

Addelyn's & Claire's Stories

My husband and I have been blessed with two amazing girls. Like all new parents we were thrilled when we found out we were expecting our first daughter. She joined our family in 2009; she was beautiful, happy and healthy. We took our baby girl home and began our journey as a family.

It wasn't until she became ill at 7 months with a respiratory infection that the doctors began to raise concern about her development and low muscle tone.

It was at this moment, we realized our lives will be changed forever with bloodwork, tests, physiotherapy, and treatment programs now going to be a daily part of our lives. Months began to pass and we had no answers. Addelyn is now an active and bright 3 year old. She is so close to walking and we are so proud of her.

Optimistic and hopeful, we decided to have another child. We were reassured from the doctors that it was less than a 1% chance our next child would have any medical issues. In July of 2011, our baby girl was born 5 weeks early at 3lbs 11 oz. We spent 33 days in the NICU where they discovered she had 2 holes in her heart. Ten months passed and she was not growing or developing, and had low energy. It was decided that one of the holes in her heart needed to be repaired. In May of 2012, Claire had open-heart surgery. She is now gaining weight and starting to meet milestones.

Over the last year, both girls had genetic tests done. They both have a rare chromosome imbalance and we do not have a true diagnosis. We may be unsure of what the future holds for them but we are certain that we love them unconditionally. With the help of therapies and specialist we are certain we will be sending our girls in the right direction to succeed.

