



"Even one day in the NICU is one day too many" is what I say to anyone who is retelling their experience of intensive care for their baby. Whether they experienced 1 day of intensive care, or 135 days like our Lucy, everyone needs to be supported. With peer support, the trauma of those days where they may have worried, mourned, and questioned can be recognized and shared as part of their recovery. For many families, there is a desire to give back to the NICU community as part of their journey to cope and thrive. Families who want to contribute can do so via the BC Women's Hospital Neonatal Program Family Council. The Family Council is a group of family representatives with lived experience in the NICU supported by healthcare professionals dedicated to promoting excellence in the principles and practice of family-integrated care. The council is responsible to help promote care for families and caregivers in the NICU and in Mother Baby Care (MBC) and prepare them for a safe transition from NICU to home or other healthcare facilities closer to home.

Our Story

We had been trying for our second child for almost 4 years and we finally conceived in early 2015. At our 20-week ultrasound, our doctor told me that I had a short cervix and I needed to see MFM at BC Women's. I ended up doing an emergency amnio followed by a cerclage. After a week at my follow-up, they admitted me to the hospital after finding out that we were severely at risk of giving birth to Lucy early. On August 3, 2015, Lucy was born at 25w0d at 800 grams. We stayed in the NICU for 135 days. She received respiratory support, experienced an arterial bleed trauma incident where she nearly lost her life, and underwent hernia surgery. Complications in our feeding journey included milk supply issues and a milk protein intolerance. Lucy also had ROP monitoring and PDA monitoring during her time in the NICU. After our stay, we had support through the Neonatal Follow Up Clinic. At the age of 2, she was admitted to BC Children's for pneumonia for a week, following that year around her 3rd birthday she contracted RSV for 8 days. From those two hospital stays she was accepted into the asthma clinic and diagnosed with severe asthma. Lucy's now 8 and thriving with assistance with a steroid puffer daily. She's in 3rd grade in an early French Immersion program. She's feisty and a whole lot of fun with a great sense of humour.

Parent to Parent Support

During our NICU stay, I learned that every family's experience is different. I met many families and engaged in conversations daily about our babies' struggles and milestones. Through these experiences, I realized I wanted to share my story and provide support to others. In 2017, I was matched with my first parent buddy with whom I could correspond and build rapport.



Bringing Parents Together

It is so important to take time for yourself while in the NICU. We spend countless hours bedside, and the hours go by quickly while we care for our babies. Working with the Family Engagement team in the NICU we held card-making classes whereby parents could drop in for an hour to make cards for their loved ones or just to have a coffee. Here they had an opportunity to meet other parents that they may not have had a chance to meet otherwise.



Introduction to the New NICU

In 2017, staying close to the NICU, Lucy and I were asked to participate as patient and family partners in an orientation video for the new BC Women's NICU. This was a meaningful experience for both of us to be able to contribute to an important cause to introduce the NICU to all the new families that would eventually have their stay in the NICU. This orientation video is displayed on the monitors in the NICU and is currently on the BC Women's Website where it is often an expectant family's first introduction to the NICU.

Introduction to the NICU at BC Women's

SCAN ME

BC Women's Glow Gala Feature

In 2019, I had the opportunity to tell the story of our need for breast milk in the first days when Lucy was born. This video tells our story on the importance of having access to such a valuable resource for our sick babies. My only wish was that our story would potentially motivate donors to give to the Glow Gala fundraiser to raise funds for the BC Milk Bank. The goal that year was to raise \$1M and that evening they surpassed their goal and raised \$8M.

The Night You were Born
by Cassiar Film Co.

SCAN ME

Developmental Care Workshop

After the pandemic in 2022, I was ready to get back to partnering at the NICU. I was invited to a workshop to discuss as a group how we see developmental care in the NICU. During the workshops and presentations, we reviewed the guiding principles of developmental care in the NICU that would help to provide a vision for the model of care.

Chatbot Pilot Project

In 2022, I was engaged as a Parent Partner to provide input to a pilot project for Mount Sinai Hospital to create an AI chatbot that would be an important resource for families going home with their preterm babies.



NICU Family Council

Currently, in my role of Co-Chair, I am working with parent partners from across BC and the Yukon and hospital staff to develop new supports for families and family integrated care in the NICU. This new role aligns with my focus on giving back to a community that has given so much to our family, to ensure the healthy upbringing of our little micro preemie who is now thriving and living life to the fullest.

Our first cuddle 12 days old



Face Care 46 days old