



ASOCIAȚIA  
**PRADERWILLI**  
DIN ROMÂNIA

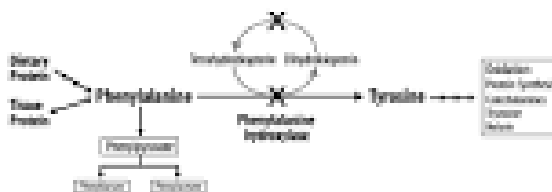


**PKU Life**  
România

# Why training for PKU?

Dorica Dan – president ANBRaRo

## Phenylketonuria (PKU)



**BIOMARIN®**



NoRo – 7 ani!!!!



[https://www.youtube.com/watch?v=7bnCobL\\_t-U&t=92s](https://www.youtube.com/watch?v=7bnCobL_t-U&t=92s)



# WHY?

*To Improve the NoRo services for patients with PKU.  
For communication and collaboration in creating training resources for professionals and families of children and adults affected by rare diseases.*

**Where: Zalau, 28– 29 June 2018**

NoRo – Resource Center for Rare Diseases

**Who: 55** participants( 53 from Romania and 1 from Greece and 1 from Portugal.  
RPWA (NoRo) & PKU life Romania, doctors, patient representatives, social and medical services providers, patients & families, other services from community;

**What:** *listen, debate, elaborate and reach consensus on nutrition in PKU, using Greece and Portugal example.*

**Initiate ideas for debate !**

# AGENDA 28 Iunie 2018

Ziua 1	Joi, 28.06.2018.
10:30 - 11:00	Înregistrarea participanților
11:00 - 12:00	<ul style="list-style-type: none"><li>– Deschidere oficială</li><li>– De ce un curs de dietă PKU? Dorica Dan, RPWA;</li><li>– Cursul introductiv: Prezentare generală a fenilcetonuriei (PKU), diagnostic, cauze;</li><li>– Obiectivele tratamentului dietetic în PKU. Dieta PKU: caracteristici nutriționale;</li><li>– Situația în România.</li></ul>
12:00 - 12:30	"Ce înseamnă consilierea genetică și beneficiile acesteia" - Maria Mădălina Radu;
12:30 - 13:30	"Importanța dieteticianului în dieta PKU" - Amelia Selariu;
14:00 - 15:00	Pauză de prânz
15:30 - 16:30	Astrinia Skarpalezou - Grecia
16:30 - 17:00	Pauză de cafea
17:00 - 17:30	"Importanța dietei în managementul PKU" - Bugi Meda
17:30 - 18:00	Dezbateri, întrebări și răspunsuri

# AGENDA 29 Iunie 2018

Ziua 2	Vineri, 29.06.2018.
09:00 - 09:30	"PKU de la depistare la monitorizare" - Biochimist Delia Corina, Chimist Toma Geanina, Chimist Cutieru Mihaela;
09:30 - 10:00	"BIOgenetix- prezentare produse" - Cojocaru Lucian, Alina Vilau;
10:00 - 11:00	"Testarea la Kuvan în PKU" - Dr. Florentina Moldovanu, Coordonator Centru PKU București;
11:00 - 11:30	Pauză de cafea
11:30 - 12:00	"Puzzle pentru adulții PKU" - Dr. Silvia Iancu, Coordonator Centru PKU Adulți Cluj-Napoca;
12:00 - 13:30	Julio Rocha – Portugalia
13:30 - 14:00	Prezentare de produse - Magda Stelian, firma Nutrient
14:00 - 15:00	Pauză de prânz
15:00 - 15:30	Dezbateri, întrebări și răspunsuri

# ORGANIZARE LA NIVEL NAȚIONAL ȘI INTERNAȚIONAL

APWR - 15 ani	ANBRaRo - 11 ani	ARCrare - 7 ani
Înființare - 2003	Lansare ANBRaRo: <a href="http://www.bolirareromania.ro">www.bolirareromania.ro</a>	Iulie 2011 - lansare
Conferința IPWSO NZ -2004 Conferința PWS Germania	Conferința națională de boli rare - nov.2007	Sept. 2011 - campania de informare privind LMC
Centrul de informare pt. BR 2005 <a href="http://www.apwromania.ro">www.apwromania.ro</a> <a href="http://www.rjrd.ro">www.rjrd.ro</a>	Ziua Bolilor Rare (2008 , 2009, 2010, 2011, 2012, 2013)	Nov.2011, sept 2012, 2013, 2014, 2015 - grup de pacienți cu LMC la centrul NoRo
Congresul Balcanic de endocrinologie - 2005	Initiere PNBR	Dec. 2011 - <a href="http://www.arcrareromania.ro">www.arcrareromania.ro</a>
Conferința IPWSO și BR - Cluj 2007	Primul program național de BR	2012 - Campania “Adriana există” ZBR
-Lansare ANBRaRo -BoD Eurordis, IPWSO	2 Conferințe Europlan, 2010, 2013	Parteneriat pentru organizarea de videoconferințe
- Acord de parteneriat MS	Congresul Balcanic de boli rare	Instruire și dezvoltare organizațională
-Implementare proiect NoRo 2011 -Centru, <a href="http://www.edubolizare.ro">www.edubolizare.ro</a> , CNBR -4 proiecte EEA Grants, 1 proiect elvetian, granturi Moll, OMV, etc.	2 Conferințe Europeană de boli rare 2007, 2011, 2013,2014 <a href="http://www.aspac.ro">www.aspac.ro</a>	Cursuri pentru jurnaliștii din sănătate in parteneriat cu ANBRaRo si APWR
COPAC, ANBRaRo, IPWSO, EURORDIS	COPAC, CNBR, EURORDIS, EUCERD, RDI	COPAC, EPF, ANBRaRo,



NoRo: 28.06.2011

28.06.2018



**Center for Rare Diseases**

**NoRo**

**Center for Rare Diseases**

www.edubolrare.ro

021 300 500 1111 - member of European network of NoRoLabs

Education: www.edubolrare.ro

Accredited training provider for professionals

Observance network with 7 medical universities

Advocacy for research capacity

Medical equipment

Specialty, monitoring and genetic

Innovative approach

NoRo is accredited both for medical and social services

Services:

- Specialized center NoRo:
  - Group of activities (10-15) / 12 patients with the same RD
  - Therapies and training
- Interdisciplinary living skills training:
  - Therapies provided: art therapy, hydro therapy, massage, physiotherapy, kinetic therapy, speech therapy, behavior therapy, occupational therapy and environmental therapy



**ABOUT THE TRAINING MISSION AND OBJECTIVES**

✓ **What is [www.edubolrare.ro](http://www.edubolrare.ro)?**

“An innovative initiative of Romanian Prader-Willi Association which aims to highlight the potential of web resources in the field of training and information on rare diseases.

**Mission:**

- to improve the competence of professionals working in the specialized social services for RD.

**Objectives:**

- Create curricula and adapt the existent training courses for professionals and add knowledge about RD, in order for provide them with necessary skills when patients with RD ask for their services.
- This way the training courses can be also authorized and accredited by the competent authorities.





## Invitație

Finanțat de:



Asociația Prader Willi din România - APWR este onorată să vă invite să participați la

**Conferința bilaterală România – Norvegia,**  
cu titlul: **AD AUGUSTA PER ANGUSTA!**

Conferința se adresează problemelor de incluziune socială ale copiilor cu dizabilități produse de boli rare din România.

Conferința va fi organizată în **Cluj - Napoca**, în zilele de **19-20 iunie**, la **Hotel Premier** și face parte din proiectele selectate ale programului EEA and Norway Grants, Fondul Național Bilateral. Programul conferinței include și o vizită la Centrul NoRo din Zalău, în ziua de 19 iunie 2014, ora 10.00.

*Sperăm să fiți alături de noi!*

Cheltuielile de transport și cazare sunt suportate de organizatori.  
Programul evenimentului va fi transmis în zilele următoare.

Vă așteptăm cu drag!

Dorica Dan  
președinte APWR

# CONTINUITY OF OUR INTEGRATED APPROACH



## OBJECTIVES:

- **Disseminate** relevant information related to the rare disease environment to all stakeholders
- **Demonstrate** the importance of specialized social services in the field of rare diseases
- **Elaborate strategies** and mechanisms for developing further exchange of information between stakeholders
- **Exchange knowledge and best practices** on all relevant health issues related to the rare disease environment



- **Contribute to addressing the challenges of healthcare pathways**
- **Understand the opportunities through a collaborative approach**
- **Develop quality services for PLWR**



## CONTINUE AND DEVELOP THE NORO OBJECTIVES



Improve the NoRo services for patients with RD – **Centre of expertise !!!**

**Ob. 1 National Committee for Rare Diseases** → became the National Council for Rare Diseases at Ministry of Health: [www.ms.ro](http://www.ms.ro)



**National Plan for Rare Diseases** → included in the National Strategy for Health 2014-2020; 13 CoE accredited – 10 HCP participate in 6 ERNs;

### Ob.2 NoRo center :

- Day care center is funded by the Local Council and County Council + NHI (BBBS, Mol, OMV Petrom)
- Patient groups & development– partly funded by the project *ExpertRARE* – Center of Expertise for RD, funded by Swiss Romanian Cooperation Program
  - *Medical department establishment and accreditation – project and County Health Insurance*
  - *ISO – Management Standards*
  - *Patient pathways are improved through case management implementation*
  - *Patient Registry for NoRo*
- HelpLine part of the Eurordis network of Helplines
- [www.edubolirare.ro](http://www.edubolirare.ro) : training courses for Personal assistants (DASC) and training for Rehabilitation teacher (County Council Alba through a POSDRU project), case management, nutrition in PKU, PWS, etc.

### Ob.3 Exchanging best practices with Norwegian partners

[http://www.romania-actualitati.ro/frambu\\_modelul\\_norvegian\\_in\\_abordarea\\_bolilor\\_rare-91118](http://www.romania-actualitati.ro/frambu_modelul_norvegian_in_abordarea_bolilor_rare-91118)

# ACTIVITIES AND PARTNERSHIPS AT EU LEVEL



Zalau, Romania, December 2012  
At NoRo Resource Centre for Rare Diseases  
Taastrup, Denmark, October 2013  
At the [House of Disabled People's Organisations](#)



# THE WORD OF THE DAY: COLLABORATION!

## Objectives:



1. To strengthen the role of NoRo Center as social services provider
2. Mentoring programs
3. To develop and assess an innovative approach to ensure continuity of care - creating a reference networks for rare diseases at national level.

## 1. Resource centre: complex services + innovation

### Who and how?

Plan → Provide → Coordinating all services that ensure continuity of care for PLWRD.

## coordination



2. Weak coordination between health care, psychosocial complementary care, between central and regional/local infrastructures, between sectors and between Ministries, leading to a lack of multidisciplinary holistic approach

## 2. Centralized approach

- Maximise patients' access to services – describing patient pathways
- Understanding the way patients move within and between different medical and social care providers
- Communication with other CoE and other services
- Training for different professionals
- Communication with other services at local, regional, national and international level

empower



How to empower the children with RD with life skills?

How to adapt our services to the inclusion needs of children and patients with RD and how to connect with other services?

### 3. Patient focus

- Understanding the way patients move within and between different medical and social care providers
- Adapting our services for children, organizing summer camps
- More activities outside of the center during summer
- Better inclusion into community



infrastructure

Insufficient resources

Insufficient sharing of best practices!

## 4. IT platforms: information and training , registries, video conferences, eHealth, online trainings.....

- The information systems have to be able to sustain communication between care providers, patient registration, etc...
- Data protection legislation
- Interoperability of different tools

## funding

### 5. Leadership

- Clear communication between equal partners
- Change for a broader vision
- Ensure representation of different providers

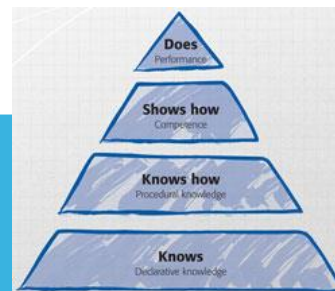
Lack of long term, funded and sustainable policies and structures at national levels and in the national strategies for the integration of people living with RD into social services and policies

### 6 Funding

- Different systems



“Never ending” debate.....



How to transform a project into reality?



Encouragement to take action

**Coordination of efforts** between PLWRD/families, patient representatives, national authorities, sharing information with our partners

**Permanent** improvement of patient pathways

Develop a **strategic approach** for integrated care of PLWRD

**Evaluate!!!**

**Re- design and adapt to the needs!**

# TEAM WORK

- Dorica
- Tibi
- Zsuzsa
- Florina
- Nelu
- Stefi
- Adi
- Bianca
- Vera
- Iulia
- Alexandra
- Ingrid
- Ela
- Rebi
- Doris
- Mia
- Alexandra
- Emese
- Paula
- Cosmina
- Diana
- Diana
- Ioana
- Mihaiela
- ...



## Grape5 Tips for Team Building

- Clear Expectation
- Commitment
- Competence
- Control
- Collaboration
- Communication
- Creative Innovation
- Consequences
- Coordination
- Cultural Changes

