

## “Even if you only remember the name, it’s a step in the right direction”

(Leonie Watson)

This is long, but it is really important to me.

This month is ectodermal dysplasia awareness month. I bet that none of you know what this is. It is a rare genetic disorder that even doctors know very little about, but I’ve been living with this my whole life.



My symptoms include a lack of teeth as well as sparse hair, poorly formed nails and lack of sweat glands which means I cannot control my body temperature, which is dangerous.

I am not as seriously affected as others, but it has impacted my day to day life for years. At primary school I was bullied because I was different to everyone else, I had no teeth, thin hair. When I overheated, I could not concentrate, and teachers thought I was disruptive in class.

I felt self-conscious growing up, only a very select few people knew I had ED as I did not want further bullying.

Some of you think I’m choosing to study dentistry next year for the money, but I just want to help people who will be going through my pain. A big moment in my life is coming up soon, I require 3 major operations for bone grafts and implants to give me a smile of my own. My whole childhood I was afraid to smile and show my lopsided and gappy mouth.

I was ashamed of not having teeth and I did not want to be seen as different from everyone else.

The charity the ED Society was set up to help people like me and my family understand more about this condition, to find medical specialist help, and to provide financial support to buy things like wigs or portable air conditioning units.

They are a small charity relying on donations and funding to continue to provide support.

They were the ones who helped me to find a specialist at Bristol Dental hospital after the John Radcliffe sent me away at the age of 3. Since then I have met many specialists who gave me my smile and I have remained under their care.



I am writing this to try to raise awareness and even if you only remember the name it’s a step in the right direction.

[#SupportingANormalLifestyle](#)

## Supporting a normal lifestyle

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