

Kayla Christine Holdaway



The birth of my second daughter, Kayla Christine Holdaway, came in April of 1992. With no forewarning, Kayla had severe physical disabilities that presented themselves immediately after her birth. She was rushed from the Special Care Nursery in Everett to Children's Hospital in Seattle. From that point on, my life has been changed forever.

Arthrogryposis (arthrogryposis multiplex congenita) is a term describing the presence of multiple joint contractures (limitation in the range of motion of a joint) at birth. The diagnosis was fully explained, but that great question remained, "Why?" And, "How could this happen?" How could I have not known about this, even with four ultrasounds? Even though the doctors could not explain what causes this disease, they immediately began to demonstrate how to care for a child with special needs.

During that first year, it was obvious that Kayla would need full-time care. We spent nearly every day at Children's, going from one clinic to the next. Her days were filled with intense physical therapy, hand splinting, leg castings, and more education. We made wedges and shells, strange-looking objects that would make her life so much easier. These creative assistive devices enabled Kayla to sit up and allowed her joints more flexibility. We were never given a glimpse of doubt but instead the assurance of hope and unconditional love. Gratitude for each and every day was what mattered. I have been tremendously blessed by a community of friends and family that surrounded me during these difficult times. After we were on a regular therapy schedule and things had settled down, Kayla began to develop pneumonia every 2nd week, lasting a full week of hospitalization.



Kayla was raised an intelligent young lady, respectful, and fully mainstreamed into regular school and classes. Although she needed total care, her brain developed normally. She was an outgoing social butterfly and taught me how to be bold, friendly and honest with others. It was important to her that I help her educate others in her life. It made things so much easier.

A key life-changing phrase that Kayla demonstrated to me over and over again was: The root word of "disability" is "ability." This has helped carve me into the work I do today.

Kayla was a very vibrant, brilliant young girl, and intelligent beyond her years. She spoke with excitement and animation about any subject, and shared her opinions - just as long as she had someone to listen.

As she would spend hours trying to recover from being sick, she would lie quietly on her bed playing with her Polly Pocket toys. Since Kayla did not have use of her arms or legs, she would play while lying down. She would manipulate the Polly Pocket toys by the use of a straw in her mouth - and paint in the same fashion with a paintbrush in her mouth. She surprised us all with her ability to sing in the Seattle Children's Choir. She is especially well known for her solo in "One Small Voice".



Several times throughout her lifetime, Kayla wanted to discuss heaven and what was to come. Kayla spoke very candidly about death, with an overwhelming joy and peace about it, unlike any other person I have known. Although she was raised to never doubt or limit her lifespan, Kayla had a certain confidence that she spoke of often. She talked quite repeatedly about what it was going to be like, jump roping, biking, swimming, and running around like all the other kids. She couldn't wait until she could get out of her body and move around on her own.



When Kayla was 6, we were leaving Children's Hospital after a long day of clinic appointments, and one physician had told us that she had been diagnosed with restrictive lung disease. (You see, her lungs were growing, but her rib cage was not. This meant that eventually she would run out of air.) After hearing the news, Kayla noticed me crying in my rear view mirror. She asked me, "Why are you crying Mom?". I told her that I was trying to process the bad news we had just heard and it was difficult to hear. She responded by saying, "well doesn't that just mean that I'm going to get to go to heaven?" When I responded, "Yes, but you know what that means". And she said, "Yes, but you said I'm just going to get to go to heaven....and what could be bad about that?" She was right. Yes, in my selfish flesh, I did not want her to go. This was just one of many occasions where she led me to greater faith and understanding of God.



In September 8, 2003, Kayla successfully underwent spinal surgery (pictured left). She had developed Scoliosis in her spine and the curve was creating a severe amount of pressure on her left lung. She spent 18 days in the PICU nearing death from one hour to the next, but on that Friday night, she turned the corner and they moved her onto the regular floor. She was off life support for the first time in weeks and was getting used to talking again without the weight of tubes pressing on her vocal cords. I left the hospital for the first time, since September 8th, and spent the weekend with my other children.

Early Sunday morning I received a phone call that she wasn't doing well. Kayla had developed a blockage and she was breathing very shallow. Her chest pain was immense, and when she saw me walk in the door she was in a constant state of panic saying, "Mom...I can't breathe, I can't breathe!" Her fragile chest was working so hard, but oxygen saturation was unsuccessful. I hurried out to the nurses station to try to gain the attention of our physician. It was too early. I ran to his sleeping quarters and knocked on his office door (this is how well I knew the hospital). He hurried with me back to her room and she was quickly put back into the PICU. During the transition time, there was a brief moment of waiting for the transfer to happen. It was during this time that Kayla asked me if I could go get my bible and read to her. I responded..."you need help here! There's no time for that but things will settle down and then I will".

We were moved very quickly to the next floor, and the team began to work on Kayla. They ran blood tests and found out that her counts were way out of whack, and oxygen was not being absorbed into her system. Again, while we were waiting, Kayla reminded me that I had promised to read to her. When I asked her what she wanted specifically, she said, "Read to me what heaven is going to be like". I read her three passages leading up to Revelation 21:1-7. When I was done, she asked us to lay hands on her and pray. I had no idea what to say, but she said, "Ask that God's will would be done." We did.

An overdose of a common diuretic dried out her lungs to a thick hardened state, and even after 20 minutes of resuscitation, there was no return. She looked up at her respiratory therapist Brad who was bagging her (he one was one out of 12 in that room at that moment) and said, "take that off me."

On September 28, 2003, Kayla went home to be with her Lord. After 11 1/2 years, she was granted her final request. Everything lavished upon her that she had faith enough to dream of. I can hear her singing to me now, "One Small Voice, can teach the world a song, start with one small voice....'til another joins along..."

Kayla Christine Holdaway

April 1992-September 2003

