

# JUGGLING CARE AND DAILY LIFE: THE BALANCING ACT OF THE RARE DISEASE COMMUNITY

Through its survey initiative Rare Barometer Voices, EURORDIS-Rare Diseases Europe carried out the first European-wide survey on the impact of rare diseases on everyday life. The survey covered issues including coordination of care, mental health, employment and economic impact. This document presents the results for rare respiratory conditions.



**30 million**

people are living with a rare disease in Europe and 300 million worldwide



No cure for the vast majority of diseases and few treatments available

## Rare respiratory diseases seriously impact everyday life

**7 in 10** patients & carers

reduced or stopped professional activity due to their or their family member's rare disease.



**7 in 10** patients & carers

have difficulties completing daily tasks (household chores, preparing meals, shopping etc.)

**1 1/2** of patients & carers

spend more than 2 hours a day on disease-related tasks.



**2 times** more people

living with a rare disease and carers report being unhappy and depressed than the general population\*

\* Rare Barometer Voices sample compared to International Social Survey Programme, 2011



Rare Barometer Voices is a EURORDIS-Rare Diseases Europe online survey initiative. It brings together over 6,000 patients, carers and family members to make the voice of the rare disease community stronger. Results are shared with policy decision makers to bring about change for people living with a rare disease.



**Thank you to all Rare Barometer Voices participants and partners!**

[www.eurordis.org/content/contribute-rare-barometer-programme](http://www.eurordis.org/content/contribute-rare-barometer-programme)

**126** people with rare respiratory conditions responded to the survey

The survey was conducted in

**23** languages across **42** countries

For more information visit [eurordis.org/voices](http://eurordis.org/voices) or email [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)