

Jo's Story

At the age of 17 after a straight forward knee arthroscopy I developed a DVT in my calf 24 hours post-op. After a series of blood tests I was diagnosed as having E.T. Prior to diagnosis and the operation I had no symptoms that would suggest a problem and I had always been very athletic and healthy. So it came as a big shock to find out that I had an incurable blood disorder. At diagnosis I had a platelet count in excess of one million. I remember feeling really scared, but what affected me most was being told that this disorder was more commonly associated to "old people" and that left me feeling totally isolated, and the "*Why Me?*" syndrome soon kicked in.

My initial treatment was one dose of Bulsulphan which reduced my platelets to half a million and the treatment lasted for approx one year, after which I was then started on Hydroxyurea and I have now been on the said drug for the past 20 years. My platelet count is stable at approx 380,000 and I have had no problems with taking Hydroxyurea.

During the last 12 years I got married and successfully went on to have 2 healthy children thanks to the care that I received from Prof. Tom Pearson and Dr Beverley Hunt at St Thomas's Hospital. Dr. Hunt in particular was brilliant. Her knowledge and encouragement helped me and my family through some very difficult and complicated times.

I am now 38 years old and although the last 21 years have not always been plain sailing I would now describe myself as fit and healthy. I attend St Thomas's Hospital every 3 months, under the care of Dr Claire Harrison, just to make sure that everything is o.k. I think that this new support group is vital because I feel that there is a lot of information on the internet that is inaccurate and dangerous advice in some cases is also being given. By having a Support Group that is backed up by St Thomas's Hospital along with its medical team it can help bring more emphasis on E.T, provide good, and accurate information and, more importantly, give people the hope that one day there may be a cure. It is also reassuring to know that E.T is no longer labelled as a disease of 'old people'.