SUMMARY

Share4Rare brings better understanding, acceptance and inclusion of those diagnosed or dealing with rare diseases in Europe. The project is initiated by the Sant Joan de Déu Foundation and has been granted by the EU, starting on January 1st 2018 and will continue for 36 months. The platform will be accessible for users at the beginning of 2019 and will be piloted with two specific groups of diseases: neuromuscular disorders and paediatric rare tumours.

INTRODUCTION

A rare disease affects less than 5 in 10,000 persons, and 80% of them are children. Upon diagnosis, rare disease families turn to the Internet as a source to find information and strength about health conditions. However, a large part of the available information is not verified, or does not come from a trustable source. Often, in the specific case of rare diseases, the official information sources are not even complete.

With this in mind, it's easy to imagine that rare disease patients and their families have to cope with delayed diagnosis, fewer therapeutic options, and isolation in addition to their disease. At the same time, there are between 6,000 and 8,000 rare diseases today - meaning that being rare is far from rare! A rare disease affects one in 17 people, meaning that in Europe alone 30 million are living with a rare condition today.

Share4Rare (S4R) is a collective online platform that makes a difference for rare disease patients and their families. It enables patients and families to interact with each other, researchers, and clinicians and to become researchers of their own disease. An online community creates a platform for sharing knowledge, expertise and strength, breaking isolation for families and allowing rare conditions to share learnings and insights. This means that being rare no longer means being alone. The project originated from the belief that progress, especially in rare diseases, requires sharing of knowledge, experiences, and clinical data. With the use of collective intelligence and deep learning, Share4Rare makes a lasting contribution to the effort of helping children with rare conditions.

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GOAL

Our mission is to break the vicious circle of the rarity, scarce investment and reduced research on rare diseases. Share4Rare aims to use co-created information as efficiently as possible, to guarantee a common approach to rare diseases across Europe. By collaborating with highly motivated citizens throughout Europe, geographical and language thresholds are conquered with the use of technology, improving awareness in education, sharing and research with the use of a collective awareness platform (CAPS). With the use of this, a collective and international platform of patient, caregivers, researchers, and other stakeholders is built to improve quality of life, and collection of scientific knowledge about rare diseases.

CAPS

Collective Awareness Platforms (CAPS) contribute to the creation of new models for collaboration and production of collective intelligence, using co-creation to enable social innovation. CAPS can help reduce the scarce knowledge on rare diseases through driving development of medicines, prioritizing research, and improving protocol designs. By taking advantage of a group of highly motivated citizens (from patients to researchers, volunteers, public health representatives and health professionals) linked to rare diseases or not, their expertise and potential can offer a collective intelligence to improve the needs of this specific community.

LAYERS

The platform is built in three layers: the first layer **Education** is created to enhance a better quality of life in the field of healthcare, management of Patient Organizations and clinical research. This layer is including different types of resources, being of open source, high quality, and addressed to lay audience.

The second layer **Sharing** is a community designed for those battling with paediatric rare diseases by offering a secure environment to share stories and knowledge about their diseases. This can be done through storytelling, forums and Q&A's, and is building on existing knowledge and initiatives, ensuring a safe space for debate and discussion, allowing the creation of patients-powered registries.

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The third and final layer **Research** is for clinicians only, creating space for further research based on the collected shared data, so priorities can be set collectively. The previous layers are merged in this community of clinicians to generate new knowledge for specific groups of rare diseases.

PARTNERS

Two World Duchenne Organization and Melanoma Patient network Europe are two patient organizations that are part of the consortium. Other members of the consortium are focused on specific areas of expertise: technology development (Omada Interactiva), biostatistics (Universitat Politècnica de Catalunya), social innovation (The Synergist), clinical background in neuromuscular disorders (Newcastle University), and socioeconomic impact (Asserta).

CONTACT

Patients are at the heart of Share4Rare. Are you a patient or patient advocate with an opinion on how we as community can drive research for children with rare diseases? Contact Suzie-Ann at info@share4rare.org to find out more!

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