



Tuberous Sclerosis
Australia

Annual Report

2020



Together we can create a better life and more
hopeful future for every individual with TSC

Tuberous Sclerosis Complex (TSC)

TSC affects more than 2,000 individuals in Australia and thousands more carers, families and friends who live with the impact of the disease.

TSC tumours can grow in any organ of the body, commonly affecting the brain, skin, heart, lungs and kidneys. TSC can cause epilepsy, developmental delay and autism. There is no known cure for TSC.



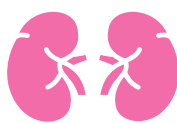
TSC can cause many different issues



Epilepsy



Autism



Kidney
tumours



Lung disease



... and more

and then there's the fear.

We have no crystal ball that can predict how any individual will be affected by TSC. This fear can be crippling.



Although the diagnosis of TSC is given to an individual, **it ripples through the family, community and our whole society.**



Tuberous Sclerosis Australia (TSA)

TSA works to connect, inform and empower people affected by tuberous sclerosis complex (TSC) as we work towards a cure.

What we do

- **Connect** and empower people living with TSC through providing **education** events and up to date, accurate **information** via channels such as e-newsletters, social media and our website tsa.org.au
- Provide **support** to individuals affected by TSC
- Ensure our TSC community has access to, and knowledge of developments in TSC **research**
- Ensure people living with TSC in Australia have access to the best possible **health care** from professionals who are committed to staying up to date with best practice in the diagnosis, surveillance and management of TSC
- **Connect** TSC health professionals so they can share the latest research and medical knowledge
- Raise awareness of TSC and **collaborate** with other rare and genetic disease organisations to **advocate** on issues such as access to new treatments, coordinated health care and support services.

Our vision

Together we can create a better life and more hopeful future for every individual living with TSC.

Our values

- **Diversity** - we recognise everyone's unique experiences and contribution
- **Excellence** - our services and activities are of high quality
- **Equity** - we aim to provide services that are accessible by all people with TSC, wherever they live in Australia
- **Openness** - our decision making and communications are clear and transparent
- **Independence** - we value our independence and we are accountable to TSA members
- **Partnership** - collaboration with other organisations and individuals is critical to achieving our vision.

Our Team

- **Debbie Crosby** President
- **Patrick Norris** Treasurer
- **Michelle Purkiss** Vice President
- **Alison McIvor** Committee Member
- **Michael Jones** Committee Member
- **Miriam Chalk** Committee Member
- **Rob Haggett** Committee Member
- **Jackie Gambrell** General Manager
- **Kate Garrard** Fundraising and Communications Lead
- **Kim Kerin-Ayres** TSA Nurse



Our Team of Medical Advisors



- **Dr Sean Kennedy** nephrologist at Sydney Children's Hospital
- **Dr John Lawson** paediatric neurologist at Sydney Children's Hospital
- **Dr David Mowat** clinical geneticist at Sydney Children's Hospital



President's Report

Debbie Crosby

What a year it's been! First, the unprecedented fire season across Australia, then the floods and then the global health pandemic! Throughout all of this TSA has stayed focused on finding the best ways to work with and for its TSC community. Despite the challenges we have all faced, with evacuations, lock downs, working from home, home schooling, reduction in the availability of supports and more, we are getting through it together. The amazing stories of kindness and support for one another help us all to deal with these difficult and uncertain times. I would like to take this opportunity to acknowledge the incredible strength of our TSC community.

“I am pleased to say our organisation is thriving despite these tough times.”

Jackie Gambrell, TSA's General Manager and Kim Kerin-Ayres, our TSA Nurse, have settled into their roles incredibly well over the past year and have taken the organisation from strength to strength. Kate Garrard has also continued to work incredibly hard to ensure TSA has the funds it needs to deliver its mission. Having such a committed and enthusiastic team in place helps us feel hopeful about the future.

TSA has also had many reasons to celebrate over the past year. We launched our new diagnosis 'Parachute Packs' for families and information sheets for health professionals on TSC Global Awareness Day. Many families and supporters joined us for a great virtual launch. We know these resources, which are available in hard copy and online, are already having a big impact.

We are also celebrating the first year of TSA's Nurse Service, which offers telehealth support to families around the country. You can read a little more about Kim and the impact she's having on page 9.

As a small charity we depend on the generosity of our donors, fundraisers and volunteers. Even in these difficult times you have continued to support us by renewing your memberships, making donations and



inspiring your communities to donate. Thank you for your ongoing support.

This includes our many volunteers who contribute their time, their stories and their expertise. We would particularly like to thank a new volunteer, Corniel Visagie, based in Queensland, who has helped improve our data and database by supporting us with many pro-bono hours.

Our TSC community always generously and willingly share their stories and advice through our publications and our online discussion group. And our dedicated volunteer management committee continues to guide our work. As well as thanking the amazing long standing committee members, I'd also like to welcome two new members who joined us this year, Miriam Chalk and Rob Haggett. They are both proving to be great additions to our small team.

Thanks also to TSA's Regional Contacts who work to ensure that people with TSC can connect to someone close to them and the members of our TSC Health Professionals Network who provide quality health care and help us improve information and health services.

Like other TSC organisations around the world, TSA is always working towards ensuring that accurate and up to date information is freely available to everyone living with the challenges of this disease. We will continue to support our health professionals to build TSC expertise and advocate for our health system to provide the tests, treatments and care to give each person with TSC the best life possible. We will also continue to focus attention on Australian and global research that takes us closer to a cure. We know there may be more tough times ahead, but we are confident we will continue to support each other. Thank you for being a valued part of our TSC community.

TSA's Achievements

This Year 19/20

Provided one-on-one support to our community via our new TSA Nurse Service.

Pioneered publication of "Research Round Up" a quarterly newsletter focused on TSC-related research and breakthroughs.

Parachute Packs launched - new resources to better inform individuals, families and health professionals at the time of a new or suspected TSC diagnosis.

Comedy for a Cure fundraiser came to Sydney for the first time.

Supported our community during the COVID-19 global pandemic.

The 2010s

Successfully advocated for TSC medicines to be included on the Australian Pharmaceutical Benefits Scheme (PBS).

Provided over \$200,000 for a clinical trial of a cream to treat and prevent TSC skin tumours.

Connections made through TSA's work led to Australian researchers and patients being part of international clinical trials into new treatments for brain tumours, epilepsy, autism and developmental delays.

Published TSC Information pages and our Resource Directory giving people in Australia free access to up to date and accurate TSC information.

Expanded access to our education events through webinars and conferences in Brisbane, Perth, Melbourne and New Zealand.

Hosted the first TSC Connect event for adults living with TSC.

The 2000s

TSA funded the first Australian genetics research project providing genetic testing for TSC.

Expanded peer support through production of film 'You Are Not Alone' telling the stories of four Australian families living with TSC.

Hosted the first combined conference for Australian health professionals and TSC families.

The 1990s

National roadshow in three Australian cities.

Leaders in the establishment of TSC International.

TSA's advocacy led to the first Australian TSC multidisciplinary clinic at Sydney Children's Hospital, bringing together specialists from different disciplines to provide a whole patient approach to medical care.

The 1980s

TSA founded as the Australasian Tuberous Sclerosis Society.

First issue of Reach Out published.

Launched social picnics for families.

First family conference.

The impact of your support on our information and support service

Our year in numbers

124 Consultations with our TSA nurse for individuals and families living with TSC

24,887 People visited our website for information about TSC

62

TSC information pages viewed each day

550

Members supported through our private online TSC discussion group

1,307 Comments posted in our online discussion group

138

Questions posted in our online TSC discussion group

92

Families participated in TSA's two recent surveys

14

Newly diagnosed TSC families accessed our Parachute Packs

2

Issues of Reach Out published

1,649

Facebook followers

Hudson

Together, we are improving TSC information and services for families like Hudson's.

Happy Hudson is just 18 months old but has already given his parents many surprises! His mum Katrina says falling pregnant with Hudson was just the first shock – it was not a planned pregnancy, but a happy surprise. With two young girls already, Katrina and her husband Mark thought they knew what to expect when they discovered they were pregnant again. However the shocks continued as Katrina developed gestational diabetes for the first time. This was followed by the devastating and shocking news of suspected and then confirmed TSC in their child.

At 32 weeks a growth scan showed something abnormal and Katrina was sent off for an MRI to further investigate. It was then that multiple brain tubers were found. If Katrina had not been sent for this MRI, an early diagnosis of TSC would not have been made. It was at this time that Katrina and Mark heard about TSC for the first time, but it wasn't until after Hudson was a few days old that his TSC diagnosis was confirmed with a genetic test and an MRI.

Katrina shares that while this diagnosis filled her and Mark with fear, sadness and anxiety about what their son's future would look like, they feel thankful they were able to be on the alert for any TSC symptoms from very early on. She says the early days were very difficult and filled with tears – although not Hudson's – he was a very happy baby!

Because Hudson's parents had been well informed about the various signs and symptoms of

TSC by their expert team at Adelaide's Women and Children's Hospital, they were aware of what the white patches were when they developed on his legs at around three months. And then, when Hudson had a minute-long focal seizure when he was four months old, his parents knew exactly what to do. Katrina captured the seizure on video and sent it off to their neurologist with whom they coincidentally had already scheduled an appointment for the very next day. Within 24 hours of Hudson's first seizure he had an EEG and was immediately started on vigabatrin to control his seizures.

An MRI done shortly afterwards showed that Hudson had many small tubers in his brain and also two small tubers in the lower section of his heart, one on his kidney and one on his right eye. Regular check-ups showed that the only tuber causing concern though was one on his brain, which was growing. The family continue to have a nerve-racking time 'watching and waiting', with six monthly brain scans to monitor the growth of this tuber.

Overall though, Hudson is now doing really well. He is a happy and social little boy. He loves kicking a ball, climbing, dancing and chasing his two dogs and two big sisters around. His family feel incredibly grateful that his development does not seem to be too impacted by his TSC so far and he is meeting important milestones. He sat up all by himself at six months, crawled at nine months and started walking



two days after his first birthday. While there is some nervousness around his speech, he is making some appropriate babbling noises and his parents are monitoring his development closely.

The old saying that 'it takes a village to raise a child' certainly is true for Hudson. The challenges of life with TSC have been made a little easier thanks to Hudson's supportive village of family, friends and health care professionals. Katrina and Mark say they have been fortunate to have access to a dedicated team of caring doctors who are experts in TSC. The family feel confident that they are giving Hudson the best opportunities through early intervention treatments. Katrina also says that what has made all the difference to how well she has coped is how involved Mark is. *"My husband Mark is truly the backbone of our family, keeping our heads above water and he has strength like no other".*

Katrina says she wishes she had reached out to TSA sooner. Having access to TSA's telehealth nurse, hopeful stories about other families living with TSC and connecting with another family living with TSC has helped them enormously. She says they are happy to know there is such good support there if they need it.

The impact of your support on improving health care



2

**Information sheets
for health care
professionals**

Thanks to funding from nib foundation, TSA developed two new information sheets for health care professionals (such as maternal fetal medicine specialists, midwives, fetal echo cardiologists, geneticists and paediatric neurologists) who may be involved in supporting families with possible TSC in an unborn baby and families whose child has been newly diagnosed with TSC.



441

**Health care
professionals**

The new diagnosis information sheets have been distributed to hundreds of health care professionals to ensure they have accurate and up to date TSC information. This will help improve the diagnosis experience for TSC families.

"The new TSC information sheets tailored for health care professionals are a very useful resource. They will help support health professionals with accurate and up to date information on the condition. TSC is a rare disease with low levels of understanding for most health professionals. The resources are informative, balanced with accurate information, and are nationally applicable." Dr John Lawson, Paediatric Neurologist, Sydney.



1

**Elizabeth
Pinkerton
Memorial Award**

Many TSC doctors go above and beyond to help TSC patients and each year TSA presents the Elizabeth Pinkerton Memorial Award to express our gratitude. In 2019 the award was presented to Dr Fiona McKenzie, Geneticist at the King Edward Memorial Hospital for Women in Subiaco, Western Australia. Dr McKenzie was nominated for her long-term perseverance in assisting one TSC adult to search for the cause of their mosaic TSC and for her considered counselling to families. Dr McKenzie said she felt very privileged to have been nominated for this award and thanked TSA for choosing her.

"Dr McKenzie counselled us when we were planning to conceive and have our first child. We wouldn't have had the confidence to go forward without her advice." Anon, TSC family Western Australia.



1

**New
TSA nurse**

Thanks to Australian Government grant funding, TSA is involved in the Patient Pathways Program managed by the Centre for Community-Driven Research. The aim of this trial, which

is being run in 11 health organisations, is to prove the need and usefulness of telehealth services. Our TSA nurse Kim has been providing a telehealth nurse service with our TSC community since joining the TSA team in July 2019.



25

**New health care
professionals added to the
TSC Professionals Network**

The TSC Professionals Network is an unpublished network listing of health care professionals that have an understanding of, and interest in, managing TSC. The network is frequently used when a person with TSC is seeking out a TSC expert or a second opinion, and when a health professional is looking for expert advice to assist them in caring for a person with TSC. Many of the professionals who agreed to be added to the network this year were recommended by our community in the TSA Survey 2019.



14

**TSC families
participated in a global
clinic trial for medical
cannabis for epilepsy**

Children and young people with TSC in New South Wales have been able to take part in the international clinical trial evaluating the use of Epidiolex® in treating their seizures. This Phase III global study, allows 210 patients access to Epidiolex. Thank you to the 14 Australian TSC families who are participating, through Sydney Children's Hospital, Randwick and to our TSA Medical Advisors for ensuring our Australian families were included in this important research. So far the results of this trial are looking positive.



2

Surveys conducted

TSA invited our TSC community to provide their feedback and input on TSA's work and share ideas for how we can best serve their needs. This covered feedback on our information services and our programs and services that help improve health care for Australians living with TSC. From the feedback we know that geographical remoteness for those not living in a major city is a significant issue. To improve support for families living in regional areas, TSA will focus on helping to bridge this gap through our telehealth nurse service and increased digital services, to ensure everyone in Australia, no matter where they live, can access quality information, support and care.

Mel

Together, we are improving health care for people like Mel.

Melinda, who prefers to be known as Mel, is in her 40s and enjoys life on the Gold Coast in Queensland. She lives with TSC but, by her own admission, did little to acknowledge her genetic disease for most of her life and had largely been able to forget about it.

Diagnosed with TSC at three years of age, Mel has experienced few TSC signs and symptoms aside from angiofibromas, for which she had undergone successful laser treatment. Mel's parents had connected with TSA and the TSC community but Mel had never felt the need to connect.

However recently, having undergone some intensive and aggressive treatments for breast cancer, Mel found that the TSC markings on her face had become much more visible than before and she was convinced she had done something to cause a flare up.

A previous operation in her 30s had also shown signs of TSC on her kidneys and liver. And, this time around, in preparing for radiation treatment for her breast cancer, her health professionals had told her that scans of her lungs had revealed she has TSC-related lymphangioleiomyomatosis or LAM. Mel had no idea what this even was. She decided it was time to take action and get better informed about her TSC.

Mel visited TSA's website as a starting point. Discovering that TSA now has its own nurse, she sent off an email asking if the nurse might know what might have caused her skin flare up and what she could do about it. Kim Kerin-Ayres, TSA's nurse contacted Mel and discussed some of the options she might like to consider, including more laser treatment and/or topical sirolimus – a cream that hadn't been available when Mel had last sought treatment for her angiofibromas. She was amazed at what was now possible.

Kim provided Mel with further information and followed up to answer her questions. Mel settled on a direction involving both laser and topical sirolimus, and Kim reached out on her behalf to connect her with a skin specialist who provided her with more detailed treatment information and took on her care.

This was just the start of Mel's relationship with TSA and Kim. They have now had more than half a dozen



calls and have exchanged several emails, discussing various other TSC-related issues, including Mel's LAM.

Having always worked in customer service and phone-based roles, Mel feels confident on the phone and is happy she can get her message across. She thinks this might be one of the reasons she finds telehealth to be much the same as a face-to-face health consultation. She jokes that it also saves her having to travel to, "yet another health appointment".

Mel says she has found the TSA Nurse Service to be so good because Kim is, ***"so relatable and easy to talk to. I feel I could talk to nurse Kim about pretty much anything. She has answered so many questions for me, and with Kim being a nurse, she understands what I'm going through. Kim has been great at helping me work through the options available to me and always follows up to see where I'm at. For me, Kim has been a wonderful support. It's really nice to have someone like her in my corner."***

TSA's Nurse Service has been made possible thanks to grant funding as part of the Patient Pathways Program, a federal government initiative developed by the Centre for Community-Driven Research. Many of our TSC families have benefited from this new service over the past year and the program hopes to gather enough evidence to secure permanent funding for this important service. Having a dedicated nurse to inform and support families has made a big impact on the help available to our TSC community. Mel's story is just one example of the difference this grant is making for people in Australia living with TSC.

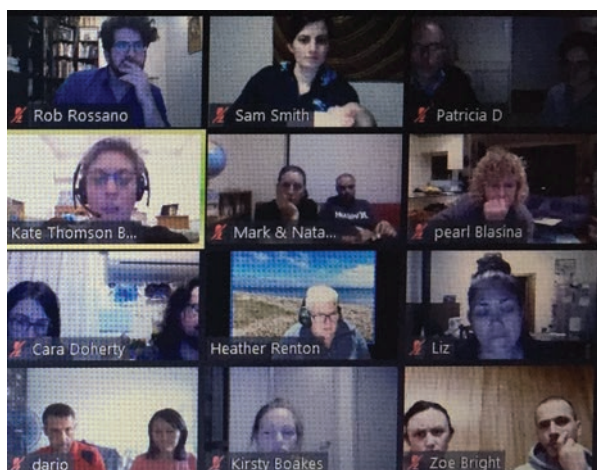
What's Next for TSA?

Zooming Forwards

So far 2020 has been a turbulent year for most. Like many organisations, TSA's plans have been severely disrupted and we had to postpone our planned face-to-face events, including our flagship national community and health professional conference.

In pivoting to the changes COVID-19 prompted, we recently developed and piloted two Zoom education events which were incredibly well received by participants (one of the pilot events was rated excellent by 100% of attendees). Based on this success, we will establish a program of regular online Zoom education events for launch in FY20/21. This new style of education event will bring our community together to learn about a wide range of topics such as identifying challenging behaviours and the NDIS. The events will provide interactive elements such as polls, chats and breakout groups to facilitate introductions and connections within our TSC community.

So, just as the outlook for a child born with TSC today has changed and is very different to that of a child born even just 10 years' ago - with earlier and more effective interventions - it seems that the way we provide information and support also needs to change. This is reflected in our 2021 Plan. TSA will continue to rise to the challenge.



Our 2021 Plan

- **Host and facilitate successful Zoom education events** on a wide range of TSC-related subjects, such as sleep strategies, getting the best out of the NDIS, legal planning and more.
- **Launch new online resources to support families** advocating for their children with TSC in the school system and a companion guide, "In Safe Hands" to help teachers and school staff better understand, educate and manage children with TSC.
- **Upgrade our data and IT systems** so that we can improve our ability to easily and readily connect and support people in Australia living with TSC with appropriately targeted resources.
- **Develop digital media** featuring interviews with clinicians, researchers, TSC affected individuals and others on topics like TSC research, TSC-associated neuropsychiatric disorders (TAND), seizure control and more.
- **Investigate virtual connection forums** for people living with the challenges of TSC eg, grandparents discussion group; phone forum for young adults.
- **Improve health care** through continued expansion of the TSC Professionals Network and creation of online forums for health professionals to collaborate on TSC cases, share treatment and research information and ensure the best possible care.
- **Revamp our popular biannual magazine, Reach Out.** A survey of readers in April 2020 revealed that 83% of respondents read Reach Out from cover to cover and find the magazine interesting and useful.
- **Continue to provide one-on-one support** to anyone in Australia affected by TSC through our telehealth TSA Nurse Service.
- **Further expand our reach and raise awareness** of TSA and our services so that everyone in Australia living with TSC knows about us and has access to our information and support.

Together we can achieve so much

We can't provide these essential supports to our TSC community without your support. With your continued help and financial support, we can deliver on our 2021 Plan.

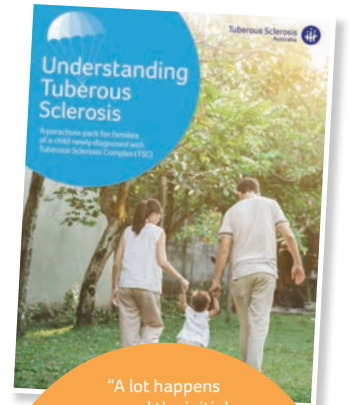
New Diagnosis Resources

Thanks to the financial support of nib foundation, in 2020 TSA launched a New Diagnosis "Parachute Pack" for parents of a newly diagnosed child or a baby with suspected TSC. The resources were informed by research conducted with 25 families and co-designed with parents and TSC health professionals.

"A diagnosis can be daunting for individuals and those who support them. The Parachute Pack will assist them by providing the up to date information, connections and support they need in the early days as they learn about this disease. I commend TSA for putting together this resource for their community." Hon Greg Hunt, Minister for Health.

"I wish we had these when Kristian was born." Jo Romios, mother of Kristian who lives with TSC, Victoria.

"I love the look of it and it is so informative. Exactly what is needed at diagnosis." Miia Groenwald, mother of Oskar who lives with TSC, New South Wales.



"A lot happens around the initial diagnosis of TSC, but once you have this and life continues it can be very lonely and confusing. Resources like this will be so helpful. Thank you to TSA for the time and expertise you have put into creating these excellent resources."

Miriam Chalk, mother of Caleb who lives with TSC, Tasmania.

Education Resources



Thanks to funding from the Disabled Children's Foundation and the Universal Charitable Fund, TSA is currently developing two online resources to support families and teachers of children affected by TSC. The guide for parents will empower them to advocate to get the best help and interventions for their child with TSC at school. The companion resource for teachers and educators focuses on helping schools better understand, educate and manage school-age children with TSC. It will include what struggles children may experience, what teachers can look out for and what interventions could be helpful. Both resources are being co-developed with parents and teachers.

How can YOU help us?

Even in this new pandemic-affected world, there are so many ways that you can get involved with TSA. Below are just a few ideas.

Foundations, Grant Bodies, Corporates and Philanthropists

- Provide grant, philanthropic and corporate funding to support our aims and help us deliver on our plan
- Sponsor our digital events and activities
- Become one of TSA's corporate partners
- Establish workplace giving for TSA
- Become a platinum member of TSA.

TSC Families and Individual Supporters

- Join TSA by becoming a member
- Sign up to be a TSC Champion making regular monthly donations
- Make a one-off donation via our website
- Share your story on social media and add a 'donate now' option to your Facebook post
- Create a #Heroes4TSC campaign in honour of the person you know with TSC
- Sign up to be a TSC Hero by participating in a physical or craft-based challenge
- Support a digital TSA fundraising event like Comedy for a Cure
- Hold your own fundraising drives and ask for donations to TSA in lieu of gifts.

Kate, who looks after our fundraising is always happy to talk to you about these ideas or any others you may have: kate.garrard@tsa.org.au or 0434 391 430.

Thank you

Thanks to your generosity TSA has helped thousands of people affected by TSC. Together we have had a major impact on the TSC community. Even during the uncertainty created by the COVID-19 pandemic, our community has continued to get involved in supporting our work and for this we are incredibly grateful. We hope you share in our sense of pride for the work we have done and will continue to do supporting individuals and families living with TSC. This wouldn't be possible without your help.

TSC Heroes raise \$21,350

Thank you to all the TSC Heroes who raised funds and awareness for TSA by joining in these events:

Pink Triathlon Kate signed up to test her strength at the Pink Triathlon. Kate completed the 300m swim, 9km ride plus 3km run and raised \$2,057 for TSA. Kate's workplace, SC Johnson matched Kate's donations bringing the total to \$4,115.

City2Surf In addition to awarding TSA a grant to develop the Parachute Packs, our partner nib foundation got a team of 30 staff together to participate in Sydney's City2Surf. They raised \$3,121 and then nib matched every dollar.

Sydney Half Marathon Natasha ran in Sydney's Half Marathon in honour of her granddaughter who was diagnosed with TSC late last year and raised \$4,000.

Melbourne Marathon In October Ben ran the Melbourne Marathon and raised \$1,345. Ben's daughter lives with TSC which is why he signed up to make a difference for people living with TSC.

New York and London Marathons Tess ran the New York and London Marathons and raised \$2,618 in honour of her niece who has been diagnosed with TSC.

Sun Run Our long-standing TSC Hero Melissa has done yet another TSC hero event for us, inspired by her godson Sammy. She has raised over \$1,200.

East Gippsland Cycle Our General Manager, Jackie and her husband John cycled 130kms on the East Gippsland Rail Trail and raised \$1,830.

TSC Champions donate \$10,782

Our regular givers, known as TSC Champions, make monthly contributions to TSA. These are vital donations we can rely upon each month to carry out our work

TSC Members contribute \$21,365

We are incredibly grateful to our new and long standing members who each year give so generously by renewing their membership and making a valuable contribution in support of TSA.

Special Events

Lizzie's Lunch 2020 was a little different this year due to COVID-19. We were unable to proceed with our usual get together but, thanks to the generosity of many of our regular guests, our call for donations to support our Lizzie's 'Calorie Free' Lunch raised \$3,060.



Comedy for a Cure came to Sydney on Saturday 26 October 2019. Over 150 guests joined us at Paddo RSL for a fantastic night of fun and laughter featuring a great line up of comedians including Peter Berner, Lizzie Hoo and Rob McHugh. We raised almost \$27,000.



Rob McHugh

Padstow Bowls and Snooker Club held their annual Christmas in July fundraiser a little late this year but still raised \$8,141 at their dinner in September. Over 100 guests attended. Thanks to John and Donna, whose granddaughter has TSC, for inspiring this support for TSA.



Padstow Bowls John and Barry

Nambour Christian College in Queensland held a "wear blue for TSA" fundraiser. Holly's brother, Koby has TSC so when Holly suggested holding a gold coin donation day to help other families like hers everyone got involved and they raised \$418.



Nambour Christian College

An in memory collection was held by the Catlow family who recently lost their beloved Betty. Betty was very close to her granddaughter Amanda who has TSC. The family requested donations be made to TSA to honour Betty, raising \$3,100.



Betty Catlow with her granddaughter Amanda

TSC Global Awareness Day and #Tatts4TSC was held despite the challenges and restrictions of the coronavirus pandemic, and our dedicated TSC community and your generous family and friends, raised almost \$7,000. Shout outs to The Rossano Family, Rachel Bennett, Amber Reid and Jamie from Green Leaves Early Learning Albany Creek. THANKYOU!



Our Volunteers and Regional Contacts



To all our wonderful volunteers around Australia, what would we do without you! Special mention to Teresa Llewellyn-Evans our editor, Cornel Visage our data expert, Belinda Johnstone our web developer, and Carolyn Place, Hannah Hartigan and Vanessa Tiernan.

Sincere thanks to our regional contacts who work with local families to share information and experiences:

- Dawn Bowra in the Australian Capital Territory
- Narelle Kerr and Alison McIvor in Victoria
- Georgina Schilg in Tasmania
- Nicole Stone in Western Australia
- Christy Herbert and Fiona Crocker in Queensland
- Debbie Crosby in New South Wales

You help make sure everyone with TSC has someone they can turn to.

Our TSC Families

We are grateful to all individuals and families living with TSC who take part in our educational events and fundraisers and support our work by sharing their experiences with us. You help inspire and motivate people to support us – thank you so much! Your willingness to share your journey helps others know they are not alone.

Our TSC Professionals Network

Thank you to all the medical specialists who continue to work with us to improve and grow TSA's information and support services. We couldn't do it without you!

Our Collaborations

TSA works closely with many organisations to ensure individuals with TSC in Australia have access to world-class treatment opportunities and information. We are an active member of TSC International and regularly collaborate with TSC New Zealand. We advocate for people with TSC through our work with a number of partners including Genetic Alliance, Australian Patient Organisation Network (APON), Consumers Health Forum of Australia and Rare Voices Australia. We are thankful for our collaborative partnerships with these organisations.

Our Partners

This year we've worked closely with two partners **nib foundation** and **Baker McKenzie**. We are delighted to be working with these organisations and thank them for their support to improve the lives of people in Australia living with TSC.

Thanks also to the **Centre for Community-Driven Research**, **GW Pharma**, **Universal Charitable Fund**, **Ian Potter Foundation**, **Lotterywest** and the **Department of Social Services** for looking favourably upon our grant applications.

Donations

We would like to thank each and every donor who has so kindly supported TSA. Every donation no matter how big or small helps.

Cynara's Movie Night

was her way of expressing thanks for the support TSA gave her family when her husband Matt almost lost his kidneys unnecessarily.

The movie night fundraiser at Ace Cinema's Rockingham WA raised \$1,321.



Cynara and Matt

In honour fundraisers were held by Catherine Panich, Sue Pinkerton and Frankie Torok who inspired their loved ones to donate in lieu of birthday gifts and raised over \$2,800



Volunteers from Baker McKenzie supported our Comedy for a Cure 2019 fundraiser



TSC Clinic team at Sydney Children's Hospital

Our Suppliers

We wish to thank our wonderful suppliers many of whom provide free or significantly discounted goods and services to us.

Our Donors and Supporters

TSC Champions

Aunt Ivy's Laundry and
Dry Cleaning
Allchin, Belinda *matched*
by Macquarie Bank
Foundation
Chick, Virginia
Clisdell, Peter

Cunningham, Jennifer
Deacon, Linda
Garrard, Julie
Goldstiver, Andrew
and Emily *matched*
by Westpac
Gregson, Sonia

Hill, Hayley and David
Mason, Steve
Mason, Sue
Nicholson, Sally and
Elliott Cunnew
O'Donoghue, Jennifer
Pinkerton, Rob

Pinkerton, Sue and Ross
Perera, Roshan
Walker, Steve and Kate
Norris

Membership contributions to Tuberous Sclerosis Australia

Life Membership

McKinnon, Andrew
Pinkerton, Ross
Pinkerton, Sue
Wilson, Lynn

Platinum Membership

Cummins, Gail
Niklaus, Kevin
Purkiss, Michelle

Gold Membership

Abery, Peter
Biddle, Matt
Blunden, Andrew
Bowra, Dawn
Bromhead, Jeffery
Chalk, Roslyn and Peter
Chow, Joyce Choi Shan
Crosby, Debbie
Crosby, Joanne
Durluk, Katarzyna
Frilingos, Peter
Liebman, Lisa
McIvor, Alison
Norris, Patrick
Osborne, Max and Julie
Penniment, Steve
Raffaut, Daniel
Walker, Stephen
Yee, Angelline
Zehnworth, Harry, Alison
and Adrian

Silver Membership

Barassi, Carl

Bell, Leisel
Boulter, C
Chalk, Miriam
Cope, Adam
Fay, Bruce
Foster, Lachlan
Haggett, Rob
Hale, Natalie
Hartley, Mary Anne
Hennings, Peter
Higham, Catherine
Hill, AK and MG
Humphrey, Belinda
Jenkins, Karen
Jones, Michael
Kamien, Benjamin
Kishan, Hari
Kyriazis, Nicole
Li, Jiayi
Lin, Evelyn
Mateffy, Adrienne
Matthews, Melissa
Mercer, Libby
Mowat, David
Nguyen, Nu
Peipman, Shirley
Salomons, Rebecca
Schilg, Georgina and
Scott
Somerville, Marianne
Stone, Darryn
Stone, Nicole
Stone, Samantha
Strosberg, Daniel

Vasara, Annika
Wakeley, Loren
Walker, Geoffrey
Wiles, Catherine
Williamson, Sue
Yardi, Jayant
Yates, Deborah

Bronze Membership

Adams, Libby
Alexander, Frederick
Bartels, Dean and
Elizabeth
Beck, Deb
Bedford, Elizabeth and
Julian
Blasina, Pearl
Bonacci, Luigino
Bright, Zoe
Carrington, Jayne
Catlow, Michael
Colman, Tania
Core, Katina
Crocker, Pat
Cummins, Louise
Curtis, Dianne
Donaldson, Patricia
Doyle, Chris
Drury, Robert and Jenny
Gambrell, Jackie
Garrard, Kate
Groenewald, Miia
Gunek, Linda
Hell, Marie

Howard, Evelyn
Jones, Gwynnydd
Jordan, Bridie
Kerr, Narelle
Lim, Cheryl
Lord, Wayne
Lowe, Jim and Lorraine
Martin, Frank
Matheson, David
May, Jenny
McArthur, Lachlan
McLean, Faye
Meredith, David
Mills, May
Morris, Emma
Murphy, Rochelle
Neville, Joelle
O'Reilly, Beverley
Oxenbridge, Kevin and
Sharlene
Panich, Catherine
Phillips, Christine
Reynolds, Janiffer
Scanlon, Hannah
Shaughnessy, Jackie and
Graeme
Simpson, Tracy
Stuart, Clare
Taylor, Daphne
Trunk, Kaylene
Whatmore, Malcolm
Woodcock, Kay
Young, Claire

Donors

\$1000 and over

Bowman, Allan
Brandon, Kate
Friedgut, Daniel
Gordon, Dale
Kelly, John
Kerfoot Pty Ltd
Lions Club of Nyah
Macquarie Group
Foundation Ltd
Mann, Edwina
O'Malley, Catherine
Orbis Investments
Ross, Olivia
SC Johnson
Will, Patricia

\$500 and over

Backes, Jessica
Beaton, Anna
Bodanac, Boris
Bromhead, Jeffery
Davis, Ben
Delbridge, Suzanne
Lavers, Lindsay
Marneros, Barbara
Mason, Anne
Toms, Roslyn
Wang, Huitong

\$100 and over

Abdalla, Khalid
Abernethy, John
Abery, Peter
Allan, Joan
Allen, Sylvia
Barwick, Mia and Grant
Beaton, Owen
Blasina, Michaela
Bobeff, Libby
Bodanac, Nicholas
Bodanac, Yasmin
Brandon, Daniel

Bright, Anne
Bright, Mark
Byrne, Donal
Cantrell, Elizabeth
Catlow, Elisha
Chalk, Roslyn and Peter
Clements, Jacob
Cook, Jan
Coughlan, Chris
Cowdell, Barry
Crosby, Debbie and
Anthony
Cullens, Lindsay
Curtain, Amanda
Daley, Stephen
Davies, Paige
Davis, Edward
Dein, Susan
Dow, Rosemary
Dureau, Ant
Eldridge, Rick
Faravoni, Shirley and
Graham
Fischer, Katalin
Fitzgibbon, Mark
Floros, Dina
Forbes, Dennis
Fraser, Steve
Gibson, Briony
Halley, Nic
Hartley, Mary Anne
Harvey, Michelle
HBF Run for a Reason
Heathcote, Nick
Heys, Ben
Heys, Daniel
Hicks, Stephen
Hicks, Tim
HMAS Stuart Crew
Homewood, Deb
Horque, Dudley
IBM virtual happy hour

Jameson, Sia
Jerga, Eileen
Jerga, Mary
Johns, Andrew
Jones, Michael
and Cathy
Johns, Peter
Karppinen, Salla
Kerr, Phoebe
Kourea, Christina
Kourea, Natasha
Lees, Daryl
Lofhelm, Tara
Lumby, Virginia
Marriott, Robert
Matthews, John
McAllister, Jennifer
McClintock, Geoff
McHugh, Alana
McPherson, Michelle
Mercer, Libby
Mobbs, Yvette
Morton, Daniel
Nambour Christian
College
Nicholls, Chris
Norris, Jamie
Nothman, Susan
O'Brien, Ann
Ogilvie, Alannah and
Keith
Ogle, Natalie
Panich, Catherine
Pearce, Krystalla
Pinkerton, Colin
Rai, Bhavna
Reid, Samuel
Reynolds, Craig
Reynolds, Nicholas
Roberts, Paul
Robinson, Martin

"I am so thankful for the support we have been given from TSA. We wouldn't be where we are without the guidance, knowledge, support and advice we have received from your organisation."

Amber Reid, mother of Samuel who lives in Queensland.



Rologas, Lucas and Maria
Romios, Kon
Rossano, Gabrielle
Rowlands, Prue
Russell, Jane
Saito, Bruce
Sanchez, Tomas
Siney, Jane
Smith, Dr Rodney
Smith, Valda
Stone, Samantha
Stuart, Allan
Stuart, Erin
Tandy, Tricia and David
Taylor, Bernadette
Webb, Ross
Westcott, Bob
Westcott, Paul
Wilson, John
Woodhead, Eric
Yates, Sally
Young, Lorraine

We'd like to thank everyone who made a contribution to TSA this year. We are grateful for each and every gift TSA has received. We have chosen to only list donations over \$100 because there were just too many of you to include each of you by name. Kindly note, this list does not include the substantial amounts people also contribute at our special events, community fundraisers or donations as part of memberships. We know some of our supporters give generously in all these areas in addition to their direct donations, and for that we are truly grateful.

Our Financial Results

TSA achieved a very good result for the financial year despite the ravages of the pandemic which caused the cancellation of fundraising events and the postponement of our conference.

It has also been a year where our growth strategy and our deliberate decision to invest in fundraising and development activities has reaped rewards and we again saw an uplift in income. We have successfully transitioned from an organisation that was predominately volunteer run to now boast a team of three dedicated, part-time paid employees, including, thanks to grant funding, our TSA nurse. We have had good success in securing grant monies. However, because these grants are typically tied to specific expenditure, we do not recognise these funds as income until they are expended.

We received \$28,000 in FY19/20 from the Federal Government's COVID-19 relief measures and are continuing to receive assistance in the new financial year.

Our bookkeeping partners, Refuge Accounting, continue to ensure that we are compliant in payroll, superannuation and GST. We use the Xero cloud-based accounting package which provides secure multi-user access for employees, bookkeepers, committee members and auditors. All invoices, receipts and documentation are stored inside Xero, facilitating transparency and auditability. As previously, we use the CommBiz business banking platform requiring double authorisation for all payments. Any two of the President, the Secretary and myself are permitted to authorise.

Our investment policy remains conservative. We invest solely in term deposits currently across Macquarie Bank and Bank of Queensland. The maturity dates of our deposits are staggered through the year so that we always have funds coming available to aid cashflow. At all times, we aim to keep enough cash available to meet payroll requirements for the next three months.

The accounts for the year ending 30 June 2020 were audited by Mark Mortimer (Registered Auditor No. 1942) of Bondy Mortimer & Co. A copy of his report is available at www.tsa.org.au/about-us/annual-reports/

The accounts of TSA align to the National Standard Chart of Accounts published by the Australian Charities and Not-for-profits Commission.

As a grandfather of a young boy with TSC, I want to see this organisation succeed and be sustainable for the future so every family and person living with this disease can benefit from the expert help and advice TSA provides. I am confident we are on track with this.



Our work with pharmaceutical companies

TSA collaborates with pharmaceutical companies in a number of ways. This year we received sizeable (unexpensed) donations from two pharmaceutical companies to support our major conference, which unfortunately had to be postponed due to COVID-19. Our policy on working with pharmaceutical companies, which is available on our website (www.tsa.org.au/about-us/policies/), describes how we maintain our independence and integrity.

Financial statements

Balance Sheet as at 30 June 2020

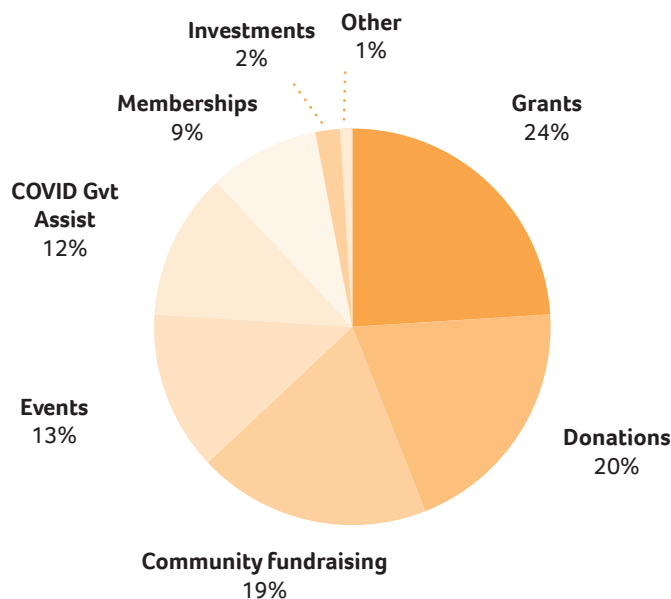
ASSETS	30 June 2020	30 June 2019
Bank		
General Cheque Account	\$45,695	\$88,728
PayPal	\$4,180	\$2,769
Savings Accounts	\$81,350	\$30,820
Staff Debit Cards for TSA Expenses	\$3,431	\$0
Term Deposits	\$192,718	\$188,359
Total Bank	\$327,374	\$310,676
Current Assets		
Accounts Receivables	\$0	\$318
Sundry Debtors	\$1,339	\$2,029
Total Current Assets	\$1,339	\$2,347
Total Assets	\$328,714	\$313,023
LIABILITIES		
Current Liabilities		
Accrued Expenses	\$0	\$8,000
GST	-\$1,110	\$211
PAYG Withholding Payable	\$3,852	\$1,648
Provision for Annual Leave	\$15,654	\$6,620
Provision for Long Service Leave	\$4,117	\$3,617
Superannuation Payable	\$3,727	\$3,131
Suspense	\$0	-\$250
Unexpended Grants	\$73,447	\$64,050
Unpaid Expense Claims	\$0	\$935
Total Current Liabilities	\$99,687	\$87,962
Total Liabilities	\$99,687	\$87,962
Net Assets	\$229,027	\$225,070
EQUITY		
Current Year Earnings	\$3,964	-\$12,152
Retained Surplus	\$225,063	\$237,222
Total Equity	\$229,027	\$225,070

Financial statements

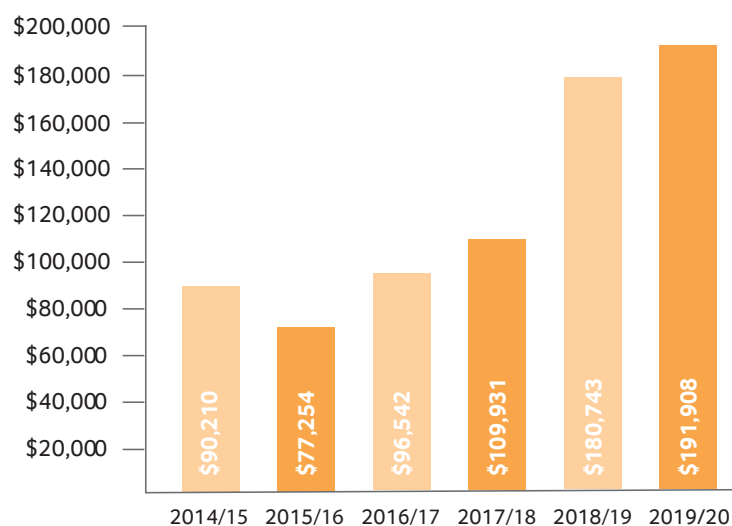
Income and Expenditure: Year Ended 30 June 2020

	30 June 2020	30 June 2019
INCOME		
Donations Received	\$92,133	\$114,015
Event Income	\$23,563	\$35,115
Grants Received	\$55,519	\$21,502
Membership Contributions and Fees	\$20,696	\$12,275
Other Income	\$4,199	\$4,967
Sales of Goods	\$1,153	\$3,403
Total Trading Income	\$197,263	\$191,277
Government support related to COVID-19	\$28,000	-
Total Income	\$225,263	\$191,277
OPERATING EXPENSES		
Accounting and Bank Fees	\$12,327	\$7,809
Advertising and Promotion	\$0	\$213
Board/Governance Expenses	\$494	\$539
Consultancy Fees	\$0	\$2,100
Educational Event Expenses	\$200	\$5,209
Fundraising and Event Expenses	\$5,923	\$16,143
Information Technology Expenses	\$12,296	\$8,351
Insurance Expense	\$2,746	\$2,839
Postage, Freight and Courier	\$2,278	\$3,197
Printing & Stationery	\$5,383	\$2,785
Publications and Information Resources	\$11,500	\$13,920
Salaries and Wages	\$165,953	\$125,238
Sundry Expenses	\$568	\$1,073
Telephone, Fax and Internet	\$603	\$1,030
Training & Development (Staff)	\$0	\$681
Travel & Accommodation	\$1,028	\$12,302
Total Operating Expenses	\$221,299	\$203,429
Deficit/Surplus	\$ 3,964	-\$12,152

Where funds came from

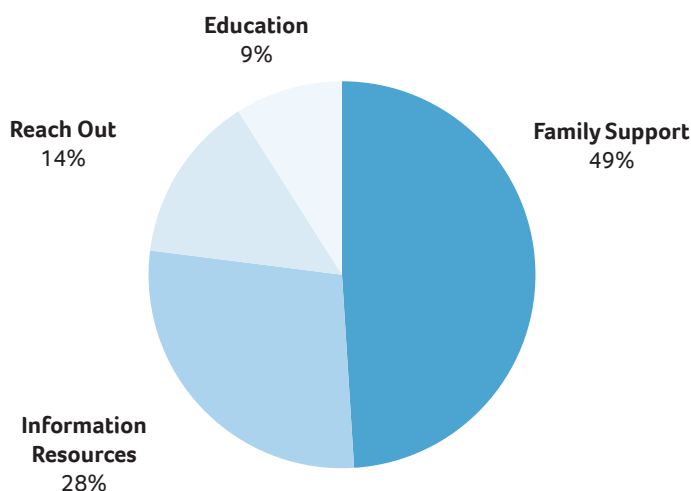


Fundraising Revenue



Revenue from fundraising activities including direct donations, grants, membership fees and contributions, fundraising events and community fundraising activities.

How program funds were used



Volunteer Contributions

During this year, TSA's work was supported by a team of volunteers. This includes our regional contacts around Australia and many others. Please refer to page 13 for more information. Their time is not shown in the financial statements but is an important resource for TSA.

Programs and Services 45%

These costs are associated with providing information and support to people affected by TSC and to health professionals. This includes costs associated with the provision of our TSA Nurse Service, education events, writing and updating our TSC information pages, our TSC Health Professionals Network and publishing Reach Out. It also includes working with policy makers and advocates in health and disability to improve the care available to people with TSC. Additionally, it includes the costs associated with reviewing TSC research and sharing it with our community.

Development 20%

We have a diverse portfolio of fundraising activities and this is time and effort spent investing in and supporting these. Activities include: grant applications, supporting community fundraisers, organising TSA fundraising events and campaigns, membership activities, Global Awareness Day, Christmas and Tax-time Appeals.

Accountability and organisation management 35%

These are the costs involved in running the organisation efficiently and with transparent governance, including activities relating to the TSA Management Committee. These essential activities provide support for TSA's programs, but are not directly attributable to any one program or service. They include direct costs such as insurance premiums, accounting and auditing, IT hosting and support.

There is still so much we need to do to improve the lives of people with TSC. Together, we can make a difference.



TSC Hero Natasha



TSC Hero Jackie



TSC Hero Kate



TSC Heroes Melissa and HMAS team

Phone 1300 733 435
Website www.tsa.org.au
TSA Nurse nurse@tsa.org.au
Email info@tsa.org.au
Facebook facebook.com/AuTSC
Mail 18 Central Road, Beverly Hills NSW, 2209 Australia



ABN 20 681 174 734
Deductible Gift Recipient Status:
DGR1 and Public Benevolent Institution (PBI)
Registered Charity CC25313
CFN 13968



Tuberous Sclerosis
Australia

A better life. A more hopeful future.