

Dear Parent/Carer,

If you are reading this letter you have probably just come away from an appointment with a doctor and you, or someone you care for, has been given a diagnosis of a rare condition. My name is Rebecca and I am mother to a little girl with not one, but two incredibly rare genetic conditions that have names that don't roll easily off the tongue. I am also part of a Patient Advisory Group within the Office for Rare Conditions, Glasgow, and we want to reach out to you, to let you know we are here. You are not alone.

I have been where you are right now, several years ago, and remember all too well the tornado of feelings that came along with her diagnosis. Getting this news may have blindsided you and come out of the blue or, as it can be for many people, it may be the culmination of battling to be heard and searching for answers. Either way, there is a good chance you are brimming with unanswered questions and confusing emotions that range from relief to fear for the future. The whys? What ifs? Why them? Relief that it wasn't all in your mind, and worry about all the questions that you forgot to ask at the appointment.

Each and every single thing you feel right now is normal and it's ok. It's also ok to grieve and feel angry.

While individually rare, rare conditions are collectively common and there are over 7000 known rare conditions. You are not alone.

A support group could become your lifeline. Many patient support groups operate through social media where the families themselves form a vital community and share their lives for the common benefit. No matter how rare the condition, you are now part of a global community who share similar journeys. The Patient Advisory Group from the Office for Rare Conditions is here to support you as you navigate this path.

The Office for Rare Conditions has been a wonderful place of support and help. They've celebrated our victories and helped encourage us to keep going when times have been tough. They run family fun days and meet ups and help give a voice to those walking a different path to what was expected. We've also made some incredible lifelong friends with other families as we weave our new tapestry of connections, who, although they have a different diagnosis, travel a very similar journey. I would love to welcome you to the patient group when you feel ready. You can get in touch with me by e-mailing or calling the Office and asking for Rebecca. They will pass a message to me and I will get in touch with you.

Yours

A handwritten signature in black ink, appearing to read "Rebecca", with a long horizontal flourish extending to the right.

Office for Rare Conditions

Phone: 0141 451 5899

Email: info@officeforrareconditions.org

Social media: (Facebook/Instagram/Twitter): @ORCGlasgow