



Share4Rare is born, the first social network to connect patients, caregivers and researchers of rare diseases around the globe

Rare diseases are a set of around 8,000 different conditions that affect approximately 30 million people in Europe alone, out of which 80% are children. Despite that, only about 10% of these diseases have a solid scientific knowledge base. To deepen the knowledge of the remaining 90% Share4Rare will offer a virtual and **safe meeting place** for **patients and families affected by rare diseases**, while collecting relevant information to advance in the research of these conditions.

Share4Rare aims to create a large social network that, unlike conventional forums, incorporates mathematical algorithms which will help connect users based on their profile, and it will make possible for people to direct their queries to those who are most likely to be able to provide an answer.

Share4Rare will also help patients and carers affected by the same disease or symptoms to connect and support each other. This is extremely important in the rare disease community where conditions have a very low prevalence and a high heterogeneity of symptoms.

The Share4Rare platform has been publicly released today, 2nd April, under the slogan "Let's make rare extraordinary". In addition to connecting families who may be living in isolation with a rare disease, Share4Rare aims to empower them to manage their condition by providing access to educational materials written by medical experts in their field.

Share4Rare will also collect clinical data from users of the platform, which will form a basis for research and development. In the first phase, the platform will collect data for two large sets of diseases: paediatric tumours and neuromuscular diseases.

Experts from the Sant Joan de Déu Research Foundation lead the project funded by the European Commission under the Horizon 2020 program. The World Duchenne Organization and the Melanoma Europe Patients Network are also participating in the project consortium. They represent the two groups of diseases on which clinical research initiatives will be carried out in the first phase. The universities of Newcastle and Politècnica de Catalunya, and companies in the social sphere such as Asserta and The Synergist, and Òmada are also part of the project consortium.