



Complex Child E-Magazine

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Alize's Story: How Alize Earned His Wings by Karen Lemieux

From the moment we saw twenty-month-old Alize in October of 2004, we were in love. He had the most beautiful brown eyes surrounded by thick, long, curling eyelashes. When he learned to smile he brightened the world. We happily took him home along with his many pieces of medical equipment.

Alize was a micropremie born at 24 weeks gestation, one pound, four ounces in weight. He seemed to have every complication a baby could have and still survive. One of his many diagnoses was hydrocephalus, in which the ventricles of his brain were unable to drain cerebral spinal fluid properly. On top of this, Alize overproduced spinal fluid. He was given a shunt that drained his spinal fluid to keep his ventricles flowing.

Starting in July 2006, Alize's shunts began to fail on a regular basis for a variety of reasons including infection, failure to absorb the fluid into the area that the shunt drained into and clotting off of the shunt. Over the next ten months, he had 20 surgical revisions of his shunt.

From May 2007 till August 2008, he gave us a reprieve, and we began to dream that our shunt problems were behind us. Unfortunately, this proved wrong, and once again we were visiting the hospital more than some people visit their families.

No More Options

As time went on, it became more and more difficult to find a place to put Alize's shunt. Finally, at the end of this March, his neurosurgeon told us that there were no more options. One more failure and Alize would not survive. We were sent home with a PICC line as an access for pain medications as needed and the intravenous nutrition he was receiving.

Within days of coming home, the shunt failed. Alize became less responsive, and fussy with pain when awake despite the IV morphine and versed he received. Then we waited. As we liked to joke, Alize didn't "read the book" and didn't know he was supposed to die. He rallied, became more alert and active. I secretly began to hope for a miracle healing. A few days later, he showed signs of blood infection either secondary to the shunt or the PICC line. We started home antibiotic therapy, but after a few doses and

much consultation with his Palliative Care doctor, we stopped them.

Again, our guy rallied and approached “near normal” for himself. There were times that he was obviously hurting even as we adjusted his IV pain medications. His famous smiles came less and less often and this once kicking, arm-throwing boy lay quietly, preferring his bed to all other places, including our arms.

This began our roller coaster ride from Hell.

The Final Months

Over the next three months, our beautiful boy changed from day to day and sometimes from hour to hour. I was terrified to leave the house for fear of not being there if or when something happened. I went nowhere without my cell phone and left it on even in places where it was prohibited. I called when I was out to be sure of his status.

Alize had a nurse with him, but even then sleep was scattered for us. Due to a stupid state law, his nurses, who were LPNs, were not allowed to push the button on his IV pain pump to deliver extra doses of pain medicine when he needed them. They had to come to our room and wake us to come give the dose. On nights when he needed many doses, one of us just stayed up.

Alize was six years old and the highest his weight ever got was 41 pounds. We watched as the weight slipped off of him. Keeping his skin free of pressure spots became more difficult as he lost what fat he had and tried to remain in one position consistently.

Our emotions ranged from hope to despair, fear of losing him to fear for him remaining in an existence of pain. We second-guessed our decisions, from minor things such as rate of feedings, to major things like wondering if we should take him back to the hospital and demand they do something. Sadly, there were many bitter arguments between my husband and myself over the direction of his care. As time progressed, we were able to talk more quietly and came to agreement by a lot of compromise on both parts.

Gaining His Wings

July 9, 2009. dawned and started out just as any other day had in the past few months. In fact, it didn't seem like one of his “bad” days and I was even comfortable going to the store in the early morning. Around 10:30am, it all changed. Alize began to gasp and was not responsive at all. Realizing how bad he was, I picked him up and sat in the recliner just holding him, touching his skin and hair and drinking in his smell. My husband paced in and out of the room working through his own grief. As time progressed, the gasping breaths came less and less often, finally stopping shortly after 1:30pm. His heart gave out a few minutes after that. My baby was gone.

We had had time to make preparations in advance so no decisions needed to be made. We called Palliative Care and their doctor signed the death certificate and faxed it to the funeral director. When my husband and I had said our goodbyes, as had our adult children, we washed and dressed Alize and drove him to the funeral home. Leaving him there was probably the hardest part of his whole death. Moms don't leave their children, especially not there.

Alize was cremated and we held a memorial service that Saturday attended by family, friends and many professionals who were part of his life. For the time being, his urn is in our bedroom, which brings some comfort.

Our faith has supported us through all of this. I now visualize Alize in God's presence. He is laughing and talking and running around playing. When I join him there, I will finally get to hear the one word I have dreamed about since he came to our home and hearts: "Mommy."