

# Tuberous Sclerosis Complex

New Zealand

[www.tsc.org.nz](http://www.tsc.org.nz) [www.facebook.com/TSCNZ](https://www.facebook.com/TSCNZ) [info@tsc.org.nz](mailto:info@tsc.org.nz) 0211547017



## Travel Funding Available to Sydney Conference, 2-3 May 2020

TSCNZ are delighted to announce that, thanks to the generosity of our donors, we have a limited number of travel grants available to support New Zealanders to attend TS Australia's conference. Email [info@tsc.org.nz](mailto:info@tsc.org.nz) to express your interest and request the information.

The TSC Conference 2020 is taking place in Sydney on May 2 and 3. This is a unique opportunity to find out more about TSC, latest treatments and research and to meet other people living with TSC and expert TSC health professionals. To find out more and to register go to <https://tsa.org.au/tsc-conference-2020/>. The Early bird rate is open until 29 February

Dr Darcy Krueger (pictured), Director of the Tuberous Sclerosis Clinic and Associate Professor of Clinical Pediatrics and Neurology at Cincinnati Children's Hospital Medical Center, will be the keynote speaker. Dr Krueger will join local and national experts in discussing the diagnosis and management of TSC with topics including epilepsy, autism and the evolution of new treatments such as mTOR inhibitors and cannabinoids. The conference, which only takes place every four or five years, has two streams—one for people affected by TSC (TSC Community) and another for TSC Health Professionals.



These conferences are always hugely informative and supportive.

## World TSC Conference, Dallas 2022

Save the date: end of July 2022 and start considering and saving! TSCNZ would love to encourage a contingent of New Zealanders to attend the next World TSC Conference in Dallas.

## IN THIS ISSUE

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## Upcoming Events

### 4 April

Brain Day at Grafton Campus, the University of Auckland, 85 Park Road, Grafton

Committee Meeting, Auckland

**2-3 May** Sydney Conference

### 15 May

TSC Global Awareness Day  
Tatts4TSC T & Scones



### 17 May

TSC Global Awareness Day  
Gatherings

### Mid July

TSCNZ AGM

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## RESEARCH NEWS

### New Zealand Research into Topical Treatment for Angiofibromas

The trial of topical rapamycin/sirolimus cream based in Christchurch is now underway. Thank you to those in our community who are taking part. The researchers would love to recruit some more participants. Travel funding is now available for anyone living in the South Island. People living with TSC between the ages of 6 and 65 are invited to take part. This is a great opportunity to be part of the research with the potential to improve life and access to effective medicines for people with TSC.

**Anyone interested in participating is welcome to contact Malina Storer on 03 364 1157 or [malina.storer@cdhb.health.nz](mailto:malina.storer@cdhb.health.nz). More information about the trial is available at <https://clinicaltrials.gov/ct2/show/NCT03826628> or contact [info@tsc.org.nz](mailto:info@tsc.org.nz) for an information sheet.**

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### TSC Global Awareness Day 15 May 2020

*TSCNZ has two major events running for this year's global awareness day.*

#### **TATTS 4 TSC**

*Raise awareness and funds for TSCNZ by holding a morning tea – could be Tea and Scones or your own specialty on Friday 15 May. For a bit of fun, give your guests a temporary tattoo so they can show their support in a tangible way. Go to [www.tsc.org.nz/tatts4tsc](http://www.tsc.org.nz/tatts4tsc) to register your event and order your tattoos.*

#### **TSC Global Awareness Day Gatherings Sunday 17<sup>th</sup> May**

*An opportunity for the TSC community to meet for a coffee and a chat. Gatherings will be held in Whangarei, Auckland and Tauranga. Email [info@tsc.org.nz](mailto:info@tsc.org.nz) if you would like to host one in your area.*

## Feedback from PHARMAC

The application for mTOR inhibitors for the treatment of complications associated with TSC was considered by the Pharmacology and Therapeutics Advisory Committee at its meeting held in November 2019.

We are delighted that the committee recommended that an mTOR inhibitor be funded for the treatment of refractory epileptic seizures (high priority) and clinically significant complications resulting from tuberous sclerosis complex (TSC) (medium priority).

PHARMAC will now consider this recommendation and make the decision on whether to fund the medicines. TSCNZ has asked for information on time frame for this decision.

Thank you to all those who contributed to our submission and to the clinicians who also made submissions. This is a step in the right direction for access to medicines for NZers living with TSC.

## Fair for Rare Campaign Launch to mark Rare Disease Day

You're invited to Rare Disorders NZ's Fair for Rare campaign launch at Parliament on Friday 28<sup>th</sup> February. RSVP to this link <https://forms.gle/dSSWK3gRsEfM562cA>.



**Dr Liz Craig MP**

Invites

you

to

***Fair for Rare NZ campaign launch***

**Friday 28 February 2pm to 4pm**

Grand Hall, Parliament Buildings, Wellington

Rare disorders collectively affect 300,000 New Zealanders – more than those diagnosed with diabetes. Rare Disorders NZ, and the support groups they represent, are calling for acknowledgement of the common challenges faced by people living with a rare health condition, along with a commitment to address these challenges through the development of a New Zealand National Rare Disorder Framework.

This event, hosted in conjunction with Rare Disorders NZ, is part of Rare Disease Day 2020. It is also an opportunity to celebrate Rare Disorder NZ's 20<sup>th</sup> birthday. Please join us to commemorate two decades of supporting the rare disorder community.

Please RSVP using the link provided in the email.

Direct any questions to Susan Langston - [admin@raredisorders.org.nz](mailto:admin@raredisorders.org.nz)

All attendees will be vetted by Parliament Security prior to the event and will need to clear security on the day. Please arrive 15 minutes before the event.

