Our ED Journey

Hey guys! My name is Chantelle, and my wonderful little boy is called Tyler, he is 5 years old and has Hypohydroctic Ectodermal Dysplasia……This is our story.

In 2015 Tyler was born, everything was fine, no issues other than he did not want to meet us. We had to force him out, I was 2 weeks overdue. When Tyler eventually came, he was born with rashes all over his body and thick hard, peeling skin. The nurses/midwives put that down to him being overdue and the fact that he had passed meconium before he was born.

As the days and weeks went on, Tyler's skin was not getting any better, it was so bad to the point his skin was weeping. We managed to get a referral to the dermatologist who said Tyler had childhood eczema, and we were prescribed creams, steroid creams, antacid creams, and bath emollients. Off we went. The creams helped loads but it did not take it all away.

Next thing I noticed was Tyler taking FOREVER to feed, he sounded stuffy all the time, so back to the doctors we went. They could not find anything wrong and put it down to being milk intolerant, so they changed his milk powder. He was not breast fed as he would not take to me, I think that is down to the way I 'developed' due to being a carrier, but I did not know this then. The new milk did not change a thing, I tried everything to take his snuffiness away, but it ended up being something we had to live with.

As time went on, in and out of the doctors and dermatologists, I also noticed Tyler was sensitive to heat, it was not until the summer after he was born, we noticed. He would scream and scream in the car because he was too hot, it also happened when we went out for something to eat, if it got too hot, he would scream until he was cool (I was not sure why at first) but we just thought that was how Tyler was.

Fast forward to October 2016, a routine dermatologist appointment. We went in there not knowing we would come out wondering what the dermatologist was on about.

Tyler had a rash around his mouth and the dermatologist asked me how many teeth he had, and I said he does not have any yet, which he should have had at over a year old. He started looking at his nails and whisped his fingers through the very little hair he had and said, 'have you noticed him sweat?' My answer was 'I don't think so?' He replied, 'Oh it is probably nothing to worry about' and just carried on as normal and off we went. I should have asked him why, but I just did not. The way the dermatologist looked at Tyler and the questions he was asking me was like he knew something, and that got me worried. I was wondering why he was asking these questions and why he looked at his hair and nails, I thought 'why would he need to look at his nails?'

On the way home I went to the trusty site, Google and typed in the things the dermatologist had mentioned and guess what popped up? Ectodermal Dysplasia! Nothing else, just that. That is when I searched on Facebook and came across The Ectodermal Dysplasia Society UK.

Oh my! I could have easily fit Tyler in with the pictures of other children affected by ED, the resemblance was uncanny. The more I was looking into it the more everything just made sense, right from when he was born. I phoned the doctors and got an appointment.

We explained everything to the doctor, she had never heard of ED so also googled it and linked Tyler to this condition. She went on to refer us to the genetics clinic, and at this appointment they clinically diagnosed Tyler with Hypohydrotic Ectodermal Dysplasia. They did not think Tyler would be offered genetic testing due to funding, but I received a letter offering it to him. He had his bloods taken and that came back, and confirmed Tyler had a faulty gene, WNT10A gene. This confirmed a diagnosis of ED

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Out of the blue I was offered genetic testing because they wanted to know where it came from, mine came back the same, which makes me a carrier. It did take me a while to get used to it all, I cried a lot, knowing that there was something 'wrong' with my baby and I did not know, and as a first-time mum that was scary. I do not see Tyler, or any other child for that matter, as having something 'wrong' with them anymore.

Ectodermal Dysplasia has made Tyler who he is, and I would not change him for the world. Yes, I would like to take away all the suffering he has to put up with, but he is who he is, and we are still learning every day.

Tyler is at school now and they are amazing! We have had hurdles to cross in the last 5 years due to illness and yearly overnight stays at the hospital. This is due to chest infections, which he does suffer with a lot, but they have recently diagnosed him with asthma so hopefully the medication will stop his 'attacks' which land in him hospital. His skin is better than it has ever been, we do have the odd flare up but its manageable and it is so comforting that he is starting to really understand how he is feeling and can let me know so I can help him.

If it were not for the ED Society, I would not have known what to do! Danielle, Jaye, and Diana have been absolutely amazing, and they should have all the recognition they deserve. They have guided me through everything from the little issues to the dreaded DLA forms, which was only successful because of their help.

I try my best to give back to them, I would even jump out of a plane for them....oh yeah, I have already done that! Scary or what?!

Also, thankyou to all the members of the ED Society for the support we all give to each other - my ED Family.

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