

Tuberous Sclerosis Complex

New Zealand

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FIRST TSCNZ RESEARCH IN NEW ZEALAND!

This summer, Alex Lewis (a medical student from the University of Otago) carried out the first ever New Zealand-based research project on TSC. Alex carried out her study at the University of Auckland under the supervision of Dr Lisa Underwood, a Research Fellow at the Faculty of Medical and Health Sciences. The project was carried out thanks to a summer research scholarship from the University of Auckland and with expert support from TSCNZ.

Alex's project had three components: a literature review; analysis of information on TSC from the Ministry of Health; and the development of a checklist for the surveillance and management of TSC in NZ.

The literature review updated previous work carried out by Dr Underwood that was published last year in the journal *Advances in Autism* (<http://www.emeraldinsight.com/doi/full/10.1108/AIA-01-2016-0003>). During 2017, there were 260 scientific articles published on TSC. This is more than previous years and reflects the increasing number of articles each year and shows that research on TSC is continually growing as awareness of the condition increases. Research was published from the USA, Europe, Asia, UK & Ireland, the Middle East & Africa, Australia, Central & South America and Canada. Among the articles, there was a clear focus on treatment compared with diagnosis, as there were only six diagnostic related articles compared with 34 that were treatment related.

The Ministry of Health provided anonymous data on all of the public hospital discharge events that were related to TSC from 2004 to 2014. This information which provides a clear picture of health service used by individuals with TSC in NZ and will be published later this year.

Individuals with TSC have to navigate a complex array of health services and systems. TSCNZ has identified enabling more co-ordinated multi-disciplinary care across NZ as a key aim for activities this year. The TSCNZ Surveillance and management guidelines for tuberous sclerosis

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2017

15 May
TSC Global
Awareness Day
7:30pm Committee
Meeting (Skype)

16 June TS Australia
Webinar

22 July TSCNZ AGM

Date TBC: Christchurch
Seminar

8 October: Melbourne
Conference

2018

NZ Family Conference

FIRST TSCNZ RESEARCH IN NEW ZEALAND! (Cont)

(http://www.tsc.org.nz/_data/assets/pdf_file/0019/52417/TSA-NZ-4pg-A4-insert-PRINT.pdf) were used to develop a summary checklist for people with TSC and their families to take to health appointments and help keep track of the assessments they need at different time points. This checklist will be further developed through a survey of individuals and families affected by TSC and NZ clinicians – **Watch This Space!!**

Two key NZ TSC clinicians reviewed Alex's project and provided this feedback...Dr Murray Leikis: "It is wonderful to see an initial study on TSC in the New Zealand setting. The review of the Ministry of Health data clearly shows that this group of patients have a significant health burden and the analysis has neatly shown where services are needed to address the management of them. The literature review has clearly outlined the rapid expansion of the literature around TSC and with the health data provided and analysed here, there is opportunity to have a substantial impact on the future for these patients. Furthermore the development of the simple, but thorough check list is a welcomed start to ensure that these patients get comprehensive care."

Dr Tonya Kara: "It has been a pleasure to work with Alex who has been efficient and enthusiastic and has produced a really interesting piece of work that I hope we can build on to provide better care for patients."

Project supervisor and TSCNZ committee member, Lisa Underwood remarked "Alex's project is the first of its kind and has provided an invaluable kick start to an extensive programme of research going forward. A key aspect of Alex's project has been collaboration between academia, clinicians, charitable organisations and families affected by TSC. Alex has contributed a great deal to an important programme of research. Alex's report and her findings continue to have impact on current knowledge of TSC in NZ and research aims to improve outcomes for people with TSC."

Finally, Alex says of her experience "I have been lucky enough to have gained many new skills and experiences that will benefit me hugely in my continued studies, and future career. I had no previous research experience coming into this project, so everything I have been exposed to has been an invaluable learning experience. The unique nature of my project was also a large factor in my enjoyment of this program. The knowledge that I was involved in the first research in New Zealand on TSC was very inspiring as it meant that whatever we were doing, hadn't been done before. It was also very motivating to know that I was researching information that might help those affected by TSC in my own community. Before this project, I had never heard of TSC, and this is a similar story for many practicing clinicians in New Zealand. This displays the need for research on TSC, especially in NZ, and confirms the necessity of my project, and others like it. With raised awareness, people with TSC will receive the care that they need and deserve, and have more people to fight their battle alongside them."

Fundraising Successes



A huge thanks to Industrial Tube Manufacturing Co. from Hamilton for their ongoing support of TSCNZ and recent generous donation of \$2000.

Another big thank you to the family and friends of TSC Grandma and TSCNZ volunteer Ruth Morton who made donations to TSCNZ in lieu of gifts at her recent significant birthday.

Happy Birthday Ruth!

Conference News

The committee have decided to postpone the National Conference until 2018 to give us more time to make progress with the research into improving care for New Zealanders living with TSC and to raise the funds required to stage a successful conference. We would love some more volunteers to help with the conference organisation, especially Wellington-based people with local knowledge. Please contact info@tsc.org.nz if you would like to join the team.

However, there are still several events this year to give people the opportunity to be informed, connected and supported. Global Awareness Month is on in May. Watch out for the social media campaign to raise awareness. Global Awareness Day on 15 May is a great opportunity to raise funds and awareness. Remember to let us know if you would resources such as brochures or balloons to support your efforts. Make sure you email us your photos of what you get up to. There will be a committee meeting via Skype on the 15 May. All welcome!

We are aware there is a sizeable group of people living with TSC in Christchurch. Plans are underway to hold an evening seminar there to inform and connect the Christchurch community. More details to come.

On the international stage, Lisa Underwood will represent TSCNZ at the upcoming meetings of TSC International and the international TSC research conference to be held in Washington DC in June.

TS Australia is holding a conference on 8 October in Melbourne. New Zealanders are very welcome to attend.

Brain Day

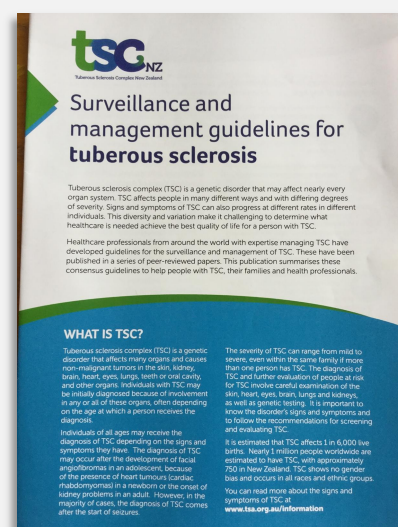


TSCNZ held a stall at the Community Expo at the Centre for Brain Research's Brain Day on 25 March in Auckland. It was an excellent opportunity to spread the word about TSC and make connections with other organisations and professionals.

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 on our website www.tsc.org.nz



Tuberous Sclerosis Australia are holding two webinars which New Zealanders may be interested in dialling in to. Dates to be confirmed. There is a AUD5 charge to register which can be paid by credit card.

Emerging treatments for epilepsy in TSC: Medicinal Cannabis and mTOR inhibitor medicines

Dr John Lawson, Paediatric Neurologist, Sydney Children's Hospital

Learn about the medicinal cannabis clinical trials being run in Australia and about the results of research [mTOR inhibitors](#) in epilepsy (Everolimus/Afinitor/Sirolimus/Rapamycin). Have the opportunity to ask your questions about access to these new treatment options for epilepsy.

Go to https://tsa.org.au/register_webinar/ to register.

Understanding the Genetics of TSC and the importance of lifelong surveillance

Dr Chirag Patel, Clinical Geneticist, Queensland Clinical Genetics

Hear about the genetics of TSC, including what we know and what questions researchers are still exploring. Learn about genetic testing and how to access genetic services in your area. Take advantage of this unique opportunity to ask questions. Registration for this webinar will be available in May.

TSC Professionals Network

TSCNZ have established a network of professionals in the TSCNZ domain who want to be keep up to date with the happenings of TSCNZ. They receive newsletters and any other important notifications from us. Please ask the professionals linked to you or your family if they would like to be part of this network. The more people we add to this network the wider our community becomes and knowledge can be spread and shared. We are teaming up with NZORD to help other health professionals know about our New Zealand experts in TSC.

COMMITTEE PROFILE

Janet Sharp is secretary of TSCNZ and has been a committee member since its inception with many years informally supporting families with TSC before that. She lives in Auckland with her husband and daughter who both have TSC. She has a wealth of knowledge about TS and LAM. Janet also works full time in administration and loves getting away to the Coromandel to re-charge.

