

# The German Acromegaly Register

## Surgical outcome in 400 patients

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### Introduction

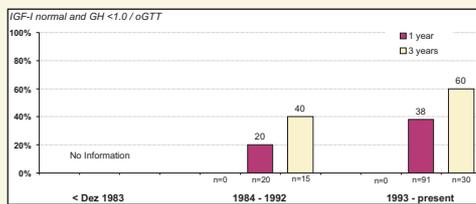
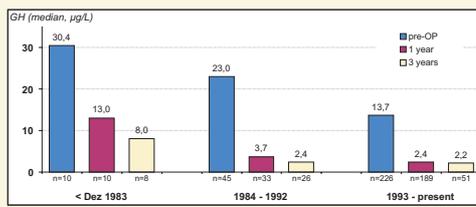
Acromegaly Registers are emerging as a useful tool for the study of large numbers of patients with this rare disease (1,2). The German Acromegaly Register performs a 10-year epidemiological study and aims to include all acromegalic patients in Germany. At the present time, patients are entered retrospectively. All new patients will be entered as they become diagnosed. Retrospectively and prospectively included patients will be followed with a backup of their data during a 10 year period. The Register aims to extract relevant data on diagnostic procedures, primary and secondary therapeutic strategies and their results, as well as on comorbidity and mortality. The German Register works in close collaboration with the UK Acromegaly Register and the new Austrian Acromegaly Register. The British software is used.

### Materials and Methods

Two trained nurses visit all centres in Germany and enter the available data into specially developed data sheets, thus ensuring uniform datasets from all different kinds of documentation. These data are then transferred into the database which is located in Berlin. Variations of patient numbers in the tables are due to non-availability of some data in patient documents at various time points. 502 patients from 18 centres were entered as of December 2003. Results from 400 operated patients are reported.

### Results 1

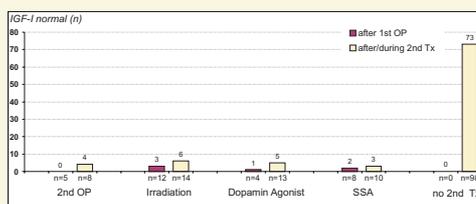
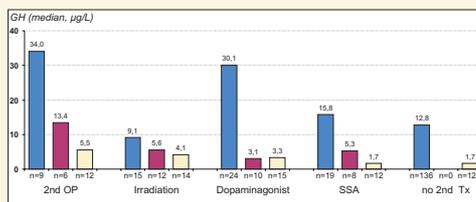
#### Operative results in different time periods



When the cure rate was defined as both GH<1.0 µg/L plus normal IGF-I concentration (3), it was only 38 % at 1 year postoperatively, even in the last time period. Cure rates were higher at 3 yrs, due to the effect of secondary treatment.

### Results 2

#### Analysis of secondary treatment effects one year after primary operation



Comparison of operative results in different time periods shows, that the median preoperative GH concentration decreased progressively from the first to the last time period, possibly due to improved diagnostic awareness and/or awareness of evolving treatment modalities. In parallel, operative results became remarkably better during consecutive time periods. However, the cure rate as defined by a GH <1.0 µg/L during an oral glucose load at 1 yr did not surpass 54%.

A detailed analysis of the choices of secondary treatment and their results shows that (1) secondary operation (2nd OP) as well as Somatostatin Analog (SSA) treatment are of considerable benefit, (2) radiation treatment (Rad) shows only a tendency towards improvement, as expected after a short period of time and (3) Dopamin Agonists (DA) have little if any effect on GH. However, subgroup numbers of patients are now mostly small.

### Summary

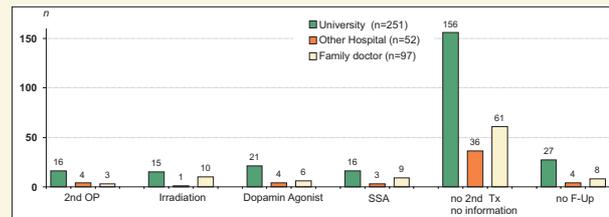
In 400 patients operative results improved over successive time periods, but remained unsatisfactory overall. Secondary operation and postoperative SSA analog treatment further reduced the GH concentration considerably, while irradiation (due to the short time period evaluated) and dopamin agonist (DA) treatment had little effect. The data are preliminary and are subject to the influence of biases, since they are based on only 503 out of an expected much larger number of patients. Nevertheless, they demonstrate the value of this epidemiological study and are expected to be useful for future improvement of diagnostic procedures and therapeutic choices.

### Outlook

At present (August 2004) the Register contains data from 1003 patients and will add 500 more patients - including follow-up data - each year. Up to 5000 patients are expected to be finally included. Comparison with the UK Acromegaly Register and the newly established Austrian Acromegaly Register will provide interesting insight into different health care systems.

### Results 3

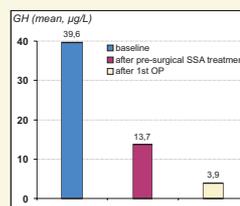
#### Distribution of patients according to treatment centres and choice of secondary treatment



We analyzed the distribution of patients who were cared for in (1) university outpatient centres, (2) other hospitals and (3) family doctors/specialists in endocrinology. The majority of the patients was registered from university outpatient departments (neurosurgical centres were not included, since they mostly return patients to the referring physician following surgery). Whether this distribution represents the overall picture in Germany, remains to be seen. It may at least partly be due to choice of evaluated centres during this early stage of the Register. There was no important difference in the choice of secondary treatment.

### Results 4

#### Pre-surgical SSA treatment



117 patients received pre-surgical SSA treatment. This represents a bias, due to the inclusion of some specialized centres in the early stage of data acquisition in the Register. However, in these patients pre-surgical medical treatment reduced GH in most patients, although less so than the following surgery. The mean GH concentration at diagnosis in this patient group was 39.6 µg/L, 13.7 µg/L at the end of SSA treatment and 3.9 µg/L postoperatively.

### References

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