

## Surveillance Recommendations for TSC

ORGAN SYSTEM	PROCEDURE	NEWLY DIAGNOSED OR SUSPECTED TSC	ALREADY DIAGNOSED WITH TSC	
<b>BRAIN</b>  	MRI with & without gadolinium (contrast)	✓	Every 1-3 years up to age 25 Periodically as adults if SEGAs present in childhood	
	Electroencephalogram (EEG)	✓	Routine EEG determined by clinical need Video EEG when seizure occurrence is unclear or when unexplained behavioral/neurological changes occur	
	TAND checklist	✓	At least annually	
	Comprehensive evaluation for TAND	If warranted by TAND checklist analysis		At key development time points, years: 0-3, 3-6, 6-9, 12-16, 28-35, and as needed thereafter
	Educate parents to recognize infantile spasms	Counsel parents of infants*		N/A
<b>KIDNEYS</b>  	Blood pressure	✓	Annually	
	Abdominal MRI	✓	Every 1-3 years	
	Glomerular filtration rate (GFR) test	✓	Annually	
<b>LUNGS</b>  	Clinical screening for LAM symptoms**	✓	At each clinic visit	
	Pulmonary function test and 6-minute walk test	In all females age 18 or older; in adult males only if symptomatic	Annually if lung cysts detected by high resolution computed tomography (HRCT)	
	High resolution computed tomography (HRCT) of chest	✓	Every 2-3 years if lung cysts detected on HRCT; otherwise every 5-10 years	
	Counsel on risks of smoking and estrogen use	In adolescent and adult females	At each clinic visit for individuals at risk of LAM	
<b>HEART</b>  	Fetal echocardiography	Only if rhabdomyomas identified by prenatal ultrasound	Not applicable	
	Echocardiogram	✓	Every 1-3 years if rhabdomyoma present in asymptomatic children; more frequently in symptomatic individuals	
	Electrocardiogram (ECG/EKG)	✓	Every 3-5 years; more frequently if symptomatic	
<b>EYES</b> 	Complete eye exam with dilated funduscopy	✓	Annually if lesions or symptoms identified at baseline	
<b>SKIN</b> 	Detailed skin exam	✓	Annually	
<b>TEETH</b>  	Detailed dental exam	✓	Every 6 months	
	Panoramic radiographs of teeth	If age 7 or older	At age 7 if not done previously	
<b>OTHER</b> 	Genetics consultation	Obtain 3-generation family history	Offer genetic testing of TSC1/TSC2 and counseling if not done previously in individuals of reproductive age	

\*Treat infantile spasms with vigabatrin as first-line therapy. Adrenocorticotropic hormone (ACTH) can be used as a second-line therapy if vigabatrin treatment is unsuccessful.

\*\*Evaluate for LAM when symptoms such as unexplained chronic cough, chest pain, or breathing difficulties are present including exertional dyspnea and shortness of breath