

“ It’s exhausting telling the same story to so many different people to get the help needed for your child.

“ When you have a rare disorder, you don't fit tick boxes. This automatically places you on the outer and everything you need becomes what feels like an impossible battle with our own health services.

“ We're not one size fits all and at times it can feel very much like we're being squashed into a box we don't fit.

“ What would be great is if doctors had more understanding towards parents who know when something isn't right with their kids.

“ Over the course of 10 months, we went through three GP practices trying to find someone, anyone to listen. I eventually refused to leave without a referral to a paediatrician.