

## Introduction

Tuberous Sclerosis Complex (TSC), also called Bourneville's Disease, is a relatively rare genetic disorder that causes benign (non-cancerous) tumors to grow in several areas of the body. The disease does not affect everyone the same way. Tumors vary from person to person with regard to number, location, and severity, and the effects of the disease range from mild to severe and debilitating. Incidence estimates range from one out of every 6,000 to one out of every 30,000 people world-wide. Approximately one million people have TSC; about 50,000 of them in the USA. Treatments vary depending on what areas of the body are affected, and a large aspect of care involves observation and imaging in order to monitor for changes in the size and number of tumors. The tumors in TSC are typically tough and fibrous. There is currently no cure.

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## Genetics

A baby receives 23 chromosomes from each parent, resulting in a total of 46. Therefore, every cell in the human body (except for sperm and egg cells, each of which has 23) contains 46 chromosomes. On each chromosome there are numerous genes, varying from hundreds on some chromosomes to literally thousands on others. The genes are like blue prints because they tell the cells what to become and how to function. This is why people are tall or short, have green eyes or blue eyes, tend to be clumsy or athletic, and so on. Sometimes problems occur with the genes, and a person may be born with a disease. This is the case with Tuberous Sclerosis Complex.

Because of advanced research techniques, we have been able to identify many of these genes and discover how they influence our health. One of the genes, known as TSC1, is found on Chromosome 9; the other is known as TSC2 and is found on Chromosome 16. Both of these genes help to control how cells grow and divide in the human body. You might say they are like police officers that regulate traffic and determine how many cars are allowed to pass through an intersection. Sometimes genes develop abnormally (called "genetic mutations") and fail to do the job they were supposed to do. This is exactly what happens in TSC. Mutations may develop on TSC1, on TSC2, or on both. The mutations on these genes can vary greatly in terms of type and extent. A diagnosis of TSC is made by the presence of a combination of different major and minor physical features of the disease. There is now also genetic testing available to determine if a person has a mutation of TSC1 or TSC2.

If either parent has TSC, there is a 50% chance that the child will get it. This happens in about one-third of the cases. In the other 66%, a spontaneous, unpredictable mutation may occur at conception or during the embryonic stage. Therefore, it is virtually impossible to tell who will or will not develop the disease.

## Manifestations

TSC can vary greatly in its presentation from person to person. In some, tumors so severely impair organ function that the disease is fatal; in others, it may be only a cosmetic problem. Most people with the disease fall somewhere in between. Generally, the tumors are non-cancerous (rarely, persons can develop cancerous tumors called “Hamartoblastomas”) and can appear at any time during one’s lifespan, although the majority of persons who develop symptoms do so between two and six years of age. Some have symptoms at birth and others do not develop any until

adulthood. The age at which symptoms appear does not necessarily correlate with how severely a person is affected.

Individuals who are mildly-to-moderately affected can live long, healthy and productive lives. Those who have more serious forms of TSC whose vital organs are affected may experience complications. About 25% of severely affected infants die before age 10 and approximately 75% die before age 25. Let us look at the impact of TSC upon several specific organs.

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## The Brain

There are three types of tumors that can appear in the brain due to TSC: Cortical Tubers (the most common type - found in over 80% of cases with brain involvement); Subependymal Nodules; and Subependymal Giant Astrocytomas (also known as SEGAs).

Cortical Tubers are areas in the Cerebral Cortex (where we do our thinking) that fail to develop normally. They often disrupt the normal wiring of the brain and can cause seizures. It is estimated that 80% of people with TSC experience seizures, and although seizure onset for the majority of persons with TSC occurs by age three, it can begin at any time during one’s life. Usually an electroencephalogram (EEG) is done to locate the region of the brain in which seizure activity is occurring. Treatment is usually with anticonvulsant medication.

Approximately one-third of infants with TSC experience Infantile Spasms, seizures that cause sudden tensing of the infant’s body. Usually they occur somewhere between five and nine months of age, and rarely before three months or after 18 months. Children outgrow them; either the seizures go away altogether, or transition into other types of seizures. Infantile Spasms can produce sudden flexion (“jackknife seizures”), or extension, of the trunk and extremities. Often, they can come in clusters, and last 15-20 minutes. Sometimes the seizures may be more subtle, such as twitching of a body part, sudden grimacing, or staring off into space, oblivious to

surroundings. It is important that parents notice subtle cues and have the child examined by a neurologist familiar with TSC because some infants can show developmental arrest or lose milestones that were previously achieved. The old adage, “Time lost is brain lost,” certainly applies here, as long-term damage may be averted. Treatment is usually with adrenocorticotrophic hormone (ACTH), or a medication called Vigabatrin (Sabril). Vigabatrin helps to prevent the breakdown of GABA, an important neurotransmitter in the brain. One potential side effect of Vigabatrin that is of concern is visual field loss. Prednisone, a corticosteroidal anti-inflammatory medication, has also been used in treatment of Infantile Spasms.

Subependymal Nodules. These form beneath the Ependymal cells, which line the ventricles of the brain and central spinal canal, and produce cerebrospinal fluid. The nodules develop inside the walls of the ventricles and begin to accumulate calcium in the first few months or years of life. They are not known to cause any damage and can be seen with Computerized Tomography (CT scan).

Subependymal Giant Astrocytomas occur in about 15% of persons with TSC. These typically develop in childhood or adolescence, and the chances of developing this type of tumor decrease after age 20. If a SEGA grows large enough, it can block the flow of cerebrospinal fluid, causing hydrocephalus, brain damage, and even death. Symptoms include nausea,

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## The Brain (continued from Page 2)

vomiting, headaches, and changes in appetite, behavior, or mood. Treatment is through surgical resection of the tumor and/or shunting the cerebrospinal fluid in order to relieve pressure. Brain imaging can spot this type of tumor even before symptoms develop; scans, either CT or Magnetic Resonance Imaging (MRI), are usually done upon diagnosis and every 1-3 years thereafter. Ongoing monitoring, not only for the brain but for any potentially affected organ, is important and an essential aspect of any treatment plan for persons diagnosed with TSC.

Brain tumors in TSC may also result in Psychiatric and behavioral involvement. Developmental delays, intellectual disabilities, learning disabilities, sleep disturbances, aggression, hyperactivity, attention deficit, OCD, Depression, Bipolar Disorder, and Schizophrenia may also stem from the disease. In addition, TSC provides the clearest link of any medical disorder to Autism; some 50%-60% of children with Tuberous Sclerosis also are diagnosed with Autism Spectrum Disorder.

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## Eyes

Tumors from TSC can be found in either the internal or external structures of the eye. In most cases they do not interfere with vision.

Angiofibromas occur on the eyelids and usually appear during childhood. There are also small tumors that can grow on the conjunctiva (the membrane covering the eye).

Retinal Hamartomas are flat, translucent tumors that grow at the back of the eye peripheral to the optic

disk, and occur in 75% of people with TSC. Mulberry lesions tend to grow in clusters on the optic disk. Again, rarely do these tumors affect vision, but if they do, an ophthalmologist can use a technique called photocoagulation, which shuts off the blood supply to the tumors, thus eliminating them.

Achromic patches are small spots which can appear on the retina that have no color.

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## Skin

Skin lesions affect 75%-80% of persons with TSC. Usually they do not cause functional problems but may be painful or disfiguring and upsetting to the patient, who may request surgical removal. These areas often consist of light-colored, thickened skin. There are different types of skin lesions, including:

- \* Hypo melanotic macules are patches of skin which are lighter than the surrounding skin and may appear in a classic "ash leaf" shape.
- \* Shagreen patches are characteristic of TSC and are considered a major feature among diagnostic criteria for the disease. They are tough and dimpled like an orange peel.
- \* Periungual or Subungual Fibromas are fibrous tumors that grow around or under fingernails or toenails. These may cause pain or discomfort, particularly on the feet, where they may become compressed by shoes, and surgical removal may be necessary to relieve the pain.
- \* Facial Angiofibromas (formerly known as *Adenoma Sebaceum*) are small, reddened or yellow papules on the face that look like acne. There may also be lesions (fibrous, hairless plaques) on the scalp and forehead. Any or all of these may be cosmetically unsightly and distressing, in which case they can be surgically removed.

## Skin (continued from Page 3)

- \* Dermatofibromas are tumors of the skin which appear on the lower extremities. Although they pose no functional problems, the patient may desire removal for aesthetic purposes.
  - \* “Confetti” skin lesions are small (1-2 mm in diameter) light-colored spots that appear on the skin and look like confetti.
- Tumors may be removed by dermabrasion (“sanding” the lesion off), shave excision (literally slicing the lesion away), cryotherapy (freezing), or laser surgery. The method employed would depend on each particular case.

## Lungs

There are three main types of lesions that can occur in the lungs as a result of TSC: Lymphangiomyomatosis (LAM), Multifocal Micronodular Pneumocyte Hyperplasia (MMPH), and Clear Cell Tumors. The most dangerous of these is LAM; the other two do not cause complications.

LAM is the development of smooth muscle tumors in the blood and lymph vessels of the lungs and is the most common manifestation of TSC in the lungs. LAM occurs mostly in women of child-bearing age, with the average onset in the early 30s. These tumors take up space and crowd out functional lung tissues. They can also rupture and cause a collapsed lung. LAM progressive and eventually destroys the function of the lungs, resulting in respiratory failure and death over a period of several years.

Shortness of breath, especially after exercise, is usually the first symptom when LAM begins forming in the lungs. A spontaneous pneumothorax (collapsed lung) results when a cyst ruptures, creating a small hole in the lining of the lung. The rupture allows the surrounding air to escape into the chest cavity, causing the lung to collapse. The result is dyspnea (difficulty breathing), chest pain, coughing, and fatigue. This requires immediate medical attention. Respiratory failure can result. Treatment is insertion of a chest tube, which allows the air to escape from the chest cavity and the lung to re-inflate. In some cases a collapsed lung may resolve on its own, however, any time a person presents with symptoms

of respiratory distress, he or she should be sent to the emergency room.

Females with TSC should have a CT scan (a chest x-ray would not detect early signs of involvement) before the age of 18 or at the time of diagnosis for both women and men if it is past the age of 18. The patient should be monitored closely and should have follow-up CT scans as needed. CT scans allow physicians to view masses and track tumor proliferation.

Many people with TSC have minor, asymptomatic lung involvement. Those with more severe symptoms should see a pulmonologist who is knowledgeable regarding LAM. It is always better to be pro-active than to wait until a crisis develops in order to treat any health problem. LAM is a major feature of the diagnostic criteria of TSC and sometimes provides the very first indication that someone has the disorder.

Treatment for LAM depends on symptoms. Common-sense approaches include exercising to tolerance, quitting/avoiding smoking, and receiving flu and pneumonia vaccines. Beta agonist inhalers (such as Albuterol) which relax the smooth muscles of the airways, can help relieve shortness of breath, as can supplemental oxygen. Medications such as Tamoxifen and Progesterone have been used also, but their effectiveness has been questionable. Rapamycin (Sirolimus) is an immunosuppressive medication that can slow the progression of LAM, but it has side effects, including increasing the risk of cancer or

## Lungs *(continued from Page 4)*

infection. Thoracentesis is a method of draining fluid from the lungs to relieve congestion. Finally, a lung transplant can be performed, but this is major sur-

gery, and complications may include rejection of the donor organ, infection, bleeding, pneumothorax, and recurrence of LAM.

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## Heart

Cardiac Rhabdomyomas appear in 47% to 67% of persons with TSC and are considered a major feature in diagnosing TSC. “Rhabdo” means “rod-like” and “myoma” means “muscle tumor.” The tumors grow during pregnancy and are largest at birth or shortly thereafter and then regress; some disappear entirely. Occasionally there may be a second peaking of tumor growth at puberty. Of all the tumors caused by Tuberous Sclerosis Complex, these are the only ones that *decrease* in size with the passage of time.

Most Rhabdomyomas are asymptomatic, but if an arrhythmia (irregular heartbeat) or some other cardiac abnormality is present, the infant should be seen by a cardiologist immediately. A child with TSC who takes Tegretol for Infantile Spasms (seizures) may develop an arrhythmia. Infants taking adreno-

corticotropic hormone (ACTH) for the same have shown an increase in the size of Rhabdomyomas. An echocardiogram is a motion picture of the heart which allows the physician to see it operating through time and notice any tumors. An electrocardiogram measures the electrical activity of the heart. Both of these tests should be done for any infants who are suspected of having Rhabdomyomas, and especially before they begin taking the aforementioned medications.

Rhabdomyomas are considered a major diagnostic feature of TSC. When tumors are large or grow on or near heart valves, they can obstruct blood flow and lead to heart failure. This occurs in only 2%-4% of children with Rhabdomyomas. Surgical resection of these tumors is reserved for severe cases.

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## Kidneys

There are several types of tumors which invade the kidneys due to TSC: Benign Angiomyolipomas, Malignant Angiomyolipomas, Renal Cell Carcinoma, Oncocytomas, and Cysts. Remember that the kidneys are highly vascular organs; their principal job is to filter waste products from the bloodstream. Therefore, along with the brain, heart and lungs, tumor invasion can have devastating consequences.

Angiomyolipomas are fatty tumors (lipomas) that form in the smooth muscles (myo) of the blood vessels (angio). The most common TSC lesions are the Benign Angiomyolipomas, occurring in 70%-80% of adults. These can remain asymptomatic for a long time. The tumors tend to begin in childhood, grow very slowly, and do not usually become a problem until young adulthood. They are multiple and bilateral. Individuals with TSC should have their kidneys

imaged at the time of diagnosis and regularly throughout their lives. When these tumors grow to be larger than 4 cm in diameter, they usually cause bleeding in the urine (hematuria), and pain in the low back, abdomen, flank, or pelvis can become a significant problem. It should be noted that a person without TSC can also develop Angiomyolipomas. People with Benign Angiomyolipomas who also have TSC have a greater risk of developing Malignant Angiomyolipomas than people with Benign Angiomyolipomas who do not have TSC.

Malignant Angiomyolipomas are life-threatening. It is very important that the physician consult with a skilled radiologist when reviewing imaging studies in order to differentiate between benign and malignant tumors. Malignant Angiomyolipomas should be surgically removed as soon as possible.

## **Kidneys** *(continued from Page 5)*

Renal (meaning kidney) Cell Carcinomas are rare in people with TSC, but when they occur, they are often bilateral. A biopsy is necessary to give a definitive diagnosis, and the tumor should be surgically removed *a.s.a.p.* As with Malignant Angiomyolipomas, Renal Cell Carcinoma is more likely to occur in people who have TSC than in people who do not. It should be noted that biopsies are discouraged for cancerous tumors of kidneys because of the high risk of hemorrhaging and spreading the tumor cells.

Oncocytomas are brown-colored tumors of the kidney which can cause flank pain and bleeding in the urine. These can be detected with a CT scan or ultrasound, but cannot be differentiated from Renal Cell Carcinoma without a biopsy. Removing the section of the kidney containing the tumors (partial nephrectomy) is recommended.

Renal Cysts associated with Tuberous Sclerosis are usually multiple and bilateral. After Benign Angiomyolipomas, they are the most commonly occurring kidney manifestation of TSC. Some of them collapse and disappear over time. They are similar to those in Polycystic Kidney Disease (PKD). Interestingly, the TSC2 gene affected in Tuberous Sclerosis is in close proximity to the Polycystic Kidney Disease gene, PKD1, located on chromosome 16.

Although kidney problems secondary to TSC can manifest anytime in life, they usually do not present until after age five or in young adulthood. When the disease is diagnosed, imaging of the kidneys is performed and subsequently routinely scheduled. Ultrasound is usually adequate to identify tumors, but sometimes a physician will want a higher-resolution image in order to differentiate as to whether a tumor is benign or malignant, so a CT scan or MRI (with or without contrast dye) may be ordered. Physicians are reluctant to perform biopsies on Angiomyolipomas because the kidneys are so highly vascular that perforating the tissues may spread potentially cancerous cells into the bloodstream. Blood tests may also be ordered to monitor kidney function. Obviously if symptoms (flank pain, blood in urine) develop, the physician should be notified.

In many cases kidney tumors caused by TSC do not present problems for the patient and careful monitoring is sufficient. There are, however, instances in which more needs to be done. Sometimes tumors on or in the kidneys can interfere with their ability to filter waste from the blood. A bi-product of protein digestion is ammonia, which converts to uric acid in the kidneys and then is excreted. When this function is compromised, the patient may need to go on a low-protein diet in order to reduce the ammonia build-up and therefore the workload on the kidneys.

Another important aspect of kidney function is regulating blood pressure, and in some people, renal cysts or tumors contribute to hypertension, and it may be necessary for the physician to prescribe blood pressure medication.

There is a procedure which allows a physician to stop the blood supply to certain tumors in the kidneys called Selective Embolization. A catheter is inserted through the renal artery into the particular blood vessel that feeds the tumor and shuts off the blood flow, resulting in the subsequent death of the tumor. In cases where this procedure fails or is not possible, surgery is performed to remove part or all of the kidney. This is called a partial or total nephrectomy.

Kidneys can be damaged so badly by TSC-related tumors that they begin to fail, in which case Hemodialysis may be necessary. This is a procedure which uses a dialysis machine to artificially cleanse a person's blood. It is time-consuming and usually tiresome for the patient. Dialysis is typically performed three times per week at a clinic.

The final available option is a kidney transplant, which has been done successfully in persons with TSC, and there does not seem to be a recurrence of tumors in the transplanted organ. Remember that early detection and frequent monitoring of renal tumors allow physicians to recognize potential problems sooner, and thus be able to use less invasive methods like embolization instead of more drastic surgical procedures like nephrectomies and transplants.

## Other Sites

Tuberous Sclerosis Complex may cause growths in other parts of the body, where they usually do not appear until later in life and rarely cause problems.

Seventy percent of people with TSC develop nodular growths on their gums (intraoral fibromas), and nearly 100% develop dental pits in the enamel of their teeth. Dentists recommend coating the teeth and good dental hygiene to prevent

tooth decay. Even though cysts on gums and pits in teeth are considered minor diagnostic features, they are good indicators that a person has TSC.

Angiomyolipomas occur in the liver about 25% of the time in people who have Tuberous Sclerosis, more often in women than in men. Usually they pose no problems, but in rare cases they require surgical removal.

Pancreatic tumors are generally asymptomatic, but can cause hypoglycemia, behavioral changes, and abdominal pain.

The spleen is generally unaffected by TSC, but there have been instances of progressive lesions called Hemangiomas that required a splenectomy.

## Diagnosing TSC

A diagnosis of Tuberous Sclerosis can be made based on clinical features of the disease or by genetic testing.

With regard to clinical features, a *definitive* diagnosis requires at least two major features *or* a combination of one major feature and at least two minor features. For a *possible* diagnosis, there must be one major feature *or* at least two minor features.

The major features include: Rhabdomyoma of the heart; Lymphangioleiomyomatosis (LAM) of the lungs; at least two Angiomyolipomas present in one or both kidneys; presence of any one of the three types of brain tumors (Cortical Tubers, Subependymal Nodules, Subependymal Giant Astrocytoma); multiple Retinal Hamartomas of the eye; a Shagreen Patch on the skin; at least two Ungual Fibromas (either on fingernails or toenails); presence of Fibrous Plaque on

the head or at least three Angiofibromas on the face (these look like acne); and the presence of at least three Hypomelanotic Macules (white spots), greater than 5 mm in diameter.

Minor features: Confetti lesions, dental enamel pits, intraoral fibromas of the gums, achromic patches in the eye, multiple renal cysts, and finally, the presence of benign tumors which are not considered major features (as listed above) growing anywhere else in the body.

Advancements in medical science now allow for genetic testing to determine if someone has TSC. A sample of cells from the patient is taken and examined in the laboratory. The identification of a mutation of the TSC1 or the TSC2 gene is sufficient to confirm the diagnosis of Tuberous Sclerosis Complex.

## Care of the Patient

Caring for someone with TSC involves a great deal of monitoring. Recall that heart tumors present the greatest danger to infants and tend to abate with time (except for a possible flare-up during the teens), and tumors in other areas of the body usually begin later in life and worsen over time. Since the most frequently involved organs include the brain, heart, lungs, kidneys, eyes and skin, periodic examinations by a physician and/or the use of imaging are standard procedure. Some people are only mildly affected by TSC and others may be facing life-threatening situations, so treatments will vary greatly. Symptoms in the same person may change over time as well. Often the health care team will involve not only the PCP but also one or more specialists, so there must be collaboration among physicians, since organs and organ systems directly affect one another.

What is essential is that the individual be diagnosed early and monitored frequently so that intervention may be timely. This is why CT scans and MRIs are ordered routinely for the brain, lungs and kidneys at least as often as every one to three years. Catching a problem early increases the chances for effective treatment. Family members and caregivers must also be observant and note any new signs or symptoms, so that the physician can be notified. Sticking with the plan of care involves observing, reporting, communicating with the physician, implementing care, noticing what is working and what is not, and documenting significant observations. Especially with individuals who have intellectual or developmental disabilities, it is important that direct supports keep physicians informed and updated in the event that the individual cannot.

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## Genetic Testing and Genetic Counseling

Advancements in technology enable us to look at the genetic material (DNA) of any person. DNA is more or less a blueprint for the structure and function of our own unique physical body. All that is necessary is to obtain a sample of cells, which can then be tested in a laboratory.

All immediate family members of someone with TSC should undergo genetic testing, as the results may help identify where the mutation arose and who may be affected. Remember that a genetic mutation can occur spontaneously and without the involvement of heredity, but if there is a familial component, genetic tests can

reveal it, and thus can help families assess the possible outcomes of decisions they make for the future. It is also important to realize that mildly affected parents do *not* always have mildly affected children; the children may, in fact, be severely affected, as the disease is quite unpredictable in how it manifests from one person to the next.

A genetic counselor can explain how mutations occur and how they are passed on, as well as help people with TSC construct a family medical history to determine where the TSC1 or TSC2 mutation (if there is one) occurred. Medical science has not found a way to

prevent an existing mutation from being passed on, so there are no guarantees that the children of a parent with TSC will not inherit it.

Finally, for expectant parents, there are ways to test for genetic mutations in the child before it is born. The first is through amniocentesis, a procedure that uses a needle to withdraw amniotic fluid from within the mother's uterus. The second is through chorionic villi sampling, which involves removing a piece of the placenta during pregnancy. A third method, reserved for in-vitro fertilization, is to sample a cell from an embryo prior to implantation in the womb.

## Tuberous Sclerosis Test

Name: \_\_\_\_\_

Role/Title: \_\_\_\_\_

Agency: \_\_\_\_\_

Date: \_\_\_\_\_

Please provide contact information (email address, fax number, or mailing address) where you would like your certificate to be sent:

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Submit your completed test, with at least a score of 80%, to receive **1.5 hours** of credit for this course.

- \* To submit via fax, please fax the test and evaluation to 814-728-8887. Please fax only the test and evaluation, not the entire training packet.
- \* To submit via email, please send an email to [training@northwesthc.org](mailto:training@northwesthc.org). Please put "Tuberous Sclerosis Test" in the subject line, and the numbers 1—10 along with your answers, in the body of the email, OR scan the test and evaluations pages and email as attachments.
- \* To submit via mail, send the test and evaluation pages to Milestone HCQU NW, 247 Hospital Drive, Warren PA 16365.

### Knowledge Assessment:

1. Tuberous Sclerosis is an exclusively inherited disease. **True False**
2. Most frequently, tumors caused by TSC occur in the bladder and small intestine. **True False**
3. Tuberous Sclerosis can be diagnosed definitively if someone carries two major features, or one major feature and at least two minor features. All of the following are major features *except*
  - a. Any of the three types of brain tumors
  - b. Angioleiomyomatosis (LAM) of the lungs
  - c. Achromic patches on the retina of the eye
  - d. Angiomyolipomas of the kidneys
4. Rhabdomyomas of the heart
  - a. Are largest at or near birth and tend to shrink over time
  - b. Only necessitate surgery in 2%-4% of cases
  - c. If suspected, warrant an echocardiogram and an EKG
  - d. All of the above
  - e. None of the above
5. Lymphangiomyomatosis (LAM) of the lungs occur mostly in women. **True False**
6. Angiomyolipomas of the kidneys can become cancerous. **True False**
7. \_\_\_\_\_ tubers tend to cause seizures in people with TSC?
8. Skin lesions caused by Tuberous Sclerosis rarely affect function, except to cause pain near fingernails and toenails. **True False**
9. Genetic testing can identify immediate family members who have genetic mutations. **True False**
10. The most important aspect of caring for any person who has TSC is
  - a. Frequent monitoring
  - b. Genetic Testing
  - c. Medications
  - d. Surgery

### Home Study Evaluation

Training Title: Tuberous Sclerosis

Date: \_\_\_\_\_

- Direct Support Professional     Provider Administrator/Supervisor
- Program Specialist                 Provider Clinical Staff
- Consumer/Self-Advocate         Family Member
- Support Coordinator                 Support Coordinator Supervisor
- PCH Staff/Administrator         County MH/MR/IDD
- FLP/LSP                                 Other (please list): \_\_\_\_\_

Please circle your PRIMARY reason for completing this home-study training:

- It's mandatory     interested in subject matter     need training hours     convenience

Please circle the best response to each question.

**5 = Strongly Agree**    4 = Agree    3 = Undecided    2 = Disagree    **1 = Strongly**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. As a result of this training, I have increased my knowledge. | 5 | 4 | 3 | 2 | 1 |
| 2. I learned something I can use in my own situation.           | 5 | 4 | 3 | 2 | 1 |
| 3. This training provided needed information.                   | 5 | 4 | 3 | 2 | 1 |
| 4. The training material was helpful and effective.             | 5 | 4 | 3 | 2 | 1 |
| 5. Overall, I am satisfied with this training.                  | 5 | 4 | 3 | 2 | 1 |
| 6. I am glad I completed this training.                         | 5 | 4 | 3 | 2 | 1 |

Suggestions for improvement: \_\_\_\_\_

\_\_\_\_\_

Additional information I feel should have been included in this training: \_\_\_\_\_

\_\_\_\_\_

I would like to see these topics/conditions developed into home-study trainings: \_\_\_\_\_

\_\_\_\_\_