Living with vWD, personal experience
~ Lauren Winders

Good morning everyone. Thank you James for the introduction. As James mentioned I was diagnosed with VWB at two years of age. It wasn't a complete shock to my family, as my mother was diagnosed at a young age also. She is 1 of ten children, 5 of which have VWB. I was diagnosed when I stood on some glass, which required some surgery and blood transfusions. At this stage blood didn't go through as many stringent tests as it does now to screen for diseases such as HIV & Hep C. I was screened years later to rule out these diseases, which although I was too young to realise the implications, I've been told was an anxious time for my family.

The treatment offered has also changed over the years. Early on DDAVP or desmopressin was the primary treatment I was offered, however due to difficulties I had with this I'm now treated with Biostate, and infrequently blood & iron transfusions. All of these treatments are very safe nowadays, as they are screened and treated for any diseases and toxicities.
As a child growing up, I wasn't really too concerned with VWB. I was a normal active child who was involved in sports. The only issue I really had was that I was always covered in bruises and at that young age, didn't really worry me at all. This aspect probably bothers me more now, as it's a bit frustrating when I have a lovely dress to wear for a special occasion and i have bruises in varying shades all over my legs.

The other main issue as a female with VWB is dealing with menstruation. When I was a teenager, I found this quite difficult and often was unable to attend school, with the flow being extremely heavy. Commencing the pill actually helped reduce the problems with this. However, it also meant that I've been intermittently anaemic throughout my life and this in turn has sometimes required extra treatment.

The main problems I have now with VWB has been because I have another chronic inflammatory condition, which has required many surgeries, both major and minor. Due to these circumstances I have encountered several problems, highlighting the importance of knowing and understanding my disease and making sure all those involved in my care take the most appropriate course of action.

I have had many instances where this has been an issue. One example is when I was having major abdominal surgery and without going in to all the details, I was essentially only having Biostate cover for 3 days. This was raised with the surgical treating team by my mother, who had just recently had minor surgery, and had 5 days of cover, at a higher dose, and still ended up back in hospital haemorrhaging. My mother's type of VWB was also a more mild form than mine. It was quite difficult, because our concerns were ignored and we were made to feel over anxious for raising these concerns. Needless to say, I ended up forming a haematoma, which became septic, or infected and I was rushed into surgery in the middle of the night, to drain the collection. This required ICU admission and an extended period of time in the hospital. I wasn't connected with the Heamaphilia centre at this stage and perhaps if there had been dialogue with the specialists there, a different treatment option may have been considered.

This type of situation has happened on other occasions for minor procedures as well. Where a surgical doctor advised that I won't require any Biostate cover as what I'm having done is a 'relatively bloodless procedure'. As seemed to be the pattern, I would end up back in hospital a few days later, haemorrhaging from the site of the procedure, requiring treatment.

These situations have usually occurred in emergency departments or in a hospital which is not my local hospital, with all my records or in GP/clinic practice. I have learnt through these

experiences that, because it is a specialised area, people outside of the haemophilia specialty, tend to minimise possible outcomes and are quite complacent in the management of people with this disorder.

Reasons for this could be that as VWB can only be a problem some of the time and there has been no bleeding for the last 5 patients that they have seen it becomes a presumption that the next patient won't have any problems.

In saying this, I am very lucky to have a great team that look after me at the RBWH and because they know my case and my history, I am very well managed and treated. After my many problems with haemorrhaging etc, my haematologist wrote me a letter, which I can show anyone treating me, detailing the particulars of the disorder and the treatment I need to be given. I at the very least, insist that my haematologist be contacted if required. We're lucky at the Royal that we have a CNC who is our first point of contact and our liaison person for any problems or surgeries etc.

Unfortunately, as hospitals are very busy and large institutions, often simple steps are missed in coordinating the care of a patient. After turning up on several occasions for procedures and then being sent home because Biostate hadn't been organised, I realised it was also much more efficient to contact my haemophilia nurse myself if I was having a procedure, so she could follow up as required.

I think it's also appropriate to emphasise the importance of seeking medical advice or treatment earlier rather than later. I had 1 situation, where I had spent a considerable amount of time in hospital and the thought of having to go back, was something that I was really not wanting to do again. So when I started haemorrhaging I tried to put off going to the hospital for as long as I could. I think I was heavily bleeding for about 8 hours before I called someone to take me to the hospital. By this stage I could hardly walk and certainly couldn't stand up and I can't count the amount of times I fainted, My blood pressure was through my boots. This required a lengthy hospital admission and treatment.

I think my experiences have shown that I need to be not only aware of my condition but also proactive and involved in my own care. If I could give any advice to the treating team (doctors and nurses) it's realising the importance of listening to your patients. They live with the disease every day. It is much better to err on the side of caution, rather than ending up in a reactive situation where extended hospital admissions and treatment is required. Obviously the impact on the patient, physically and emotionally is dramatically reduced if bleeding is prevented or reduced.

To people with vWD, it is a disorder that is relatively easy to cope with, it just complicates simple procedures like having dentistry work or choosing an alternative to aspirin for common problems. If you have a team that manages and plans your care well, it can be a very simple and problem free outcome. I also suggest that everyone has a medic alert bracelet, so at the very least people in the case of emergencies are aware of any potential problems and can start putting appropriate treatment measures in place. I know how to contact my haemophilia team, which includes medical, nursing and social work staff whom I can ask for information or advice if I have any concerns. It is probably easier to ask them questions, then to have problems. Thankyou