

Centres of Expertise – Actual Situation and Plan Development in Romania

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Actual situation in Romania

- (+) 7 Medical Genetics Centers (clinical setting, cytogenetics lab, DNA lab);
- (+/-) Neonatal screening;
- (+) Connection with European networks (Orphanet, Dyscerne);
- (-) Limited connection between centers,
- (-) No prevalence data;
- (+/-) No national registry;



National Plan for Rare Disorders

National network of expertise centers

- 2008 – **partnership** Health Ministry – National Alliance for Rare Disorders;
- **National Council for Rare Disorders** (professionals, patients' organizations) → National Plan for Rare Disorders;
- **Network of expertise centers:**
 - **Reference centers** (1/ country);
 - **Competence centers** (1/ region);
 - **Basic medical centers** (1/ county);

REFERENCE CENTERS - attributions

- ✓ management of the national register;
- ✓ diagnosis, specialized investigations, therapy initiation and elaborate patient management directions;
- ✓ monitor patients;
- ✓ correlate research;
- ✓ guidelines;
- ✓ management of health programmes;
- ✓ regularly inform stakeholders;
- ✓ cooperate with the European network of centres;
- ✓ train professionals and patients.

COMPETENCE CENTERS - attributions

- ✓ apply guidelines;
- ✓ monitor and transmit information to reference centres/ basic medical centres;
- ✓ organize screening;
- ✓ database with professionals;
- ✓ prevention, diagnosis, therapy, recovery.

BASIC MEDICAL CENTERS - attributions

- ✓ implement screening;
- ✓ solve simple cases, refer complex cases;
- ✓ inform and training (physicians from other specialties, patients etc);
- ✓ maintain connections with patient's associations.

Thank you !