

Leo's Story



There was a snow storm the day my son came into this world. Leo was born in Fredericton, NB on April 5, 2007. Mario and I had waited so long to have a second child and couldn't be more excited about his safe arrival. His big Sister Emma and Grandparents shared our joy on that very special day. When Leo was 2 days old we were told something was seriously wrong and that our newborn was critically ill. Leo and I flew to Halifax to the only children's hospital in Atlantic Canada. It took an agonizing three weeks of constant blood work, many invasive exams, two MRIs and finally a muscle biopsy from our son's tiny leg to diagnose Leo's illness. We were devastated when we were told that Leo had a severe case of a fatal disease called Mitochondrial disease.

After a month in the NICU we learned how to look after our sick son. We practiced placing an nasal gastric tube through his nose and learned how to precisely measure his extremely unique formula. Leo began his journey with us at home just as the snow had finally melted and the spring flowers were starting to bloom. Wow, were we ever scared. Leo had an alarming amount of medications to administer around the clock. He struggled with bottle and tube feedings. Leo had lots of trouble keeping his formula down. At two months of age Leo's diagnosis ruled out the need for his complicated formula and I was able to give my son breast milk for the first time since he was born. I was so happy to be able to do something so natural for my baby. We continued to care for Leo at home and gained a little confidence as new parents of a special needs child. Mario and I decided to do as much as we could to normalize Leo and Emma's new life together. Leo went to nearby festivals, hikes through the forest and swimming at the local wading pool. We took Leo to restaurants, neighbourhood get togethers, visits with extended family and even dipped his toes in the ocean at his cousin's beach birthday party.

In the middle of the summer Leo got pneumonia and was not expected to recover. We sat by his hospital bed stunned. We had only just begun to know our fragile son. To everyone's surprise Leo fought back and recovered. We triumphantly took our son home again and continued his constant care. Our paediatrician told us Leo was doing so well because of our good Karma. At the end of the summer I felt Leo was stable enough to travel to Ontario to meet some more of his extended family and my close friends. I had been searching desperately since Leo's diagnosis with Mitochondrial disease for other families with sick children. I found Christine Gowland by searching for Mitochondrial disease on Facebook. With anxiety I decided to call her since I was so close to where she lived. I was greeted with such warmth, compassion and positive energy when we met in person. It was her Daughter's second birthday that day. Megan and her brothers played with Emma the whole afternoon at a park by the lake in Burlington. Christine shared all the information she had collected about Mitochondrial disease, medical treatments, support groups and Megan's specialist. She urged me to call Dr Tarnopolsky at the McMaster children's hospital to see Leo. It was only a few months before we got an appointment with the Mito specialist. Although there was not a lot Dr Tarnopolsky could do for our son, he did make some crucial changes in Leo's drug regimen. Within a month we saw big changes in Leo's ability to relax and be comfortable. Leo had horrible spasticity that contorted his whole body and now was able to lie flat on his back for the first time since he was a newborn. Halloween was the first day Leo joined a local church playgroup. I wanted to be close to other Moms and share the joys and sorrows of parenting.

Just before Christmas, Leo contracted RSV, a serious respiratory virus that can be fatal in fragile babies. Terrified again, Mario and I sat day after day with our son hoping for another miracle. Leo was very sick. He struggled to breath and required lots of help. Leo fought back again and recovered in time to share his first Christmas with his family at home. In the New Year we were given more scary information about Leo's health. His heart was not growing normally. We were told that eventually Leo would develop arrhythmias and need to start cardiac medications. It seemed that as soon as Leo could jump over one hurdle there was not much time before he had to tackle another.

With growing trepidation we continued to love Leo as much as we could. No one could tell us how long he would live. Over the winter Leo changed again. His neurology was slipping. Leo grew quiet and did not move very much. Eventually he stopped opening his eyes and seemed to be sleeping all the time. Days before his first Birthday Leo had a series of seizures. Fear crept in further. Was Leo getting closer to the end? I was so afraid about what might come next for Leo. Little did Mario, Emma and I know that Leo was weakening with each day.

Our precious boy, adored Grandchild, loved by so many, died on Earth day, April 22, 2008. He left this world gently. Leo took his last breath shortly after his tremendously proud big Sister read him a bedtime story on her lap and

kissed him goodnight. Leo's last gift to her was an amazing smile. We miss him terribly. The physical pain is unbearable at times. Some days, the truths I have learned from the experience of caring so deeply for my son, bring small gleams of hope. The challenges of living with Leo seemed insurmountable at times and the knowledge, strength and insight my family gained came at the highest price. The mystery of Leo's life may never unravel, but I know he will live in my heart for the rest of my days.

Written by: Sarah Boucher

