

Czech Registry of Neuroendocrine Neoplasms (NEN)

Jaroslava Barkmanova¹; Eva Sedlackova¹; Hana Honova¹; Oldrich Louthan²;
Pavel Vitek³; Jiri Novak⁴; and Jan Muzik⁵

¹Dept. Of Oncology, General University Hospital and 1st Faculty of Medicine, Charles University, U Nemocnice 2, Prague 2, 128 08, Czech Republic

²Dept. Of Internal Medicine, General University Hospital and 1st Faculty of Medicine, Charles University, U Nemocnice 2, Prague 2, 128 08 Czech Republic

³Institute of Radiation Oncology and Proton Therapy Center Czech Na Truhlance 100 and Budinova 2437/1a, Prague 8, 180 00 Czech Republic

⁴Masaryk Memorial Cancer Institute, Zlutý kopec 543/7, Brno, 60200, Czech Republic

⁵Institute of Biostatistics and Analyses, Masaryk University, Kamenice 126/3, Brno, 625 00, Czech Republic

Background: The aim of "Cooperative Group for Neuroendocrine Neoplasms", is to consolidate diagnostic and therapeutic procedures, establish consulting centers, promote and conduct the second reading of histological samples and create a registry of NEN in the Czech Republic.

Why NEN registry?

NEN belong into the category of rare tumors. Any empirical data on the course of NEN are affected by a potential bias for the following reasons:

- the majority of NEN remains undiagnosed
- patients with localized NEN after resection are not referred to an oncologist
- long duration course of differentiated NENs with another causes of death
- evaluation of therapeutic effects in advanced disease with long course requires specific criteria
- standard effective treatment of disease symptoms
- few standards in antineoplastic treatment
- minimal data available from clinical studies

Methods: For the past 5 years, registry of patients with NEN in all localizations has been kept. It collects:

- identification data
- basic demographic data
- data of basic diagnosis, therapy and current condition

The registry is kept by the IBA Brno with secured access, electronical insert by an interactive form. Access is provided to verified contributors, authorized to possess data from patients with NEN.

Results: In June 2013, data of 998 patients were entered into the registry. We present data of all valid patients. There are apparent additional positive "secondary" trends documented by case reports rather than by statistical evaluation:

- an increasing number of diagnoses adjusted, based on the second reading of the sample; there is an increasing number of rare variants of NEN
- growing number of patients with completed staging, with disease course monitoring based on biomarkers and imaging examinations.

Czech registry of NEN, fully compatible with the forthcoming European registry, is an important tool for high quality (standard) diagnostics and therapy.