

FOR A LIFE BEYOND THE CURE

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I didn't expect that pregnancy. I really wanted it; but after going through a fertility treatment to have my first son, I couldn't imagine that the second would come so easily. It was only eighteen months between one birth and the next one. First a boy and then a girl. A girl we called Alice.

She was a beautiful baby. Delicate. From the first sight, we knew she would have great hair. She was never bald. When her newborn hair started to fall out, strong thick hair grew immediately covering her cute round head. She had a perfect body. Slender and – believe me! – with a well-defined waist.

At three months, the color of her eyes began to change. One eye changed first, followed by the other. Is that normal? I don't know. But that is how it happened. One eye was already brown, while the other still had shades of light green.

She smiled for the first time. She used to grab all the objects surrounding her crib and, several times she watched her own hand moving in awe as if there was magic about it. She sat, crawled and walked all at the proper ages. She spoke her first words and quickly expanded her vocabulary. She admired her chatty brother, and there was no shortage of stimuli.

She started to go to school. She was a happy and clever student. Praised by all her teachers. She actively participated in all activities. She rehearsed for presentations and cultural events. My sole contribution was to smile filled with pride – and to sew costumes for her plays and dresses for dancing around.

She made bonds. Her friends were dear. They played together all the time. Her gang consisted of two boys, the twin girls, the two other girls who loved to make mischief and her best friend. Alice was the peacemaker of the group; she didn't like conflict.

Her birthdays were celebrated with many guests. When she started to understand what a party was, she made sure to always choose a theme: Little Red Riding Hood, Enchanted Fairies and Doll Tea Party complete with a full set of porcelain tea cups and pots for the stuffed guests.

One day, running to get to the door to greet her best friend, she tripped and fell, hitting her mouth on the floor. Her two front teeth blackened. I didn't worry. They were her baby teeth. After several toothless smiles, new strong teeth would grow. My life was normal, like any other mom.

Until in January 2014, when everything changed.

"Unfortunately, Alice has a very aggressive tumor called Diffuse Intrinsic Pontine Glioma, a.k.a. DIPG. In ninety-five percent of cases, the child dies after a few months."; that was her diagnosis.

What?! How could a routine medical appointment end up like that? I brought to the doctor a simple question: do we have to do something about her right eye being a bit misaligned? How can a question as simple as that require several appointments, examinations and two MRIs?

After a crash course in neuro-oncology, we understood that Alice's right eye couldn't move to the right because of the sixth cranial nerve. And that nerve was connected to a time bomb about to explode.

Our first reaction was of shock and awe. There must be a mistake. The doctors weren't considering a second opinion when interpreting the images? Couldn't it be something else? Maybe some dirt on the lens?

When reality finally struck me, I faced a storm. The picture that comes to mind is a dam bursting; my body taking all that chaotic energy to avoid complete devastation. A torrential flow of conflicting emotions compounded each other. It took from me and my family our capacity to breathe, to feel and think – it got into our bones. It made us physically crumble on top of ourselves. But, no matter what, we needed to make the most important decision of our lives, so we didn't fall apart.

And we chose life.

It didn't matter how much time Alice had to live. Her life would be worth it. Each hour, each minute and each second would have meaning.

Our first reaction was to avoid medical treatment. To put our plan in motion and to wait for the inevitable outcome. But it is too hard to do nothing. So, we chose the treatment that had the least impact on quality of life. Which until then was perfect. As I said, it was only her eye...

What marked that period was the sorrow for the loss of what could be. It was the death of all the dreams we once dreamt for Alice: a long life full of accomplishments. The ending would be a family picture, a big family with grandkids all around and great grandkids on her lap.

With our goals reevaluated, our objective was to live intensely in her last months of life. We travel to several places. The kids learned karate. We camped in the forest. We went fishing. We played in the snow. Anything was worthy of celebration. A sunny day. A fun movie. The birth of a puppy at the farm. A shower in the rain. And, against all odds, we celebrated three more birthdays.

During those three years, we held our breath and focused on the present. One day, that effort took a toll on us. We were exhausted. After several MRIs that didn't show any change in the tumor, nobody could tell if it was really dead. But suddenly, the uncertainty became certainty; the tumor started to grow again.

Without the same energy we had before, we had to start a new plan. To face the most feared challenges we had avoided until now — the devastating symptoms that would take Alice from us piece by piece.

The loss of movement on the right side of her face. The loss of movement of her legs and arms. The loss of her muscular tone. The loss of her ability to swallow. And, in the end... the loss of her heartbeat.

Alice left the scene at nine years old.

She is deeply missed; it's painful. It's a void that establishes itself as a physical being that we learn to live with.

Drop by drop, I began to fill this void with memories. Writing helped me to get closer to my daughter. I wrote a book. These memories are dear to me. They are forever etched in paper.

And like that, whenever I sit to write, I chat with my daughter Alice.

What do we talk about?

We talk about the beautiful life she lived.