

RARITY ON WHEELS-ROW

EXPLOITATION

ROADMAP





ABSTRACT

This document presents the Exploitation Roadmap aimed to guide and involve all partners in exploitation activities. This Roadmap includes the mapping of potential stakeholders at regional, national and EU level, the identification of forums and/or events where potential users and stakeholders can be contacted, the work plan for each partner for presentation and demonstration of results. P1 designed templates to be used by all partners, who identified potential stakeholders and policymakers in their context, to whom disseminate project results and policy recommendations.

PARTNERS



The European Commission's support for the production of this publication does not constitute an endorsement of the contents, which reflect the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein. Project: Rarity on Wheels-RoW Nr. 622387-EPP-1-2020-1-IT-SPO-SSCP.



Co-funded by the
Erasmus+ Programme
of the European Union



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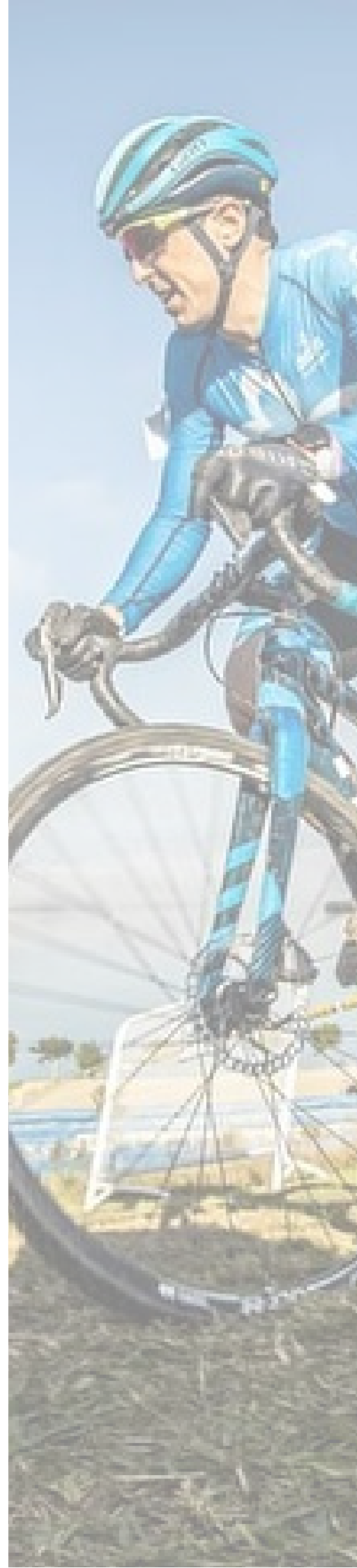


INTRODUCTION

The project "Rarity on wheels" addresses the topic "Encourage social inclusion and equal opportunities in sport" of the Erasmus+ program. 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. These criticalities are revealed on several occasions and touch different levels of seriousness. Therefore, it is fundamental to support patients and caregivers, facilitating the resolution of these problems through different means. 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.

Starting from these premises, our project started 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 aimed 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 disease/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 association helps patients, race after race, make their voice louder and listened to, and to make them visible not only as patients, but also as people who love sport and athletes.

Being aligned with the European Disability Strategy (2010-2020), RoW contributes to "improve the accessibility of sport, leisure and recreational organisations, activities, events, venues, goods and services, [...]; promote participation in sport events and the organisation of disability-specific ones".

Indeed, RoW aims to ensure equal participation rights in sports activities and sports competitions for people whose disability is connected to their rare disease. This action will be pursued through both awareness raising campaigns carried out by people with disabilities, the creation of a sport team (cycling) promoting the participation to sport competitions for people with rare diseases and the final development of policy recommendations on the topic.

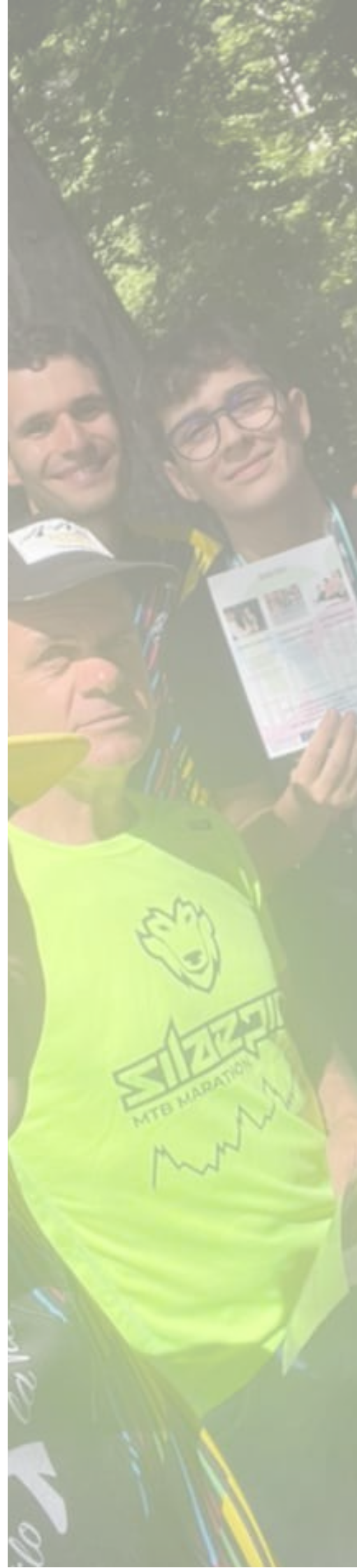




While carrying out research on the topic over the years, we observed that while several policy actions exist with the aim of supporting people affected by rare diseases, no specific policies on sports have been designed. Considering the context described above and the particular condition that people with rare diseases are experiencing every day also in the recreational and sports environment, the RoW project focuses on the development of clear guidelines and recommendations addressed to policy makers.

Besides fostering awareness raising on rare diseases, spreading knowledge on the topic through sport, the main objective of the project is 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.

In fact, although the EU has launched two important documents on the European strategy on rare diseases, the Communication "Rare Diseases: Europe's Challenges" and the "Council Recommendation on an action in the field of rare diseases", they mainly address the strategy that must be pursued in terms of health policy, while the recognition of the disability connected to RD and their participation to leisure and sports activities still lacks of recognition as a real European issue.





This document represents the Exploitation Roadmap, one of the core outputs of the project that supports and will support project partners in maximizing the impact of the RoW project even beyond its end.

This Roadmap includes the mapping of potential stakeholders at regional, national and EU level, the identification of forums and/or events where potential users and stakeholders can be contacted, the work plan for each partner for presentation and demonstration of results. P1 designed templates to be used by all partners, who identified potential stakeholders and policymakers in their context, to whom disseminate project results and policy recommendations.

For more information on the project activities and outputs, please visit our [webpage](#).





THE EXPLOITATION STRATEGY

The strategy and plan set out below define the successful exploitation of the project results.

The overall strategy focuses on defining:

- the outputs that can be exploited
- target groups (internal and external stakeholders)
- exploitation activities.

This Roadmap builds on the initial exploitation plan which has been discussed by the partners in the project proposal and is based on how to successfully maximize the RoW results. Partners are dedicated to the exploitation of RoW to ensure that the results are disseminated and used beyond the duration of the project.

At the beginning of the project, in order to produce this Roadmap, UFPLV designed this template to be used by all partners to identify potential stakeholders and policymakers in the local and national context, to whom to disseminate project results and in particular the policy recommendations outside the partnership.

In the template form provided, partners were asked to give detailed information about the National Exploitation Plans after the project is finished.





Partners described the plans for each of the following target groups:

Direct target groups:

- Policymakers
- Sport organizations and their staff
- People with RD/with disability
- Families

The aim of the National Exploitation Plan is to specify concrete actions for:

- a) ensuring that project results come to the attention of national decision-makers, and
- b) convincing end-users to adopt the project's results.

Exploitation roadmap





THE NATIONAL PLANS

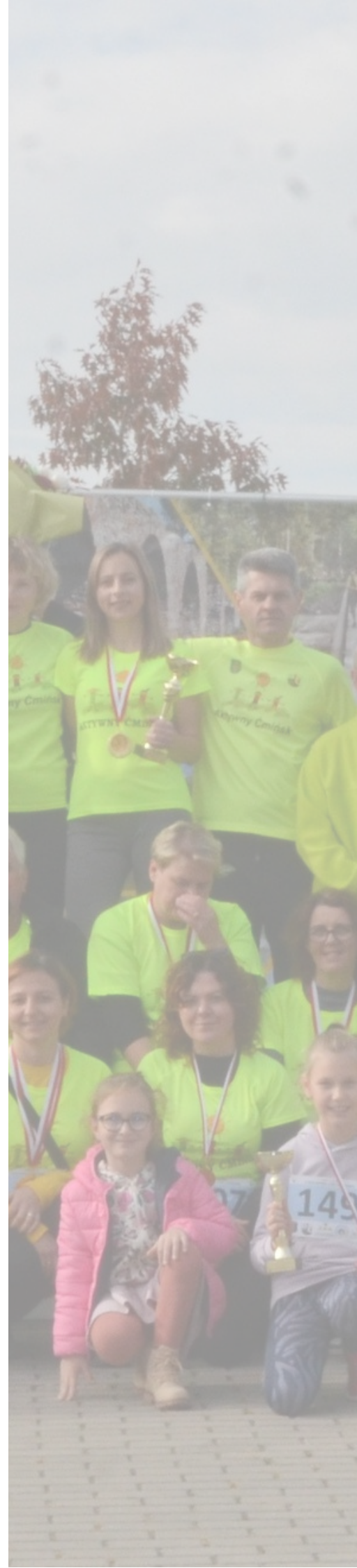
Poland

The Polish partner identified the main stakeholders at the local and national levels that will support the exploitation of the RoW activities beyond its end.

At the local and national level:

- Town Hall of the City of Kielce, Department of Sport and Culture.
- The mayor of Kielce is the former player and coach of the handball team so his main priority is to develop activities connected with sport in the city and promote sports as the tool for social integration. Kielce is the city where there are great facilities to practice sport of many kinds. That is why its main objective is to promote it as the city sport friendly. International projects of that kind as "RoW" make the process easier and more international.
- Sports clubs of the city of Kielce (Vive Łomża Kielce, Korona Kielce, Dap Kielce, Megamocni)
- Marshal Office of the Świętokrzyskie Region (Department of Sport, Culture and Education) - local policy maker responsible for regional development.

At the international level, Stowarzyszenie "Projekt Świętokrzyskie" will make the best of the RoW

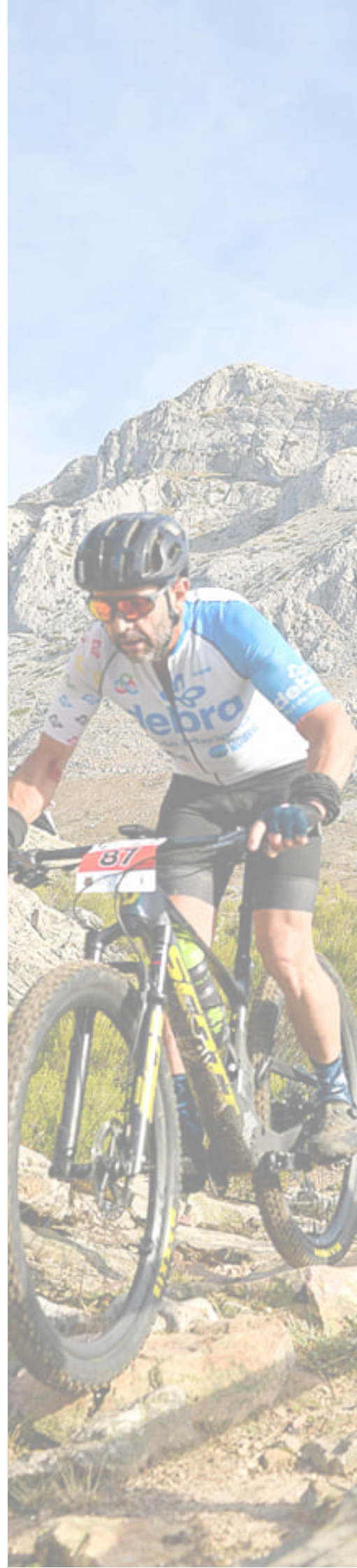


results through:

- The international network of NGOs connected with sport
- National Agency of Erasmus+
- Members of the EU Parliament

The organization is going to use the well-established personal contacts which have been built through many years of acting locally in the field of sports. They are planning to organize some meetings locally to disseminate the project results (eg. meeting to present the project outcomes on the meeting of board members of the Association Projekt Świętokrzyskie). The association is regularly presenting some short films to present the project results and activities to promote cycling as a tool for social integration and a way to spread knowledge on rare diseases.

Each year the Association Projekt Świętokrzyskie organises a very big annual sports event called Paragedon. This is the Festival of Activity of People with Disabilities. Each year it gathers more than 800 sports people with disabilities from the Świętokrzyskie Region. This is the perfect place to disseminate the RoW project outcomes and the idea behind it. The festival is attended by people with both physical and mental disability. All very motivated to take part in various sports activities organised for them. The Association is also planning to cooperate with the Action Foundation whose aim is to promote boccia (petanque) as the sport which can integrate people of different disabilities.





The President of the Action Foundation, Andrzej Janowski, is ready to cooperate within the topic of promoting sport as a social integration and a great tool for promoting the idea of rare disease knowledge exchange.

Spain

For the Spanish partner Equipo Santi Perez, the main actors that will be involved at the local and national level in the exploitation of the project are:

1. the municipality of Grado
2. Debra
3. The municipality of Burela
4. Pedalando por la Piel de Mariposa.

One of the founding members of the cycling group is a father of a child with EB (Butterfly Skin) who is also a health professional, so he will be one of the Association's Ambassadors.

The association will be able to make the best of the DEBRA network by sharing photos and videos of our trips, events, etc.

DEBRA, the national Butterfly Skin Charity in Spain, will help to maximize the impact of the project in Spain and all over Europe. For instance, the Charity DEBRA will support the project through its social channels having more than 17.000 followers. RoW will also be included in the annual report of the charity



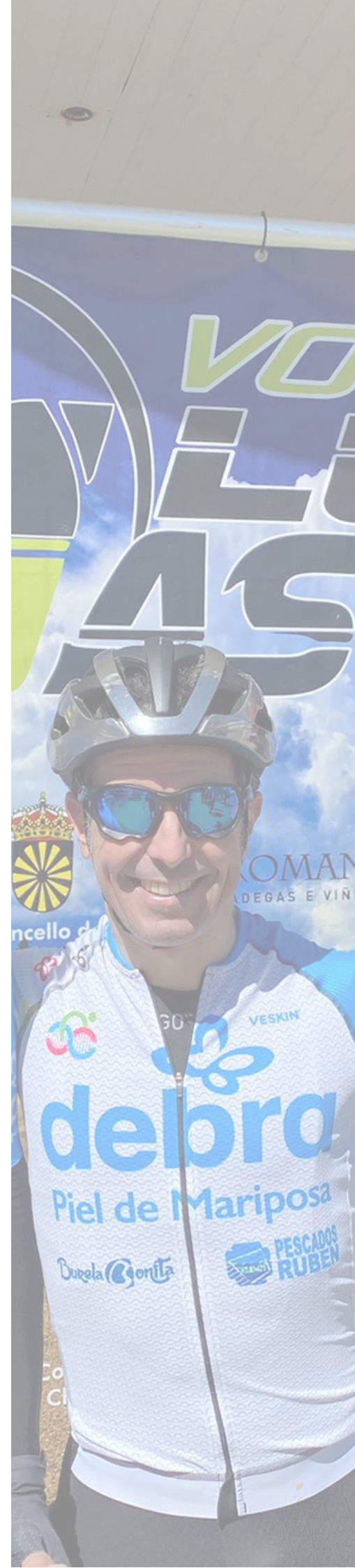


In addition, the biking team will participate in every cycling event to raise awareness, both in Spain and internationally. All members of the group share the same cycling jersey so also each member can use it and raise awareness individually during competition.

Since EB (Butterfly Skin) is a rare condition Equipo Santi Perez truly believes that the best channel to reach the families affected will be through the national Charity DEBRA. It represents more than 300 families with EB in Spain and also is part of DEBRA International.

DEBRA, the Butterfly Children's Charity is an organization that exists specifically to help people with Epidermolysis Bullosa (Butterfly Skin). A non-profit organization dedicated to improving the lives of people with EB and their families in Spain. It is recognized as "Utilidad Pública" by the Spanish Government. From DEBRA, the Association knows that nowadays one of the best channels to get in contact with families and stakeholders is through social media which is why we count on DEBRA visibility to make the best of RoW.

With regards to the events during which RoW will be promoted even after its end, every year on the 25th of October the International EB (Butterfly Skin) Day will be celebrated. The two municipalities that were involved in the project will support also the future organization of events.



Italy

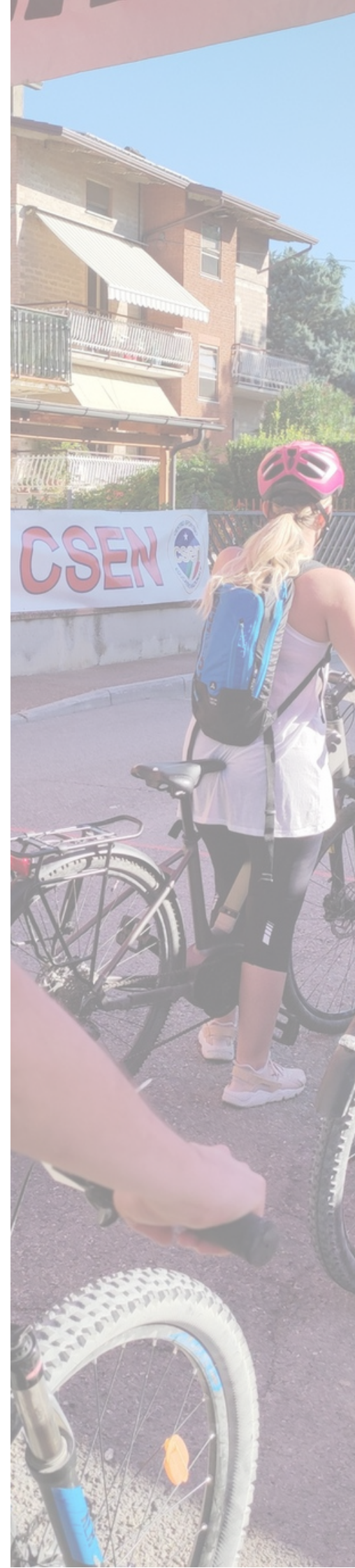
In Italy, the two partners of the RoW have built relevant connections over the years and have identified several stakeholders to be involved in the exploitation of the project:

- CONI (Italian national Olympic committee)
- CIP (Italian paralympic committee; members of the regional committee took part in the focus group of the project)
- INAIL (Istituto Nazionale Assicurazione Infortuni sul Lavoro - the public entity supporting people with disability in the work environment)
- CSEN network (one of the biggest Italian networks for sports associations)
- Ospedale Bambino Gesù Roma (Pediatric hospital carrying out research in the field of rare diseases. The organization hosted the final event of the RoW project)
- UNIAMO - Italian Federation of Rare Diseases.

The partner also identified specific events where the RoW results will be maximized and in particular:

- the European Week of sports
- the International Day of persons with disabilities
- Rare Diseases day.

The partners will organize communication of the project results around press releases, sending of in-depth information materials, newsletters,



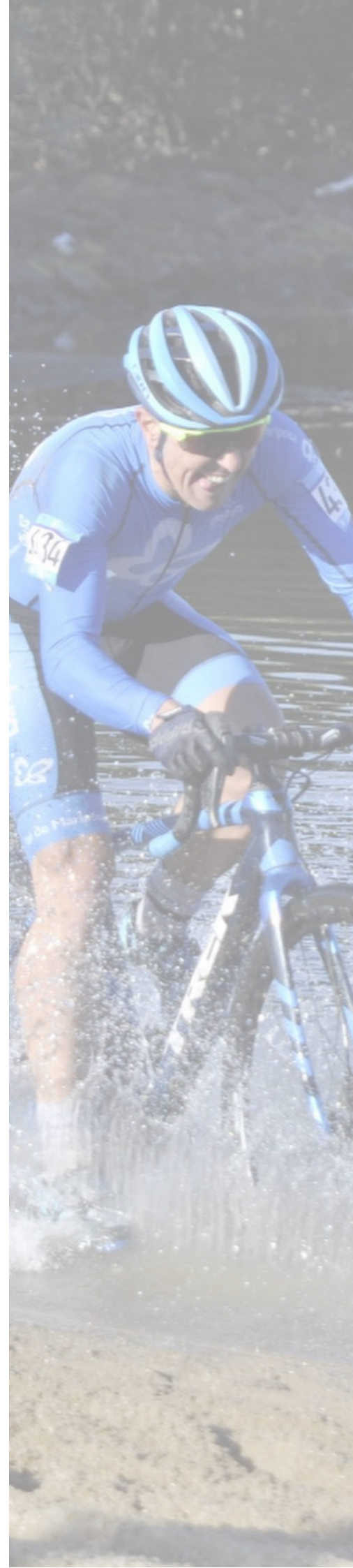
organizing one-to-one meetings wherever possible directly with the contact persons.

In addition, communication activities aimed at publicizing the project in all its underlying aspects will be continued.

Integrated communication activities related to the project will be continued with the structuring of promotional campaigns aimed at giving visibility and dissemination to specific initiatives, on the occasion of regional events related to sports, Paralympics, and sports inclusion.

The local committee of CSEN Perugia will contribute to reaching out to regional and national stakeholders through its network and moreover will organize sports events focused on increasing the visibility of rare diseases patients and athletes. CSEN Perugia is the promoter and organizer of several biking events in the Umbria Region that could be combined with raising awareness initiatives. Namely, each year CSEN is involved directly in the organization of:

- Villanova Trail MTB
- Sui Sentieri di Francesco
- La Francescana.





EXPLOITATION INDICATORS

With the aim of ensuring concreteness to our exploitation and sustainability strategy, the Consortium will:

- Organize a minimum **2 awareness raising sports events** in each country to maximize the visibility of the project results and engage new audience. This will help to ensure the exploitation of these products beyond the project's life cycle.
- Organize a minimum **2 meetings with policy makers/public authorities** in each country to make them aware of the project results and discuss about the Policy recommendations delivered throughout the project.
- Implementation of 2 local/national/European projects in each country in line with the objectives and priorities of the RoW project.
- Each partner will contact and involve the **appropriate stakeholders and professionals** in the field of rare diseases and sports at local, regional and national level to ensure an adequate build-up of momentum necessary to ensure sustainability.
- The consortium also commits to create **positive synergies** with complementary projects already under implementation.
- The **project webpage** will remain active for 3 years after the end of project. Partners will work to make the project outputs freely available and usable by all, also after the end of the project.

With the aim to engage a wider target audience across Europe and to promote the project results and their impact, all the resources developed by the RoW Consortium is published under a Creative Commons (CC) license, which allows access at no cost, adaptation and distribution by third parties in order to maximize the benefits of Open Education.

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