

Tuberous Sclerosis Complex

New Zealand

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TSCNZ AGM

TSCNZ's second AGM was held on 17 July at the McKenzie Centre in Hamilton. The management committee elected for the 2015/2016 year are Helen Willacy (President), Janet Sharp (Secretary), Helen Gempton (Treasurer), Leah Bos, Lisa Underwood and Amanda Sayer. Our main project for 2017 will be a national conference, tentatively in Wellington. If you are keen to get involved in the management of TSCNZ or organization of the conference, please email info@tsc.org.nz and let us know how you would like to help. We welcome volunteers for the committee or specific projects. The committee usually meets bimonthly on Skype so distance is no barrier.

Annual Memberships are now due for renewal. The \$30/year fee helps us provide Reach Out magazine and continue to cover our modest operating costs. A membership form is enclosed. Your membership fee can be deposited into the bank account Tuberous Sclerosis Complex NZ, 03 1550 0447063 00. Please put your name and membership in the reference fields and email your contact details to secretary@tsc.org.nz.

See Page 3 for Helen Willacy's report on TSCNZ's activities for the past year.



Fundraising Success

A huge thanks to Nicky Geary, superstar TSC Mum, for fundraising \$2500 for TSCNZ making and selling preserves on Global Awareness Day!



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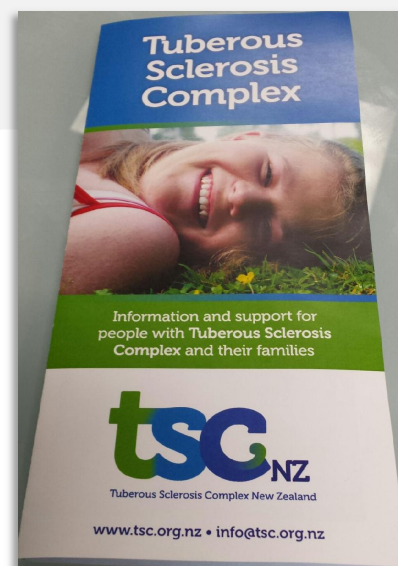
President's AGM Report

Upcoming Events

2017

National Conference

More details coming soon



Research News

TSCNZ is excited to announce the first New Zealand-specific research project into TSC. Dr Lisa Underwood will be working with a medical student on a summer scholarship to look at national hospital data to find out some baseline data about how many individuals there are in New Zealand with TSC and which medical services they are most likely to access. We hope this will help us advocate for more co-ordinated care for people living with TSC.



THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

Recent Kidney Paper

S. Brakemeier, F. Bachmann & K. Budde have recently published a paper in the journal Paediatric Nephrology entitled, Treatment of renal angiomyolipoma in tuberous sclerosis complex (TSC) patients. It is a concise summary of the trials using mtor inhibitor to treat angiomyolipoma and suggests future directions for treatment.

Facebook

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. <https://www.facebook.com/groups/AuTSC/>

TSC Professionals Network

TSCNZ have established a network of professionals in the TSCNZ domain who want to be keep up to date with the happenings of TSCNZ. They receive newsletters and any other important notifications from us. If you have anyone in particular that is linked to your family, please ask them if they would like to be part of this network. The more people we add to this network the wider our community becomes and knowledge can be spread and shared. We are teaming up with NZORD to help other health professionals know about our New Zealand experts in TSC.

TSCNZ Resources Available

TSCNZ has published a number of resources including:

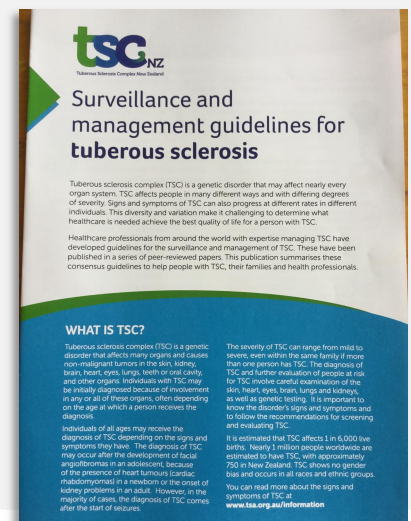
3-fold brochures

Surveillance & Management Guidelines

Balloons with the TSCNZ logo

TAND (TSC Associated Neuropsychiatric Disorders) checklist

Email your address to info@tsc.org.nz and we will send you copies. They are also available on our website www.tsc.org.nz

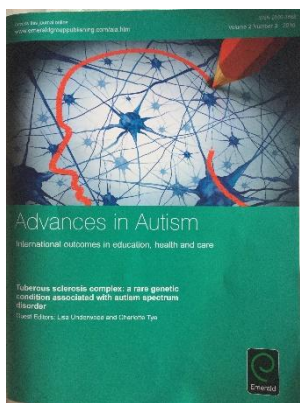


President's Report for Tuberous Sclerosis Complex NZ 2nd AGM

The second year of Tuberous Sclerosis Complex New Zealand has been one of consolidation as we refined our purpose and continued to work towards achieving our overarching goal of informing, supporting and connecting the New Zealand TSC community.

This year TSCNZ's achievements include:

- a. Launching a membership scheme by inviting members of the TSC community to support TSCNZ's work through a \$30 membership fee. 13 individuals and families joined the society
- b. The committee met 4 times via teleconferencing to exchange information, views and ideas and administer the society. The committee also met in person in Auckland in March to discuss strategic planning. Short-term and mid-term goals were identified including developing the website, advocating for more co-ordinated multi-disciplinary care and access to medicines, developing relationships with other groups in the sector and supporting research into TSC in NZ.
- c. Lisa Underwood, Helen Willacy and Dr Murray Leikis attended and presented at the Tuberous Sclerosis Australia conference in Sydney, November 2015. Travel grants were offered but no-one from the TSC community were able take them up. This highlights a need for NZ based activities.
- d. TSCNZ liaised with Tuberous Sclerosis Complex International (TSCi) to send Dr Murray Leikis, a NZ kidney specialist to the TSCi meeting and international TSC research conference in London, UK, September 2015.
- e. 3 fold brochures, and brochures of the International Surveillance Guidelines were printed and distributed to individuals and families with TSC and relevant medical professionals. The website www.tsc.org.nz was updated. Four newsletters and two issues of ReachOut magazine were sent to members and people in the TSCNZ network. Business cards were printed for officers to distribute.
- f. Support was provided by email, phone, a picnic day to mark Rare Disorders Day and the facebook pages <https://www.facebook.com/TSCNZ> (153 likes), <https://www.facebook.com/groups/AuTSC>.



g. Lisa Underwood, a committee member of TSCNZ edited and contributed to an international research journal Advances in Autism special issue on TSC. Helen Willacy, President of TSCNZ wrote an article on the impact of TSC on a family which was published in the journal.

h. Committee and community members held a stall at the community expo at Brain Day held at Auckland university in March, 2016. This was an excellent opportunity to network with other groups and raise awareness of TSC amongst the public.

i. TSCNZ took part in TSCi's global awareness day campaign in May, publishing the 31 Facts on our Facebook page and contributing videos to the global awareness day video.

j. The society was successful in attracting financial support through donations totalling \$7,870.00. Special thanks to Industrial Tube and Nicky Geary for their generous donations and fundraising efforts.

The committee has put many volunteer hours into making these achievements happen and I would like to thank them very much for their efforts. I would also like to acknowledge the time that Jacqui Stokes has donated working on the website and Vanya Wallis with book-keeping. Thanks also to NZORD and Tuberous Sclerosis Australia for their support this year.

Helen Willacy

July 2016