

# Tuberous Sclerosis Complex

New Zealand

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## TSC Global Awareness Day May 15

Global Awareness Day is a great time to raise awareness of TSC and support for TSCNZ. Our small volunteer committee achieves a lot on a very small budget. Your support and the support of your friends, family and colleagues encourages and enables our work. This year we have a range of ways to get involved.

### For those who like Tattoos, Tea and Scones:

TSCNZ is pleased to announce that we are partnering with TS Australia in their very cool initiative – #Tatts4TSC. Sign up at [www.tsc.org.nz/tatts4tsc](http://www.tsc.org.nz/tatts4tsc) to order your temporary tattoos and organise a morning tea at your work, school, playgroup or home with Tea and Scones (Get it!?) or your own specialty. Collect a gold coin donation for TSCNZ and upload your photos of you and your guests wearing their tattoos to our facebook page or tag #Tatts4TSC.

### For the active:

Join our team at The Nugget Multisport Event in Waihi on Saturday 11 May. Register for The Nugget at <https://thenugget.co.nz/> and sign up as a fundraiser for TSCNZ at <https://givealittle.co.nz/event/thenugget4tscnz> or just ask your supporters to donate at [www.tsc.org.nz](http://www.tsc.org.nz).

### For the online community:

Tuberous Sclerosis International will be publishing 15 facts for the first 15 days in May leading up to May 15. We will share these on our Facebook page. Share them on your social media pages to raise awareness and knowledge. Use TSC profile picture frames on your own Facebook and Instagram profiles to get people talking about TSC, see <https://www.tscinternational.org/tsc-global-awareness-day/>.

### For the creative:

We are very open to hearing your ideas. In other parts of the world TSC groups have persuaded councils and companies to light up buildings blue in support of TSC. If anyone has a contact in that area, let's do it! Contact [info@tsc.org.nz](mailto:info@tsc.org.nz) to let us know how you are raising awareness.



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Thanks to Clare

## Upcoming Events

**11 May**

The Nugget Multisport Festival, Waihi.



**15 May**

TSC Global Awareness Day



**Saturday 15 June**

Management Committee Meeting

TSCNZ AGM Owen G Glenn building, Auckland University

## RESEARCH NEWS

### New Zealand Research into Topical Treatment for Angiofibromas

We are delighted to announce that planning is underway for New Zealand to be one of the centres for a clinical trial of a new formulation of topical rapamycin.

At present it is looking like South Islanders living with TSC will be invited to take part. Travel costs will likely be reimbursed for the initial clinic and subsequent follow up visits required to monitor progress.

**Anyone interested in participating is welcome to contact [caroline.mahon@cdhb.health.nz](mailto:caroline.mahon@cdhb.health.nz) if they have any questions. More information about the trial is available at <https://clinicaltrials.gov/ct2/show/NCT03826628>. Scroll down for the Eligibility Criteria.**

### Prof Petrus de Vries TAND Research Project

Congratulations to Prof Petrus de Vries, Prof Anna Janzen and Eva from the Belgian TSC organisation on securing funds for this exciting worldwide project to help researchers and clinicians better understand and treat neuropsychiatric disorders.



"The two-part project will first focus on the development of a self-report TAND checklist and identification smartphone app, to measure how people are affected by TAND.

The second part of the study will investigate the best ways to treat TAND, including agreement on suitable clinical guidelines for TAND."

### Gene Sequencing Study Opportunity

Mind for Minds have spaces left in their genetics study. They are sequencing individuals with features of ASD to develop, and transfer into clinical practice, novel technologies, materials and protocols for cost-effective screening of the most frequently affected genes in individuals diagnosed with ASD.

If you are interested contact [arnnz@auckland.ac.nz](mailto:arnnz@auckland.ac.nz) or visit <http://www.mindsforminds.org.nz/sequencing-study-opportunity/>.

## TSCNZ Annual General Meeting

You are invited to attend TSCNZ's AGM on

**Sat 15 June @ 4pm**

Owen G Glenn building at the University of Auckland and on Zoom conference call for those unable to attend in person.

The AGM will be followed by a social get together dinner!

Please email [info@tsc.org.nz](mailto:info@tsc.org.nz) if you intend to attend

If attending the dinner there will be a cost of approximately \$40/head to be paid on the day.

Nominations for the position of President, Treasurer and Secretary need to be emailed to [info@tsc.org.nz](mailto:info@tsc.org.nz) by Saturday 8 June.

There is no expectation of joining the committee if you attend the AGM but new committee members are always welcome. We meet on a Monday evening bi-monthly by Zoom conference call. Health advocacy and fundraising skills would be greatly appreciated.

## Brain Day, Auckland

Leah and Helen were pleased to attend the community expo of Brain Day again this year at its new venue – the Faculty of Health Sciences of Auckland University. Thanks to the Centre for Brain Research for providing this opportunity and a fascinating range of activities, speakers and research about the brain. We loved our spot with the lime green background next to the balloon animals. A lot of our conversations began with “Tu..be..rous.. Scle.. ro..sis. I’ve never heard of that, what is it?” It was great to be able to raise awareness and give hopeful messages thanks to all the research that has improved care and treatments. Also wonderful to meet a family living with TSC.



## TSCNZ Resources Available

TSCNZ has published a number of resources including:

- 3-fold brochures
- Surveillance & Management Guidelines
- Balloons with the TSCNZ logo
- TAND (TSC Associated Neuropsychiatric Disorders) checklist
- Newsletters
- Stickers
- Tatts4TSC

Email your address to [info@tsc.org.nz](mailto:info@tsc.org.nz) and we will send you copies. They are also available as pdfs on our website [www.tsc.org.nz](http://www.tsc.org.nz)

## TSC Connect Brisbane 25 and 26 May 2019

*Are you an adult with TSC? You are invited to join TS Australia at their very first TSC Connect for adults living with TSC.*

The event will include TSC expert speakers, a chance to meet and connect with others living with TSC and an opportunity to discuss what further support you’d like. An informal dinner will be held on Saturday 25 May from 6:30pm.

Visit <https://tsa.org.au/tscconnect-2019/> for all the information and to register.

Unfortunately, TSCNZ is unable to offer travel grants this time. You may be able to apply to local grant organisations to assist with travel and expenses.



## Health and Disability Review

Have you ever wanted to let the government know about your suggestions for the health and disability system? Here is your chance!

The government is undertaking a review of the Health and Disability System. TSCNZ and NZORD will be making submissions but it would be great to have individuals give their feedback also. TSCNZ will be suggesting improved access to medicines for rare disorders and better systems for co-ordinated care across a range of medical specialties.

Go to <https://systemreview.health.govt.nz/overview/give-us-your-views/> to complete the survey. Submissions close 31 May 2019.



### CONNECTING WITH TUBEROUS SCLEROSIS ASSOCIATION

It was a pleasure to meet up with Julie Rainer, Information Officer for the UK TSC organisation Tuberous Sclerosis Association who was visiting New Zealand recently.

TSA has recently published a UK version of the clinical guidelines which is now available on their website [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org).

Thanks to Julie for sharing the information about their annual Tea and Scones fundraiser which we are combining with Tatts4Tattoos.



Inform, Connect, Support



Tuberous Sclerosis  
Australia



TSCNZ would like to acknowledge Clare Stuart's huge contribution to TSCNZ and the global TSC community. Clare has recently resigned as General Manager of TS Australia.

Clare has a wealth of knowledge and experience of TSC and health advocacy. She sourced the funding which enabled our first conference in New Zealand in 2014 which also led to the formation of TSCNZ. Clare has been with us every step of the way since then, generously sharing the resources TS Australia have developed and the experience they have gained in seeking the very best, empowered outcomes for individuals with TSC. I know many of us have benefited from her helpful, empathetic answers to questions about our individual TSC situations.

Clare has also been a positive, hard-working member of the Tuberous Sclerosis International committee and we thank her for her work supporting TS organisations world-wide.

We wish Clare and her family all the best for the future and welcome new General Manager Jackie Gambrell to the TS Australia team.