

INTRODUCTION

Madeline – 34 weeks gestation

In 2019, Madeline was born at 34 weeks and required ventilator support due to Respiratory Distress Syndrome. She was in the NICU at The Ottawa Hospital (TOH) & the Children’s Hospital of Eastern Ontario (CHEO) for 10 days.

John – 24 weeks gestation

In 2021, I had uterine rupture due to placenta accreta. John was born via emergency c-section without an opportunity for pre-birth steroids or magnesium at 24 weeks gestational age and 640 grams. He was resuscitated at birth and had an APGAR total of 3 at 15 min post-birth.

Some of the challenges he experienced during his NICU stay included:

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| Grade IV IVH | PDA |
| NEC Perforation | Intubated for 7 weeks |
| Multiple hernias | ROP |
| Chronic Lung Disease | BPD |

Following John’s birth, we were advised that due to his brain bleeds, his quality of life was likely to be extremely low and that we should consider comfort care measures for him.

These conversations were repeated as he battled NEC at four weeks old and required a penrose drain. We understood the gravity of what was being presented. That said, it went against our convictions to choose to end his care based on unknowns about his future quality of life.



NICU LIFE

Life in the NICU

During John’s admission, he was transferred between three hospitals: TOH Civic Campus, the General Campus, and CHEO. We were thankful to end his stay at the hospital where he was born at, due to its proximity to home. Even more importantly, he was given the time to come off oxygen and he had his own room for multiple weeks. This provided us with needed bonding time. This “slower” pace for growing and feeding also enabled me to realize my milk production wasn’t as high as typically expected and a lactation consultant referred me to a physician, who could provide evidence-based recommendations and prescription to domperidone to increase my milk supply.

After 133 days John was discharged from the hospital without oxygen.

Life after the NICU

Post-NICU medical events of note:

- Obstructed bowel operation
- Admission for a focal seizure
- Hernia operation
- Approximately 100 appointments since discharge

While John’s myChart is exceedingly full, his life at home has been a joy. Every time he is discharged from a therapy or follow-up service, it’s time to rejoice and look back at how far he has come. He is a walking, talking miracle who loves music, magnetic tiles, and his family.

COMMUNITY

Community proved so helpful to our family during John’s 133-day NICU journey. Within the first few days of understanding what John was facing, I joined a Facebook group called “Micro Premie Support Network (Gestation of 28 weeks or less)”. Given our concerns about his future, it was helpful to realize we were not the only family going through these challenges and there was hope that his life might be brighter than we were warned.

Friends who had children born prematurely became confidants with whom we shared the daily challenges John was going through. Coworkers reached out to share stories of their children facing health challenges. Church members prayed for us and set up a meal train that fed us for months. Family members gave rides to the hospital when I wasn’t yet able to drive and provided childcare for our daughter so we could spend more time at the hospital with our son. All of these acts of kindness helped tremendously as we navigated the emotional challenges that come with a long NICU stay.

Since John’s time in the hospital, it’s been gratifying to be able to provide others with similar support, encouragement and hope via Facebook support groups and to others who have come into our lives whose children are facing unexpected health challenges.

ELGA WORKING GROUP

Joining TOH’s ELGA Working Group as a parent partner has been very interesting to see the practices and guidelines that shape the care of <28 weeks gestational age infants. This past summer I was able to share an update about how far John has come during one of the meetings, which was quite meaningful.

Photos

Top left to right: John at 2 weeks old with his earmuffs, kangaroo care at 2 months old, discharge day outfit, discharge day with mom & dad.
Bottom left to right: John loves a beach (18 months), Madeline and John love parks (4.5 and 2.5), John loves trucks (2).

