

## **The German neuroendocrine tumor (NET) registry: Quality of Data Documentation**

U. Plöckinger, H.Franz, R. Lohmann, B.Wiedenmann and the members of 13 NET-Registry Centres

### **Introduction:**

In 9/2003 the German NET-Registry was introduced. With 13 centres and 904 pts included, we analysed the quality of data documentation in patient's files of 13 active university centres.

### **Methods**

Data were retrieved from the German NET-Registry database. Data were analysed according to the documentation of diagnosis, histology, imaging, biochemical investigations and therapy.

### **Results:**

**Diagnosis:** Classification [foregut/midgut/hindgut/cancer of unknown primary(CUP)]was available for 896 (99%), localization of the tumor (specific organ or CUP) for 780 (86%) and functionality for 222 (24%) pts. MEN-1 was documented in 30 (3.3%), excluded in 60 (6,7%) and not documented in 812 (90%).

### **Histology:**

Histological findings were documented in 529 (66%), while immuno-histochemical neuroendocrine markers were documented in 394 (44%), mitotic indices in 272 (34%), WHO classification of the tumor in 170 (21%), and invasive behaviour in 106 (13%) of the pts.

### **Imaging:**

Somatostatin receptor scintigraphy (SRS) was done in 566 (62%). Tumors in 349 pts without SRS were classified as foregut (60%), midgut (24%), hindgut (5%) and CUP (7%) resp. Imaging (sonography, CT, MRT) was documented 1.7 times per pt in small, 1.8 times in large, 2.8 times in very large and 3.5 times per pt. in medium centres.

**Biochemical investigations** were documented at least once per pt. in 619 (69%).

**Therapy (tx)** The first tx was surgery in 651(72%), medical tx in170 (19%), radioreceptor tx in 10 (1%), or ablative tx in 8 (0,9%) pts. 65 (7%) pts had no documented tx. Pts were treated with up to 6 different tx. The number of tx correlated positively with, while the type of therapy was unrelated to the number of patients treated per centre.

### **Discussion**

Documentation was almost complete with respect to diagnosis. However, important histological data were poorly documented, as were some imaging procedures considered essential in these tumors. Documentation of different therapies was highest in very large centres. The number of pts per centre did not significantly influence the quality of the documentation.