

Chopping off my loooooong hair

Hi everyone, my name is Tina Lloyd.

I just wanted to say a huge thank you to everyone who donated and wished me luck at the last social. The total from you came in at £170!! I am overwhelmed with the support.

After talking to a few of you last night I thought I'd answer a few of the questions (in case you are curious).

I'm chopping off my hair and, in the process, raising money for the charity Ectodermal Dysplasia Society. The condition is very rare, and I thought I'd explain what it is and why I'm involved.

Ellie, my daughter, has Ectodermal Dysplasia (ED). ED affects the outer layer of the body and is a lifelong syndrome that isn't out grown. For Ellie and others with the condition, it means that their skin, eyes, nails, teeth and certain glands (eg sweat glands) do not grow or function properly and often become infected, as they are malformed or absent. Ellie isn't 2 yet, but she has glasses, hearing aids and many medical appointments, including 5 operations so far. There is a website for ED if you are interested in reading more about this - www.edsociety.co.uk.

The charity offers support and advice with the day-to-day management of ED, as well as the emotional and practical side of it. One thing they have done is help with the support and cost of getting wigs for the few people who have needed it due to ED. My hair will be going directly to my daughter, when she is old enough to understand the sentiment and decide if it's something she wants.



A large majority of children with Ellie's type of ED have light sparse, brittle hair that has patches of Alopecia from previous infections and scars on the scalp. Some children have managed to grow their hair to a short length before it has stopped growing and has all fallen out and others never manage to grow theirs; a few have gone into adult hood with their hair. The future is uncertain for Ellie which is why I'm planning ahead. If she is lucky enough to not need the hair, then it will be donated to someone else who needs it.

So, there's a little snap shot of what it means to me and why I'm being a pain and dancing around telling everyone about it. I've included some photos of my daughter and from my virgin money giving page for you to have a little look through too.

Once again thanks so much for your kind support, I'm so touched and grateful that Ellie will grow up surrounded by a community that has such big hearts.



Supporting a normal lifestyle

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