



## Tuberous Sclerosis Complex New Zealand

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Professor Petrus de Vries



Dr Anna Jansen

### **TAND+ Conference Grants** **Saturday 20th November 3pm-6pm NZT**

Kia ora koutou and welcome to this TSCNZ newsletter. We are excited to offer another opportunity to attend an excellent online education event thanks to TS Australia and TSCNZ's generous donors. Those of you who attended our Wellington conference will remember informative and empathetic key note speaker Professor Petrus de Vries.

This 3 hour virtual event via Zoom will focus on the updated TSC Management and Surveillance Guidelines which have recently been published. Significantly, this is the first update since 2013 and Dr Darcy Krueger, will be telling us what has changed and why.

Many of the updates are in the area of TAND (TSC Associated Neuropsychiatric Disorders). We know this can be one of the most challenging aspects of TSC for many families and adults living with the disease. You will have a unique opportunity to hear from two international experts in this field – Psychiatrist Professor Petrus de Vries and Paediatric Neurologist Dr Anna Jansen. They will discuss and answer your questions on:

- What is TAND?
- How does it present?
- Managing TAND – the latest research and the new clinical guidelines for identifying and treating TAND

This event provides a valuable opportunity for TSC-affected families and adults to hear from and ask questions of expert TSC health professionals and to connect with and learn from each other.

The event fee is just AU\$15 and covers everyone in your household for both days of the conference. However, we do not want anyone to miss out on participating due to the registration cost. Thanks to our generous donors, TSCNZ is able to sponsor a limited number of registrations for the conference. To access this support on the registration form, click on the option "I live in New Zealand and request sponsorship of my event fee from TSCNZ - \$ 0.00"

For more information and registrations go to <https://tsa.org.au/tandconference2021-virtual/>

Thanks to TS Australia for welcoming NZers to their information session on Sleep, an aspect of TAND which is hugely important to individuals and their families. If you missed or want to rewatch Associate Professor Honey Heussler's excellent zoom education event on sleep issues in children with TSC, it is now available on their website - [tsa.org.au/sleep](https://tsa.org.au/sleep)

**Register Here for TAND+**



## AGM News

We were lucky to be able to meet in person in Auckland on 1st August before our recent lockdowns. Thanks to those who attended at Crave and on Zoom.

The Management Committee for 2021/2022 is:

Helen Willacy (President)

Frances Morton (Secretary and Membership Officer)

Julianne Managh (Treasurer)

Ryan Powell

Lisa Underwood

We sadly farewelled Leah Bos after 7 years of service as a committee member. Her input to our committee as an individual living with TSC has been invaluable and she has given many hours of her time to support our initiatives. We wish her well with her work commitments and know she will continue to support the TSC community where she can.

We always welcome new volunteers so if you have some capacity to join the committee, take on a project or help out in some way with this meaningful work, please contact [info@tsc.org.nz](mailto:info@tsc.org.nz).

## Parachute Packs Launch

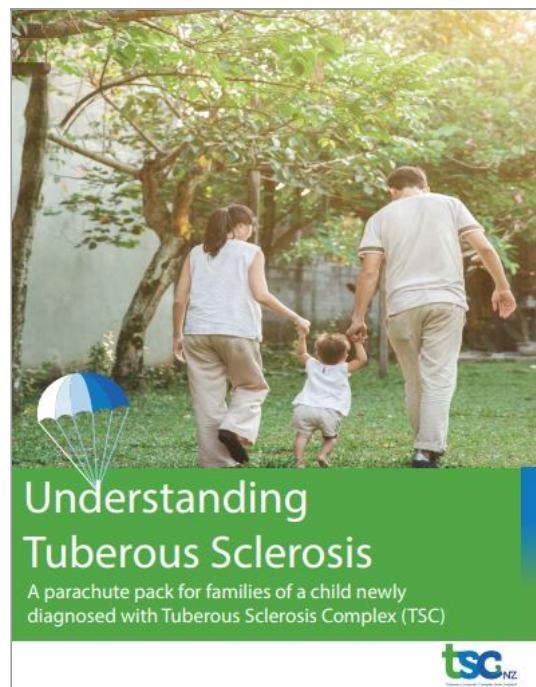
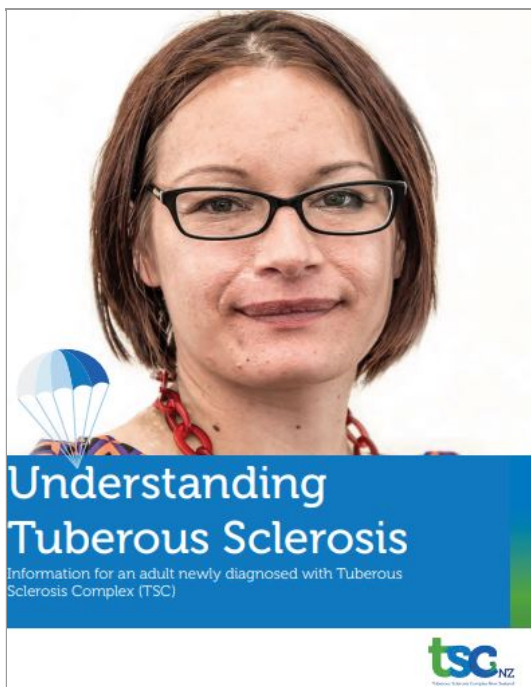
The Parachute Packs were officially launched at our AGM. They include up-to-date, hopeful information for individuals and families facing a new diagnosis of TSC. There are three versions - one for

families with a diagnosis in an unborn child, one for diagnosis in a child and one for a diagnosis as an adult. They are in the process of being printed now and will soon be sent out to hospital information services, specialists and our mailing list. They have also been added to the [Resources](#) section of our website. We look forward to being able to send this resource out when we are contacted by people with a new diagnosis.

We have also purchased copies of Tuberous Sclerosis Australia's [excellent information sheets for health professionals](#) and will be including those in the mail out.

Thanks to Mac Willacy for using his graphic design skills to adapt the TS Australia parachute packs for a New Zealand audience and to Leah Bos for becoming the face of the Adult version. We are very grateful to Tuberous Sclerosis Australia for so generously sharing the content they developed.

A huge thanks for the generous donations from the family and friends of Jo Maling, the Geary family and Aft Pharmaceuticals which have made this project possible.



## Memberships Renewals

If you haven't renewed your membership recently, it's that time of year again. Your membership contribution of \$30/year helps ensure everyone can access TSCNZ's quality information and support services for free. Your continued support is much appreciated by our volunteer committee.

Join by clicking on the JOIN TODAY button below on our website <https://www.tsc.org.nz/support-us>

Alternatively, make an online payment to the bank account Tuberous Sclerosis Complex NZ at Westpac 03 1550 0447063 00, quoting your name and 'Membership' in the reference fields. If you are taking the online banking option, please email [info@tsc.org.nz](mailto:info@tsc.org.nz) with your contact details and to let us know whether you would prefer to receive the paper or online versions of TS Australia's Reach Out Magazine and TSCNZ newsletters.

**JOIN TODAY**

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## **International News**

### **Comedy for a Cure**

**Saturday 30th October, 9:30pm NZT**

Tuberous Sclerosis Australia welcomes New Zealanders to join them for their online Comedy for Cure fundraiser.

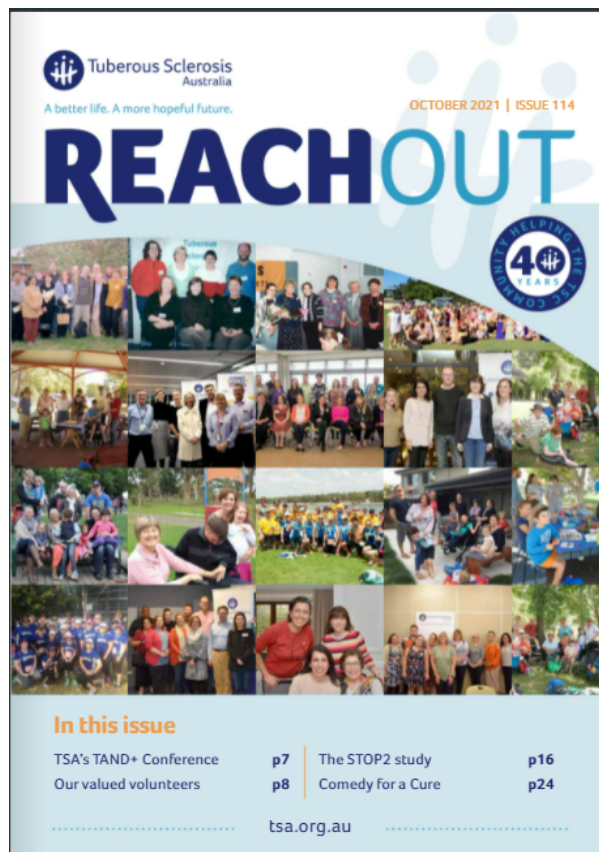
Let's get together online and harness the power of laughter to raise vital funds to help improve the lives of individuals and families impacted by this rare and devastating disease, Tuberous Sclerosis Complex (TSC).

It will be a great night with a fantastic lineup of comedians from the Sydney and Melbourne International Comedy shows. No matter where you live, you'll be able to join us for a night of laughs where you can snort out loud to the hilarious comedians without disrupting the show.

Visit <https://tsa.org.au/help/comedy/> for tickets and information.

### **Reach Out Magazine**

The latest Tuberous Sclerosis Complex Australia Reach Out is now available to read online at <https://tsa.org.au/reach-out-october-2021/>



## Covid 19 Vaccine Statement from Tuberous Sclerosis Alliance (USA)

Unfortunately, it is looking more and more likely that Covid 19 will be infiltrating all our communities. We found TS Alliance's updated position statement on vaccines from TSC experts helpful. As stated, this content was created for general information purposes and is not a substitute for professional medical advice. Keep in mind that the Pfizer vaccine is the one available in New Zealand and talk to your medical professionals for individualized advice.

In collaboration with members of their Professional Advisory Board, the TSC Alliance has issued an Updated COVID-19 Vaccine Position Statement to provide recommendations to the TSC community on COVID-19 vaccines and public health measures to protect them and their loved ones.

View the Full Position Statement at this link: <http://ow.ly/LFNA50FTMOA>

The main take home messages are:

- If you have not yet received a COVID-19 vaccine, get vaccinated as soon as possible, even if you have already had COVID-19 infection.

- If you are currently taking Everolimus or Sirolimus for TSC, stay on these medications unless otherwise directed by your clinician(s).

## Updated TSC Diagnostic and Management Recommendations

The International Guidelines for Tuberous Sclerosis Complex Diagnostic and Management Recommendations have recently been updated and published in *Paediatric Neurology*. The full papers describing the changes can be found at ["Updated International Tuberous Sclerosis Complex Diagnostic Criteria and Surveillance and Management Recommendations"](#) and ["Beyond the Guidelines: How We Can Improve Healthcare for People with Tuberous Sclerosis Complex Around the World."](#)

With an emphasis on the need for greater access to specialized TSC and comprehensive coordinated care, most recommendations for diagnosis, surveillance and management of TSC remained consistent with previous guidelines, but some major changes were made, including:

- Increased emphasis on early screening for EEG abnormalities, which could indicate impending epilepsy and higher risk for poorer developmental outcomes.
- Increased understanding of TSC-Associated Neuropsychiatric Disorders (TAND) and the need to identify and address issues to enable appropriate support. The concept of TAND was born at the 2012 TSC Consensus Conference, and these updated guidelines reflect how much has been learned about the importance of accurately and urgently dealing with TAND and many other aspects of TSC in the last nine years.
- Regulatory approval in the United States and many other countries since 2013 of everolimus for adjunctive treatment of focal-onset seizures in TSC, cannabidiol for epilepsy in TSC and sirolimus for lymphangioleiomyomatosis, a lung disease that affects women more often than men, usually between the onset of puberty and menopause.

We will learn more about the changes and implications of them at the TAND+ conference in November.

## Topical Rapamycin Trial Update

The Topical Rapamycin trial with a base in Christchurch has finished recruiting. Despite all of the COVID restrictions the team was pleased to be able to recruit the numbers required.

The investigators will share the results when the time comes. Thank you to all those in our community who participated for the greater good. We're excited to see the results and hopeful this will lead to easier access to this treatment for the skin manifestations of TSC.

## Financial News and IRD Number Correction

Grateful thanks to Dianne Widgery, a long time friend of Jo Maling who recently made a very generous donation to TSCNZ in memory of Jo. Thanks also to Dr Murray Leikis, Mary Kingscote and Ana Parraguez for your ongoing support.

Thanks to our member who notified us that there was an error on the IRD number in our donation receipt. The correct IRD number is **114-401-420**. Sincere apologies for this oversight. Please contact [info@tsc.org.nz](mailto:info@tsc.org.nz) if you require an updated receipt.



Please include your contact details on the reverse of this sheet

Rare Disorders NZ colouring competition featuring the rare but beautiful kotare. For all the details visit <https://raredisorders.org.nz/fair-for-rare-nz/childrens-day-2021/>

## Rare Disorders NZ News

## **Health Select Committee Hearing**

Rare Disorders NZ was disappointed to receive a response from the Ministry of Health dismissing our collective call for a rare disorder's national framework. You can read the response on their [website](#).

However, they are continuing to advocate and as part of the broader call for a National Framework for rare disorders Fair for Rare campaign, they are running a colouring competition to highlight International Children's Day which takes place on Saturday 20 November 2021. Young and old are welcome to enter with the chance to win multiple Smiggle vouchers. Entries close Friday 5 November.

RDNZ is also asking you to include a message for our Prime Minister, Jacinda Ardern about what it means to have a rare disorder. These will be handed to Dr Liz Craig MP and chair of the Health Select Committee who they have asked to hand directly to the Prime Minister.

## **Wellington Catch Up**

If you're in Wellington you're invited to join the Rare Disorders NZ team for a cuppa and catchup.

Following some time to connect with others and learn more about what they have been up to, they will also take this opportunity to hand over the entries for the Fair for Rare colouring competition enters to Dr Liz Craig who will attend this event

Date: Friday 19 November 2021

Time: 10:30 - 12pm

To find out more details and RSVP please visit their [website](#).

## **22 Great New Zealand rides for Rare Disorders NZ**

80 year old Jim is cycling 22 Great New Zealand rides from the top of the North Island to the bottom of the South Island. A total of 2345km over 45 days! Jim has three grandchildren with Fragile X and is raising awareness and much-needed funds for Fragile X and Rare Disorders NZ.

You can help support and donate [here](#) and you can follow Jim as he [goes](#).

## **New Brochure Photos Request**

If you would like to contribute, please email a high resolution photo of you or your family member with TSC to [info@tsc.org.nz](mailto:info@tsc.org.nz)

[illegible]

Website YouTube Channel info@tsc.org.nz Facebook

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