are massive. Some of the risks include: hearing loss, organ failure, bacterial infections, fungal infections, GI damage, respiratory failure and death. We knew these risks were upon us, but Owen would be doing transplant with the greatest transplant doctor in the country, Dr. Yanik. He reassured us that he would take great care of Owen, and we knew he would. Over the next couple of weeks we had scans which showed Owen's cancer to be COMPLETELY GONE! Nothing on his scan lit up! Owen was officially NED (no evidence of disease) - something we didn't know if we would ever achieve! We were elated and so proud of Owen. He had endured so much, but was still so full of joy and life. This is exactly what the doctor wanted to see, from a disease standpoint. In this case, this is when transplant is said to work the best. There was just one concern we had in regards to Owen doing transplant, and that was all of the lung issues he had throughout all of his 6-7 months of treatment so far. Dr. Yanik assured us by looking at Owen's scans, that his lungs looked just fine. This gave us some relief but for some reason, we still had a sense of worry about this. The same day that he assured us that his lungs were fine, he called us around 11pm that night and told us he reviewed different scans more in depth. He now told us that he does see some concerning areas in Owen's lungs. We found out the scans that were sent to Dr. Yanik were not Owen's most recent ones. Later that week, we ended up getting a repeat CT scan of his lungs. Once the results were in, we sat down with Dr. Yanik and he informed us that we could not proceed with transplant. We were shocked and worried but a sense of calmness and relief came over us. This was the supposed to be. Owen was leading the way, just as he was meant to. That day, changed us. We were so set on doing transplant, and knew the entire treatment plan like the back of our hands. But, by the grace of God, that treatment plan changed.

Now what? What option will we have left for Owen, that still gives him the best chance to beat this? The doctors now shifted our focus to the next plan - additional rounds of low dose chemotherapy combined with immunotherapy. We had no idea how many rounds, because there was no set protocol for this. While in the midst of planning this new route, we were weighing our options of staying at our home hospital for this treatment, or going to University of Michigan for this. We knew immunotherapy had many risks as well. We wanted Owen safe. Then, another bomb was dropped on us. Owen began complaining of stomach pain. He was still eating and drinking, playing and running. We thought maybe it was just from all of the treatment he had been through. Or maybe a slower moving gut from resection surgery. They took an x-ray of his stomach and assured us, it was just a slow moving gut and it'll resolve with time. We were happy to hear this, but as days went on, Owen got worse. He was now vomiting every time he drank anything. He couldn't keep it down. We advocated sternly and never stopped. University of Michigan ended up ordering a dye study. Owen had to stop eating and drinking and they put dye into his stomach and took x-rays periodically to see if he was passing it through his entire digestive system, if the dye stopped at any point in his intestines, that would indicate an obstruction/blockage. We waited eight long hours at the hospital and ended up getting a call from the surgeons office - Owen has an obstruction but they're unsure if it's a full blockage or a partial blockage. We were then admitted for a stay where they could examine Owen and keep an eye on him. The surgeon who was taking care of Owen wanted to have a conservative approach. He didn't want to do surgery unless Owen absolutely needed it and we agreed with him. He allowed Owen to drink the next morning and said if he were to vomit, then surgery was necessary. Within 30 seconds of allowing him to drink juice, he threw it all back up. At that moment, the surgeon said - he needs surgery. Immediately.

Within an hour we began signing the consents for Owen's surgery and within 2 hours we were heading down to the operating room. Seven long hours went by and we finally got the page that Owen was out of surgery. We met with the surgeon and found out that the surgery was successful, however, the cause of the obstruction was due to scar tissue from the healing process of his tumor resection surgery. The resection surgery was just 8 weeks prior to the obstruction. We were informed that it was extremely rare and nearly impossible for a human body to form such thick scar tissue so quickly. Typically something like this is seen 5-10 years AFTER a resection surgery.

Given the stress, worry and fear all of this gave us, we leaned into each other and into God. We quickly realized that had Owen been cleared for transplant, this obstruction would have happened in the middle of it and he would not have survived the surgery, let alone the obstruction. This was such a moment for clarity for us. It felt like everything leading up to this obstruction was all God's plan. Something we had no control over, someone else was driving this ship. We learned that we could do everything in our power to educate ourselves and advocate for what we thought was in Owen's best interest, but ultimately these decisions were out of our control!

Owen went on to heal from his obstruction surgery. Recovery was pretty much identical tho the resection surgery recovery plan. While recovering at the hospital we had many discussions with our doctors at University of Michigan about what would cause such a hyper inflammatory response. We decided to do full genetic work ups on Owen and us. These tests would later come back negative (which is good). Owen did not have any pre existing conditions that made him susceptible to this, we more just chalked it up as - this is Owen's body, and it has a very rare response to things. Between his lung inflammation and his gut inflammation, Owen was put into a category all by himself and a case study was opened. We began preparing ourselves for the next portion of treatment which was low dose chemotherapy combined with immunotherapy. This was our plan in place of transplant. We were extremely nervous as the first round came about, but we had decided it was best to move this care up to Michigan and leave our home hospital. Ultimately, our home hospital agreed with this decision as well. All of Owen's specialists were up at Michigan and with him having so many rare issues, it was safest for him to be where all of the "experts on Owen" were at. We cautiously entered our first round of this new regimen, knowing immunotherapy was a scary thing. The side effects were known to be high fevers, extreme pain, nerve pain, loss of appetite, diarrhea, and even vomiting. These side effects are controlled with constant drip pain medications and various other drugs that are given around the clock, because the immunotherapy infuses for about 20 hours. Owen started his infusion of immunotherapy and immediately needed a pain medication adjustment. The pain medication was not only ineffective, but it also irritated his stomach after having the bowel obstruction which caused the stopping of the infusion and ultimately, we didn't finish the rest of the immunotherapy that first round.

We proceeded with the next few rounds of chemotherapy immunotherapy combination for a couple more rounds, with a better pain regimen for Owen. The adjustment to his pain medication ended up working very well! However, we still experienced fevers that pushed 105 degrees. After we completed the first three rounds, we transferred to Beaumont hospital for Owen's precision proton beam radiation. He did all of the work up for his radiation cradle and proceeded with 12 rounds of proton beam radiation. We chose proton over photon because it preserved more of the surrounding organs and areas. It was a pin point precision beam, something we thought was much safer for Owen given his problems with his lungs and his bowel.

We went every day for radiation except for the weekends. During this time, Owen had zero side effects and felt great! After 12 rounds, Owen rang the radiation bell at Beaumont! We transferred back to Mott's for the remaining three rounds of his chemotherapy immunotherapy treatment. We went right from radiation into his next round of treatment which was round four. At this point we knew what to expect like clockwork when it came to this drug combination. Owen successfully and safely completed rounds four, five and six. Completing this portion of treatment was a huge milestone for us! We went into scans a few weeks later and those came back all clear/NED (no evidence of disease)! This was yet again a huge relief for us because Owen was now that much closer to completing his treatment regimen.

Now, Owen would move into the final portion of treatment which would consist of five rounds of immunotherapy by itself. We knew that this carried a risk going into it because Owen was taking Lorlatinib still, and this was known to have a reaction with immunotherapy, but only for some children. Given Owen's inflammatory response to certain things, we were worried about how out of control his inflammation may get from just plain immunotherapy. Having the chemotherapy combined with the immunotherapy offset his blood counts just enough to keep his inflammatory levels down, without the chemotherapy we were unsure what was going to happen. Our main concern was his lungs. We were balancing a fine line of keeping the lungs healthy while continuing his cancer treatments. Our team decided that we would check his lungs after just two rounds of the immunotherapy to make sure his inflammatory burden did not change. We agreed to this even though it made us nervous doing two rounds without knowing what's going on inside his body. Owen completed both rounds of immunotherapy without any additional side effects. We did not have any evidence of additional lung issues being caused from the two rounds we did. Once Owen was recovered from his second round, we went and got his lung CT. The results were heart shattering. Owen's lungs had progressed immensely. Our team had us stop Lorlatinib immediately, and at this point, we agreed. As much as we did not want to lose one of the drugs that we felt was vital to his disease response, we knew we had to save his lungs from further damage. The scan results showed massively progressed inflammation, thickening in his bronchioles, and pulmonary fibrosis at this point could not be ruled out. We were horrified at the thought of pulmonary fibrosis because this is progressive and ultimately leads to a double lung transplant or even death. Owen was removed from treatment and started on a three month steroid regimen to relieve the inflammation in his lungs. Once that was completed, we would check with a CT to see how he responded to it. Stopping cancer treatment was nerve wrecking. We had lost our safety net of keeping the beast away. Treating the lungs became our top priority. Owen was on oral steroids, inhaled steroids and also albuterol. What puzzled everyone is - how could a scan look so horrible, yet Owen has no symptoms? Another mystery - which at this point, Owen's team knew he had a way of keeping them on their toes. A case study was opened on Owen, and our team reached out to top Neuroblastoma doctors around the world, not a single doctor had seen what was going on with Owen. Our team now considered Owen one of the most unique patients that they had ever treated.

Owen went on to complete his steroid regimen. We got another CT scan. Waiting for the results was almost painful. These results would ultimately determine if we would even be able to proceed with cancer treatment completion. When the results came in, we were ecstatic to see that things were nearly completely resolved! This was fantastic news. Our team could still see that there was more chronic inflammation in some areas, but nowhere near as serious as it was. We were given the green light to continue treatment! But what would it look like if he can't do plain immunotherapy? Our oncologist suggested reverting back to doing chemotherapy immunotherapy combination. Although Owen didn't really need the low dose chemotherapy anymore for the cancer, he did need it to keep the inflammation balanced from the immunotherapy. Our oncologist wanted three more rounds of this so that Owen could get all of the recommended doses of the immunotherapy. We jumped back into treatment and it was almost as if Owen's body hit reset. His side effects such as fevers and pain were back all over again. His body had to get readjusted to the immunotherapy all over again. Having three months off was a long time without exposure to immunotherapy so it was a shock all over again.

But, we managed and Owen successfully completed the last three rounds of his treatment! In June of 2024, Owen walked out of the in patient unit at C.S. Mott's Children's Hospital from his last stay! It was a huge celebration — Owen style! We marched through his chemo clap out like a true warrior. The overwhelming emotions that overcame all of us at that moment, was something that cannot be put into words. July of 2024 Owen had his end of disease evaluation with scans, a liquid biopsy and urine test. All of this came back ALL CLEAR! Owen has been done with treatment since June of 2024 and will have his scans every three months for the first year, and then transition to every six months after that. We are thankful for the highs and lows of this journey, we are blessed with the best medical team, and we are SO blessed to cherish this time with our son.