

Incontinentia Pigmenti - My Story

My name is Joanne. I am a thirty-seven-year-old woman living with Incontinentia Pigmenti. I was born on the 5th of September 1969. As soon as I was born the Doctors noticed that I had a rash on my body. Within a few days I was covered from head to toe. Not knowing what it was I was put into isolation and examined by a number of doctors, who later gave my parents the diagnosis. I was at last able to go home, with an antiseptic powder and cream for the rash that had blistered.

After a while (I am not sure how long) the blisters healed, and I was left with some scarring. At eight months they found what they thought was a tumour in my right eye. So, it was removed, and I was left with only one eye (I was told last year that it actually wasn't a tumour but the effects of IP). I have had an artificial eye since being eight months old.

It has been a pain for me for most of my life because if I'm honest, I have been in physical and emotional pain with it, but I have learned to live with it. I had to have regular eye examinations on my other eye to make sure that it was ok. I last went two years ago, and things were ok.

The other thing that affected me with IP was my teeth. I have some of my back teeth missing and some of my other teeth. Some of my front teeth were crooked. I have had dental work on them. They now look like I have a full front set. It's amazing what they can do these days. My hair was very thin when I was a child. I had a bald spot on the crown of my head. The hair has grown back and is quite thick.

After all that I grew up as any child, although my mother says that I was very often ill with stomach pains, but I still to this day don't know if it was anything to do with IP. I was fine in my teenage years apart for my artificial eye which hurt a lot of the time.

When I was 18 I became pregnant. Sadly 5 months into the pregnancy I was told that the baby had died. I didn't know at that time that it could have something to do with IP. I was never told about how IP could affect my chances of having a healthy child. It was only when I was referred by my doctor to the Geneticist that I was told I had miscarried a boy and he most likely died of IP. I was also told of my chances of having another child with IP. It didn't look good for me and I was very upset with the news; I was very young at the time and that kind of information didn't sink in.

I have had four miscarriages now and one ectopic pregnancy (The ectopic had nothing to do with IP.) I have now decided not to have children at all as I don't want to pass IP on to my children. I feel it's for the best. My partner and I did consider egg donation not too long ago, but later decided against it. Not having children is a big thing to me. Children were the one thing that I wanted in my life, but it's just not meant to be. I am only just coming to terms with it. It has taken me a long time to accept what IP has done.

Supporting a normal lifestyle