

Tuberous Sclerosis Complex

New Zealand

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TSCNZ PICNIC DAYS SUNDAY 28 FEBRUARY

We're marking Rare Disease Day with get-togethers from 2-4pm on Sunday 28 February. Our new brochure of the Surveillance and Management Guidelines will be available. Grab a coffee or bring a picnic and enjoy a summer afternoon with the TSC community.

Auckland/Northland, Mission Bay Playground. Contact Janet 021 216 1322
Waikato/Bay of Plenty, Hamilton Lake Domain. Contact Helen 021 154 7017
Canterbury, Christchurch Botanical Gardens Playground. Contact Aeny 021 056 8224.

We'd love to hold picnics in other parts of the country. If you are able to coordinate one in your area, please contact us on info@tsc.org.nz and we'll send you an information pack and promote it on our facebook page and website.

Australian Tuberous Sclerosis Conference

Thanks to the committee of TSCNZ for the grant which enabled me to travel to Sydney to attend this informative conference in November 2015. It was a very busy programme with some exciting new learning for me and a good opportunity for relationship building with members of the TSC community, both patients and professionals.

All speakers' videos are available online on the Tuberous Sclerosis Australia's youtube channel and I encourage you to use them as resource, <https://www.youtube.com/playlist?list=PLj3QmZGRXBIDs5Uq0Izbsk-7wUHegumI>

Highlights of the programme for me were:

- Dr Elizabeth Thiele's talk which included a clear summary of the history and efficacy of using marijuana to treat epilepsy. Clinical trials are underway for pharmaceutical grade cannabidiol (CBDV).
- Dr Lisa Henske' explanation of the science of the TSC/LAM cells and the possibility of a cure for TSC through killing the TSC cells.
- Our very own committee member Dr Lisa Underwood's excellent talk on TSC Associated Neuropsychiatric Disorders (TAND).
- The talk on the genetics of TSC by Dr Chirag Patel.

By Helen Willacy, President, TSCNZ

TSCNZ Brochures Available

Need help explaining TSC to school, friends or family?

Email your contact details to info@tsc.org.nz and we will send you copies of our brochure.



SURVEILLANCE AND MANAGEMENT BROCHURE

We are delighted to have been able to partner with Tuberous Sclerosis Australia to produce a readable, glossy brochure containing the recommendations for surveillance and management of TSC. A great resource for giving to your clinicians and GPs. Contact info@tsc.org.nz to order your copies or come along to the picnics where we have them available.

Fundraising Update

Thanks to those who have joined TSCNZ as members. If you would like to continue to receive the printed copy of Reach Out magazine and this newsletter two times per year, please email us your details or ask us for an application form. Your \$30 annual fee will cover the cost of supplying Reach Out and help with our ongoing expenses. Your membership fee can be deposited into the bank account Tuberous Sclerosis Complex NZ, 03 1550 0447063 00



Thanks very much to Rachel Salmond and Industrial Tube Manufacturing Co Ltd for their generous donations over Christmas.

Brain Day

TSCNZ committee members will be manning a community stall at this year's Brain Day to be held at Tamaki Campus of the University of Auckland on Saturday 12 March. Come on down, say hello and help raise awareness of TSC! The Brain Day programme features the latest research findings, brain health workshops, discussion groups and talks, engagement with community groups, interactive research labs, brain activities for all ages – including science experiments for children

Committee News



Every wondered who is on our committee? Introducing Leah... Hello, my name is Leah Bos. I'm 33 years old, I live in Whangarei and I have TSC. I was diagnosed at roughly 15 months diagnosed by an "ashleaf" white patch on thigh. I have the characteristic angiomyliomas (kidney lesions), angiofibromas (red raised rash) over my cheeks and chin, to name a few. I decided to join TSCNZ to help advocate with people by spreading awareness and share knowledge and my experiences. It's always a pleasure to be a part this community, to help and inform.

Upcoming Events

28 February

Picnics for Rare Disorders Day

12 March

Brain Day 9am-3pm Tamaki Campus, University of Auckland, 261 Morrin Rd, St Johns, Auckland

13 March

Committee meeting, Auckland

15 May

Global Awareness Day- a great opportunity to raise awareness and funds in your local area.

16 July

TSCNZ AGM

Facebook

Remember to sign up to the closed group *Discussions of Tuberous Sclerosis in Australia and New Zealand* if you would like to connect online with others living with TSC.