



GENETICS AND GENODERMATOSES

## EPIDEMIOLOGY OF INHERITED EPIDERMOLYSIS BULLOSA IN THE RUSSIAN FEDERATION IN 2014-2016

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**Objective:** to examine incidence and prevalence of inherited epidermolysis bullosa in the Russian Federation in 2014-2016.

**Materials and methods:** questionnaire survey of head doctors of state dermatological medical organizations of 85 territorial entities of the Russian Federation.

**Results:** the data were collected from 70 (for 2014) and 60 (for 2015-2016) of 85 territorial entities of the Russian Federation. It was reported about a total of 438, 404, and 417 patients with inherited epidermolysis bullosa in 2014, 2015 and 2016 respectively. The prevalence estimate was 3,6 per 1 million population in 2014, 3,8 - in 2015, and 3,9 - in 2016.

During this period the peak prevalence rates were reported in three republics of the North Caucasian Federal District. In 2014 the prevalence rate in Dagestan and Chechen Republics was 19,82 and 14,72 per 1 million population respectively. In 2016 the prevalence rate in Ingushetia Republic was 14,68 per 1 million population.

High prevalence of inherited epidermolysis bullosa was also revealed in Mordovia Republic (21,03 in 2015 and 2016), Tambov (15,31 in 2016) and Tomsk (17,72 in 2014) regions.

Only 7 territorial entities in 2014 and 4 territorial entities in 2015-2016 reported of no patients with inherited epidermolysis bullosa.

The number of newly diagnosed cases of inherited epidermolysis bullosa was 23 in 2015 and 35 in 2016. Diagnosis was established within the first year of life only for 14 (61%) and 19 (54%) of these patients. The corresponding incidence rate was 9,96 and 13,90 per 1 million live births in 2015 and 2016 respectively.

**Conclusion:** due to limitations of the survey the prevalence estimates of inherited epidermolysis bullosa in the Russian Federation are lower than those reported in literature for European countries. Still the incidence rates are within the ranges reported.

