

The German Acromegaly Register

Quabbe H.-J.*, Franz H., Skrobek-Engel G., Lohmann R. and the Participants of the German Acromegaly Register Abstract Nr. V62 48. Symposium der DGE, 03.03.2004 - 06.03.2004 , Dresden

The German Acromegaly Register is an initiative of the Pituitary Working Group of the German Endocrine Society (DGE). Formally established in January 2003 by the Board of the DGE, long-term financial support is guaranteed by a sponsor's contract between Novartis Pharma GmbH and DGE (April 2003). The Register cooperates closely with the United Kingdom Register. Aims : Acromegaly is a rare disease (incidence 3-4/mill/year, prevalence 40-70/mill; up to 5700 pts in Germany; approx. 300 new pts/yr. Diagnostic/therapeutic possibilities have dramatically improved, but treatment results remain unsatisfactory due mainly to belated diagnosis. Most publications are from experienced centres and may not represent the true overall situation. A database of sufficient epidemiological strength is necessary in order to (1) document co-morbidity and mortality, (2) provide data on diagnostic and therapeutic procedures/effectiveness, (3) enable comparison of procedures in different centres and (4) with the whole dataset, (5) provide information for patient support groups/interaction with health care providers, (6) enable comparison of the German and the UK data and possibly – in a later stage – with other European countries. The Register has at present 68 participants. Data acquisition is done by two trained nurses, who visit the individual centres, assuring a high degree of correct and uniform data entry. The Registry uses the UK electronic database to assure comparison between two countries with different health care systems. Data of 500 pts will be presented at the DGE Symposium. Members of the steering board: M. Buchfelder/Göttingen, B. Gerbert/Dresden, S. Petersenn/Essen, H.-J. Quabbe/Berlin (chairman), M. Reincke/Freiburg. Data acquisition and logistics by Lohmann & Birkner Health Care Consulting GmbH, Berlin. Once yearly all participants will be invited to a general meeting. All Health Care Providers with acromegaly patients are invited to participate.