



Share4Rare



Share4Rare is here! A new collective awareness platform for social innovation focused on two groups of paediatric rare diseases: neuromuscular disorders and rare tumors

Sant Joan de Déu Foundation has been granted for the European Commission to coordinate the Share4Rare project. This is a collective awareness platform of patients, caregivers, researchers and other stakeholders involved in the growing health challenge of Rare Diseases (RD). Based on a socially innovative approach, and building on citizen science and collective intelligence, we will engage and connect all relevant stakeholders towards improving quality of life, disease management and collection of scientific knowledge and data on RD. The platform will be built around three important pillars: Education, Sharing and Research.

Share4Rare (S4R) will take advantage of the highly-motivated group of citizens (from patients to researchers, volunteers to public health representatives and health professionals) linked directly or not to rare diseases, and their expertise. It will build on existing knowledge and initiatives, and will ensure a space for debate, co-creation, and further research through shared data and a patient centered approach.

The new platform is based on the expertise of the coordinator managing a previous project: Rare Commons (RC). This is a platform that currently includes 9 different diseases. RC has demonstrated that the collective intelligence coming from parents of children with rare diseases is needed to increase the current knowledge available. A broad sample from the patient community has been identified, in several cases with a higher number of patients compared with previous initiatives.

S4R is proposing dealing with two important challenges that will improve the previous experience with the RC project:

1. Increase the power of the users of the platform, developing a platform based on a bottom-up model with a patient-centered design.
2. Promote synergy by grouping diseases that share common features, instead of individual diseases.

The platform will be accessible for the users at the beginning of 2019 and is going to be piloted with two specific groups of diseases: neuromuscular disorders and paediatric rare tumors.

The voice of the patients is at the heart of the project. Two relevant patient organizations are part of the consortium: The World Duchenne Organization (UPPMD) and the Melanoma Patient Network Europe (MPNE). Other members of the consortium are focused in other important areas of expertise: technology developers (Omada Interactiva), biostatistics (Universitat Politècnica de Catalunya), social innovation (The Synergist), clinical background in neuromuscular disorders (Newcastle University) and socioeconomic impact (Asserta).

The launch meeting of the project was held in Barcelona on the 11th and 12th of January. During the next year, centered on the development of the platform, several activities are scheduled to ensure that the voice of the patient is included from the outset. The mission of S4R is to improve the quality of life of rare disease patients and their families by working collaboratively to increase the scientific knowledge on Rare Diseases.

Do you want to hear more about the project?

Do you want to be get involved?

We would love to hear from you! Your ideas, suggestions and volunteer participation are welcomed and much need!

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About Sant Joan de Déu Research Foundation

Sant Joan de Déu Research Foundation was created in 2002 to provide a framework for the research activity carried out in the biomedical and social spheres at Sant Joan de Déu Maternal and Children's Hospital in Esplugues, at Sant Joan de Déu Healthcare Park in Sant Boi de Llobregat and in others.

We work jointly with centres of “Hospitaler Order of St. John of God – Aragon-San Rafael Province” to expand scientific knowledge and to improve the care given to patients. We approach our research as a participative and interdisciplinary process based on the interaction between our healthcare professionals and society.



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The Foundation's fundamental aim is to contribute to the improvement of people's health and welfare by fostering, supporting and coordinating research and innovation. We strive to achieve efficiency and to strengthen our networked activities while always bearing closely in mind our institutional values and ethical commitment.

● **Universitat Politècnica de Catalunya**

The Universitat Politècnica de Catalunya-BarcelonaTech (Technical University of Catalonia, UPC, <http://upc.edu>) is a public institution dedicated to higher education and research, specialised in the fields of engineering, architecture and science. It offers higher education in technical fields (69 degrees) and it is composed by 23 schools in 8 different campuses, with a total of 35.000 students and 2.780 researchers. The UPC is ranked 1st in Spain in the Field of Engineering and Technology. UPC participates in Share4Rare from the Bioinformatics and Biomedical Signals Laboratory (B2SLab) at <http://b2slab.upc.edu> with data analysis technologies. Contact: Dr. Alexandre Perera <Alexandre.Perera@upc.edu>

● **Omada Interactiva, S.L.**

Òmada Interactiva has 15 years of experience in consulting, support, design, creation and development of interactive solutions, developed mostly on open source software. We have collaborated with both public and private institutions, companies and sectors with various profiles and needs.

We are a multidisciplinary team focused on offering a solid, innovative and agile approach to web development, communities design, process management and online marketing. Health, education and NGOs are the three major axes we have specialized in. Collaboration and shared knowledge are the basis for Òmada's work philosophy.

We have been collaborating with The SJD Barcelona Children's Hospital for more than 8 years in the development of patient communities, information content and tele rehabilitation projects. www.omada.es

● **World Duchenne Organization/UPPMD**

World Duchenne Organization/UPPMD is a worldwide organization, owned and managed by patient organizations set up by parents of children with Duchenne and Becker Muscular Dystrophy in many different countries all over the world. It is dedicated to finding a cure and viable treatments for DMD, to promoting good standards of care, and to informing parents around the globe. <http://www.uppmd.org/>

● **Melanoma Patient Network Europa**

MPNE is a loose multidimensional network of European national and regional Melanoma patient forums advocating on behalf of patients and operating across language barriers with shared principles. Our mission is to systematically address problems faced by the European Melanoma community (Adult and Paediatric, Rare and less rare) in a constructive, result-oriented and collaborative manner by providing a platform for advocates to interact and through targeted capacity-building.

● **University of Newcastle**

The John Walton Muscular Dystrophy Research Centre is part of the University of Newcastle upon Tyne and works to perform world class translational research to bring diagnosis, care and therapy to people with neuromuscular diseases. The European Reference Network for Rare Neuromuscular Diseases (EURO-NMD) is coordinated from the Centre and aims to improve health outcomes in NMD patients across Europe, provide new opportunities for translational research, and reduce the burden of these chronic disabling conditions.

● **The Synergist**

The Synergist is a social venture that addresses a growing societal need for collaboration by building partnerships to accelerate societal impact.

The Synergist acts as an independent, neutral backbone and incubator bringing together the right people, organizations, and institutions together to focus on solving societal issues both personally and with technology tools. <http://www.thesynergist.org/>

● **Asserta Global Healthcare Solutions**

Asserta Global Healthcare Solutions SL brings together a team of professionals with years of experience in clinical practice, health management, teaching and research, who are putting their knowledge and expertise at the service of improving processes and results in the healthcare area. While becoming a reference in the Medication management processes, and improving healthcare processes, we have opened a new lines of business related to innovation management, and social impact measurement in international projects. We have consolidated our expertise in Organization and Strategy, Social Innovation in International environments, Real World Data analysis, and international research consultancy. www.asserta.net



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