

“Haemophilia rarely stops me”

Dan Jolley*

Dan Jolley is a teenager who has severe Haemophilia A. The following excerpts were taken from a speech that Mr. Jolley delivered.

I was diagnosed at eight months old after my parents had struggled to find out why I kept bruising. I started my home treatment at eight years of age and I was far from easy to inject. I have always had access to a high purity product. From the period of 9 to 10 years old I developed problems with my veins and eventually had to have a port-a-cath for one year. After my veins recovered, I progressed to self-infusion and now I'm totally self-sufficient with injections into both arms. During this time, I have always been very active and sporty. My parents' attitude throughout was not to wrap me in cotton wool.

At age five, I was spotted by a local tennis coach and began to play “short” tennis. I played in a local club and won some tournaments and soon I progressed to tennis. Today, I play doubles and singles for two clubs and I have won local and county tournaments in both. I have always played football and now, at secondary school I also play basketball, and badminton cricket. I've recently started shooting and joined a club in order to give my ankle a rest! I tried playing trumpet and got to Grade III but breath control and the serving action of tennis gave me repeated stomach muscle bleeds which led to periods of inactivity and bed rest and lots of treatment and pain. This is not what I like so I gave up the trumpet and I'm very careful with my serve now! All of this activity is only possible with good treatment – prophylaxis is supposed to be three times a week.

When I was eight years old, my ankle kept bleeding and wasn't getting any better and they found I had inhibitors. This led to damage and arthritis. I received a high treatment regime and got rid of the inhibitors. Today I use a genetically manufactured Factor. The first one I tried I had an allergic reaction to, but the one I use today is great. My headmaster learned to inject me and he is my backup for many school trips abroad. At school and with my family, I have visited ten countries and in July, I visited Malaysia with the school and my big bag of Factor VIII.

The future today looks great. My life is very full and active. I hope to do four A levels and go on to do medicine. I have an active social life at church and school and recently I passed my driver's test. Haemophilia rarely stops me. I fully appreciate

*Dan Jolley was a teenager living in the UK at the time of publication of this article in 2002. Dan Jolley suffers from severe Haemophilia A and this article is based on a speech he delivered.

the difference that regular high purity injections and the support of the center and the doctors has made to the sort of life I can lead compared to what it would have been if I had been born 10 or 20 years earlier. So I'm going to make the most of my life, live it to the fullest and hopefully, if I become a doctor, be sympathetic to those in need of lots of injections and who suffer pain.

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