

## KAYDENCE'S STORY

The members of Kaydence's family would like to extend their deepest thanks and gratitude to the ladies of Ashcroft Royal Purple Lodge No. 263 and the Elks & Royal Purple Fund for Children for all of their help during our daughter, Kaydence's, hospitalizations at BC Children's Hospital and her recovery process.



Special thanks go out to Charity Chairperson Helen Corley, who invested a huge amount of time writing letters and making phone calls on our behalf. She is truly a force to be reckoned with! She was 100% committed to helping our family once she heard of the challenges that our daughter faced including the costs of her specialized care, medical equipment and supplies. Helen went out of her way to use her contacts with other local service organizations, such as the Lions and the Cache Creek Recreation Club to gain further attention to Kaydence's needs and was very persuasive and persistent in getting further support for our family.

Thank you Helen!

Baby Kaydence with her mother, Vida, and Helen Corley, Charities Chairperson at Ashcroft Royal Purple Lodge No. 263.

Helen heard about our daughter through a chance meeting with her own daughter at the local hospital. Helen was very concerned when she heard what a sick child Kaydence was and all of the medical procedures that she would have ahead of her for a long time to come. She visited with our family on numerous occasions and Kaydence came to have a special place in Helen's life as Helen has in ours.



Kaydence's challenges began when she was born on July 1, 2008 with a hole in her heart.

A heart repair at 31 days of age was performed to provide Kaydence with time to grow before a major repair could be attempted. She was only 5 pounds, 2 ounces at birth and the surgeons wanted her to be at least 10 pounds before the next procedure. Many complications later including, but not limited to:

- 179 days in hospital
- 6 failed extubations (removal of breathing tube on ventilator)
- enforced isolation as she contracted MRSA while in hospital (**Methicillin-Resistant *Staphylococcus Aureus*** (MRSA) is a bacterium responsible for several difficult-to-treat infections in humans and patients with open wounds, invasive devices, and weakened immune systems are at greater risk for infection than the general public
- hearing loss
- double vocal chord paralysis (requiring a full-time nasal feeding tube as she would not swallow ANYTHING!)
- mild astigmatism in both eyes
- horseshoe-shaped kidneys



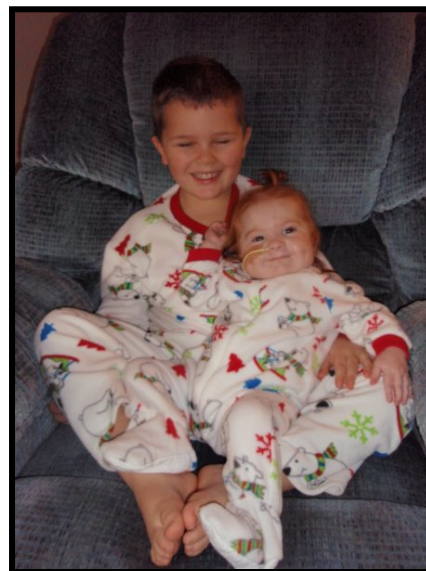
Kaydence being monitored following surgery in BC Children's Hospital.



We were able to take Kaydence home for the first time on Christmas Eve 2008. This was the best Christmas present that we could have ever asked for thanks to BC Air Ambulance!

Kaydence was able to stay at home with us after being discharged at Christmas and thrived outside of the hospital atmosphere. It was such a joy to be able to take her outside and watch her play with her 4-year-old brother, Colton. No matter how hard we tried, while Kaydence was in the hospital, one child was always left behind in the care of another family member

as we have two beautiful children. Seeing the two kids together at home was the best tonic ever for all of the hardships that we had endured thus far. Colton is the best brother and playmate that Kaydence could have ever wished for and he helps with every aspect of her care. Kaydence loves him to bits and thinks that it is very funny to pull on his ears so that she can get him close enough to kiss his nose!



Kaydence with big brother, Colton

August 25<sup>th</sup>, 2009 brought the major heart repair that we had been dreading for months as our last hospital stay had been less than a positive experience! Kaydence went into the OR at 8 a.m. and we were able to see her in the ICU at 3 p.m. It was heartbreaking to see the little girl that had been laughing and playing that morning now hooked up to a ventilator as she could not breathe on her own. They had left Kaydence's sternum open to help ease any of the swelling and she had two chest tubes to drain any extra fluid. There was an IV in each of her limbs and numerous other tubes and wires. We were hopeful for a speedy recovery, but were very nervous.

After 2 days, Kaydence decided to pull out her ventilator tube and all of her doctors were excited that maybe she was doing better than expected. This was not the case as she had to have an emergency re-intubation 23 hours later. The unplanned extubation by Kaydence was seen to be a good thing as the ICU team kept trying to kick her out of ICU as they felt she was ready for the ward. Little did they know that ICU would be our home for the next 5 weeks!

Reoccurring infections, temperatures, blood clots in her neck (requiring 6 weeks of shots twice a day that Vida then had to administer at home), blocked IV lines, and the insertion of a permanent pacemaker followed, but Kaydence still came through the procedures like a champion! A chylothorax (a serious complication caused by her thoracic surgery) would be our biggest challenge during this hospital stay as it meant that her body could not absorb the fat in her formula and instead was pouring all of the undigested fat back into her chest cavity, compressing her lungs! Two chest drainage tubes were immediately put in and stayed in for a few weeks until the drainage stopped. The only way to ensure that the fluid build-up would not happen again after the chest tubes were removed was to give Kaydence IV fluids only for the next 10 days and then put her on a very specific formula for the next 5 weeks. The formula was very expensive (\$51 a can!) and one can only lasted for 2½ days! Luckily, x-rays showed that there was no further accumulation after the treatment period. Aside from it being expensive, Kaydence was also not allowed to have any supplementary food while on the formula and she had finally started to show an interest in eating!



Since then, we have had to go back for many follow-ups with her cardiology team in Vancouver as well as for check-ups with her other specialty teams. Our most recent hurdle was a surgery at the end of October which dilated Kaydence's right pulmonary artery. Luckily, we were able to spend the night with Kaydence at Easter Seal House that night rather than in the hospital and were on the road back to Ashcroft the next day!

Monthly appointments with the pediatrician in Kamloops as well as monthly RSV vaccinations have kept us busy. (Respiratory Syncytial Virus (RSV), which causes infection of the lungs and breathing passages, is a major cause of respiratory illness in young children). Kaydence also has a physiotherapist, an occupational therapist, a feeding specialist, speech-language pathologist, and a consultant from the Infant Development Program who all come to our house from Kamloops once a month to help monitor Kaydence's progress and give us hints and tips on how to help her thrive. Vida is still on leave from work and has no plans to return anytime soon as Kaydence's home care is still too challenging.

We are currently waiting to have a custom-made titanium stent to be placed in Kaydence's pulmonary artery to help keep it open. We are hopeful that a G-tube (feeding tube that is placed directly through the abdomen into the stomach) will be placed at the same time to allow Kaydence more independence and will save the skin on her poor face! Both of these procedures are supposed to be a day surgeries but we will have to see what Kaydence has planned for us.

Every time something is supposed to be simple, it seems to become much more complicated! It must be her red hair!

The daily tasks associated with looking after Kaydence remain daunting. She vomits 2-3 times each night and a few times during the day. Each of these episodes requires immediate suctioning of her mouth and nose to ensure that her airway is maintained and are very painful for Kaydence as a result of her severe acid reflux. She has developmental challenges as well as a result of being hospitalized for so long and is slowly making progress towards age-appropriate milestones, such as walking unsupported. The financial aspect of Kaydence's care will continue to be a huge factor until she is able to eat independently. Her daily feeding supplies are quite costly and are not all provided by the At Home Program assistance that Kaydence is on. We are all currently learning sign language to enable our family to communicate more effectively with Kaydence and she is attempting to sign a few words in return. A further open-heart operation will also be in our near future as Kaydence will have to have one of her valves replaced around the age of six. Throughout all of these adversities, we remain positive in our overall outlook for Kaydence's health as she is a very happy, (if not healthy!) little girl and we are fortunate to have a very good support network for our family.

Throughout all of Kaydence's procedures and lengthy hospital stays the kindness of the Ladies of the Royal Purple was much appreciated. We cannot thank Helen and her group enough for all of their support. Thank you to everyone!



Kaydence and her mother and ladies of Ashcroft Royal Purple Lodge No. 263  
Left to right: Vida Ferris, Helen Corley, Gina Talarico, Lillian Munroe.

*(Kaydence's story was submitted by Vida, mother)*