

## Our Journey

When my friend Laura asked me to do this presentation, I jumped at the chance. After all, my babies survived, it was a happy ending. But I struggled a bit, working in Diagnostic Imaging, I knew a bit more than the average patient. Do I make a power point with results, numbers and reports or do I speak from the heart? I chose the latter, I chose just to tell you our story. As a patient, not a healthcare worker. It was emotional, which I was not expecting. This all happened years ago, it's in the past. But as I started to write my story, I soon realized how fresh some of the moments were. They felt like just yesterday. And with that our story begins.

Like most of the people I knew, I went and got my rhogam injections during my 1st pregnancy and thought nothing of it after.

On November 10, 2010, we had our first daughter, Grace Elizabeth 8 lbs 8 ozs and everything seemed to have gone perfectly.



Fast forward 2 years to 2013 and I go for an ultrasound for my 2nd baby, the findings showed by our baby was in trouble... increased fluid, MCA dopplers were irregular, organs were enlarged.

I got sent to OB triage, we were told we have to get to Toronto, our baby was anemic.

I called my husband who was working out of town to fill him in. My parents, Grace and I jump in the car and start driving to Toronto. We met Dave on the 401 and continued on.

We pulled up the hotel at almost midnight, checked in and tried and get some rest before going to the OB clinic at Mount Sinai first thing in the morning.

Dave and I snuck out early leaving everyone else sleeping. We got to the clinic and they knew nothing about us. After some explaining and not very good explaining since we didn't know 100% why or what was happening, they brought us in for blood work, ultrasounds and to meet the amazing Dr. Ryan. The Doctor who actually saved my little cousins lives by performing surgery for twin to twin transfusion. I knew we were in good hands.

He explained that I had been RH sensitized, and that my body was making antibodies that were attacking our precious little baby. Still to the day, I'm unsure how this happened.

He ran some more testing and said we were ok. Our baby was borderline anemic and rather than do an intrauterine transfusion, he'd send us back to Windsor and have them do serial MCA Doppler ultrasounds and bloodwork.

We went home and met the High Risk OB in Windsor, Dr. Mundle. He went through everything

and agreed with Toronto. Although I went back to my regular OB, Dr. Hasen, he stayed in touch.

Another Fast forward.

My water breaks 1 week early.

On May 14<sup>th</sup>, 2013, Megan Marie Campbell was born, 8lbs, 10 oz... glad she didn't stay in any longer. She was jaundice, like our last baby,

It was the next day and I was looking forward to that 1st shower that every new mom told me was heaven. And boy was it, but when I got out... a nightmare.

I vividly remember walking out of the washroom to see Dave and my nurse staring at me.

I knew something was wrong. "Kelly, we have to take your baby to NICU". I thought, no way, we are going home today. Boy was I wrong.

The next 9 days were a blur, I remember walking into the locked down unit and seeing my beautiful little girl squished in the incubator under the lights... she was a giant compared to the other babies in there

They didn't have a room for me to stay, but they let me stay down the hall one night. Then I got the "closet" the remainder of our stay, a teeny, tiny room with a pull out love seat inside the NICU. They showed me the routine to follow. Every 3 hours I would breast feed, then pump, then clean everything then sleep for what was left of those 3 hrs, typically 1, then start again. Nights were short.



She had pick after pick in her little heels. They would squeeze the blood into a little tube, to get to that important line for testing.

The NICU doctor seemed happy with her progress and was even talking about discharge, after a blood transfusion.

Did we consent? Was it going to save our baby and get us home, absolutely!

She received the transfusion and on day 9 we went home!

We have 2 beautiful girls!

Summer 2015... I'm 20 weeks pregnant with baby number 3. Knowing bit more and having a great OB, he sent me back to the high risk Doctor for this pregnancy. I had Bi-weekly MCA Doppler ultrasounds and blood work. I basically knew we were waiting for the boot to drop and we would have to go back to Toronto.

And it did, when I was 28 weeks, on July 29<sup>th</sup>. I remember the Sonographer being particularly quiet, she slipped out of the room and someone else came in, my friend who was also a tech, with a wheelchair. "Kelly, we have to go up to OB triage, I've already called up and spoke to them, I'm bringing you up and I will stay with you as long as you need me".

Even though I knew it was coming, I was still terrified. My OB was on vacation, so I went to see Dr. Polsky. He made the call and we were off to Toronto again the next day. We left our 4 and 2 year olds with my parents and headed up the 401.

We had all the testing again, including bloodwork for Dave. His blood type showed that every future pregnancy will be affected like this one, each pregnancy the problems will occur earlier.

This time, all the tests showed this baby was definitely anemic and needed an intrauterine transfusion. We went back to the hotel and tried to get some sleep.

July 31st, we headed to Mount Sinai.

They drew my blood and we waited. NPO and getting really good at candy crush, because Dave was annoying when I was hangry, everything was annoying.

They struggled to get an IV in, which happened every transfusion to follow. They wheeled me into this dark, cold procedure room. Dave came too, he wasn't as annoying when he was holding my hand ♥.

There was a big glass window and I remember them saying, "there's the lab tech, they are there getting everything ready"

There were a lot of people in the room: doctors, residents, nurses, the anesthetist and Dave. They explained they were going to put this huge needle through my belly, into the baby's hepatic vein, which was insane to me. They medicated me and the baby to keep us calm and still.

Dr. Ryan did it, the needle was in place. After the sampling, he injected syringe after syringe of donated blood. I don't know exactly what they did behind that window but I knew they were important. I'll let the experts explain what was being done, I was a little out of it.

Pre-transfusion the baby's hemoglobin was 72, post it was 158.

I stayed for a bit, usually ready to throw up and just wanting to get home. Then we would head back down the 401. Those 4 hour plus drives there and back were dreadful.

We would have to do that 3 more times but with a different doctor, Dr Keunen. August 13, September 3 and September 24<sup>th</sup>. While each time was a bit different, essentially they were the same with the same outcome.

September 24<sup>th</sup>, our last procedure, we were asked to be part of a study. We had to go to sick kids for an MRI pre and post transfusion.

I was really sick, this was the most awful trip, the trip I couldn't stop crying and thinking the worst.

But I remember Dave saying "Keep the faith...soon we will look back and this will just be a memory". It was hard to hear at the time, but boy was he right. We made it to the hotel just outside Toronto that night and I managed to get a couple hours sleep.

We headed to sick kids very early and they squeezed me in for an MRI and by squeeze I mean I literally squeezed my 38 week belly into that MRI machine. It wasn't the best moment for me. But I survived and I got these amazing pictures emailed to me the next week... our golden baby.



That scan showed borderline anemia, but we continued with the last transfusion, since we didn't want to come back before delivery.

Two weeks later we were ready to be induced. Oct 15<sup>th</sup> we got the call and headed in to Windsor Regional Hospital. Dr Tomc broke my water at 7:00pm and she arrived at 11:00pm on the button.

We didn't have a name, and they took her away... I didn't even see her face. Dave looked at me and said what about "Faith". We had driven past a church with a Faith sign every time we drove to Toronto. They brought her over to me and rested her on my chest for a minute... Faith was perfect.

They took her right to NICU. Only for 5 days this time and one transfusion.

After discharge, we were referred to Dr.Jarrar (paediatric hemo/oncologist) He was amazing, and sent us for bloodwork at the hospital.

In November, her haemoglobin was 66 and we were sent in for a transfusion. She had no IV sites, nurse after nurse tried. She would scream and blow every one. It felt surreal standing there watching her suffer. I'm sure I was in shock.



They talked about getting a PICC line put in and other options. I wasn't really comprehending any of it. The Nurse Practitioner then told me the last option before shipping her off to a different hospital would be an IV out on the side of her head. They needed to shave her head and try to insert it there. It felt like an eternity, but they did it. They got the IV in.



I sat in a big empty room rocking her while she got the transfusion. She just slept in my arms. Thank goodness for cute little bows to cover up her new bald spot. We were scheduled to go back in January.



In December, she seemed off to me, quiet, sleepy, something was wrong. I called Dr Jarrar, and his secretary told me to follow my “Mommy gut” and go into the hospital. That gut was right her hgb was 75 and she received another transfusion. She was back to herself ♥

On February 16<sup>th</sup>, her hgb was 121! She was perfect!

Our long journey had come to an end, our hearts were full. We decided to stop with three children, although we had the right outcome and kept the faith, we had our happily ever after.

Thank you everyone.

