

Tuberous Sclerosis Complex

New Zealand

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Wellington Conference a Success

Wellington put on a stunning weekend at the end of September for the National TSC Conference. 43 members of the TSC community from all over the country gathered and went away feeling informed, connected and supported.

Thanks to the knowledgeable speakers who generously gave up their time to present at the event and our generous sponsors Industrial Tube Limited, Silver Linings Charitable Trust, Brian & Nicky Geary and TSCNZ for making the event possible. Dr Petrus de Vries, from Cape Town, was outstanding with his in-depth knowledge of TSC and his heart for the TSC community. The presentation of the inaugural Dr Tonya Kara Award to New Zealand TSC Champion Dr Murray Leikis by Dr Helen Evans was an emotional highlight and a fitting tribute to two wonderful doctors.

TSCNZ is delighted to announce that videos of several of the talks are now available on our You Tube channel. Find the link at our website www.tsc.org.nz and scroll down to TSC National Conference in the Latest News section. The slides of Dr Colina McKeown's talk on the Genetics of TSC are available on the Newsletters/Resources tab of the website. We encourage the community to share these links with medical and educational professionals and family.



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Upcoming Events

2019

11 February
TSC Management Committee meeting by conference call

11 May
The Nugget Multisport Festival, Waihi.

15 May
TSC Global Awareness Day

July
AGM

New Research Published on Skin Treatment

Congratulations to TS Australia and the dedicated team at Sydney Children's Hospital, led by Drs Orli Wargon and David Mowat, who were the only international site in this multi-centre trial and joined other TSC centres of excellence around the USA to complete a randomised study into the efficacy and safety of the use of topical rapamycin for angiofibromas. The project was funded by over \$200,000 raised through hundreds of donations and fundraising efforts of members of Tuberous Sclerosis Australia. The research has now been published at <https://www.ncbi.nlm.nih.gov/pubmed/29800048>.



Dig Deep for TSCNZ at The Nugget, Waihi

Living with TSC takes grit, resilience, team work and a sense of humour. On Saturday 11 May 2019, we are celebrating TSC Global Awareness Day by taking part in an event which also requires these qualities. Choose your challenge from the Full Nugget multisport event to the 6km walk and raise funds for TSCNZ or show your support by sponsoring a participant. Spread the word to friends and family and get training! Register for The Nugget at <https://thenugget.co.nz/> and sign up as a fundraiser for TSCNZ at <https://givealittle.co.nz/event/thenugget4tscnz>



Membership

If you haven't joined in the last 6 months, it's that time of year when we ask our TSC community to renew their annual membership for 2018/2019. 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* twice yearly.

The new website design makes it super easy to join TSCNZ. Go to the Support Us tab and follow the directions to pay by credit card. Alternatively, make a bank deposit to Tuberous Sclerosis Complex NZ

03 1550 0447063 00.

Email your name and address to info@tsc.org.nz and be sure to let us know if your details change.

If you prefer to pay by cheque, please send to 11 Riverlea Drive, Katikati 3129.



TSC Word Conference, Dallas, USA – A report from Frances Morton, TSCNZ delegate

I attended the 2018 World TSC Conference in Dallas, Texas in July. It took place at the most enormous hotel I've ever been in, which I stepped outside of only once in four days. This wasn't because it was 37 degrees outside, but because there was such a packed programme of talks and meals and get togethers.

I arrived in Dallas a day before the conference started to attend the TSCi workshop hosted by Novartis, the pharmaceutical company behind everolimus Afinitor. There were representatives from patient advocacy groups in Australia, US, Norway, Sweden, Denmark, Italy, Portugal, Hungary, Hong Kong, Greece, Brazil, Mexico, Israel and NZ. We had the chance to talk about what issues TSC patients and their families faced in our home countries – on a broad level as well as access to drugs. We were easily able to relate to each other, despite coming from different places. Key themes that recurred were around raising awareness of TSC, educating people generally and in the medical community and the importance of multidisciplinary teams for patient care.

The following days were a series of expert talks by leading medical specialists, researchers, patients and families. It was fantastic to see that people impacted by the disease personally were given just as much respect on the podium as the professionals who spend their days in a white coat. There is a very well-connected global team of expert practitioners in TSC and a lot of optimism. They feel lucky to working in an area of medicine that is seeing huge advancements. Overall, m-Tor inhibitors (everolimus/sirolimus) were regarded as a breakthrough drug that is having very positive impact in the treatment of TSC symptoms – SEGA, AMLs and epilepsy..

Some key takeaways from the conference:

- **Everolimus for Angiomyolipoma (AML)**

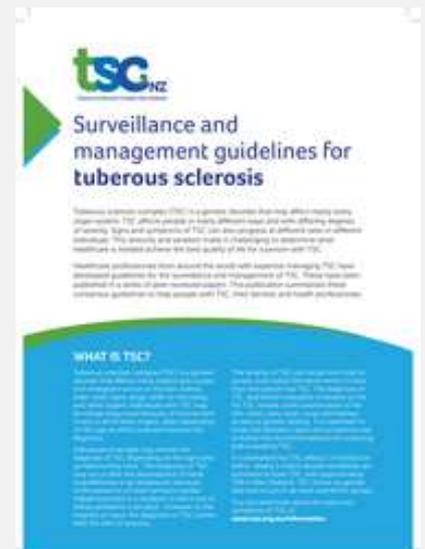
Dr Chris Kingswood, nephrologist from the UK has done extensive research on the use of everolimus to treat AML and says it should be the first treatment for AMLs in New Zealand. He was very surprised to hear it's not standard practice for this to happen.

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



TSC Word Conference Report Continued...

- **Specialist Clinics**

Neurologist Peter Crino set up the first specialist TSC clinic in the US and most countries have followed suit. A specialist clinic with multidisciplinary teams is considered the best model for patient care.

- **Entrenching the Consensus Guidelines**

The medical specialists at the conference got together to update the consensus guidelines that they last reviewed in 2012. In Europe, the US and the UK the guidelines are widely used by families and practitioners and in Portugal they are even written into law.

- **Getting to Know TAND (TS-Associated Neuropsychiatric Disorder)**

Until recently TAND was an overlooked part of a TSC patient's experience. South African professor of psychiatry Petrus de Vries is doing a lot to change this. He says TAND needs to be monitored annually. It covers a wide range of things that relate to how people think, feel, behave and interact, including autism, anxiety, depression, intellectual disability, academic performance, neuro function, self-esteem and more.

- **Personal Experience Leads to Change**

One great thing about the conference was the family members who were working to make a difference in various ways, including quite a few doctors who had TSC children. Rob Moss is a web developer who started a tech company because he wanted a solution to a problem he was having with his son Ethan. He launched Seizure Tracker from ICU when Ethan was hospitalised. As a dad, he struggled to keep track of the seizure info for doctors on pieces of paper, so Rob developed a website where he could log them. This has grown into an app with a range of capabilities including videoing the seizures.

TS Alliance has made recordings of the conference presentations available to view online at <https://www.tsalliance.org/2018-world-tsc-conference-videos>/<https://www.tsalliance.org/2018-world-tsc-conference-videos/>. The conference is held every 4 years. Thanks to Frances for taking time out of her busy life to represent New Zealand at this one. It would be great to have a larger New Zealand contingent able to attend in future so keep it in mind for planning.

TSCNZ AGM

The TSCNZ AGM was held in Katikati in August. A warm welcome to new committee member Nicky Geary who has already helped out hugely with fundraising and conference planning. She joins Helen Willacy (President), Frances Morton (Secretary), Julianne Managh (Treasurer), Janet Sharp (Membership Officer), Leah Bos, Lisa Underwood and Amanda Sayer. The full President's report of the society's activities is available at our website. The committee meet bi-monthly by conference call. We welcome new committee members and ideas. Contact info@tsc.org.nz for more information.



Nicky, Frances and Helen

More from the Wellington Conference

Thanks to all the individuals and families who made the substantial effort to attend the Wellington conference. It was wonderful to receive such positive and constructive feedback on the information and organization.

"I have come away a lot more informed of TSC and what steps to take for ongoing management. A great bunch of people and we look forward to attending the next one."

"I loved the personal stories and meeting other NZers affected by TSC."

"Wonderful speakers with very relevant knowledge to share who were willing to mingle and talk afterwards."

"Thank you for having Dr Petrus from Cape Town join us at the conference. His wealth of knowledge and understanding of every facet of TSC was invaluable and got us pumped up to help us through the onslaught of the next few years caring for a child with this condition"



Hannah Jairam shares her inspiring story



Remembering Dr Tonya Kara and acknowledging Dr Murray Leikis' contribution to TSC care in New Zealand.



Prof Petrus de Vries informing, understanding, entertaining and giving hope



Dr Colina McKeown's sensitive, informative genetics presentation

Meet the Committee: Frances Morton

Hello. I am a journalist and I live in West Auckland with my husband and our 4 year-old-daughter. I didn't know anything about TSC until my first nephew was diagnosed with it when he was a few months old. This was a confusing and uncertain time for our family, particularly my sister and brother-in-law. Over the years, I've frequently admired how they have navigated this reality together - it's not always an easy journey. I've joined the management committee to support my nephew and his family, learn more about TSC myself and do what I can do to raise awareness of TSC in New Zealand. I had a fascinating time at the international conference in Dallas this July connecting with families and experts from all over the world.