

We Can All Learn to Fly...

Written by Lisa Fedorak

Let me tell you about a remarkable little girl, my little cherub-cheeked bumblebee, Scarlett Rose Fedorak.

Just like a bumblebee, Scarlett has learned to fly. Despite impossible odds against her, Scarlett just keeps on flying, suspended in the breeze, carried along by a wish and a dream, giving hope and life to children and families around the world.

I read a quote a while back about a bumblebee and that it should not be able to fly given its dimensions, body size, wingspan, and fuzzy plump-ability. So why CAN it fly? Is it just that no one has yet told them they cannot? Is that the case for all of us? That we are more than capable of doing and dreaming anything until we are told we cannot?

Well let me tell you that Scarlett CAN fly!

Scarlett was born with a rare neurodegenerative disease called Krabbe (Globoid Cell) Leukodystrophy, the same devastating terminal disease that took the life of her big sister, Chloe, just shy of her second birthday. Krabbe disease is a genetic disease where both parents are carriers and there is a 1 in 4 chance that a child in the family will be affected. There is no cure for Krabbe disease and it progresses very quickly and cruelly, however there is a new treatment that is showing promising results, a stem cell cord blood or bone marrow transplant.

Sadly it was too late to save our first daughter, Chloe, as we had no idea she had the disease until she was about 6 months old when little by little the disease took away her sight, hearing, movements and finally her last lyrical breath and sigh. However, thanks to the beautiful soul that Chloe was, we were led on a journey of hope and miracles when we learned that we were once again pregnant and expecting another daughter with the disease. Scarlett's life has been miraculously saved. When Scarlett was only a few days old we began the treatment to save her life, a cord-blood stem cell transplant.

The treatment is horrendous and heartbreaking, but oh my goodness the results have been astounding! Scarlett is now a rambunctious, amazing, spitfire of a three and a half year old, with very few signs of the disease. You would never know, to see Scarlett, all that she has been through and overcome. She is like any other toddler, full of life and character. However, getting to this day of celebration and beauty has not been without a lot of determination, hope, belief, support and the will of an incredible little girl. It brings tears to my eyes thinking of the amazing people that have touched our lives and helped lift Scarlett's gorgeous little body off the ground.

The BC Centre for Ability has been by our side with every wing vibration – holding, lifting, pushing, cheering, and letting go as we have prepared Scarlett to take flight.

After Scarlett's first year of life we needed a lot of support to start the work of bringing Scarlett back to life so to speak. At only a few days old, a time when most newborns should have the luxury of eating, sleeping and snuggling, Scarlett was receiving poisons in the form of chemotherapy to remove the diseased blood running through her veins, in preparation for the transplant. Walking into the small little hospital room that we called home



for many months, all you could see were wires intertwined with more and more wires and each wire was connected to a larger and more potent machine. It was easy to miss the 7 lb miracle beneath the blanket of wires and hope.

Scarlett was basically robbed of her first year of life due to the treatment to try to save her. At one year old it was like a re-birth for her, a time to learn how to eat, to move, to smile, to cry, and to take her little bumblebee body to new heights. Within her first year we had been told on more than one occasion that the treatment didn't work and we would have to take Scarlett home to suffer the same horrible and tragic ending as her sister and that if she did survive she most likely would not walk, talk and would in all likelihood live a life with severe disabilities.

Thanks to the BC Centre for Ability's (BCCFA) Early Intervention Therapy Program, the Infant Development Program and the Supported Child Development Program and her gifted therapeutic team, Scarlett has finally learned to fly! At first it was just little vibrations and movements to get her little cherub-body moving. Then there were little lifts and wobbly flights followed by courageous and determined flights – soaring higher and higher and now the sky's the limit for our little girl.

Scarlett loves her BCCFA Speech-Language Pathologist, Kim Weselak and Physiotherapist, Jude Rushdon so much! If there is anyone to be credited with Scarlett's ability to fly, Kim and Jude are high on the list. Kim, in her sweet and playful way, has given Scarlett the confidence to express her wishes, dreams, wants and needs. Jude arrives so full of life, ready to take Scarlett on her next adventure; catching butterflies is a favorite of Scarlett's and with each butterfly she is closer to jumping and skipping (both of which seemed impossible mere months ago). And just the other day we talked about preparing for Scarlett's next adventure, to ride her bike alongside her daddy (an avid rider). Jude will do everything she can to make this dream a reality for both daddy and daughter. If you could see the sparkle in Scarlett's eyes and the dance in her step as she anticipates Kim and Jude's arrival you would know how much they have impacted her life. At the end of each session Scarlett is already asking "Jude coming?" and "Kim coming?" she wants them to be alongside her every step of the way.

The BC Centre for Ability not only gives us essential services for Scarlett to achieve all that she wishes, it has given Frank and I the confidence to move forward into the future, to believe that Scarlett really can achieve her every wish and dream. Lisa Kang, BCCFA Social Worker, has added a new breath of fresh air beneath Scarlett's wings, preschool! My beautiful girl is going to attend preschool!! I am overwhelmed and thrilled beyond belief! Scarlett will be achieving her dreams alongside every other boy and girl. Although I am nervous about letting my baby go, I know it is time to let my little bumblebee fly. Fly Scarlett Fly!! Soar to heights beyond all possibility...

Scarlett's transplant has been successful. Every morning and every night and sprinkled throughout the day, Scarlett gives Frank and I a big hug and kiss and says "I WUV YOU!" and each and every time the tears of happiness well up.

Thank you BC Centre for Ability for the breath of fresh air beneath Scarlett's wings. With a little help we can all fly like a bumblebee!