A 5-year follow-up of adults, with childhood-onset GH deficiency, 
treated with GENOTONORM® in France

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BACKGROUND

Growth hormone deficiency (GHD) is a rare condition caused mostly by pituitary disorders. Young adult patients with childhood-onset GHD whose growth hormone replacement therapy (GHRH) is discontinued exhibit negative metabolic and physiological effects, reversible through GHRH. Therefore, continuation of GHRH therapy without interruption is recommended for adolescents transitioning to adulthood by guidelines of the American Association of Clinical Endocrinologists and The Endocrine Society [1,2]. In GHD adults, benefits of GHRH have been shown in body composition, bone health, cardiovascular risk factors, and quality of life [2].

The aim of the present study was to report the characteristics and 5-year GHRH in adults with childhood onset GHD.


PATIENTS AND METHODS

KIMS is a large international pharmacoepidemiological registry monitoring long-term safety and clinical outcomes of GHRH (Genotropin®) in hypopituitary adults with GHD.

In France, KIMS was initiated in March 2003 and is open to:
- all adults receiving Genotropin®
- not treated patients, either because reimbursement was denied by the French health insurance system, the patient refused GHRH or stopped it.

KIMS was conducted in all French centers with at least one adult treated with Genotropin®.

All patients had to provide written informed consent for recruitment in the study.

Data were collected through case report forms until December 2010 and data entry has been web-based since. Data were monitored at the country level, and in the Stockholm centralized database.

All recorded study data were collected as part of patient routine clinical care. Timing of visits, Genotropin® dose and dose titration were at each treating physician/investigator’s discretion.

We report here the analysis of the 5-year follow-up of the subgroup of adults with childhood-onset GHD included between March 2003 and October 2006 in KIMS, in France.

The analysis is descriptive, median and inter quartile range are displayed.

RESULTS

Overall 120 adults with childhood-onset GHD were included, by 80 centers.

Upon inclusion in KIMS

Slightly more patients were males (64 (53.3%) males). Median age at inclusion in KIMS was 22 years (19 years; 30 years). All patients had severe GHD, associated with one or more other pituitary hormone deficiency in 104 (87%) patients.

Tumor size monitoring and tolerance

The percentage of patients with a Magnetic Resonance Imaging available at the visit tended to decrease over time, down to 5.1% at 5 years. Increase in pituitary tumor size was reported, 26 months after inclusion, in one female.

No new safety concern was reported.

CONCLUSION

The relatively weak prescribed doses may preclude highlighting long-term benefit of GHRH.