Spotlight on possible link between pancreatic tumors & TSC

Researchers continue to study pancreatic neuroendocrine tumors (PanNETs) associated with tuberous sclerosis complex. PanNETs are a rare type of tumor that may be malignant or benign.

The pancreas is a small gland located behind the stomach and plays an important role in digestion and hormone function. Pancreatic lesions, which can be seen by abdominal MRIs, have been assumed to be benign cysts or small angiomylipomas that do not require immediate attention. However, PanNETs have been documented in some people with TSC, and researchers are wondering whether many of these TSC-associated pancreatic lesions are PanNETs rather than cysts or angiomylipomas.

In a 2012 paper, researchers at Massachusetts General Hospital (MGH) in Boston reported results from their retrospective study of pancreatic lesions and PanNETs. What was found? They reviewed abdominal imaging on 219 patients followed at the Herscot Center for TSC at MGH. Nine of the 219 patients had a pancreatic lesion. One patient had two lesions, and the other 8 had a solitary lesion. They also reviewed pathology records for all PanNET cases at MGH from 1977 to 2011, of which 6 were associated with TSC. They found 12 more TSC-associated PanNET cases reported in the literature between 1959 and 2009. The average age of the 18 TSC-associated PanNET cases was 26 years compared to 56 years in the 168 non-TSC PanNET cases at MGH. The researchers were not able to assess the risk of malignancy because of the small number of cases and lack of long-term follow-up.

The important takeaway from this study? Early detection from more complete abdominal imaging should include the pancreas rather than the standard renal imaging. Talk to your specialists and continue scanning.

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