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## Abbys article

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Our story begins like many others. We were excited our our new unexpected addition to our family. When I was pregnant with Abby, I was told that she would be healthy. That was not the case at all when she was born. The doctor first noticed the expected cry from a few moments ~~old~~ baby, was very weak and quiet. Then he noticed how weak Abby was. We were assured she was ok. When she tried to eat there was a squeak. That squeak made her father and I nervous. Once again we were assured she was ok. The way Abby ate did not settle well with us. Like all parent instinct, we were right. We had Abby hooked up to a monitor while she ate. Her oxygen dropped to low to mid 70s. The doctors like to have you no lower than 90. I'm not in the medical field and that scared me. She had a ~~gas~~ <sup>first</sup> trip to the NICU. (Neonatal Intensive Care Unit) On her 28 day stretch at Sacred Heart Hospital we learned quite a bit more than I would ever want to. Abby had been diagnosed with a Chromosome duplication. She had a duplication of 16p11.2 and we found out she is severely hypotonic. Abby was also diagnosed with micrognathia. (small chin/recessed jaw line) these are also part of her chromosome disorder along with seizures. Which she also has. Well Abby started OT (Occupational Therapy). We tried several different bottles and even tried different positions. Nothing changed that she couldn't breathe and eat at the same time. It was time for a swallow study. Abby fortunately was assigned a very experienced pediatric speech therapist. Abby of course failed her swallow accompanied by more terrible news. Abbys epiglottis was completely blocking her airway. The epiglottis is supposed to shelter the airway and protect from aspiration. Abbys blocked it completely which explains why she couldn't breathe and eat at the same time. Not long after that an ENT doctor came and saw Abby in the NICU. She said Abbys airways are being pushed back by her jaw, so they are half the size they should be. It was a concern. But not life threatening. Abby was scheduled for surgery. She was to receive her feeding tube in August of 2011. Surgery was a success. The 10 days it took to heal were successful also. We were going home. Abby gave us another surprise. After starting OT and PT (Physical Therapy). She started getting harder to sooth. She started to turn a gray color. She held her to the right side all the time. It started to shape her head wrong. We started talking about getting her a helmet. I later learned that having her head to the right side opened her airways. It your bodies way of surviving with your airway is obstructed. We started to get concerned. We went to the ENT doctor. And of course, more bad news. Abby needed a tracheotomy tube placed. (tube in the throat to help you breathe) She let us know she didn't think Abby would make it past 2.5 yrs. She told us Abby may not have the strength to make her chest rise and fall as well as she was supposed to. She pretty much told me my daughter was going to suffocate to death and there was nothing I could do. She told me the trach would help prolong her life. Devastated her dad and I agreed to do the trach surgery. Her trach was placed in November of 2011. Abby returned home. Upon a short stretch of PT and OT Abby appeared to be getting better. Then she woke up one more with a temperature of 105.7. She was quickly admitted. We learned Abby has kidney reflux. (when the urine goes back into the kidneys). She was scheduled for surgery. The right kidney was fixed in Feb of 2012. Abby bounced ~~had~~ <sup>grew</sup> beautifully. Abby started to ~~go~~ <sup>grow</sup> up and want to be more active. Things seemed to be getting better when her dad and I were losing hope. Abby started butt scooting across the floor at 2 years old. Her dad and i were overwhelmed with joy. Her brother Isaac was Abby inspiration. She loved seeing him get excited for her. That made her want to do more. BY 3 ~~had~~ <sup>Abby</sup> was walking. She was also starting to talk. Abby was then invited to the Cleft Palent clinic to see about getting her trach removed. Jaw reconstruction

Pins  
 surgery came into the conversation. Several doctors went over different aspects of it for Abby. She was cleared to do it. Abby went to the Maxillofacial clinic in Spokane Valley to Dr. McClelland. He was prepared for Abby and had a plan. He would break the jaw line and move the jaw forward. This was terrifying for her dad and I. But her small jaw was the last thing holding us back from getting her trach removed. We would have to crank her jaw a little everyday. It sounded horrifying. But we wanted the trach out. Dec 10th was surgery. The procedure took a few hours but Dr. McClelland was aware how scared I was and he had the nurse check in to let me know how the procedure was going. It definitely made this easier for me. Abby recovered from jaw surgery quickly. She went home after 24 hrs. We cranked her jaw without problem over the 30 days. We were seen every week to make sure that the procedure was moving along as planned. After 30 days Abby got the pins in her neck removed. May 19th Abby was cleared to get her trach removed along with the rest of the appliances from her surgery. She went from so weak she laid where you put her and couldn't move and fighting for life to running riding a tricycle, and talking up a storm. Abby still has her feeding tube. But she is learning to eat now. There is nothing she can't conquer.

Captain

Under Doctor #1 Baby Abby

#2 Hypoplastic + Happy

#3 Surgery Time

#4 After Surgery with distraction  
arms visible

#5 After Removal of Distraction  
Appliance

#6 Normal A-P projection of  
Mandible - Still Trached

#7 Glad it's done

#8 Trach removed + gauze over  
trach site