



NoRo - a reference centre for RD

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



www.eucerd.eu; www.eurordis.org

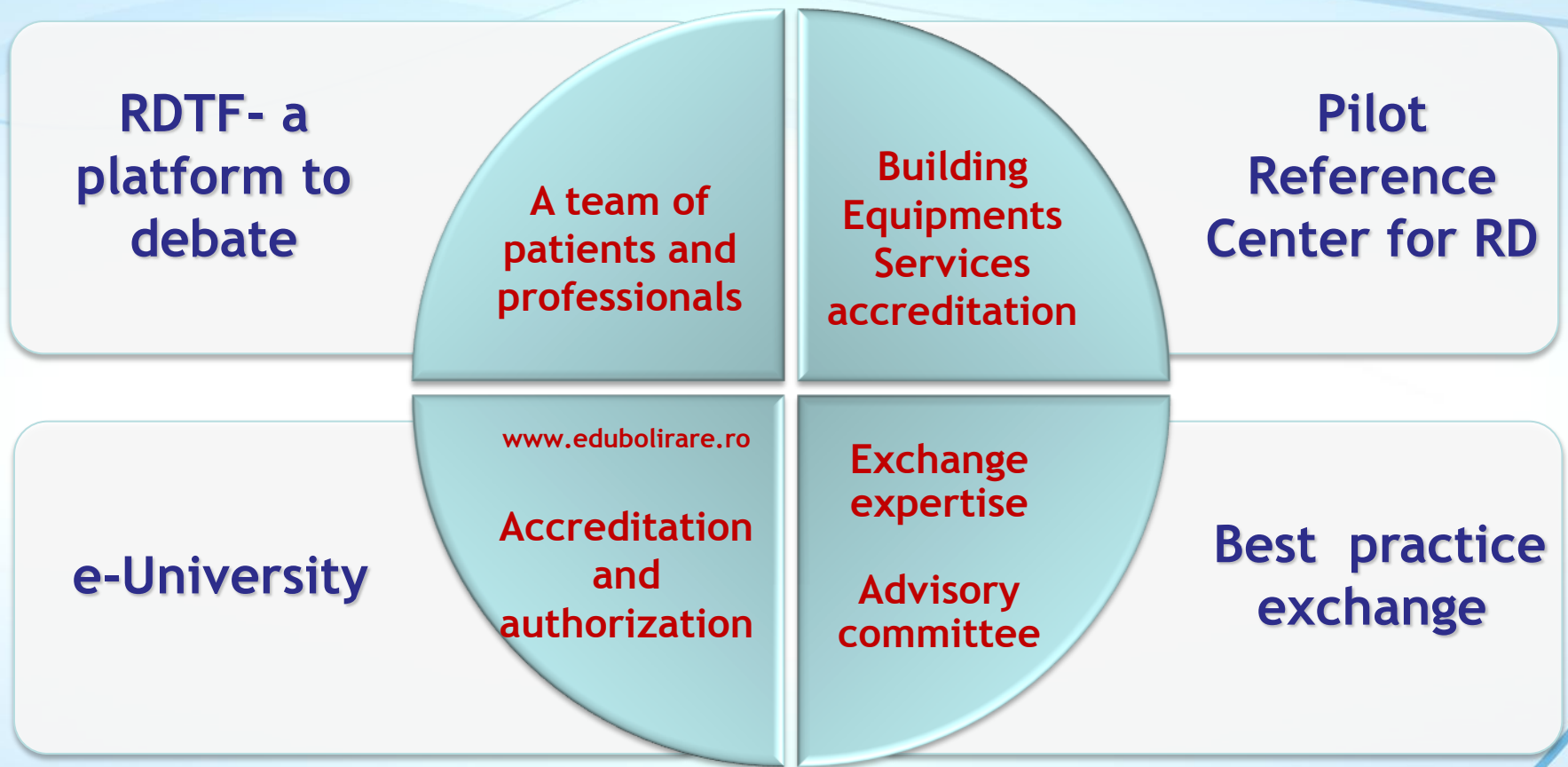
Partners in the project:

- 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



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.



ASOCIAȚIA **PRADER WILLI** din ROMÂNIA

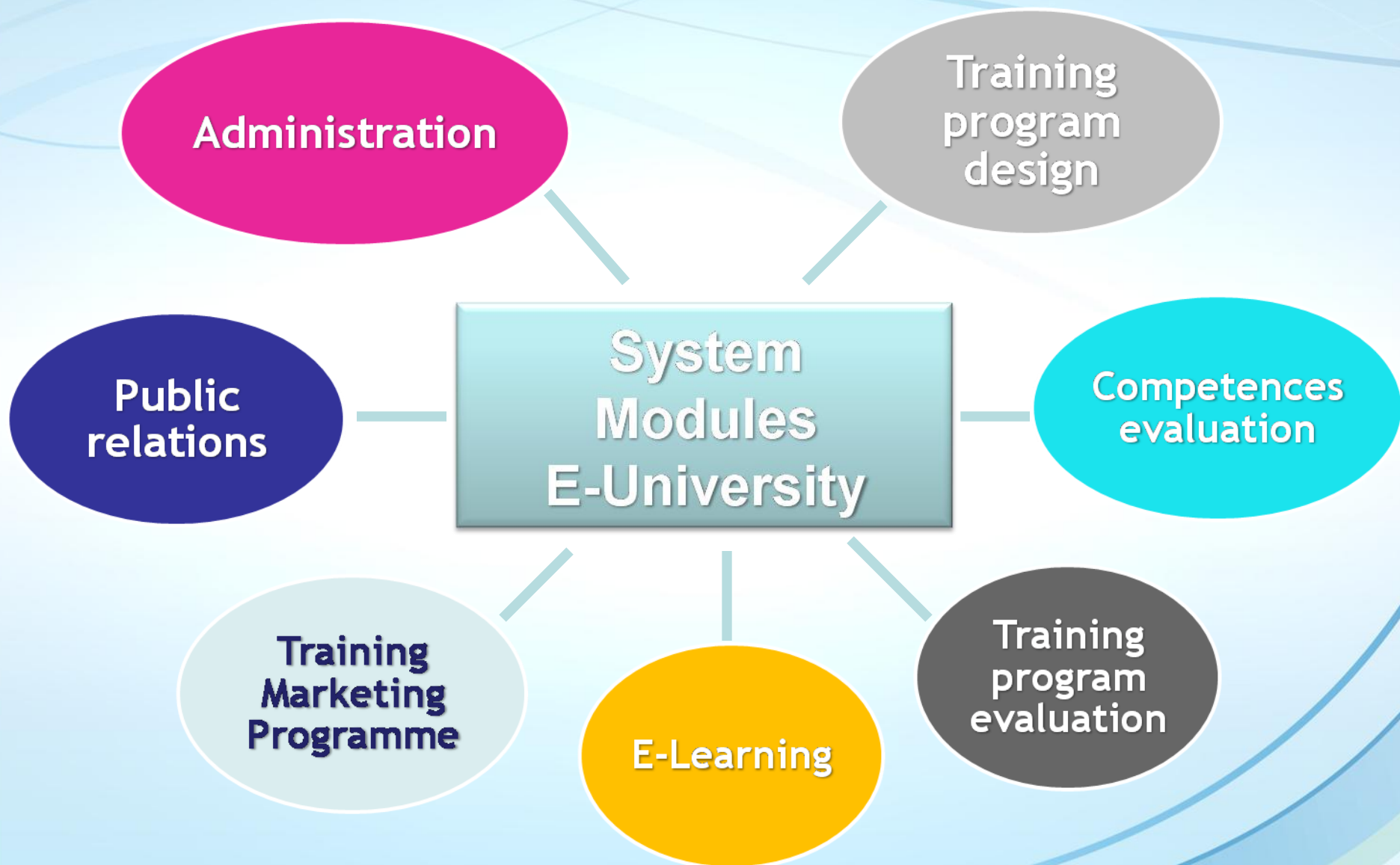


Continuity of care:

- **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);*
- **Continuity of care: <http://prezi.com/yvmtrf-j3jyd/the-patient-circuit/>**
 - 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!