

# INNOVCare

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

## INNOVCare pilot of case management for rare diseases

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*Workshop: Creating a Sustainable Environment for Holistic & Innovative Care  
for Rare Diseases & Complex Conditions*

Frambu Resource Centre for Rare Diseases, Oslo, 12-13 April 2018

[www.innovcare.eu](http://www.innovcare.eu)



[www.creenfermedadesraras.es](http://www.creenfermedadesraras.es)



[www.cjsj.ro](http://www.cjsj.ro)



[www.apwromania.ro](http://www.apwromania.ro)



[www.eurordis.org](http://www.eurordis.org)



[www.finovatis.com](http://www.finovatis.com)



[www.ier.si](http://www.ier.si)



[www.ki.se](http://www.ki.se)



[www.zsi.at](http://www.zsi.at)



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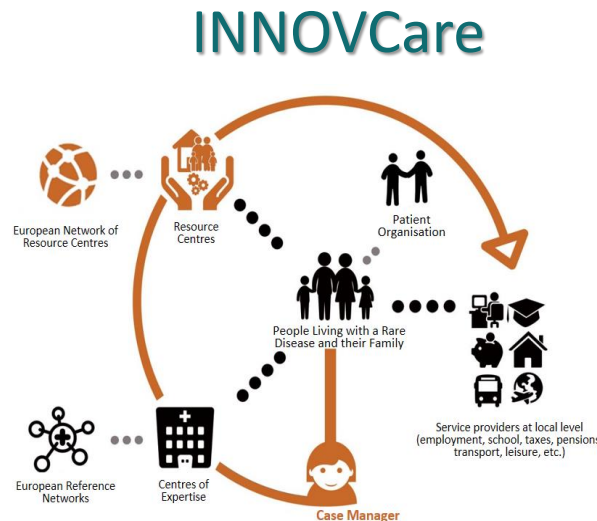
# RDs in Romania

- ✓ **Rare Diseases in Romania:** declared a national priority, too often forgotten, considered to be costly and that the patients have NO real chance for cure...
- ✓ *The lack of integrated services addressed to those affected by rare diseases, to facilitate the diagnose and to give the power to go forward and look for treatments, therapies, rehabilitation, inclusion in school and community...*

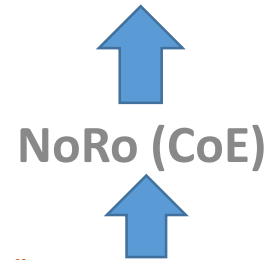
**Mentoring Program**

**NoRo – Frambu**

> 10 years of partnership !!!



**Ro-NMCA-ID (RoNetwork Multiple Congenital Abnormalities with ID)**



# Introduction: NoRo Center

2009



## OPPORTUNITIES

- ✓ EEA&Norway grants opportunities
- ✓ Members of EURORDIS
- ✓ Local strategy and NPRD
- ✓ Sustainable partnerships
- ✓ Involvement at national and EU level
- ✓ EUROPLAN Project, EJA RD, INNOVCare & RD Action
- ✓ Partnership with Local/ County Council & MoH

2011

## CHALLENGES

- ✓ Low numbers → low interest!!!
- ✓ No other services like this!
- ✓ No collaboration between social and medical services, national and local;
- ✓ Not accessible information
- ✓ No understanding at community level

19/04/2018

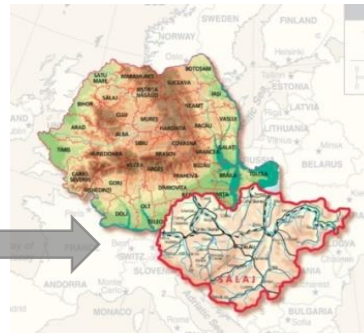


# “One stop shop service” :

Medical services in contract with NHI – HCP Accreditation	+ C A S E  M A N A G E M E N T	Different specialties, permanent staff: 21 psychiatrist and geneticist, nurses, therapists;
Individual therapies:		Psychological intervention, hydrotherapy, medical gymnastic(MIRA), speech therapy, behavior, sensorial, electric therapy and social counseling;
Group therapy and interventions:		Psychological counseling, occupational therapy, ergo therapy;
HelpLine		Part of the EURORDIS network of Help Lines Website, Facebook, blog, magazines, conferences and workshops
Information and counseling		
Trainings and online platform: <a href="http://www.edubolirare.ro">www.edubolirare.ro</a> & 2 magazines ( <a href="http://www.rjrd.ro">www.rjrd.ro</a> )		Diseases management, “Trial for flight”- life skills, trainings for professionals;
Registry		NoRo Patient registry
CoE & RO-NMCA ID –NMCA ID		ERN ITHACA (ePAG) & RareResourceNet

# WP6(NoRo-CJSj)

*Case management is the coordination of services on behalf of an individual person who may be considered a case in different settings such as health care, nursing, rehabilitation, social work, disability insurance, employment and law, accompanying the patient/family and filling the existing gaps.*



**a Resource Centres for Rare Diseases in Romania in partnership with Salaj County**

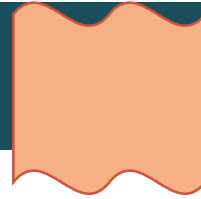
- ✓ **one-stop-shop style of service**, specifically designed for people living with a rare disease, combining **medical, social and educational services**;
- ✓ **included patients** at local and county level in case management through INNOVCare project
- ✓ **testing** a holistic, personalized care pathway & implement a **pilot of this pathway** in Romania
- ✓ created a **bridge** between patients/families and professionals & care services
- Involved in the steering group of **RareResourceNet**

# Activities: NoRo and SJ County/ WP6

- ✓ Collected and shared information:
  - ❖ focus groups with patients on case management role and expected outcomes , site visit from ZSI and meeting with stakeholders, shared opinions on what case managers will do and what these interventions would change in patient lives;
- ✓ Study on care provision for people with rare diseases in the County of Salaj
  - ❖ Mapping care providers, payers, patient and disability organizations in Salaj, other community services or community support - who does what
- ✓ Advisory Committee & Ethics Committee;
  - ❖ Support on contacting the potential beneficiaries, coordination and intervention of the case management;
  - ❖ Focus groups with patients on case management role and expected outcomes (September);
  - ❖ Ethics certificate issued;
- ✓ Preparing curricula, case managers' training, translation;
- ✓ Case management – 2<sup>nd</sup> faze
  - ❖ Creating and developing community support network
  - ❖ Organizing meetings, presentations in different settings & workshops on case management for RD
- ✓ Up scaling at national level
  - ❖ Policy framework created
  - ❖ Introduction in the Romanian code of occupations – ongoing (NADP)



# Training curricula



## 1. Introduction

- ✓ Project presentation
- ✓ Vision, Definition of case management
- ✓ Skills, qualification and abilities for case managers
- ✓ Case studies – other national experiences: case management project on MDD, patients navigator in cancer;

## 2. Rare diseases - general information

- ✓ Access to diagnosis in RD
- ✓ Assessment of the degree of disability
- ✓ Access to education
- ✓ Employment
- ✓ Social inclusion

## 3. Case management and communication

- ✓ Communication
- ✓ Efficient communication
- ✓ Developing communication skills
- ✓ Conflict solving & Networking

## 4. Resilience

- ✓ General information on family resilience
- ✓ Empowering patients and families
- ✓ The announcement of diagnosis and it's impact on the family
- ✓ Personal development and self-esteem

## 5. Development and coordination

- ✓ Description, definition and possibilities
- ✓ Legislation - rights and obligations
- ✓ Finding the right information and accessible
- ✓ Available Services

## 6. Work methodology

- ✓ Methodology of case management for people with rare diseases and their families
- ✓ Working Tools used in case management of people affected by rare diseases and their families



# Case management implementation

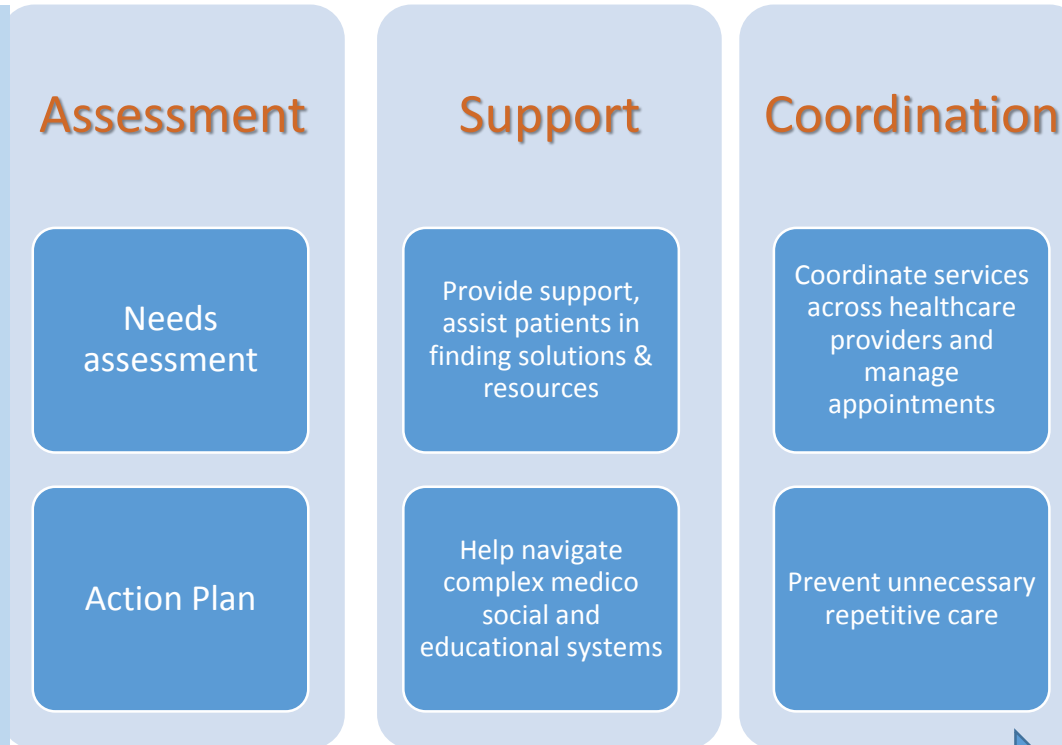
✓ **Time frame:** 18 months, starting from 03/2017 to 09/2018

✓ **Target population:**

- ✓ patients with **complex conditions**;
- ✓ **current beneficiaries** of NoRo and **new ones**;
- ✓ **NoRo's beneficiaries**– 30/period;
- ✓ **120 beneficiaries needed**, identified 265, contacted 148, and **118 included**, remaining **115**;
- ✓ Number of **case managers: 4 (1/2 )**
- ✓ **Simultaneous “cases”** per case manager : 15;

✓ **Profile of case managers:** 2 social workers, 1 legal advisor and 1 special education teacher;

✓ They all have **previous contact with rare diseases**;



„Creating a Sustainable Environment for Holistic & Innovative Care”

# Stories...



- 3 people in the same family with MD;
- appointment to orthopedics and neurology;
- wheelchair approved;
- training to use the wheelchair and how to adapt the house;

1 patient with MD, no personal assistant, all his relatives abroad;

- re-evaluation of the case – personal assistant
- wheelchair approved;
- His niece returned from Italy and became his personal assistant;

Person of 74 years old diagnosed with MS

Appointment and investigations – new diagnostic added: multiple myeloma;

No access to free treatment after 65 years;

Contacted NDA and solved the access problem;

One of our beneficiaries in the Day Care Centre but, stopped our services before case management started;

Case manager organized an appointment to the psychiatry and tried to convince family that the child needs to be hospitalized as he became dangerous for the family and others;

Discussions with the psychologist – no agreement with the family; They accepted finally the need for specialized residential care and currently are looking for the right service



Young person with MG

Contacted the patient organization and have been invited to meet other people with the same diseases – support group

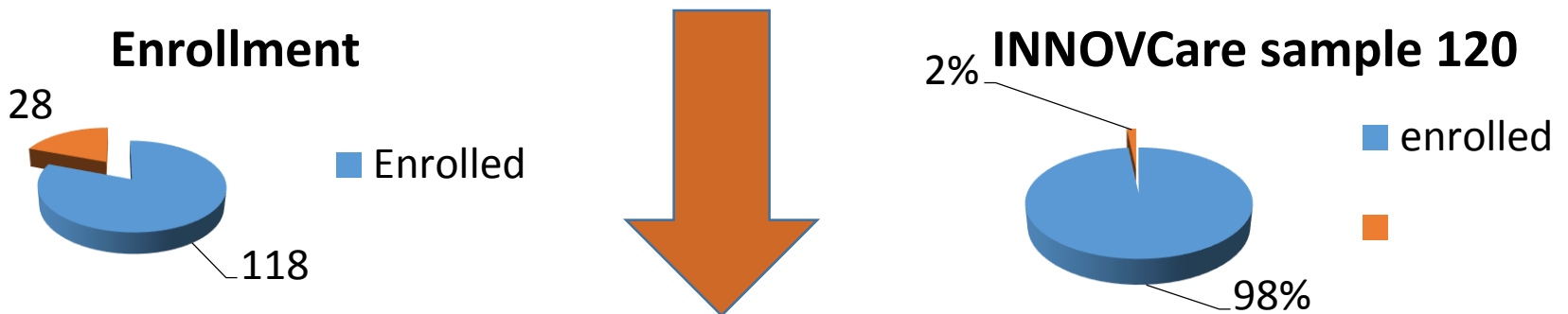
Facilitated meeting with a project consultant to start a small business

He is on a waiting list for rehabilitation

# The current situation:

## ✓ Beneficiaries:

- ☐ Total contacted: 146
- ☐ Total enrolled: 118 (the goal was 120)



*\*3 drop-outs during implementation*



# Activities of case managers

- ✓ Evaluate the situation of the person, to identify their needs (which are not always those expressed) - multidimensional evaluation in consultation with experts if needed
- ✓ Assist patients to communicate when the communication with professionals is not working
- ✓ Inform patients/families on rights, financial, human and psychological support, social and community services
- ✓ Development of holistic and patient-centred individual action plans, based on what matters to patient/family
- ✓ Accompany patients/families in administrative procedures, access to rights and services, participation in research
- ✓ Mobilise care providers to find a solution more adequate to the needs that seem to be the most recurrent
- ✓ Support and advise professionals
- Outreach to professionals involved in the assessment of individual functioning (disability certificate)
- Encourage the development and take part in networks of specialised experts
- Developed activities that support empowerment of patients and families

# Challenges for case managers

Distance... - longest route to a case 70 km



- ✓ Not enough services to direct patients to
- ✓ Lack of service infrastructure for RD patients
- ✓ Availability of some people only after work hours
- ✓ Longer periods beneficiaries are missing from home – being in hospitals, rehabilitation centers, at relatives...
- ✓ Need to do more than facilitating access
- ✓ Sometimes, CM can't solve the problem!
- ✓ Collaboration of the institutions is absolutely necessary!
- ✓ Financial situation of beneficiaries can not be changed through CM

# Collaboration between case managers

There is a need to have **regular meetings** of the case managers in order to:

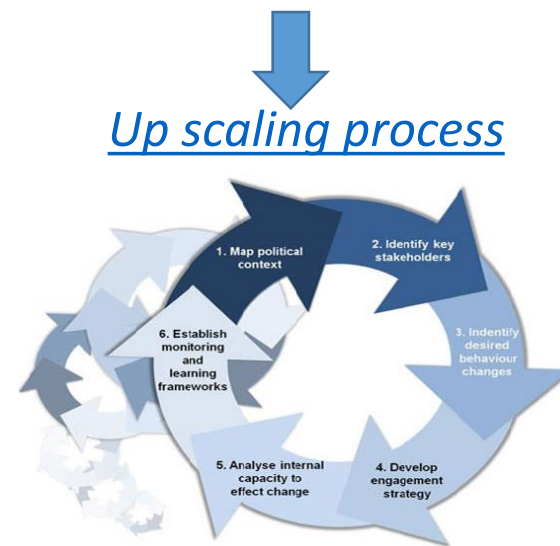
- ✓ Identify cases with the **same problems** handled by different case managers – solutions that can be addressed together
- ✓ **Information exchange** regarding network contacts, resource persons, other resources
- ✓ **Brain storming** for special situations
- ✓ Meetings as **support group** to handle easier the emotional burden of the work



# Up scaling process- on going at national level

- ✓ County Council and Advisory Committee involvement
- ✓ Training program developed
- ✓ Initiated new national and EU collaborations
- ✓ Introduction of case management in RCO - ongoing
  - ✓ Cooperation with professionals and National Authorities for Disabled People and Ministries of Work, Health and Education!

- ✓ involvement in *elaboration of national policies – included in the law*
- ✓ *integrated care approach & case management in community care strategy*
- ✓ *cooperation with other social, medical and educational services*



# Upscaling process

- ✓ **Good news regarding the upscaling process on case management:**  
<https://legeaz.net/monitorul-oficial-920-2017/hg-797-2017-reguleamnte-cadru-organizare-functionare-servicii-asistenta-sociala>

- ✓ **National strategy for community nursing**


- ✓ **Social Assistance Law no. 292/2011 modifications and completions:**

- ✓ *a case manager for 50 children with disabilities ( where a care plan is implemented) , a case manager for 100 personal assistants, a case manager for 50 adults with disabilities*





# Conclusions:

- ✓ Interinstitutional collaboration is essential
- ✓ Sometimes there is more than facilitating access that the case manager has to do
- ✓ Close to beneficiaries
- ✓ A multidisciplinary approach to providing care is critical
- ✓ Case managers should be well informed and proactive
- ✓ They need tools available: services map, guidelines, contacts...
- ✓ Improved coordination of individual care  improve the quality of life for people with rare diseases!

*Thank  
you*

