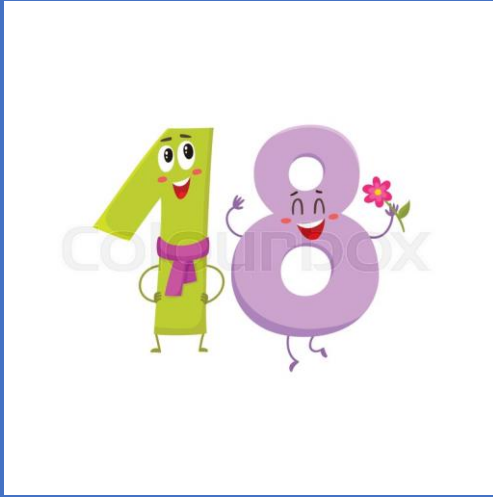


Webinar ITHACA

ePAG co-chair Dorica Dan





APWR & NoRo Center

- Direct services (accreditation)
- Local and County Strategy for services
- International cooperation



RONARD

- 48 national organizations
- NPRD in NSH
- 27 Centers of Expertise
- 10 CoE in 6 ERNs and 8 in evaluation
- > 20 of innovative drugs updated list
- NCRD
- Good cooperation of all stakeholders
- National, EU and international networks



ARCrare

- National and EU cooperation for a NPC
- Direct services at NoRo
- Campanii de informare
- Conferinte, seminarii, etc.



Goal: *To provide integrated care for patients with rare diseases and their families according to their health, social and everyday needs*

integrated care according
to the unmet needs
breaking down barriers
access to care

ensure
continuity
of
care

Improve access to
treatment, therapies,
abilitation &
rehabilitation,
psychological support and
all aspects of social
inclusion

equal access to
quality education
for children with
rare diseases

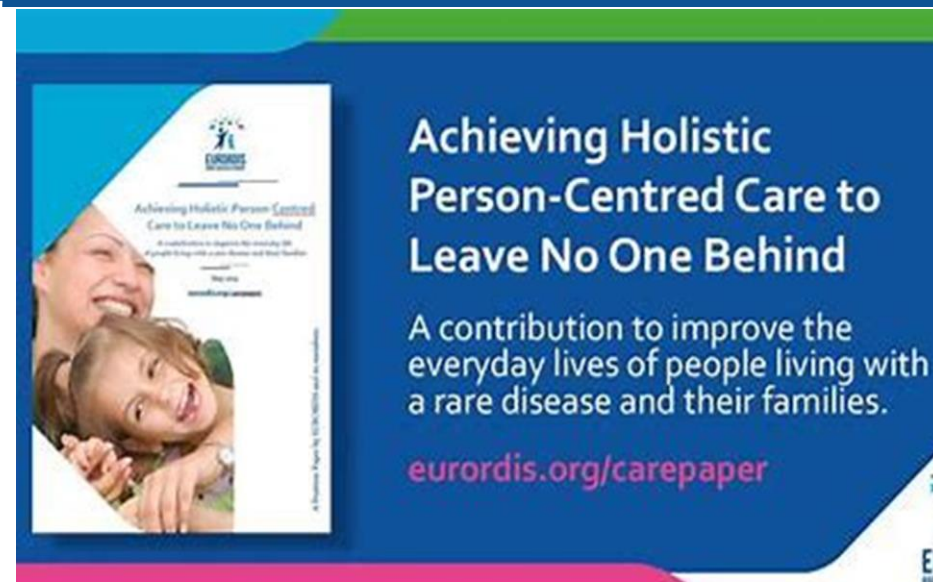
respecting human
rights
and dignity

Opened in June 2011- to improve the quality of life for PLWRD

Our principles for integrated care at NoRo



- ✓ Care and support are organised within a person-centred, multidisciplinary, continuous and participative approach, considering both people living with a rare disease and their families;
- ✓ We involve care providers across sectors in trainings, providing them knowledge, good practice and case management;
- ✓ Integrated care is delivered in an effective manner, in coordination within and between health, social and community services and patient organisations;
- ✓ developing social and affective skills for the better integration of the children in the educational system;
- ✓ best practice sharing events, including teachers from the community;
- ✓ Involve organisations in the design, implementation and monitoring of policies and services;
- ✓ Ensure that social and disability policies take into account the specificities of complex conditions and disabilities, such as rare diseases;
- ✓ prepare school communities and students to accept the challenges of integrating a RD child in their services is a continuous activity too.
- ✓ **Patients are empowered to understand and manage their condition!**



**European
Reference
Network**
for rare or low prevalence
complex diseases

Network
Intellectual Disability
and Congenital
Malformations (ERN ITHACA)

- ✓ RPWA - established in 2003, RONARD in 2007 and ARCrare in 2011
- ✓ Opened the **Center for Information about Rare Genetic Diseases**
- ✓ The 6th International PWS Conference in Cluj- Napoca, June 2007
- ✓ Establish National Alliance for Rare Diseases
- ✓ 1st National Conference about Rare Diseases, 1-3 November 2007
- ✓ 1st European RDD – 29 February 2008 –NPRD partnership with the MoH; every year RDD Campaign; Renewed partnership 2013; 2014 – National Strategy for Health;
- ✓ 1st National Program for Rare Diseases - 2008;
- ✓ Implementation of the NoRo Project: 2009 -2011
- ✓ 2011 – June 28, Official opening of the NoRo Center
- ✓ 2016 – Accreditation of CoE
- ✓ 2017 – Participation in ERNs
- ✓ 2021 – In Transparency the Ministerial Order 540 / 2016



National, EU and international level

National	European	International
2007- RONARD	Commission Communication in 2008	2007 –Eurordis & IPWSO
2008 – NPRD	Council Recommendations in 2009	2009 – 2010 EE Conference PWS
Since 2009 Europlan conferences	EUROPLAN Project 2008-2015	
2011 – Opened NoRo Center	Europlan conferences – Eurordis Europlan adviser	2015 – RDI
2014 NCRD 2018 – Ashoka Fellow 2018 – 2020 – Member of CES	Eucerd member 2011-2017 & EJA - Working groups in Eurordis: SPAG, DAG	2021 – Global Commission for RD WHO CGN4RD Europe Expert Panel
2016 – accreditation of CoE , <i>Revision in 2021 – in transparency!!!</i>	New Strategy for the rights of persons with disabilities 2021-2030 Rare 2030 – Recommendations	<u>CGN4RD Project is a collaboration with the WHO</u> to improve the organisation of healthcare services through the establishment of a global network of specialised
<div>Local strategy to create & develop care services</div>		

- ✓ 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

12/04/2021

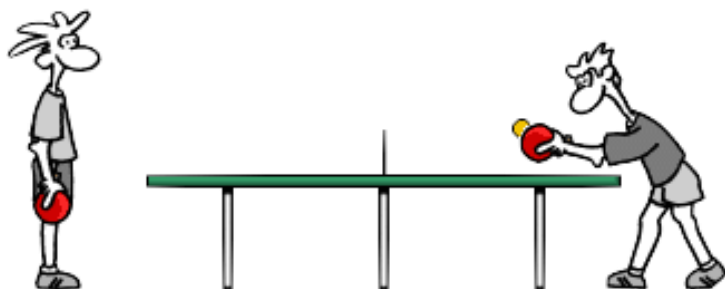
Mentoring
Program



People affected by RD need integrated care



People affected by RD need integrated care



Health

Social





OPPORTUNITIES

- ✓ Members of EURORDIS & IPWSO
- ✓ Good Collaboration with professionals and authorities
- ✓ Local strategy and NPRD
- ✓ Funding opportunities & responsible implementation
- ✓ Sustainable partnership
- ✓ Involvement at local, national and EU level
- ✓ Rare Diseases Day 2008 - 2021
- ✓ EC Communication and CE Recommendation for RD
- ✓ Participating in the EUROPLAN Project, EJA RD, INNOVCare & RD Action

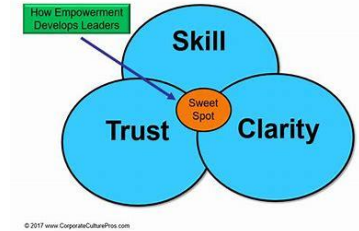
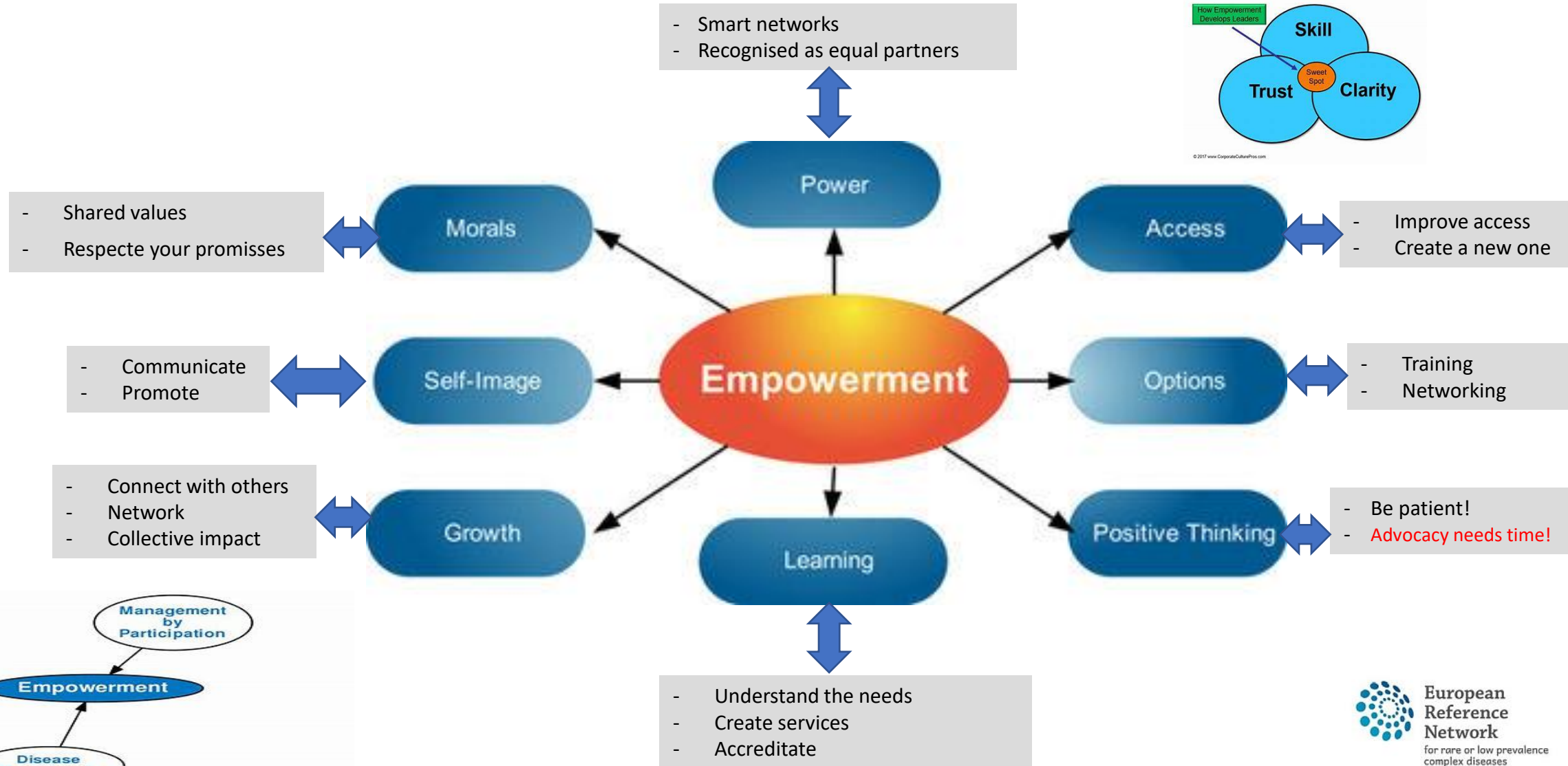
CHALLENGES

- ✓ Low numbers → low interest!!!
- ✓ No other services like this!
- ✓ Care infrastructure discrepancies
- ✓ No collaboration between social and medical services, national and local;
- ✓ No information accessible
- ✓ No intersectoral cooperation
- ✓ No real interdisciplinary teams

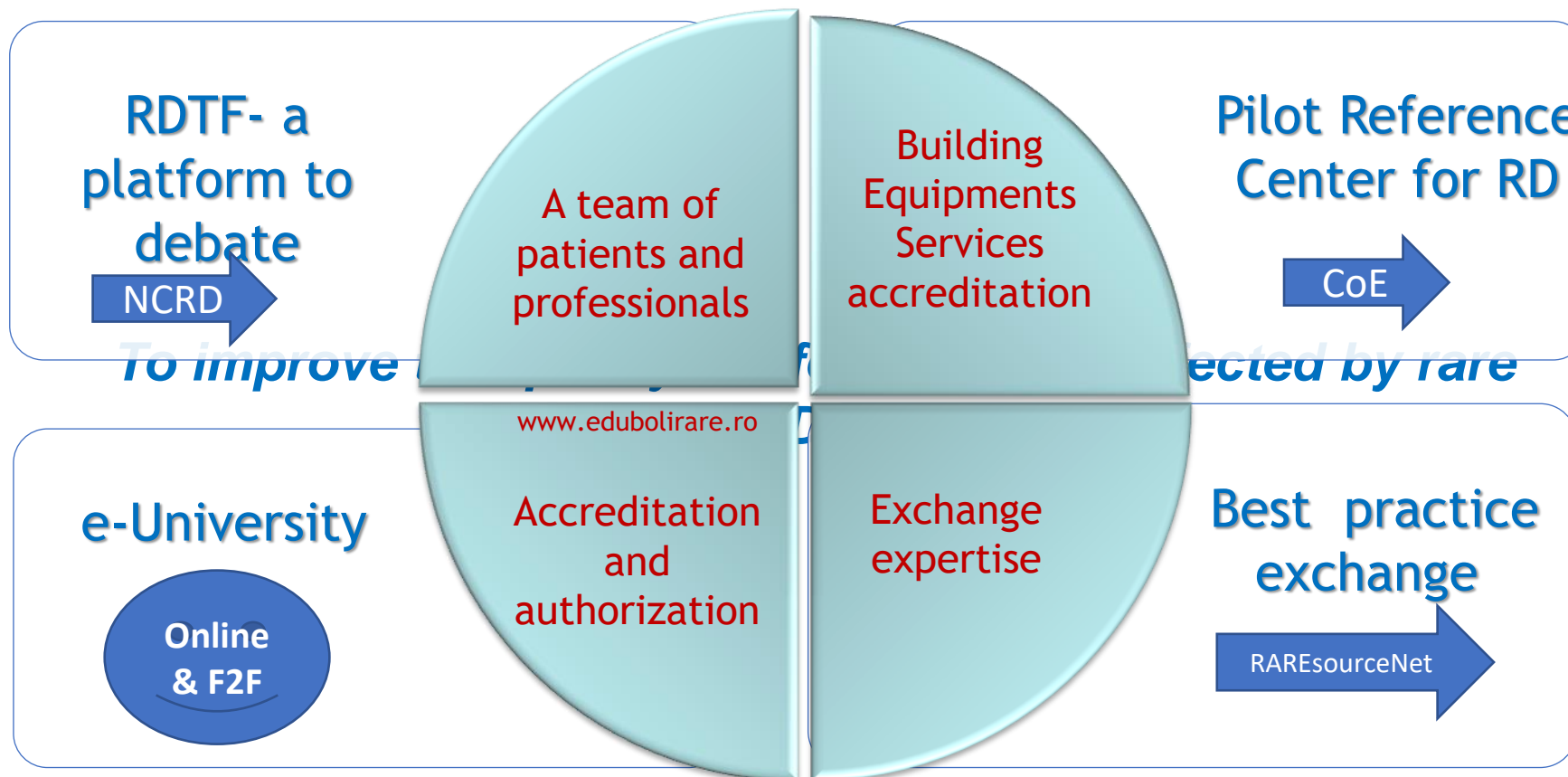
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Learning by doing



NoRo Center – from project to a HCP



Case study: NoRo Center Romania

- ✓ **Goal – to improve integrated care for patients with rare diseases in Romania**
- ✓ NoRo is also a “**one stop shop service**”, combining therapies, therapeutic education, training, medical & social services
- ✓ Day care center funded by Local Council and County Council Salaj & Residential center (funded through projects) – **70 beneficiaries** + National Health Insurance for medical services
- ✓ ~ 90 groups of patients organized since 2011 & “trial for flight”, **>1000 patients**
- ✓ Medical department accredited (**2 doctors + 2 nurses**) and interdisciplinary team of therapists and social workers – **15 people (psychologists, speech therapists, art therapist, kineto therapists, special education teachers, social workers)**
- ✓ **Patient registry since 2015**
- ✓ **Letter of endorsement** from MoH in order to participate in ERNs & initiated a **national network of CoE in 2016**, members of ITHACA since **2017**
- ✓ **Onsite visit and audited by EC !!!**



Our achievements so far



1722 
PATIENTS RECEIVED THERAPIES AT NORO

900
PATIENTS IN REGISTRY
SINCE 2015 


2226
GOT CONNECTED TO CARE SERVICES


3400
PATIENTS IN CLINICAL
CONSULTATIONS



115 
PATIENTS IN
CASE MANAGEMENT


1800
PEOPLE EDUCATED
IN WORKSHOPS
AND CONFERENCES

420 
PROFESSIONALS TRAINED
ON RARE DISEASES

70 
NEW THERAPIES IN THE NATIONAL
HEALTHCARE PROGRAMS FOR RDS SINCE 2011

230 
COMMUNITY NURSES TRAINED

2 
NPRD INTEGRATED INTO THE
NATIONAL STRATEGY FOR HEALTH


TRAINING CURRICULUM
FOR DOCTORS INCLUDES
NOW RARE DISEASES



ACCREDITATION STANDARDS
FOR CENTRES OF EXPERTISE
FOR RARE DISEASES IN 2016


214
PATIENTS IN ONLINE THERAPIES
AND THERAPEUTIC GROUPS


JOB DESCRIPTION FOR
COMMUNITY NURSES INCLUDES
CASE MANAGEMENT FOR RD

2 
NPRD INTEGRATED INTO THE
NATIONAL STRATEGY FOR HEALTH

200 
JOURNALISTS HAVE
BEEN TRAINED AT RDSJ


NATIONAL COUNCIL
FOR RARE DISEASES
APPROVED IN 2014


850
COMMUNITY
NURSES ENROLLED
FOR TRAINING


European
Reference
Network
for rare or low prevalence
complex diseases
Network
Intellectual Disability
and Congenital
Malformations (ERN ITHACA)

Integrated care provision at NoRo



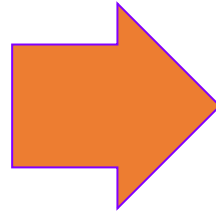
Medical services in contract with NHI – HCP Accreditation	I N T E R D I S C I P L I N A R T E A M	Different specialties, permanent staff: pediatric psychiatry and geneticist, other specialists if needed
Individual therapies:		Psychological intervention, hydrotherapy, gymnastic, speech, behavior, sensorial, 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: www.edubolirare.ro ; www.centrulnoro.ro ;		Diseases management, “Trial for flight”- life skills, trainings for professionals; online consultations, counseling, therapies;
NoRo Registry		NoRo beneficiaries
Information & casemanagement		Training for community nurses, virtual case

EC recommendations for RDs & our participation



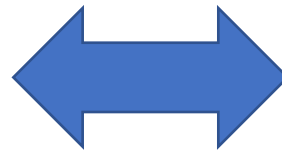
EUCERD member as a patient representative from EURORDIS

National Plans and Strategies –
EUROPLAN project and EJA RD



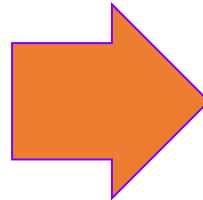
EUROPLAN – NPRD

Specialised social services



NoRo Center – RareResourceNet

Centers of Expertise



Ministerial order for accreditation
CoE in 2016

Participation in European Reference Networks since 2017



Collaboration and involvement



Empowerment of patient organizations

Collaboration and networking

Transfer of best practices



Improvement of care



Creating new services



Facilitate access



Improve care coordination

NoRo area of expertise



- NoRo was established in June 2011 as the first Pilot Reference Centre in intellectual disability (ID) from Romania, with:
 - ✓ **NoRo is accredited as a Center of Expertise by MoH.**
 - ✓ Became part of the ***Ro-NMCA-ID*** - *a national network with the aims to provide integrated services and ensure continuity of care for people with rare congenital anomalies and/or ID from Romania. Received a letter of endorsement for ERN in 2016 and became member of ITHACA since 2017.*
 - ✓ ***Audited by EC in 2017;***



Ro-NMCA-ID is based on five existing structures with previous collaboration. The four hospitals have expertise in diagnostic, preventive and treatment procedures in genetic diseases, while NoRo center offers diagnostic, educational and supportive therapy.

These centers are:

- 1. Louis Turcanu Paediatric Emergency Hospital Timisoara** (Regional Centre for Medical Genetics Timis - coordinator Prof Maria Puiu);
- 2. County Emergency Hospital Craiova** (Regional Centre for Medical Genetics Dolj -coordinator: Assoc. Prof. Mihai Ioana)
- 3. “Sfanta Maria” Paediatric Emergency Hospital Iasi** (Regional Centre for Medical Genetics Iasi - coordinator: Prof Cristina Rusu)
- 4. Municipal Hospital “Dr. Gavril Curteanu” Oradea** (Regional Centre for Medical Genetics Bihor-coordinator Dr. Claudia Jurca)
- 5. NoRo Pilot Reference Centre for Rare Diseases in Zalau** (coordinator: Dorica Dan);

Ro-NMCA-ID centres



A one-stop shop style service designed for people living with a RD and their carers

- ✓ Complementary to health care and social services
- ✓ Holistic care and support
- ✓ Create a bridge between patients/families and various stakeholders providing health care, social care and social support
- <https://www.eurordis.org/specialised-social-services>
- <https://www.eurordis.org/specialised-social-services#rc>
- ✓ **Documentation, information, referral and counselling** services on health and social issues
- ✓ **Training courses** for patients/families and professionals
- ✓ **Case management** services
- ✓ **Therapeutic recreation and respite care** services
- ✓ **Occupational activities** and day care
- ✓ **Rehabilitation and therapies**
- ✓ **Medical/psychological consultations**

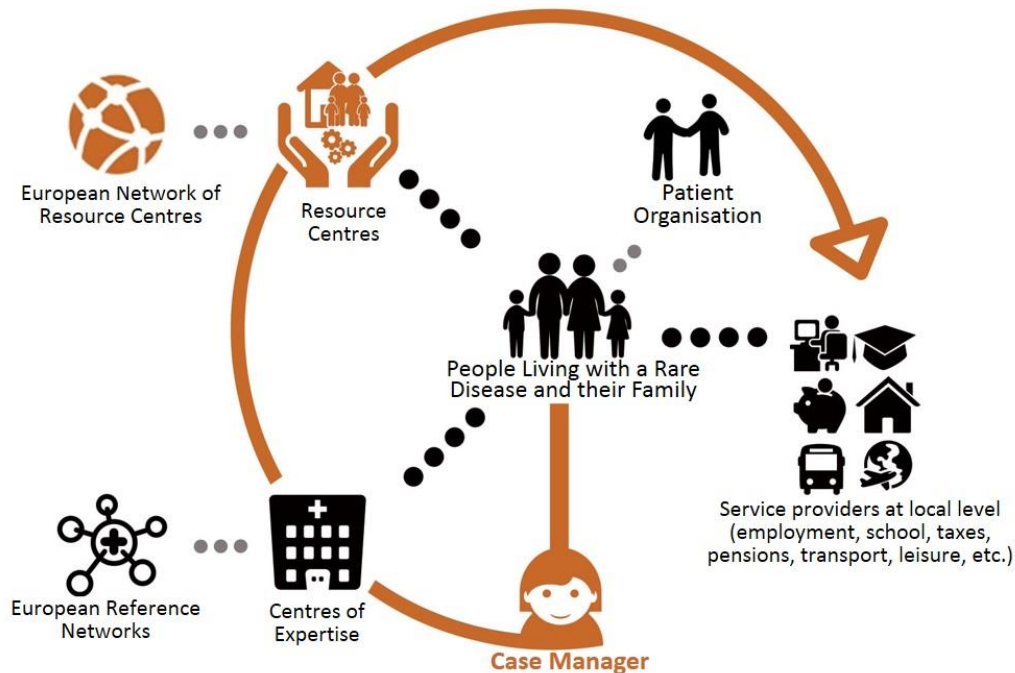
Holistic care?

Addressing the multidimensional health, psychosocial, educational, and daily life needs, abilities and wishes of people with a RD and their carers

The opportunity for RareResourceNet!



- ✓ RareResourceNet was created within the [INNOVCare project](#) (2015-2018);
- ✓ The network creation was possible following the mapping of specialized social services for rare diseases, conducted within the European Joint Action for Rare Diseases ([EURCERD Joint-Action](#), 2012-2015)



Who is part of the network?



Members:

1. Agrenska, Sweden: Anders Olauson – full member since 01/2018
2. NoRo, Romania: Dorica Dan – full member since 01/2018
3. Frambu, Norway: Lisen Julie Mohr - full member since 01/2018
4. Eesti Agrenska, Estonia: Tiina Stelmach – full member since 02/2018
5. CREER, Spain: Marta Fonfría - full member since 03/2018
6. DEBRA Centre, Croatia: Vlasta Zmazek - full member since 03/2018
7. Raríssimas, Portugal: Maria João Freitas - associate member since 04/2018



COVID – 19 IMPACT: Challenges at different level

Patients at NoRo

- 2 months of **isolation**
- Family impact : psychological, social, lack of access to therapies or other support.
- Since 18th May – F2F therapies have been restarted but **not without challenges**

NoRo Team

- Unemployment for 50% of the team
- Unpredictable future
- Sustainability challenges
- Keep the team motivated
- Making plans for the future
- Freezing and closing some projects
- Involved unemployed people in activities, too
- Keeping them busy to increase our faith and hope

RONARD

- Isolation and fear to be infected
- Treatments interrupted
- Home care challenges
- Limited access to hospitals & NO access to treatment in hospitals
- Limited access to expertise
- Surveys: RONARD & Eurordis at the end of April and end of December
- No access to rehabilitation and other therapies
- no access to psychological support or support groups



Solutions: new collaborations, networks and a new approach

Patients at NoRo

- NoRo provided support for families (phone, WhatsApp, etc.): **psychological counseling, therapeutic strategies, material support**
- Local council decided **to reimburse our online intervention at a low level**
- Prepared different projects & **digital solutions** to answer to our patient's needs and to be able to ensure continuity of care
- Since 18th May – **F2F and online therapies** supported by County Council and Local Council
- Reimbursed **online medical consultation at NoRo ambulatory**

NoRo Team

- **All team** returned to work in May
- **Ensured security** of our beneficiaries in F2F therapies
- **New type of projects** on digital solutions: AHA, European Changemakers United, Hackathons, nutrition in RD, online platforms, case management, virtual case management, etc.
- New opportunities created: launched www.centrulnoro.ro
- **> 214 patients benefited from online therapies and 6 groups of patients** (each group / 5 days)
- Started **online training registration for 850 community nurses** on case management for rare diseases, using the ECHO method (trained 230).

RONARD

- **Regular zoom meetings** with RONARD and CoE, NCRD to update the NPRD
- **Advocacy** to solve the problems: hospital admissions, home care, telemedicine framework, etc.
- Involved all the stakeholders
- Presented the results of our surveys and compared with other results at **national and international level**
- Organized **European conference, RDSJ** and participated in many consultations on national strategies and evaluation of the previous strategies
- **Participated in international activities**





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Fundraising strategy or online services and mixed services

Working in networks and network of networks

Advocacy for integration of digital tools in health care system



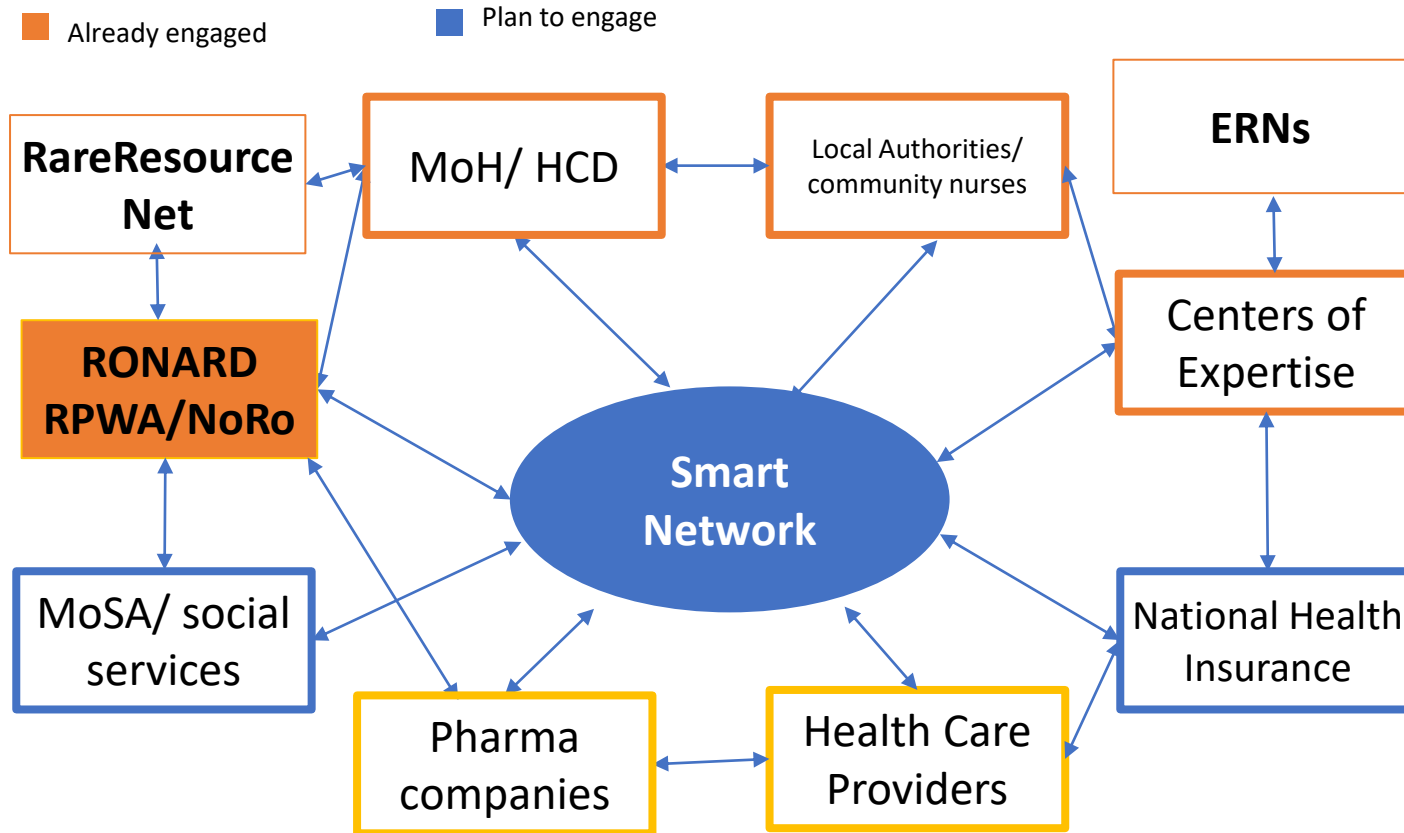
European Reference Network
for rare or low prevalence complex diseases

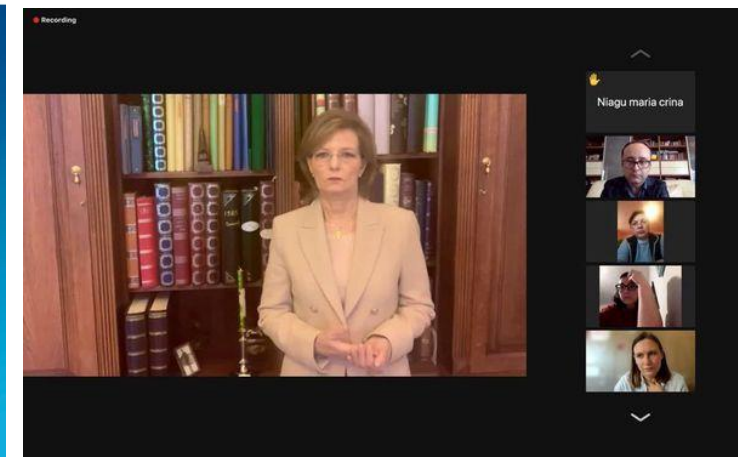
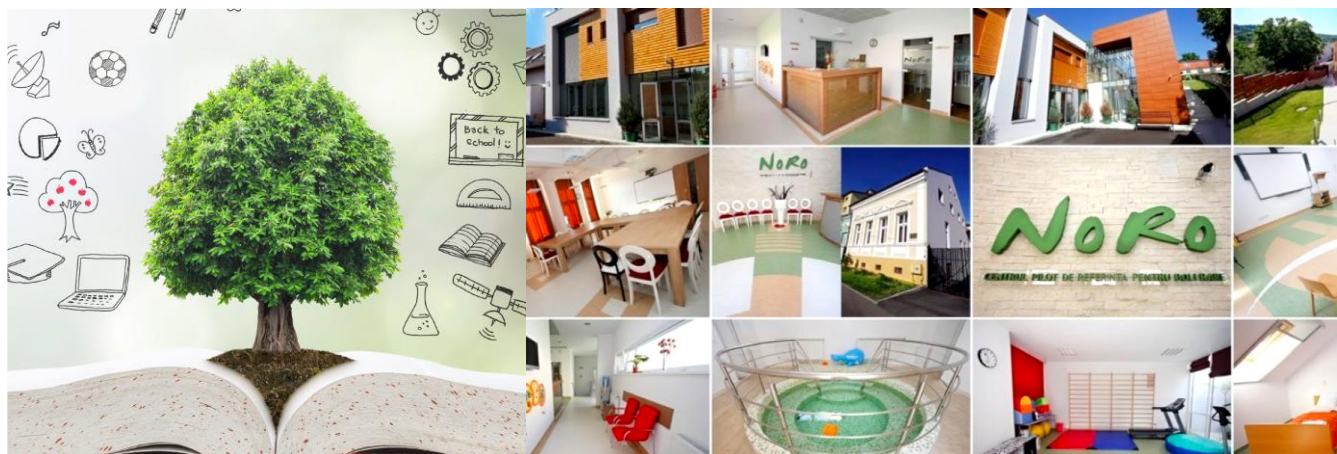
 **Network**
Intellectual Disability and Congenital Malformations (ERN ITHACA)

Partnerships



ENGAGING THE RIGHT PARTNERS





**Social innovation:
inspirational practices
supporting people
throughout their lives
Social Europe**

**The World Economic Forum's Davos Agenda,
which recently took place online, has mentioned
in one of their topics related to systems social
entrepreneurs a Romanian solution as an ally for
governments in tackling the challenges societies
face.**

**The report seeks to
emphasise the European
added value of the
described actions and to
single out potential good
practices.**

Rare Diseases Day 2021

**156 media & social media appearances
37.202.800 impressions**



THANK
YOU!

