



MEMBERSHIP

MEETING

12-14 MAY 2021

**Shaping the next 10 years of rare disease policies:
Europe's Action Plan for Rare Diseases
#30millionreasons**

Launching projects in a virtual world

Dorica Dan – president RONARD, RPWA, ARCrare, BoD Eurordis, ePAG ITHACA





WHY?



It's all the 
Little moments  that make
life a ... 
BIG adventure!

QUOTEDIARY.NET





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.



NoRo Center

✓ **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 in 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

PROBLEM

2. Consequences if problem is not solved (relevance)

Poor quality of life for patients and families

Severe economical and emotional burden for families and society

No real inclusion in society

1. Our *Big Problem* and the impact of COVID- 19

More than 90% of the rare disease's patients in Romania are still undiagnosed. RDs affects >1.000.000 patients in Romania and approx. 4.000.000 people who are their family members/ caregivers, which constitutes 20% of the total population of Romania. Approx. 50% of the population live in villages with no access to services they need.

COVID -19 affected all the world. PLWRD were often refused in hospitals or too scared, they needed faster diagnose, care coordination, home care and monitoring.

3. Systems that drive the big problem - No systemic approach!!!

1: The system of education

No curricula for rare diseases in the universities. There is no a medical specialty for RD.

2. The system of diagnosis and care for rare diseases in Romania

Care pathways are not structured; Fragmentation of the few existing care services & lack of coordination.

3: The system of monitoring and funding

No national registries, no accurate data. No proper funding of the National Plan for Rare Disease.

OUR APPROACH

1. Direct services at NoRo

- Social
- Medical
- Educational

www.centrulnoro.ro

2. Networking and more services delivered

- Working with CoE
- Involving and training community nurses
- Creating community support networks
 - New Networks

3. Advocacy for policy Change

- NPRD
- Accreditation of CoE
- Strategic approach and funding



4. EU and International cooperation

Eurordis
ERN
RDI
IPWSO
Ashoka

Vlad Voiculescu: „Vor exista fonduri și pentru centrele de expertiză în bolile rare”



februarie 27

Universitatea de Medicină și Farmacie „Carol Davila” București

Măsurile luate în acest sens sunt un rezultat al activității desfășurate în cadrul proiectului de cooperare internațională...

Universitatea de Medicină și Farmacie „Carol Davila” București



Direct services

NoRo- A Resource center for rare diseases/ Center of Expertise

Training of community nurses

Who?

- NoRo is a "one stop shop service", combining therapies, therapeutic education, training, medical and social services;
- Connected with majority of Centres of Expertise in Romania and ERN + RareResourceNet

How?

Integrated & holistic health and social care

Medical services
(Ambulatory): paediatric
psychiatry & genetics

Social services
1. Day care centre
2. Trial for flight
3. RD Patient groups +
case management

Training for:
Patients
Parents
Professionals

Advocacy & up scaling

Strategy - NPRD
Integration into
National Policies
& Local Strategy

Standards of care
Center of
Expertise
Resource Center
ISO 9001

Training
for professionals
and patients
Case management

Communication
Workshops, RDD,
trainings, conferences,
publications,
Radio NoRo, RDSJ;

Recognition
The Prize for
innovation in
Health

Opportunities created:

Impact

Improved
Services

*Intersectorial
Partnerships*

Accreditation
of CoE

Case
management
policy: 1/50
persons with
disability

Training
curricula
INNOVCare &
ECHO

Sustainability
Case
managers are
hired by Local
Authorities

Advocacy

- 2020 - 2021...online...
- Measured the impact of COVID-19 for patients
- Updating National Plan for Rare Diseases
- Improve access to treatments
- Home care delivery for PLWRD
- Secured access in hospitals
- Ensure access to rehabilitation and therapies
- Telemedicine and eHealth solutions
- Increase the number of CoE accredited

www.centrulnoro.ro

www.riskalert.ro

EURORDIS.ORG



comisarul

prima pagină politic actualitate sport economie life externe picanterior



Eurodeputatul Cristian Bușoi: Bolile rare reprezintă o prioritate-cheie în noul Program de Sănătate al UE



Working at EU and International level

EURORDIS
RDI
IPWSO
ASHOKA
ERN ITHACA



Long-term, integrated European and national plans and strategies

Access to high-quality health care



Innovative and needs-led research and development

Available, accessible and affordable treatments



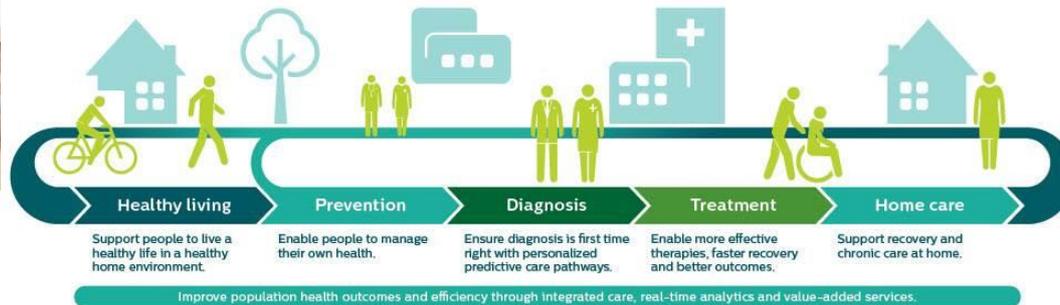
Earlier, faster, more accurate diagnosis

Integrated and person-centred care



Partnership with patients

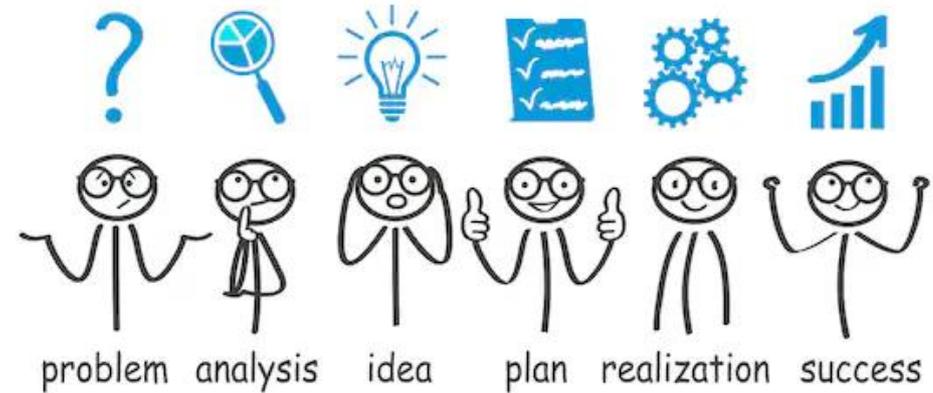
Optimising data for patient and societal benefit



A global problem! COVID – 19 & Rare Diseases

450 patients
participated in our
survey

> 1 million patients with rare
diseases in Romania



shutterstock.com • 650764684

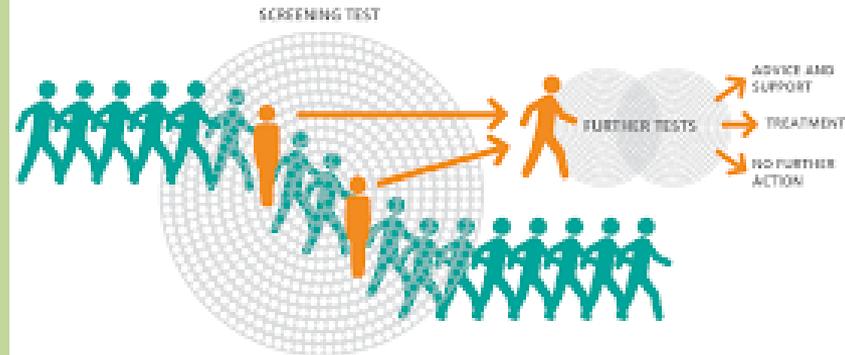
- COVID 19 demonstrated that the biggest problems for RD patients were: lack of access to care services combined with the fear of infection, isolation and the need of home care and monitoring: [Evaluarea sondaj Pacientii cu boli rare din Romania in perioada Covid-19_0.pdf \(bolirareromania.ro\)](#)





Our wishes

✓ To ensure continuity of care, access to therapies, monitor patients at home, “flag” patients with rare diseases with risk in case of emergency, coordinating care and ensure their secured access to hospital.



Access

Online consultations, therapies, training & support groups

Home care :



- Advocacy for legal framework
- 3 pilot projects

Risk alert:



- Challenge presented
- Team
- Working together
- Establish an NGO



Virtual Case Management

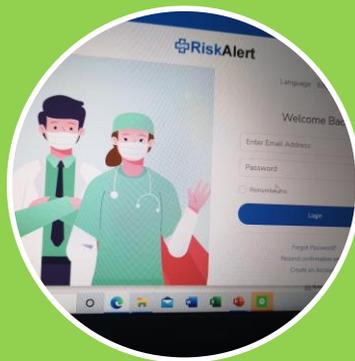
- Systemic change
- Training community nurses
- Connect with CoE

PROJECTS



Online therapies:
www.centrulnoro.ro

Ashoka Changemakers
United EU + Industry



Risk alert:
www.riskalert.ro

Hackathon – Team – Smart
Health Cluster



Virtual Case
Management &
*ECHO training for
community nurses*
Ashoka AHA Philips
Partnership with MoH

New services to ensure continuity of care

Opportunity

Technology is the unique way to end the odyssey for diagnosing rare disease in Romania.

Debate on digital solutions need in the Romanian Parliament for RDD 2020.

Needed for policy framework!!!!

The pandemic crisis was opening the door to implement digital solutions;



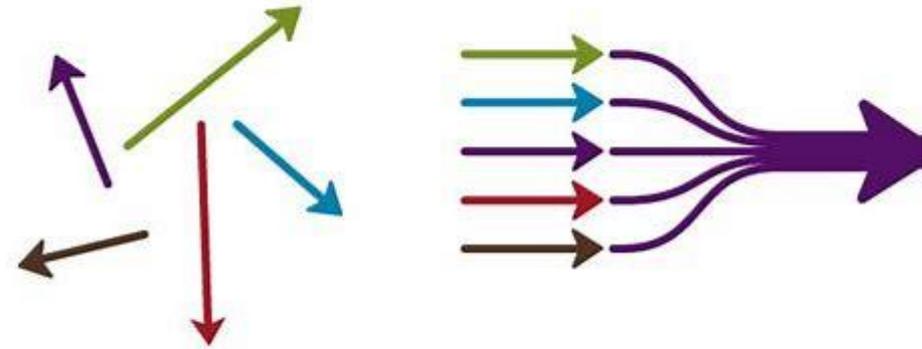
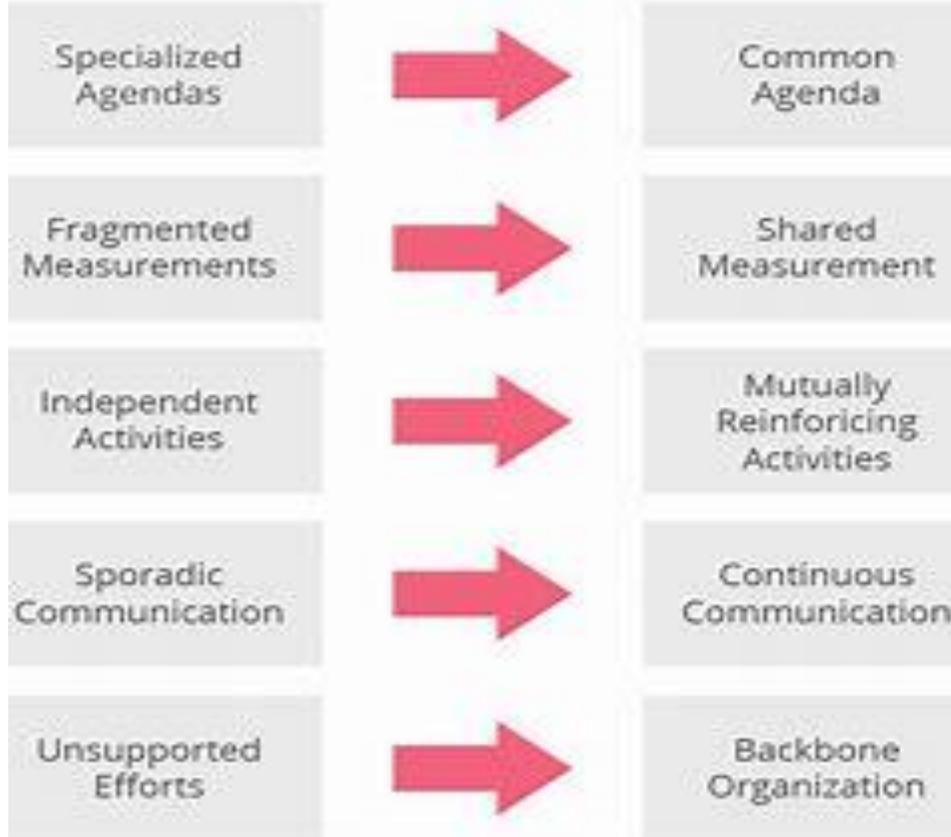
Actions

1. Participate in different partnerships, networks, events & ecosystems
2. Learn about different solutions
3. Promote inclusive measures in different policy frameworks
4. Training community nurses (case responsible)
5. Involve Centers of Expertise (case managers)
6. Referring patients to CoE
7. Ensure communication among all parties
8. Access and adapt solutions already implemented



The future is now!

Five Conditions For Collective Impact



BEFORE

AFTER

