

**LAUNCH EUROPEAN MOBILE APP PROJECT
TO IMPROVE HEALTH AND QUALITY OF LIFE OF CHILDREN WITH CYSTIC FIBROSIS**



Will new technology be able to improve health outcomes and quality of life of children with Cystic Fibrosis (CF) around Europe?

Cystic Fibrosis (CF) is the most common life threatening inherited disease in Europe. 1/30 people carry the gene causing CF and more than 40.000 children and young adults live with the disease in Europe. Sticky mucus causes severe damage to the respiratory and digestive systems. The majority of patients suffer from lifelong pancreatic insufficiency leading to malabsorption and indirectly to more severe lung disease. With the treatment available today, there is no reason to accept malnutrition and growth retardation in CF patients. The combination of an adequate nutritional intake and a personalized pancreatic enzyme replacement therapy is generally able to ensure a normal growth and nutritional status, avoiding complications associated to the progression of the disease. Unfortunately, many children with CF still suffer from underweight and gastro-intestinal complications due to limited access to optimal nutritional and enzyme replacement therapy. Children have to take up 30 or 40 enzyme pills a day and it is not easy to know which dose to take with each meal or snack. This leads to a lot of insecurity, lack of adherence and risk of under- or overdosing of the treatment.

The MyCyFAPP project aims at self-management of enzyme replacement in children with CF by means of a mobile application (APP) that allows for a personalized and accurate control and monitoring of the disease. We want to develop an innovative and portable ICT tool that may encourage the child's adherence to the treatment and the best outcome of the nutritional intervention through a multidisciplinary and complementary approach. The ultimate goals are a better understanding of enzyme replacement therapy in children with CF and an easy to use app leading to improved health and nutritional status. Since MyCyFAPP will be clinically validated and tailored to the needs of each individual child in different countries across Europe, it could become a model for self-management in children with many diseases and a competitive market product in Europe.

The initiative is financed by the European Commission under the Framework Program for Research and Innovation Horizon 2020, and integrates CF reference centers, universities, patient representatives and ITC companies from Spain, Italy, Norway, Germany, Portugal, Belgium and the Netherlands.

The MyCyFAPP consortium:

Spain: Fundaciom para la Investigacion del Hospital Universitario La Fe de la Comunidad Valenciana (HULAFE), Soluciones Tecnologicas Para La Salud Y El Bienestar Sa (TSB), Universitat Politecnica De Valencia (UPV), Servicio Madrilenio De Salud (SERMAS); Italy: Università Degli Studi Di Milano (USM), Imaginary Srl (IMA); Norway: Stiftelsen SINTEF (SINTEF); Germany: YOUSE GmbH (YOUSE); Portugal: Associação para Investigação e Desenvolvimento da Faculdade de Medicina (AIDFM), Belgium: Katholieke Universiteit Leuven (KU LEUVEN), Cystic Fibrosis Europe (CFE) and The Netherlands: Erasmus Universitair Medisch Centrum Rotterdam (EUMCR).

For more information: www.mycyfapp.eu