



# RD-CODE Workshop Country Presentation

Romania

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★ <http://rd-code.eu>



# Romania: Overview

- > In Romania there is no national register for rare diseases; cases are reported using ICD10 coding;
- > Iasi Regional Medical Genetics Centre covers 20% of the population of the country; with more than 2,400 patients with rare disorders evaluated/year and being part of ERN ITHACA (congenital anomalies & intellectual disability), it is a reliable pilot centre to start to introduce Orpha coding;
- > Orphanet national team has been involved in the development of the project;

# Romania: RD-CODE Project

- > IsRMGC used as a pilot centre to introduce Orpha coding;
- > Invite the other Romanian services - members in different ERNs – to join;
- > Training with those who accept and extend the use of the IT tool developed;
- > Periodic meetings and adjustment of the IT tool and workflow;
- > IT tool extended nationally;

# IT Tool Development & Orphacode Training

- > After developing the IT tool, we have trained young physicians to introduce cases and started uploading cases that have been evaluated in 2019 – precise diagnosis of rare disease – more than 200 cases recorded;
- > We have evaluated the section of reports and statistics;
- > We have trained all our physicians locally (multiple sessions locally);
- > Due to COVID 19 pandemics all the activity was paralysed:
  - ★ Center closed for 3 Mo; started reduced activity in the last month;
  - ★ Numbers started to increase dramatically after relaxation ...

# Way forward on Orphacode training

- We started meetings online;
- We plan to organize further training with ERN members online (we are developing online training materials);
- Due to the change of plans, we also intend to transfer travel and subsistence budget to purchasing and installing a teleconference system – to be used now for training and later for periodic meetings to monitor IT tool application extension;

# IT tool

- > In Romania each hospital is having a different database, but all of them report synthetic data to a national database (used by the National Institute of Statistics);
- > Our IT tool has been developed to fit with the databases used by different hospitals and with the national one;
- > Simple, easy to use, comprehensive enough;
- > Sections:
  - ★ Administrative data;
  - ★ Clinical data;
  - ★ Investigations;
  - ★ Reports and statistics;

# Challenges and possible solutions

## > Due to the crisis:

- ★ The system is busy with specific issues related to this;
  - ★ The patients try to avoid hospitals for safety reasons;
  - ★ Scientific meetings where we could present RD-CODE are cancelled;
- The extension of the IT tool use is difficult;

**Possible solutions:** use extensively online communication;

## > Use of Orpha codes – physicians are used to ICD10 codes (more general)

**Possible solutions:** teach them to use Orphanet encyclopedia;

## > Our IT tool has to be comparable in efficiency with the ones of our partners

**Possible solutions:** to have workshops like the present one to discuss practical issues and challenges.