

## C19

### Neuroendocrine Tumors in Children and Young Adults: Incidence, Survival, and Prevalence in the United States

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**Background:** Neuroendocrine tumors (NET) arising from the diffuse endocrine system are thought to be quite rare in children and young adults. However, a surprising number of young people have been referred to our neuroendocrine tumor clinic and the NCI has targeted NET as a high priority for development of new diagnostic and therapeutic options. This analysis of the SEER database was undertaken to determine the incidence, prevalence, and survival of NET in young people. Their incidence, prevalence, and survival were compared with neuroblastoma, a related pediatric malignancy arising in the neural crest.

**Methods:** The SEER data were obtained from 9 standard SEER registries for the diagnosis years of 1975 to 2004 using SEER\*Stat version 6.4.4. ICD-9 codes related to neuroendocrine tumors and to neuroblastoma were characterized as to patient age, gender, racial and ethnic background, stage, grade, histology, incidence, survival, and prevalence.

**Results:** Neuroendocrine tumors occur more often in females among children and young adults with the most common sites being bronchial, ovarian, and breast. The overall incidence of neuroendocrine tumors was lower than for neuroblastoma in the age range 0-30 years. However, the 30 year limited prevalence of neuroendocrine tumors in the 9 SEER registries was 698 compared to 881 for neuroblastoma. This extrapolated to over 7000 children and young adults with neuroendocrine tumors across the United States. Survival rate of young people with neuroendocrine tumors declined from 84% in 1975-1986 to 80% in the 1987-2004 era.

**Conclusions:** These results indicate that neuroendocrine tumors constitute an unrecognized cancer threat to children and young adults. Survival of children and young adults with neuroendocrine tumors has decreased over the past 30 years in the United States. We recommend the establishment of centers of care for children and young adults diagnosed with neuroendocrine tumors with the expectation that earlier diagnosis coupled with targeted therapies will decrease the incidence of metastatic disease and improve survival.