

We think all families living with TSC should have someone to turn to...

“To be a well informed, connected and supported TSC parent is the best gift we can give to our TSC affected children.”

HANNAH, A PARENT OF A CHILD WITH TSC

TSC CONFERENCE FEEDBACK



“Helps you understand the great unknown of TSC”.

“The conference made me feel not so alone with dealing with my TSC son. The speakers were very informative and relevant to our journey.”



“With a teenage son with TSC, it was great to have him here to learn as a family what he has, how to work with it and how to get on with life.”

Please support our work

Tuberous Sclerosis Complex

Tuberous Sclerosis Complex New Zealand is a registered charity*. We rely on your donations to provide information and support to families affected by TSC.

Every bit of assistance helps us improve the lives of individuals and families affected by TSC.

Visit our website or donate at www.givealittle.co.nz/org/TSCNZ



Information and support for people with Tuberous Sclerosis Complex and their families



Tuberous Sclerosis Complex New Zealand

www.tsc.org.nz
info@tsc.org.nz

If you would like to speak to someone about TSC in New Zealand, please email us (info@tsc.org.nz) with your name and phone number and we will call you back.

*REGISTERED CHARITY NUMBER: CC50554



Tuberous Sclerosis Complex New Zealand

www.tsc.org.nz • info@tsc.org.nz

About TSC

Tuberous Sclerosis Complex [TSC or TS] is a genetic disorder that affects people in many different ways and with differing degrees of severity.

TSC is thought to occur in approximately 1 in 6,000 births. The name TSC derives from the tuber-like growths on the brain, which calcify with age and become hard or 'sclerotic'. TSC commonly affects the skin, kidneys, brain, heart and lungs.

Receiving a diagnosis of TSC can come as a shock to the entire family. You can find further information and personal stories from Tuberous Sclerosis Complex New Zealand [TSCNZ] and Tuberous Sclerosis Australia [TSA]

See these websites for more information:
www.tsc.org.nz
tsa.org.au/information/new-diagnosis/

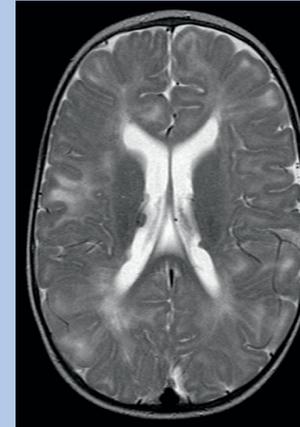
TSC is genetic but not necessarily inherited from a parent. In about 70% of cases TSC has come as the result of a new genetic mutation, and no one else in the family is affected. It may be important for parents or siblings to find out whether they also have the TSC gene because anyone with this gene has a 1 in 2 chance of passing it on to their children. Genetic counselling is recommended for all families with TSC.

IT'S IMPORTANT TO REALISE THAT THE EFFECTS OF TSC VARY GREATLY

- People can have TSC without any visible symptoms
- About 50% of people with TSC will have an IQ in the same range as the general population
- There are rarely problems with mobility
- Life expectancy for the great majority of people with TSC is normal
- Although there is no cure for TSC, treatment is available for most symptoms and an active research programme is uncovering new therapies.

Signs and Symptoms

BRAIN: Almost all people with TSC have signs of TSC in their brain, in the form of tubers, nodules or subependymal giant cell astrocytomas [SEGAs]. People with TSC may experience epilepsy, intellectual impairment, specific learning difficulties, autism, difficulties with attention and are more likely to experience anxiety and depression. The severity of these symptoms varies greatly between different individuals with TSC.



Ongoing surveillance and care for people with TSC can minimise the impact of the disease.

SKIN: A facial rash called facial angiofibroma may develop across the nose and cheeks. Small fibromas or nodules of skin may form around the finger or toenails.



KIDNEYS: Most people with TSC will develop some kidney signs during their lifetime. TSC can affect kidneys in a number of ways, including: cysts and benign tumours called angiomyolipomas [AMLs]. A small number of people with TSC will have polycystic kidney disease and people with TSC are at a slightly increased risk of kidney cancer.

TSC can affect other organs including the heart, lungs and eyes. Read in detail about features of TSC, including internationally recommended surveillance guidelines at:
www.tsa.org.au/guidelines-tsc/

Tuberous Sclerosis Complex New Zealand [TSCNZ]

TSCNZ is the only organisation dedicated to TSC in New Zealand. We are run by a dedicated team of volunteers. We work closely with Tuberous Sclerosis Australia and are a member organisation of Tuberous Sclerosis Complex International.

WE HELP IN THE FOLLOWING WAYS:

- Provide email and phone support for TSC affected individuals and families
- Maintain an up-to-date website of TSC related information and resources
- Participate in a network of TSC families across New Zealand and Australia, including a facebook group, Discussions of Tuberous Sclerosis in Australia and NZ
- Publish an email newsletter and contribute to Reach Out – a regular journal published by Tuberous Sclerosis Australia
- Hold conferences and seminars for families and healthcare professionals
- Advocate to improve access to best practice care
- Support TSC research activity in New Zealand.

Photo: Stephen Jones Photography

