NoRo - a reference centre for RD

EUCERD Joint Action 2012 - 2015,
Workshop on Guiding Principles for Specialized Social Services,
Zalau, Romania – 6th Dec 2012

Dorica Dan
president APWR/ARCraRe/ ANBRaRo
BoD EURORDIS & BoD IPWSO, member EUCERD

www.eucerd.eu; www.eurordis.org
Partners in the project:

- 01. Romanian Prader Willi Association (RPWA)
- 02. FRAMBU - Centre for rare diseases - Norway
- 03. Norwegian PWS Association
- 04. Ministry of Health Romania
- 05. Medical University Timisoara
- 06. Romanian Genetics Society
- 07. ACASA Foundation
- 08. City Hall Zalau
- 09. County Council Salaj
- 10. St. Family Church
- 11. Romanian National Alliance for Rare Diseases

The project to establish the NoRo Center was funded by a grant from Norwegian Cooperation Programme for Economic Growth and sustainable Development in Romania.
Needs assessment:

- Under diagnosis → low number of patients/disease;
- Lack of visibility → NO monitoring system;
- No designated centers of expertise → NO place for evaluation;
- Distance among patients and professionals;
- Lack of awareness on patient and health provider level;
- Only few patients are eligible for treatments;
NoRo’s goal & objectives

RDTF - a platform to debate

A team of patients and professionals

Building Equipments Services accreditation

Pilot Reference Center for RD

e-University

www.edubolirare.ro

Accreditation and authorization

Exchange expertise

Best practice exchange

Advisory committee

Improved quality of life for people affected by rare diseases (RD) in Romania
• Patient access to a multidisciplinary team of experts
• Combination of research and care
• Coordination between professionals
Sharing knowledge and best practice
• Training activities for patients and careers
• Activities to empower patients and collaboration with other patient organisations
TEAM - Together everybody achieve more!
Quality standards in our services
Pilot Reference Centre for RD - response to the needs of the patients
eUniversity
Information for general public and training for professionals
Authorized and accredited
• A global approach (holistic, comprehensive) integrating medical and social aspects
• Education, information and communication
NPRD - Information is a source of learning, but unless it is organized, processed, and available to the right people in a format for decision making, it is a burden, not a benefit.
Continuity of care:

- Day care center (individualized therapy for 45 children);
- Residential service care for RD patient groups (5 days/group/12 patients);
- Help Line
- Organizing videoconferences: equipment for Center + 7 Medical Universities in Romania (Timisoara, 2 in Cluj, Oradea, Iasi, Bucuresti, Tg Mures);
  - 1 interdisciplinary consultation/week;
  - No more traveling for family; Distance training for patient groups;
  - Visiting families to train them at home (2 weeks/year);
  - Cooperation and exchange of best practice with schools where our beneficiaries of the Day Care Center are integrated;
  - Involving teachers from schools where our beneficiaries are studying to improve the results and ensure continuity of care;
  - Better approach of the patients and savings in the budget;
  - Improved cooperation with professionals;
Activities in the Center:

- The personalized intervention and therapy
- Medical consultation and Helpline
- Educational Activities
- Recreational and social activities
- Educational and vocational guidance and counseling
- Advice and support for parents
- Database of patients- registry
- Administration and management
- Social research
- Day care center, Residential Center for RD & Medical Department;
- NoRo is accredited for both medical and social services
General Information on the Service

Address of the Resource Center:
Zalau, Romania, Str.22 Decembrie 1989, nr.9;

Name of Service: The Pilot Reference Centre for RD NoRo

Dates: all year long

Target Population: Patients/Families/ Rare Diseases
Age-Groups: children/teenagers/adults

Countries of Origin: Romania
Languages Spoken: Romanian

Contact Person: Dorica Dan

Webpage: www.apwromania.ro ; www.edubolirare.ro;
https://www.facebook.com/NoRo

Email: dorica.dan@eurordis.org

Telephone: +40 260 610033
It takes a lot of courage to stand up and defend your ideas, but it is equally courageous to sit down and try to understand the others…

Thank you!