

RARE DISEASES & SPORT

ENCOURAGING SOCIAL INCLUSION AND EQUAL OPPORTUNITIES IN SPORT

The *Rarity on wheels- RoW* addresses to people affected by rare diseases (RDs) and their actual possibility to participate in sports activities and competitions.

Patients affected by rare diseases, both children and adult, manifest multiple difficulties in their daily lives: from health and clinical issues to school, work and social exclusion, due to their particular and often invisible disability status.

Sport is a healthy recreational activity that allows the reduction of physical and psychological stress. It is also, and above all, a means to challenge one's own limits and to promote social inclusion and equal access to leisure activities

RoWt starts from the will to disseminate and scale up in 3 different EU countries the good practice “La rarità su due ruote” developed by the project coordinator “Un filo per la vita”. This practice aims to promote equal access in sports activities (in particular cycling) and in sports competitions for people affected by rare diseases and to foster awareness raising on rare diseases, spreading knowledge on the topic through sport.

In order to reach these objectives, the good practice is based on the creation of a bike team made by people affected by a rare diseases/ families/ caregivers crossing Italy (therefore mixed, including people with and people without disabilities) on bike, participating to national competitions and sports events, spreading knowledge on their right to access sports activities, on their rare disease and on positive effects of sport on patient's health.

The key to improving overall strategies for rare diseases is to ensure that they are recognised- This is why RoW is based on the implementation of awareness raising campaigns on the topic, breaking the silence around RDs and show them under a new light, as people that can make sport, as well as and influencing policy makers in taking real measures to allow the full participation of people with RDs in sports activities and competitions.

PROJECT OBJECTIVES

- to identify the main problems and difficulties faced by athletes and patients affected by RDs in participating to sports activities
- to promote the acquisition of knowledge, competences and skills among NGOs and sport managers, trainers and coaches on RDs and Sport
- to foster awareness raising on rare diseases through sport
- to influence policy makers in order to promote the definition of specific sports policies for RD patients and in particular for the recognition of their disabilities in Paralympic games.

TARGET GROUPS

- Patients and athletes affected by rare diseases
- Trainers and coaches working within partner organisations
- Participating organisations
- Other sport clubs and other potential stakeholders in the field of sport, health, disability, rare diseases.

RESULTS



INITIAL RESEARCH REPORT

Initial research on difficulties faced by RD patients in the participation to sports activities and competitions.

Data from national surveys and Focus Groups will be collected and processed together in the initial research report.



April-June 21

AWARENESS RAISING SPORTS EVENTS

Each country will organize 1 local sports event -mainly focused on cycling, but also other sports- aimed to spread awareness on Rare Diseases and on the relationship between RDs and sports.



September-October 2022

POLICY RECOMMENDATIONS

Based on initial research findings and on the evaluation of implementation activities (awareness raising campaigns), project partners will produce policy recommendations addressed to national and European policy makers and international sport organisations



February-June 2022

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