

Bianca's Story

My daughter Bianca, at the age of 2 weeks, was diagnosed with biliary atresia, which means she had no bile ducts to the liver. At this point we were told that she would need a liver transplant, but chances of survival were not good as the wait for a donor organ can be long. She immediately underwent the Kasai procedure which helps to drain bile from the liver, but it is not always successful.

And so our life began to keep Bianca healthy until an organ became available for her.

Bianca required special feeding formula, many liquid vitamins and antibiotics. If her temperature spiked, she was hospitalized, high fevers could lead to many complications, dehydration being a major concern. We flew her to Toronto for a full assessment before putting her on the waiting list for a liver transplant. We were told to be prepared since during the wait she could become very ill and possibly could not withstand the transplant surgery. It then became my job to be very cautious of any changes in her normal patterns such as appetite, skin and eye color turning very yellow, fevers, etc. etc.

Once Bianca was on the transplant list, I was required to carry a pager at all times should a suitable donor become available. It was at the age of 18 months that Bianca underwent her transplant surgery. During that 18 months, she probably spent 50 per cent of the time hospitalized ~ always spiking fevers, appetite getting less, skin appearing more yellowish. I was then trained to tube feed her to keep her weight on in order to be healthier for the transplant.

When we were called for her surgery, the emotions are unexplained. The gratitude of someone making that choice to save our daughter, even now after all this time, I have tears. Tears for the loss of someone dear to others, tears for the children lost waiting for an organ.

Our slogan for Bianca was "Please don't take your organs to Heaven, because Heaven knows we need them here". As a parent your struggles to deal with a sick child are not ever thought of as a struggle, because to save your child is an "inner will" beyond words. But to lose that struggle because there was no organ is an "inner pain" beyond words.

Everyday of my life I am thankful to everyone who helped to keep Bianca with us, but many times I remember the families that lost their child because an organ wasn't there for them. To the family that made the choice to give life to my daughter I carry you in my heart always. The joy you have given me to watch my daughter grow up to a beautiful, successful young woman. who can now give back by helping the Canadian Liver Foundation as a Regional Coordinator for Manitoba. I am so proud of her and her accomplishments!

