

Incidence and prevalence of growth hormone deficiency in the Russian Federation – an analysis of two registries

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Objectives:

To determine the prevalence and incidence of GHD in children and adults in Russia

Growth hormone (GH) therapy for growth hormone deficient (GHD) children in Russia is
 ➤ fully state funded
 as part of the “**Seven high expenditure diseases**” (7HED) federal program.
 Thus, it is important to thoroughly understand the disorder, including the epidemiology.

In Russia, there are two parallel functioning registries:

- the official federal medical statistics (OFMS) which provides purely statistical information
- the 7HED registry which must contain a given patient's data to provide him/her with free treatment

Methods:

Statistical data analyzed:

- 1) Official Federal Medical Statistics (year 2015)
 - 2) 7 High Expenditure Diseases Registry (year 2015)
 - 3) Official federal Russian population statistics – age and gender (year 2015)
- Both medical registries collect data from the whole of the country

| Prevalence of GHD in different population groups | Federal Medical Statistics | Rare disease Registry | Comparison |
|--|----------------------------|-----------------------|----------------------------------|
| Total population | 1:20200 | 1:21900 | OFMS > Registry 7,6% |
| Adults | 1:37300 | 1:46300 | OFMS > Registry 19,33% |
| Children | 1:6950 | 1:6860 | OFMS < Registry 1,3% |
| Boys / Girls | --- | 2,52:1 | --- |
| Children / Teens | 1:1,57 | --- | --- |
| Incidence of GHD in children | Federal Medical Statistics | Rare disease Registry | Comparison |
| Total | 1:40800 | 1:48500 | OFMS > Registry 15,91% |
| Boys/ Girls | --- | 2,42:1 | --- |

Results:

According to OFMS

- Prevalence of GHD among children is **1:6950**
- Prevalence of GHD among adults was shown to be **1:37300**

The 7HED registry shows similar, yet slightly different results:

- Prevalence of GHD among children is **1:6860** (difference of 1,2%)
- Prevalence of GHD among adults is **1:46300** (19,4%)

Out of the 4132 children registered, 1173 were girls and 2959 were boys,

- **boys:girls ratio 2,52:1**
- child (age 0-14) to teen (age 15-17) **ratio of 1:1,57**

The incidence of GHD for children varies between

- **1:40800** children per year (OFMS) and **1:48500** children per year (7HED)

In several regions of Russia, the prevalence/incidence of GHD among children turned out to be unusually high (1:1155 in total and 1:7867 per year)

or low (1:30490 in total and no new cases at all in 2015) in comparison to the average.

Conclusions:

Considering how dependent GH therapy outcome is on a timely diagnosis our suggestion was to

- widen the functional ability of the 7HED Registry by
- adding clinical data, which would allow for a transformation of the registry into a fully functional tool for **GHD patients monitoring and therapy quality control**
- The discrepancies mentioned above, including the differences between the OFMS and the 7HED registries call for a clinical and organizational audit

Vorontsova M.V. "Treatment of GHD children with recombinant growth hormone: medical and economical aspects"

Vorontsova M.V. Incidence and prevalence of growth hormone deficiency in the Russian Federation according to the official medical statistics data and the growth hormone deficiency patients registry // Problems of Endocrinology. 2016. 62. № 4. C. 18-26.