

Social media platform dedicated to rare diseases, using collective intelligence for the generation of awareness and knowledge

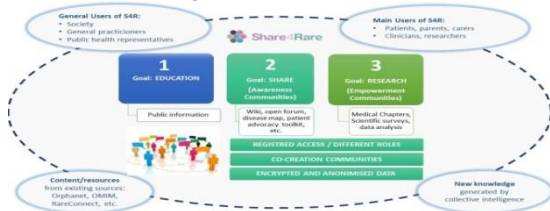
Rare diseases: are they so uncommon?

- ✓ We define as **rare** a disease when it affects less than 5 in 10,000 people.
- ✓ To date, we know between 6000 and 8000 rare diseases (RD).
- ✓ This means that **30 million** of Europeans suffer a rare condition, and **half of them are children** (approx).

What Share4Rare is?

- ✓ Is a European project of the CAPSSI framework – Collective Awareness Platforms for Sustainability and Social Innovation.
- ✓ Is a **collaborative network** of patients, families, carers, researchers, clinicians: all of them share their efforts and increase the **collective intelligence** on RD.
- ✓ Is a space to increase the scientific knowledge on RD that affect children.

The three pillars of Share4Rare



Share4Rare is structured in three levels:

- **Education.** Public layer informing people about RDs.
- **Sharing.** Increasing the awareness of the RD communities with innovative social media tools.
- **Research.** Generating knowledge from the collaboration between patients/families and researchers/clinicians, in a private and secure environment to collect clinical data. It is the core of the platform.

Patients and families are involved in:

- ✓ Contributing to the progress of medicine by their direct contact with clinicians and researchers.
- ✓ Ensuring that the design, the tools and the content of the platform suit their own needs.
- ✓ Giving a feedback in every phase of the project.
- ✓ Choosing the IT and social media tools that best tailor for sharing their stories and experiences.

Patients are the heart of S4R



Specific objectives...

- ✓ To increase the awareness on RD in Europe and generate social conscience.
- ✓ To exchange experiences between patients, researchers and general practitioners in the field of RD.
- ✓ To reduce the isolation between patients and families.
- ✓ To develop registries where the whole RD community can use and take advantage from the reported outcomes and clinical data generated.