

IP – Our Story

When Louise was born in 1999, she was covered in blisters. I held her briefly with my husband and then she was taken to another room where all I can remember is seeing this tiny baby with a group of doctors all looking at her with a huge light. I also remember feeling very faint as it all happened only minutes after she was born. She was so small - just over 5 lbs. in weight.

We spent a week in hospital which was horrible, because at the time doctors didn't know it was Incontinentia Pigmenti (IP) and thought Louise had something that was contagious! We spent 3 days in a separate room that was just off the main ward and had a window. All the other mums would stare and whisper as they passed by – it was horrible.

Once we were told about IP I was allowed to go onto the main ward, but I couldn't make friends as they still remembered me being in that isolated room - I couldn't wait to leave. We had no idea what IP was and went up to London when Louise was 2 weeks old for her to have a skin biopsy to double check it was IP.

At her checkups we had many calls asking if doctors could take a look at Louise to help with future studies of IP, although we wanted to help others, we eventually stopped this as it was all getting too much, and we didn't want Louise going through any more.

We tried to make sure Louise had the best childhood, yet at the same time we were always wondering what will happen next with this unknown IP. I always said that we would explain to Louise about IP when she was older which we have now done. Nothing much happened for the first 10 years apart from the usual IP stages, but we felt so alone - I thought there must be other people out there with IP and that's where the amazing Facebook group came in - I've learnt so much about IP since being in the group who have all become our second family. When Louise turned 11 the seizures started. The doctors prescribed medication as they thought it was epilepsy even though nothing has ever shown up on the tests. When she was about 16 the doctors took Louise off the medication and said she has non-epileptic attack disorder (NEAD) which is similar to epilepsy but is more to do with stress and anxiety and no medication will help only something like talking therapies.

The main issues Louise has had with IP is her teeth and learning. She has dentures on her bottom teeth which took a few years to get and she went through painful procedures to get them, but wow what difference they have made, I remember the dentist asking her why she wanted the dentures and because Louise was shy back in those days I answered "of course she wants teeth", but they said they needed hear it from Louise who said "I just want to eat properly"

As she has got older (19 now) it seems things like seizures, that seem to be linked to her monthly's and anxiety, have got worse - is IP to blame I'm not sure.

When Louise was about 2 and a half, I became pregnant with my boy Matthew. We didn't ask the sex or if the baby had IP, we were anxious but knew we would love this baby the same no matter what. When he was born, and they said it was a boy I said, "are you sure?". Matthew doesn't have IP.

We have had tough times and amazing times over the years. Louise once said that if she had the chance to be born again without IP she wouldn't want to because IP, as horrible as it is, has made her the strongest, craziest, unpredictable, funniest woman she is today, and we wouldn't want it any other way.

Supporting a normal lifestyle