



The German neuroendocrine tumour (NET) registry: Centres and Epidemiology of neuroendocrine tumours

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Introduction NET are rare. No epidemiological data of NET are available in Germany. Thus, the AG NET/DGE introduced the German NET Registry in 9/2003. First data of the registry are presented.

Methods A NET specific database was constructed. 5903 specialists (gastroenterology, endocrinology, oncology) were invited to participate. Centres (C) had to treat at least 5 pts with NET to be included in the database. C are grouped according to the number of pts treated: small (SC), medium (MC), large (LC), very large (VLC): 5-10/11-20/21-100/>100 pts, resp. C are visited by 2 study nurses, patient files are analysed and data transferred to the database. Only pts with a diagnosis of NET after 1.1.1999 are included.

Results As of 10/2006 136 C participate, 13 C have already been visited. All are university clinics (Fig 1). Pts are cared for by specialists of internal medicine, surgeons or by both specialities at one C (Fig 2) 904 pts (452 f, 57 ys (13-87) (median, range) at diagnosis are evaluated. MEN-1 pts (N=30) are younger at diagnosis [45 ys, (24-61), MEN-1 vs sporadic NET, $p<0.0001$]. Tumours are classified as foregut, midgut, hindgut, cancer of unknown primary (CUP) and no classification available (Fig 3, Table 1). Functioning tumours are identified in 222 (25%) pts (Table 2). Mean follow-up is 1y (0-7), with more than 1 visit/pt documented in 72%. Mortality is 8 % during follow-up, with a median survival time of 1 y (0-5) (Fig 4 and 5).

Conclusion The German NET-registry is an effective tool to analyse epidemiological data of NET pts. However, as the number of pts included is still rather low, definite data await the inclusion of larger numbers. In addition, the data base reflects the structure of care, provided in Germany. Despite the observational character of the NET-registry changes are already implemented with respect to the organization of patient care. Further information: www.net-registry.org

Fig 1 Participating active centres (N=13) and percent of pts. in each centre (total N=904)

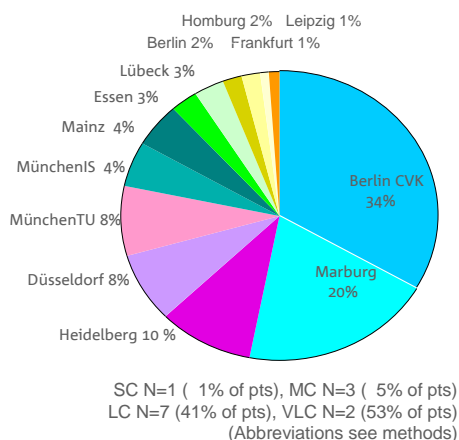


Fig 2 Participating centres N=136 according to medical specialities

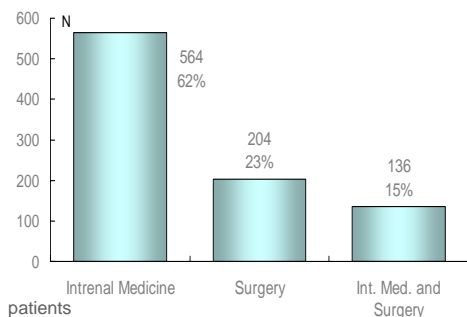


Table 1 Neuroendocrine cancer of unknown primary (CUP)

CUP	N=108	% of all CUP
Foregut	12	11%
Midgut	4	4%
Hindgut	----	
Unknown	92	85%

Fig 3 Classification of neuroendocrine tumours (N=904)

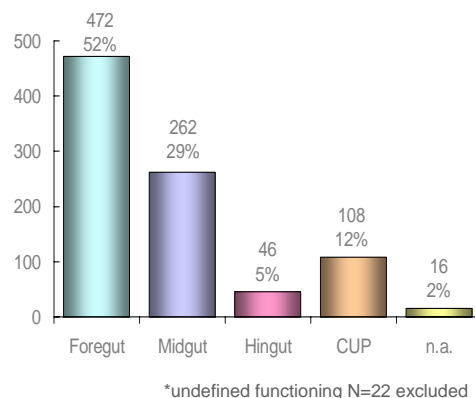


Table 2 Functioning tumours

Functioning tm	N=222*	Percent of Fore-/Midgut Tm
Insulinoma	64	13%
Gastrinoma	37	8%
Glucagonoma	9	2%
VIPoma	4	0,8%
Somatostatinoma	3	0,6%
Cushing's Syndrome	1	0,2%
Atypical Carcinoid S	1	0,2%
Carcinoid Syndrome	103	38%
Functioning (?)	22	2%

Fig 5 Follow-up (N=904)

