



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

On March 25<sup>th</sup>, 2020, our daughter Lacey was diagnosed with Anaplastic Ependymoma. The variances of this diagnosis are Group A and RelA with a 1q gain which differentiates her diagnosis from others with this specific disease. Anaplastic ependymoma is a type of tumor that forms when cells in the central nervous system (including the brain and spinal cord) begin to multiply. An ependymoma is anaplastic if the cells grow rapidly and are significantly unusual in shape. Ependymomas can occur at any age. Sometimes, ependymoma tumor cells can spread in the fluid that surrounds the brain and spinal cord. Of all individuals who are diagnosed with anaplastic ependymoma, approximately 55% survive five years after the initial diagnosis.

Lacey began experiencing fatigue as she headed to football practice at school one day. When she arrived home, she vomited and stumbled a bit as she climbed the stairs. She continued experiencing nausea and vomiting on and off for the next week. She complained of white specs in her eyes as well. Shortly after, she expressed to me that she had not gone to the bathroom in over a week. We immediately headed to the ER. The doctors wanted to treat her for a virus, but I explained that I did not feel it was just a virus. I knew it had to be more as she was not experiencing any fever or bloating. A CT scan was done, and she and I were trauma

hawked within an hour to Nicklaus hospital in Miami. Her father had to then drive down and with a bit of a fight he was able to be with us. Upon arrival she was admitted quickly and then began a twelve and a half hour, surgery.

Everything happened quickly, and we had no time to digest what was happening. We were terrified for Lacey and the unknown. So many emotions overcame us as we sat during her surgery. So many questions we had that we did not even have a chance to ask due to the severity of what was happening. Lacey stayed in the hospital 9 nights to heal from surgery. Her father and I stayed in the hospital with her the entire time. Her siblings were not allowed to visit, so her oldest brother Josh slept in his vehicle outside the hospital during her surgery, while her other siblings remained at home. The day after Lacey's surgery we celebrated her 14<sup>th</sup> birthday. Our entire family came and stood outside her hospital room window and sang Happy Birthday to her. With the help of the nurses, she was able to walk to the window so she could see everyone and hear them sing. That meant the world to her, but it did not take away the pain and fear she was experiencing. No child should have to celebrate their birthday in a hospital room. Our Lacey is a warrior though and she was determined to make the best of it.

Lacey has been incredibly quiet about her diagnosis as she just wants to be a normal teenager. Her struggles are daily, but she does her best to traverse through them. Her older siblings have been determined to support her the best way they know how but they carry a lot of the burden of the unknown of this diagnosis. Her younger sibling has been noticeably quiet not being able to understand the extent of this type of cancer. Her father has not been able to be a part of the conversations with the doctors regarding her diagnosis as it is too hard for him to hear therefor, he chooses to stay in the room with our daughter while I speak with them. I am deeply involved with educating myself and working to ensure that we will not be blindsided with not knowing what to do next. I refuse to return to the fog and solely depend on the doctors knowing that unfortunately they do not have enough information due to lack of funding for proper research. Emotionally we each struggle in our own separate ways. There is no way of knowing the extent of how this has affected our children right now. For myself I can honestly say that I am heartbroken but determined. Our family would be nothing without our extended family, friends, and people from the community's support during this journey. The hardest part has been watching my daughter filled with fear and struggle to express that fear. It has been exceedingly difficult to navigate and find a family balance through it all. The unknown leaves me feeling so angry and leaves me terrified for my daughter and the many others that have endured a journey like this. It saddens me as well to think of how many more children and families will have to go through what we have.

About 10,470 children in the United States under the age of 15 will be diagnosed with cancer in 2022. This is alarming to say the least. Sadly, the medicines alone that they administer to our children for treatments are meant for adults, but we have no other choice. That is why it is so imperative that more is done to change this. To make that happen we all need to sign this petition. Right now, the federal government is allocating a mere 4% for funding for childhood cancer research and that is simply not enough. We need to do all we can to see that the 4% is raised to 8%. By signing this petition, you will help facilitate lobbying and the passing of a healthcare policy that will designate a higher percentage of resources for childhood cancer research. It is my mission to advocate for childhood cancer awareness and do all I can to help change the percentage for proper research. I simply cannot do this alone. Please help us give these children a voice that will be heard. Please join us by signing and sharing this petition.

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