

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



ARMENIA

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European Project for Rare Diseases National Plans Development

Strategies for rare diseases



- No official register of rare disease
- According to hospitals information - about 300 patients with hemophilia, 15 patients with thalassemia, 5 patients with Partial Red Cell Aplasia, 4000 patients with Familial Mediterranean Fever (FMF), also patients with sceletomuscular, endocrine problems as well as cancer which number is not clear yet for this moment



Funding of actions, regarding rare diseases



- Prenatal and Neonatal screenings are not being performed yet
- There is a Center of Genetics in Armenia, where genetic analyses for some rare diseases, such as FMF, endocrine hereditary diseases, cancer can be done.
- We do not have any orphan drug registered in Armenia yet, but a pharmaceutical company is going to register medication for chelation therapy for the patients suffering from thalassemia
- There is a rehabilitation center in Armenia for patients with skeletal muscular problems
- Social care is developing in Armenia



Provision of information for rare diseases



- No official website for RD and orphan drugs
- A wide use of e-net information and online literature for diagnoses and treatment
- Consultations with specialists abroad
- Forwarding patients to specialized clinics for treatment in Europe or USA



Research on rare diseases



- Research programme for RDs is actual in our country, but it is not performing yet!
- There is a need of sponsors for performing clinical studies on rare diseases.



Prevention

- Prenatal screening - not available yet
- Neonatal screening - not available yet
- Delay of diagnosis – frequent



Empowerment of patients organisations



- Support to the activities of local patient organizations in Armenia is low.
- Representation and consultation of patient organisations in Armenia by experienced EU organizations is needed.



Specialised social services



- Not well funded Respite Care Services in Armenia
- A need for Therapeutic Recreational Programmes
- A lot of work ahead towards improving the activity of services aimed at the integration of patients in daily life

