

Orphanet Turkey National Team Highlights

Institution /Team composition

Turkish Institute of Health Sciences- Institute for Public Health and Chronic Diseases

- Main Representative: Prof.Dr.Uğur Özbek
- Substitutes:
Prof.Dr.İlhan Satman, Assoc.Prof.Dr.Onur Dursun
- Information Scientists:
Merve Yemenici, Nazlı Ertürk, Emrah Yücesan



www.orpha.net/national/TR-TR/index/orphanet-türkiye/

Highlights

- National Plan: Under preparation by MoH and responsible stakeholders.
- Turkey is the official part of the Orphanet Network since October-2019
- Codification: ICD10 is used in nationwide. Orphacodes are planned to be established in pilot reference centers after establishing Nomenclature translations
- Orphanet Nomenclature Translation is being concluded
- Orphanet National Advisory Board on Rare diseases has been established.
- Collection of expert resource-related data has started.
- Publication of data for officially designated expert centers is planned.
- TUSEB Rare Diseases Report had been published in Turkish on September 2019 in downloadable format. The report is composed of 58 diseases/syndromes that are relatively more commonly encountered in Turkey

Challenges

Sustainability; «the Directorate of Autism, Special Mental Needs and Rare Diseases» has been established within the Ministry of Health, on January 2020. The Department coordinates activities to increase awareness; to prepare the legislations for these unfavorable health conditions; to create an infrastructure for screening, early diagnosis/intervention, and management of autism, mental disorders and rare diseases. Directorate is responsible for supporting health services related activities within Orphanet TurkishTeam, Currently 2 full time dedicated information scientists are on training for registration of national Orphanet activities.

Take away message

- Expert resource-related data collection will resume
- Translation of the International website into Turkish language is planned to commence next year.
- Ongoing collaboration projects with other EU bodies and neighborhood countries are being planned.