

# Saleha's Story



*Saleha*

I was born in the tail end of the seventies and the youngest of three children. I've been told that it was when I was five days old (and just about to go home) that one of the doctors noticed a murmur... It seems strange to me now that it took so long for anyone to notice there was anything wrong with me, especially since my older brother also had a heart condition!!! Anyhow I was duly diagnosed with Fallot's and kept in hospital for a week or two for monitoring.

Of course I can't really remember the very early years of my life, but I do have fleeting memories of my first surgery carried out when I was 3 years old. It was a BT shunt and to all intents and purposes it was a resounding success. I never really had any bad episodes as a child-thank God, but I do recall going a lovely shade of bluey-purple in cold weather and having to curl into a ball following a crying fit or tantrum.

My brother and I had very regular appointments (at times as often as every six weeks!) we were looked after by a lovely lady called Dr Hallidie-Smith. Even though I was really young I always had the sense that there was something pretty special about us. We were often taken along to meetings and conferences and were given loads of chocolate at the end of another day full of strangers poking us and listening to our chests! Now as an adult I realise that back in the eighties the field of congenital heart disease was just teetering on the brink of becoming the sophisticated and technical "art" it now is, hence there was much excitement and lots to still learn.

I had a pretty uneventful childhood, I think I kinda always knew what I could and couldn't do and as I was always more fond of story books and teddy bears I guess I never really had any problems with exertion. However as the summer came closing in on my 10th birthday, I remember being asked if I fancied having an operation?!? I was of course slowly but surely outstripping the benefits of the BT shunt and desperately needed to have corrective surgery. I was sent to Great-Ormond street hospital for the operation, 2 weeks to the day after my tenth birthday. The surgery was carried out by a certain Mr Elliot (who now, I believe, goes by the title of Professor) and I'll always remember him as being somewhat small and referring to me as his little star ;). I can honestly say that following that I was always in very good health and could never really complain to severely. True, I was always the last to be picked for team sports in PE, but hey, running around and getting sweaty wasn't really my thing anyway so who cares?!

When I was 16 something happened that would forever change my life and unbeknown to me shape my future. My brother Rehan passed away suddenly. He was 21 years old and could not be helped in the

same way that I could, as his condition was far more involved than mine. I know that it was from that point onward that I seriously contemplated where my future lay.

As a bit of a science buff by nature, I did my first degree in King's college in Biomedical sciences and straight after that I joined a lab in the Rayne Institute in St Thomas' to start doing cardiac research. Its funny how providence often plays a hand in life, quite by chance my soon to be supervisor had recently written a grant investigating the novel expression and function of two genes in the developing and mature heart (it was definitely fate because that department had nothing to do with cardiac development at all at the time). It was the perfect project for me. I got to spend 4 years learning all about how the heart develops and see how and occasionally why things can sometimes go wrong. My project was in collaboration with the Institute of Child Health across the river, so I spent a lot of time with the research groups in Great Ormond Street (with which it is joined)! Incidentally I also met my husband in the research labs of St Thomas', but that's another story for another day. I was awarded my doctorate in the summer of 2004 and by then I already knew that I didn't really want to pursue a career in bench side research. It was still a bit removed from where I actually where I wanted to be. Al (my better half) suggested I try something really hands-on: echocardiography. He put me in touch with someone in the field and on went life. In early 2005 I came to know that I was expecting our first baby, Zaki (see his story on page 4 & 5). All thoughts of work were put on hold and I became a first-time mummy.

As it happens, six months ago I was contacted about a job I might be suitable for.... So here I am now, training to be an echocardiographer in St Thomas' with no doubt in my mind that at some point in the future I would like to go into the congenital heart disease side of thing and perhaps resume some research activities therein.

My health care was continued by Hammersmith hospital until I was about 19 when, I'm ashamed to say, I allowed myself to get lost to follow-up. This was not entirely my fault as they really didn't have a dedicated congenital heart specialist there and I got bored of having to tell the ever changing registrar (who, it appeared to me, often knew less about Fallot's than I did) what was wrong with me, as they couldn't be bothered to read my weighty tome! Anyhow, once I was due to get married I thought I'd better do something about this lack of care on my part, so I asked my department head (who was also a clinician) if he knew of anyone. He gave me the name of Eric Rosenthal and thankfully he agreed to take me on as a patient and so I still am.

As you may be able to tell life has been far from dull. Having Fallot's has never really hindered me personally and although I wouldn't say that it has defined me, it has always been there in the background somewhere. Of course there is pain and loss and I am not ignoring it, but (with Gods help) it's given me a drive to do something and a direction to follow. I'll never forget something Eric said to me at the end of my first appointment with him. He was with a training registrar and perhaps was hoping for something more exciting, but he grinned and said, "Well you're quite normal and boring aren't you!" All I can say is Amen to that and long may I continue to be so.

**Saleha**