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ПРОЕКТИ НА БЪЛГАРСКА АСОЦИАЦИЯ ЗА ПРОМОЦИЯ НА ОБРАЗОВАНИЕ И НАУКА (БАПОН)

National registry of patients with thalassemia major – initial data (January 2010)

On 28 October 2009, BAPES was officially given the status of data privacy administrator of rare diseases registries by the Commission for Protection of Data Privacy. After that, the collection of epidemiological data for the project “National registry of thalassaemia major patients in Bulgaria” started. Initial information shows that by January 2010 there are 208 thalassaemia major patients in Bulgaria, who are treated in seven centres – Sofia (95), Plovdiv (36), Varna (26), Burgas (14), Stara Zagora (19), Pleven (18). Currently, the data is being analyzed and the results will be published in March 2010.

The project is implemented as a result of the common work and cooperation between BAPES, ICRDOD, Medical Centre „RareDis“, Bulgarian Scientific Society of Clinical and Transfusion Hematology and regional transfusion hematology centres in Bulgaria. Its main purpose is to create an epidemiological tool for identifying and tracking each patient. The registry will help doctors, researchers and health authorities to determine prevalence, morbidity, long-term outcomes and quality of life of the Bulgarian patients with thalassemia major. Moreover, this experience can be used as a model for creation of registries for other rare diseases.

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Last modification: 16:23 15.01.2010
