

The German Acromegaly Register: Results in 1000 Patients

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The Register aims to include data of all acromegalic patients in Germany. **Statistics:** At present (12/2004) 1000 pts from 30 centers have been entered. Sex (f/m) ratio 1.21. Distribution of centers: 13 university (522 pts), 6 other hospital (143 pts), 11 family doctor (335 pts). Time from 1st symptoms to diagnosis (Dx) <5 yrs in 27.2%, 5-10 in 14.5%, 10-15 in 11% and >15 yrs in 6.5%, (unknown 40.8%). Age at Dx (yrs): <20 in 26 pts, 20-40 in 374, 40-60 in 467 and >60 in 103 pts (unknown 30). Primary treatment (Tx): surgery (OP) 800 pts, irradiation (RAD) 16, dopamin agonist (DA) 67, somatostatin analog (SSA, intended as permanent Tx) 43, no Tx as yet 74 pts. **Results** (median values, GH in µg/L): Primary OP: GH was 16.4 before and 2.4 post-OP. Pre-OP SSA-Tx for volume reduction was given to 183 pts (21.7% of OP-pts). GH was 15.7 pre- and 2.0 post-OP with and 16.4 and 2.5 without pre-OP SSA-Tx. Post-OP GH<1.0 (GH-cure) was achieved in 193/800 pts (24.1%) and (GH>1.0 in oGTT, but random GH<2.5 [GH-control]) in 72 pts (9.0%). Results were better in micro- (N=83) than extrasellar macro-adenomas (N=195) with GH-cure in 49.4% and 24.0% resp. Before 1984, from 1984-1992 and from 1993 to present 109, 205 and 486 pts were operated. GH-cure was achieved in 3.9%, 15.1% and 32.5% and GH-control in 1.9%, 8.8% and 10.3% resp. Paired data were analyzed from 185 pts (OP 1993 to present) for criteria "GH<1.0 in oGTT plus IGF-I normal" (GH/IGF-cure) and GH-control: 41.6% GH/IGF-cure, 9.2% GH-control (94 pts in all). The rates were 66.7% and 4.2% for microadenomas and 29.8% and 14.0% for extrasellar macroadenomas. Of the 94 pts GH/IGF-cured or GH-controlled, 41 had pre-OP SSA-Tx for volume reduction and 53 had not. Primary RAD (16 pts) reduced GH from basal 4.2 to 2.9 at 1 yr after Tx. Primary DA (67 pts) reduced GH from basal 12.6 to 6.1 and primary SSA (43 pts) from basal 8.3 to 2.8 after 1 yr. Secondary Tx was given to 415 pts following primary OP, but only data from 110 pts could as yet be evaluated after/into one yr of 2nd Tx: GH was <1.0 or <2.5 following repeated OP (n=25) in 5 and 2 pts (28% in all); RAD (n=21) in 3 and 7 (48% in all), DA (n=43) in 8 and 6 (33% in all) and SSA (n=63) in 10 and 15 (40% in all). **Conclusions:** OP-Tx-results remain unsatisfactory. The register provides a basis for further analysis and improvement. The data are preliminary, since subgroup numbers are small and analysis is based on only approx. 20% of the expected total number of pts.