National registry of patients with thalassemia major – preliminary data (August 2008)

National registry of patients with thalassemia major in Bulgaria is a project in the field of rare diseases which BAPES started in August 2008. Its aim is to establish an epidemiological tool to identify and follow up regularly the medical history of each patient. The registry will help doctors, scientists and health authorities to determine the incidence, prevalence, long-term clinical outcome and quality of life of Bulgarian patients with thalassemia major. They will also be able to compare overall management of thalassemia patients in Bulgaria with other countries. Moreover, this experience could be used as a model for starting registries for other rare diseases in the country.

Initial data, based on consensus of the national expert group for thalassemia major show that currently there are 211 patients treated at 7 regional centres – Sofia (72), Plovdiv (54), Stara Zagora (37), Varna (23), Burgas (14), Pleven (11). This project is currently awaiting its final approval through the Commission for personal data collection and expected to start effectively in September 2009.

This information is distributed free of charge, respecting the correct and complete citation of the original source.

Last modification: 10:48 01.08.2008