Subject: Make your voice heard: take the new Rare Barometer survey on rare disease patients’ experience of COVID-19

The new **Rare Barometer** [**survey**](https://www.eurordis.org/covid19survey) on rare disease patients’ experience of COVID-19 is now live.

**You can access the online survey** [**here**](https://bit.ly/2xCUw9l)**.**

This survey is essential for the rare disease community. It will enable us to measure how the virus is affecting rare disease patients’ lives and give us the possibility to communicate facts and figures to decision-makers, so that people living with a rare disease are not left behind when handling the crisis.

The survey should take no more than 15 minutes to complete. All responses are anonymous and will be kept in secure storage only accessible to the Rare Barometer research team.

You can find more information about the survey here.

Through asking questions such as how the COVID-19 pandemic is affecting patients’ care, social care, employment situation, and mental-health, we will be able to better understand this unprecedented situation.

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 23 languages.

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!

Thank you very much in advance for your participation,

Kind Regards,