



Press release

First Rare Barometer Voices survey on the impact of rare diseases on daily life

Paris, 2 August 2016 - EURORDIS-Rare Diseases Europe today launches a [new survey](#) on the impact of rare diseases on daily life.

The survey is the first to be launched under [Rare Barometer Voices](#), a community of people living with or affected by a rare disease who participate in EURORDIS surveys and studies.

People living with a rare disease, parents and other family members can take part in the survey (**available in [23 languages](#)**) and patient organisations are also invited to encourage their members to participate.

What is the survey?

EURORDIS wants to hear from rare disease patients, parents and family members on how living with a rare disease has impacted their independence and daily life including at work and school. EURORDIS also wants to learn more about the level of support received, how care is organised and the costs of care.

In order to respond to this survey, participants will first be required to register to [Rare Barometer Voices](#). Anyone who has already registered will automatically receive an email invitation to participate in the survey.

Why?

[This survey](#) is crucial to increase knowledge of the needs of people living with or affected by a rare disease and their families in terms of daily life, social care and coordination of care.

To ensure the quality of the survey's results it is crucial that as many people living with a rare disease as possible take part. The results will help EURORDIS and EURORDIS members to advocate for better care and support for people living with a rare disease in Europe.

The results will be available for EURORDIS members to use according to country (48 European countries), disease when possible and in 23 languages.

How?

The questionnaire is available in [23 languages](#). The study is divided into two stages and people who answer the first will also be invited to answer the second.

Stage 1: Starting from now - questions on care needs, access, costs and coordination.

Stage 2: Starting in October - questions on employment and school in relation to how rare diseases impact parents' or adult patients' daily life.

The full survey report will be **available in January 2017**. The shaping of the study has been a collective process closely involving EURORDIS members and volunteers.



Please contact **Sandra Courbier**, **EURORDIS Surveys and Social studies Manager**, with any questions regarding the survey or Rare Barometer Voices: sandra.courbier@eurordis.org.

This survey is carried out in the scope of the [INNOVCare](#) project. This European Union-funded project addresses the social challenges faced by people living with rare complex conditions and the gaps in the coordination between health, social and support services in European Union Member States.

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EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe, 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

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.