

RARE DISEASES & SPORT

ENCOURAGING SOCIAL INCLUSION AND EQUAL OPPORTUNITIES IN SPORT

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1. POLICY RECOMMENDATIONS

The document **POLICY RECOMMENDATIONS**, available in [English](#), [Italian](#), [Spanish](#) and [Polish](#) on the project webpage, is the last output of the RoW project and thus is based on the work done by the Consortium in the project's lifespan.

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 RoW Policy recommendations aim 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.

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.

The 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.

2.FINAL EVENTS IN ITALY, SPAIN AND POLAND

With the aim of maximizing the visibility of the project results, an awareness raising sports event was organized in each partner country between September and November 2022.

AWARENESS RAISING SPORTS EVENT IN ITALY

Last 7th October 2022, Un Filo per la Vita Onlus held the RoW final event in Rome, at Bambino Gesù Children Hospital. Un Filo per la Vita Onlus organized an event dedicated to RoW and aimed to raise awareness on rare disease.

Being Bambino Gesù Children Hospital an Hospital specialized in rare diseases, the realization of the event played a key role in sharing the project results and contributing to the sustainability of the project.

The event was devoted to discuss the experience and challenges of people suffering from rare disease and the involvement of professionals, patients and caregivers.

The event aimed to introduce the RoW project and its results, with a special focus on the Policy Recommendations.



AWARENESS RAISING SPORTS EVENT IN SPAIN

The Spanish final event took place last September 2022. The awareness raising sport event in Spain was organized over three days:

- Project presentation (19/9/22)

The event was hosted by the Municipality of Burela and both the Mayor and the Head of sports of the Xunta de Galicia in Lugo attended the event.

The staff members of the Spanish project partners presented the project and results of the RoW project

- Raising awareness walk (24/09/2022)
- Trail Race and Hiking (25/09/2022).



AWARENESS RAISING SPORTS EVENT IN POLAND

Last 16th October the final event was organized in cooperation with the association Aktywny Ćmińsk, which is very active in the region of the Świętokrzyskie region.

Both RD patients and their families, the association Nadia Szostak (which gathers RD patients and their families), some local sports associations attended. The event was a run promoting healthy lifestyle and the knowledge on rare diseases and sport as a tool for social integration.

A workshop has been implemented to present the RoW project, its aims and results. The Polish partner presented the project results and Piotr Pawełko, rare disease patient on a wheelchair who is in the national team of basketball, presented his story and motivated the participants to be active though sport.

