



The economic impact of rare disease

Patient Testimonials

Lise Murphy, EURORDIS Volunteer

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ECDR, VIENNA

EURORDIS.ORG



Heavy time-burden for patients and carers

- **42% of carers and patients spend more than 2h/ on illness –related tasks per day**
- **70% of patients and carers had to reduce or stop their professional activity**



http://download.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20ofinal.pdf

Ebbe and Lise

Marfan syndrome







Annalena and Augusta

Fibrodysplacia
Ossificans Progressiva
(FOP)

Heavy time burden for patients & carers

30% Of patients & carers spend **more than 6h/day** on illness-related tasks

49% Of carers attending **severely affected individuals** spend more than 6h/day on these tasks.

Annika and Milla

Amyotrophic Lateral Sclerosis (ALS)





**Thank you for your
attention.**

Lise Murphy

EURORDIS-Rare Diseases
Europe Volunteer

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