

Project title: Comprehensive support for women with rare disease challenges

Project leader: Rare Diseases Croatia

Partner 1: Centre for Education, Counselling and Research

Partner 2: Inclusive house Bell

Partner 3: National organisation rare diseases Montenegro

Partner 4: FRAMBU competence center for rare diagnoses, Norway

Project implementation period: September 1, 2022 – November 30, 2023

Project total value: 86.044,53 €

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Link to relevant internet pages: <https://rijetke-bolesti.com/>

Project summary:

Women from vulnerable groups, especially those dealing with rare health conditions, face multiple marginalizations and discrimination due to an underdeveloped support system. These issues span legal, psychological, and medical domains, significantly affecting their roles in business, private, and social contexts. A lack of awareness of their rights and limited capacity to advocate for them, coupled with systemic barriers, further exacerbates their challenges.

The project introduces an innovative Case Management (CM) model, providing a stable contact point and a holistic, person-centred 1-on-1 approach. A multidisciplinary team of experts and volunteers delivers legal, psychological, and medical support, along with education, information, networking, and coordination of external support resources. CM also enables systematic data collection and analysis for long-term sustainability and public awareness of the unique challenges women face.

The project addresses external factors through a conference and a public campaign to foster the inclusion of empowered women and their rights. Raising citizen and public awareness of these issues contributes to a more inclusive and equitable society prepared to support vulnerable groups.

Case Management and research will be expanded to less developed areas (Osijek-Baranja County) and diverse regional settings (Montenegro), enabling the multiplication and decentralization of support. The model can also be applied to related target groups, such as women with disabilities and mothers of children with developmental difficulties.