

2015 TSC Global Awareness Day

31 Facts

The 31 facts are one activity in which the TSC community can participate to raise awareness of TSC on social media. They are intended to increase the understanding of TSC in the general public.

This year there is a focus on facts related to TAND - TSC-Associated Neuropsychiatric Disorders.

The TSC International working group welcomes your feedback on the facts.

Suggestions for how to use the facts:

- *Share one fact each day during May on your organisation's facebook page*
- *Create an image file of each fact. Images reach more people on facebook than text-only statuses*
- *Provide more information or links to related information in the description of the image. This could include the TSC guidelines and the TAND checklist.*
- *Images can also be used on twitter (useful when the fact is too long!), instagram and other social media platforms.*

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. TSC is most often diagnosed by examining different parts of the body. TSC can also be diagnosed by finding a change in either the TSC1 or TSC2 genes.
3. Many babies with TSC are now diagnosed before or soon after birth when rhabdomyomas (a type of heart tumor) are detected during routine ultrasounds.
4. In about 30% of the cases, TSC is inherited from an affected parent. In the remaining 70% of cases, the person with TSC is the first in the family with the condition. This is likely to have occurred due to a change in one copy of a TSC gene during the formation of the egg or sperm, during conception or shortly after conception.
5. If a parent is affected, his or her children have a 50% chance of inheriting TSC from the parent. People with TSC can consider using pre-implantation genetic diagnosis (PGD) to detect a TSC gene change in embryos created through in vitro fertilization (IVF).
6. TSC affects everyone differently; some have very mild symptoms while others are severely impacted.
7. TAND stands for TSC-Associated Neuropsychiatric Disorders. TAND includes difficulties across various dimensions: behavioural, psychiatric, intellectual, academic, neuropsychological, and psycho-social.

Most people with TSC will have TAND difficulties at some point in their life.

8. The TAND Checklist is a screening tool to help identify TSC-Associated Neuropsychiatric Disorders (TAND). Every person with 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.
9. Tuberous sclerosis can lead to the formation of fibroids or tumors in the pancreas, bone, and liver.
10. At least half of people with tuberous sclerosis have normal intellectual ability, but they may still have difficulties with specific brain skills that can affect their daily life functioning
11. At least a third of school-aged children with tuberous sclerosis have academic difficulties including reading, writing, spelling, and mathematics difficulties. Additional educational support can help with these difficulties.
12. 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 TSC should see an ophthalmologist when diagnosed to check for eye and vision problems
14. Research into cancer, autism, epilepsy and other diseases is benefiting from TSC research
- 15. Around 1 in 6000 babies born are affected by tuberous sclerosis complex. Worldwide, more than one million people have TSC**
16. Every 20 minutes somewhere in the world a child is born with tuberous sclerosis complex.
17. People with TSC should have regular check-ups to monitor the disease and treat appropriately. Guidelines describe the monitoring recommended by international experts in TSC. You can view these at www.tscinternational.org/documents/TSCI%20Consensus%20Guidelines.pdf
18. Promising treatments for some aspects of tuberous sclerosis complex have developed from a naturally occurring substance derived from bacteria in the soil of Easter Island.
19. Tuberous Sclerosis is the leading genetic disorder associated with epilepsy and autism.
20. More common than Lou Gehrig's disease (ALS) or cystic fibrosis, tuberous sclerosis is far less known
21. Male and female rates of autism spectrum disorder (ASD) and attention deficit disorder (ADHD) are equal in tuberous sclerosis complex.
22. Seizures occur in 90% of people with TSC, making epilepsy the most common brain manifestation of Tuberous Sclerosis.
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.



24. Behavioural difficulties in tuberous sclerosis complex can include anxiety, depressed mood, overactivity, restlessness, aggression, temper tantrums, self-injury, social communication difficulties and sleep problems.

25. There is no cure for TSC.

26. Many teenagers and adults with tuberous sclerosis will have anxiety and depressive disorders that will benefit from treatment

27. Angiofibromas are raised red bumps that grow on the face of people with tuberous sclerosis. These generally appear by five years of age and affect up to 90% of individuals with TSC.

28. Almost half of people with tuberous sclerosis can be diagnosed with an autism spectrum disorder.

29. Up to 90% of people with 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 should have an appointment with a geneticist when diagnosed.

31. Lymphangiomyomatosis (LAM) can occur in the lungs of people (almost exclusively females).

LAM develops over time at different rates in different people. Some young women can be severely affected by LAM; for some women LAM does not cause significant symptoms.

June 1st is worldwide LAM awareness day.