

Katie Mary Eleanor Ling – 1st Day at School

This is a small synopsis of my daughter's ED story; I hope it doesn't bore you to tears! I would hate you to think that due to my diatribe, that her life has been an endless tale of scary and depressing woe; I wanted to share some poignant experiences but I would like to add that these were but hiccups in a life that is full of love, smiles, laughter and as many happy moments that we could hope for.

My daughter Katherine Mary Eleanor was born on the 23rd May 1998, a beautiful sister to Matthew and was welcomed into our little family with a joy that could not be equalled. We used to laugh at her lack of hair and say how sure we were that she would soon have a head of blonde curls like her brother. Temperatures were high and nose bleeds rife but as she was a second child I didn't panic and dutifully sat up with her through the night, not thinking for a moment that this was especially abnormal or that they seemed harder to get down in that first year. We called her a 'Drama Queen' as the tantrums were explosive but again, in my book, just a personality trait and not to be confused with anything to do with what may have been a cry for help. Oh the guilt!

I can remember the day that I took Katie to the dentist, her first check up when she was just a tot at two years old. I was very uncomfortable about her very sharp abnormal looking teeth and the fact that only a couple had emerged. She sat in the chair like a 'big girl' and after examination, I distinctly remember the dentist disappearing for about 10 minutes and coming back with a book open on a page. He said, "I think your daughter has this condition". At that moment my world fell apart as I slowly read in intricate detail about every possible extreme case of ED contained in the book and looked at all the pictures of children and adults with the condition, focusing on the worst case scenarios in graphic detail. I was told that I should make a hospital appointment immediately so that this diagnosis could be confirmed. I can remember being very polite and thanking the dentist profusely before putting the children in the car, putting a nursery rhyme tape on and crying silently all the way home.

I had never heard of ED and nor had anybody that I knew. I spent a number of years working for a big Pharmaceutical Company full of Medics but even those that I contacted in desperation knew little or nothing about the condition. I made a Doctor's appointment for a referral, the Doctor had to get a medical journal out to look the condition up; I was referred on to a hospital and dedicated all of my time leading up to it, finding out everything I could about ED.

Katie was 3 years old by the time she had her first hospital appointment. Again, a medical directory was produced alongside a blank look admitting (to my horror) that the Consultant had not come across it before, or bothered to look it up before we came. I gave the Consultant a thick file of information that I had gathered, largely from the ED Society, in the hope that it might help. After a lot of 'discussion with colleagues' it was agreed that Katie should have a sweat test and that the first thing she would have to do was to get sweaty by running up and down the hospital stairs. Katie had iodine painted on her back and I asked if I could also be painted so that we were 'in it' together (not a great look and was stained yellow for ages!) It wasn't until we got to the top of the very steep, very slippery, very hard hospital stairs, it dawned on me that my daughter was not that adept with the stairs at home and needed the banister to keep her balance, let alone run up and down these hospital steps. As I had waited so long for the appointment and didn't have any other choice we slowly clambered up and down amongst the general public covered in yellow dye and after the third ridiculous slow attempt we went back to see the Doctor in defeat. His next grand plan was for us to go down to the Physiotherapy Pool where the humidity was high and 'blow' my daughter with a hair dryer to heat her up! I cringe when I think that I actually did as he asked – it was absolutely bonkers

- modern medicine – I think not! After failing miserably to get Katie to sweat he said that we needed to go home and come back to our next appointment with a fan heater – they didn't have any in the

hospital that we could use!

Cutting a very, very long story short, over the next few years we became regular attendees at a number of clinics

and eventually Katie was given an unconfirmed diagnosis of Hypohydrotic Ectodermal Dysplasia. When I asked what the future expectations might be (in addition to those symptoms that Katie already had, lack of sweating, tooth and mouth deformity, lack of hair which didn't grow in places, nail problems, eczema, nosebleeds, an enlarged pupil in her eye and 'thin skin'), I was given a list of possible scenarios to be aware of which frankly scared the life out of me for a number of years (most of which have never happened). I was determined to try and get a confirmed diagnosis so that we would have as much information as possible to hand, however, after years of having her bloods tested in various trials on the MSX1 and EDAR genes in this country and abroad, I have been told that her diagnosis still goes unconfirmed but "Hypohydrotic ED cannot be ruled out" (I feel it is fairly obvious what her condition is).

At this point in our lives, my husband upped and left, moving on to pastures new and my children at 4 and 5 had to deal with this horribly emotional change on top of everything else. I went to work at my children's Primary School, allowing me flexibility for hospital appointments and immediate access to Katie when she needed me in those early days of too hot/too cold (she used to go into a catatonic state).

Due to the problems that Katie was experiencing with chewing, eating and speaking, also with her self esteem in the tooth department, we started to attend the Eastman Dental Hospital where she was introduced to our saviour, Prof. John Hobkirk who, for the next few years until his retirement, spent hours fashioning the most perfect set of top dentures any little girl could ask for. Katie loved them (and him) and all other dentures (and dentists) since have paled into insignificance against those amazing hand finished creations. I will never cease to be amazed by Katie's bravery and patience in the Dentist's chair; she recently sat for a total of 5 hours with a rubber mat over her face and her mouth forced open having a procedure carried out, with not a word of complaint. When she was very young she needed some compacted teeth taken out of her gum and the Dentist said that it might be best if she had a general anesthetic as the work was quite tricky and extensive. She asked them if they could just 'get on and do it' as she 'didn't want to go home and worry about it'. They went ahead, much to my trepidation, with lots of local anesthetic injections and gas and air and managed the procedure on both sides of her mouth. When they had finished, her gums were bleeding and very bruised and they suggested that she might have to have time off school to recover. She got out of the chair and shoved in her denture (with everybody wincing) ready for the two and a half hour train journey back from London. She did not complain about the pain once and insisted on going to school the following day despite not being able to eat and the inside of her mouth being black with bruising! Katie, despite persistent oral infections and many oral complications over the years, will not leave the house without her 'Hollywood Whites' as we call them. She has a bottom set but has never really got on with them and presently has some caps topping precariously wobbly baby teeth with no roots at the bottom and nothing to replace them with. There is still a long road ahead for Katie in this department; we have always been told that she will be offered implants but I am not sure that this is going to be possible now, I am told that this is due to the lack of density in her jawbone and needing too much grafting – although I have an appointment at the Eastman shortly to discuss this. Sadly, as money in the NHS becomes tighter and waiting lists longer, recently I have had to fight hard to make sure that she gets the care that she needs and deserves.

After those early years of being mistaken for a boy over and over again because of her lack of hair, incredibly upsetting for a little girl, Katie was strategically chosen as Mary in the Pre-School Nativity Play. Overjoyed, we went on the hunt around the charity shops for some royal blue material to make her a costume. Sadly, in one shop the lady serving us commented, "Why on earth would they

choose a little boy to be Mary, how ridiculous!" We walked out with Katie in tears. When we went swimming, children laughed at 'the boy in the bikini'. After a couple of terms in her Reception Class, it was time for a wig!

One day, sporting a blond bob (not a very nice acrylic wig – you can get gorgeous real hair ones nowadays) that she was very proud of, Katie was sat with the rest of the Reception class listening to a story that I was telling. A 'lively' little lad sat behind her and was having great fun pulling the back of her wig so that it came off the front of her head, Katie would patiently pull it forwards again. I was acutely aware that this was happening over and over again and I could see that Katie was getting more and more annoyed, as was I. I had to stop myself from interrupting the story and telling the boy off which would have embarrassed Katie and I am very glad I did. Katie suddenly whipped off her wig and swiped it around the boy's face before quickly putting it back on. I am not sure who was more

shocked, Katie, the boy or me; either way it did the trick and he didn't touch it again! The wigs lasted for a couple of years until they got in the way of life, they were then demoted to the Dressing Up Basket and I took out a second mortgage to spend on hair products (which had little effect) and top Hairdressers who charged £50 for the two minutes it took to cut approximately three of Katie's hairs! Katie spent the best part of about four years wearing a 'Hoodie' or hats - whatever the weather or occasion, before having her hair cut really short all over which suits her down to the ground!

We also realised around that time that Katie had become violently allergic to horses and cats. She had her first riding lesson and was absolutely fine and then suddenly, taking her on a horse and trap ride, she came back with a very swollen, red face. With each exposure she got worse until even walking through our local high street and encountering a Jockey (we live near Newmarket, with its racecourse) was a trial. Her face would swell so much and so quickly, that it would be bruised when the swelling went down but luckily did not affect her airways; a real shame as we have horses in the family and I thought that this would be a fantastic hobby for Katie to have. My poor sister would have to clean her car, house and herself extensively on our regular visits and Katie had to be monitored very closely on school trips and trips out. Her allergy seems to have abated slightly as she has got older and is not as severe as it was.

Temperature control was a nightmare when Katie was younger often leaving her with very high temperatures for long periods and in the extreme, in a catatonic state. There are too many incidences to mention here that left her in severe difficulties. However, moving on to today, apart from her acute awareness of how to manage her temperature control, she also only seems to be affected when the temperature changes suddenly, ie. from extremely cold to hot or vice versa which I find interesting as when she was younger I thought that she was only affected when it was either really hot or really cold and didn't really think about how a sudden change would affect her..I am a little dim. OH THE GUILT!

Katie and I talked endlessly, about life, people and the world. I wanted Katie to be able to deal with difficult situations when I wasn't around to protect her from every Mother's worst nightmare - bullying. I was quite hard on her and would try not to get involved in her issues, instead giving her strategies to use herself and then talk about their effectiveness. I would never allow her to use ED as a means to get the sympathy vote or, in as many situations as possible, stop her from leading a perfectly normal life. Having coped beautifully at Primary School in her 'little family' of 220 and her Mum at hand, it was with huge trepidation on both our parts that Katie started senior school and was thrown headfirst into approximately 1,350 other children and immersed in the boiling pot of life!

From an early age Katie has had to deal with prejudice and bullying and learnt that people can be very cruel. ED or no ED, there is nothing worse for a Mother than to see your child crumble and their world destroyed by flippant comments made, not only by children but adults too. Katie has been called 'Worzel' (Gummage) and 'Jaws' amongst other wicked names over the years; she has been told that she couldn't be part of a group because she 'fell out of the ugly tree' and has been laughed at on many occasions. I remember the day she came home at 11 years old, with no shoes and a huge cut and lump on her forehead, her shoes had been 'stolen', disposed of over a fence and she had a stone thrown at her head – I don't think I have ever been so angry in my life and the situation was taken to the highest level and dealt with immediately. We have learnt over the years that this type of behaviour can be directed at any child, no matter what appearance whether it be glasses, colour of hair or size and actually, having ED does not necessarily make you an automatic target, although it doesn't help!

Each year brought different challenges for Katie and her early teens were beset with the normal horrors of teenage angst with a large dollop of lack of self esteem. I was therefore surprised that one day Katie came home and told me that she was 'in love'. I met the young man of her 14 year old dreams, a very attractive and popular boy at school and although horrified in one sense (protective Mummy syndrome) I had never seen Katie so happy. Three weeks into the romance and Katie announced to me that she was going to tell her beau about her condition, as she knew he wasn't aware that she had ED. I pointed out to Katie that as he obviously loved her for who she was, why would her having ED make any difference to him? She said that she wanted to be honest with him from the outset and so told him later that day - he dumped her on the spot and then made a sport of telling everybody at school it was because she had false teeth and was a weirdo.

The six months that followed are best skipped over as I dealt with the fall out of a very trying year for Katie, when fickle friendships came to the fore in loyalty tested by a popularity poll. Emotions ran high with some pretty difficult behavioural consequences. The limited contact over the years and total refusal to discuss her condition on the part of her Father came to the fore amongst many other issues and I felt myself gripping to that cliff edge with white knuckles alongside Katie in her attempts to pull herself out of the dark place she was in. Refusing to speak to a Councillor or accept any help that was offered, Katie slowly addressed that difficult time, again spending hours cuddled up on the sofa with me talking about life, society and people...she slowly picked herself up....she came through that chapter and into her bright future.

There are not enough adjectives to describe my daughter. Brave, beautiful (inside and out), kind, empathetic and loving are but a few. Katie is not defined by her ED, however, it is a part of who she is. Each challenging life event she has had to face as she has grown, has shaped her personality and enabled her to become a stronger and emotionally deeper human being; one that everybody loves. Obviously I am her Mum and very biased but this is not just my opinion and you would be hard pressed to find anyone who feels otherwise.

If ever there is a child at school who has a problem or is being bullied, Katie is there for them, sometimes to her own detriment. Throughout her education her teachers have always commented that, alongside being a lovely young lady with a wonderful sense of humour, she is very wise for her age and is one of the most empathetic children they have taught. Her debating skills are phenomenal and she often will leave me speechless and feeling somewhat at a loss!

We are extremely close and I know that this will never change whatever the future holds. She is a huge support to me and we only have to look at each other to know what the other is thinking. Katie is hilarious; very laid back (although has a fiery temper), she will always find something funny in any situation, however dire. She loves her brother, when she is not fighting with him (and winning) and I know that they too will still be very close when they are older. She still suffers from a lack of self esteem and is very body conscious, she still has obstacles to overcome with regard to her

teeth but she is quite frankly an amazing young lady for whom nothing is insurmountable, and who puts most adults I know to shame in the 'non complaining' category.

We are all individuals, from all walks of life, with different personalities, ideals, dreams and hopes but if you are reading this, we all have one thing in common; ED is a part of our lives. I hope that by writing about Katie, you may be able to see that you are not alone, I am sure that we all have similar stories to tell. Parents I salute and applaud you, it can be a long, hard road at times and I'm right there with you on that one! However, as Katie's sixteenth birthday looms, I look at myself in the mirror and examine the lines, which are not caused by stress - but laughter - and I look back at all the wonderful years full of smiles and love that nothing, least of all ED, can touch!

Sue Ling (Mum)



Katie Mary Eleanor Ling

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