

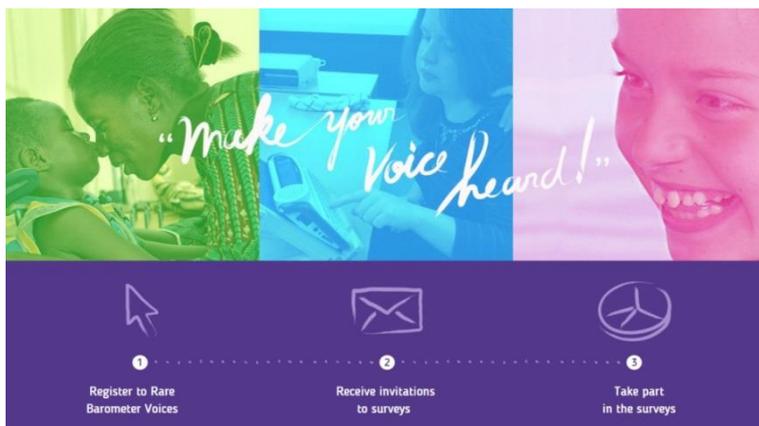
Register for Rare Barometer Voices to make your voice heard!

www.eurordis.org/voices

9 March 2016, Paris – EURORDIS, the European Organisation for Rare Diseases, invites rare disease patients, family members and patient representatives to [register for Rare Barometer Voices](http://www.eurordis.org/voices), a new interactive survey panel available in 23 languages that collects the experiences of people that are living with or affected by a rare disease.

Rare Barometer Voices seeks to make the voice of rare disease patients stronger and ensure it is heard across Europe.

After registration, participants will be sent an email to request their participation in each new survey related to specific subjects that concern them. They are free to decide which surveys they wish to participate in. All responses are anonymous, completely [confidential](#), owned by EURORDIS and will not be used for commercial purposes.



Participants that register should live in one of the European continent countries (as defined in the [EURORDIS membership criteria](#)).

Survey results will be sorted according to country and ultimately disease and will be also available to survey respondents.

Rare Barometer Voices is part of the new EURORDIS initiative, the [Rare Barometer Programme](#).

Spread the word!

Support for Rare Barometer Voices from EURORDIS member organisations is essential to ensure the quality of the results. By letting members of your organisation know about Rare Barometer Voices you can help to make the voice of the rare disease community stronger:

- Share the dedicated webpage (eurordis.org/voices) on social media using **#RareBarometer**
- Download a template email to encourage people to register (available in 23 languages: [EN](#), [BG](#), [CS](#), [DA](#), [DE](#), [EL](#), [EN](#), [ES](#), [ET](#), [FI](#), [FR](#), [HR](#), [HU](#), [IT](#), [LT](#), [LV](#), [NL](#), [PL](#), [PT](#), [RO](#), [RU](#), [SK](#), [SL](#), [SV](#))
- If you would like to receive a Facebook post announcing the launch of Rare Barometer Voices in any of those languages, please email rare.barometer@eurordis.org
- Download the [Rare Barometer Voices logo](#):

How does Rare Barometer Voices feed the advocacy work of the rare disease community?

By collecting the opinions of rare disease patients across Europe through Rare Barometer Voices, they can be presented to policy and decision makers, patient organisations and the general public and used to raise awareness and influence policy that directly affects those living with or affected by a rare disease.

This unique survey panel creates an opportunity to collect patient experiences and expectations with validated methods in qualitative and quantitative data collection thanks to Rare Barometer Voices.

The wider [Rare Barometer Programme](#) will help to:

- Produce evidence on topics relevant to European legislation and policy
- Inform legislation and policy on topics relevant to rare disease patients
- Promote and improve research on patients' perspectives
- Effectively communicate the opinions of rare disease patients on transversal topics and minimise gaps in disease-specific knowledge via [RareConnect](#) polls.

The Rare Barometer Programme has been created to make the rare disease patient voice stronger by ensuring that the patient perspective is entrenched in the advocacy work of EURORDIS and its members.

Evidence-based policy equals more effective policy. EURORDIS' strategic positioning at the heart of the policy and regulatory framework in Europe allows for the direct transformation of patient perspectives into policy and action.



Please contact Sandra Courbier, Rare Barometer Leader, with any questions:

rare.barometer@eurordis.org

For media enquiries please contact Eva Bearryman, EURORDIS Junior Communications Manager: eva.bearryman@eurordis.org

###

Rare Diseases

The European Union considers a disease as rare when it affects fewer than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

EURORDIS

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing over 700 rare disease patient organisations in 63 countries. EURORDIS represents the voice of an estimated 30 million people living with a rare disease in Europe. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information visit: www.eurordis.org