

# LIVING WITH A RARE OR UNDIAGNOSED CONDITION: THE EMOTIONAL IMPACT AND EFFECT ON MENTAL HEALTH



Your chance to take part in new research.

**Do you have a rare or undiagnosed condition?**

**Does your child have a rare or undiagnosed condition?**

**Would you like to take part in a study that will help us to understand more about the emotional impact of living with a rare or undiagnosed condition, and how support might be improved?**

Living with a rare or undiagnosed condition can have a huge impact on patients and families. However, our recent patient experience report showed that many individuals are not getting the support that they need. This new study will involve being interviewed by phone about your experience of living with a rare or undiagnosed condition, or having a child with a rare or undiagnosed condition, and particularly the emotional impact that this has had on you, and/or your child. We would also like to hear your thoughts about accessing psychological and emotional support services.

**If you would like to take part in this research or would like to ask further questions, please contact Rosa Spencer-Tansley via e-mail on [rosa.spencer-tansley@geneticalliance.org.uk](mailto:rosa.spencer-tansley@geneticalliance.org.uk) or call 0207 831 0883.**

We will be carrying out the interviews over a short period of time and it is possible we will not be able to interview everyone who volunteers if we have a huge response. Before you sign up, we will ask you some basic questions about your and/or your child's condition; your and/or your child's age; and your location. This is to help us with selecting participants for the study so that, if we cannot manage to interview everybody, we will be able to include a broad range of people and conditions. The information you provide will be deleted after selection has taken place.

*Please note: this research is not approved under the Mental Capacity Act (2005). Therefore we will not be able to interview individuals who do not have capacity to consent for themselves.*

We will also be releasing a survey online later in the year, so that everybody who wishes to take part in the research will get the chance to have their voice heard. This project is funded by public donations to Rare Disease UK, the national campaign for all those affected by rare diseases, run by the charity Genetic Alliance UK.

**Please also contact Rosa if you would like this information in a different format or in the Welsh language.**

Rare Disease UK  
[www.raredisease.org.uk](http://www.raredisease.org.uk) [info@raredisease.org.uk](mailto:info@raredisease.org.uk)

Rare Disease UK is a campaign run by Genetic Alliance UK  
Registered charity numbers: 1114195 and SC039299  
Registered company number: 05772999