Incontinentia Pigmenti - A Mother's Story

by Christina Lakeman

On the 24th July 2000 our daughter Jessica was born. We had 2 surprises, firstly we anticipated a second son and secondly, straight after her birth, it was my husband who noticed small pustule blisters on her legs.

My daughter was taken to the Special Care Baby Unit and tested for chicken pox and put straight onto antibiotics. I was also screened for chicken pox and then left in a room waiting to hear news on Jessica. The hospital Dermatologist put the blisters down to Benign Pustule Melanosis and after 1 week in hospital we were finally discharged. The blisters returned along with the scabbing, but we were told there was nothing to worry about. Inwardly we were not happy that this was a common condition and went to various lengths and measures to get a second opinion, including a trip to A and E.

At the same time Jessica failed to gain weight and after consulting with the Health Visitor it was felt she may be Dairy Intolerant. We decided we could not wait 3 months for an NHS referral and went privately to see a Paediatrician for the Dairy Intolerance (this again was quite unusual with neither me, my husband nor my son having any allergies/intolerances that we know of). He also took an interest in her skin. He recommended we see a Paediatric Dermatologist and referred us to David Atherton at Great Ormond Street Children's Hospital in London. We had no idea what was to be diagnosed and I shall always remember Mr. Atherton asking me if I had all my teeth!

We were both devastated when it was explained and thought likely that Jessica had Incontinentia Pigmenti. I will never forget sitting in the car as my husband drove home with our 2 children in the back feeling completely numb - just wanting the results to know one way or another. The results confirmed Jessica did have Incontinentia Pigmenti and I was devastated. If only it was me and not her I kept saying.

I phoned Contact - a - Family who put me in touch with the ED Society. It was so good to speak to somebody at the end of the phone who had some idea of what I was feeling. I read every article available and friends and family were all very supportive. My father bought me a computer for my birthday in order that I had access to information on the web. I am by nature a very impatient person, but I was now in a situation where there was nothing I could do except wait and see!

It is now 5 years later and none of my fears have come true. I have a beautiful daughter who is intelligent, remains with good eye sight, yes her teeth are different but she eats crusty bread and apples like the other children in her class. So far, the other children do not seem to notice any differences - there have been a couple of remarks - Have you lost some of your teeth already? And why is Jessica's skin dirty? (when they see the pigmentation).

We have been very lucky - Great Ormond Street have monitored her eyes, teeth and skin, and I have great admiration for Dr Atherton and his team, who always take great interest in our appointments and who co-ordinated the initial appointments with dental and ophthalmology on our behalf. The dental department has also been superb. The consultants are always on hand to speak to you on the phone and will fit you in for emergency appointments as Mrs. Calvert in Dental Maxillofacial will confirm!!!!

We are lucky, Jessica had no fits as a baby and her eyesight remains good. Though her hair is a little dry and thin in places it is plentiful in others and is golden blond. She also has a slight kink in her hair which I have read in some reports is a characteristic of IP. People often comment "I wish I had hair like that" which is music to my ears.

I still have times when I talk about IP and tears well in my eyes, not feeling sorry for myself but I suppose wishing that it was me that had the condition and not my little girl. I worry about when she may decide to have her own children (boys with IP often do not survive full term gestation). Get a grip I hear some of the readers shouting - but who wants their child to have to go through surgery and medical tests throughout their life, especially when oneself has never had any medical problems. Then I cheer myself up and think the gene responsible has been identified and who knows what the future brings in terms of developments.

Supporting a normal lifestyle

The ED conferences that my family attended have been so informative and we feel so grateful for their existence. We would very much love to meet up with other families with IP at the Conferences and hope that this article will inspire anybody who has a baby daughter diagnosed with Incontinentia Pigmenti. The whole experience has changed our lives and put everything into perspective.

Some names and locations have been changed in order to preserve confidentiality. This article was first published in our newsletter (Volume 5 Issue 4 - October 2005)