

Hi From an American Teen

Hello my name is Kimi; I'm 16 and was born with Ectodermal Dysplasias. I came across your site when I was looking up research for a science project and just decided to look up pictures of ED.

My story may be a little different than others because I actually didn't even know I had ED until my sophomore year (2nd year student) in high school when I went in for my physical. The doctor, who I have never seen before in my life, asked me 2 questions and told me I had ED.

He wasn't my regular physician, so for him to have just met me and diagnosed this, was a huge shock because my normal doctor, family, friends, in fact everyone, just thought I was born normal. No one knew. Ever since then I have been putting out the word that I have ED on my MySpace and Facebook (which any teen nowadays knows about) so that everyone who knows me can on it, Google and find out more about it, which they all have, and still love me the same and don't judge me any different.

Back before the diagnosis, I knew that there was something wrong with how my hair wasn't growing like all the other girls around me, and that my fingers and toes were just a little off. I always just joked around with it or just sat there wondering. Growing up was brutal for me and still is. I would ALWAYS get teased, picked on, got called names and had assumptions made by people in my school. Once I entered high school I would come home in tears almost every day because of what people would say about me and even to me. It got to the point where I had absolutely no self-esteem or self confidence whatsoever; I couldn't take it anymore, so this year, my junior year in high school, I knew I would not repeat the past and refused to go to school without making a change. So I spent week after week going online trying to find a solution. One night I was sleeping over at a friend's house and we discovered that Locks of Love helped those with ED, so my mom and I tried that solution, but I didn't go through with it because I didn't want to shave off what little hair I had! That was a bust so again, I spent week after week trying to find a wig that I could wear for the school year. I found a synthetic one, but soon realized it was just too much of a mess to handle; I still wasn't happy; everyone knew it was fake and I couldn't style it. In November 2008, after looking for a human hair wig, I got one with a more natural look. I like it better because everyone still cares for me the same, my confidence has boosted tremendously and I've gotten some looks from the boys :] Everyone knows it's fake, but I continue to put the word out about it and am so surprised that even the boys that are interested, don't even care I wear a wig. However there is a down side, I can't accept sleepovers from new friends because I'm scared to take it off now; it still gets matted up and damaged like the synthetic one, I am still on the verge to finding a solution to making my life happier and easier for me and my mom, who doesn't like spending so much money on new wigs every couple months.

So, this is me, and this is my story.