

## Instinct Knows Best - Zoe Dunham

Hello, my name is Zoe and I am a carrier of HED. It first became apparent to my parents that I was a carrier when my baby teeth started to come through pointed, and missing. My Uncle has HED, and my Nan, Mum and Aunty are also carriers.

As a child I was very aware of my 'strange' teeth and would get hot faster than everyone else, but other than that, the condition never affected me. When I started to hit puberty and all my friends were developing breasts, I of course began to compare myself to others. I used to tell my mum that I thought I was deformed, and I wasn't growing properly. I never showed her, as I was too embarrassed. My mum just put it down to being a teenage girl worrying about having boobs like everyone else. She would say, "You're still young, they will grow!".

At 20 years old I decided that if I was going to develop 'normal' breasts, it would have happened by now. I plucked up the courage to properly talk to my mum and show her why I had been saying my breasts were not developing as they should. I wish I had done it sooner. She organised to go to the doctor with me, however at first the doctor just said I had a small amount of breast tissue, and that was just the way I was. I knew in myself that it wasn't right, but we always think that doctors "know best".

Later the same year I got in contact with Diana Perry and found the ED facebook group. After emailing Diana, I applied for genetic testing, in preparation for when my partner and I wanted to start a family. It was then that I met my genetic counsellor, Janet Rezzougui, and geneticist, Dr Sarkar. Talking through the usual symptoms and family history of HED, breast development was brought up. Female carriers of HED may also present a lack of breast development, sometimes with no breasts at all being the case. I had never thought until then, that being a carrier of HED may have caused my breast issues growing up. My geneticist referred me to the Lincoln County Hospital where I began my journey to breast reconstruction.

My consultant, Dr Gvaramadze, at Lincoln County was fantastic and caring. He explained that in my case, it was not a simple breast augmentation. Because my right breast lower pole was completely missing, he had to reconstruct the breast using expandable implants. I went for my operation in December and am so happy that I did. It has really boosted my confidence and made me feel content. I will have to go back as they gradually expand the implants but I know that I can see a finish line. I always used to joke and put on a brave face, but inside I was embarrassed and self-conscious. I can now move forward and not have to think about it.

Any female that believes they have a problem with breast development, and you are a carrier of HED, please go to your doctor or even ask your geneticist for a referral. Don't wait as long as I did as there is help out there. It is nothing to be embarrassed about, although I know it is such a personal subject for any woman.

I hope that anyone reading this, and any parents with a daughter, if you think this could be an issue, please talk about it openly and know that something can be done.

## Supporting a normal lifestyle

Ectodermal Dysplasia Society (Registered Charity No. 1089135). Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.

## **Supporting a normal lifestyle**

Ectodermal Dysplasia Society (Registered Charity No. 1089135). Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.