



RARITY ON WHEELS-ROW POLICY RECOMMENDATIONS



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ABSTRACT

The document is the last output of the RoW project and thus is based on the work done by the Consortium in the project's lifespan. Based on initial research findings and the evaluation of implementation activities (awareness raising campaigns), this document aims at suggesting clear policy objectives aimed to encourage policy makers to take action to support people affected by rare diseases and to support the participation in sports as well as to get the recognition of RDs as disabilities included in major sports competitions such as the Paralympics.

PARTNERS



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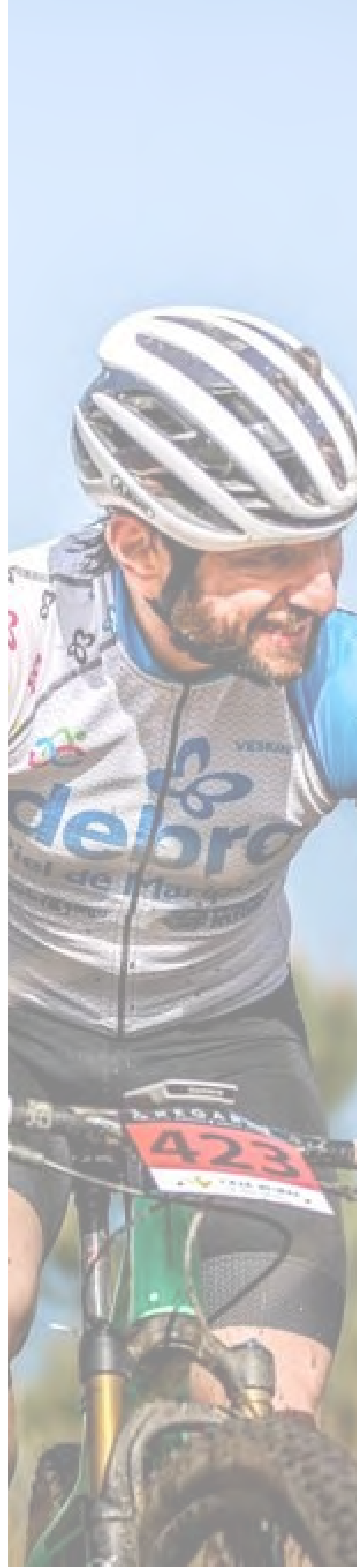
INTRODUCTION

The project "Rarity on wheels" addresses the topic "Encourage social inclusion and equal opportunities in sport".

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.



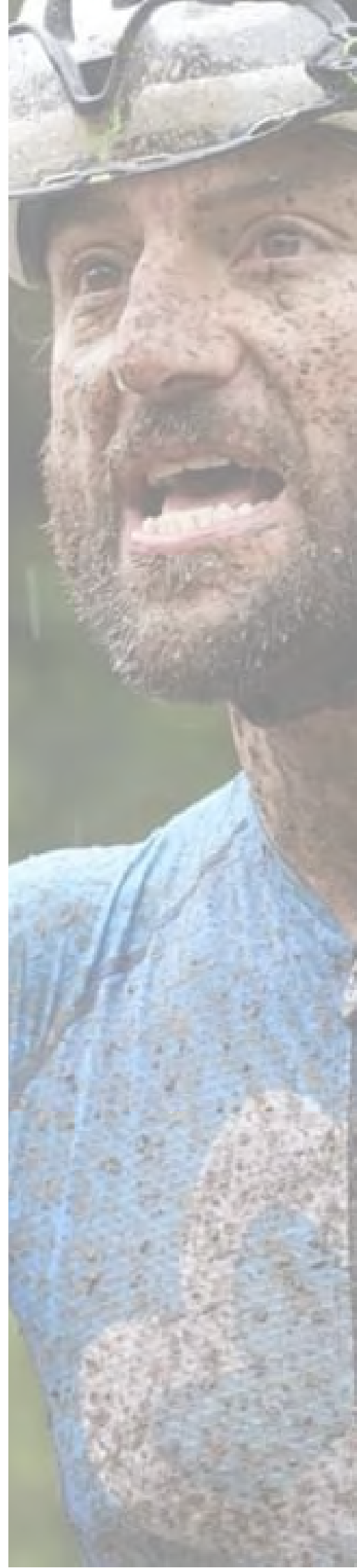


This document is the last output of the RoW project and its milestones, thus it is based on the work done by the Consortium partners in the project's lifespan. Addressed to sport authorities, federations and policy makers, this document is therefore crucial for the "political" recognition of RD patients in the world of sport which is a fundamental step towards their social inclusion and participation.

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

RESULTS OF THE PREVIOUS ACTIVITIES

Being the final output of the project, this document builds on the results of the activities implemented throughout the project: the initial research findings (WP2) and the evaluation of the awareness raising campaigns in partner countries (WP3) which helped the consortium to observed how the inclusion of people with rare diseases is taking place in sports events and what are the difficulties that are facing in practice.





THE FINDINGS OF THE INITIAL RESEARCH

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. The findings of this joint report constituted the basis for the implementation of the activities foreseen under WP3 (Organization and implementation of awareness raising campaign).

The RoW research report summarises the results emerging from the surveys and the national focus groups represent a solid basis for identifying the needs of the main target groups in relation to the participation in sport activities. The comparative analysis has found strong consensus on the role of sport as a driving force for:

- promoting people with rare diseases' cognitive, social and emotional development;
- encouraging social inclusion of people with RD.

The comparative analysis results also highlight some crucial obstacles (e.g. lack of preparation of coaches to support people with RD shortage of facilities and clubs/associations willing to welcome people with RD; lack of accessible facilities, health and safety)



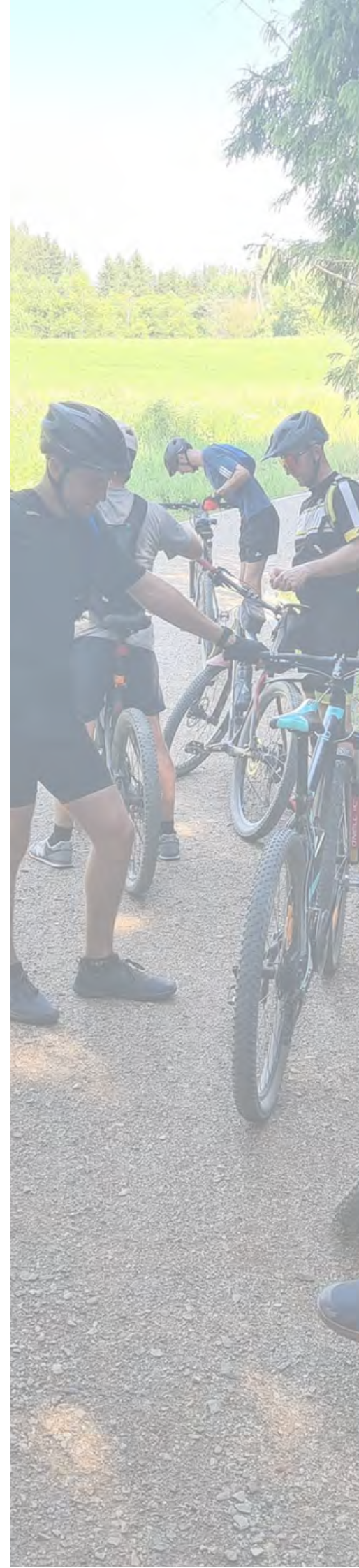
to sport participation.

As already pointed out, our research shows the scarce and sometimes even missing knowledge of any activities - implemented at national, and above all at European level - aimed to encourage social inclusion and raising awareness about rare diseases.

Nevertheless, the analysis of the results shows how in the three partner countries involved the need for ensuring people with RD better access to sport is a priority.

Hence, the implementation of awareness raising campaigns in partner countries, the organisation of awareness raising sports events (WP3) and the elaboration of policy recommendations (WP4) represents not only an innovative approach but also needed tools for supporting social inclusion and equal opportunities in sport and enhancing the participation in sport, physical activity and health enhancing activities in people with RD.

The implementation of the three project results mentioned above is key to developing a real movement on sport for rare diseases across Europe and facilitating the creation of a standard methodology aimed to promote the connection between people with RD with local sport options.





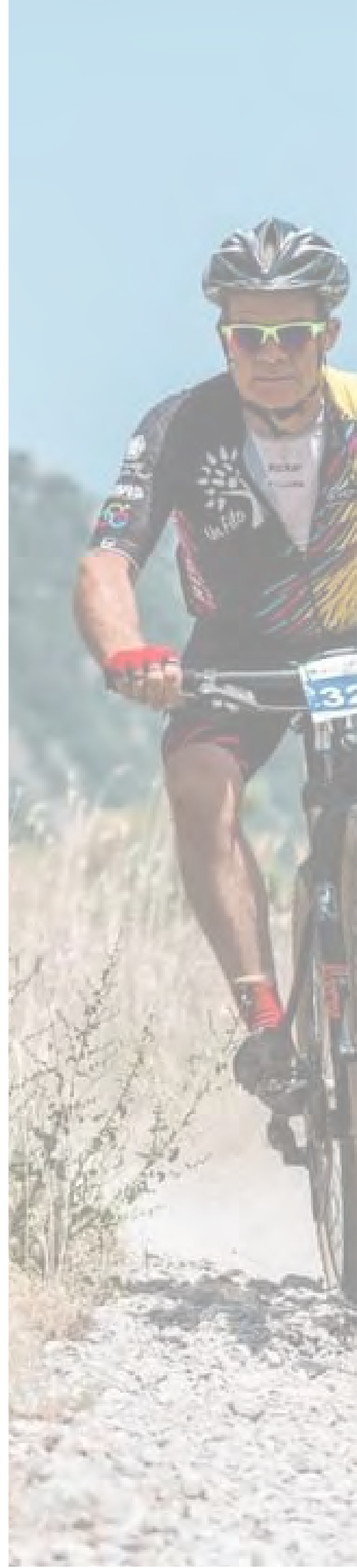
THE EVALUATION OF THE AWARENESS RAISING CAMPAIGNS

In the last phase of the two years of the Row Project, the partner organizations implemented three raising awareness campaigns in each country. The format of the campaigns was focused on the participation of the biking teams in three events organized by other entities. The purpose was at the same time to promote the activities of the project and raise awareness about rare diseases in sport but also to test the availability and interest of third parties in welcoming such initiatives. The campaigns were a real success although the results were not to be taken from granted.

The experience of the participation in the three events in each country is presented in the [RoW Booklet](#).

This phase of the project allowed the project partners to observe:

- How rare diseases are perceived by the general public in the sport field
- The interest and approach of sport clubs and organizers in supporting initiatives such as the RoW project
- The level of accessibility of sports events and competitions for people affected by rare diseases and disability.





First of all, we acknowledged how limited is the knowledge and awareness of the general public with regards to rare disease. People generally know what a rare disease might be but many of the people engaged were not even able to name a rare disease. Just like rare diseases were almost invisible in our health and social care systems until some years ago, the society needs to make some steps forwards in terms of awareness and collective responsibility as well.

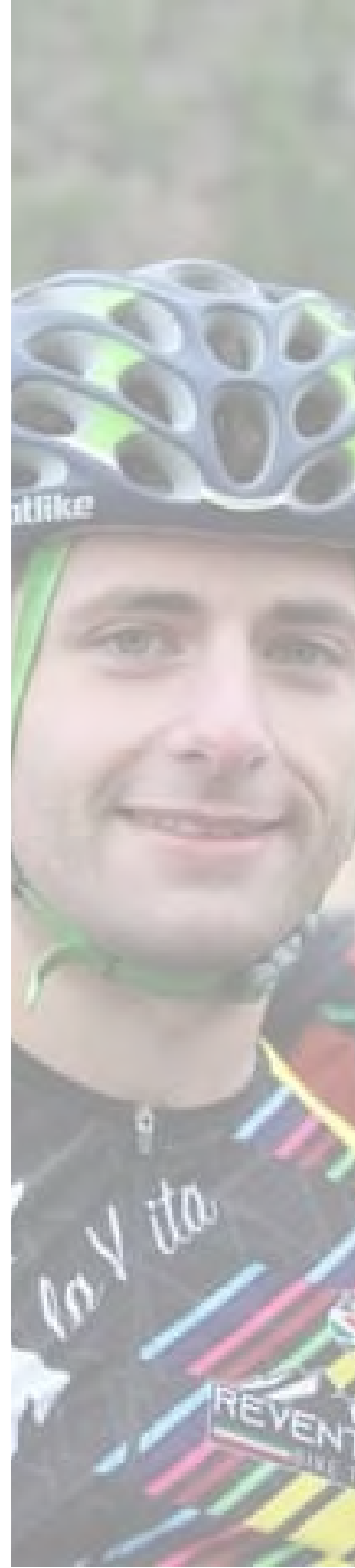
Secondly, although all the organizers accepted having the RoW project as a partner to their event, we observed how without having common elements (e.g. direct acquaintance of people affected by rare disease or their families) it was less effective to talk about the Row project and the importance of sport for raising awareness about rare diseases. People connect more deeply with situations they know directly and for example in Spain, where one of the RoW team member is a well-known biker whose daughter is affected by butterfly skin, the events were much more powerful then when we presented the RoW project to a public with no connection to the speakers.

Finally, we experienced how a competition is not the best moment to create spaces for discussion and awareness raising initiatives as people attending were very focused on the sport side of the event.





In this document, we highlighted the challenges rather than the strengths of the campaigns that can be observed in the Booklet. This is because the points discussed above were of great inspiration for putting into writing the policy recommendations that the readers can find below.



WHY POLICY RECOMMENDATIONS?

Rare diseases patients were almost invisible in the health and social care systems of EU countries until some years ago. Thanks to the progresses made both in terms of research and policy, rare disease patients are recognised as a public health and human rights priority. A milestone in the long and ongoing fight to improve the quality of life of rare disease patients was the policy framework defined by the Commission Communication on 'Rare Diseases: Europe's Challenges' (2008) and the Council Recommendation of 8 June 2009 on "An action in the field of rare diseases" setting the road map for several legislative acts and policies. While significant progresses have been made, a lot is still necessary for the 30 million people in Europe living with a rare disease. As a matter of fact, huge challenges are still unsolved with regards to diagnostic, treatments, decreased quality of life and isolation access to the quality healthcare, invisibility in healthcare and societal systems.

In this difficult scenario, the access to healthy and inclusive environments such as sports seems to have a very limited space in the societal and political discussions. The needs of our communities and of people affected by rare diseases, their families and caregivers must be met with a more strategic and collective decision-making processes in the field of sports.





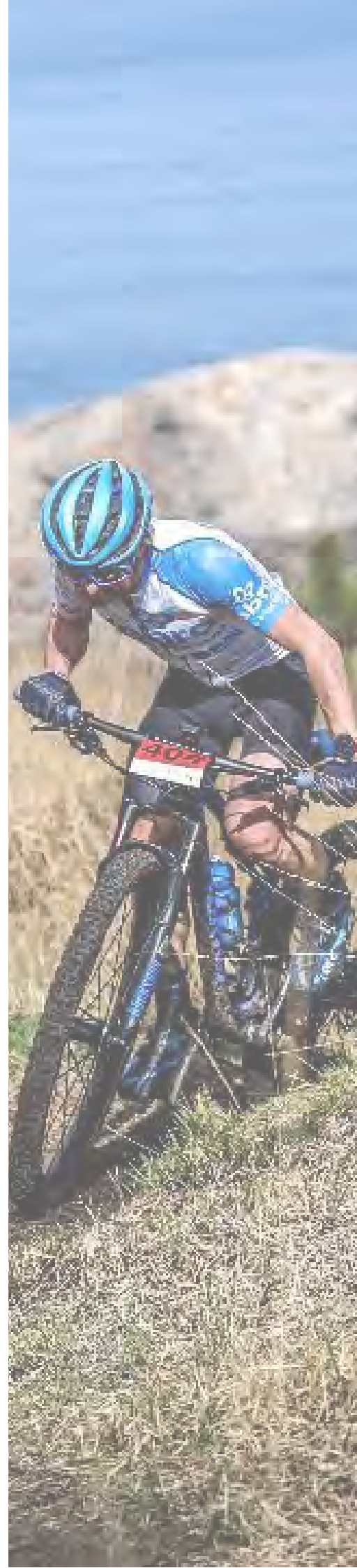
The social role of sports, its powerful inclusiveness, its benefits from mental and physical health are nowadays taken for granted but not for everyone. Public and private entities, sports clubs, associations, coaches and professionals have new technologies and new expectations that need to be reflected in policies from the European Union and its Member States.

The society needs a policy framework for rare diseases and sports representing a further step in the improvement of the quality of life of rare disease patients. The recommendations should work together with ongoing European strategies and programmes such as the European disability strategy.

The RoW policy recommendations address two main target groups:

- National and European policy makers
- National and European sport organisations

Through the policy recommendations, addressed to policy makers, including the European Commission itself, and sports associations we aim to promote a political action at international level towards the inclusion of athletes with disabilities in sports competitions at the highest levels such as Paralympics. This document also aims 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.





THE POLICY RECOMMENDATIONS OF THE ROW PROJECT

Stemming from the experience of project partners the following recommendations have been designed:

RECOMMENDATION #1

RECOGNITION OF A DISEASE AS A RARE DISEASE

RECOMMENDATION #2

INCREASED AND IMPROVED TRAINING OF SPORTS PROFESSIONALS AND COACHES

RECOMMENDATION #3

INCREASED SUPPORT TO THE CAREGIVER

RECOMMENDATION #4

INCREASED INVESTMENTS ON ADAPTED SPORT

RECOMMENDATION #5

MOVING TOWARDS AND INTEGRATED AND PERSON-CENTRED CARE

RECOMMENDATION #6

ENCOURAGING A CULTURE OF MEANINGFUL PARTICIPATION AND ENGAGEMENT OF PEOPLE LIVING WITH RARE DISEASES IN SPORT

RECOMMENDATION #7

IMPLEMENTING A LARGER NUMBER OF SPORT PROJECTS WITH INTERNATIONAL FOCUS

RECOMMENDATION #8

CREATING OPPORTUNITIES TO APPOINT LOCAL SPORT LEADERS

RECOMMENDATION #1

RECOGNITION OF A DISEASE AS A RARE DISEASE



Rare diseases represent a complex clinical entity. They constitute a major health issue in Europe: an estimated 30 million people live with one, and of these, 50% have not received a diagnosis. This results in a disparity of treatment within the community of patients suffering from the same disease from country to country within the European Union. It is necessary to recognize uniformly at the national and European level the status. Only then can all patients be assured equal health and social care and specific measures can be taken for their inclusion in sports activities. In particular, the recognition of the rare disease would facilitate the recognition of the difficulties patients experience in sports activities and would facilitate their participation in special sports competitions such as the Paralympics.

RECOMMENDATION #2

INCREASED AND IMPROVED TRAINING OF SPORTS PROFESSIONALS AND COACHES



The rarity of a rare disease makes it little known to many in the sport field, creating further obstacles to the safe and inclusive participation of RD patients in sports events. Specialized training pathways need to be implemented for all professionals involved in sport activities (managers, coaches, trainers, event organizer) in order to better prepare them in welcoming RD patients in their daily activities and events. At present, in fact, the integration in sport education of specialized training focusing on sports and rare disease is very poor when not completely missing.

RECOMMENDATION #3

INCREASED SUPPORT TO THE CAREGIVER



Support for the caregiver (family member or other dedicated) is essentially conditioned by the degree of autonomy that the RD patient is able to gain and the element that has the greatest impact on the quality of his/her life and on the recreational and sport activities. Therefore, the role of the caregiver is fundamental in providing adequate support to the patient thus guaranteeing the full and safe participation in sports activities and events.

It is also desirable, given the complexity of rare diseases, to offer educational pathways to caregiver so that he/she will be able to support sport professionals and coaches in the preparation and during the activity.

RECOMMENDATION #4

INCREASED INVESTMENTS ON ADAPTED SPORT



Too often sport facilities are not equipped for people with disabilities and in many cases rare diseases cause severe disabilities and/or impediments that prevent people with RD to practice sports.

It is then fundamental to accompany educational actions with investments for both sport facilities and equipment thus allowing for a real inclusiveness of the sport activities and events.

RECOMMENDATION #5

MOVING TOWARDS AND INTEGRATED AND PERSON-CENTRED CARE



The need for an integrated social and health approach to person-centred care is particularly important for people living with a rare disease, for which only around 6% of conditions have a dedicated therapy of any kind.

Therefore, for the vast majority, the greatest gains in quality of life will result from social determinants as often as clinical determinants. In this context, sport can play a major role and it should be integrated as part of the social support a RD patient receives. Each patient should be offered the opportunity of practicing one or more sport activity regularly as part of a person-centred care.

RECOMMENDATION #6

ENCOURAGING A CULTURE OF MEANINGFUL PARTICIPATION AND ENGAGEMENT OF PEOPLE LIVING WITH RARE DISEASES IN SPORT



An active and meaningful participation of people with rare disease in sports activity can only be guaranteed if the whole society (clubs, professionals, supporters, stakeholders, sponsors, etc.) understand the added value of creating inclusive sport environments.

To this end, all actors involved must strive to encouraging a culture of meaningful participation and engagement of people living with rare diseases in sport by implementing awareness raising campaigns, facilitating the access to sport activities and contributing to progressively make the participation of RD patients as common as possible.

RECOMMENDATION #7

IMPLEMENTING A LARGER NUMBER OF SPORT PROJECTS WITH INTERNATIONAL FOCUS



The gathering of people with rare diseases from diverse environments would give them, their families, caregivers, coaches and professionals a chance to exchange ideas, solutions, promote physical activity and show good examples of those who found a way to practice sport and be active despite the disabilities they suffer from. Therefore, opportunities moving in this direction should be created: the RoW experience clearly showed how traveling, meeting and attending sports events is a priceless source of social wellbeing for people with rare diseases and people with disabilities in general.

RECOMMENDATION #8

CREATING OPPORTUNITIES TO APPOINT LOCAL SPORT LEADERS



The lack of specialized sports centres and support for people with rare diseases in the sport field results in very few sport opportunities. Besides the actions to be taken in terms of investments and training, social engagement actions should be encouraged.

From the RoW experience, it was possible to observe the powerful role of local sport leaders as initiators of local and then international activities integrating the environment of rare disease patients. To this end, local authorities and stakeholders should work together with local leaders among people with and without disabilities who would draw in the whole community.



CONCLUSIONS: AN OPEN INVITATION TO POLICY MAKERS

The story of Borja, Paolo, Ines, Piotr and Ilaria, people with disabilities and patients affected by rare diseases that we met during our project are only some among the 30 million of people living with a rare disease in Europe as we speak.

The daily challenges that RD patients, their families and caregivers experience can be eased by facilitating their access to sports. This can only happen if three factors align: the policy, the awareness and the will of those working and living every day in the sport field, the investments in both research and infrastructures.

While the European Union has made significant progress in the past decade to improve the life of people living with a rare disease in Europe, it is undeniable that in the sports field there is a lot to be done.

Too often the inclusion of people with rare diseases as well as people with disabilities in sport activities is left to individual initiatives rather

than collective and political responsibility.

It has taken some decades to get where we are. It is now time that the political action takes the leads and lay the foundation for the other two factors to align also in the sport field. Policy makers together with sports clubs, associations, coaches, families, public entities have the opportunity to produce an extraordinary change in the next decades and in particular by 2030, a significant year for human rights and the quality of life of our society as whole.

Without a meaningful participation of people affected by rare diseases and people with disabilities in sport activities there cannot be a real inclusion and a real improvement in the quality of life.

By 2030, sport will have to play a fundamental role in building a more inclusive society that recognises all our needs and challenges.

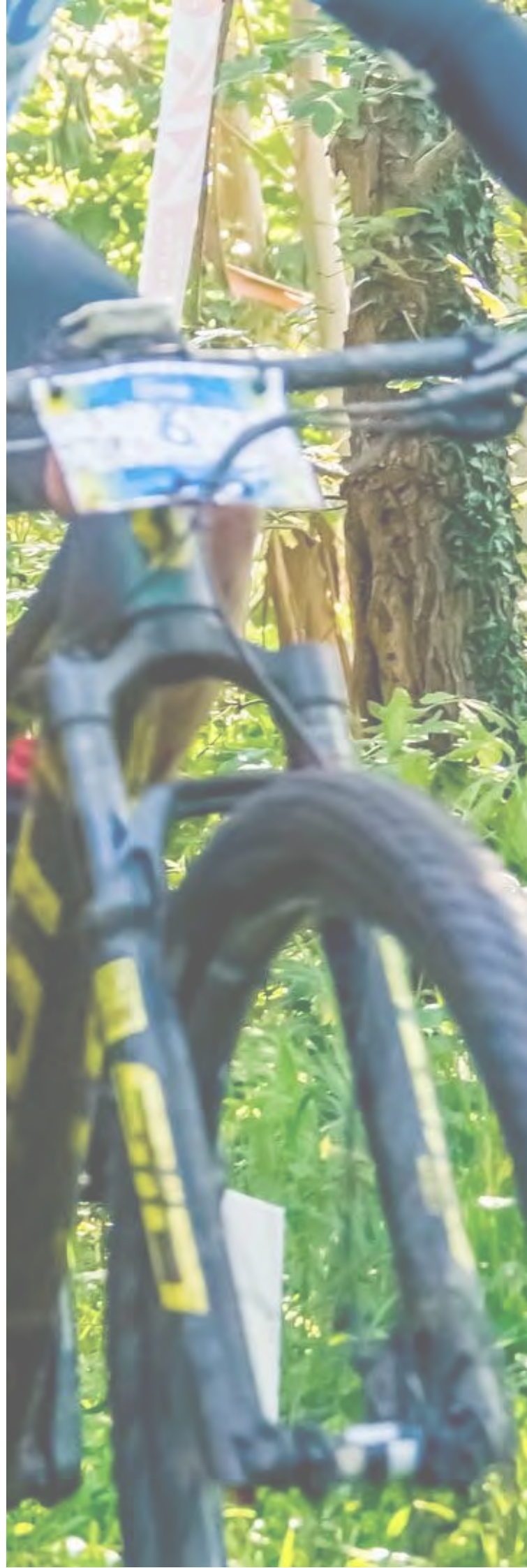


It is now time for the sport world to become a truly inclusive environment where competition can make way for cooperation, fun and health for all so that also people with rare disease can have the healthiest and best life they can.

As the leaders of today you can produce an extraordinary impact, to drive change in the sport field, and the generations of rare disease patients, carers, coaches and professionals to come.

Dear Members of the European Parliament, dear European Commissioners, dear national and local policy makers, you now have the power to speed up the process and improve the quality of life of people with rare diseases through sport in the next few years without letting the well-being of 30 million people be left to luck or chance.

Please consider our words so that the world of sport and the policymaking together can make this possible.





FURTHER READING

- European Commission (2021) Union of Equality Strategy for the Rights of Persons with Disabilities 2021-2030
- European Commission (2008) Rare Diseases: Europe's challenges
- Kole, A., Hedley, V., et al. (2021) Recommendations from the Rare 2030 Foresight Study: The future of rare diseases starts today
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