



## Heather

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Heather is a dedicated mom of two and the full-time caregiver to her daughter, Leah. It was during a routine ultrasound that Heather and husband, Brad learned that there were challenges with their second pregnancy that required further investigation and a referral to Mount Sinai's genetics and high-risk obstetrics programs. For them, this meant flying or driving well over eight hours from Sault Ste. Marie to Toronto for regular and weekly checkups, tests and procedures until the risk became too high and Heather was admitted.


Then Leah arrived – delivered at only 26 weeks – she was tiny but mighty at just 680 grams or 1.5 lbs. To give you a sense of how incredible she is, that is the size of three small apples, or a large Tim Horton's cup. Shortly after, Heather's keen maternal instincts told her that Leah's symptoms were more than a cold – something already uncommon for a baby her size. Heather's persistence and the NICU team's concerns, led to Leah becoming the smallest cystic fibrosis patient in the history of Mount Sinai Hospital at only 21 days old. This is the first of many records that Leah would challenge as she defied every expectation.

To continue their care, Heather and Leah remained in Toronto, transferring to The Hospital for Sick Children. It would be nine days before Leah's first birthday that they were finally discharged, but sadly this would only last a few short days as Leah, Heather and their family would endure another grueling year long admission until they would be home together in Saul Ste. Marie. Throughout all this time, Brad travelled back and forth with Leah's older brother, Kevin as he balanced care, support and work as the family's sole provider.

Leah, a sweet, bright girl, with a contagious smile and laugh, would face more medical complexities and diagnoses over the years, including congenital heart disease and bone marrow failure. She requires life sustaining supports like the use of an oxygen machine full-time and receives all her nutrition, hydration and essential medications through a special IV tube that goes through her chest wall directly into her heart.

As you can imagine, this means Leah requires 24/7, complex, hands-on care – all of which is provided by Heather, who stepped away from her career as an audiologist. Her role extends beyond being a mother, as Jessica told us, "She is Leah's full-time caregiver, advocate, nurse and protector."

To manage and support Leah's highly complex needs, Heather has become an expert. Her encyclopedic knowledge of diagnoses, medications, surgical history, treatments, therapies and nutrition is



astounding. Heather does this and so much more as she manages and balances a family of four's full calendar with a precise care routine. This is compounded by the time and mental load of scheduling, tracking, documenting and communicating with multiple specialists and care team members and providers both locally and in Toronto.

Before the age of 7, Leah has spent over 1,000 days in hospital, had over 200 surgical procedures, 18 blood transfusions and has been airlifted 29 times some of these proudly represented by the lengths of unique bravery beads she's collected over the years. Amongst the needed appointments and travel to and from Toronto, Heather and Brad do what needs to be done. They just want their children to be happy and that happiness is their biggest motivator.

Being from the North where high-needs products are not easily accessible or can simply be found at the local pharmacy, Heather makes sure she's always prepared and plans ahead, determined to make Leah's every wish a reality. They embrace her curiosity and find creative ways to make activities like camping and even tobogganing as safe as possible.

For Heather and family, the goal is always simple, to help Leah live her best life. Despite her medical complexities, Leah like any younger sibling, wants to play and keep up with her older brother. And that for her, meant learning how to ride a bike. And like everything else, their family found a way. Through fundraising, Heather sourced a special pedal bike from England that was able to be adapted and modified to carry Leah's IV pump, bags and oxygen tank. Now today, Leah can ride alongside side Kevin – her big brother, best friend and loyal protector – and now, dedicated steering coach.

The family has even found a way to modify “swimming” for Leah, by adding some water into a small pool, always carefully standing by to ensure she does not get her dressings wet. They are making memories – including their much anticipated wish trip - and each of these are cherished moments and milestones that the family never thought would be possible.

With unending love and support and incredible sacrifice, Heather and her family have made it their mission to help Leah enjoy every moment. Now 7, Leah continues to surpass all expectations. In speaking with cousin, Jessica and the family's Ontario Health atHome care coordinator, it is clear this is due in large part to Heather's exceptional care and unrelenting advocacy and of course, Leah's fierce determination. Together, they're an unstoppable pair.

**Thank you for going Above and Beyond!**