



### **PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH**

Griffin Jones was diagnosed on July 4th, 2020 with Acute lymphoblastic leukemia also known as ALL. Acute lymphoblastic leukemia is a cancer of the lymphoid line of blood cells characterized by the development of large numbers of immature lymphocytes. There are about 3,000 cases of ALL in children and youth up to age 21 each year in the United States. The 5-year survival rate is 89% for people under the age of 20. In 2021 alone, the estimated new cases of ALL were at 5,690. The estimated deaths for ALL in 2021 were at an alarming 1,580. That is just in children under 20 years of age.

Griffin began experiencing spiked fevers that would stay between 102 and 103 degrees. His appetite decreased rapidly which was not normal for Griffin. We took Griffin to our local ER (Deaconess Union County) in Morganfield, KY. While stating our concerns, we were simply ignored. A covid test was given and we were prescribed allergy medicine for Griffin and sent home. Once home, Griffin's symptoms became increasingly worse. His father took him back to Deaconess Union County to only be told that it was necessary to just keep him quarantined and wait for the results of the covid test they had given Griffin prior. Within days Griffin was unable to sit up or walk. He was in excruciating pain and his fevers continued to stay elevated. I called Deaconess Union County Hospital on a Friday and spoke to an after hours nurse demanding that something more be done. We knew this was not just a case of covid. The nurse then asked us to bring Griffin to Deaconess Gateway in Newburgh, IN. We did immediately

and numerous blood tests were done as well as other tests I requested be done on Griffin.

The doctors initially thought Griffin had Meningitis until his lab work came back. Griffin's white blood cell count came back at an alarming 79.5 thousand. I was then told at 2am by the doctor about the elevated white blood cell count and that they thought it could potentially be leukemia. I was alone with Griffin and had no one to console me. My husband was not allowed at the hospital so he was at our home with our children. Thank goodness for a nurse working the night shift who sat with me as I tried to understand what I had just been told. We were immediately sent to Riley's Children's Hospital in Indianapolis, IN by ambulance. I had no time to process anything that was happening. Due to Covid protocols, I was the only person who could go with Griffin in the ambulance. The drive alone took us almost 4 hours to get to the hospital in Indianapolis. During that time, I was already completely numb. I think I cried almost the entire way. I was mentally exhausted and had so many things running through my mind. I was terrified for Griffin as well as being terrified for my husband and our other children. I was scared of being alone and not having my husband by my side.

Once we arrived at Riley's Children's Hospital more blood work was done. A lumbar puncture and bone marrow biopsy were done as well. I remember sitting alone in the hospital room watching my son moan in his sleep from the pain he was suffering. It took a dose of Morphine to allow Griffin to calm down enough just to be able to fall asleep. That night, nurses came in throughout the night to take his vitals. I was unable to fall asleep. I had no tears left to cry until the doctors came in and gave me Griffin's diagnosis. Hearing those words knocked the wind out of me. I could not focus, let alone absorb what the doctors were telling me. I had no time to react other than crying uncontrollably, knowing I had to call and tell my husband. We were 4 hours apart and now we were left with deciding our next steps over a phone call. We also had to figure out a system so we could both spend time with Griffin.

We were told that Griffin would be in the hospital for at least a month. I would stay with Griffin for 3 days then go home while my husband came to stay with him for 2 days. We had no other choice because of our other children along with Covid protocols. We were not able to see one another or embrace one another for over a week or two. I was alone with Griffin with no car, no clothes, nothing. Our phone calls between one another were to discuss our son's life. While trying to comfort Griffin and be by his side, I had to take on everything that came with Griffin's disease alone. I missed my other children so much and not having my husband with me was a nightmare.

Numerous tests continued including surgery to put in Griffin's port on July 8th. My sweet baby boy has been poked and prodded more times than I have my entire life. Yet our Griff is still fighting so hard and has never stopped. He continues to smile even through all the pain like the little warrior he is. Doctors planned to do a genetic test which included another lumbar puncture and bone marrow biopsy. The results of that test came back on July 16th, 2020 and concluded that Griffin had the Philadelphia chromosome known as Ph+. Not only had we already had to digest that Griffin had ALL but now another blow. Philadelphia chromosome is when a piece of chromosome 9 and a piece of chromosome 22 break off and trade places. This new diagnosis changed everything. Griffin was now fighting an even harder battle. A battle that none of us saw coming including the doctors. Philadelphia Chromosome positive acute lymphoblastic leukemia (Ph+ ALL) is a rare subtype of the most common childhood cancer, acute lymphoblastic leukemia. Like ALL, Ph+ ALL is a cancer of a type of white blood cell called lymphocytes. Ph+ ALL typically presents with a very aggressive clinical course, responds poorly to standard chemotherapy and carries a high risk for relapse.

A more intense IV chemotherapy was now our only choice for Griffin. This meant we had to switch clinical trials and treatment. With the higher doses of chemotherapy came mouth sores. These mouth sores would often become infected and cause Griffin so much pain and discomfort. He now takes the drug Imatinib every night to target Philadelphia chromosome. I cannot tell you how many times my husband and I have questioned why this is happening. I have played the guilt game over and over in my mind thinking about the what ifs. It is a haunting feeling that leaves me broken. A feeling that I will most likely live with the rest of my life. Due to this type of cancer, Griffin has had to undergo many medical procedures. He has had to have scopes down his nose passage into his lungs while awake multiple times to check for infection. Griffin has had to undergo a few Bronchoalveolar lavage (BAL) procedures. This procedure is what is known as bronchoalveolar washing. BAL is used to collect a sample from the lungs for testing. During the procedure, a saline solution is put through a bronchoscope to wash the airway and capture fluid samples. There was no way for any of us to comfort him through these procedures. All we could do was sit by and comfort him to the best of our ability

On August 5th, 2020 Griffin was able to leave Riley's Children's Hospital and go to Ronald McDonald House in Indianapolis. Our family was placed in a 1-bedroom apartment which was setup to immunize compromised children, but at the time it was our safe place since we had nowhere else to go. We were only able to stay there until August 18th due to unavailable space. Griffin was only at RMH for a little over a week when he got very sick and ended up back at the hospital. My other children and I then went home to take care of some things while my husband stayed with Griffin. He was

released from the hospital on August 16th and returned back to Ronald McDonald House once more. We remained at RMH in Indianapolis until August 25th, 2020. We all then made the trip back to Morganfield, Kentucky to our new home. From there we would commute back and forth between Indianapolis, IN and Morganfield KY for a few more hospital visits for Griffin.

After certain things took place at the hospital in Indianapolis that raised red flags for us, my husband and I made the choice to have Griffin transferred to Monroe Carell Jr. Children's Hospital in Tennessee. We then would commute from Kentucky to Tennessee for Griffin's clinical appointments and inpatient stays, taking turns. On September 22nd, 2020 Griffin went back into inpatient at Vanderbilt due to illness and was there for two days. From November 13th to the 28th, Griffin was again inpatient at Monroe where he would undergo his first Consolidation block 1. This is a form of chemotherapy that is used for children with Ph+ ALL. After this first phase Griffin was able to return home, until it was time for Consolidation block 2. This is where chemotherapy continues and often it is done on an outpatient basis, to keep the disease in remission. However, Griffin stayed in the hospital until December 22nd, 2020. His third Consolidation block 3 came soon after on December 31st, 2020 and he was not released until January 15th, 2021.

During the next several months Griffin would end up in the hospital due to spiked fevers. He would then have delayed intensification #1. Delayed intensification is similar to another induction phase and lasts for 8 weeks. This is a very important phase because it can ultimately improve a child's event-free survival, which is the period after treatment in which a patient does not experience cancer symptoms or recurrence. This process was extremely hard on Griffin. Once he recovered from this, we had interim maintenance which he did amazing with. But unfortunately, delayed intensification knocked him out again and he had to be placed back in Monroe for a while supported only by iv.

I cannot begin to tell you how emotionally draining this entire process has been, not only on Griffin but on our entire family. Constantly worrying about fevers or any type of virus he may contract. The slightest virus would be enough to put him back into the hospital fighting to pull through it. The hardest part was not being able to take his pain or fear away. Watching him struggle through all the numerous tests done on him not to mention the intense chemotherapy has been gut wrenching to watch him go through.

The federal government is only allowing 4% funding for childhood cancer research. This is absolutely not enough funding to make a difference. We desperately need that amount to increase to 8% and the only way that can happen is by signing this

petition. Each year in the U.S. there are an estimated 15,780 children between the ages of birth and 19 years of age who are diagnosed with cancer. Approximately 1 in 285 children in the U.S. will be diagnosed with cancer before their 20th birthday. Globally there are more than 300,000 children with cancer each year. We must come together to make a change. We are in need of 12 million signatures to make this change and reach the next phase. These children along with their families deserve to have a voice and be heard. Please join us in making this possible by signing and sharing. Let's put an end to childhood cancer once and for all.

**[CLICK HERE TO SIGN](#)**