## Surveillance and management recommendations for newly diagnosed or suspected tuberous sclerosis complex (TSC)

<table>
<thead>
<tr>
<th>Organ System or Specialty Area</th>
<th>Recommendation</th>
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| Genetics                      | - Obtain three-generation family history to assess for additional family members at risk of TSC  
- Offer genetic testing for family counseling or when TSC diagnosis is in question but cannot be clinically confirmed |
| Brain                         | - Perform magnetic resonance imaging (MRI) of the brain to assess for the presence of tubers, subependymal nodules (SEN), migrational defects, and subependymal giant cell astrocytoma (SEGA)  
- Evaluate for TSC-associated neuropsychiatric disorder (TAND)  
- During infancy, educate parents to recognize infantile spasms, even if none have occurred at time of first diagnosis  
- Obtain baseline routine electroencephalogram (EEG). If abnormal, especially if features of TAND are also present, follow-up with a 24-hr video EEG to assess for subclinical seizure activity |
| Kidney                        | - Obtain MRI of the abdomen to assess for the presence of angiomyolipoma and renal cysts  
- Screen for hypertension by obtaining an accurate blood pressure  
- Evaluate renal function by determination of glomerular filtration rate (GFR) |
| Lung                          | - Perform baseline pulmonary function testing (pulmonary function testing and 6-minute walk test) and high-resolution chest computed tomography (HRCT), even if asymptomatic, in patients at risk of developing lymphangioleiomyomatosis (LAM), typically females 18 years or older. Adult males, if symptomatic, should also undergo testing  
- Provide counsel on smoking risks and estrogen use in adolescent and adult females |
| Skin                          | - Perform a detailed clinical dermatologic inspection/exam |
| Teeth                         | - Perform a detailed clinical dental inspection/exam |
| Heart                         | - Consider fetal echocardiography to detect individuals with high risk of heart failure after delivery when rhabdomyomas are identified via prenatal ultrasound  
- Obtain an echocardiogram in pediatric patients, especially if younger than 3 yr of age  
- Obtain an electrocardiogram (ECG) in all ages to assess for underlying conduction defects |
| Eye                           | - Perform a complete ophthalmologic evaluation, including dilated funduscopcy, to assess for retinal lesions and visual field deficits |