

Orphanet-INSERM and Mapi Research Trust are pleased to announce:

## The ERICA Project European Rare disease research Coordination and support Action

**2020 ended on a very enthusiastic and exciting note:**

Mapi Research Trust (MRT) and Orphanet-INSERM received the approval for a 4-year European grant in the rare diseases (RD) field, after months of remarkable collaborative work on the dossier submission.

The European Rare disease research Coordination and support Action (ERICA) Project is about joining forces to integrate research and innovation capacity across all 24 European Reference Networks (ERNs). The ERICA Project received a positive evaluation for a H2020 grant to establish a structural framework in support of the research activities of the ERNs. ERICA will strengthen research and innovation capacity through the integration of ERN research activities, the outreach to European research infrastructures with the aim of synergistically increasing impact and innovation in RD. This will result in safe, accessible and efficient access to therapies for the benefit of patients suffering from these conditions.

# Collaboration in Rare Disease

RD are defined as diseases that affect not more than 1 person per 2000 in the European population. However, while individual RD affect only a small percentage of the population, they collectively affect up to 30 million people in the EU. With the objective to facilitate access to high quality cross-border healthcare and promote and foster cooperation on RD healthcare between member states, the 24 European Reference Networks were established by the European Commission in 2017. The ERICA Project builds on the strength of these individual ERNs by promoting inter-ERN research activities and by establishing firm collaborative ties with existing European and international infrastructures and consortia involved in RD research and innovation.

The ERICA Consortium consists of 29 partners, amongst which are all 24 ERNs, EJP RD, the European Joint Programme on Rare Diseases, EURORDIS, a non-governmental patient-driven alliance of patient organisations, Orphanet, MRT, and EATRIS, a non-profit European Research Infrastructure Consortium.

The fruitful partnership between MRT and Orphanet led to an initial work on RD nomenclature alignment with other terminologies, allowing the identification of 275 Clinical Outcome Assessments (COAs) developed in about 80 RD. The European grant will support the completion of this preliminary work by expanding it to the analysis and coding of functional consequences of RD and the identification of a much larger list of validated COAs measuring the coded functional impacts. The identified COAs matching ERNs specific clinical criteria will be gathered in a common repository and connected to MRT's COAs database, PROQOLID™ in order to provide meta-data for each COAs. During the Project, all consortium members will be granted full PROQOLID access to review information on the conditions of use, the available translations, the content, and the development and validation of all identified questionnaires.



### **About Mapi Research Trust:**

Mapi Research Trust is a non-profit organization founded to promote the use of Clinical Outcomes Assessments (COAs) in health research and practice, and encouraging exchanges of Patient-Centered Outcomes and COAs information among academics, pharmaceutical companies, health care organizations and health authorities. With the web-based platform ePROVIDE™ that includes the databases PROQOLID™ and PROLabels™, Mapi Research Trust has become the first source of reliable, up-to-date and comprehensive information about COAs, e.g. from practical information about copyright and conditions of use, to scientific information about the instruments and measurement properties as well as strategic information such as compilation of COA labelling claims granted by FDA and EMA.

Mapi Research Trust, the largest curator of COAs worldwide and the most trusted name in licensing and distribution of COA instruments, representing over 600 exclusive questionnaires on behalf of their developers and copyright holders.  
Visit <http://mapi-trust.org> for more information

### **About Orphanet:**

Orphanet is a unique resource, gathering and improving knowledge on rare diseases so as to improve the diagnosis, care and treatment of patients with rare diseases. Orphanet aims to provide high-quality information on rare diseases, and ensure equal access to knowledge for all stakeholders. Orphanet also maintains the Orphanet rare disease nomenclature (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems.  
Visit [www.orpha.net](http://www.orpha.net) for more information

