



NoRo



**Alianța Națională
pentru Boli Rare
România**



**Asociația
PRADER WILLI
din România**



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Cooperation between patient organisations and professionals

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NoRo Summary:



- ✘ Background of the cooperation of RPWA/ RONARD and professional organization: RSHG
- ✘ Challenges and outcomes: RD national strategy, national realities and contexts;
- ✘ How to integrate national perspectives into the European debate to have a stronger patient voice;
- ✘ Advocacy capacity of patient organizations in EE countries;

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Background of the cooperation of RPWA/ RONARD and RSHG

- ✘ **RPWA** established in May 2003, with the main goal to bring together: patients, families and professionals in order to offer a better life for people affected by rare diseases in Romania;
- ✘ **Accredited** to offer:
 - + Information and counseling for RD
 - + Personalized intervention therapy for autistic children; (Behavior therapy)
- ✘ **Authorized** for:
 - + research capacity;
 - + training.





Needs assessment:

- × Under diagnosis → low number of patients/disease
- × lack of visibility → NO monitoring system;
- × **no designated centers of expertise** → **NO** place for evaluation;
- × lack of visibility of the genetician profession in Romania;
- × distance among patients and professionals;
- × **lack of awareness on patient and health provider level;**
- × only few patients are eligible for treatments;





Patient & professionals organizations

- × **Are part of the Health Care System, not outsiders**
 - + - clear for professionals
 - + - not so clear for patients
- × **Patient and professional organizations had to:**
 - + Take a more active role in the healthcare system in creating better treatments.
 - + Create new resources together, not just passively wait for the needs to be fulfilled by someone.
 - + Share common goals and objectives.





Common goals and objectives

- × **The cooperation among RPWA and RSHG have started in 2006**
- × **Common goal and objectives:**
 - + To improve the access to information about RD in Romania
 - + To raise the awareness of community and policy decision makers on RD
 - + To create new services addressed to patients' needs
 - + To increase the interest of professionals in research projects on RD
 - + **Enhancing patient and health professional organisations' mutual understanding and building trust**





Milestones for such a partnership

- ✘ 9 August 2007 – establishing RONARD
- ✘ Essential in 101 Rare Diseases
- ✘ 29 February 2008 – partnership with MoH Romania for a NPRD
 - x Rare Diseases Solidarity Project
 - ✘ June 2008 – the first national program for rare diseases
 - ✘ Seed money project for NoRo
 - ✘ Permanent meetings PO and professionals
- ✘ 8 June 2009 - The Council Recommendation on an action in the field of rare diseases
 - + Help Line
 - + Romanian Journal for Rare Diseases
 - + EpiClinGen project – research on PWS and Angelman
- ✘ 2009-2011 – Implementation of the project: Norwegian – Romanian (NoRo) Partnership for Progress in Rare Diseases





Challenges and outcomes

- ✘ Organizing the 6th International PWS Conference in Cluj- Napoca 2007
- ✘ The 1st National Conference on RD in Zalau – november 2007
- ✘ Rare Diseases Day Campaigns 2008-2011
- ✘ NCRD – for designing the NPRD
- ✘ Balkan Congress for RD- Cluj- Napoca 2009
- ✘ RSHG National Congress and Balkan Congress for Human Genetics 2010, 2011 with dedicated sessions for RD
- ✘ 2 Eastern European Conferences on PWS 2009, 2010 (Timisoara and Zalau)
- ✘ Europlan Conference, Bucharest June 2010



NoRo Challenges for both professionals and PO

- ✘ To access all available diagnosis and screening : impossible at National level.
- ✘ To consider quality of life and cover the social needs of the patients: schooling, home care, respite care, adapted housing, as well as the needs of carers: support and respite.
- ✘ To reimburse medicinal products used off label, drugs without marketing authorizations (e.g. dietary produces, creams and bandages, special dental care, special clothing)
- ✘ To cover the high prices of innovative drugs and ensure broad and equitable access;

NoRo Opportunities

+ At EU and international level:

- × European policies : Communication of the EC, Council
- × Recommendation, Directive on cross border health care, orphan
- × drugs policies, European framework programmes, IRDiRC...
- × Work of the EUCERD (2009) to foster exchanges of experiences

+ At National level:

- × An adverse economic context!... If choices have to be made, it
- × should be in favor of the most vulnerable
- × Expert centers working together in networks : diagnosis,
- × Experimentation of new models to link expertise at national and
- × European level, to provision of care and disability policies at
- × regional level





Case study : The NoRo project

- ✘ **AIM: To improve the quality of life for people affected by rare diseases (RD) in Romania**
- ✘ **OBJECTIVES:**
 - + Establishing a **NCRD** - to define a team of professionals and patients' representatives;
 - + Development of **new high quality services** for rare diseases in Romania on the national level through the creation of a Pilot Reference Center for personalized intervention for those affected by rare diseases.
 - + To enhance the **training capacity**:
 - ✘ to design and implement a training network for specialists and staff;
 - ✘ to create accredited online training courses (eUniversity) about rare diseases for professionals: social workers, psychologists, nurses, teachers, doctors, etc.
 - + Permanent development and maintaining of a **shared best practice network** on RD – NoRo.



- × Opened in June 2011
- × Components:
 - + Day Care Centre
 - + Residential center for respite services
 - × Training and therapy for patient groups (professionals involved)
 - × “Trial for flight”
 - + Trainings - eUniversity:
 - + Center for Information - Help Line
 - + Conferences and Teleconferences

- × The plan:



- × The reality:
<http://www.youtube.com/watch?v=M9YTd47NPB0>



NoRo Importance

- ✘ How to address the main factors that isolate the patients and lock their chances to be integrated into community?
 - + Appearances
 - + Behavior
 - + Ability to move
 - + Mentality of patient and family
 - + Lack of understanding of community and professionals



NoRo Services in the NoRo Center 1

× Day Center - for children with RD from autistic spectrum (35 children)

- + 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 2

- × Residential part/ groups of patients
- × Group of 12 patients with the same diseases and personal assistants will attend a 5 days training periodically
- × Content of the training courses:
 - + Diagnoses
 - + Heredity
 - + Symptoms, signs, course and complications
 - + Measures and treatment
 - + Educational possibilities and training facilities for patients
 - + Independence and work
 - + Adult life



- × Trial for flight – training for life-skills
- × Training for an independent life - 6 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



NoRo 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
- + 2 magazines (1 for PO and 1 for professionals)
- + 2 books, guidelines, etc.





The importance of the NoRo Center

× Better quality of life for patients with RD through:

- + Quality services
- + Shorter way to diagnose
- + More informed patients
- + Better treated patients
- + More qualified specialists





Functioning of the NoRo Center

- × It is a big **challenge** to assure the functioning of these services
 - + Innovative
 - + Socio-medical
 - + National
- × **Funding:**
 - + Local authorities
 - + Sponsors?
 - + State subventions for social services?
 - + New projects
 - + Economic activities?





How to integrate national perspectives into the European debate;

- × **Connection with other European actions, projects and EU actions:**
 - + Council Recommendation on an action in the field of rare diseases
 - + Rare Diseases Day annually campaigns
 - + EUROPLAN: Recommendations for the development of National Plans and Strategies for rare diseases
 - + Joint Action to implement the European Union action in the field of Rare
 - + Directive of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare



NoRo The way it works...

- × International strategies → National → Local
→ *Services for patients*
- × EURORDIS → RONARD & RPWA → local
collaboration with professionals and authorities,
other social/medical services
- × International collaboration in RD and shared best
practices is essential because of the limited
 - + resources
 - + number of patients
 - + expertise



- ✘ Both sides *proud* and *self sufficient* feeling
- ✘ *Hopeless* in changing the system
- ✘ Finding ways to prove the organizational capacity of patient organizations
- ✘ *Lock of a “clear communication” & loosing the “right” level of understanding*
- ✘ No clear understanding of the common objectives

NoRo Advocacy capacity

- × What are the needs national and EU level in order to strengthen patient and health professional cooperation?
 - + To improve the organizational capacity of PO
 - × training POs to become stronger partners
 - + To promote common projects
 - + To share expertise and support each other
 - + To learn how to work together
 - × **TEAM** – together, everybody achieve more



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THANK YOU!



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