

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



TURKEY-TÜRKİYE

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Strategies for rare diseases



- **Organization and Duties of the Turkish Ministry of Health”**
- a) Maintaining consistencies in physical and mental well-being throughout the lifespans of individuals;
- b) Improving the equal public health status within the country;
- c) Struggling with threats posed by potentially hazardous factors towards public health;
- d) Regulating the principles related to the establishment, organization and duties of the MOH, with the intent to:
 - i) Plan each and every healthcare body solely under one authority;
 - ii) Ensure a standard supply of healthcare services from these bodies;
 - iii) Provide public access to healthcare services; and,
 - iv) Promote easy and appropriate public access to healthcare services.



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- At present, the Turkish Ministry of Health (MOH) has not yet recognized a National Plan with reference to “rare diseases” and “orphan drugs”, as readily defined inside the European Union (EU).
 - Health Services are given by MoH (State Universities, Universities, Private Hospitals and Organization) to all the citizens free of of charge in general.
 - There is a exemption from patient participation in the cost of relevant healthcare for the patients with disabilities and inherited diseases

Funding of actions, regarding rare diseases

Funding of issues concerning RDs in Turkey

- *Prenatal screening- Ministry of Health*
- *Neonatal screening- Ministry of Health*
- *Diagnostic genetic services- Ministry of Health,*
- *Treatment (clinical management)- Ministry of Health*
- *Rehabilitation- Ministry of Health*
- *Social care- Ministry of Health*
- *Orphan drugs*



Funding of actions, regarding rare diseases

- *Orphan Drugs-*

Patients suffering from known rare diseases in Turkey access treatment with nationally licensed or non-licensed human medicinal products which have been granted marketing authorization (MA) by the European Medicines Agency (EMA) under “orphan designation”, and/or indicated for the treatment of specific rare diseases.



Provision of information for rare diseases



- *Turkish Orphanet website link is under construction*
- *No specific help line specifically devoted to RDs*
- *The Orphanet list for RDs available in Turkish language*

Research on rare diseases

- *Availability of research programme for RDs:*
 - *Turkish State Planning Organisation (DPT),*
 - *The Scientific and Technological Research Council of Turkey (TUBITAK)-*
 - *EU Framework Programmes 6 and 7*
 - *E-RARE*
 - *University Research Funds and Private Funds*



Prevention



- *Prenatal screening available if there is a genetic or medical indication*
- *Nationwide neonatal screening for hypothyroidism, PKU, biotinidase deficiency and thalassemia*

Empowerment of patients organisations



- *Patients organizations are active for certain diseases although there is an immediate need to cover national rare disease alliance.*
- *Support to the activities of patient organisations*
- *Representation and consultation of patient organisations*

Specialised social services



- *Tax reduction for patients with disabilities*
- *Positive discriminative legislation for government employment*
- *Respite Care Services*
- *Therapeutic Recreational Programmes*
- *Services aimed at the integration of patients in daily life*