

Sharing best practices on integrative approach to rare diseases in different countries



Country name: Romania

Speaker's name: Dorica Dan

Integrative approach on RD in Romania

Romanian National Alliance for Rare Diseases

BoD Eurordis; IPWSO;

Why establishing a RD association?

- Because you or one of your family member is affected by a RD;
- You are a professional involved in the diagnosis and management of the RD;
- Simply, because you think that *you have to do this*.
 - In my case:
 - *I have a daughter Oana with PWS, 24 years, diagnosed at 18.*



In collaboration with

EUROPLAN

European Project for Rare Diseases National Plans Development

Strategies for rare diseases

- *Official definition of RDs :*
- those affecting no more than 5 per 10 000 persons
- **isolation, loneliness, feeling that you have been forgotten, vulnerability....LESS HOPE**
- **6000 to 8000 different rare diseases...**
- almost **NO HOPE...**



REALITY:

- *It is time for Public Health Authorities to consider rare diseases as a Public Health priority and take action to concretely support patients and families affected by rare diseases.*

- **NEEDS:**

- **Unite the efforts of the different rare disease patient organizations in Romania.**
- **Work to end the ongoing isolation for rare disease patients that the health system, mass media, and scientific researchers in our country foster.**
- **Advocate for an adequate national strategy, to ensure better health care, educational and social services for our patients.**

In collaboration with

EUROPLAN

European Project for Rare Diseases National Plans Development



Beginning



Romanian Prader Willi Association has been established in May 2003 and the **Information Centre for Rare Genetic Diseases** was officially opened on the 16th of October in 2005.

It is **the first centre** of this kind in Romania and we wanted it to be a resource centre for patients who suffer from rare genetic diseases, their families, and professionals involved in diagnosis and management of these diseases.

» www.apwromania.ro

In collaboration with

EUROPLAN

European Project for Rare Diseases National Plans Development

RONARD

- Established in 2007 through a project funded by CEE Trust;
 - *As a consequence:*
- We became able to advocate for **all rare disease** patients at national level and constitute a powerful stakeholder that governments must take into account.
- We are **better listened**
- **Gained social recognition** for rare disease patients and families

In collaboration with

EUROPLAN

European Project for Rare Diseases National Plans Development

Partners:

- Romanian Society for Medical Genetics
- Medical Universities from Timisoara, Cluj-Napoca, Iasi, Tirgu Mures and Bucharest
- ORPHANET Romania and Europe
- EURORDIS
- National Center for Studies in Family Medicine Romania
- Romanian Ministry of Health



In collaboration with

EUROPLAN

European Project for Rare Diseases National Plans Development

Achievements:

- Member of Council of National Alliances at European level in **EURORDIS**.
- First **National Conference on Rare Diseases in Romania** titled, *RD: From Evaluating Needs to Establishing Priorities*, in Zalau in November 2007.
- Organized efforts in Romania for the **European Rare Disease Day 2008** and the **First International Rare Disease Day 2009**.
- **RONARD** and **Romania Society for Medical Genetics** initiated the **National Plan for Rare Diseases in Romania** and on February 29th, 2008, we signed a partnership agreement with the **Ministry of Health** to implement a National Plan for RD in Romania. The first national program for rare diseases have been approved and orphan drugs are compensated by Ministry of Health Romania.

In collaboration with

EUROPLAN

European Project for Rare Diseases National Plans Development

Provision of information for rare diseases

- *RPWA is accredited by MoW to provide **information and counseling services** for patients with RD, their families and professionals;*
 - *Other PO – members of our alliance are also accredited for the same service in regard to the specific diseases that they approach;*
 - *As a center, we are also accredited for **behavior intervention therapy** ;*
 - *We are **authorized for training courses** for personal assistants and organizational development;*
 - *Thanks to the good cooperation we have with RSHG and the Medical Universities, we are authorized for research capacity;*

Empowerment of patients organisations



- *Partnerships established with LA and co-funding partners on different projects and actions:*
*Ex: MoH is covering our own contribution in a project called: **Partnership Norwegian Romanian (NoRo) for progress in RD** – project funded by Innovation Norway with the main goal to:*
- *To contribute to the improvement of the quality of life for people affected by rare diseases in Romania by providing equal access to early diagnosis, quality treatment and rehabilitation services through a comprehensive and accessible network of facilities and resources as set forth by the **National Plan for Rare Diseases**.*

Funding of actions, regarding rare diseases



- *Orphan drugs* :-**Order MoH No. 417 / 431 /31.03.2009-RD** **included** in the national programs for health;
- *Rehabilitation*- many rehabilitation centers and hospitals have been established; The number of the centers is not enough and not all have very good services. They were not designed for RD patients, but some of them are very good;
- *Social care*: social financial aids and personal assistant for RD patients with severe disabilities, etc;
- *Centers of expertise*: there are several centers around Medical Universities which are well known to have expertise in certain RD but, they are not called like this and there is a need for MoH to establish the **criteria's for designation** and for funding these centers.

Specialised social services

- *Respite Care Services*
- *There have been established (1 or 2) by patient organizations; not enough and not specifically for RD, don't have a permanent financial support;*
- *Services aimed at the integration of patients in daily life*
- *Many projects implemented by patient organizations, many centers have been established but they have not sustainable financial resources;*



Can we talk about an integrative approach to RD in Romania?



- NO.
- We can talk about an integrative thinking/ intentions;
- When we talk about expensive treatments, always the LA, MoH will always say that the budget is not enough and we believe them.
 - But we are patients and parents; we were not prepared to have these diseases but, we have to learn every day how to cope with our problems**living together and learning together !**

Looking forward to welcome you in Cluj: 26-27 June 2009! Thank you!



Fourth Eastern European Conference for Rare Diseases and Orphan Drugs
"Together for Integrative Approach to Rare Diseases"
13-14 June 2009 - Plovdiv, Bulgaria

In collaboration with

EUROPLAN
European Project for Rare Diseases National Plans Development