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TSCNZ - Newsletter 28, January 2026



# Tuberous Sclerosis Complex New Zealand

Inform | Connect | Support

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## Rounding up 2025 for TSCNZ

You can read our 2024/2025 Performance Report & Review [here](#)

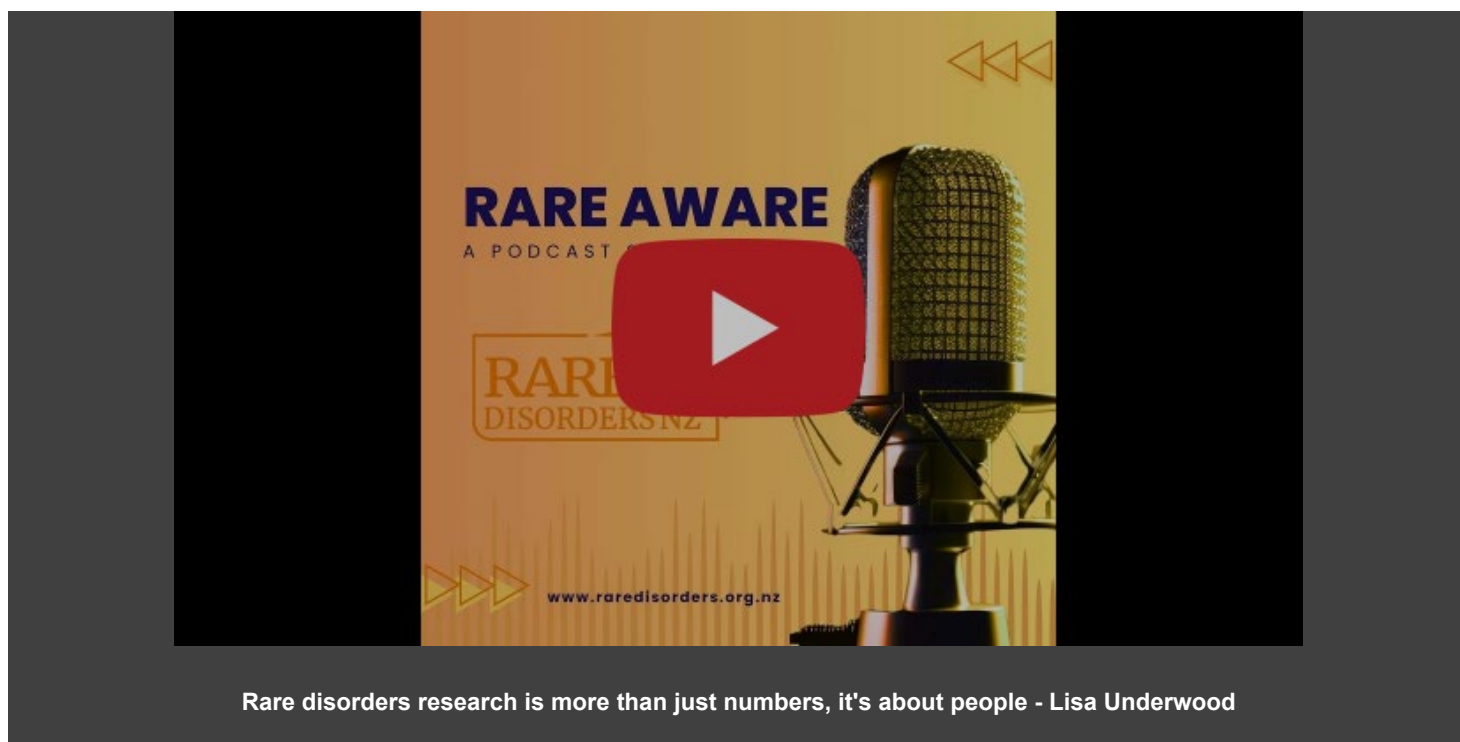
We also had a lovely catch up in Christchurch & started planning for our next National Conference!

We supported Rare Disorders NZ with their advocacy work which had some great wins, read more [here](#).

TSCNZ Community Organiser Lisa was interviewed for the Rare Aware podcast about TSC & her Rare Disorders research.

Listen to the podcast below, [here](#) or on [any major platform](#)

|                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                  |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Financial support</b><br>\$10,626 from fundraising, grants & donations<br><a href="#">New Fundraising Sheet</a>                                                                                                                                                                                   | <b>Events</b><br>👥 3 Get-togethers for Rare Disorders Month<br>🏆 Judging at the Rare Beer Challenge                                                                                                                              |
| <b>Website</b><br>📄 New page for TSC Stories from our community<br>🔍 New Search function<br>Updated Who are we? Page<br>Updated TSC Heroes information                                                                                                                                               | <b>Resources</b><br>📄 4 Newsletters sent to mailing list<br>✅ TAND Checklists: <a href="#">multi-lingual downloads</a> & Duraprint hard copies<br>📄 TS Australia Clinician/GP Guide<br>📄 Everolimus & Sirolimus talk/video       |
| <b>Community organiser</b><br>Funded for up to 16 hours a month<br>Providing <a href="#">email &amp; phone support</a><br>Sending out <a href="#">resources</a>                                                                                                                                      | <b>Committee</b><br>6 Committee members<br>6 Management meetings<br>AGM 2024                                                                                                                                                     |
| <b>Advocacy</b><br>Campaigned for:<br>Pharmac funding for topical sirolimus<br>Implementation of Rare Disorders Strategy<br>Represented TSC community at <a href="#">Rare Disorders NZ &amp; Neurological Alliance</a> meetings<br>International liaison with <a href="#">TSC &amp; TS Australia</a> | <b>Achievements</b><br>Helen Willacy (TSCNZ President) nominated for Rare Disorders NZ 25th Anniversary award<br>Increased <a href="#">mailing list</a> to 90 subscribers<br>Increased followers on <a href="#">social media</a> |



Rare disorders research is more than just numbers, it's about people - Lisa Underwood

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## Looking forward to 2026...

### Call for volunteers!

We are in need of a new Treasurer and would welcome any other new Committee Members from the TSC Community.

If you could spare a few hours a month to serve on the TSCNZ Management Committee, please email us at [info@tsc.org.nz](mailto:info@tsc.org.nz)

### TSCNZ National Conference

Our next conference will be in Christchurch following on from previous successful events in [Wellington](#) and [Auckland](#)

Keep an eye out for news on this in the new year!

We'll be in touch to ask your views on the topics we should cover.

If you have any ideas to share or could join our Conference Working Group (especially if you're in Canterbury), please let us know.

We have set up a dedicated Givealittle page for the conference:  
<https://givealittle.co.nz/cause/tscnz-national-conference-fundraiser>

# Fundraising for TSCNZ

**If you'd like to fundraise for TSCNZ, you can...**

**Download our [fundraising information sheet](#) to print or send out.**

**Ask people to make a one off donation directly to us via:**

- <https://givealittle.co.nz/donate/org/tscnz>
- <https://givealittle.co.nz/donate/cause/tscnz-national-conference-fundraiser>

**They can mention your fundraising activity in the comment section.**

**Or, set up your own TSCNZ Fundraiser page on Givealittle via:**

- <https://givealittle.co.nz/org/tscnz/fundraise>
- <https://givealittle.co.nz/cause/tscnz-national-conference-fundraiser/fundraise>

**More information is available here: <https://www.tsc.org.nz/support-us>**

## Donating to TSCNZ

**We appreciate any donation you can give, so we can 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 <https://givealittle.co.nz/org/tscnz>**

Alternatively, you can 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](mailto:info@tsc.org.nz) to let us know so that we can send a donation receipt.

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

**Click here to buy TSC Hero t-shirts. 10% of sales go to TSCNZ!**

**July 30 to August 1 2026**



Information on how to register & scholarships for conference fees and accommodation here: [www.tscalliance.org/event/2026-tsc-world-conference/](http://www.tscalliance.org/event/2026-tsc-world-conference/)

**New research on:**

- The safety and effectiveness of mTOR inhibitors for SEGAs <https://tsa.org.au/research/38556/>
- Long-term cannabidiol use for seizures <https://tsa.org.au/research/long-term-cannabidiol-use-for-seizures-in-tsc/>

**New information from the UK on TSC genetics:**  
<https://tuberous-sclerosis.org/no-two-stories/>

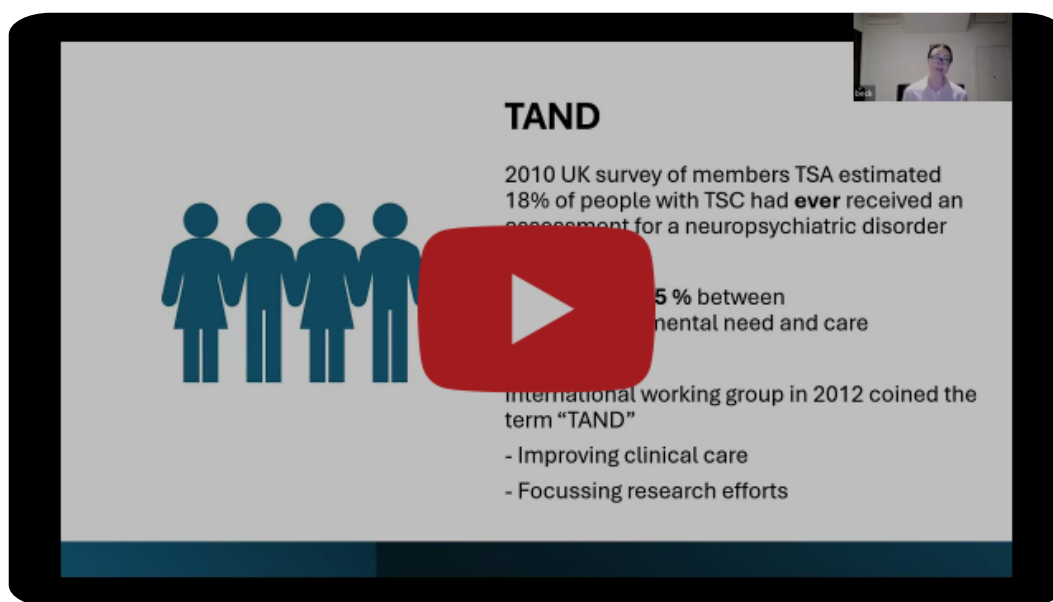
**All TSCNZ's resources are available to download from our [website](#) but [please get in touch](#) if you'd like hard copies and we'll post them out.**

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

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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 Beck Mitchell, a developmental paediatrician, researcher, and member of TS Australia's Medical Advisory Panel shares her expertise on understanding [TAND](#).



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## Upcoming Dates

2 February 2026: TSCNZ Committee Meeting (online)

28 February 2026: Rare Disease Day

March 2026: Rare Disorders Month



**SUPPORT OUR WORK**

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

