

Tuberous Sclerosis Complex

New Zealand

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CHRISTCHURCH ROADSHOW

TSCNZ held our first event in the South Island with committee members Amanda Sayer and Helen Willacy heading to Christchurch in October to present at an evening seminar.

Amanda Sayer shared her family's inspirational story about living with TSC and Helen Willacy spoke about the Management and Surveillance Guidelines, advocacy and the work of TSCNZ. It was lovely to meet some newer families and reconnect with some familiar faces. We hope you went home feeling a little more informed, connected, supported - and full of supper!



Upcoming Events

2017

10 December TSC Management Committee meeting on conference call

2018

Wed 28 February
Rare Disease Day
Great opportunity for fundraising/TSC awareness raising/connecting

Oct/Nov NZ TSC conference

Radiology Talk at Middlemore Hospital

Leah Bos and Helen Willacy were delighted to raise awareness of TSC at a Continued Professional Development Education session for 20 radiologists and radiology trainees at Middlemore Hospital. Leah's story of her journey with TSC, complete with gasp-inducing MRI images, highlighted the need for ongoing surveillance in people with TSC and informed the group about newer therapies such as m-tor inhibitors.

A couple of examples of the positive feedback received...
"Very informative, never knew about TSC - so great to have that understanding. Amazing to have Leah talk about her journey! Gives a real insight to TSC." "Very well presented, nice to get an idea from an individual and family that have been affected. Also great to see how our job is related to your diagnosis and treatment."



Lisa Goes to Washington

Thanks to committee member Lisa Underwood for representing New Zealand at the TSCi Improving Care workshop, early career research meeting and International TSC research conference in Washington DC in June. Lisa presented a poster on her and Alex Lewis's research into TSC in New Zealand which was well-received. The meeting with other TSC organisations showed common ground in struggles and successes. See insert for more information.

Membership

It's that time of year when we ask our TSC community to renew their annual membership. Your \$30/year really helps our organisation inform, support and connect New Zealanders living with TSC.

Financial members receive a copy of TS Australia's excellent magazine *Reach Out*

2018 is shaping up to be an exciting year for TSCNZ with a national conference planned along with a website re-vamp. We look forward to your continued support.

Thanks!

To Silver Lining Charitable Trust for their generous donation.

AGM News

The 3rd AGM for TSCNZ was held in Auckland on a very wet, cold afternoon in July. All management committee members were re-elected and Frances Morton was elected for the first time. Frances is a journalist and aunty of an individual with TSC. New committee members are always welcome. Please email info@tsc.org.nz if you would like to be involved. The President Helen Willacy presented the following report.

Tuberous Sclerosis Complex New Zealand has had another successful year informing, supporting and connecting the New Zealand TSC community. Highlights include supporting Dr Lisa Underwood and medical student Alex Lewis undertake research into New Zealanders affected by TSC and strengthening networks with professionals and families.

This year TSCNZ's other achievements include:

- a. Maintaining a mailing list of 51 individuals, families and professionals in the TSC community including 14 financial members
- b. The management committee met 6 times via teleconferencing to exchange information, views and ideas and administer the society.
- c. Two newsletters and two issues of ReachOut magazine were sent to members and people in the TSCNZ network. Two other email updates were emailed to the TSCNZ network.
- d. Support was provided by email and phone and the facebook pages <https://www.facebook.com/TSCNZ> (204 likes) and <https://www.facebook.com/groups/AuTSC>.
- e. Information packs including brochures on TSC, surveillance and management guidelines, TAND checklist were sent to newly diagnosed families and new contacts.
- f. Committee members held a stall at the community expo at Brain Day held at Auckland University in March, 2017. This was an excellent opportunity to network with other groups and raise awareness of TSC amongst the public.
- g. 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.
- h. The society was successful in attracting financial support through donations totalling \$5498.50. Special thanks to the Geary family, Industrial Tube and Ruth Morton 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. Thanks also to NZORD and Tuberous Sclerosis Australia for their continued support this year.

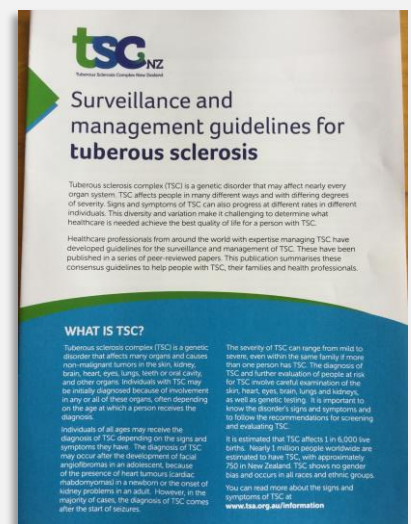
INFORM, CONNECT, SUPPORT

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 as pdfs on our website www.tsc.org.nz



TSCNZ

Topical Sirolimus Cream for Facial Angiofibromas

TSCNZ has had several queries about the availability and access to Sirolimus cream for facial angiofibromas. Here is the process that several individuals and families have followed to trial the treatment.

Process for Accessing Topical Sirolimus in NZ

1. See a dermatologist or another specialist who is willing to prescribe the cream. You can do this through the public hospital by asking your GP to refer you. This could be a long waiting list however. The other option is to go to a dermatologist in private practice which will cost several hundred dollars. Taking along copies of journal articles can be helpful to inform the dermatologists if they do not know about topical sirolimus already (although most do). Here are a couple of links to relevant papers.

<http://onlinelibrary.wiley.com/doi/10.1111/ajd.12125/full>, <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-0960.2011.00837.x/abstract>

2. The dermatologist can apply for a Special Authority from Pharmac to fund the cream. These are issued for a period of time (usually 12 months) but seem to be renewable fairly easily. It is quite a lengthy form for doctors to fill in. Without a special authority the cream costs around \$400 for a 6 month supply.

3. Get the prescription filled. A compounding pharmacy needs to make up the prescription and some people have experienced difficulty getting this done. You could ask the dermatologist to recommend a pharmacy. You may still have to pay something for the prescription. Gisborne Hospital Pharmacy has compounded it and sent it to patients around the country so they would be worth a call if you experience difficulty getting the prescription filled. Optimus Healthcare Limited in Penrose also compound the cream and supply pharmacies.

4. Apply as directed and hopefully have good results!



Thanks to Tuberous Sclerosis Australia for making their excellent information events available to New Zealand viewers. It was fantastic to be able to live stream into their recent family information day in Melbourne. Most sessions from that meeting are now online on Youtube.

The two webinars on the Genetics of TSC by Dr Chirag Patel and Emerging Treatments for epilepsy by Dr John Lawson were also highly informative and clearly presented. They are available to view online at www.tsa.org.nz

Best wishes for the festive season and a joyful 2018