Living with Factor V Deficiency

To discuss living with factor V deficiency, I must first give a brief history of my family and where it all started.
There are five siblings in the family, two boys and three girls. Both my older sister and I have factor V deficiency, the rest are unaffected. When my older sister was six months old she bumped her head against the side of a coffee table. She was brought to hospital and did not respond to the treatment given. Blood tests were completed and it was then found that she had factor V deficiency. When I was born I was checked and also found to have factor V deficiency. Subsequent tests revealed that both my parents had low levels of factor V in their blood. Needless to say this was a great shock to my parents who had never heard of factor V.
I remember my sister and I received treatment at the same time. Joint bleeds, biting our tongues, bumps which would turn into bleeds were common for us at the time.

We were living in Chicago ILL and it was common practice for hospitals to pay for blood from anyone who would walk in off the street. My parents organised 'blood drives' for us inviting friends to donate blood to us. This blood would then be stored and used for us when required. This was very progressive thinking for the 1960's. Even though we had a good quality of life in Chicago the medical bills for the two of us were crippling my parents and they decided to return to Ireland in 1973.
I don't remember my parents telling us not to do certain activities but I do remember being told to 'be careful' always. My mother would say that we would only learn through experience ie if we did something and got a bleed then we would not do it again. I think this was very good as we tried everything and knew what we could and could not do. The simple things like riding a bike, gymnastics and basketball were a risk for us. I spent more time with my fingers taped together due to bleeds in the finger joints with basketball. Eventually, I gave up. Gymnastics the same, too much pressure on the joints resulted in bleeds. The bike was a necessity so I learnt to be more careful.

The teenage years brought many challenges, especially the onset of puberty and having periods. Despite having identical diagnoses, both my sister and I had very different experiences with periods. The answer in those days to heavy periods was the pill and cyclokapron. John Bonnar was my gynaecologist at the time and he was excellent. My parents were horrified that their 13-year-old daughter had to be put on the pill and there was often heated discussions between my mother and John Bonnar about this. The first ten years of having periods were hell for me regardless of being on the pill. The majority of my hospital visits at this time were for heavy periods. I often received blood as my haemoglobin was so low. I was never encouraged or allowed to stay at home from school with heavy periods, I was told it was something I would have to get used of and if I got a job I wouldn't be able to stay home anyways. This time also coincided with a transfer from Harcourt Children's Hospital to Top Floor Hospital 1 in St James's. Gone was the relaxing carefree environment of Harcourt St to the absolute depression of Top Hospital 1 in St James's. I can still remember my first in-patient stay, being in a ward with older and very sick people. Even though the wards were depressing the care was good and the matrons kept everyone on their toes!

I was doing my Leaving Certificate when testing for HIV became available. We were not aware at the time that we were being tested but on a subsequent hospital visit, I was told that I was negative. I was on my own at the time and this just slipped into the conversation when I was speaking to the doctor. There was a lot of ignorance regarding HIV at the time and this is just how it was done. I would hope that this would not happen today! Did my parents' blood drives save me from HIV? I don't know but I am truly grateful to them.

Starting a family brought its own challenges. It was not a question of my husband and I making a decision to have a family but a whole team of people were involved. Private decision be damned! I was initially referred to a consultant who told us that due to the bleeding disorder the only way forward was IVF and that there were no other options available. This did not sit well with me as I could see more bleeding problems with IVF that anything else so I changed gynaecologists to Hugh O'Connor in the Coombe. Another great man which put us at ease! A plan was agreed upon and hospital visits, scans and treatment followed every month. Thank God when I was pregnant all went well and I went the full term to 40 weeks. We have a lovely healthy daughter so all the hard work was worth it in the end.

Looking back on what I have written, I may have given the impression that factor 5 deficiency is a doddle. This is not and was not the case. I had many trying times throughout my life with my bleeding disorder. With great family support and a good medical team, the hard times were bearable. I would advise any bleeder to protect their mental health during the hard times. A bleed can be rectified easily but the mind needs gentle care. Take care and thanks for reading!

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