

Stories of Support

We are a family.....

Ectodermal Dysplasia runs in my family. My grandmother, father, uncle and cousin all have ED. Growing up I didn't know what it was called, and I never realised any children I have could possibly be affected.

When my son Harrison was born, it quickly came to light he also has ED. I have my family for support, and they have been amazing, but even having a slight understanding of what ED entails is still not enough to prepare you for what the future holds.

After trying to discuss ED with many medical professionals, and them not having any idea what ED is, I soon began to feel very alone. I worried my son would not get the help and care he needs and deserves. I came across the ED Society on Facebook.

Firstly, I spoke to Stuart Atkiss (ED Society's Fundraising Coordinator), who then put me in touch with Jaye Keen-Dix. Jaye has been incredibly supportive from the beginning, always listening to my concerns whilst fully understanding what we are going through.

Harrison had been to see dental specialists who refused to do anything to help him until the age of 8 years old. After seeing the specialist and being told they would not be doing anything for several years, I felt like I had hit a brick wall and was unable to help my son, yet Jaye supported with a referral to Bristol Dental Hospital. They will now be providing Harrison's dental care. Jaye has also guided me through our application for Disability Living Allowance for Harrison.

The support and help that Jaye has provided has really helped me to stand up and advocate for my son. For a long time I struggled to accept that Harrison has ED, but now I see ED as a positive thing, and it is what makes my son extra special to me.

I am so glad I contacted the ED Society as they have really helped me to mentally embrace ED for what it is, as well as provide advice, tips and support to help us continue living our daily lives to the best of our ability.

Before the ED Society, I felt so alone and like I had no one to turn to, but now I feel empowered to fight for my son and spread awareness about ED for everyone affected.

I am eternally grateful to the ED Society, particularly Jaye, who has not only helped my son, but has been more like a friend who genuinely cares. Thank you Jaye, and the ED Society. We are not just a group of people; we are a family.

Jennifer & Harrison



Supporting a normal lifestyle

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