



Tuberous Sclerosis  
Australia

# Annual Report 2019



**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.



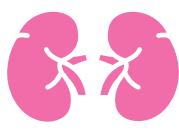
## TSC can cause many different issues



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 those 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](http://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 Australians with TSC 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 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
- **Alison McIvor** Secretary
- **Michelle Purkiss** Vice President
- **Michael Jones** Committee Member
- **Jackie Gambrell** General Manager
- **Kate Garrard** Fundraising and Communications Lead



TSA staff Jackie and Kate



TSA Committee 2018/2019

## 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, President

It has been an exciting year with lots of changes and new projects underway for Tuberous Sclerosis Australia (TSA). While we were sad to farewell our long-time leader, Clare Stuart as our General Manager, we are pleased that our team is strong and growing as we welcome our new General Manager Jackie Gambrell, and Kim Kerin-Ayres, our new TSA nurse. I would like to take this opportunity to thank Clare Stuart for her hard work over the past decade. Her passion and advocacy to improve the lives of people living with TSC has been exemplary. TSA has benefitted enormously from Clare's vision and leadership and we know we are in a strong position to continue the organisation into the future.

TSA has had many reasons to celebrate over the past year. We launched our children's book "A Little Book about TSC" and began work on a new diagnosis or "Parachute Pack" that will be available soon. Both these projects have been in development for some time and we are thrilled to be able to deliver these resources. We know they will have a big impact on families living with TSC. And, of course, we feel fortunate and celebrate the fact that we've been able to operate for another year. As a small charity we depend on the generosity of our donors, fundraisers and volunteers. Thank you all for your ongoing support.

This includes our many volunteers, who contribute their time, their stories and their expertise. Our Australian TSC community always generously and willingly share their stories and advice through our publications and our online discussion group. There has also been wonderful support from all around Australia for our fundraising events and TSC Global Awareness Day.

Our dedicated management committee guide our work and contribute many hours of their time. As well as thanking the amazing current committee members featured on page 3, I'd also like to thank and acknowledge the work done by outgoing committee members, Georgina Schilg and Kate Veach, both of whom recently stepped down.

Our regional contacts ensure that people with TSC can connect to someone close to them and the members of our TSC Professionals Network help us to provide access



TSA President Debbie Crosby

to quality health care and to improve information and health services.

I'd also like to thank Kate Garrard and Jackie Gambrell. Kate has worked incredibly hard this past year to ensure TSA has the funds it needs to deliver its mission and has been able to secure grant funding and grow our fundraising revenue to support our new projects. Jackie, our new General Manager, has only been with us for a few months, but has already proven to be a valuable addition to the team and delivered our first TSC Connect event for adults living with TSC.

Like other TSC organisations around the world, TSA is always working towards ensuring that accurate and up to date information is freely available to every individual living with TSC and their family. 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 TSC research that takes us closer to a cure. Thank you for your help and support and for being a valued part of our TSC community.

*Thank you,  
Debbie*

Debbie and Anthony with their daughters, Alana and Sophie.





# TSA's Achievements

## This Year

First TSC Connect event for adults living with TSC.

TSA nurse joined the team.

New diagnosis resource for TSC families funded and development underway.

Comedy for a Cure fundraiser comes to Melbourne for the first time.

Our first corporate partnership, with law firm Baker McKenzie.

First education event in Adelaide.

## 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 lead 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 Australians 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.

## 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 leads 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

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

**94** TSC families helped through our TSC Information Service

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**32,618** People visited our website for information about TSC

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**67**

TSC Information pages viewed each day

**520**

Members supported through our online discussion group

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**1,384** Comments posted in our online discussion group

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**172** Questions in our online discussion group

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**25**

Families participated in a research project sharing insights around their new diagnosis experience

**2** Issues of *Reach Out* published

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**65**

Australian TSC families have received their free children's book about TSC to help discuss the disease with their child, siblings and friends

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# Oliver

Oliver's family participated in the PEEK study research project that is helping TSA develop a Parachute Pack to better inform and support families at the time of a TSC diagnosis. It's called a Parachute Pack because some parents describe their TSC diagnosis experience as like being in 'free fall'. We can't stop them falling, but we can provide the support, information, connections and hope they need.

It took Jeremy and Michelle nearly two years to fall pregnant with Oliver. They can clearly remember the day they started on their roller coaster with tuberous sclerosis complex (TSC). It was a Friday. In the middle of their 28 week scan the sonographer stopped and consulted a large book. They did not know what was going on, and up until that day, nothing unusual had been picked up. After she left the room and came back, they were told that the obstetrician would see them immediately.

He said: ***"Something has been found on the scan. We are not sure exactly what it means but I have booked you in to see the cardiologist at the Children's Hospital on Monday."***

Jeremy remembers them both being like deer in the headlights that weekend.



On Monday the cardiologist did another scan and said: ***"We suspect it is tuberous sclerosis and we will arrange for the genetics team to see you in an hour."***

The geneticist told them not to worry too much, and that they would confirm the diagnosis with a genetic test after their baby was born. Jeremy and Michelle decided not to tell anyone about the tumours or about TSC until they were 100% confident of the diagnosis.

They were in a haze. The whole experience was a blur. Of course, despite being told not to, both Jeremy and Michelle researched TSC online and both reacted differently to all the information they found. Jeremy was able to understand that many of the stories he read were 'worst case scenarios' and that they would have to monitor their baby to look out for these different issues. Michelle found these stories caused her anxiety and uncertainty.

***"We would have benefited greatly by being presented with a TSC Parachute Pack at this point, to read positive information and hopeful stories, not just worst case scenarios. This may have helped to alleviate some of the anxiety I experienced. I think it will be a wonderful resource for families facing a TSC diagnosis in the future", says Michelle.***

When Oliver was six weeks old tests confirmed that he had a mutation on his TSC2 gene. Neither of his parents have this mutation. Soon after, Jeremy and Michelle made



the decision to start telling friends and family what was going on.

***"The Parachute Pack would have helped so much, not just for us as parents dealing with the uncertainty and then the diagnosis, but also supporting our extended family and friends too. It's great this resource will give families suggested wording about how to communicate this news with family. We found this incredibly challenging" says Jeremy.***

As the months went by, Oliver started to miss some of his milestones. This was very noticeable as close friends had a baby born on the same day as Oliver and his cousin was born only six months later. So, these other babies were a bit of a benchmark. Oliver started seeing a team of therapists – occupational and speech particularly.

Oliver's parents have given him as normal a life as possible. He loves both exploring the outdoors and watching sport on the couch. He loves planes, trains and cars and asks 'why?' constantly. He does have some delays and attends school in a support unit with just five other peers. As Michelle and Jeremy told us, ***"he is a typical seven year old and has all the attitude that comes with that."***

# The impact of your support on improving health care

Together, we are improving health care for families like Emily's.



**1** New TSC medicine included on the PBS

We are pleased to share that Everolimus (Afinitor) for epilepsy was added to Australia's Pharmaceutical Benefits Scheme (PBS) from 1 January 2019. Epilepsy is one of the most common symptoms of TSC and approximately 90% of people with TSC will have seizures. For many, seizures start when they are a baby and they can be very difficult to manage, with up to half of those affected not being able to get adequate seizure control with other available anti-epilepsy medications. This new medicine has been shown, in clinical trials, to be useful to many people with TSC and difficult to control epilepsy.

TSA made a submission to the committee that makes recommendations on which medicines are included on the PBS. Thank you to all members of the TSC community who assisted us with this. Listing on the PBS has secured funding for this new treatment option for people with TSC.

But the good news doesn't stop there. Everolimus (Afinitor) has also been approved by the Therapeutic Goods Administration (TGA) as a safe and effective treatment for several signs and symptoms of TSC - subependymal giant cell astrocytomas (SEGAs), kidney angiomyolipomas (AMLs) and seizures.

Australia continues to be a world leader in affordable access to Everolimus and other mTOR inhibitor medicines. Thank you to all the researchers and clinical trial participants, particularly, Dr John Lawson and the Australian families who participated in the Exist-3 trial at Sydney Children's Hospital Randwick.

**84**



**Families attended TAND education events across the country**

TSA hosted three education events in Sydney, Adelaide and Brisbane focused on TAND (Tuberous Sclerosis Associated Neuropsychiatric Disorders), a term developed to diagnose, understand and better treat the array of neuropsychiatric

challenges that come with TSC. These challenges include autism, ADHD, anxiety and depression, aggressive behaviour, and learning difficulties. The events, presented by Professor Petrus de Vries, a visiting academic from the University of Cape Town, focused on helping Australian families better understand TAND issues, how to identify them and how to seek early interventions and treatments.



**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

and encourage them to continue. In 2018 the award was presented to Dr Orli Wargon, a paediatric dermatologist at Sydney Children's Hospital. Dr Wargon has been particularly focussed on TSC as a part of the treatment trial investigating the effectiveness of topical rapamycin for facial angiofibromas.

Several members of our TSC community nominated Dr Wargon, including Kate Norris: "We've been in Orli Wargon's good care since our son Liam was a baby. Participating in Orli's fantastically well-run rapamycin trial was a privilege. Liam has continued to use his 'magic cream' and his face is looking so clear."

The topical cream used to treat facial angiofibromas continues to change lives. In children, this new cream can even stop these tumours from forming.

**15**



**Adults participated in TSC Connect**

Our first ever event for adults living with TSC was held in Brisbane in May 2019. This is a very positive addition to our services and support for adults living with TSC and, in addition to

connecting them with other adults living with the condition, will increase their ability to access the best possible health care to help them manage their disease.



# Emily

Together we've helped families like Emily's access Everolimus for epilepsy without needing to be part of a clinical trial.

Emily's history with epilepsy has been a roller coaster ride ever since she started having infantile spasms. Her mum, Dawn, says they had exhausted all seizure medication options, even trying some more than once. Surgery wasn't a safe option for Emily as she also has a connective tissue disorder and there wasn't a clear target for epilepsy brain surgery.

Emily was having around 60 seizures a day of many different types which sometimes needed emergency trips to hospital.

It was fortunate that, because Dawn charts all of Emily's seizures, she could prove that Emily met the criteria for the EXIST-3 clinical trial of Everolimus (Afinitor). The trial was 'blinded', which meant neither her parents nor her doctors knew whether Emily was on the medication or a placebo sugar pill. Within the first few weeks, they saw a dramatic reduction in her seizures and just hoped this wasn't a coincidence.

Emily had side effects from being on the medication. Mouth ulcers, a common side effect of the medication, were managed with frequent teeth brushing. Emily also had poor healing, frequent infections and constant hay fever. Taking a break for around five days helped with infections or when Emily needed to have surgery for something else.

On the plus side, Emily's white patches started to shrink and her angiofibromas started to disappear. Her MRI showed that her kidney and brain tumours were also shrinking.

Emily's family say that her awareness has also increased. Because Emily is having less seizures, they've seen her speech develop and she's started communicating her needs and choices using her iPad. She's even learning to read. Dawn says: **"We've seen even more of her dark sense of humour as she's**



***emerged from what, I imagine, was a fog of seizures. Everolimus has given us so much. The reduction in Emily's seizures has given her cognitive awareness, and the reduction in her tumours has increased her life expectancy and we expect that it will have reduced her chances of developing lymphangioleiomyomatosis (LAM) as she gets older."***

The flipside of Emily's better awareness is her increasing anxiety and the family face challenges finding mental health services to help Emily with these issues.

Dawn says she is: ***"150% happy with what we have done. Even though it meant we have had to experiment on Emily, for us the pros outweighed the cons. Emily will never go to university to get a degree, but she is a pioneer in medical research for TSC and this is her professional contribution to our society."***

The federal government's decision to include this medicine on the Pharmaceutical Benefits Scheme (PBS) means families don't need to pay for this themselves. Whilst Everolimus might not work for everyone, Emily's family feel confident it will improve the quality of life for many others like themselves.

Dawn asserts that: ***"Without TSA's representation and advocacy in the PBS listing process, I am not sure if a decision would ever have been made in our favour. There are thousands of genetic conditions and we are fortunate to have TSA get behind the issues that affect the Australian TSC community."***

# What's next?

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

Since it was formed in 1981, TSA and its TSC community have already seen huge advances in the understanding and treatment of this complex condition. The outlook for a child born with TSC today is very different to that of a child born even just 10 years' ago. Through earlier and more effective interventions we can continue to bring hope as we work towards a cure for TSC.

## In 2020, we will focus on:

- Assisting more families and individuals affected by TSC in Australia, through launch of our new TSA nurse service.
- Launching the new diagnosis Parachute Pack resource for the 50 babies that will be diagnosed with TSC in Australia in 2020.
- Hosting TSC Connect 2020 events on both the east and west coasts of Australia, to bring together TSC families and TSC medical professionals to learn about new treatments and research.
- Improving health care through expansion of the TSC health professionals network.
- Ensuring we are helping and meeting the needs of individuals living with TSC in a way that is meaningful by conducting an Australia-wide survey of our TSC community.
- Expanding our reach and raising awareness of our services.

## New TSA Nurse Service

Thanks to Australian Government grant funding through the Centre for Community Driven Research (CCDR)'s Patient Pathways Project, TSA is delighted to have expanded its services to now provide support through a dedicated TSC nurse. Kim Kerin-Ayres (pictured) is a very experienced nurse and will be a huge asset to our TSC community. TSC families can book an appointment with Kim who will be able to support them in managing their own or their child's complex TSC health needs.

"It doesn't matter where you live or how far you are from a major city or hospital. Anyone who has a phone can get help and support. I am thrilled to be part of TSA's new nurse service which is a free, confidential information and support service providing information and links to practical support," says Kim.



## TSA remains committed to the following strategic goals:

### GOAL 1

Australians with TSC have access to relevant, accurate and balanced TSC information and have the support that allows them to face the challenges of TSC.

### GOAL 2

Australians with TSC have access to the best possible health care.

### GOAL 3

Our TSC Community in Australia is aware of and has access to the Australian and global TSC research program.

### GOAL 4

TSA's work is funded through diverse, effective fundraising to create a sustainable organisation.

### GOAL 5

TSA is strong, reputable and well-governed.

**nib** foundation

Thanks to the support of nib foundation, TSA is developing a New Diagnosis "Parachute Pack" for parents of a newly diagnosed child or a baby with suspected TSC. Informed by research conducted with 25 TSC-affected families, this new resource will provide parents with details about TSC, the genetics, who to contact and what steps they can take after their child is diagnosed. Here's a quote from one of the families who has helped review our draft pack: "Wow, this will be a wonderful resource. I think it's brilliant. So wish such a thing had been in existence when we had Amelia. Far superior than rushing off to the nearest search engine, or in our case the library, full of outdated, scary information."

# Our 10 Point Plan

There's always more we can do. Our needs are big. Our resources and our funding are small. With your help to secure additional funds, we will be able to deliver on our 10 Point Plan.

- 1 Hold at least biennial Australian medical and TSC community connect events to provide access to the latest research and treatments
- 2 Establish TSC Connect events for adults living with TSC in every major city in Australia
- 3 Promote the benefits of the holistic care approach with the aim of establishing a TSC clinic in every state and territory
- 4 Champion new research here in Australia that supports global research developments particularly in investigating early intervention and the potential of mTOR inhibitor treatments
- 5 Build upon our regional network to better connect those who are living with the challenges of TSC, enabling them to share experiences and provide peer support
- 6 Fill gaps and improve our connections with TSC health professionals – including GPs – enabling TSA to provide its community with referrals to TSC health professionals across Australia
- 7 Create forums for TSC health professionals to collaborate on TSC cases and ensure the best possible care
- 8 Ensure everyone in Australia living with TSC knows about us and has access to our information and support
- 9 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
- 10 Provide regular, free, informational calls for those living with the challenges of TSC wherever they live

## How can YOU help us deliver on our 10 Point Plan?

There are so many ways that you can get involved with TSA. Below are just a few ideas. Kate, who looks after our fundraising is always happy to talk to you about these ideas or any others you may have.

### Foundations, Grant Bodies, Corporates and Philanthropists

- Provide grant, philanthropic and corporate funding that supports our aims and helps us deliver on our 10 Point Plan
- Sponsor our 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

- Become a member of TSA
- 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
- Talk to your workplace, your local Lions Club or Rotary Club and others about choosing TSA as a charity partner
- Sign up to be a TSC Hero by participating in a physical challenge like a fun run or walk
- Come along and support a TSA fundraising event like Lizzie's Lunch or Comedy for a Cure
- Hold your own fundraising activities like asking for donations to TSA in lieu of gifts, organising a trivia night or inspiring your child's school to have a gold coin day

*"I am thrilled the firm I work for has chosen to support TSA. I know we can make a great difference by contributing even in a minor way. I've seen how desperately in need of assistance TSA is and I look forward to this partnership having a positive impact on families and their communities affected by TSC."*

**Mia, mother of a child with TSC and a lawyer at Baker McKenzie.**

**You can contact Kate on [kate.garrard@tsa.org.au](mailto:kate.garrard@tsa.org.au) or by phoning 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. We hope you share in our sense of pride for the work we have done and will continue to do supporting individuals living with TSC. This wouldn't be possible without your help.

## TSC Heroes raise \$17,116

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

**City2Surf** Sophie, whose big sister has TSC ran Sydney's iconic City 2 Surf with her dad, Anthony and Auntie Tash.

Michelle from our management committee also joined the team, as did Melissa, who runs as part of #Heroes4Samuel. Together they raised \$5,042.

**Bridge2Brisbane** TSC heroes Miranda and her mum Kerri took on the Bridge2Brisbane challenge for the third time and raised \$827.

**Cole Classic** Edwina signed up to Manly's Cole Classic Ocean Swim, inspired by her nephew and godson Sammy who has TSC, and raised \$3,030.

**Martin climbed Mt Everest** In April Martin reached Mt Everest's base camp raising funds for TSA in honour of his sister who has TSC. Martin raised \$8,217.

## TSC Champions donate \$5,864

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 \$12,272

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

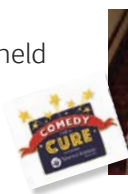
## Special Events

**Lizzie's Lunch 2019** raised over \$22,000 at Hills Lodge, Castle Hill. Enormous thanks to the Pinkerton family for being the driving force in running this successful fundraiser each year in honour of their daughter Lizzie who had TSC.



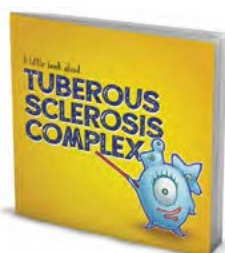
Sue Pinkerton with guests at Lizzie's Lunch

**Comedy for a Cure** raised \$12,000 at our first event held in Melbourne in October 2018. It was a fantastic night of fun, laughs and hope, featuring comedian Josh Earl. This event was made possible by the wonderful efforts of a few TSC families in Victoria.



Melbourne's Comedy for a Cure committee and volunteers

**Book Launch** A special event to launch A Little Book About TSC was held in late 2018. This is the first children's book of its kind in Australia to explain this complex condition to the children who live with TSC. Thank you to Mano and Jeff Place for making this happen.



TSA's new children's book

## Padstow Bowls and Snooker Club

held a Christmas in July fundraiser and raised \$11,036. Over 100 guests attended. Thanks to John and Donna, whose granddaughter has TSC, for inspiring this support for TSA.



Donna raising funds at their community event

## Kalymnian Philanthropic Brotherhood of Melbourne

raised \$4,600 at a car show in Melbourne in March 2019 in honour of Jo and Kon Romio's son Kristian. Shout out to Jo, Kon, Jim and all the team.



Alison from TSA accepting the giant cheque from the car show team

## TSC Global Awareness Day and #Tatts4TSC

Over \$12,000 was raised with people all around Australia holding #Tatts4TSC community fundraising events on TSC Global Awareness Day in May. Special thanks to Rob and Mimi Rossano, Miriam and Ros Chalk, Gayle Rockstroh and Rachel Bennett.



#Tatts4TSC PJ day at Blackmans Bay Primary School



## Our Volunteers and Regional Contacts



To all our wonderful volunteers around Australia, what would we do without you! Special mention to Teresa Llewellyn-Evans, Belinda Johnstone, Carolyn Place and Jackie Schmidt. Sincere thanks to our regional contacts who work with local families to share information and experiences.

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

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

## Our TSC Community

We are grateful to all our TSC affected individuals and families who come along to our education 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 professionals 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 NZ. 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 wonderful organisations.

## Our Partners

This year we welcomed two new corporate partners **nib foundation** and **Baker McKenzie**. We are delighted to be working with these organisations to improve the lives of Australians with TSC.

Thanks also to the **Centre for Community Driven Research**, **Disabled Children's Fund** and **National Disability Conference Incentive Scheme** for looking favourably upon our grant applications



*A little book about TSC writers and illustrators:  
Camila, Dean, Clare and Manoela*



*First TSC Connect weekend in Brisbane for  
adults affected by TSC*



*TSC Clinic team at Sydney Children's Hospital*

### 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.

### Our Suppliers

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

# Our Donors

## TSC Champions

Allchin, Belinda *matched by Macquarie Bank Foundation*  
Aunt Ivy's Laundry and Dry Cleaning  
Baker McKenzie

Clisdell, Peter  
Cunningham, Jennifer  
Garrard, Julie  
Goldstiver, Andrew and Emily *matched by Westpac*

Gregson, Sonia  
Hill, Hayley and David  
Kourea, Nina  
Mason, Sue  
Nicholson, Sally and Cunnew, Elliott

O'Donoghue, Jennifer  
Pinkerton, Sue and Ross  
Pinkerton, Robert  
Rologas, Melissa  
Vettom, Lucy  
Walker, Steve and Norris, Kate

## Membership contributions to Tuberous Sclerosis Australia

### Life Membership

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

### Platinum Membership

McKillop, John  
Niklaus, Kevin  
Purkiss, Michelle  
Stewart, Luke

### Gold Membership

Abery, Peter  
Aisbett, Shirley  
Alexander, Frederick  
Bell, Leisel  
Bowra, Dawn  
Bromhead, Kerry  
Chandra, Adish  
Crosby, Anthony  
Crosby, Debbie  
Crosby, Joanne  
Cummins, Gail  
Dawkins, Louise  
Delbridge, Suzanne  
Durluk-Sierra, Katarzyna  
Epilepsy Action Australia  
Fay, Bruce  
Foster, Lachlan  
Gill, Adarsh Deepak  
Hill, Kelven  
Hopwood, Berice

Humphrey, Belinda  
Jones, Michael  
Jordan, Bridie  
Kishan, Hari  
Lee, Jeff  
Liebman, Lisa  
Lim, Vanida  
Mathewson, Vanessa  
Matthews, Melissa  
McIvor, Alison  
Mid West Concrete  
Mowat, David  
Mustard, Jill  
Niklaus, Kevin  
Norris, Patrick  
Oxenbridge, Sharlene  
Penniment, Steve  
Romios, Kon  
Somerville, Marianne  
Stone, Nicole  
Strosberg, Daniel  
Vasara, Annika  
Wakeley, Loren  
Zehnwirth, Harry

### Silver Membership

Al'e, Mia  
Barassi, Ray  
Bartels, Dean and Elizabeth  
Blunden, Andrew  
Bright, Zoe  
Foster, Lachlan

Hennings, Peter  
Hill, AK & MG  
Kittel, Pauline  
Kyriazis, Nicole  
Lin, Evelyn  
Lord, Wayne  
Lowe, James  
Mateffy, Adrienne  
McCormack, Sue  
Mercer, P  
Meredith, David  
Nguyen, Nu  
Peipman, Shirley  
Raffaut, Danny  
Schilg, Scott and Georgina  
Stone, Samantha  
Vasara, Annika  
Wiles, Catherine  
Williamson, Sue  
Young, Claire

### Bronze Membership

Alexander, Frederick  
Beck, Deb  
Bonacci, Luigino  
Boulter, C  
Colman, Tania  
Core, Katina  
Curtis, Dianne  
Doyle, Chris  
Drury, R and J  
Early Connections Coffs

Frilingos, Peter  
Garrard, Kate  
Hell, Marie  
Herbert, Christy  
Jenkins, Karen  
Jordan, Bridie  
Kerr, Narelle  
Lee, Gary  
Llewellyn-Evans, Teresa  
Marshall, Christopher  
Martin, Frank  
Matheson, David  
McArthur, Lachlan  
McLean, Faye  
Meredith, David  
Miller, Glenda  
Mills, May  
Morris, Emma  
Neville, Joelle  
O'Reilly, Beverley  
Phillips, Christine  
Reynolds, Janiffer  
Rockstroh, Gayle  
Scanlon, Hannah  
Shaughnessy, Jackie and Graeme  
Simpson, Tracy  
Stuart, Clare  
Taylor, Daphne  
Trunk, Kaylene  
Williams, Penny  
Woodcock, Kay

## Donors

### \$1000 and over

Beaton, Anna  
Bendigo Bank  
Bright, Tess  
Brisbane Trivia Night  
Mid West Concrete

Chandra, Adish  
Head, Tracey  
Kalymnian Philanthropic Brotherhood of Melb  
Kelly, John

Jenkins, Kristie-Lee  
Padstow Bowling & Snooker Club  
Poole, John  
Rossano, Rob

Rotary Club of Orange  
Daybreak  
Tait, Jan  
Will, Patricia  
Zorbas, Harry

### **\$500 and over**

Assured Home Care  
Chalk, Miriam  
Chalk, Roslyn  
Clark, Marian  
Cummins, Gail  
Dance 4 Fun  
Delbridge, S  
Delpech, Chauntelle  
and Hiotellis, Michael  
Dreyer, Todd  
Du Bois, Barry  
Lee, Gary  
Niklaus, Kevin  
Paterson, Jacqui  
Runner, Virtual  
Vietnam Veterans  
Association of  
Australia  
Wilson, John

### **\$100 and over**

1 O'Connell Street  
Abbott, Lynne  
Ablett, Nicky  
Aboucham, Billal  
Agarwal, Manjul  
Arslan-Sibo, Selcen  
Auty, Bruce  
Baker, Cathy  
Baker, Michelle  
Barp, Camila  
Barrett, Patricia  
Baruah, Dean  
Bayliss, Nick  
Baynes, Val  
Beal, David and Regina  
Beaton, Roslyn  
Blackshaw, Kay  
Blackwood, Emma  
Boreham, Greig  
Bowen, Narelle  
Boyd, Jack  
Braine, Piret  
Bray, Dudley  
Brown, David  
Bryant, Ray  
Bunnings, Caringbah  
Capper, Sandra  
Catlow, Catherine  
Chau, Wing  
Chow, Joyce Choi Shan  
Cocking, Angela

Cook, Jan  
Costa, Kim  
Costa, Natalie  
Coubrough, Brett  
Crosby, Anthony  
Crosby, Debbie  
Crosby, Joanne  
Crowe Horwath  
Curran, Matt  
Dale, Tom and Marney  
Darcy, Lydia  
Darcy, Nicole  
Davies, Jacqui  
Dordevic, Denis  
Doshi, Moulik  
Duff, Henry  
Durluk, Katarzyna  
Ebert, Bridgette  
Edwards, Yvonne  
Evans, James  
Faravoni, Shirley  
Fay, Bruce  
Fernandes, Hannah and  
Ralston  
Fitz, Ross  
FitzGerald, Elizabeth  
Floros, Dina, Flo, Luka  
and Max  
Fowler, Debbie  
Freeman, Kerrie  
Gagliolo, Christine  
Garrard, Kate  
Gascoyne, Chris  
Geddes, Victoria  
Gibbs, Christopher  
Gillies, Greg  
Gupta, Anuj  
Gurney, Jeff and Joanne  
Halkitis, Helen  
Halsey, Brett  
Hansen, Robin and Tony  
Hartley, Mary Anne  
Heales, Katherine  
Heggie, Suzette  
Henry, Anthony  
Hertz, Seth  
Herzog, Matthew  
Hesseling, Joke  
Hesseling, Rutger  
Hoffmann, Gloria  
Humphrey, Belinda  
Intune Gardens  
Jacaranda Lodge

Jerga, Eileen  
Jerga, Mary  
Jones, Anita  
Keane, Jonny  
Kiely, Colm  
Kiening, James  
Kirby, Thomas  
Kitts, Michael  
Knowles, Anne  
Kourea, Con and  
Maria  
Kourea, Natasha  
Kowalewski, Jill  
Langelaan, Ron  
Lavers, Lindsay  
Lockwood, Julie  
Logan-Halaj, Amanda  
Lynch, Chris and Kat  
Madden, Jannene and  
Colin  
Maher, Melissa  
Malsher, Alan  
Mann, Harpreet  
Maris, Simone  
Mason, Sue  
Mathewson, Vanessa  
Maude, Kerry  
McAllister, Jennifer  
McClintock, Geoff  
McHugh, Rob  
McIvor, Alison  
McQuillanm, Chrissie  
Moorshead, Christina  
Nagel, Samantha  
Naiman, Betina  
Neustein, Michael  
Noreen, Tanya  
O'Brien, Ann  
Ogilvie, Alannah  
Osborne, Max and Julie  
O'Sullivan, Tom  
Page, Daniel  
Palan, Romy  
Panich, Catherine  
Papadopoulos, Sasha  
and George  
Pratt, Ann  
Quinn, Aidan  
Ramsay, Mills  
Reid, Yvette  
Robinson, Barry  
Rogers, Jeremy  
Rologas, Lucas and Maria

*"My son Caleb was diagnosed with TSC earlier this year. I am on the TSA web-site almost every day, reading and re-reading testimonials, and all the other invaluable information TSA publishes. We would have honestly been completely lost this year without it."*

**Miriam  
Tasmania**



Rologas, Peter  
Romios, Kon and Joanne  
Sakoulas, Carolyn  
Sayce, Marc  
Scanlon, Clare  
Silk, Rebecca  
Simmons, Lynne  
Stuart, Allan  
Stuart, Erin  
Sudagar, Mahesh  
Symons, Gary  
Szczybor, Andy  
Thomas, Emma and Matt  
Thomas, Greg  
Ungaro, Scott  
Van Leeuwen, Albert  
Van Leeuwen-Hughes,  
Monique  
Waight, Carole  
Walker, Keith  
Warburton, Julie  
Webb, Alan and Kaye  
Webster, Sue  
Weir, Peter  
Wilson, David  
Yardi, Jayant  
Zehnirith, Alison  
Zheng, Michael

**We'd like to thank everyone who made a contribution to TSA this year. We are grateful for each and every gift TSA received. We have chosen to list above only donations over \$100, because there were just too many of you to include each of you by name.**

# Our Financial Results

**This has been a year of change for TSA with the departure of our inaugural General Manager. To facilitate a smooth handover, this change in management entailed investment in a period of transition for the team and so we finished the year with a small deficit of \$12,159.**

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 saw a significant uplift in income. We have also moved 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 new telehealth nurse. We have had a dramatic increase in securing grant monies. Because these grants are typically tied to specific expenditure, we do not recognise these funds as income until expended.

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. We also 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 3 months.

The accounts for 2018/19 were audited by Mark Mortimer (Registered Auditor No. 1942) of Bondy Mortimer & Co. A copy of his report is available at <https://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. Building upon our strong foundations will help us ensure we will be around for the long-term. TSA is committed to continue to work with the TSC community to secure the funding we need to achieve our goals and a sustainable future.



*Patrick Norris, TSA Treasurer  
and grandfather of Liam*

## Our work with pharmaceutical companies

TSA has previously collaborated with Novartis and other pharmaceutical companies in a number of ways. This year we did not receive any project funding or support from the medicines industry. Our policy on working with pharmaceutical companies, which is available on our website [www.tsa.org.au](http://www.tsa.org.au), describes how we maintain our independence and integrity.



## Financial statements

# Balance Sheet as at 30 June 2019

ASSETS	30 June 2019	30 June 2018
<b>Bank</b>		
General Cheque Account	\$88,728.34	\$32,849.72
PayPal	\$2,768.68	\$0.00
Savings Accounts	\$30,820.45	\$10,117.88
Term Deposits	\$188,359.02	\$203,207.42
<b>Total Bank</b>	<b>\$310,676.49</b>	<b>\$246,175.02</b>
<b>Current Assets</b>		
Accounts Receivables	\$317.50	\$0.00
Sundry Debtors	\$2,029.35	\$2,916.01
<b>Total Current Assets</b>	<b>\$2,346.85</b>	<b>\$2,916.01</b>
<b>Total Assets</b>	<b>\$313,023.34</b>	<b>\$249,091.03</b>
<b>LIABILITIES</b>		
<b>Current Liabilities</b>		
Accrued Expenses	\$8,000.00	\$0.00
GST	\$210.64	-\$769.71
PAYG Withholding Payable	\$1,648.00	\$2,037.00
Provision for Annual Leave	\$6,619.67	\$6,511.82
Provision for Long Service Leave	\$3,617.07	\$0.00
Salary Sacrifice Payable	\$0.00	\$0.09
Superannuation Payable	\$3,130.53	\$2,367.04
Suspense	\$0.00	-\$350.00
Trade Creditors	\$0.00	\$56.27
Unexpended Grants	\$64,049.47	\$0.00
Unpaid Expense Claims	\$693.93	\$2,016.37
<b>Total Current Liabilities</b>	<b>\$87,960.31</b>	<b>\$11,868.88</b>
<b>Total Liabilities</b>	<b>\$87,960.31</b>	<b>\$11,868.88</b>
<b>Net Assets</b>	<b>\$225,063.03</b>	<b>\$237,222.15</b>
<b>EQUITY</b>		
Current Year Earnings	-\$12,159.12	-\$55,653.92
Retained Surplus	\$237,222.15	\$292,876.07
<b>Total Equity</b>	<b>\$225,063.03</b>	<b>\$237,222.15</b>

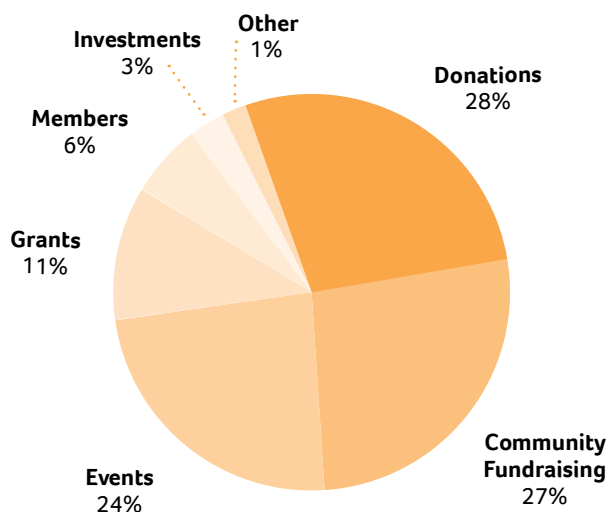
## Financial statements

# Income and Expenditure: Year Ended 30 June 2019

	30 June 2019	30 June 2018
<b>INCOME</b>		
Donations Received	\$114,012.83	\$64,397.35
Event Income	\$35,114.70	\$24,060.00
Grants Received	\$21,501.47	\$13,785.24
Membership Contributions and Fees	\$12,272.75	\$11,911.12
Other Income	\$4,967.51	\$5,283.39
Sales of Goods	\$3,403.53	\$3,760.01
<b>Total Trading Income</b>	<b>\$191,272.79</b>	<b>\$123,197.11</b>
<b>Gross Profit</b>	<b>\$191,272.79</b>	<b>\$123,197.11</b>

<b>OPERATING EXPENSES</b>		
Accounting and Bank Fees	\$7,806.89	\$8,245.32
Advertising and Promotion	\$213.47	\$97.27
Consultancy Fees	\$2,100.00	\$8,200.00
Educational Event Expenses	\$5,208.80	\$4,669.13
Foreign Currency Gains and Losses	\$0.00	\$325.62
Fundraising and Event Expenses	\$16,143.76	\$15,163.20
Information Technology Expenses	\$8,352.70	\$9,970.71
Insurance Expense	\$2,839.19	\$1,864.08
Postage, Freight and Courier	\$3,197.25	\$2,636.78
Printing & Stationery	\$2,784.60	\$5,932.75
Publications and Information Resources	\$13,920.45	\$3,883.57
Research Grants Awarded	\$0.00	\$2,495.45
Salaries and Wages	\$125,240.33	\$101,914.08
Sundry Expenses	\$1,611.89	\$2,997.36
Telephone, Fax and Internet	\$1,029.87	\$1,734.00
Training & Development (Staff)	\$681.55	\$314.81
Travel & Accommodation	\$12,301.16	\$8,406.90
<b>Total Operating Expenses</b>	<b>\$203,431.91</b>	<b>\$178,851.03</b>
<b>Deficit/Surplus</b>	<b>-\$12,159.12</b>	<b>-\$55,653.92</b>

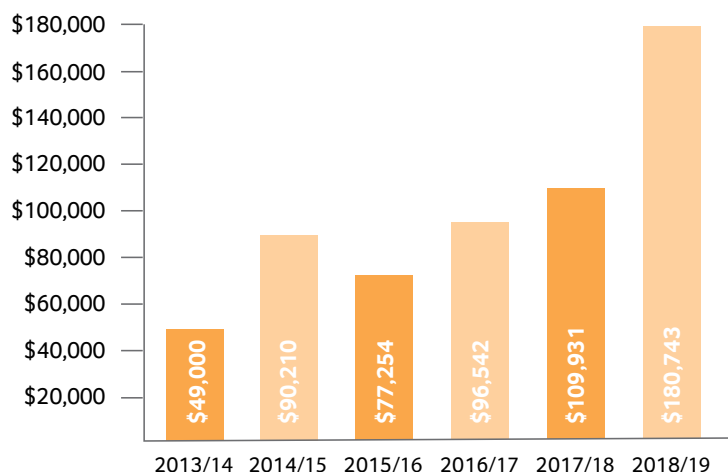
## Where funds came from



## Volunteer Contributions

During this year, TSA's education and support work was supported by a team of volunteers. This includes Debbie Crosby, who answers many of the TSC Information Service calls, as well as our regional contacts around Australia. Their time is not included in our financial statements but is an important resource for TSA.

## Fundraising Revenue



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

## Programs and Services 38%

These are the costs associated with our provision of information and support to people affected by TSC. This includes all costs associated with our education events, the TSC Information Service, writing and updating our TSC information pages, our resource directory and publishing Reach Out. Additionally it includes time spent working with health professionals, policy makers and advocates in health and disability to improve the care, support and access to research available to people affected by TSC.

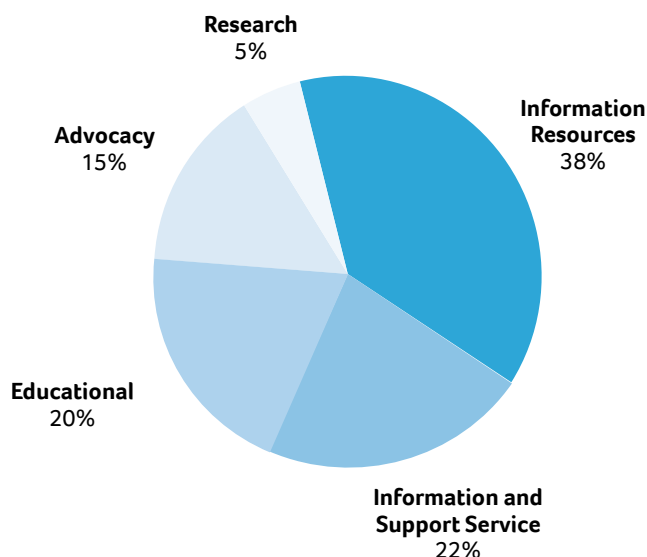
## Development 40%

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. Also associated direct costs include promotional and thank you materials, event costs such as catering, and merchandise for TSC Hero fundraisers.

## Accountability and organisation management 22%

The costs of running the organisation efficiently and with transparent governance, including activities relating to the TSA Management Committee. Direct costs include insurance premiums, accounting and auditing fees, IT hosting and support. These activities and expenses provide necessary support for TSA's programs, but are not directly attributable to any one program.

## How program funds were used





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



*The rainy weather didn't deter our TSC Heroes team at the Bridge to Brisbane*



*TSC Hero Melissa at Bondi Beach*



*Sophie and her dad Anthony at the City2Surf*



*Melissa with Samuel who inspired her to become a TSC Hero*

Phone 1300 733 435  
Website [www.tsa.org.au](http://www.tsa.org.au)  
TSA Nurse [nurse@tsa.org.au](mailto:nurse@tsa.org.au)  
Email [info@tsa.org.au](mailto:info@tsa.org.au)  
Facebook [facebook.com/AuTSC](https://facebook.com/AuTSC)  
Mail 18 Central Rd, Beverly Hills NSW, 2209 Australia



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Registered Charity CC25313  
CFN 13968



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Australia**

*A better life. A more hopeful future.*