



RARITY ON WHEELS-ROW

BOOKLET



Co-funded by the
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ROW BOOKLET

The *Rarity on wheels- RoW* Project 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 adults, 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.

The RoW project aims at spreading knowledge on RDs and the right of people affected by RD to access sports activities. To this aim, the project foresees the realization of three main results

INITIAL RESEARCH REPORT

- 1 The report, available on the [project webpage](#), summarizes the findings of the desk and field research emerging from the analysis implemented in Italy, Spain and Poland. The research consisted in the implementation of two key activities (surveys and focus groups) aimed to identify the difficulties faced by RD patients in the participation to sports activities and competitions and share good practices on the topic.

AWARENESS RAISING CAMPAIGNS

- 2 Each partner organization participated in 3 local/regional/national cycling races and sport events to maximize the visibility of the RoW project and raise awareness about its key topics.

POLICY RECOMMENDATIONS

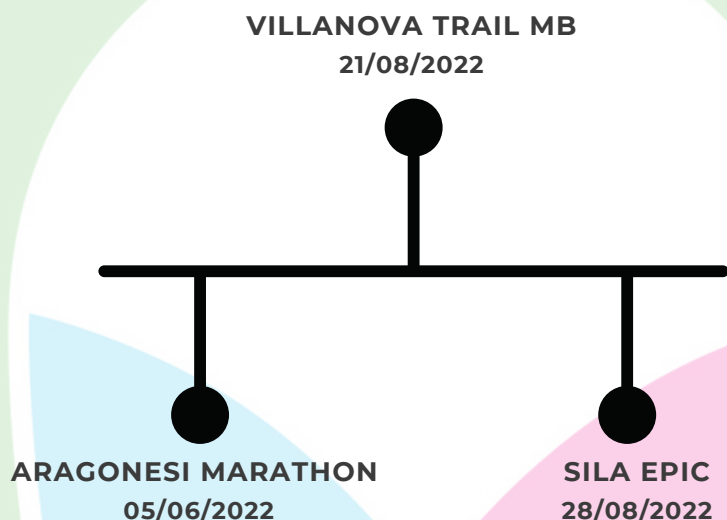
- 3 Based on initial research findings and on the evaluation of implementation activities (awareness raising campaigns), project partners produced policy recommendations addressed to national and European policy makers and international sport organisations. The policy recommendations are available on the [project website](#).

This Booklet aims to give an overview of the awareness raising campaigns implemented in Italy, Spain and Poland from December 2021 to August 2022.

After the training activities implemented in Grado (Spain) in September 2021, project partners started working on the development of their own national plans aimed to identify some relevant biking competitions/sport events (at least 3 per country) to which each national cycling team could participate. Each national plan has been evaluated and validated by the RoW partnership.

1. AWARENESS RAISING CAMPAIGNS IN ITALY

The RoW cycling team set up by Un Filo per la Vita and CSEN Perugia implemented the following awareness raising campaigns:



ARAGONESI MARATHON

"Aragonesi Marathon" is a Gran fondo ("big ride") competitive mountain bike (MB) competition in Castrovillari, Southern Italy. The 8th edition of the Marathon attracted about a hundred cyclists and attendees from all over Italy and had a total length of 63 Km.

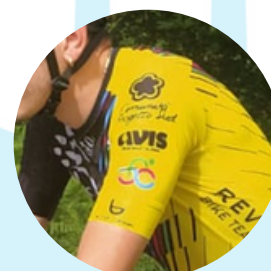
For the first time in Calabria, the Marathon has been combined with a sport event (Aragonesi Kids) addressed to racing cyclists.

While participating in the competition, the Italian team, coordinated by Paolo Mazzei, a young cyclist with rare disease, had the opportunity to promote the RoW project.

An exhibition stand was allocated to the RoW Staff. Acting as a meeting place and also it securing the RoW promotional material (leaflets and posters), the exhibition stand played a key role in engaging the attendees.

All the members of the RoW cycling team wore the RoW uniform with the project logo.

People reached (approximately): 300





VILLANOVA TRAIL MTB

The competition is a cross-country race with two trails: one has a length of 17 KMs and the other 34 KMs.

"Villanova Trail MB" is also a journey across Umbria, known as Italy's green heart, offering an opportunity to discover its countryside.

The competition was a great opportunity to distribute the project promotional material and enhance the visibility of the project.

CSEN Perugia staff also had the chance to be interviewed by the official speaker before the competition explaining the main objectives and activities of the RoW project.

People reached (approximately): 100



SILA EPIC

"Sila Epic" is a Gran fondo competitive mountain bike competition held in the Sila National Park (Southern Italy). The 6th edition took place in August 2022. Participants can choose among three epic trail races from – the 108 KMs EPIC, 32 KMs CLASSIC, and 28 KMs with incredible views of the Sila National Park and surroundings.

Before the event took place, the Italian Team contacted the organizers of the Sila Epic to talk about its involvement in the competition aimed to raise awareness about the RoW project. The organizers were so interested in the initiative that they offered to support publicly in the website of the competition.

While participating in the competition, the Italian team had the opportunity to raise awareness about the RoW project and reach our targeted audience by giving an overview of the project sharing the project promotional material and All the members of the RoW cycling team wore the RoW uniform with the project logo.

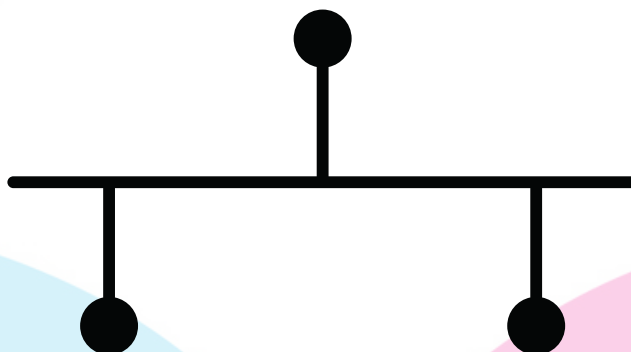
People reached (approximately): 200



2.AWARENESS RAISING CAMPAIGNS IN SPAIN

The RoW cycling team set up by Un Filo per la Vita and CSEN Perugia implemented the following awareness raising campaigns:

ORIGEN DEL CAMINO BIKE EXPERIENCE
23/04/2022



LIGA XC BTT CAJA RURAL ASTURIAS
20/03/22 - 17/7/22

TRANSPYR BTT
13/06/2022



LIGA XC BTT CAJA RURAL ASTURIAS

Liga XC is an annual multiple-stage bicycle race held in Asturias (Northern Spain) from March to July.

The RoW Spanish team participated in two stages: the first in S.Martina Laspra and second in Rioseco.

While participating in the competition, the Spanish team coordinated by Francisco Muñoz, father of a daughter with rare disease and cycling lover, had the chance to promote the RoW project distributing flyers and introducing the project. The organizers of Liga XC presented the RoW project to the public with the official speaker before the competition started.

All the members of the RoW cycling team wore the RoW uniform with the project logo.

People reached (approximately): 300





ORIGEN DEL CAMINO BIKE EXPERIENCE

Origin of the Camino-Bike experience" is a mountain bike race of 71 km between Oviedo and Tineo.

It is a MB race supported by the Royal Spanish Cycling Federation (RFEC) and the Principality of Asturias Cycling Federation, which consists of 2 stages.

Besides distributing promotional material and sharing information about the RoW project, the Spanish staff had the chance to be interviewed before the competition started and give an overview of the RoW project.

In addition to this, the Spanish team also had the opportunity to meet Carlos Coloma, former cross-country mountain biker and bronze medalist at the Rio Olympic Games. During the meeting with Carlos Coloma, the Spanish team presented the project activities and results.

People reached (approximately): 250



TRANSPYR BTT

"Transpyr" is a mountain bike stage race in the Pyrenees mountains on a very special bike route linking the Atlantic Ocean with the Mediterranean. It is a cycling adventure consisting of crossing the Pyrenees in 7 stages between Roses (Girona) and Hondarribia (Guipúzcoa).

With the aim of fostering the participation of stakeholders and attendees in a process of raising awareness on rare diseases and the relevance of sport as a tool for social inclusion, the Spanish team had the opportunity to be interviewed by the official speaker before the competition and give an overview of the RoW project. Dissemination material was distributed before and after the event.

All the team members participated in the competition wearing the RoW uniform with the project logo.

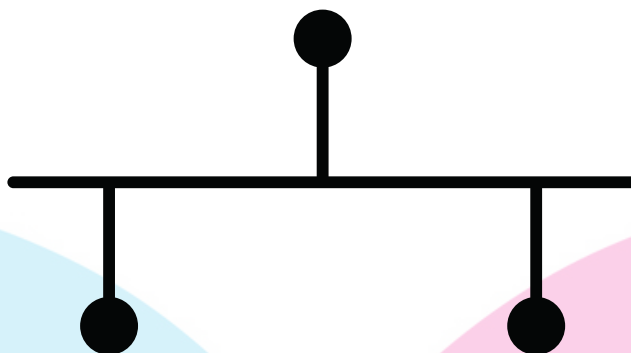
People reached (approximately): 250



3.AWARENESS RAISING CAMPAIGNS IN POLAND

The Polish cycling team set up by Projekt Świętokrzyskie implemented the following awareness raising campaigns:

BIEGU O TYTUŁ GÓRALA
ŚWIĘTOKRZYSKIEGO/AKTYWNY ĆMIŃSK
12/06/2022



PĘTLA MAZURSKA
30/06/22

ACTIVELINGUA
13/07/2022



BIEGU O TYTUŁ GÓRALA ŚWIĘTOKRZYSKIEGO/AKTYWNY ĆMIŃSK

The event was a running competition to select the most sporty inhabitant of the Świętokrzyskie Mountains/ Active Ćmińsk. The sport event was organised in cooperation with the local Municipality of Ćmińsk with the purpose of promoting sport and healthy lifestyle.

There were also some activities aimed to promote sport among children. Apart from the competition itself there were also some stalls organised where people could find info and discuss with the specialists about the healthy lifestyle.

During the event there was a workshop run by a local doctor from Ćmińsk who made a presentation about the rare diseases in Poland and the situation on that topic.

He gave some statistics and invited two patients of his who told the story of their diseases and their sports careers. During the workshop, a presentation of the RoW project was delivered.

People reached (approximately): 300





PĘTLA MAZURSKA

It was a cycling event organised around the Mazurian Lakes region. The participants come from the Świętokrzyskie Region and they are members of the Association "Stowarzyszenie Pod bartkiem". The idea was to combine sport with some educational activities.

Each year the event is organised in a different part of Poland. The participants not only meet to practise sport but also to commemorate big events in the history of Poland (entrance to the European Union, constitution in Poland etc.)

During the event a workshop on rare disease has been organised and a quiz on rare disease.

Its outcome showed that the knowledge on the topic is very low. The participants of the workshop couldn't even name one rare disease. During the workshop an overview of the RoW project was given.

People reached (approximately): 100



ACTIVELINGUA

Activelingua was a small event aimed at children with rare disease. During the event youth and kids were practising sport (yoga, acroyoga, played volleyball and took part in a race).

During the event Jan Bobrowski, suffering from Achalasia, and his mother told their rare diseases experience. There were 40 youth and kids participating and 20 parents.

People reached (approximately): 60





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