



Social & Medical Services Initiated by Patient Organisations

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Romanian Prader Willi Association

The Pilot Reference Center for Rare Diseases, Romania



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“Placing one foot in front of the other, I've climbed to higher lengths. Reaching beyond my own limitations, to show my inner strength. No obstacle too hard, for this warrior to overcome. I'm just a man on a mission, to prove my disability hasn't won.”

**Robert Michael Hensel, Born with Spina Bifida
Guinness World Records holder for the longest non-stop wheelie in a wheelchair (6.178 miles)**

GENERAL INFORMATION ON THE SERVICE

Name of Service: The Pilot Reference Centre for Rare Diseases

Country: Romania

Type of Service: Resource Centre with:

1. **Day care service** for children with rare diseases from autistic disorders spectrum and other rare diseases;
2. **Respite care services** for patients with RD
3. **Help-line:** 0800801111
4. **Training of professionals:** www.edubolirare.ro

Origins of funding: *Norway grants* for creating and refurbishing the centre;

Running costs: public funds, private funds – companies and individual donors;

Contribution from beneficiaries: 12 euro/ month/ family as a non mandatory contribution and membership fee;

The cost / beneficiary:

218 euro/ beneficiary in the Day care centre/ month;

298 euro/ beneficiary/week Respite care;

27 euro/ month/beneficiary/ HelpLine

Dates/Times of the Year: all year long

Target Population: patients with RD, families, professionals

Age-Groups: children, adults

Countries of Origin: Romania

Webpage: www.apwromania.ro



MAIN FIGURES



Total Budget/Year: 2012

- Incomes: 115.150 euro
- Expenses: 120.742 euro

Total Nr. of Beneficiaries/Year: 2012

1. Day care service – 45 children
 2. Respite care services – 144 beneficiaries/ year & 12 benef./ month;
 3. Help line – 240 beneficiaries
- Total: 441 beneficiaries

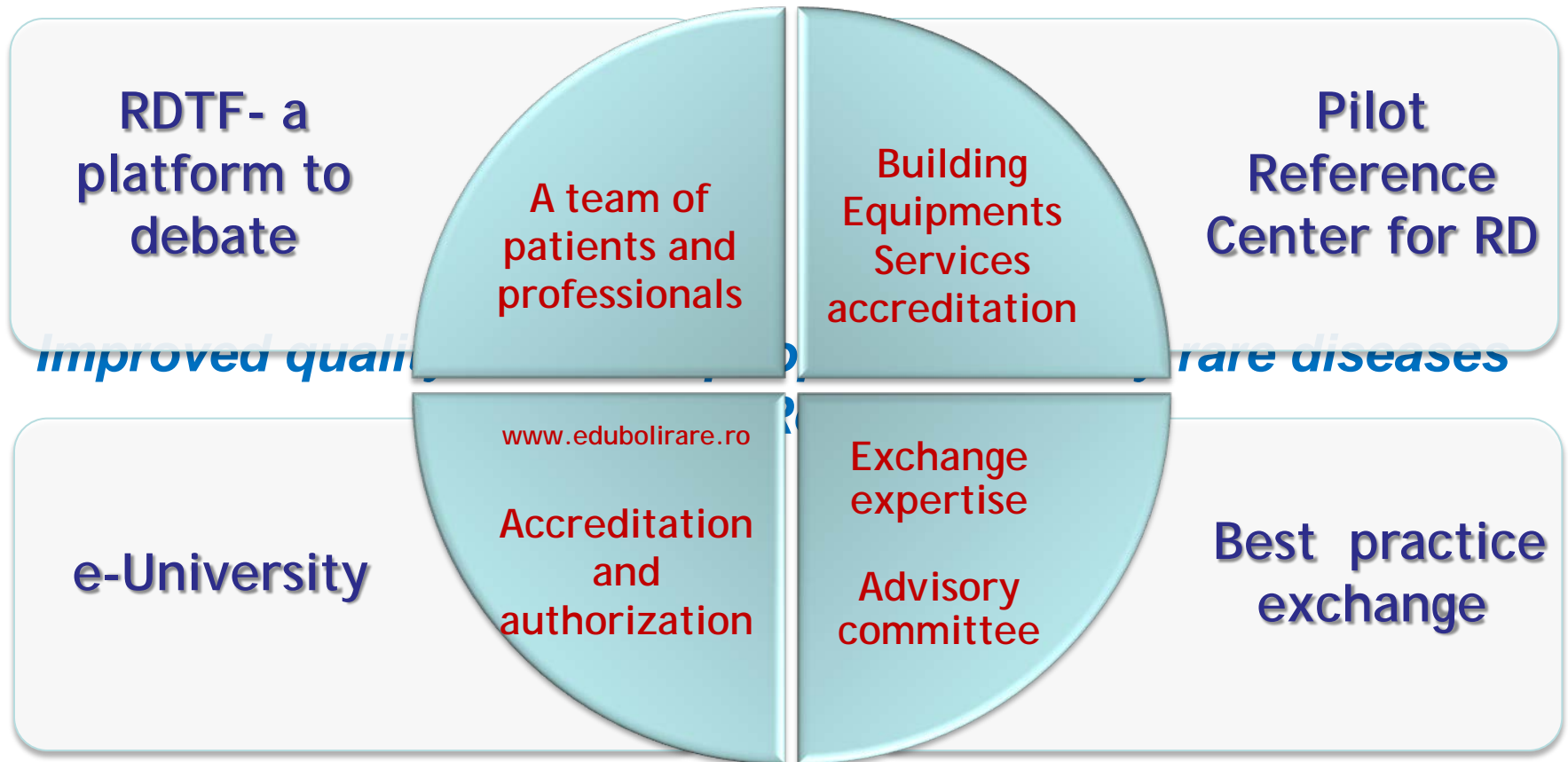
Training plan for staff

Total Nr. of Permanent Staff: 15 (2 x 1/2)

Total Nr. of Intermittent Staff: 10

Volunteers & practitioners;
Nr. of Volunteers/year: 24

NORO'S GOALS AND OBJECTIVES



BRIEF HISTORY

Date of Start: July 2011

Created by RPWA in partnership with: PW Norway, FRAMBU and other partners from Romania, including local and national authorities;

Short History:

Created by the implementation of the 2009-2011 project: Norwegian-Romanian Partnership for Progress on Rare Diseases.

Goal : to improve the quality of life for people with rare diseases.



GOVERNANCE AND MANAGEMENT



Established by Romanian Prader Willi Association

Funded by: Innovation Norway Grants for building and equipment;

Function funding from the local & national authorities and sponsors;

Governance structure:

- 4 members of the RPWA board are involved in the running activities of NoRo (2 volunteer, 2 as paid staff);

Are medical experts involved in the governance process? 1 doctor in the BOD APWR;
1 doctor hired and 5 volunteers

What is their role and their scope of action?

To support the developing of the medical aspects in the activities of the centre, medical advise, patients counselling and medical checking;

Interdisciplinary team of professionals– 15 hired staff

QUALITY ASSESSEMENT

Are patients evaluating the service after attending?

- Questionnaires to assess the degree of satisfaction;
- Evaluation session;
- **Medical, kinetic, psychological and social evaluation performed;**

Is the service accredited by any authority performing quality control?

- ✓ Social accreditation by the Ministry of Work
- ✓ Medical accreditation from MoH
- ✓ Authorisation for training from Ministry of Work and Ministry of Education
- ✓ Authorisation for Capacity of Research from ANCS;

Is the service connected to a Centre of Expertise/Hospital?

- Videoconferences /with hospitals and 6 medical universities
- HelpLine



THE NORO CENTER

Opened in June 2011

Components:

- Day Care Service
- Residential center for respite services
- Center for information: Help Line
- Trainings -eUniversity:
www.edubolirare.ro



The plan



The reality



SERVICES IN THE NORO CENTER

Day care service – for 45 children with RD from autistic spectrum

- ***Behavior therapy***
- ***Speech therapy***
- ***Physical therapy***
- ***Massage***
- ***Sensorial therapy***
- ***Hydro - kinetic - therapy***
- ***Ergo-therapy***
- ***Weight management***
- ***Educational and entertainment activities***



SERVICES IN THE NORO CENTER

Respite care services/ groups of patients

Group of 12 patients with the same diseases and personal assistants will attend a 5 days training each month

Content of the training courses:

- *Diagnoses, Heredity*
- *Symptoms, signs, course and complications*
- *Measures and treatment*
- *First aid*
- *Educational possibilities and training facilities for patients*
- *Independence and work*
- *Adult life, daily life*
- *Access to social and medical services*



SERVICES IN THE NORO CENTER

Respite care service – training for life independent skills

12 weekends to train groups of young people with RD to be independent and to organize their life

Activities and training:

- *Evaluation of skills and competences of the beneficiaries*
- *Cooking*
- *Using money and shopping*
- *House cleaning and gardening*
- *Orientation in town*



CENTER OF INFORMATION: HELP – LINE NORO

Free call:
00-080-11-11

E-mail address:
office@apwromania.ro
office@bolirareromania.ro

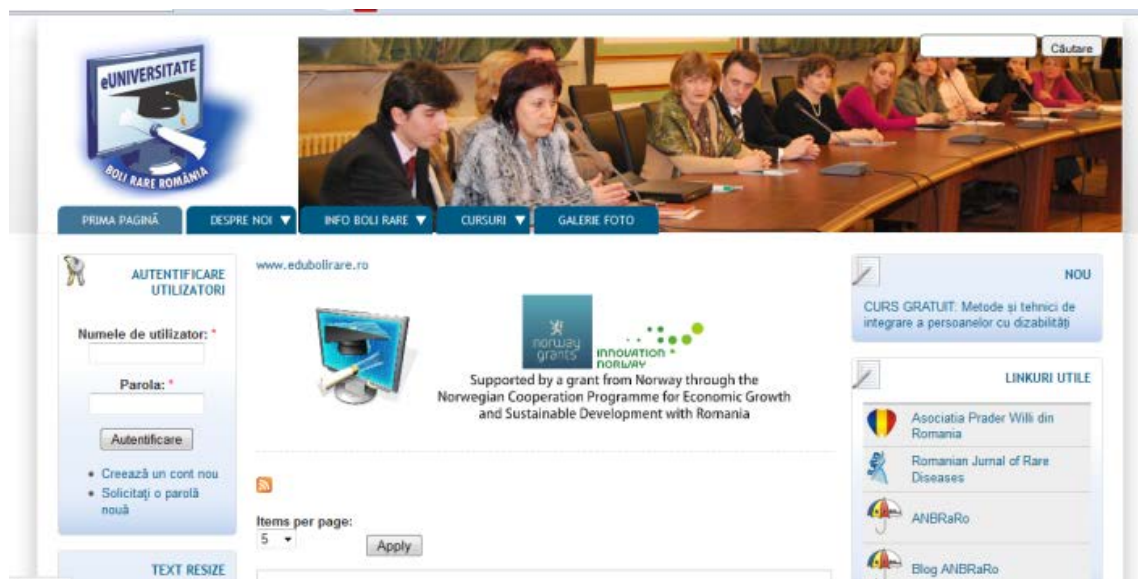


**Help Lines
for Rare
Diseases**

TRAINING FOR SPECIALISTS

www.edubolirare.ro – training courses for doctors and other specialists working with people with RD

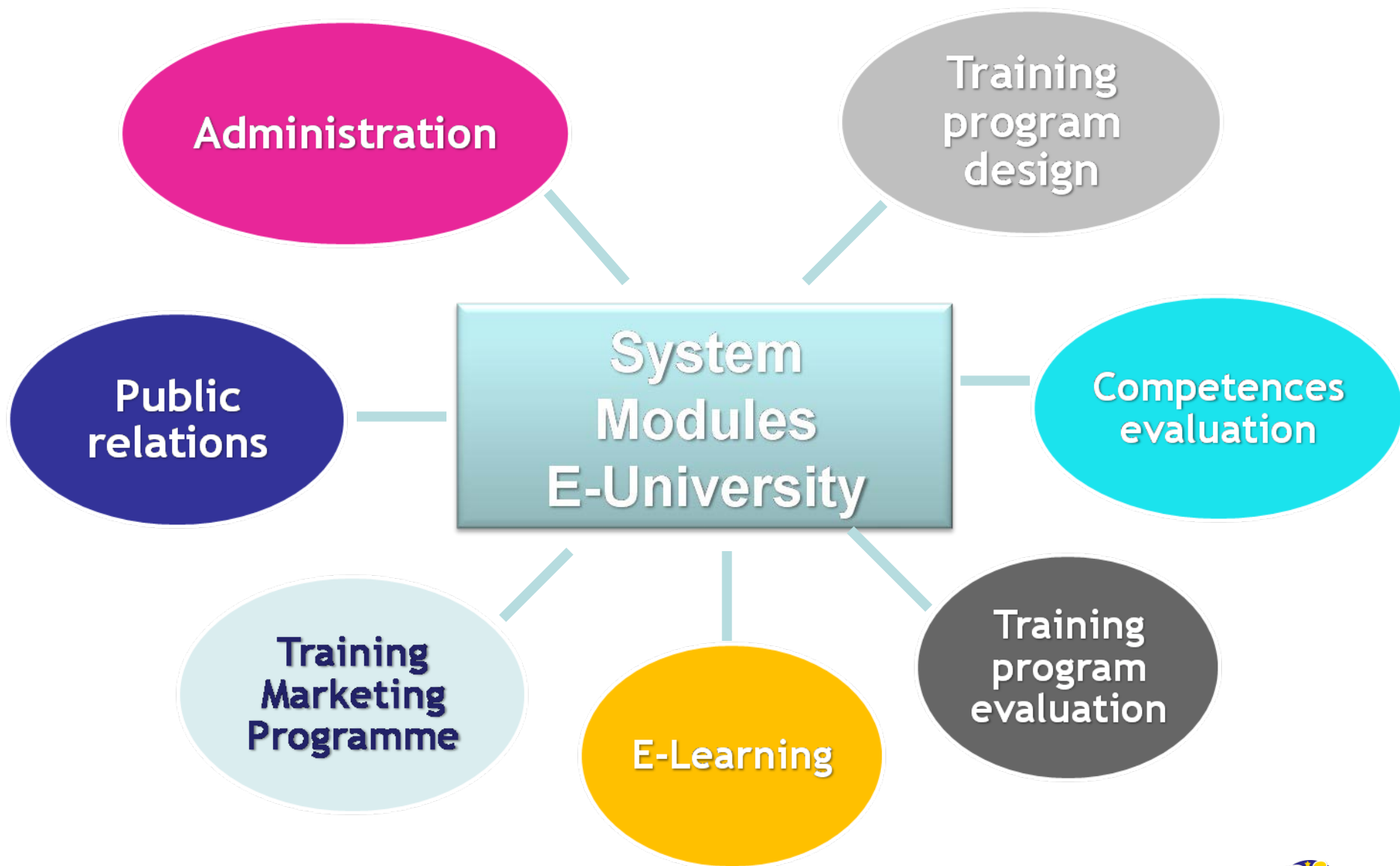
- Face to face training
- Blended learning
- Online trainings



ACTIVITIES

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*



STANDARDS OF CARE: RIGHTS AND PERSONAL IDENTITY

MISSION: To improve the quality of life for patients with rare diseases through access to therapies and rehabilitation, training of parents, patients and professionals, guidance and counseling, sharing of best practice and creating support groups for patients and families.

NoRo ensures respect for the dignity, rights and individuality of each beneficiary, particularly regarding the privacy and choice;

NoRo has internal procedures & regulations regarding the support of the beneficiaries in terms of equal opportunities for treatment and therapy and equal participation in accessing the social services (ROI, ROF, Chart of the patients; rights);



PERSON/FAMILY CENTEREDNESS

- NoRo provides services according to the needs of beneficiaries;
- Individualised intervention plans;
- Cooperation with family;
- Exchange information with other services and schools;
- Providing guidance, training and counselling for patients, families, professionals and other services;
- Data protection registration;

HOLISTIC, COMPREHENSIVE, INTEGRATED APPROACH

MULTIDISCIPLINARY TEAM:

- Staff
- Medical
- Volunteers
- 2 meetings/ week to discuss the cases



Psychiatrist, Psychologist, Art therapist, kinetotherapist, speech therapist, behavior therapist, special education teacher, social worker, nurse, etc.)


All staff and volunteers are qualified and attend trainings;

Volunteers, students, etc.

➤ *Monthly meetings with parents;*

- *Domiciliary visits of the therapists;*
- *Meetings with other services in the community;*

GOVERNANCE STRUCTURE

- NoRo is part of the RPWA  The board of RPWA is composed by over 50% of patients and their representatives;
- **4 members of the RPWA board are involved in the running activities of NoRo (2 volunteer, 2 paid staff);**
- The managing team of NoRo include professionals from the medical field and from the social, educational and economic field;
- An evaluation meeting of the activities performed at NoRo is organized every Monday morning;
- Parents and patients are involved in organization and evaluation of the services;
- The centres' procedures are communicated to the staff and beneficiaries and it can be checked any time;

ORGANISATION AND ADMINISTRATION



The Strategic plan is communicated to the staff and the beneficiaries, also policies and rules for admission in the centre;

NoRo has developed and implemented internal regulations including registration and admission procedures, care guidelines, a strategy for the mediation of conflicts and settlement of claims presented by beneficiaries, their families or legal representatives;

EVALUATION AND CONTINUOUS IMPROVEMENT OF QUALITY

NoRo is evaluated periodically by the accreditation institution - MoW;

- Self-evaluation, beneficiary evaluation and external evaluation;
- **NoRo staff and volunteers** are attending training courses and exchange of best practice with other services ;
- The social services' accreditation is renewed every 3 years;
- A report is performed for each service/ every month;

CONNECTION TO CENTRES OF EXPERTISE/MEDICAL INSTITUTIONS

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

- Cooperation with professionals in 7 Medical Universities by videoconferences;
- 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;

VISITS of doctors during the groups;

ADMISSION PROCEDURES AND INDIVIDUAL ASSESSMENT

Selection Criteria for Children in the Day Care centre:

- Age: <18 years
- Rare diseases, autistic spectrum;
- From Zalau and Salaj county

Selection Criteria in the Residential Centre:

- All ages
- Rare diseases;
- From Romania

Admission procedures and individual assessment: medical checking
interdisciplinary evaluation, social assessment, individual plan for
rehabilitation;

TRAINING OF STAFF AND VOLUNTEERS

TRAININGS:

- Organizational development project
- Strategic plan updating
- Team-building
- Management of RD patients
- Combined Art therapy
- Rehabilitation teacher
- Nutrition
- Behavior therapy
- Communication
- **Attending and organizing events;**



RARE DISEASES AND HEALTH CARE NEEDS

- **Some groups of patients require** experts on multiple disabilities might need to be present or within reach, in order to manage day-to-day needs and to be on call for the management of any unexpected/serious event;



training of the staff in **first aid**

- **special diet requirements;**
- **special equipment: respiratory, cooking , medical items, etc.**
- **a special program is created for each group disease, according to the medical needs;**



**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!

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