



Tuberous Sclerosis Alliance

Adults with TSC

February 2019

Volume 36

Because rare diseases really aren't that rare.

#IAMTSC



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 angiomyolipomas 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 angiomyolipomas.

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 lesions. 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.

--- *Clinical Genetics* 2012; 82:558-563. Short Report: *Pancreatic neuroendocrine tumors in patients with tuberous sclerosis complex.* Larson AM, Hedgire SS, Deshpande V et al.

2019 REGIONAL TSC & LAM CONFERENCE SERIES

The Tuberous Sclerosis Alliance and The LAM Foundation are partnering to present five innovative educational conferences in 2019. These free, one-day conferences will deliver the most current information about scientific and clinical advancements in tuberous sclerosis complex (TSC) and lymphangioleiomyomatosis (LAM) and will feature local and national experts in both conditions. Additionally, speakers from The Arc, Child Neurology Foundation and MassMutual will discuss transition issues for individuals with TSC.

Please mark your calendar for the event nearest to you and join us to meet regional experts and other families and individuals from your area. The conferences will offer three separate educational tracks that focus on: Pediatrics (Track 1), Transition Topics (Track 2) and an Adult Track with sessions specific to LAM and TSC (Track 3).

BOSTON, MA APRIL 13, 2019
ST. LOUIS, MO JUNE 15, 2019
CHICAGO, IL SEPTEMBER 7, 2019
ATLANTA, GA SEPTEMBER 21, 2019
LOS ANGELES, CA NOVEMBER 2, 2019

Adult Resources



TUNE IN

Jill Woodworth hosts TSC Talks! – a podcast devoted to all things tuberous sclerosis complex. She aims for honest discussions of what it is like for those diagnosed. She seeks to lessen the fear that can accompany TSC and to share valuable information for the medical and scientific community. Tune in on Stitcher or Spotify and be sure to follow TSC Talks! on Facebook so you won't miss an episode.

CONSIDER VOLUNTEERING

The TS Alliance seeks volunteers to facilitate local connections for those affected by TSC, raise revenue and increase awareness. There are several ways to participate, including TSC Connect, the Government Action Team and the Junior Leader Program.

Find out more at <https://www.tsalliance.org/volunteer>

You may also contact Dena Hook at: dhook@tsalliance.org or 1-800-225-6872, ext. 215.