

Tuberous Sclerosis Complex

New Zealand

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TSC Global Awareness Day May 15

A very special thanks to all our members and supporters who took part in our Global Awareness Day activities and raised over \$7000 to keep our small, volunteer organization on track financially.

The Nugget Multisport Event was a lot of fun and everyone achieved the challenges they set themselves from the 6km for the youngest and oldest participants to the grueling walks, runs and mountain bikes.

Tattoos, Tea and Scones was a new initiative in conjunction with Tuberous Sclerosis Australia. Thanks to those who donned their tattoos and raised awareness and funds for TSC with events and donations. We have plenty of temporary tattoos in stock for next year so start planning your event now!

TSCNZ was also fortunate to receive generous donations from Industrial Tube and Brian Geary Building. Their continued support is greatly appreciated.



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2 December

Management Committee Meeting on Conference Call

3 February

Management Committee Meeting

6 April

Management Committee Meeting

15 May

TSC Global Awareness Day



Mid July

TSCNZ AGM

RESEARCH NEWS

New Zealand Research into Topical Treatment for Angiofibromas

Christchurch, New Zealand is now confirmed as one of the centres in a trial of topical rapamycin/sirolimus cream and is recruiting now. 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. More information about the trial is available at <https://clinicaltrials.gov/ct2/show/NCT03826628>. Scroll down for the Eligibility Criteria.

ACCESS TO MEDICINES

Research conducted by TSC International has shown that New Zealanders living with TSC lag behind other OECD countries for access to m-TOR inhibitors such as sirolimus and everolimus for the treatment of symptoms TSC.

TSCNZ has recently submitted an application to PHARMAC to request a broadening of funding for m-TOR inhibitors. We are grateful to the kidney and epilepsy specialists who have also made submissions and the New Zealand families and individuals living with TSC who shared their heart-felt personal stories to support our application. The PHARMAC committee will consider the application in November. Updates will be posted on the Tuberous Sclerosis Complex New Zealand Facebook page.



AGM participants

TSCNZ Annual General Meeting

The TSCNZ AGM was held at the Owen Glenn building at the University of Auckland on 15 June followed by a dinner at Da Vinci's. Thanks to the University of Auckland for making this excellent venue available to us.

The committee elected for 2020/2021 is Helen Willacy (President), Frances Morton (Secretary), Julianne Managh (Treasurer), Leah Bos and Lisa Underwood.

We regretfully farewelled Janet Sharp, Nicky Geary and Amanda Sayer who are stepping down from the committee for the time being to focus on caring for their families. They have all contributed a huge amount to TSCNZ and we wish them all the very best.

New committee members are always welcome. We meet on a Monday evening bi-monthly by Zoom conference call. Our aims for the next year are to improve access to medicines and investigate multidisciplinary care.

Please contact info@tsc.org.nz if you are interested in getting involved in this way.

Farewell to Paul Sharp

The TSC community was saddened to hear that Paul Sharp passed away in June. He had been suffering from cancer for several months. Our love and condolences to his family especially Jan and Brianna. Paul was an inspiration to many and a great supporter of TSCNZ. He was a warm, funny, kind and devoted family man with a great zest for life, fishing and motorsport! He is missed by many.



More images from The Nugget

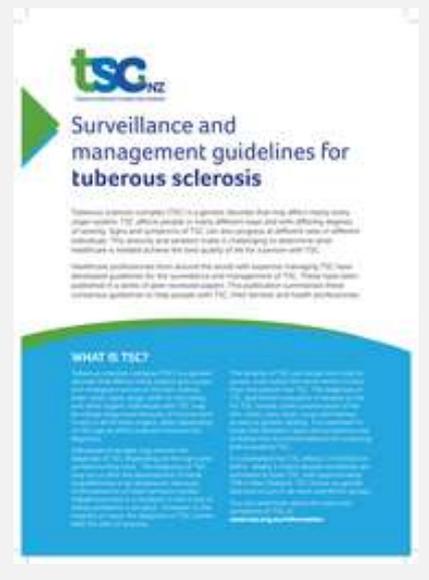


TSCNZ Resources Available

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
- Newsletters
- Stickers
- Tatts4TSC

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 President's Report June 2019 presented at the AGM

Tuberous Sclerosis Complex NZ has had another successful year informing, supporting and connecting the New Zealand TSC community. The volunteer management committee and wider networks have worked very hard to achieve these outcomes.

Highlights include holding our second national conference in Wellington on 29 September 2018 with Prof Petrus de Vries, world expert on TAND as our keynote speaker. The conference was attended by 43 members of the NZ TSC community and feedback was extremely positive. Travel and accommodation grants were provided to several participants to assist with the financial cost of attending. It was wonderful to be able to acknowledge two of our TSC Champions – Dr Murray Leikis and Dr Tonya Kara with the first presentation of the Dr Tonya Kara memorial award to Dr Murray Leikis for his contribution to the TSC community. Many of the conference sessions were videoed and uploaded to YouTube for the benefit of those unable to make it to Wellington and for future reference. Special thanks to our generous sponsors Industrial Tube Limited, Silver Linings Charitable Trust and Brian and Nicky Geary and TSCNZ donors for making this conference a reality.



Another highlight was upgrading our website to a more modern look that is easier to update and can accept card payments through Stripe. Thanks to Cara at NY Art Dept and Tam Willacy for their work on this and Industrial Tube for their sponsorship.

This year TSCNZ's other achievements include:

- a. Maintaining a mailing list of 72 individuals, families, professionals and supporters in the TSC community including 12 financial members. There are 2 fewer financial members than the last financial year, perhaps due to a less obvious renewal strategy. However, the mailing list has increased from 61 to 72.
- b. The management committee met 5 times via teleconferencing to exchange information, views and ideas and administer the society and held 1 Special General Meeting to approve two minor rule changes.
- c. TSCNZ took part in TSCi's global awareness day campaign in May 2018, publishing the 15 Facts on our Facebook page leading up to Global Awareness Day on 15 May. Nicky Geary held a fundraising/awareness event at her daughter's school with a muffin day and cupcake and sausage sizzle which raised \$231 for TSCNZ.
- d. TSCNZ liaised with Tuberous Sclerosis Complex International (TSCi) to send Frances Morton, committee member, aunt and journalist to the TSC World Conference in Dallas, USA in July 2018. She also attended a TSC International meeting of delegates from patient groups from around the world.
- e. Leah Bos and Helen Willacy held TSCNZ stalls at the Centre for Brain Research's Brain Day community expos in July 2018 and March 2019. There were good opportunities to network with other organisations and raise awareness of TSC with the public, medical students and professionals
- f. Two newsletters and two issues of ReachOut magazine were sent to members and people in the TSCNZ network.
- g. Support and updates on the society activities were provided by email, phone and the facebook pages <https://www.facebook.com/TSCNZ> (281 likes - up from 251) and <https://www.facebook.com/groups/AuTSC>.
- h. Information packs including brochures on TSC, surveillance and management guidelines, TAND checklist were sent to newly diagnosed families and new contacts.
- i. The society was successful in attracting financial support through donations totalling \$5,367.00. Special thanks to the Geary family, Silver Lining Charitable Trust, Industrial Tube Limited and for their generous donations and fundraising efforts.

The committee has put many volunteer hours into making these achievements happen and I would like to thank them very much for their dedication. To achieve our goals going forward, it will be necessary to consider how to best manage the financial and human resources to create a more sustainable organisation. Thanks also to NZORD and Tuberous Sclerosis Australia for their continued support this year.

Helen Willacy