

# An insight into the participation of patients affected by rare and complex epilepsies in research

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

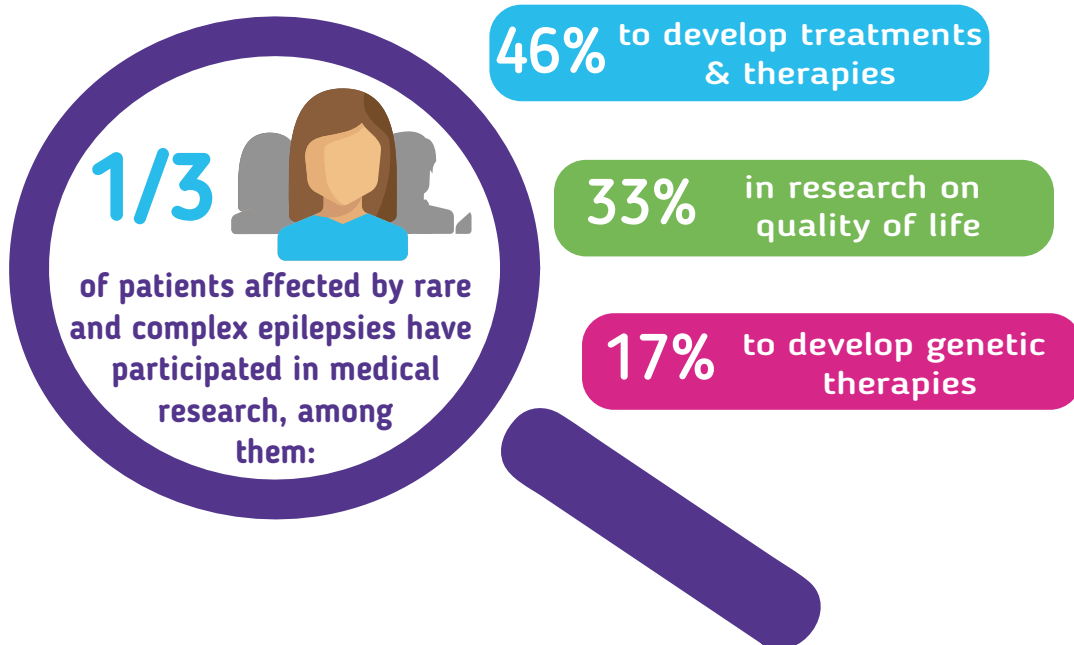


No cure for the vast majority of diseases and few treatments available

**65** patients and their families affected by rare and complex epilepsies responded to the survey, conducted in 23 languages across 42 countries worldwide

## Key findings of a Rare Barometer Voices survey on the participation of patients affected by rare and complex epilepsies in research:

### What type of research do patients participate in?



### Top 3 obstacles to rare disease research

Lack of public funding

Lack of private funding

Insufficient dialogue between scientists, patients and clinicians



Rare Barometer Voices is a EURORDIS–Rare Diseases Europe online survey initiative. It brings together over 8,000 patients, carers and family members to make the voice of the rare disease community stronger.

Thank you to all Rare Barometer Voices participants and partners! To read the full report, register to participate in future surveys or for more information, visit: [eurordis.org/voices](http://eurordis.org/voices)