

## Duration and Type of Presenting Symptoms in Patients with Neuroendocrine Tumor (NET)

Monica Ter-Minassian<sup>1,2</sup>; Jennifer A. Chan<sup>1</sup>; Susanne M. Hooshmand<sup>1</sup>; Lauren K. Brais<sup>1</sup>; Anastassia Daskalova<sup>1</sup>; Rachel Heafield<sup>1</sup>; Laurie Buchanan<sup>1</sup>; Zhi Rong Qian<sup>1</sup>; Xihong Lin<sup>3</sup>, David C. Christiani<sup>2</sup>; Matthew H. Kulke<sup>1</sup>

<sup>1</sup>Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA 02115

<sup>2</sup>Department of Environmental Health

<sup>3</sup>Department of Biostatistics, Harvard School of Public Health, Boston MA 02115

**Background:** Delayed diagnoses are reported to be common in NET patients (pts). Few studies have prospectively characterized the type and duration of presenting symptoms in this pt population.

**Methods:** Of 937 NET pts enrolled in a prospective study, 717 completed questionnaires regarding the type and duration of symptoms prior to diagnosis. We summarized symptoms in the cohort overall and in subgroups of pts with small bowel carcinoid (SBC), pancreatic NET (panNET), or other NET. Estimation of time from symptom onset to diagnosis was based on analysis of 213 symptomatic patients who completed questionnaires within 6 months of diagnosis.

**Results:** The cohort comprised 289 SBC, 158 panNET and 270 other NET; 400 pts had localized and 316 had metastatic disease. 76% (67% localized and 84% metastatic) of the pts were symptomatic prior to diagnosis. Abdominal pain was the most common single complaint, and led to diagnosis in 39% SBC, 27% panNET, and 17% of other NET pts. Diarrhea and flushing were reported in only 12% and 7% of SBC and 13% and 0% of panNET patients, respectively. 24% (20% SBC, 20% panNET, 30% other NET) had incidental diagnoses. Incidental diagnosis was more common in pts with localized disease (33%) than in those with metastases (16%). The median duration of symptoms prior to diagnosis was 2.69 months (2.92 mos SBC, 3.41 mos panNET, 2.10 mos other NET). However, the reported range was broad, and the mean duration of symptoms was 11.3 mos (14.1 mos SBC, 10.9 mos panNET and 7.8 mos other NET).

**Conclusion:** Our study suggests that abdominal pain is the most common symptom leading to diagnosis of gastrointestinal NET. While the majority of NET patients appear to be diagnosed less than 3 months after symptom onset, prolonged symptom duration prior to diagnosis remains a prominent feature of this disease.