

## Wigs from the NHS—YES!



At the age of four Lucy was diagnosed with Ectodermal Dysplasia which we had never heard of before and her dermatologist explained what it was. On the way home after the diagnosis I was still confused and shocked as I didn't know what it actually was, so I searched the internet and found more information about how hair is affected in ED as Lucy's hair hadn't grown longer than an inch! I was very concerned as I realised that my little girl would want to have long hair - all little girls love long hair - bobbles, etc.

When Lucy started school she so wanted to be like other little girls and asked for a wig. With the help of Ectodermal Dysplasia Society Lucy was funded her first wig - she was delighted, as was Mum and Dad - happy tears all around !!!

Unfortunately human hair wigs don't have a lengthy life span so when it was time to get a replacement we made an appointment with the Dermatologist. He is a lovely man but told us Lucy could have a synthetic wig, but it's very difficult to get funding for human hair wigs as it is seen as "cosmetic"!!! Don't think so!! So we had to fund her next wig as synthetic wigs are so unnatural and hot to wear. Lucy has come to depend on her wig and is extremely anxious, frustrated and upset if she can't have her wig to wear to school.

The NHS criteria for a natural hair wig is that you have to have a scalp skin condition which prevents you from wearing synthetic wigs, as synthetic wigs are hot and scratchy to wear and ED causes overheating and sensitive skin, I decided to launch into a mission!

We were given six monthly appointments with the Dermatologist, but I went back earlier as I really was on a mission and there was NO way I was going to back down on this!! So every appointment was the same.. "Hi how's Lucy?" I would explain that she is fine but I still think the NHS should be funding a natural hair wig for her. At one appointment I was told that it would be passed on to "NHS Funding Manager" who would look at Lucy's case. I was then informed that they couldn't help with natural hair wigs, but she would be entitled to an NHS synthetic wig. I don't think so! I had many receptionists telling me, no, the idea was crazy, call back, anything to try and get rid of me! I had had enough - I called the Dermatologist's receptionist and told her I wanted to take it higher than the funding manager. I was calm, direct and assertive. I then had a call a week later saying they wanted me to write a letter! After 4 years they wanted a letter?!?!? OK, I wrote a very long letter including every detail possible which I found very draining and emotional! I explained the NHS fund people with methadone - they chose to have that drug... they give anti obesity drugs at the cost of thousands of pounds, incentives for stopping smoking - they chose to light that cigarette!!! My daughter didn't make the choice to have Ectodermal Dysplasia - genetics chose it for her.

I was then asked to go into hospital for another meeting where the Dermatologist said he would put Lucy forward for an Individual Funding Request (IFR) review under my local PCT, this involved our family doctor, more letters, more phone calls, more examples etc., etc. Whilst all this was incredibly draining there was no way I was backing down. Lucy's panel review was on the 15th June. On the 20th June I had a letter telling me that she is entitled to 2 HUMAN hair wigs every year until she is 16 years old!!! Result!!!! Absolute result - thrilled was not the word for it after 4 nearly 5 years my personal battle was at last over.

The secret to all of this .... DON'T BACK DOWN.... Be prepared to be told no, but don't let that dishearten you. Carry on and on and on and on.... I thought I was going mad at times repeating myself over and over again to the point where I thought my Dermatologist dreaded my appointments. He's a lovely man and knew I was doing the right thing for my daughter. Be armed with your facts, with examples of what the NHS funds are for - relate that to what you actually want funding for... Keep strong ... Keep calm and there should be success.

If any Mum or Dad of a child who has ED and is currently fighting the NHS for a natural hair wig or would like to, please feel free to contact me via the ED Society office and I will try to help.... You can do it !!!

## Supporting a normal lifestyle