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) 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

**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

**References:**

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