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

- The Sant Joan de Déu Research Foundation of Barcelona leads this European project that aims to connect and empower families living with rare diseases, and collect data to advance research.

- Unlike the existing forums, Share4Rare is unique as it brings together all rare diseases without limiting the issues that can be treated and in a safe and secure environment.

- Share4Rare incorporates the technology of dating platforms to facilitate contact between patients and carers. Share4Rare connects people based on the information they provide about their disease, their symptoms, areas of expertise and country of origin.

Barcelona, April 2, 2019. - Rare diseases are a set of around 8,000 different conditions that affect approximately 30 million people in Europe alone (80% are children). Surprisingly, only about 10% of these diseases have a solid scientific knowledge base. To deepen the knowledge of the remaining 90%, the European Commission has financed a project to address this problem, led by the Sant Joan de Déu Research Foundation in Barcelona. Share4Rare will offer a virtual and **safe meeting place** to **patients and families affected by rare diseases all over the world** and it will collect relevant information to advance in the research of these conditions.

The Share4Rare project includes the creation of a large social network that, unlike conventional forums, incorporates mathematical algorithms, such as those used by dating platforms. These will help to connect users based on the information they provide in 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 so they can 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 get to know some day their natural history. In the first phase, the platform will collect data for two large sets of diseases: paediatric tumours (1) and neuromuscular diseases (2).

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.

(1) Rare paediatric tumours: melanoma, giant congenital melanocytic nevus, xeroderma pigmentosum, gliomatosis cerebri, rare tumours of the pancreas, myofibromatosis, superficial or desmoid fibromatosis, myofibroblastic inflammatory tumour and various valvulopathies.
(2) Neuromuscular diseases: Duchenne muscular dystrophy (MD), Becker MD, limb girdle MD, fascioespapulohumeral MD, myotonic dystrophy, congenital muscular dystrophy, congenital myopathies, spinal muscular atrophy, amyotrophic lateral sclerosis, peripheral neuropathies, congenital myasthenias.