

NICU JOURNEY

- Freddie was my 4th pregnancy (2 miscarriages, 1 ectopic)
- After 2 first losses, I underwent fertility treatment; Freddie was my 8th IUI
- Referred to McMaster's MFM @11 wks due to high fetal heartrate
- Fetal heart rate normalized, but fetus was sizing 2 weeks smaller than gestational age.
- At 18 weeks, my Integrated Prenatal Screening test was positive for Trisomy 21 (50% chance)
- At 22 weeks, amniocentesis revealed baby did not have Down Syndrome and that I was having a boy
- I was diagnosed with Placental Insufficiency and the baby had Intrauterine Growth Restriction (IUGR).
- Baby monitored bi-weekly, then weekly, and daily for the last 5 weeks of my pregnancy (ultrasounds and NSTs).
- Ultrasounds were reported as a girl. Genetics consults recommended testing amniotic fluid for genetic abnormalities to explain the sex discrepancy. I
- was prepared to have a child that was genetically a boy but appeared to be a girl.
- On October 4 (29 weeks) Freddie was born, diagnosed with ambiguous genitalia

WHAT I WISH I HAD KNOWN

- Leaving the hospital = losing support system
- You will need support after discharge and as child grows - types of support changes, but need doesn't
- "Celebrating" birthdays means reliving the traumatic birth experience – birthdays are hard (until age 5 for me)
- You are at risk for PTSD. You are NOT alone in this.
- Relating to a mom with a "normal/term" pregnancy is HARD
- Even amongst all the joy, there will be sadness and a need to grieve the loss of "normal" experiences
- You will always be a NICU mom – the experience will change you forever and it will define who you are.

IN THE NICU



- We spent 87 days in the NICU
- At discharge, Freddie was exclusively breastfed and weighed 4.8 pounds.

EARLY CHALLENGES

Preparing for & Recovering from Surgery:

- Freddie had 2 major reconstructive surgeries (age 2 and 2.5 yrs) to correct severe hypospadias (each 7 hrs)
- Freddie was catheterized for 2 weeks after each surgery
- For 18 months post-surgery, Freddie didn't sleep through the night on his own and refused to go back into a crib

Readiness for School:

- Significant behavioural challenges adjusting to Montessori (age 3 years) which did not appear in daycare
- I was unaware of the "preemie phenotype", challenges preemies may have with readiness for school
- We hired a one-on-one in the classroom so that he could stay at that school. Montessori not a good fit.

Medical Follow-up

- Didn't know who/where to go to for school help because it wasn't medical; Difficult to get help without a diagnosis
- "Preemie follow-up" ended at 3 yrs old when school challenges arose.

CURRENT CHALLENGES & SUCCESSES

Currently:

- Grade 4 public school, very smart, hilarious, quick wit!
- Developmental Coordination Disorder diagnosis at 5
- Loves swimming & karate, dislikes sports due to DCD
- Accommodations with iPad due to fine motor challenges
- He makes everyone laugh! ASK ME for a Freddie story ;)

Self-Regulation:

Occupational Therapy for "size of problem, size of reaction", zones of regulation and other tools for managing problems

Social Skills:

- Unthinkables from Social Town through OT
- Attends weekly "Social Smarts" groups with psychologist to work on social skills with other children of similar ages

