TSC affects everyone differently, even identical twins.
TSC is a “linchpin” disease, one that can potentially unlock new treatments to a wide array of disorders. Because of its diverse symptoms, research into tuberous sclerosis complex (TSC) is leading to a better understanding of other common diseases, such as cancer, autism spectrum disorders, and epilepsy.

Every 20 minutes somewhere in the world a child is born TSC.
If parents are unaffected by TSC and have one child with TSC, the probability of having another child with TSC is around 1-2%.
Babies with TSC can now be diagnosed before birth when rhabdomyomas, a type of heart tumour, are detected during routine ultrasounds.
TSC occurs equally in men and women and occurs in all races and ethnic groups.
Angiofibromas are raised red bumps that grow on the faces of 90% of people with TSC. Daily application of broad spectrum sunscreen is recommended by TSC experts because UV radiation contributes to the development of angiofibromas.
Seizures occur in approximately 85% of people with TSC, making epilepsy the most common brain manifestation of this disease. Approximately 60% of people with TSC cannot achieve seizure control.
May 15

is Tuberous Sclerosis Complex Global Awareness Day

7 days to go

The TAND Checklist is a screening tool used to help identify TSC Associated Neuropsychiatric Disorders. Everyone with TSC should be screened for TAND at least once a year with the help of a doctor or nurse.
Magnetic resonance imaging (MRI) of the brain is recommended every 1-3 years until a person with 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.
There is no cure for TSC, but with early intervention treatment and regular surveillance the impacts of the disease can be minimized.
The severity of TSC symptoms varies widely. Symptoms range from mild—allowing people to live independent, productive lives—to more severe symptoms that can affect everyday life and even be life-threatening.
Up to 80% of people with TSC will have tumours in their kidneys called AML’s (angiomyolipomas). While in many cases these cause no major issues, regular ultrasounds are recommended to monitor these tumours and minimise complications.
Today, most people with TSC have a normal life expectancy and thanks to earlier diagnosis and better treatments, people affected by TSC are living healthier and fuller lives.
Research in 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.

There is so much more we need to do!
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0 day to go

We need YOUR help today on TSC Global Awareness Day. Please help us raise awareness and funds for TSC so one day we may find a cure.