

Testimonial SB74

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Jake's Dragon Foundation

On December 12, 2003 the most amazing Christmas present I've ever received arrived. Jake Patrick McHugh, our youngest of three children had arrived. Our little family was now complete. I remember feeling so content and so at peace. As Jake grew, we began to notice that he was falling behind in some his milestones like walking and talking. We had him evaluated and came to learn that he had a mild form of autism. As a special education teacher, I knew what that meant. A lifetime of supports and services. An uphill climb. I grieved over this briefly. I say briefly because one day we were down at CHOP having some tests done and as I looked around, I saw children who were very sick. It snapped me into reality really quickly that our struggles would be nothing compared to this. I would have Jake with me, healthy and we could conquer anything. Or so I thought. I quickly went to work advocating for him at every turn to make sure that his educational needs were met. Jake amazed us always.

We soon learned that despite his challenges he also had some special gifts. He had an imagination like no other. He once told me he sees pictures in his head and from that he could create almost anything from memory. We would take him to visit special places that he liked such as old abandoned train lines, shipyards, museums, cities, you name it. He would come home and find whatever he could to recreate what he saw with legos, blocks, sticks from the yard, old boxes. He loved to explore. He enjoyed hiking, parkour and dragons. Dragons were his favorite for a long time. If you ever watched the movie or read the book Pete's Dragon, you would understand why. It allowed him an escape and a protection of sorts from his daily challenges. We should all have an imagination so big. Because of this Jake always, **always** had a big bright smile. He was the happiest kid you'd ever want to meet. So full of joy and wonderment about the world. We were inseparable.

In August of 2017 our whole entire world came crashing down with the ring of a phone call. We had been up all night at the emergency room with Jake because he had been complaining about a pain in his shoulder for several days. He had also gotten sick one day prior. After a visit to the pediatrician with no answers we decided to go to the ER. They sent us home telling us the x-ray had showed nothing and he probably just strained it at camp. A few hours later they called us back. They had taken a second look and found a large mass in his chest. I could hear the doctors voice straining to sound steady as she calmly tried to deliver this bombshell. I stood there repeating myself over and over in complete shock which quickly turned to hysteria. She told us to choose between the two childrens' hospitals in our area and "get there". When we arrived, they were already waiting for us and the next several hours were a complete frenzy of doctors, nurses and specialists in and out of our cubicle testing literally every part of his body. By the end of the day the doctors pulled us out of the room to confirm that Jake had cancer. What kind they were not sure of. Where it came from, well they had no idea. **In the year 2017, two oncologists from one of the top childrens' hospitals in the country stood in front of us and said "We don't know why kids get cancer"**. I will never forget those words. It took 2 full weeks to diagnose Jake.

We were at one of the top childrens hospitals in the country but they could not identify it. Nor could the other closest childrens hospital. His biopsy had to be sent to the National Cancer Institute at the NIH. When we finally learned the diagnosis, Peripheral T cell lymphoma-NOS, we began researching like mad. The only line of treatment available was one that was used for adults. So, we started that. And we thought we had it beat. But because there was so little known about Jake's cancer in children, there was no clear path for maintenance therapy. Our doctors recommended a stem cell transplant. Before we could get the transplant, Jake relapsed. Our doctors had no idea what to do next. So, they called on doctors from all around the country to seek other opinions. They came back with 10 **Best Guesses**. **Jake's life was hanging in the balance on ten doctors best educated guess about which drugs to try next.** Nine out of ten agreed on one line of therapy so we went with it. At first, we thought it was working wonders. But then complication after complication started. We feverishly called every research institution we knew of, other major cancer centers and pharmaceutical companies begging them to let us try whatever drugs they had in their clinical trials. We were told Jake did not qualify for the clinical trials because he was too young. These promising new treatments were denied even though they may have saved his life. We were forced to have to choose an FDA approved drug even though it had never been tested on Jake's cancer. We had no choice, we had to do something. The day before Jake passed away we were connected to doctor at Columbia University who had just finished a trial of two drugs that were approved for Jake's cancer but had never been given together before. It sounded like the hope we needed. Our doctors ordered it immediately. But sadly, it became a race against time. The time it took for us to find this information, get it to our doctors and get the treatment was too long. Jake's body could not hold on any longer under the strain. He passed away just 6 months after he was diagnosed. Our family is shattered. **It did not have to be this way.** We had the most amazing team of dedicated doctors and nurses. But they can only be as good as the information and treatments that they have access to. In the past 18 months I have heard story after story that is similar to ours. This is not acceptable. **We must do better for our children.** Childhood cancer is the number one cause of death by disease for children yet there have only been 4 new drugs developed for pediatric cancers in the past 50 years. Many of the drugs used on children were developed for adults. Children who do survive are subject to a lifetime of life threatening complications and secondary cancers not mention the emotional trauma. Did you know that there are some pediatric cancers that have a 0% percent chance of survival? There is no treatment at all. How is this possible??

As I stated earlier, I spent Jake's whole life advocating for his educational needs. I am standing here today to advocate for all the children who come after Jake. There is a national disparity between adult and pediatric cancer research. Only 4-5% of a billion dollar budget goes toward children, creating an URGENT MANDATE AND RESPONSIBILITY for our states to fill in the gap. **Please** support SB74 which will provide 100 million dollars toward pediatric cancer research over ten years. We **need** better treatments designed for childrens bodies. We **need** more problem solving for innovation and we **need** information readily available to the doctors who go to battle each and every day for children. **It is critical.** The children are waiting.