

## **Concurrent Session: “Women’s Issues”**

*“My Journey with Haemophilia B”*

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Mum often thought it was very strange that I had so many bruises. She often put it down to the fact that I was a tom boy, just typically getting into all sorts of trouble.

Mum approached the child health nurse several times about my bruises, but they continued to ignore her pleas of worry. Instead almost reporting mum to the Department of Child Services for what they thought could be an abuse case.

I discovered I had mild Haemophilia B at the age of 10 due to a severe bleed from a bike accident. I was rushed into the Emergency Department bleeding heavily. On that occasion I required several units of blood to be transfused to save my life. After one week of continuous bleeding it was suggested by a nurse to my parents that I may have a bleeding disorder called Haemophilia. After a positive test for Haemophilia I then received Factor 9.

Going into my teenage years I didn't know much about haemophilia and I continued to do all things a teenager would do. I played all kinds of sports and led a pretty active lifestyle. At times I often did some pretty hair raising things, which I now look back on and think “what an idiot I was”.

I remember one incident in which I dropped a wooden outdoor chair on my foot. I obviously broke a bone but being as tough as I was continued to ignore it. Today I have this bone in the wrong place, reminding me about the pain I endured. In hindsight I probably should have sort some medical treatment for the injury.

I got my menstrual cycle in my early teens. It was awful. I use to get really bad stomach cramps and it was always so heavy. I remember being at school and often having to change pads frequently. Often getting an overflow and leaking through onto my school uniform. I would have to go home and get changed. I was always thinking why I can't just be normal. It would always last for at least 8 to 10 days. It was just horrible.

Mum took me to the hospital several times for nose bleeds, then finally for advice on my menstrual cycle. I was put on the pill in my early teenage years. This helped a little. It did feel really strange being such a young girl going on the pill. I had to grow up a lot faster than those teens around me.

I continued to play a fair bit of sport in my early 20's. I had some minor injuries which I required treatment for. The week before my wedding I broke my wedding ring finger. At first I didn't think it was broken but after about 12 hours of intense pain, swelling and it looking very black I thought it best to go to the Haemophilia Treatment Centre. There I had some x-rays done and yes it confirmed a break. I had Factor 9 and intensive physiotherapy treatment for one week in order to get the swelling down. Finally on my wedding day I could just fit my wedding ring on.

Mum was always very protective of me growing up. Always telling me to be careful. Sometimes she asked me not to do things but I would always ignore her pleas. Mum felt guilty that I had haemophilia. It was worrying to her that her little girl may not be able to have children. For me, this was a little worrying to.

Eight years ago I got married. Following discussion with my husband, we decided to have a child. Eighteen months later I fell pregnant and very quickly to my surprise. We made the decision to have chronic villi sampling done on the baby to determine

whether the baby had haemophilia. This was a very stressful time and the night before the test I was a real mess. The thoughts that were rushing through my head were just crazy. I was thinking, that I was going to die from a bleed as a result of the long needle going into my belly and the pain the needle might inflict. I was concerned about the baby's wellbeing with the needle going into my abdomen. I braved on and the test was performed at 11 weeks. I received Factor 9 prior to the test. There was no bleed, only a small amount of bruising and a little cramping.

After two weeks of waiting which was as stressful as having the test done, we received the good news that our child did not have haemophilia. We opted not to find out the sex of our child.

Nine months into the pregnancy and with no complications at all it was my turn to deliver our baby. We opted for a caesarean section with a general anesthetic. In real terms after discussion with our haematologist, anesthetist and obstetrician we all agreed that this would be the safest way to deliver the baby as no-one really knew what was going to happen.

I had Factor 9 just before I was anaesthetised. Forty five minutes later Joshua was born. My doctor informed me I bled less than anyone else.

I had made the decision to try and breastfeed Joshua. He attached onto me well, but there was simply no milk. My breasts were very sore and eventually they started to bleed. I was then expressing and only expressing blood. Tears and emotions were running really high. I then had to come to terms with the fact that I couldn't breastfeed and this was really hard to accept. I don't think I initially bonded well with Joshua. Not having a natural delivery or being awake for the delivery made me feel as though this wasn't my child.

Joshua's first hour of life outside the womb consisted of blood tests one after the other. We had to put a stop to this and say no as it was very distressing for us to see and finally his paediatrician agreed with us. Three months later he was again tested for Haemophilia and the results confirmed he did not have Haemophilia.

I stayed in hospital for two weeks after the delivery for observation and treatment. It felt like the longest two weeks of my life. Yes, I bled and bled. I was treated every day for two weeks with Factor 9 and my levels of Factor 9 were closely monitored. Joshua was not a new born baby when we left the hospital. In fact he was the oldest and biggest baby in the ward. I then had to come to terms with the fact that I was bringing a two week old baby home and not a new born.

Today we are both doing really well. My husband and I often think about the whole pregnancy and remember how stressful it was. It took a large amount of strength, energy and courage to go through the pregnancy and delivery process. It was all very risky but we came through with flying colours.

Two years ago I delivered my second child, a baby boy named Samuel. Samuel also doesn't have Hemophilia. I had an elective caesarean under general anesthetic at 38 weeks of pregnancy. The caesarean was planned very carefully. My replacement therapy was delivered to the Hospital, and was available pre and post-operatively. This time we were prepared.

One hour prior to surgery I received some Benefix. The nurses were very confident in mixing the Benefix and administering it. If they did not know how to mix or administer the product they were happy to learn. Benefix was also taken down to surgery with me just in case of a bleed. Once again I was given a general anesthetic. In surgery I

had a PICC line inserted into my arm through a large vein as it was difficult to access my veins.

After surgery I felt pretty good. My obstetrician informed me that I had minimal bleeding. My clotting factor levels were good. Each morning I received 2000mls of Benefix through the PICC line. Blood was also taken from the PICC line which meant less jabbing. My levels were consistent and thus this made my recovery was very quick. The Factor 9 product I received for my second delivery was also a better product. This definitely helped in my recovery. I made such a good recovery that I was allowed to go home very early.

Before Samuel's birth I had made my mind not to even try breastfeeding this time around, so I was really prepared with bottles and all. In fact the Factor 9 product I was receiving clearly indicated on the instruction sheet "Do not Breastfeed" whilst taking this product. Hence I had no other option but to bottle feed.

The delivery of my second child Samuel was very stress free and easy. It was well organised. The logistical planning of my caesarean delivery made it a pleasant experience. Some of the doctors and nurses had little experience with haemophilia but all were really interested and prepared to learn.

I had an excellent obstetrician, hematologist and haemophilia nurse. It was a positive outcome for me, my baby and our family and I thank them for this.

Today I am suffering from heavy menstrual cycles. I believe this is the effect of getting older and having two children. My husband keeps asking me where all the toilet paper is going. I am currently taking some Tranexamic tablets in the first couple of days to lighten my flow. This seems to be helping. If I don't take the tablets I just feel awful. I often get a headache within the first 24 hours and feel very tired.

We have decided to not have any more children. The successful delivery of two healthy boys is a great outcome. Three deliveries I think is putting my health and life at risk.

I do get a few aches and pains on the colder days. Particularly in the joints I have damaged over my teenage years. Last year we moved from Perth Western Australia to Tasmania and since living in Tasmania I been aching a lot more due to the cold weather. I try to keep moving as much as I can but sometimes the cold just gets to you and all I can do is rug up and keep warm.