

Personal History: Tim, Suffolk, UK - ET diagnosed at 29 years of age in 1989

Married in 1987 and with our first child born one year later, I started to feel very tired and apathetic. Believing this to be a normal occurrence for such a change in lifestyle I shrugged this off and, like most would do, just carried on.

Fortunately my elder brother was not convinced and as a rather unique Christmas present sent me off for a full private health assessment. This is where my ET journey begins as my blood tests revealed an elevated Platelet count. I was referred back to my GP and after several tests that included a BMB test at my local hospital in Orsett, Essex was referred on again to St. Bartholomew's Hospital in London.

It was at St. Barts that Essential Thrombocythaemia was confirmed and, with a platelet count in excess of 1.1 million, was quickly prescribed Hydroxyurea (Hu). At the time of diagnosis, a platelet count in excess of 600,000 was considered as critical, a fact that I did not learn until my doctor managed to get mine to below this level!

I have to confess I was somewhat concerned about my condition, particularly so given the close links it has with Leukaemia and the fact that my father died at St. Barts Hospital, at the age of 48, from Acute Myeloid Leukaemia.

After a number of months my platelet count was reduced and stabilised at around the 350 level and I must say, other than the inconvenience of an 8 weekly check-up and the continuing treatment with Hu, continued with a relatively normal and pretty active life.

Four years later and with our daughter aged four we decided it was time for a second child! Realising that Hu was not conducive to a healthy sperm count, I switched, after much deliberation, onto Interferon (INF). This was not a pleasant change and I experienced the typical flu like symptoms, headaches and aching muscles. However, I got through these side effects with the help of paracetamol and after 6 months life continued as normal.

Our second child, born in March 1994, was a healthy boy and again life continued as normal, or at least so it seemed!

My INF treatment lasted approximately eight years and was terminated due to my experience with depression. Looking back over those years I can now see what my wife had been telling me about the Interferon side effects. I had progressively become more tired, irritable and withdrawn, presumably due to the continuing side-effect of the drugs.

Having moved to Suffolk in 1995, I was now under a consultant at Ipswich Hospital and choosing the next drug was not easy. I was faced with the dilemma of switching back to Hu, aware of the various theories about this drug increasing the risk of Acute Leukaemia (remember my father!), taking just Aspirin, with the associated risk of elevated platelet counts, or switching to the new wonder drug Anagrelide (Ag) that had no real track record. Unfortunately, I chose Ag.

Armed with my new drug Ag and my experience of depression behind me my next four years continued with relative normality albeit with rather more muscle/joint aches and pains than I would have liked. I accepted these aches and pains as the consequences of getting old but I must say I had my suspicions about the drug.

Two to three years into this course of treatment I became aware of the increasing concerns that Ag might cause a transformation of my ET condition into the more serious

Myelofibrosis. Again, after much deliberation, I chose to stick with Ag until the beginning of 2005 when, after undertaking a long overdue BMB, it was discovered that my condition had now progressed to level 4 Myelofibrosis.

Needless to say that this was devastating news, particularly so given that my wife had just discovered that we were, rather unexpectedly, going to have a third child. Armed with hindsight, I could not help think that I'd made some pretty bad decisions. Still frightened by the thought of switching back to Hu and, despite knowing the possible outcome, I opted for a spell on INF whilst waiting for a hastily arranged appointment with Professor Green at Addenbrooke's. Needless to say, given the outcome from my previous experience with INF, my choice of drug was not well received at home.

My appointment with Professor Green in April went well and after reassurances that there was no real evidence supporting the theories of Hu developing into Leukaemia, I switched back to the Hu drug. Also, whilst now diagnosed with level 4 Myelofibrosis, I was not experiencing an enlarged spleen or any of the other conditions that are often found with this stage of condition.

My mistakes; well going from 1989 to 2005 with no BMB was, in my view, a big mistake. Choosing and sticking with Ag was another. However, I realise that we are all different and that we tolerate and react to these various drugs in very different ways. So, for some, Ag might well be the best course of treatment and is clearly a decision that you and your Consultant will make together. My only word of advice for those that stick with Ag is for you to discuss, agree and stick to acceptable intervals between BMB's.

At the time of writing, still on a relatively low dose-age of HU, I feel fine. I am also lucky to be the husband of a caring wife and the proud father of three children aged 17yrs, 11yrs and 8 weeks! Like us all, I have a lot to live for and I intend to do what I can to be around as long as possible.

Tim – 22nd September 2005