



# Pilor Reference Center for Rare Diseases NoRo

**Romanian Prader Willi Association – RPWA's** vision is a world where people affected by diseases have a real chance to diagnosis and treatment, having in the meantime proper opportunities for integration in the community.

Since 2011 the **Pilot Reference Center for Rare Diseases–NoRo** (opened by RPWA) is providing **integrated services** to people affected by rare diseases and their families by improving access to care, information, research and education. As a resource centre, it offers therapeutic and medical services in order to raise the quality of life of patients affected by rare diseases.

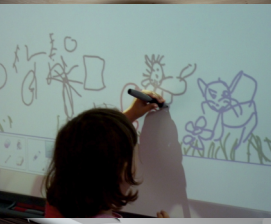


## General Objectives:

- to facilitate access to information as a Resource Centre for Rare Diseases in Romania
- to create a support network among patients affected by the same disease
- to create a support network between specialists and families
- to stimulate research in the field of managing rare diseases
- to create a national data base on rare diseases
- to collaborate with national and international organizations and networks
- to encourage early diagnosis, prevent and manage disability at all levels
- to implement case management as an integrated, holistic approach for rare disease patients - a one-stop-shop style of service

## Accredited/licensed services in NoRo Center

- Social services** - Day Center, Residential Center, Training Center for independent life
- Medical Services** - recognized as a HCP to participate in ERN & CoE, part of a national consortium,
- Information Center** - Help Line NoRo
- Training courses** – face to face and online trainings ([www.edubolirare.ro](http://www.edubolirare.ro)), workshops, conferences
- Research activities** – in collaboration with national and international partners
- Publications** - for general public and for specialists
- Lobby and Advocacy**



## INNOVCare objectives addressing case management:

- minimizing fragmentation in the care provision
- using evidence-based guidelines in practice
- navigating transitions of care
- incorporating standardized practice tools, expanding the interdisciplinary team in planning care for individuals, and improving patient safety
- recognition of case managers as experts and essential participants in the rare diseases care coordination team who empower people to understand and access quality & efficient care.



## Conclusions of InnovCare project implementation in Romania

- WP6 - Pilot of integrated & personalized care, social care provision – NoRo Center is **testing** the innovative holistic pathway approach in Salaj County
- Establishment of vertical integration partnerships & Assessment of service provision in the region is facilitating the intervention
- 4 case managers providing holistic services for a total of 118 beneficiaries will **improve quality of life** of people with rare diseases
- collecting data for the services provision efficiency evaluation throughout the intervention will support the upscaling activity
- participating in the establishment of the network of resource centers for rare diseases – RareResourceNet and collaborating with other resource centers is also a support for the upscaling activity
  - upscaling** the model is the next step needed.

