



Alianța Națională
pentru Boli Rare
România

INNOCare

NoRo
radio

Collaboration for the management of rare diseases – ColaboRARE



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Romanian National Alliance for Rare Diseases - RONARD is involved and work for the improvement of the quality of life of patients with rare diseases and the intensification of the communities' and authorities' responsibility towards these people.

Objectives:

1. Development of inter-sectorial partnerships for monitoring and reassessment of care needs and improvement of the quality of existing specialized social services
2. Strengthening internal capacity of RONARD, including its members, to promote public policy and advocacy, and monitoring their implementation

Main results: intersectorial meetings, training sessions for patients organizations, national conferences, national campaign for RDD, an online platform of cooperation among services: www.participrare.ro, resources for diagnoses (London Medical Database and DNA extractor), an online radio „NoRo radio- the voice of patients”, a partnership with National Agency for Disabled People to improve the access to specialized social services for patients with rare diseases and a Ministerial Order for accreditation o CoE for RDs in Romania.

Conclusion: Organizing intersectorial meetings and specific trainings to bring together many stakeholders and „opinion liders/ journalists” is increasing communities' and authorities' responsibility towards these people, understanding better and better the complex problems of rare diseases.

