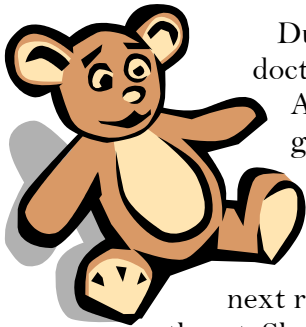


# Alyssa Rae: Part I

**H**ello Dear Friends...

SHE DID IT! Alyssa Rae Johnson came into the world at 9:03 a.m. Tuesday November 17, 1998. And, like her parents, she savors a challenge and so entered our fine world with not a whimper but a BANG.



During Mary's C-section, while I watched, stunned, as the team of doctors pulled her head out, followed by her shoulders, torso and legs, Alyssa chose to let the world know that she intended to fight the grim prognosis of the various doctors by screaming at the top of her little lungs—those same lungs that we were worried may not work.

She cried out as the transport team whisked her off into the next room and she kept crying until they put the breathing tube down her throat. She hasn't made a sound since then, as the tube robs her vocal cords of their precious right to holler. But we have a girl. A brave, courageous, fight-filled wonderful GIRL, with all of her parts intact (though some of them happened to be outside of her in what turned out to be a smaller-than-anticipated omphalocele!).

She has astounded the doctors at Sick Kids Hospital and hopefully will continue to astound those around her for at least the next 123 years! A girl... a beautiful little girl. Mary and I are the proud parents of a baby girl with downy blonde hair, blue eyes, a cute button nose and an attitude!

We've had a week of crying, relief, some laughter, countless needles, spinals, i.v.'s, hospital food, light cat naps on lumpy hospital couches, wonderful cards and flowers from friends and family (thanks to all!) and diapers! I never dreamed I'd be excited to see a diaper filled with the black tar they refer to as "Baby's first poop!" but it was a sign that her plumbing worked! She's jumped so many hurdles to get here, folks. I feel like applauding her... but I'm too busy just looking at her.

We won't get to hold her for a few weeks yet and that is truly torture—for us and Alyssa—but we get to touch her 24 hours a day while she stabilizes herself in the neonatal intensive care unit (NICU) in Toronto. She gets a nurse all to herself around the clock and will soon begin receiving Mary's breast milk, though it'll be through a tube through her tiny nose.

And wonderful Dr. Sigmund Ein, he with the ancient crackled white shoes and the hospital badge with his photo showing a cut-out of Hulk Hogan: this man operated on our baby within her first few days of life and managed to tuck in most of her liver and, more importantly, cover her heart with skin. He basically took Alyssa out for a test drive to see what she'd do. She "did" just fine.

A confident man, that Dr. Ein. As they were wheeling Alyssa toward the surgery room, I said to a nurse: "Excuse me, I see that no one witnessed my signature on the surgical consent form."



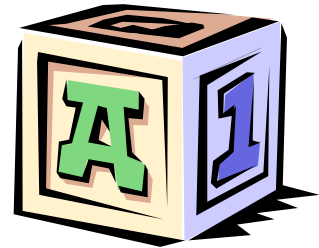
The nurse smiled and called to Dr. Ein, ahead of us in the hall. "Dr. Ein, Daddy Johnson says that you didn't witness his signature."

The good doctor stopped at the door, pulled his mask down and said to me, smiling: "God is my witness." The kind of confidence you want to see in the man who, forty minutes later, would be holding your daughter's tiny beating heart in his hand.

Alyssa is recovering well now and they plan to start weaning her off of the respirator tomorrow. This may be a slow and painful process but we have every confidence she can do it!

And Mommy? Mary did what she always does—she came up big! I married the strongest woman in the world and she continues to amaze me daily with her "Let's get it done" attitude. There are claw marks from where I've had to drag her back across the street via an underground tunnel to the maternity hospital where she recuperated for four days after the C-section. She would have camped out at Alyssa's bedside had the nurses allowed her to do so.

She is healing fast and filled with whispers of encouragement and songs of endearment which she sings to our newborn miracle. Our family has grown by one. Please keep sending Alyssa your kindest thoughts as she still has a ways to go on her road home to Wasaga Beach. The guardian angels people have sent are spread around her, her beautiful dream catcher hangs above her and the nurses and doctors pay frequent visits to see what the best dressed baby in the NICU is wearing day by day thanks to Aunt Cathy's forays into Baby Gap and Gymboree.



Thank you dear friends for sending your thoughts and prayers, Alyssa can't wait to meet you all...

*Bruce & Mary*

*(from an e-mail sent November 23<sup>rd</sup> 1998)*



## Alyssa Rae: Part II

Dear Friends...

It's 1:07 a.m. and we are in tears.

Our little Alyssa left us last night (Sunday, December 6<sup>th</sup>) at 8:06 p.m.

She had been doing so well up until last Sunday (November 29<sup>th</sup>), when she was enduring yet another suctioning of her breathing tube. She suddenly arrested and the nurses and doctors flew into the room and began trying to revive her. Mary and I were with her at the time—we were with her nearly all of the time!--and so we nervously watched them as the minutes ticked past. Over 20 minutes, in fact.

The great fear of brain damage due to oxygen deprivation was realized when, four days later, a CT scan revealed great amounts of damage to our little Alyssa's white and grey matter in the brain. It also revealed that her brain was small for her skull size and that her brain stem had severe problems as well.

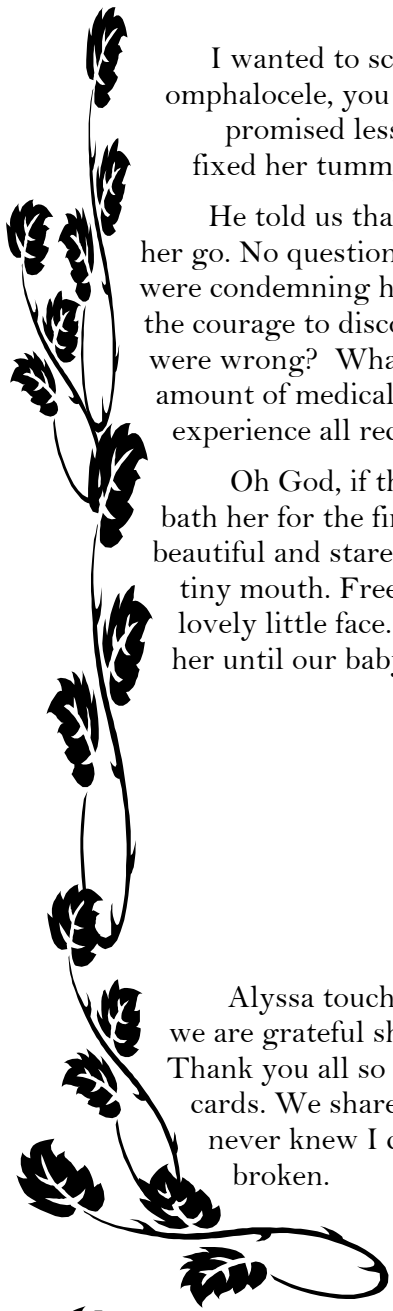
Soon the doctors came to have "THE TALK" with us. If it were just the omphalocele, she could make it, the surgeons told us. We believed them. If her lungs weren't so hypoplastic, she could make it, the neonatologists told us.

But her lung size, her omphalocele and her heart being outside the chest cavity, all coupled with a damaged brain, a brain stem abnormality and the horrific seizures she began shortly after arresting last week all pointed to one thing: a 100% chance that she would not have anything close to a normal life.

Dr. Whyte, the neonatologist in charge of Alyssa's care, kept telling us that Alyssa faced a life of severe physical and mental debilitation as a result of her combined challenges. And then we'd glance down at our baby girl in front of us, stretching her little arms and legs out, yawning like a tiny kitten, looking around the room with her beautiful dark blue eyes. Let her die? This was the doctor's recommendation?

We wanted a second opinion and so Dr. Moore, Alyssa's earlier neonatologist, concurred with Dr. Whyte. And so did Dr. Pearlman, and every NICU nurse we spoke too. We were still wavering. This was our daughter's life we were discussing.

And then our Dr. Ein came along Thursday evening and he took us into the Parent Care room—the bad news room. The man who had just a few days before saved Alyssa's life with his great surgical skill, was now recommending that we choose the hardest path of our lives so that Alyssa could have the easiest path: to let them disconnect her from the ventilator. Dr. Ein, he of the take-no-prisoners school of surgery.



I wanted to scream, “But you told us if we brought you our baby with her omphalocele, you could fix her!” but I realized that he had done just what he so boldly promised less than one month before when this nightmare had begun. He had fixed her tummy and covered her heart magically with skin.

He told us that, as hard as it was to choose, if she were “an Ein baby” he would let her go. No question. And then his eyes filled with tears and he left the room. So we were condemning her to a life of pain chosen selfishly by us, her parents, if we lacked the courage to disconnect her from the machines that breathed for her. But what if we were wrong? What if... but there was no “what if” here. There was an overwhelming amount of medical evidence and a few hundred years of combined doctor and nurse experience all recommending the same end to our story.

Oh God, if that wasn’t the hardest day of our lives yesterday. We finally got to bath her for the first time and hold her, free of all machines. She was clear and beautiful and stared into our eyes as the nurse pulled the breathing tube from Alyssa’s tiny mouth. Free of the tape finally, we got our first look at her upper lip. Such a lovely little face. She was so warm and smelled of baby lotion. And we sat and held her until our baby died. I was kissing her heart when it beat it’s last beat.

*“Golden slumbers kiss your eyes,  
Smiles awake you when you rise;  
Sleep pretty darling, do not cry,  
And I will sing a lullaby...”*

Alyssa touched so many of you in her short 20 day life. She was wonderful and we are grateful she chose us to be her parents—as painful as it was to let her go. Thank you all so much for your love and prayers and flowers and stuffed bears and cards. We shared you all with her, and her with you and we are all richer for it. I never knew I could love something so small so much. My heart is completely broken.

*Bruce & Mary*



*Alyssa Rae Johnson  
November 17<sup>th</sup> - December 6<sup>th</sup> 1998*