



## *NoRo – a Resource Center for Rare Diseases*

*Advancing holistic and innovative care for rare diseases and complex conditions*

*Cluj-Napoca, 1-2 June 2017*

*Dorica Dan – president RPWA, RONARD, ARCrare*



# How do people understand us sometime?



# RPWA brief history:

- ✓ RPWA was established in 2003
- ✓ First international meeting in 2004 in Zalau
- ✓ Attending the 5<sup>th</sup> International PWS Conference in Christchurch, New Zealand
- ✓ Opened the Center for Information about Rare Genetic Diseases in 2005
- ✓ 1 Session about PWS at the Balkan Congress for Endocrinology Bucharest
- ✓ The 6<sup>th</sup> International PWS Conference in Cluj- Napoca, June 2007
- ✓ 1<sup>st</sup> National Conference about Rare Diseases, 1-3 November 2007
- ✓ 1<sup>st</sup> European RDD – 29 February 2008 –NPRD partnership with the MoH; every year RDD Campaign; Renewed partnership 2013; 2014 – National Strategy for Health;
- ✓ 1<sup>st</sup> National Program for Rare Diseases;
- ✓ May 2009 – 1<sup>st</sup> EE Conference on PWS, Timisoara; 2010 Zalau;
- ✓ Balkan Congress for RD, Cluj – June 2009
- ✓ Implementation of the NoRo Project: 2009 -2011
- ✓ 2010 – EUROPLAN1
- ✓ 2010 – The 2<sup>nd</sup> EE Conference on PWS
- ✓ 2011 – June 28, Official opening of the Center



## ❑ Projects implemented in partnership with Frambu:

- **2011 – Opening of NoRo Center** (*Norwegian-Romanian, partnership for future in rare diseases*)
- AD AUGUSTA PER ANGUSTA
- NoRo- Frambu, partnership for the future
- TEAM – Together, everybody achieve more
- DocumentRARE - **2017**



# Our objectives as a resource center:

- ✓ Delivering social and medical services/ integrated care for PLWRD
- ✓ Gather and disseminate information/ raising awareness
- ✓ Produce good practice and guidelines for care
- ✓ Training for patients, personal assistants and professionals
- ✓ Implementation accreditation of quality standards in our services
- ✓ Promote innovation in our services
- ✓ Collaboration with all the stakeholders involved



# National context:

- ✓ Rare Diseases in Romania: declared a national priority in the last years, too often forgotten, considered costly and patients with 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...*

**NoRo – Frambu**

**Mentoring  
Program**



# Challenges & opportunities



## OPPORTUNITIES

- ✓ Patient organization – national and international
- ✓ Collaboration with professionals and authorities
- ✓ Local strategy and NPRD
- ✓ Funding opportunities & responsible implementation
- ✓ Sustainable partnership
- ✓ Involvement at national and EU level
- ✓ Rare Diseases Day 2007 -2017
- ✓ EC Communication and Recommendation for RD
- ✓ EUROPLAN Project
- ✓ EJA RD

## CHALLENGES

- ✓ Low numbers → low interest!!!
- ✓ No other services like this!
- ✓ No collaboration between social and medical services, national and local;
- ✓ No information accessible
- ✓ No cooperation between professionals and patients and not even between POs



# Case management

*“Case Management models will not deliver better care for patients and produce cost savings unless they are well designed, involve appropriately and professionally trained case managers and teams and embedded in a wider system of care that supports and values integrated and coordinated care.”* Nick Goodwin

**Law 292/2001**, regarding the social services in Romania, case management is defined as follows: *„Case management is a method of coordination and integration of all the activities for vulnerable groups, a method of organization and handling the specific social care measures, done by social workers and/or other specialists, in accordance to the established goals of the intervention plans.”*

The **main role of the case managers**: to develop and implement the rehabilitation plan for the children with disabilities (appointed by the DGASPC- General Directorate of Social Protection and Child Protection) and can be an employee of the DGASPC or of a private, accredited entity.

# Romanian legislation

- ❑ *The case manager has to make sure of the involvement and collaboration of a team of specialists, during all the stages of case management, if needed inter-institutional collaboration as well.*
- ✓ a case manager can have a maximum load of 30 active cases in the same time!!!
- ❑ Case management in child protection has the following main stages:
  1. identifying, initial evaluation, taking over the case
  2. detailed evaluation of the situation
  3. planning the services and interventions in a Personalized Intervention Plan (PIP) or other Plan (*Action Plan in our case!!!*)
  4. delivering services and interventions for the child, family, etc.
  5. monitoring and periodical re-evaluation
  6. closing the case.



# Problems in the current legislations

- ✓ The gaps that it **does not cover detailed regulations for adults**
- ✓ It is **not highlight** the special needs of disabled people, and **the very specific needs of the persons affected by RD.**
- ✓ The public sector (DGASP) has case managers for people with disabilities, but, having too many cases, **they work mainly with public social and educational services**
- ✓ **Recognise the benefits** of having case managers but have **not enough resources to cover even all the children needs**
- ✓ **Members of the Advisory Committee** consider that it is **a need to train people from different sectors**

# Case management at NoRo

- ❑ *The **coordination of care and establishing the link between patients and professionals** involved in the management of the care, create the **link between patient/ family and health, social and local/support services**, monitor the patients from diagnostic until they enter/ leave the services they need, **periodic reevaluation of needed services and access to them**.*
  - ❑ *INNOVCare care pathway focuses supporting patients through **regional case managers hired by the Romanian national resource centre for rare diseases (NoRo)**.*
  - ❑ *The resource centre is also **connected to a European Network of services**. The case manager role is related to coordination of care and to making the link between health, social and local/support services, including employment, school, financial support, housing, transport, leisure, etc.*
- ✓ **The case manager does not take roles of other professionals**
  - ✓ **The case manager have to have information** from social, medical, educational field, collaborate with the patient and family members, collaborate with all the service providers and authorities.

# Vision

- ❑ **Vision:** Case managers are recognized as experts and essential participants in the rare diseases care coordination team who empower people to understand and access quality & efficient health care.
- ❑ **Case management** is a collaborative process of assessment, planning, counseling and information on options and services to meet patient and family's care needs through communication and available resources.



# Skills for case managers

- ✓ positive approach;
- ✓ effective communication;
- ✓ negotiation skills;
- ✓ knowledge of contractual and risk arrangements, the importance of obtaining consent, confidentiality and client privacy;
- ✓ ability to perform ongoing evaluation;
- ✓ critical thinking and analysis;
- ✓ ability to plan and organize;
- ✓ promote client autonomy;
- ✓ knowledge of health, education and care services;





# The role of case managers

- ✓ Single and stable point of contact
- ✓ Listen, inform, support and empower patients and families
- ✓ Assessment of needs
- ✓ Holistic and patient-centred care planning and care co-ordination
- ✓ Hub of information and knowledge
- ✓ Inform, support and empower professionals involved in care provision
- ✓ Facilitating networks of service providers
- ✓ Prevention of avoidable high risk situations
- using evidence-based guidelines in practice
- navigating transitions of care

## A case manager should not:

- ✓ Take decisions instead of the patient
- ✓ Take over tasks of other professionals



# Activities to be performed

- ✓ 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 care 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
- Develop working methods that support empowerment of patients and families

# Background of case managers

- ✓ Social workers – 2
- ✓ 1 special education teacher- 1
- ✓ 1 lawyer - 1



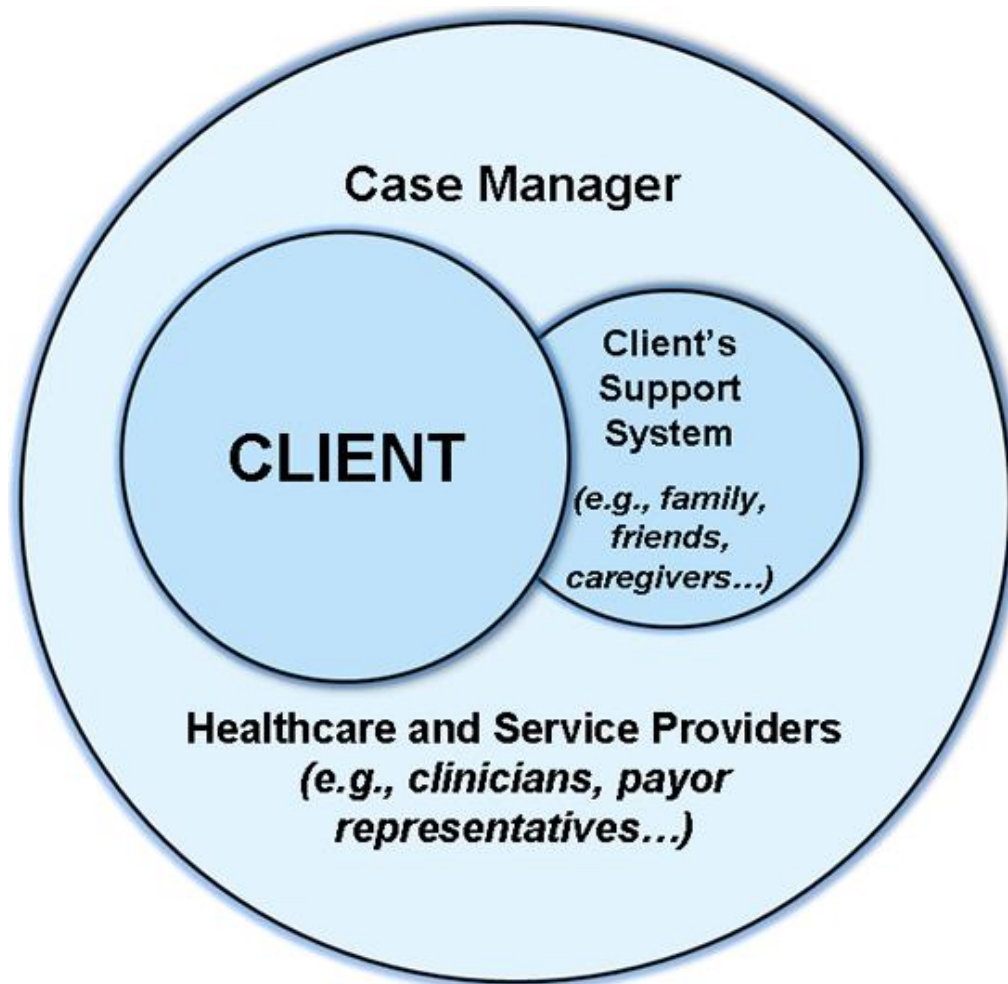
✓ they have also experience from their families and/ or from working in the social field

## □ Daily activities of the case manager:

- ✓ Explain to patients, families about the intervention;
- ✓ Give time to patients to decide if they need this service;
- ✓ Evaluating the needs;
- ✓ Deciding the objectives and activities for Action Plan;
- ✓ Communicate, create network with professionals and monitor the services/information available;
- ✓ Take into consideration, that every case is different, could need more or less time to get to the goals.

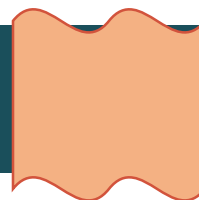
# Who can be trained?

- case managers from child protection
- doctors
- nurses
- community nurses
- psychologists
- social workers
- sp. education teachers
- genetic counsellors
- pharmacists
- physiotherapists
- occupational therapists
- speech therapists
- teachers
- social reference persons





# Training curricula



## 1. Introduction

- ✓ Project presentation
- ✓ Vision, Definition of case management
- ✓ Skills, qualification and abilities of 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
- **Annexes:** General information on RDs, Map of services,

# Certification and ongoing actions

- ✓ It is not in the Code of Occupations in RO;
  - ✓ Different certification from Professional Associations;
  - ✓ It is included in the curricula of the Faculty of Social Assistance;
  - ✓ Train supportive networks in the community and find the right way to certificate the skills gained by participants;
  - ✓ Workshops & conferences;
  - ✓ Videoconferences and webinars;
- ✓ Disseminate relevant information related to the rare disease environment to all stakeholders
  - ✓ Demonstrate the importance of integrated care services
  - ✓ Elaborate strategies for developing information and training for social services providers
  - ✓ Exchange knowledge and best practices on all relevant health, social and educational issues related to the rare diseases
  - ✓ Involve all the authorities at local and national level
  - ✓ Collaborate and communicate !!!
- 



# Up scaling process

Participate in the evaluation of the impact of rare diseases on the every day life of patients and families (Rare barometer)

Improve organizational capacity and network through collaboration, training of/ with different stakeholders

Advocate for patients' centred – personal intervention plans and interdisciplinary and holistic approach in RD

Long-term - Sustain the implementation of case management in the National Plan for RDs

## 3 main objectives:

To strengthen the role of NoRo Center as social services provider

To implement a mentoring program with other social services providers and to upscale our experience at national level

To develop and asses an innovative approach to ensure continuity of care for patients with rare diseases.

Integrated care for patients with rare diseases!



# Integrated approach:

Medical services:	I N T E R D I S C I P L I N A R Y  T E A M	Different specialties, permanent staff: pediatric psychiatry and geneticist, other specialists if needed
Individual therapies:		Psychological intervention, hydrotherapy, medical gymnastic, 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
Trainings and online platform: <a href="http://www.edubolirare.ro">www.edubolirare.ro</a>		Diseases management, “Trial for flight”- life skills, trainings for professionals;
Registry		NoRo Patient registry
Information		Website, Facebook, blog, magazine



# Our approach

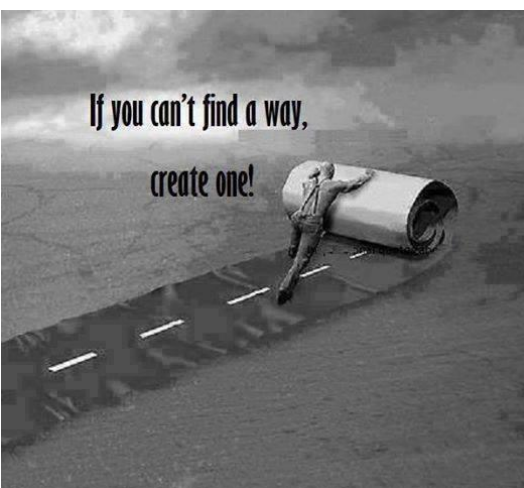
- Disseminate **relevant information** related to the rare disease environment to all stakeholders
- **Demonstrate the importance of integrated care services** in the field of rare diseases
- Elaborate **strategies for developing information and training for social services providers**
- Exchange **knowledge and best practices** on all relevant health, social and educational issues related to the rare diseases



- **Contribute to addressing the challenges of healthcare pathways**
- **Understand the opportunities through a collaborative approach**

# Inter sectorial and international collaboration

- ❑ **Innovative care pathway** bringing together national resource centres for rare diseases and regional case managers, **in partnership with public bodies**;
- ❑ **Evaluation of the socio-economic impact** and a **cost-benefit analysis of the care model**;
- ❑ **Exchange of good practices & initiate European network of services**;
- ❑ [https://www.youtube.com/watch?v= 2jy\\_saqxq0](https://www.youtube.com/watch?v= 2jy_saqxq0)



# Thank you!

- Questions?
- Advices?
- Suggestions?
- Examples?





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