**National TSC Awareness Month -- May**

**31 Facts for 31 Days**

1. Tuberous sclerosis complex (TSC) is a genetic disorder that causes tumors to form in vital organs, primarily the brain, eyes, heart, kidneys, liver, lung and skin.

2. Tuberous sclerosis complex (TSC) is caused by a mutation in either the TSC1 or TSC2 genes.

3. Many babies with tuberous sclerosis complex (TSC) are now diagnosed before or soon after birth when rhabdomyomas (a type of heart tumor) are detected during routine ultrasounds.

4. Tuberous sclerosis complex (TSC) affects everyone differently, even identical twins.

5. Tuberous sclerosis complex (TSC) shows no gender bias and occurs in all races and ethnic groups.

6. More common than Lou Gehrig’s disease (ALS) or cystic fibrosis, tuberous sclerosis complex (TSC) is far less known.

7. Everolimus and rapamycin, which are used to treat some aspects of tuberous sclerosis complex (TSC), were developed thanks to scientists studying bacteria in the soil of Easter Island.

8. The TAND Checklist is a screening tool to help identify TSC-Associated Neuropsychiatric Disorders (TAND). Every person with tuberous sclerosis complex (TSC) should be screened for TAND at least once a year with the help of a doctor or nurse. The TAND Checklist is freely downloadable from the internet. <http://tscinternational.org/pages.aspx?content=14>

9. A team approach to health care, with multiple specialists working together, can benefit people with tuberous sclerosis complex (TSC). Most people with TSC do not have access to this style of care.

10. At least half of people with tuberous sclerosis complex (TSC) have normal intellectual ability, but they may still experience difficulties with neurological manifestations that affect their daily life functioning.

11. Yearly blood pressure checks and urine tests are recommended for people with tuberous sclerosis complex (TSC) to monitor how well their kidneys are working.

12. Tuberous sclerosis complex (TSC) affects more than <insert estimate> individuals in <country> and many more carers, families and friends who live with the impact of the disease.

13. People with tuberous sclerosis complex (TSC) should see an ophthalmologist when diagnosed and annually thereafter to check for eye and vision problems.

14. Research into cancer, autism, epilepsy and other diseases is benefiting from tuberous sclerosis complex (TSC) research.

15. Around 1 in 6,000 babies born are affected by tuberous sclerosis complex (TSC). Worldwide, more than 1 million people have TSC.

16. Every 20 minutes somewhere in the world a child is born with tuberous sclerosis complex (TSC).

17. People with tuberous sclerosis complex (TSC) should have regular check-ups to monitor the disease and treat appropriately. Guidelines are available to describe the monitoring recommended by international experts in TSC. You can view these at [www.tscinternational.org/documents/TSCi%20Consensus%20Guidelines.pdf](http://www.tscinternational.org/documents/TSCi%20Consensus%20Guidelines.pdf).

18. Magnetic resonance imaging (MRI) of the brain is recommended every 1-3 years until the person with tuberous sclerosis complex (TSC) is 25 years old. This is to look for a growth in the brain called a subependymal giant cell astrocytoma (SEGA) that can be life-threatening if left untreated.

19. Tuberous sclerosis complex (TSC) is the most common genetic disorder associated with epilepsy and autism.

20. Angiofibromas are raised red bumps that grow on the faces of people with tuberous sclerosis complex (TSC). These generally appear by 5 years of age and affect up to 90% of individuals with TSC.

21. Daily application of broad spectrum sunscreen is recommended by tuberous sclerosis complex (TSC) experts. This is because UV radiation contributes to forming angiofibromas, one of the signs of TSC on the skin.

22. Seizures occur in approximately 85% of people with tuberous sclerosis complex (TSC), making epilepsy the most common brain manifestation of TSC.

23. Very large mutations involving the TSC2 gene and adjacent PKD1 gene on chromosome 16 can lead to severe polycystic kidney disease during childhood. This occurs in less than 5% of people with tuberous sclerosis complex (TSC).

24. Infantile spasms are a common type of seizure in babies with tuberous sclerosis complex (TSC). Vigabatrin is recommended by TSC experts as first line treatment, where available, to control these seizures.

25. There is no cure for tuberous sclerosis complex (TSC).

26. TSC International (TSCi) tuberous sclerosis complex (TSC) organisations work with local health care professionals to improve the care given to the 1 million people around the world living with TSC.

27. Research in tuberous sclerosis complex (TSC) has already provided new treatment options for people with TSC. However, many people around the world do not have access to these medicines or the recommended surveillance for TSC.

28. Almost half of people with tuberous sclerosis complex (TSC) will be diagnosed with an autism spectrum disorder.

29. Up to 90% of people with tuberous sclerosis complex (TSC) will have tumors in their kidneys called angiomyolipomas. Regular MRIs are recommended to monitor these tumors and minimise complications.

30. All people with tuberous sclerosis complex (TSC) should receive genetic counseling when diagnosed.

31. Lymphangioleiomyomatosis (LAM) can occur in the lungs of people with tuberous sclerosis complex (TSC), almost exclusively in females. High resolution computed tomography is a test recommended for all adult women with TSC to test for LAM. June 1 is worldwide LAM awareness day.