



Tuberos Sclerosis Complex New Zealand

Inform | Connect | Support

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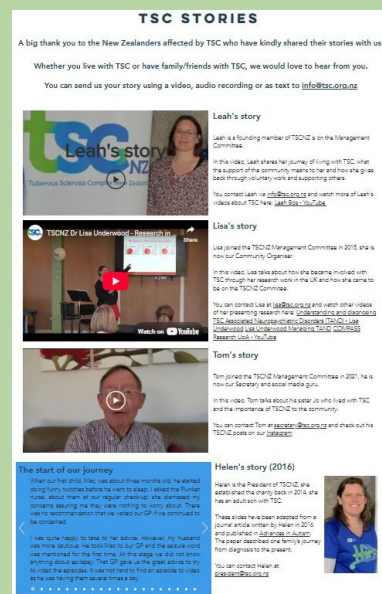
Introducing TSC Stories...

We've added a [new page to our website](#), dedicated to stories of New Zealanders affected by TSC.

So far, we have videos and a slide show from our Committee members. Check out the page to hear from Leah, Helen, Lisa, and Tom about their involvement with TSCNZ.

We'd love to include more stories from the TSC Community.

Share your experiences by email to info@tsc.org.nz. Send us a photo, text, audio recording or video, or get creative and send a visual or audio artwork.



Glow Up Show Up events for Rare Disorders month

A lovely time was had at TSCNZ Glow Up Show Up picnics around the motu on 8th March - [update and photos here](#)

Rare Disorders NZ have made great progress this year:

- Establishing a [Cross-Party Parliamentary Group](#) on Rare Disorders
- Raising awareness for [Rare Disorders month](#)
- Celebrating 25 years of outstanding achievements at a [special awards event](#)



TSCNZ President Helen Willacy was nominated for an award for the amazing contribution she makes to the TSC and rare disorder communities.



If you haven't already, please sign the [RDNZ petition](#) to demand Health NZ develop a plan to implement the Rare Disorders Strategy

TSC Global Awareness Day is on 15th May



[Global Awareness Day](#) is a great opportunity to join the TSC community worldwide in boosting understanding of TSC & its impacts.

You could...post on your socials using [#TSCglobalday](#) [#tscawareness](#) [#tsc_nz](#), share [TSC Facts](#), host a [fundraiser](#) or direct people to our [website](#) and [Givealittle](#) pages.

Check out the [TSC International website](#) and [Facebook page](#) for ideas on how to mark the day and raise awareness of TSC.

Click here to buy TSC Hero t-shirts for global awareness day. 10% of sales go to TSCNZ!

TSC Hero



**Tom has raised
over \$3,000 for TSCNZ!**

Not only does committee member and Secretary, Tom, generously give his time to TSCNZ, he has climbed Mt Maling (1825 metres) with his family to fundraise for us.

Read more about it [here](#).

Thank you Tom and everyone who made a donation!

To find out more about being a TSC Hero, head to our [website](#) or [givealittle](#) page.

Tea & SCones for Global Awareness Day

A great way to let people know about TSC and raise money by hosting a morning or afternoon tea for family, friends, neighbours or colleagues.

The idea for Tea & SCones comes from the [TSA in the UK](#).

Print or send out our TSCNZ [fundraising sheet](#) to let people know why you're raising money and how they can donate.

Get in touch with our Community Organiser, [Lisa](#), if you'd like us to send you [TSC brochures](#) to hand out at your event.

If you've got a fundraising idea, let us know at info@tsc.org.nz

We'd love to hear from you with ideas to help us raise funds in 2025 (and beyond!) - whether it's getting sponsorship, organising an event, giving us your time or making a non-monetary donation.

Donating to TSCNZ

We greatly appreciate any donation you can give.

Donations help us continue to:

- Provide [email and phone support](#) for TSC families
- Maintain the [TSCNZ website](#)
- Produce and distribute [TSC Resources](#)
- Hold [conferences and seminars](#)
- Advocate with [Rare Disorders NZ](#) to improve access to best practice care

To make a donation visit our website www.tsc.org.nz/support-us or <https://givealittle.co.nz/org/tscnz>

Alternatively, make an online payment to the Tuberous Sclerosis Complex NZ bank account at Westpac 03 1550 0447063 00, quoting your name and 'Donation' in the reference fields. If you are making a donation direct to the bank account, please email us on info@tsc.org.nz to let us know so that we can send a donation receipt.

Donations of over \$5 are eligible for a New Zealand charitable giving tax credit.

TS Australia Zoom Information Event

Everolimus and sirolimus - what are they and what do they do?

Many people living with TSC are now prescribed everolimus or sirolimus, which are the mTOR inhibitor treatments. Over the past decade or so, these treatments have had life-changing impacts for many people living with TSC.

When: Wednesday 7 May 2025
07:00 pm – 08:30 pm AEST

In this Zoom Information Event, Dr Clara Chung (Clinical Geneticist) and Dr Denise Chan (Paediatric Neurologist) from Sydney Children's Hospital will help us understand more about these very important medications. These two expert TSC clinicians will tell us more about:

TSCNZ members are welcome to join this event hosted by TS Australia on 7th May at **9pm-10.30pm NZ time.**

Details and registration [here](#).

Not a TSCNZ member?

It's free and easy to join by signing up to our [mailing list](#) or click [here](#) for information on becoming a financial member.

Resources

Did you know that there are different language versions of the TSC-Associated Neuropsychiatric Disorders (TAND) checklist?

They are available to download here: [CHECKLISTS - TANDem](#)

The [TAND Toolkit](#) has great resources to help you and healthcare professionals understand the range of behavioural, psychiatric, scholastic, neuropsychological, and psychosocial difficulties commonly seen in people with TSC.

The TAND Checklist and all TSCNZ's resources are available to download from our [website](#) but [please get in touch](#) if you'd like hard copies and we'll post them out.

We have a 3 fold brochure, Parachute packs, revised Surveillance & Management Guidelines, TAND checklists and [Tubee](#), a children's book that helps explain TSC.

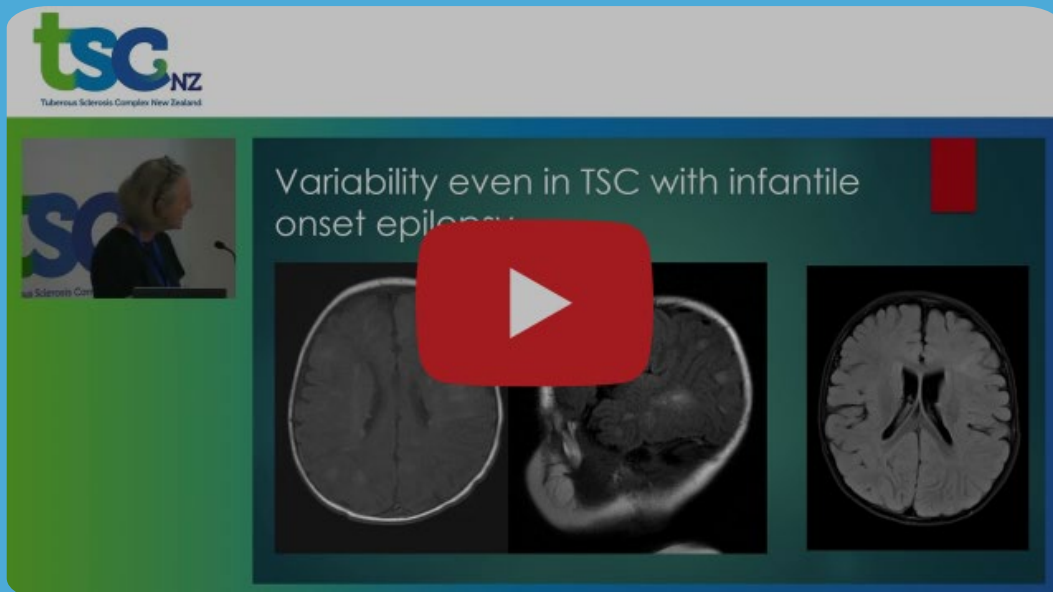
The collage features several resource materials:

- Left Panel:** A brochure titled "We think all individuals and families living with TSC should have someone to turn to..." with a quote from a parent and contact information for TSCNZ.
- Middle Panel:** A brochure titled "Connect with us to find out more & support our work" featuring a QR code and social media links for TSCNZ.
- Right Panel:** A brochure titled "Tuberous Sclerosis Complex" with a photo of a smiling child and the text "Information and support for people with Tuberous Sclerosis Complex and their families".
- Bottom Row:** Three informational graphics:
 - About TSC:** Explains that TSC is a genetic disorder affecting approximately 1 in 6,000 births, caused by mutations in the TSC1 or TSC2 genes.
 - Signs and Symptoms:** Lists various symptoms such as skin lesions (shagreen, facial angiofibromas), kidney issues, and neurological symptoms.
 - Tuberous Sclerosis Complex New Zealand [TSCNZ]:** Provides information about the local support organization, including its website and social media presence.

We share a [private group on Facebook](#) with Tuberous Sclerosis Australia - *Discussions of Tuberous Sclerosis in Australia and New Zealand* which is a great place to go with a specific question or to offer support to others.

This newsletter's featured video: Dr Claire Spooner talked about TSC and Epilepsy at the TSCNZ 2023 Conference.

Check out the [TSCNZ You Tube Channel](#) for more videos from our conferences.



The Tuberos Sclerosis Australia [Resources](#) webpage has a wealth of information to read online and/or download, including...

- [Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder](#)
- [Identifying emerging challenging behaviours in young children with TSC](#)
- [An introductory guide to TSC for teachers and educators](#)
- [How to be a good advocate for your child with TSC at school](#)
- [Sex and sexuality in young adults with TSC](#)
- [Life expectancy of people living with TSC](#)
- [Getting the most out of a visit to your GP](#)

Upcoming Dates

- 15 May 2025: TSC Global Awareness Day
- 9 June 2025: TSCNZ Committee Meeting (online)
- 4 August 2025: TSCNZ AGM (online)



SUPPORT OUR WORK

If you need information or support on any aspect of living with TSC
please [email us](#) or call 021 154 7017