

ED - A Personal Prospective

Throughout my life I've been brought up to be "thankful for what I've got" but realistically, as any normal person would, I generally viewed ectodermal dysplasia as a massive inconvenience. As you can imagine, being a 16 year old girl with hair that doesn't grow further than your ears, one practically blind eye and an overall vision that potentially won't be good enough to pass your driving test - isn't fun. You can avoid the subject as much as possible, and cover it up with synthetic plastic wigs that boil your brains when it comes to summer but it's always going to be there. I've come to grips with that.

A few months ago the BBC came into contact with my Mum through the ED Society asking me to speak a little bit about myself, what I've been through, and how a potential treatment being trialled by Angus Clarke in Cardiff could benefit me. Of course, my overly protective mother hesitated about asking me to speak about such a personal subject, but 2 minutes on the news? I wasn't going to say no to that! I've always tended to be open about my 'situation' as you might call it. I feel that it's easier to make jokes than to be overly sensitive and make people feel uncomfortable – that's just my opinion. My friends are amazing and have somehow managed to joke without being insensitive about the fact that I wear a wig and can barely read a sentence without my hilariously strong glasses. This has astounded me massively as I never imagined that I'd be able to 'fit in' to the mixed comprehensive school that I've attended for five years now. I suppose this is what may have given me the confidence to speak on the television about everything? I don't know. Either way, I found the whole experience very exciting. I know it was only a short clip, but with the camera man/reporter coming into my house and shining bright lights on me (which may I add, I wouldn't have been able to stand if this were happening several years ago – my eyes were truly horrendous back then) I felt almost famous! I was asked about my hair, my eyes, and all the usual things which I'm very used to talking about.



I liked that people were interested in what I had to say, but it was only when I was asked about the hereditary side of the condition that I was suddenly made hugely aware that I could pass this onto my children. Of course I had thought about it, but not really to the point where I remembered everything that my parents had to go through with me and then acknowledged the possibility that I could be put in a similar position in the future. The whole news section was based around the discovery of this treatment therapy and all I had really thought about was which outfit I was going to wear whilst being filmed. It made me realise the importance of this potential treatment, and made me determined to ensure that my children would not have to go through what I have. Despite this, I don't want any sympathy at all. I hate all the extra attention and the 'oh it must be so hard for you' because there are billions of people who are going through much worse than myself. Without this sounding cheesy and somewhat clichéd I'm really happy with where I'm at now, and I don't think I could've done it without my ever-so-wonderful family and friends. I most definitely never thought I would have the confidence to be on the news and honestly, I couldn't be more thankful.

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