

“This feels like a little family to me – we are not alone!”

February was Ectodermal Dysplasia Awareness Month, and I would like to say a few words about how the ED Society and ED community have helped me and my family throughout the years.

I am a carrier of Hypohidrotic Ectodermal Dysplasia, and even though I carry the condition, I never knew that much about it until I gave birth to my son 6 years ago. Shortly after this, I started noticing differences about him compared to my other friends' children and soon after, we received the diagnosis.

Since then, I have turned to the ED Society for advice and support many times, whether that be on keeping him cool or pushing for referrals with his GP.

My main support has been Jaye, the ED Society's Family Liaison. She has always made me feel welcome, and that no question is too big of an ask. She has helped me when filling in DLA forms to get my son the appropriate help he needs.

This feels like a little family to me, I can relate to so many of you and I am so relieved that the support will always be there, and we are not alone.



Supporting a normal lifestyle

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