

<https://www.czpz.org/info/index.php/normativni-aktove/podzakonovi-normativni-aktove/1364-naredba-redkite-zabolavania>

At the above showed link you will find **REGULATION No. 16 OF 30 JULY 2014 ON THE CONDITIONS AND PROCEDURE FOR REGISTRATION OF RARE DISEASES AND FOR EXPERT CENTERS AND REFERENCE NETWORKS FOR RARE DISEASES**. This regulation determines:

1. the conditions and procedure for registering rare diseases;
2. the procedure for establishing, designating and operating expert centers and reference networks for rare diseases;
3. the conditions and criteria for participation of medical institutions in European reference networks.

Information about the **RARE DISEASES COMMISSION**, established at the Ministry of Health:

<https://www.mh.government.bg/bg/ministerstvo/komisii/komisiya-po-redki-zabolyvaniya>

The Commission assists the Minister of Health and the Director of the National Center for Public Health and Analysis by: Expresses opinions to the Minister of Health on proposals for including diseases in the list of rare diseases established in the Republic of Bulgaria; Sends proposals to the Director of the National Center for Designation of Expert Centers and Reference Networks for Rare Diseases; Evaluates the activities of the National Registry of Patients with Rare Diseases; Evaluates the activities of the expert centers and reference networks for rare diseases; Prepares opinions and sends proposals to the Ministry of Health, the National Health Insurance Fund, the Executive Agency for Medicines, the National Council for Prices and Reimbursement of Medicinal Products, higher education institutions, medical institutions and other bodies and persons on issues of prevention, diagnosis, treatment, follow-up, rehabilitation and medical expertise of rare diseases, including medical training in the field of rare diseases.

It cooperates with authorities in the Member States of the European Union, other countries and international organizations that carry out activities in the field of rare diseases. It also carries out other activities specified by Regulation No. 16 of 2014 on the conditions and procedure for registering rare diseases and on expert centers and reference networks for rare diseases.

<https://ncpha.government.bg/index/131-registur-na-ekspertnite-centrove-po-redki-zaboliavania.html>

The above link is for **REGISTER OF EXPERT CENTRES FOR RARE DISEASES IN BULGARIA**, containing information about: i) Hospital where the Expert centre is located; ii) Head of the centre; iii) Designation date; iv) Phone and email contacts; v) List of included disorders with their ICD-10 and ORPHA codes

RECORDS OF DISEASES INCLUDED IN THE LIST OF RARE DISEASES IN BULGARIA:

<https://ncpha.government.bg/index/132-dosieta-na-zaboliavania-vkliucheni-v-spisuka-na-redkite-zaboliavania.html>

Contains 171 diseases' records with the Definition of the disorder, Epidemiological data, Diagnostic criteria, Algorithms for disease' diagnostics; Algorithms for disease' treatment, monitoring, rehabilitation; suggestions for healthcare organization in relation to the disease; Scientific publication and own experience with affected patients.

SITE WITH THE NEWS FROM RARE DISEASES COMMISSION, including: Composition of the commission; Minutes of committee meetings; Register of expert centres for rare diseases in Bulgaria; Application for a disease proposal for inclusion in the List of Rare Diseases; Application for a designation of an expert centre for a rare disease:

<https://ncpha.government.bg/index/115-komisii.html>

With the Orders of the Minister of Health, since 2015 till now in the List of Rare Diseases in Bulgaria were included 274 rare diseases.

USEFUL LINKS

- [European portal for rare diseases Orphanet](#)
- [Genetic and Rare Diseases Information Center, National Institutes of Health, USA](#)
- [Information center for rare diseases and orphan drugs](#)
- [Directorate-General for Health and Food Safety \(SANTE\), European Commission](#)

- [European reference networks for rare diseases](#)

INFORMATION OF NATIONAL HEALTHCARE INSURANCE FUND FOR THERAPY OF RARE DISEASES

https://www.nhif.bg/bg/medical_requirements/transplant

SITE OF LABORATORY OF GENOMIC DIAGNOSTICS, ENGAGED IN GENETICS DIAGNOSTICS OF RARE DISEASES IN BULGARIA

<https://lgdbg.org/>