

# Tuberous Sclerosis Complex

New Zealand

[www.tsc.org.nz](http://www.tsc.org.nz), [www.facebook.com/TSCNZ](https://www.facebook.com/TSCNZ)

## First AGM held

The first AGM of TSCNZ was held on Saturday 13 June in Katikati. Thanks to those who travelled or joined us on the teleconference. It was a time to reflect on the many achievements of our first year and make plans for the year to come.

Thanks to our founding donors and some significant donations, the organization is in a sound financial position to continue and grow its work. As you will see from the membership letter attached to this newsletter, we are requesting a membership donation of \$30/year so that we can provide Reach Out magazine and continue to cover our modest operating costs. Please consider supporting TSCNZ in this way.

A new management committee was elected at the AGM along with office holders for the 2014/2015 year. The committee are Helen Willacy (President), Janet Sharp (Secretary), Helen Gempton (Treasurer), Leah Bos and Lisa Underwood. Jacqui Stokes has kindly taken on the role of Website and Amanda Sayer will be managing our grant applications. If you are keen to get involved in the management of TSCNZ, please email [president@tsc.org.nz](mailto:president@tsc.org.nz) and let us know how you would like to help.

We farewelled Martina Kavanagh who is moving on from the Treasurer position and thanked her for her valuable contribution to the establishment of TSCNZ.

Our major project for this year is to help enable New Zealanders to attend the TS Australia conference which will be held in Sydney on 14/15 November. We are delighted to be able to offer a limited number of travel grants. Read on in this newsletter for more details.



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Travel Grant Applications open for TS Australia Conference

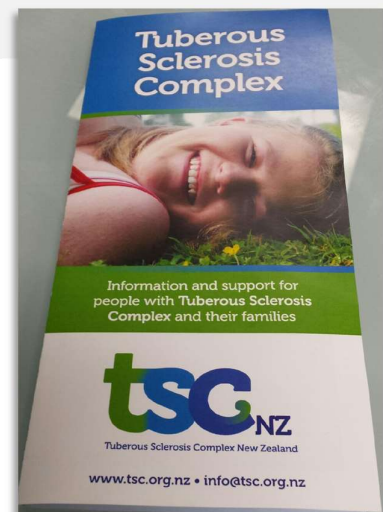
Medicine News

TSC Global Awareness Month

## TSCNZ Brochures Available

Need help explaining TSC to school, friends or family?

Email your contact details to [info@tsc.org.nz](mailto:info@tsc.org.nz) and we will send you copies of our brochure.



## TRAVEL GRANTS TO SYDNEY

We have a limited number of grants of up to the value of \$500 available to assist with travel costs for individuals with TSC and the families of people with TSC to the 2015 Australian Tuberous Sclerosis Family and Medical Conference to be held at the University of NSW in Sydney 14/15 November 2015.

This will be a fabulous opportunity to learn more about recent developments in TSC research and to meet with individuals and families from around Australia and New Zealand. There is also a stream for medical professionals so please tell your doctors about it!

Please email [info@tsc.org.nz](mailto:info@tsc.org.nz) for information about how to apply for a travel grant. Priority will be given to people who have not yet attended a conference and TSCNZ volunteers.

For more information about the conference visit [tsa.org.au/2015-conf/](http://tsa.org.au/2015-conf/).

## Medicine News

### Everolimus Funded for SEGAs

In 2014 PHARMAC approved funding in New Zealand for the mTOR inhibitor Everolimus (Afinitor®) for the treatment of progressively enlarging sub-ependymal giant cell astrocytomas (SEGAs) subject to some conditions. Go to [www.pharmac.govt.nz/HMLOnline.php?osq=everolimus](http://www.pharmac.govt.nz/HMLOnline.php?osq=everolimus) for more information. Some patients have also been successful at getting individual funding for Sirolimus or Everolimus from PHARMAC for kidney angiomyolipomas (AMLs) under the NPPA category. Please talk to your Doctor about what is available for you.

### FDA approves Sirolimus for LAM

The US Food and Drug Administration (FDA) recently approved the mTOR inhibitor Sirolimus (Rapamune®) to treat lymphangiomyomatosis (LAM), the lung disease which occurs in some individuals with TSC. This is the first drug approved to treat the disease in the USA. This is often the first step to getting a drug funded in other countries such as New Zealand although this is not a quick process. More info at

[www.fda.gov/newsevents/newsroom/pressannouncements/ucm448523.htm](http://www.fda.gov/newsevents/newsroom/pressannouncements/ucm448523.htm)



## Give a Little Campaign

**We would love to be able to offer more people the opportunity to attend the Sydney conference.**

Please share this crowd-funding campaign with your friends and family on facebook, twitter, email or any way you can to help raise funds and awareness.

[www.givealittle.co.nz/cause/tscconference#](http://www.givealittle.co.nz/cause/tscconference#)

### Global Awareness Month

TSCNZ got on board with TSC International's Global Awareness Day with gatherings held in Auckland, Tauranga and Christchurch. The Fact of the Day campaign on Facebook for the month of May was informative and helped raise awareness of TSC.

Special thanks to Nicky Geary for her amazing effort on Global Awareness Day selling jams and chutneys to her generous colleagues at Zespri NZ Ltd and raising over \$2000 for TSCNZ. Also thanks to Private Asset Management for their donation.