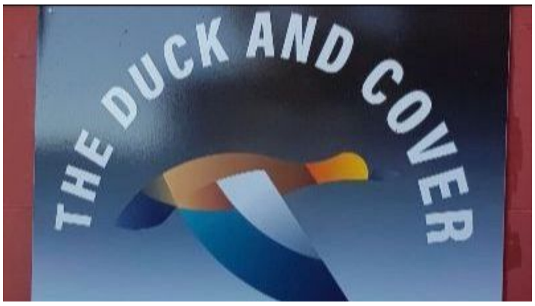
News from TSCNZ - Newsletter 18, April 2022

Tuberous Sclerosis Complex New Zealand

Inform | Connect | Support



Te Aroha Music Festival

Kia ora koutou and welcome to the April 2022 TSCNZ newsletter.

Global Awareness Day came early to The Duck and Cover in Te Aroha! Thanks so much to the Sayer family and the Te Aroha community for a wonderful music festival and day out. Not only did they raise awareness of TSC, they also raised an awesome $1500 for TSCNZ and supported Rylee who lives with TSC to attend the Oceania Asia Games in Brisbane later in the year! Rylee was invited to compete after breaking the under 16 NZ record for breastroke in her class. It was so heartwarming to see the aroha for Rylee and her family & we wish her all the very best for her swim training & upcoming competitions!

Keep an eye on our social media for some online facts to share and raise awareness for TSC Global Awareness Day on 15th May.

QR Code to Survey

TSCNZ Survey 2022

As the country and world open up again, we thought it would be a good time to take stock of where we are as an organisation. TSCNZ aims to inform, connect and support the NZ TSC community through support for individuals, lobbying and representation to medical professionals and government and keeping the community up to date with research and information.

Your feedback is really important in helping us focus our efforts and further improve our services. Please complete this survey to help us reflect and set priorities for the future. It will take just 10 mins of your time and all responses are confidential. PLEASE complete the survey during April or May to go in the draw to win a $100 Prezzy Card. https://forms.office.com/r/LavKaJNW0k

Link to TSCNZ Survey 2022

Committee News

The committee is happy to announce that we have contracted Helen Willacy for 16 hours per month to carry out work for TSCNZ. This is possible thanks to kind donations from our supporters. Helen was one of the team who started TSCNZ in 2014 to support families who, like her own, were learning to live with TSC. Her son Mac was diagnosed aged six months. As president of TSCNZ, Helen has worked tirelessly to help people with TSC, connect with health professionals, seek out information, run conferences, advocate for and communicate to the TSC community of Aotearoa and beyond. This work has been entirely voluntary, and we’re delighted that we’re now able to support her in a small way. She makes a huge contribution to achieving better outcomes for people with TSC and their loved ones. In her new role Helen’s responsibilities include advocating with government and medical professionals, updating the strategic plan and fundraising strategy, developing networks within NZ and internationally and providing support for individuals and families living with TSC. A big thanks to Helen for all you do.

We are delighted to welcome Tom Maling to the TSCNZ Management Committee. Tom is now retired after a career in marketing and advertising which took him around the world promoting NZ wine. We're also happy to have Katey Pearson on board and we will introduce her properly in the next newsletter.

We farewelled Ryan Powell from the committee in February. Ryan has been a committee member for two years and his skills as a researcher have been extremely helpful. We wish him well with his final year of his PhD at Otago University focusing on TSC genetic research and look forward to staying in touch. Thanks Ryan for your commitment and support to TSCNZ's mission.

We always welcome new volunteers so if you have some capacity to join the committee, take on a project or help out in some way with this meaningful work, please contact info@tsc.org.nz.

Membership Restructure

The Management Committee has decided to change our membership structure to better reflect the nature of our organisation and our members. At our recent meeting, we voted to change the membership fee to $0 and ask instead for annual donations. The website has been upgraded to reflect this change. Our mailing list continues to be open to all interested parties.

To make a donation, visit our website **https://www.tsc.org.nz/support-us**

Alternatively, make an online payment to the bank account Tuberous Sclerosis Complex NZ at Westpac 03 1550 0447063 00, quoting your name and 'Donation' in the reference fields.

If you are taking the online banking option, please email **info@tsc.org.nz** with your contact details and to let us know whether you would prefer to receive the paper or online versions of TS Australia's Reach Out Magazine and TSCNZ newsletters.

JOIN TODAY

InternationalNews

World TSC Conference

We have a wonderful opportunity to attend this global conference from the comfort of our own homes.

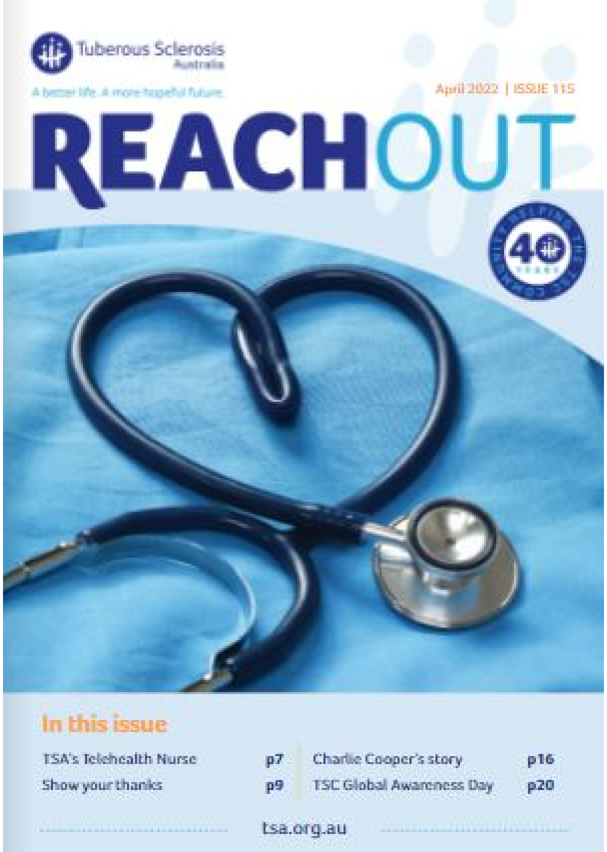
Virtual registration is US$50 and includes all livestreamed and hybrid programming. Email info@tsc.org.nz if cost is a barrier to your attendance.

The following content is included for virtual attendees: three general sessions, two Q&A sessions at the end of Friday and Saturday and three of the five different learning paths

1. panel presentations,
2. large group lectures
3. specific topic presentations

When registering be sure to choose “Attendee (Virtual)” as your registration type.

Click the image above to register or go to https://web.cvent.com/event/6f99d393-3d9c-4d2c-a09c-a71a78986884/summary



Reach Out Magazine

The latest Tuberous Sclerosis Complex Australia Reach Out is now available to read online at https://tsa.org.au/reach-out-april-2022/ In this issue we acknowledge and thank some of the amazing health care professionals who support and care for our TSC Community including a couple of our wonderful NZ TSC Heroes Mandy Talijancich and Dr Claire Spooner.

The Tonya Kara Memorial Award

Continuing the theme of appreciation of our incredible health professionals, especially throughout this challenging pandemic environment, we would like to call for nominations for the Tonya Kara Memorial Award. This award recognises the contribution of Dr Tonya Kara who was an empathetic, skilled paediatric nephrologist who sadly passed away in 2018. Tonya was a strong advocate for multidisciplinary care and made a positive impact on the TSC community in New Zealand.

Being a health care professional can be hard. The workload is demanding, the hours often long, the conditions can be tough and literally a matter of life and death. And yet, many of us have been lucky enough to meet that doctor or nurse who goes the extra mile to make a difference in our lives. This award is an opportunity to acknowledge those unsung heroes. it is presented to a health professional to recognise their efforts to improve the lives of families and individuals affected by TSC.

All you have to do to make a nomination is to email info@tsc.org.nz to tell us who you are nominating and why you think they deserve to win this award. All nominations will be considered by the committee who will decide the winner. Every health professional who is nominated will be told but we will not tell them who nominated them (unless you want us to share it). We look forward to receiving your nominations.

Keep in Touch

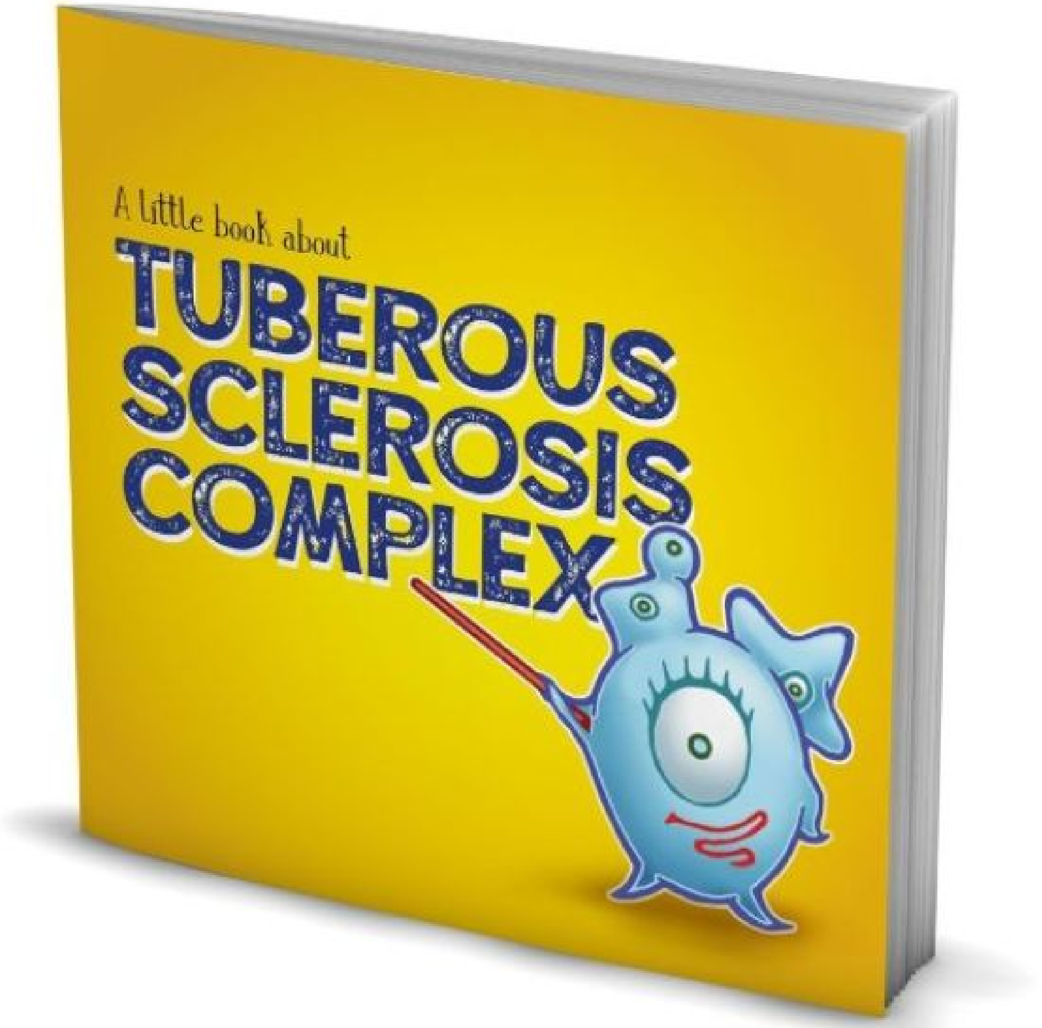
In addition to Facebook, TSCNZ is now on Instagram tsc_nz, Twitter @tsc_nz and LinkedIn . Please like and follow us to raise awareness and stay in touch whichever platform you prefer!

Research News

ClinVar Submission

TSCNZ was pleased to act as the associated organisation for Ryan Powell's submission to ClinVar, a public database where researchers ‘publish’ identified genome variants in patients with a known disease phenotype (i.e. a previously described disease manifestation, including TSC). As part of Ryan's PhD, he identified a previously undescribed mutation in the *TSC2* gene, causative for TSC in a single patient. Adding this variant to the database will build on the knowledge and help others to find their gene change. Congratulations Ryan and thanks to the individual who participated in his research to help achieve this step forward for the global community.

Resources



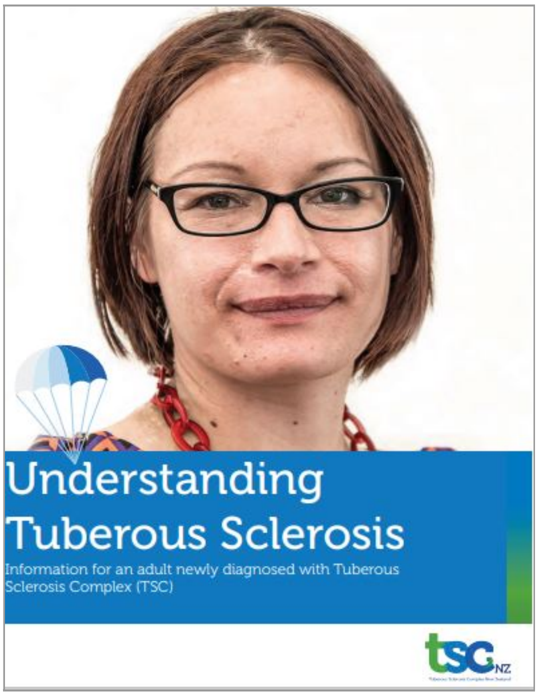
Tubee Books

A Little Book about Tuberous Sclerosis Complex is a gorgeous book which helps to explain this complex condition to the children who live with TSC, their friends, family members and classmates. The book features a cell named Tubee, who explains that although each child with TSC is different, for many children TSC means medicine, hospital visits and seizures.

Manoela and Jeff Place have been the driving force behind this project in honour of their daughter Zarah, who lives with TSC.

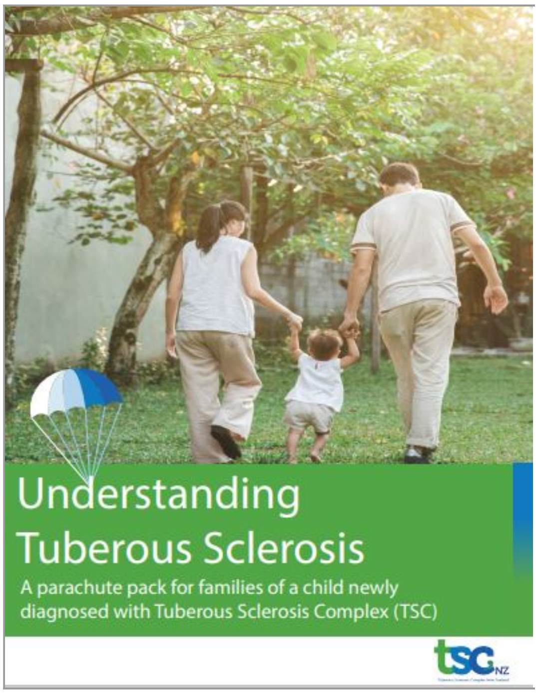
"When our daughter Zarah started school, her teachers were amazing at helping her new friends understand why Zarah needed additional help at school. We searched for a book to explain TSC to Zarah's classmates, siblings and cousins, but found nothing. The response from our friends and family to our fundraising project was amazing. We are grateful for the pro bono contributions of illustrator Dean Crawley, and graphic designer, Camila Hardy, who helped us create this book for Zarah and all children living with TSC."

Please email info@tsc.org.nz if you would like a copy or two of this lovely publication from TS Australia.



Understanding Tuberous Sclerosis

Information for an adult newly diagnosed with Tuberous Sclerosis Complex (TSC)



Understanding Tuberous Sclerosis

A parachute pack for families of a child newly diagnosed with Tuberous Sclerosis Complex (TSC)

Parachute Packs

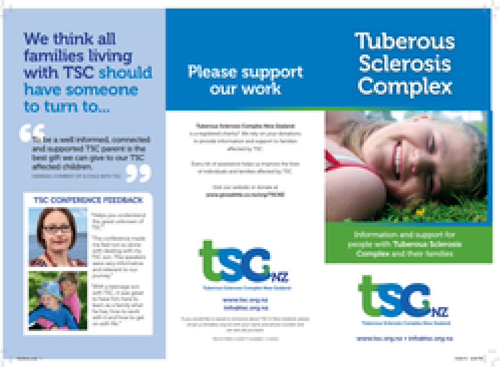
Thank you for the suggestions of medical professionals to send out the Parachute Pack brochures to. They have been posted out to hospital information services, specialists and our mailing list. Thanks to Rare Disorders NZ who also have copies to be distributed at the Rotorua GP CME - a conference attended by 1000 GPs. Please email your address to info@tsc.org.nz if you would like copies.

We also have copies of the revised Surveillance and Management Guidelines and information for health professionals available on request.

New Brochure Photos Request

One of our projects for 2022 is to update our 3-fold brochure. We would love some recent photos that reflect the diversity of ages and cultures in the TSC community.

If you would like to contribute, please email a high resolution photo of you or your family member with TSC to info@tsc.org.nz



We think all families living with TSC should have someone to turn to...

"To be a well informed, connected and supported TSC parent is the best gift we can give to our TSC affected children."

TSC CONFERENCE FEEDBACK

Please support our work

Tuberous Sclerosis Complex

Advocacy News

Pae Ora (Health Futures) Submission

TSCNZ made a submission on the Pae Ora (Healthy Futures) Bill which you can read at this link or on the NZ Parliament Submission website. Our key points highlighted the need for early diagnosis and co-ordinated expert care with timely access to specialists and best practice medicines regardless of where you live and how old you are. Helen also gave a 10 minute oral submission which was well-received by the select committee and can be viewed if you fast forward through to 9.55 on this video.

Although disappointing to not have the rare population officially recognised as yet, it was great that we could take this opportunity to have a say in the re-structure of the health system and advocate for co-ordinated care for all NZers living with TSC. Thanks for your input into the submission.

TSCNZ also gave feedback on Pharmac's Covid Anti-viral proposal advocating for broadening the eligibilty criteria.

Rare Disorders NZ continues to advocate for the Rare Disorders community. You can read their full April update shortly on their website. Below are some key points.

Their focus has been on ensuring that we are represented as a collective and have a voice in the process, and a seat at the table within the changing tides, which includes the dizzying array of Ministry of Education Highest Needs Review, Hira (National Health Information Platform, which is setting up virtual electronic health records so people do not need to repeat themselves many times over to different health professionals), Mental Health Commission, Establishment Unit for the new Health NZ, Māori Health Authority, Establishment Unit for the new Ministry of Disabled People (new name pending) and Ministry of Social Development regarding family/whānau carers voice, funding and respite.

Another vital focus area for RDNZ is raising awareness with both the public and the politicians that there is a central body, and a strong, unified population of persons with rare disorders who deserve and need recognition.

Rare Diseases Survey Results

Thanks to those who participated in Rare Disorders NZ's survey last November. The summary of results and white paper can be found at this link on their website.

Mind Map project

We have discovered that mind maps are a powerful way to illustrate the web of services involved in the care of someone living with a rare disorder.

We would love to use these in our advocacy work calling for a National Rare Disorder Framework, but we need your help! No one knows your situation better than you do, so would you be able to help us out by creating one based on your situation that you could share with us?

We have found an easy and free online tool to create a mind map.

You don't need to create an account - you just go straight to Create a Free Map to get started. The maps can be exported for free up to 100KB.

We have attached an example that someone in our collective kindly did for us to trial the tool.

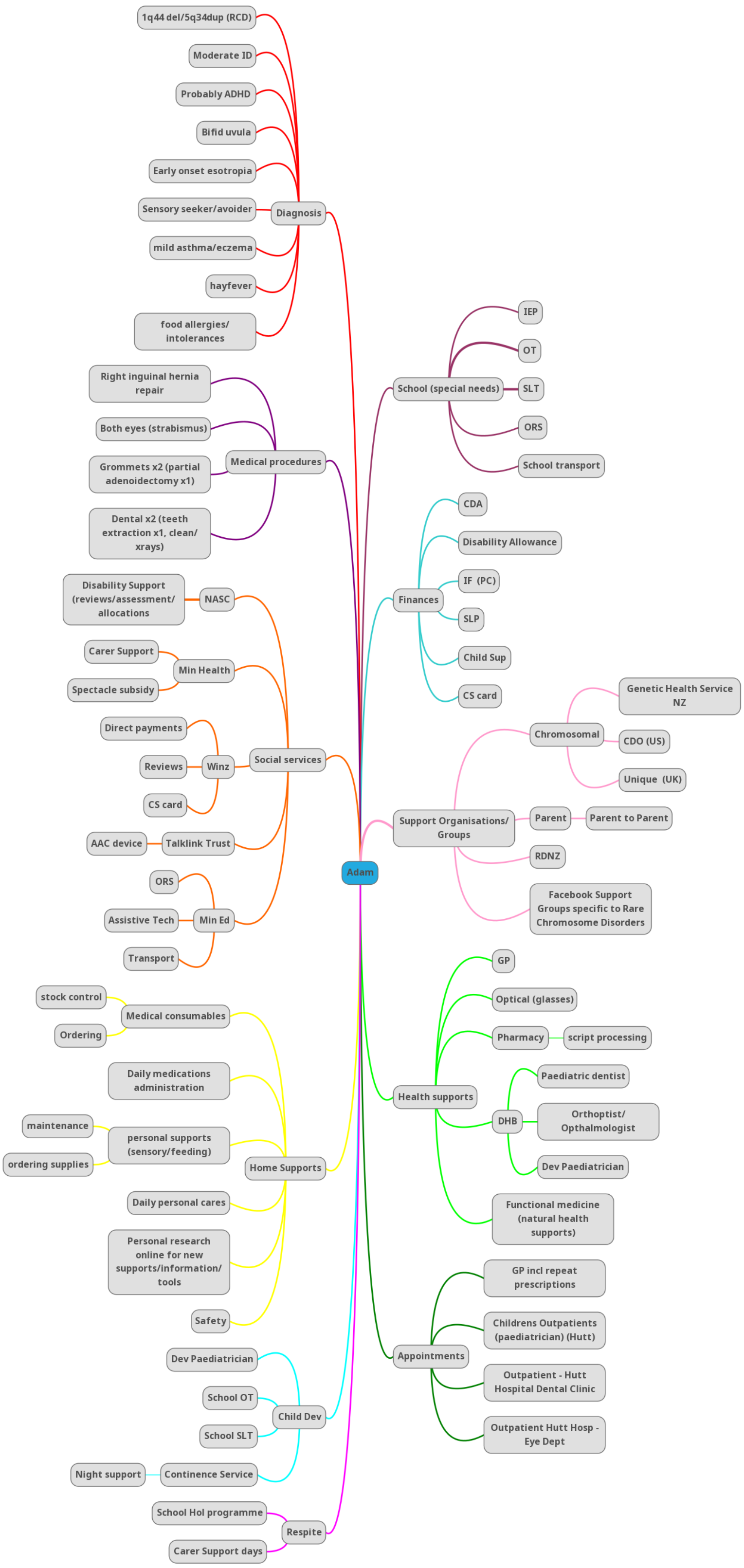
Some tips she passed on for using the tool:

- As you are creating, set your line colour and size as you go, otherwise it gets fiddly going back and altering later.
- You can’t save the mind map online unless you sign up for an account, but you can export it as a PDF or PNG file once you are finished, which you can download and save on your computer (just go to File, Download As…). This means you can’t go back and make changes later on.
- Don't worry if you realise after you have completed it that you have missed something out.

We also recognise that care and services change over time, so the way your mind map is now is just a snapshot in time and doesn't necessarily represent the care and services required over a lifetime.

Finally, please note that as we would like to use these mind maps in our communications and advocacy work, only do one to share with us if you feel comfortable with the wider public viewing your mind map. We would also like a paragraph about the person or family used.

If you have any questions, please let Kim know Kim.McGuinness@raredisorders.org.nz. Thanks so much for your help!



2022 Rare Beer Challenge fundraiser

We're excited to announce that the new date for the 2022 Rare Beer Challenge fundraiser for RDNZ is Friday 3rd June!

Place: 7 Leeds St, Te Aro, Wellington

Time: From 5pm

Hosted by our lovely friends at Fortune Favours, this event is a fun evening to get together, try some unusual brews and support a good cause! We look forward to seeing you there!

Maori engagement

Kia ora! Tēnā koutou katoa,

We have created a Facebook page for Māori whānau with rare disorders to join. If you could please share it far and wide so that it can be accessed by those whānau who would benefit from it.

The kaupapa will be evolving as we get a better understanding of where the needs lie. For any enquires please get in touch.

Ngā manaakitanga, Julian.

IRD Number Correction

Thanks to our member who notified us that there was an error on the IRD number in our donation receipt. The correct IRD number is 114-401-420. Sincere apologies for this oversight. Please contact info@tsc.org.nz if you require an updated receipt.

TSC
Global Awareness
May 15
Day

Upcoming Dates

15 May - TSC Global Awareness Day

12 June - TSCNZ Management Committee Meeting on Zoom
28-31 July - 2022 TSC World Conference
7 August - TSCNZ AGM at Auckland Botanical Gardens, Manurewa
2 October - TSCNZ Management Committee Meeting on Zoom
4 December - TSCNZ Management Committee Meeting on Zoom

If you need information or support on any aspect of living with TSC please email us or call 021 154 7017