

The German Acromegaly Register: Update and Results in 400 Operated Patients

H-J Quabbe, G Skrobek-Engel, H Franz, R Lohmann and the Participants of the German Acromegaly Register, Charité, Berliner Universitätsmedizin, Berlin, Germany

The German Acromegaly Register aims to extract relevant data on diagnostic procedures, primary and secondary therapeutic strategies and their results, as well as on co-morbidity and mortality. At present (10/2004) 1000 pts from 30 centers have been entered. Male/female ratio was 453/547. Distribution between centers was: 13 university (522 pts), 6 other hospitals (143 pts), 11 family doctors (335 pts). Time between 1st symptoms and diagnosis was unknown in 408 pts !!, >15 yrs in 65, 10-15 yrs in 110, 5-10 yrs in 145, <5 yrs in 272. Age at diagnosis was <20 yrs in 26 pts (14 m, 12 f) and >60 yrs in 103 pts (38 m, 84 f). Primary therapy consisted of surgery (OP) in 797 pts, irradiation (RAD) in 16 pts, a dopamin agonist (DA) in 67 pts and a somatostatin analog (SSA, intended as permanent therapy) in 43 pts. Preoperative SSA therapy was used in 181 pts (21.7% of operated pts). A preliminary analysis of 502 pts entered until 12/2003 was performed. It showed, that 400 pts had surgery as primary therapy (79,7%; including pts with preoperative SSA therapy for tumor volume reduction, not intended as permanent therapy). During consecutive time periods (<1983; 1984-1992; 1993-present) median preoperative GH decreased progressively, possibly due to improved diagnostic awareness and/or awareness of evolving therapy modalities (although changes in assay technology may also have contributed). In parallel, operative results (median postoperative GH) became also remarkably better. However, the cure rate at 1 yr was only 54% (GH nadir <1.0 µg/L oGTT) and 38 %. (GH<1.0 µg/L plus normal IGF-I), resp., even after 1993. An analysis of secondary therapy after primary OP shows that (1) 2nd OP as well as SSA are of considerable benefit, (2) Rad shows little improvement after 1 year (as expected at this short time period) and (3) DA have little effect on (median) GH. However, the data are preliminary, since subgroup numbers of patients are small and subject to the influence of biases, since the analysis is based on only 502 out of an expected much larger number of patients.