Kayda

Contributed by Laura
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Kayda - A Person of Value

By her mother, Barb

This story is different than most, because Kayda lived. And she was not raised by her birth mother.

I'm the mom to 3 precious children. My only biological child died at 17 weeks gestation. I never even knew if it was male or female but had always thought it was a boy so named him Ben. All the drs could tell me about him was that he was severely deformed. My 2nd child is Kayda. She came to live with me at the age of 4 1/2.

Let me tell you about Kayda:

Kayda was born with a rare neurological condition called Hydranencephaly. In Hydranencephaly, unlike Anencephaly which happens at conception, the baby's brain grows and develops normally until "something" happens that cuts off the supply of blood to the baby's brain. That something can be a prenatal stroke in the baby, the death of a twin in utero, or effects of drug use in the mother. In the majority of cases the cause is unknown. That interruption in blood flow can take only a fraction of a second. But, after that the baby's brain starts to die and the skull fill with fluid. It is thought to usually happen after the 2nd trimester of pregnancy and can occur up to and after birth. A child with Hydranencephaly will only have a brain stem and perhaps small amounts of other parts of their brain. The popular opinion in the medical profession is that a child with hydranencephaly will be in a permanent vegetative state, never recognize anyone, be aware of anything and will die before or shortly after birth. I knew none of this when I agreed to become Kayda's mom.

She was born to a teenage mom who didn't want to be pregnant and took drugs to try and cause a miscarriage. She had always planned to give Kayda up for adoption. Shortly after her birth a CT scan was done and it was discovered that she had Hydranencephaly. Kayda was transferred to a Rehabilitation hospital nearby that had a unit for drug addicted babies. She lived there and in a couple of different foster homes for her first 4 1/2 years. She had many health problems, most problematic were feeding and breathing issues. She was frequently ill. She got a feeding tube at the age of 18 mos which helped with the feeding issues.

When I met her, she was mostly unresponsive although she did smile sometimes. She was totally immobile and every breath was a struggle. When she got her 6th pneumonia in 8 months a few days after she came to live with me, I was told she'd die very soon and that it really was best to let her die as he life had no quality. She recovered from the pneumonia but her first month or so with me had us at the doctor's office or emergency room very frequently. Her breathing was horrible and congested most of the time. After several trips to the ER where by the time a dr saw her, she was breathing fine, I finally realized that she was breathing fine lying down but got congested the minute she was sat up. I started keeping her lying down most of the time and her breathing cleared dramatically. Within a few months her breathing was clear most of the time. I noticed too that her hands were starting to move a bit. She was still mostly unresponsive and immobile.

But there were signs of sparks showing through even in those early days. Just a couple of weeks after I got her, we were out in the community and she was very stony faced and unresponsive. The minute we got home her face lit up and she became very animated and interested in her surroundings. A few weeks later we went on a trip to see my grandmother. It was an all day trip and when we got to where we were going she was tired and again very stony faced. Not a great introduction to family members who didn't know how to act around her. But, when I started to get her ready for bed, I put on a tape of Pachelbel's Canon with seagull sounds in it that I'd always played at bedtime for her. Right away she started to smile and become animated. She stayed that way for our whole trip. Once again, these were signs that perhaps she wasn't in a truly vegetative state.

At Christmas it had been hard to find gifts for her. I got her a few infant toys that were touch activated and a pink dinosaur from Fisher Price that squeaked when squeezed. I used it to properly position her arms when lying down and hoped that one day she'd figure out how to squeeze it herself. One day shortly after Christmas, she discovered Bruce (the dinosaur) with her mouth. She then turned away and then back to him and started chewing on his head. Within 24

hrs she'd figured out how to draw him closer and how to push him away. Here was the beginning of a miracle. From that day on Kayda developed at an amazing pace as far as using her hands went. She quickly learned how to activate toys and loved to touch toys or anything within reach and seemed to compare textures. At first I thought I was imagining what I saw as the drs told me she couldn't possibly develop; I still believed them. But before long Kayda had me thoroughly convinced of her abilities. She taught herself to suck, swallow and cough by chewing on the dinosaur. She even learned to eat orally.

No, Kayda didn't get up and walk and talk. She remained severely disabled and had many health problems. But she was in no way in a vegetative state. I always said that no one had told Kayda she wasn't supposed to do anything. A few years after I got her I got internet access. I immediately did a search on Hydranencephaly. All I found were autopsy reports and really dismal articles. I started contacting any disability matching site to try and find more people whose children had this condition. In 1998 I put up a website about Hydranencephaly. At that time I'd heard from just 5 or 6 families of children with this condition. We thought there were likely fewer than 30 alive at any one time in the world. When our mailing list started in Sept. 1998 we had 8 families. Now (July 2005) we have 163 families on our list and have been in touch with at least 100 more families over the years. What we've learned is that Kayda wasn't totally unique among children with Hydranencephaly. We have learned that children with only a brain stem aren't only conscious but can learn. As families we are doing our best to spread the word of the potential of a child with Hydranencephaly.

Kayda did some amazing things in her years with me. After hip surgery at the age of 6 1/2 she suddenly developed a love for stories on tape. At first she liked the short preschool ones. She especially loved a series of tapes called Classical Kids. They were stories of composers with their music in the background. 4 of them (Beethoven, Mozart, Vivaldi & Handel) were actual stories with a plot. Two (Bach & Tchaichovsky) were just the composers talking to children. It soon became clear that Kayda preferred the ones with the stories. One day a nurse who had known Kayda since birth and had told me how low functioning she was, was visiting. Kayda was on the couch fussing. I told the nurse to try turning the tape to the other side as it was on Bach. Sure enough, the minute the Beethoven story was on, she settled down and relaxed and listened to the tape. The nurse then became one of Kayda's staunchest supporters. Kayda also developed a love for Star Trek Deep Space 9. Some nights she'd start to fuss and I'd look at my watch and realize it was time for DS9. Sure enough the minute I turned it on she stopped fussing. As she got older she suddenly decided that she didn't play with "baby" toys. They always got tossed to the floor. The only things she would play with were her piano keyboard and her big macks (talking switches). She also wanted to just listen to longer multi tape books. And, if you put on a book that had more than one tape at bedtime she would stay awake all night until the book was finished. I tested her many times on this and every time she stayed awake until the end of the book. She also had strong preferences and especially loved the Dragon stories by Anne McCaffrey (and got me hooked too) and the Indian in the Cupboard books. This certainly doesn't sound like a child in a vegetative state. She also developed an attachment to 2 stuffed animals and knew which had to be in what arm.

Despite all her problems Kayda lived a very full active life. She attended school with her typical peers. We went on many holidays including Niagara Falls, Disney Land and many visits with friends and family in different areas. We went camping, hiking, boating and many other things.

Sadly Kayda had constant health problems. At the age of 10, she developed a very servere pneumonia and nearly died. From that time on she developed new problems almost constantly. By her 11th birthday her small 20 sec. seizures had increased from 4 or 5 a day to many hundreds each day. She also started getting sick every time she was taken out. Over the next few months she developed one problem after another and in March of 2000 at the age of 11 & 4 mos she started sleeping all the time. It soon became clear that she was dying. It appeared like her brain stem just was worn out and couldn't continue on controling a whole body. The hardest change for me to accept was when she stopped enjoying stories and only would listen to quiet music with nature sounds. By May she was having trouble accepting formula into her stomach and in early June it was decided that she now qualified for end of life care at the Children's hospice in our area. I never expected her to go so soon though. Just 6 days after coming home from a 5 day stay at the hospice for her evaluation (Canuck Place) it became clear her stomach could no longer tolerate even water or pedialyte via her tube. I knew it was time to go to the hospice. I can't describe the pain of carrying Kayda out of the house for what I knew was the last time. On our way to the hospice Kayda was sitting in the front seat near me so I could keep an eye on her oxygen tank and general condition. I noticed that one of her stuffed animals had fallen to her side. I reached over and put him in the "right" arm. A minute later I looked and there he was right where he'd been when I interfered. That's where she wanted him. That was the last bit of spunk I saw in her.

When we arrived at the hospice I expected her to die quickly but she hung on for 8 days. She finally died very late one night while being held by me in her favorite position. She died so peacefully I didn't know she was gone until after I put her down nearly a half hour later.

Yes, losing her hurt like heck. It still does. It's been 5 years since her death and this year the anniversary of her death was just as painful as all of the previous ones. Yet, I wouldn't have given up one minute that I had with her. She touched my life deeply and that of many other lives. Because of Kayda families of children with Hydranencephaly know they're not alone and that it's possible for a child with that condition to learn. After she died, I felt there was nothing for me to live for but then I realized that I needed to finish the book I'd started with information on how to care for a child with Hydranencephaly. That took 4 months and the book was over 500 pages long. Just in the last month I've completed the 2nd version which is much larger (over 1800 pages) and more complete. In this way Kayda's life lives on and continues to touch people who never met her.