**Subject:** Make your voice heard: Take the new global Rare Barometer survey and share your experience of seeking a diagnosis!

We need your help to ensure as many people as possible from the rare disease community complete the survey. The more people will take the survey, the stronger our voice will be!

[You can access the online survey here.](http://tiny.cc/survey_diagRD)

It should take no more than 20 minutes to complete and closes on 15 June 2022.

Obtaining a diagnosis can be a long and difficult journey for both patients and their families. By asking questions on the support you had, the difficulties you encountered, or on the consequences of being undiagnosed or misdiagnosed, we will be able to better identify how to improve the diagnosis journey of people living with rare diseases.

**This survey will enable us to communicate facts and figures to decision-makers**Overall results will be shared with everyone who responded to the survey and communicated to patient organisations, policy makers and the general public, in order to drive real change for the rare disease community. We can organise meetings to discuss the findings from your country, disease, or disease group, and discuss how you can use the results in your own advocacy work.

[You can find more information on this survey, and the Rare Barometer initiative here.](https://www.eurordis.org/diagnosissurvey)

This survey is open to people living with a rare disease and their family members from any country in the world. It is translated in 26 languages.

**Please note:**

* All responses are anonymous and will be kept in secured storage only accessible to the Rare Barometer research team.
* All of the information shared with us is completely confidential, and complies with the General Data Protection Regulation (GDPR).

Thank you very much in advance for your participation!  
Kind regards,  
The Rare Barometer Team