

# EMOTIONAL WELLBEING AND MENTAL HEALTH SURVEY



**We need your help to understand the emotional impact of living with a rare or undiagnosed condition.**

Earlier this year, Rare Disease UK carried out interviews with patients and carers for a study on mental health. Interviewees told us about their experience of living or caring for someone with a rare or undiagnosed condition, and the emotional impact that this has had on their lives. We also heard about people's experiences of accessing psychological and emotional support services, and how things could be improved.

We found that living with a rare or undiagnosed condition can have a huge impact on patients and families. However, as our recent [patient experience report](#) has shown, many people are not getting the support they need when they face mental health challenges.

In order to gain greater understanding of the relationship between mental health and rare disease we need your help. **We want the views of as many people as possible, click here to take part in our [online survey](#). The survey will be open until Sunday 10 December and takes 20 to 30 minutes to complete.**

By taking part and sharing your experience, or that of your loved one, you can help us to identify the gaps that exist in care and support. Your input will help us to develop recommendations and to call on policy makers to improve the mental health support available for patients and families affected by rare conditions.

**Follow the link above to fill in the survey, or if you have 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.**

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

If you would like to talk to somebody about mental health or wellbeing please contact a healthcare professional such as your GP. You can also access information or support about mental health from:

[Samaritans](#), who offer a free, confidential, 24 hour support over the phone (116 123) or by email (jo@samaritans.org).

[Mind](#), the mental health charity, also offers information over the phone (0300 123 3393) by email (info@mind.org.uk) or by text (86463). You can also visit Mind's [website](#) for information and advice about support services and mental health.

[The Carers Trust](#) also provide [information and support](#) to carers, including around [mental health and wellbeing](#).

This project is funded by public donations to Rare Disease UK.

To help us to continue to conduct vital research, text RDUK01 £5 to 70070 to donate £5 to Rare Disease UK - and make a difference today. JustTextGiving by Vodafone.