

Tuberous Sclerosis Complex

New Zealand

www.tsc.org.nz www.facebook.com/TSCNZ info@tsc.org.nz 0211547017



World TAND Expert to speak at TSC National Conference 2018, Wellington Saturday 29 September

We are delighted to announce that registrations are now open for the TSC National Conference to be held in Wellington on Saturday 29 September. Search for Tuberous Sclerosis Complex New Zealand at www.eventbrite.co.nz to register or go to www.eventbrite.co.nz/e/tsc-national-conference-2018-tickets-46043600649.

Professor Petrus de Vries, a world expert on Tuberous Sclerosis Associated Neuro-psychiatric Disorders (or TAND for short!) will be our key note speaker. He has a lot of experience and empathy working with families and will be sure to be an informative and interesting speaker. We are very grateful to him for arranging a stop in New Zealand on his travels from his home in South Africa to share his knowledge with us.

We also look forward to hearing from New Zealand experts on TSC, family stories and having time to connect and re-connect with the New Zealand TSC community.

Thanks to Industrial Tube and the generous donations to TSCNZ which have made this conference possible. At this stage, we have not been successful in funding applications for travel grants. Individuals and families may be able to look into applying for grants in their local areas. Please contact info@tsc.org.nz if you require any paperwork to help with grant applications.

TSC Conferences are an invaluable opportunity to get informed about the complexities of TSC. I can honestly say I have learned absolute gems of information that have helped with our journey with TSC from every conference I have attended. I really encourage people to make the most of this opportunity and lock in 29th September in Wellington.

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Upcoming Events

2018

10 June

TSC Management
Committee meeting

21 July

Brain Day, Auckland

12 August

TSCNZ AGM, Katikati

29 September

TSC National Conference,
Wellington

Farewell to Tonya

We were deeply saddened to hear that Dr Tonya Kara passed away in January. Tonya was one of our TSC Champions – she supported us, guided us, gave us hope and supplied us with endless knowledge, compassion, enthusiasm and giggles! She was passionate about supporting her colleagues in nephrology and paediatrics to provide the very best of care for their patients with TSC. She will be greatly missed and our hearts go out to her family and friends.



Global Awareness Day 15 May

Thanks to all who took part in the 15 Facts Facebook campaign.

A special thank you to Nicky Geary and family who held a fundraising/awareness event at her daughter's school. They had a mufti day with a blue and yellow theme as well as a lunchtime cupcake and sausage sizzle. "We raised a whopping \$231 for TSCNZ but best of all I have already seen a new level of understanding from the children and parents towards Orlaith – the power of sharing information." 🧡💙

Awesome effort Nicky. I'm sure you have inspired some of us for next year!



Membership

Thanks to all those who have renewed their memberships and a warm welcome to all our new members. A special shout out to the Boakes family who have encouraged their relatives to join.

Unfortunately, it has come to our attention that some mail went missing during our membership drive.

If you have not received a receipt for your membership fee, we may not have received your cheque. Please contact us on info@tsc.org.nz and we will endeavour to resolve any issues.

Our mailing address for all correspondence is now
11 Riverlea Drive,
Katikati 3129.

TSC Word Conference, Dallas

TSCNZ committee member Frances Morton will be representing New Zealand at the TSC International workshop and Novartis Advisory Board meeting in Dallas, USA in late July. We look forward to hearing your feedback on your return. Bon voyage!



NEW WEBSITE LAUNCHING

Thanks to the talented Cara at NY Art Dept and a generous donation from Industrial Tube Limited, we are delighted to announce the launch of our re-vamped website. It is linked to PayPal so membership payments and donations should be a breeze. We also plan to update it more regularly. Check out the pretty pictures and stylish design at www.tsc.org.nz.



NEW HORIZONS: The New Zealand Rare Disease Day Symposium

Frances also attended NZORD Symposium on February 22nd at Auckland Hospital and found it a great opportunity to meet with people with shared experience and connect with NZORD board members. It was a reminder that although it feels like we're quite isolated sometimes, approximately 8 percent of the population has rare diseases, so there is a quite a community there to connect with.

INFORM, CONNECT, SUPPORT

TSCNZ AGM

Our AGM will be held at Momentum co-working space Unit 4, Talisman Drive, Katikati on Sunday 12 August at 2pm. We will also have a conference call option for those unable to make it in person. Please contact info@tsc.org.nz for more details. New committee members and supporters are always welcome!

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



29 SEPTEMBER TSC NATIONAL CONFERENCE 2018

An opportunity for individuals, families and professionals in the Tuberous Sclerosis Complex community to come together to learn more about TSC from a range of speakers including Professor Petrus de Vries from South Africa, world expert on Tuberous Sclerosis Associated Neuro-Psychiatric Disorders.

Register now at www.eventbrite.co.nz/e/tsc-national-conference-2018-tickets-46043600649



**Inform, Connect,
Support**

**Feedback from
previous events:**

**“Helps you
understand the great
unknown of TSC.”**

**“The conference
made me feel not so
alone.”**

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