

Tuberous Sclerosis Complex

New Zealand

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International News from Dr Murray Leikis

I was very pleased to attend the 2015 International Tuberous Sclerosis Complex Research Conference and TSC International meeting in Windsor, England from 9-12 September. This was made possible by a generous travel grant from Novartis Pharmaceuticals to TSCNZ to enable a representative to attend. The TSCi meeting was a fantastic gathering of representatives from 22 different countries and many good friends were made. Some TSC support groups have been going for many years and some like ours are new. This gave us all the opportunity to hear what others are doing and their plans for raising awareness of TSC. It was also apparent that equity of access to quality health care for those affected by TSC is difficult across the world and medication availability is not universal. It was also clear that local support groups such as our own TSCNZ remain vital in keeping patients and medical staff up to date on what the best treatments are as more evidence becomes available.

The research conference was extremely well attended with over 30 talks and nearly 60 poster presentation on work from around the world presented to over 200 delegates. The themes were moving "from treatment to prevention" and "starting treatments early in life", sometimes before clinical signs have even developed. An international group called TSCure is working on prioritising research in this area and some new clinical trials are already underway using drugs such as Vigabatrin to stop infantile spasms before they start in the hope this will lead to a reduced risk of intellectual and behavioural difficulties later in life. The research consortiums are also listening to patients and their carers about what matters to them and directing research to area that they see as important. The use of mTOR inhibitors was presented in many talks and for now there is excellent sustained long term outcomes on all the parts of the body affected by TSC although the optimal doses and lengths of course are still be researched.

There was some outstanding science based research further unravelling how the cells in the body work in relation to TSC and it is hoped that by understanding some of these mechanisms new treatments will emerge in the not too distant future.

Patient and carers' stories were also presented to keep us all on track with why the research is so needed and valued. The burden of caring for patients with TSC was recognised with calls for more use of the TAND checklist and development of interventions for it.

Overall, this was one of the best conferences I have been too. The enthusiasm and dedication of those involved in caring for TSC was clear for all to see with the future looking very promising.



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TSCNZ Brochures Available

Need help explaining TSC to school, friends or family?

Email your contact details to info@tsc.org.nz and we will send you copies of our brochure.



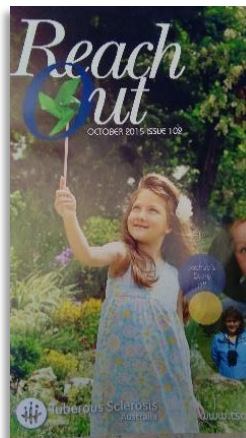
SURVEILLANCE AND MANAGEMENT GUIDELINES ON STARSHIP WEBSITE

We are delighted that a link to the international surveillance and management guidelines in TSC is now available on the Clinical Guidelines page of the Starship website www.starship.org.nz/for-health-professionals/starship-clinical-guidelines/#T. Thanks to Dr Tonya Kara and Clare Stuart at Tuberous Sclerosis Australia for their work achieving this. It is wonderful to have this information so accessible for professionals and people living with TSC.

Fundraising Update

Thanks so much to those who responded to our financial membership request. Many of the new members gave additional donations which were greatly appreciated.

If you would like to continue to receive the printed copy of Reach Out magazine and this newsletter, please email us your details or post in the completed application form. Your \$30 donation will cover the cost of supplying Reach Out and help with our ongoing expenses.



Special thanks to the Norris family for their amazing support. Janet and Pat are grandparents of a child with TSC. Instead of receiving presents for Janet's recent significant birthday, she requested donations to TSCNZ and we were blown away by the generosity of the donors. What a great idea!

We also received heart-warming donation from a 7 year old girl who donated a portion of her earnings from selling free range eggs to TSCNZ!

We have been delighted to be able to award several travel grants to Sydney for members of the NZ TSC community to attend the conference there in November. Watch out for the reports from Sydney in our next newsletter.

Upcoming Events

9 November

Committee Meeting

14/15 November

2015 Australian Tuberous Sclerosis Family & Medical Conference
<https://tsa.org.au/2015-conf/>

28 February

Family Picnics to mark Rare Disorders Day (and get together at a warmer time of year!) Please email info@tsc.org.nz if you are interested in co-ordinating or attending one in your area.

15 May

Global Awareness Day- a great opportunity to raise awareness and funds in your local area. Last year NZers organized a mufti day, sold chutney and jams and had a garage sale for TSCNZ. Put your thinking caps on and let us know your ideas!

16 July

TSCNZ AGM

Facebook

Remember to sign up to the closed group *Discussions of Tuberous Sclerosis in Australia and New Zealand* if you would like to connect online with others living with TSC.