

INNOVCare

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

NoRo - resource centre for RD

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INNOVCare - Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions

Ågrenska, Gothenburg, 8-9 September 2016

www.innovcare.eu



www.creenfermedadesraras.es

www.apwromania.ro

www.cjsj.ro

www.eurordis.org

www.finovatis.com

www.ier.si

www.ki.se

www.zsi.at

 This project is co-funded by the European Union

National context :

- Rare Diseases in Romania: declared a national priority, too often forgotten, considered to be costly and that the patients have NO real chance for cure...



- *The lack of integrated services addressed to those affected by rare diseases, to facilitate the diagnose and to give the power to go forward and look for treatments, therapies, rehabilitation, inclusion in school and community...*

NoRo – Frambu

**Mentoring
Program**



Brief information on NoRo service

- ❑ **Country:** Romania, Salaj County, Zalau
- ❑ **Currently managed by:** Romanian Prader Willi Association

- ❑ **Target Population:** patients, families, professionals from *Romania*, affected by rare diseases (*give examples or total nr of diagnosis*); all age groups;
- ❑ **Type of institution:** *NGO, patient organization;*
- ❑ **Origins of funding:** *Local and County Council for the Day Care Center, National Health Insurance for the Medical Department and projects for patient groups and development of the center;*
- ❑ **Total Budget/Year:** **440.000 eur** (*86000 eur provided from Local Authorities to support our services and the rest are from projects, services and sponsors*)
- ❑ **Cost for beneficiaries:** **350 eur/ person/ month** (*less than 50% funded by Local and County Authorities*)

Relation to health, social and community services

- **Total Nr. of Beneficiaries/Year:** 50 beneficiaries in the *daily rehabilitation program* and 144 patients and personal assistants for *patient groups*, 12 patients in *Trial for flight*, 20 on *BBBS program*, and on *HelpLine*; (≈300 patients / year)
- **Total Nr. of Permanent Staff:** 18
- **Nr. of Volunteers/year:** (if applicable): 35



- *Disseminate relevant information to all stakeholders*
- *Demonstrate the importance of integrated care services*
- *Elaborate strategies for developing information and training for social services providers*
- *Exchange knowledge and best practices*
- **Contribute to addressing the challenges of healthcare pathways**
- **Understand the opportunities through a collaborative approach**



Services provided

➤ Medical department:

- ✓ Diagnostic, medical evaluation (echography, EEG, EMG, DNA Extractor, LMD, EKG, Body Fat Monitor, Polisomnography, etc);
 - ✓ A part of the patients are oriented to other services
 - ✓ A part are included in NoRo services: (Day Care Centre or patient groups)

➤ Day Care Centre:

- ✓ **Interdisciplinary team** of therapists: Ergo therapy, gymnastic, massage, hydro therapy, sensorial therapy, behaviour therapy, speech therapy, electric stimulation and deep oscillation;
- ✓ **Social assessment and Individual Plan for Rehabilitation**
- ✓ **Patient electronic registry**
- ✓ **Coordination with Social Services department of the Local and County Council**
- ✓ **Orientation to other services**
- ✓ **Collaboration with kindergarten, schools and families in order to ensure continuity of care**

Services:

□ 1. Day care center: 50 children from Zalau and Salaj county:

- ✓ **Daily intervention program:** ergo therapy for groups, 2 hours / day, 5 individual therapy/ child/ week;
- ✓ **Multidisciplinary evaluation** and yearly re-evaluation (medical, social, kinetic, psychological);
- ✓ **Therapeutic weekends** for families & training for increasing of the family resilience;
- ✓ **Summer camps;**
- ✓ **Connected** with other services at community level to ensure continuity of care;
- ✓ **Home visits of our therapists** (2 weeks/year)



Services:

□ **2. Patient groups:** 12-14 patients (and personal assistants x 5 days/group with the same RD)

- ✓ **Multidisciplinary evaluation** (medical, social, kinetic, psychological)
- ✓ **Therapies** (gymnastic , massage, hydrotherapy, speech, sensorial, behavior, electric stimulation, MIRA, occupational therapy)
- ✓ **Therapeutic education and counseling** (first aid, disease information, sharing best practice, meeting professionals, support groups, etc.)
- ✓ **Information** and connection with the social services in their proximity: www.participrare.ro
- ✓ **Patient registry** (*data protection, confidentiality, informed consent*)



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NoRo- a Pilot Reference centre for RDs

❑ Opened in June 2011 through a project of the RPWA, funded by Norway grants (Frambu as partner)

❑ NoRo is:

❑ a **Resource Centres for Rare Diseases** in Romania

recognized as a HCP to participate in ERN & CoE, part of a national consortium;

❑ a **one-stop-shop style of service**, specifically designed for people living with a rare disease, **combining medical, social and educational services**;

❑ creates a **bridge** between patients/families and various professionals and services involved in patient care;

❑ **Involve patients** at local, county and national level in our services;

NoRo



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Innovation in our services

Definition: *Creating the new or re-arranging the old in a new way!*

A continuous updating of our services to the needs of patients, in an efficient way,...considering the realities of our environment;

- ❖ Day care center for rehabilitation of children with RDs and autistic spectrum disorders;
- ❖ Pilot center for rehabilitation
- ❖ Center for independent life training
- ❖ Medical Ambulatory (neurology for adults, psychiatry for children and genetics)
- ❖ Training services & www.edubolirare
- ❖ Research capacity accreditation

Innovation is needed in RDs as:

- ✓ many questions has no answers yet
- ✓ most of the patients have not accessible treatments
- ✓ we can't talk about social inclusion without education for all and employments opportunities for patients and families;

Development and sustainability

- ❑ Established by a PO
- ❑ Day care center and medical department are funded by the Local and County Authorities;
- ❑ Accreditation and ISO 9001 quality standards in the management of our services;
- ❑ Developed through different projects: Norwegian grants, Swiss Cooperation Program, small grants;
- ❑ Mentoring program with Frambu;
- ❑ Cooperation with Professionals;
- ❑ **Identification and involvement in elaboration of national policies for supporting the integration of people living with a rare disease into social services and polices:**
 - ✓ integrated care, social economy, case management in child protection system,
 - ✓ organisation of **care pathways**, cooperation with CoE and other social, medical and educational services;
 - <http://www.edubolirare.ro/downloads/ghid2016/#/26>



Quality in our services

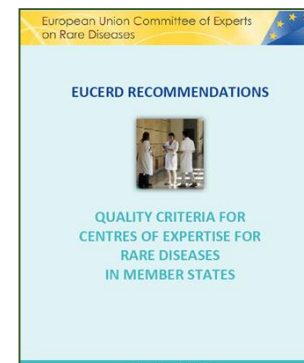
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- ✓ Demonstration of a multi-disciplinary approach
- ✓ Capacity to participate in data collection for clinical research and public health purposes – patient registry
- ✓ Organisation of collaborations to assure the continuity of care between childhood, adolescence and adulthood – Trial for flight
- ✓ Organisation of collaborations to assure the continuity of care between all stages of the disease: diagnostic, treatment, rehabilitations, HCP, social services, education and social economy
- ✓ Links and collaboration with other CE at national, patient organisations where they exist, European and international level
- ✓ Consideration of E-Health solutions: training platform, videoconferences, mapping services, elaboration of guidelines, factsheets and documents
- ✓ Sharing resources and best practice with other HCPs
- ✓ Creating networks at national level & defining patient pathways

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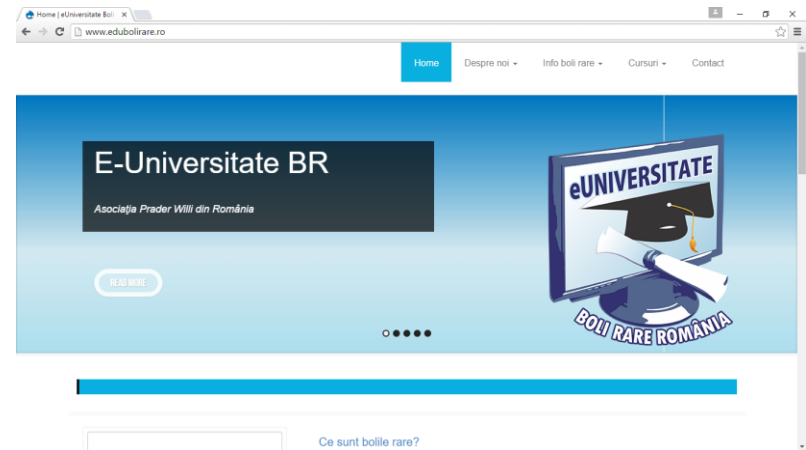


HelpLine

- *Help Line NoRo* : 0260-610033
- or e-mail: office@apwromania.ro și office@bolirareromania.ro

www.edubolirare.ro

<https://www.youtube.com/watch?v=hlgOXHdcLjg>



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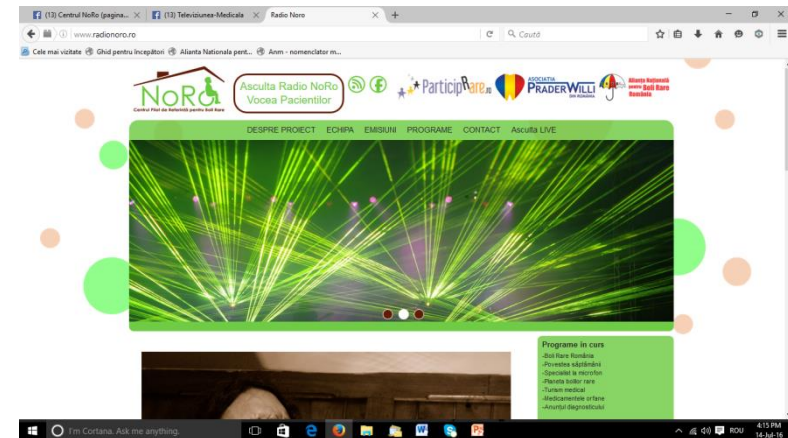
Redesigning the services:

Medical ambulatory:

- ✓ 3 doctors (1 with experience in research projects)
- ✓ **Equipment:** EEG, EKG, EMG, Echography, DNA Extractor, Body fat monitor, LMD;
- ✓ **Psychological tests:**
- ✓ **Therapies:** MIRA & Deep Oscillation;
- ✓ **Summer camps;**
- ✓ **Videoconference system**
- ✓ **Guidelines** for emergency services, integrated care, services' map;
- ✓ **2 magazines;**

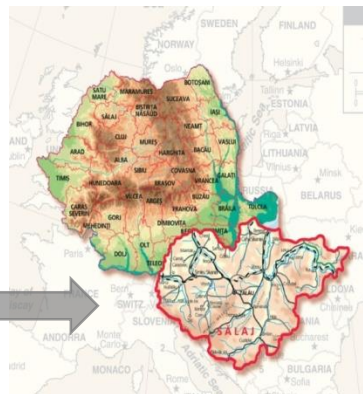
✓ Promotion:

- ✓ **National campaigns in cooperation with RONARD**
- ✓ **Presentations, films and videos;**
- ✓ **Guide of NoRo Services**
- ✓ **www.participare.ro**
- ✓ **www.radionoro.ro**



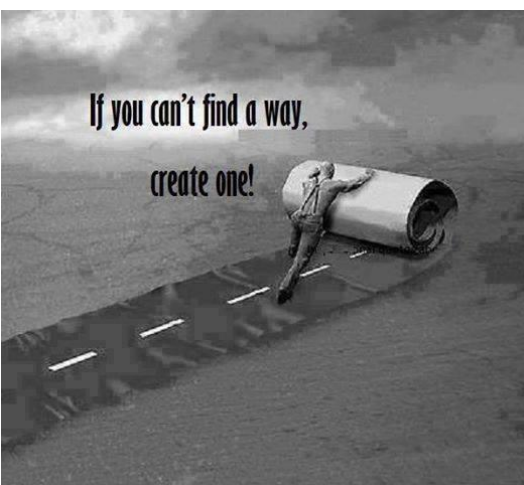
Next steps INNOVCare

- To **give voice** to the social needs of people living with a rare disease
- **Testing** a holistic, personalized care pathway
- Implementation of a **pilot of this pathway** in Romania;
- **INNOVCare** (*Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions*) addresses the social challenges faced by people living with rare complex conditions and the gaps in the coordination between medical, social and support services in EU and MS;



Inter sectorial and international collaboration

- ❑ **Innovative care pathway** bringing together national resource centres for rare diseases and regional case managers, **in partnership with public bodies**;
- ❑ **Evaluation of the socio-economic impact** and a **cost-benefit analysis of the care model**;
- ❑ **Exchange of good practices & initiate European network of services**;
- ❑ https://www.youtube.com/watch?v= 2jy_saqxq0



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Thank you

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The information contained in this publication does not necessarily reflect the official position of the European Commission