



Tuberous Sclerosis  
Australia



# Impact Report 2022

*We are stronger together*

# Tuberous Sclerosis Complex (TSC)

TSC is a rare genetic condition that causes tumours to grow on major organs of the body. Most commonly TSC affects the brain, skin, heart, lungs and kidneys. There are a wide range of signs and symptoms of TSC and, while it affects everyone differently, it can cause epilepsy, brain and kidney tumours, developmental delay and autism. TSC affects more than 2,000 people in Australia and thousands more carers, families and friends. Over one million people worldwide live with TSC.

Although a diagnosis of TSC is given to an individual, it ripples through the family, community and our whole society. There is no known cure and no crystal ball to predict how any individual will be affected but with appropriate support most people with TSC can live fulfilling lives.

## Tuberous Sclerosis Australia (TSA)

TSA is a non-profit organisation that exists to support people living with TSC. For over 40 years TSA has been providing accurate and up-to-date medical resources on the disease and current treatment options, along with involvement in ground breaking international research. We work to connect, inform and empower patients and their families to access appropriate medical care, treatment and surveillance to ensure they can live the best life possible.

### Our Purpose

To help create a better life and more hopeful future for everyone affected by TSC by providing knowledge, support and connection.

### Our Beliefs

- We believe in the power of community and that we are stronger together.
- We respect the uniqueness of every person and their experiences.
- We believe knowledge is power.
- We will never be done fighting the fight until there is a cure for TSC.

### How we deliver on our purpose

1

#### Through information and education:

We provide accurate, balanced information about TSC, best practice management and surveillance, latest research and treatment options.

2

#### By empowering people in the TSC Community:

We enable people living with TSC to proactively manage their health and wellbeing and provide both emotional and practical support and advice.

3

#### By providing essential and valuable connections:

We connect people living with TSC to expert health professionals and relevant services and to other people facing similar challenges.

4

#### Through advocacy:

We raise awareness of TSC and advocate on issues such as access to health care and new treatments.

**TSA is Australia's go-to resource for information, advice and support for anyone affected by TSC**

A close-up portrait of a young girl with light brown hair, wearing a beige knitted headwrap and a white hospital gown. She is looking directly at the camera with a gentle smile. The background is a clinical setting with a light blue wall, medical equipment, and a red sign that partially reads "Cautious during procedure" and "Please if you".

Hope for  
our kids



# President's Report

We are proud of what Tuberous Sclerosis Australia (TSA) has been able to achieve with and for individuals and families living with Tuberous Sclerosis Complex (TSC) over the past year, and since our inception over 40 years ago. We hope you enjoy learning more about our work and our achievements in our inaugural Impact Report that has been made possible thanks to the devotion of our TSC Community. We are stronger together.

It is a great privilege to be part of this organisation, which is making a huge impact for families like mine. I would like to start by thanking you, our TSC Community. Thank you for choosing to get involved with TSA's work again this year by sharing your stories, connecting and supporting other families facing similar challenges and inspiring your families and wider networks to support our work. We honestly couldn't do it without you.

TSA's real strength is the way teams come together, dedicated to improving the life and health outcomes of everyone impacted by TSC. We are fortunate in our abundance of volunteers who have shaped TSA over the past 40+ years; the trusted relationships and reputation we have built with health professionals and researchers in Australia and around the world; our steadfast TSC Community; and the high quality and diversity of work our small but mighty TSA staff team accomplishes.

We acknowledge this past year has seen continued challenges for many of us due to COVID-19. Yet this didn't stop you from getting involved in TSA's first Light the Way Giving Day which was a smashing success (read more on page 12). As a small charity we depend on the generosity of our donors, fundraisers and volunteers. Even in these uncertain times you have continued to support us by renewing your memberships, making regular donations and encouraging your communities to donate. Thank you all for your enduring and generous support.

We've achieved so much together over the past year which you can read more about in our CEO's Report on pages 6 and 7. We can all feel proud of our achievements. Together we are making a real impact on living well with TSC.

We know there may be more tough times ahead, but we are confident we will continue to be there for each other. Thank you for being a valued part of our TSC Community. We encourage you to reach out to us if we can provide any help and support to you and your family as you navigate life with TSC.

*Debbie Crosby, TSA President and mum of Alana who lives with TSC*

## The TSA Team FY21/22

- **Jackie Gambrell** CEO
- **Kate Garrard** Fundraising and Communications Manager
- **Katrina Watt** TSA Nurse

## Our Management Committee

- **Debbie Crosby** President
- **Patrick Norris** Treasurer
- **Michael Jones** Vice President
- **Rob Haggett** Secretary
- **Alison McIvor** Committee Member
- **Miriam Chalk** Committee Member
- **Nova Young** Committee Member
- **Rob Rossano** Committee Member

# Our Achievements

## This Year

Hosted a national TAND+ Conference in Perth and online and held 3 Zoom Education Events.  
Updated TSA's medical information website pages with the new international TSC Surveillance and Management Guidelines.  
Advocated for abdominal MRIs to be more widely available and free to access for people with TSC.  
Recorded and distributed the first podcast on TSC for General Practitioners (GPs).  
Welcomed our new TSA Nurse, Katrina Watt.

## The 2020s

Provided one-on-one support to our TSC Community via our new TSA Nurse Service.  
Pioneered publication of *Research Round Up* a quarterly newsletter focused on TSC-related research.  
*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 TSC Community during the COVID-19 global pandemic.  
Produced *In Safe Hands* - new educational resources for parents and teachers of school-age children living with TSC.  
Presented a 2-day virtual Conference for the TSC Community and Health Care Professionals.  
Hosted 7 Zoom Education Events on a diverse range of TSC-related topics.

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 4 families in Australia living with TSC.  
Hosted the first combined conference for health professionals and families living with TSC in Australia.

## The 2000s

## 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 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 1980s

TSA founded as the Australasian Tuberous Sclerosis Society.  
First issue of *Reach Out* published.  
Launched social picnics for families.  
First family conference.

National roadshow in 3 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 1990s



# CEO's Report

## **TSA achieved a lot in 2022 thanks to your ongoing help and support.**

The 2021/22 financial year got off to a less than ideal start thanks once again to COVID-19, with many states and territories in lock down for extended periods. Overall though it has been a good year with many important achievements and progress for people living with TSC in Australia. At TSA one of the ways we adapted was through the delivery of TSC-specific Zoom Education Events. We had excellent presentations on autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD); sleep issues in children living with TSC and transitioning from child (paediatric) to adult health care.

In November we hosted a hybrid in-person and virtual conference. Unfortunately travel restrictions prevented any of the TSA team getting to Western Australia for our TAND+ Conference. But, thanks to our fantastic facilitators – Rob, Belinda and Adam – and our great community team in WA – Nicole, Sue, Sam and Lisa – things ran very smoothly.

The keynote presentations at the conference were on TSC Associated Neuropsychiatric Disorders (TAND) which are frequently experienced by people living with TSC. The impacts on behaviour, learning and mental health are often the most difficult symptoms to cope with.

Almost 100 households participated in this event. We received very positive feedback with 87% of survey participants rating the event excellent/very good and 100% saying they would take specific actions as a result of what they had learnt. We are indebted to our health professional presenters both here in Australia and overseas and also to our sponsors, the Department of Social Services and Lotterywest, who made this event possible.

At the end of 2021, Dr Clara Chung from Sydney Children's Hospital helped us go on another foray into the virtual world, creating a much-needed introductory podcast to TSC for GPs and primary health care professionals. We also updated the information on our website and in our information sheets to reflect changes in the newly released international TSC Surveillance and Management Guidelines.

In February of this year Katrina joined as our new Pathways telehealth nurse, providing one-on-one support. Katrina says she loves her new role and is always happy to hear from our TSC Community and health care professionals who have patients with TSC.

In the April 2022 issue of *Reach Out* we celebrated the work of some of the dedicated TSC health care professionals who support our Community. Here at



TSA we feel honoured to be collaborating with some amazing medics and we look forward to working with our expanded advisory panel in 2023 (see page 14 for more).

As the 2022 financial year came to an end, we were amazed, astounded and awed by the response of our supporters to our first ever Light the Way Giving Day in May (see page 12). The campaign raised almost \$60,000 allowing us to continue our work and focus on providing services and support to people living with TSC in Australia. Our sincere thanks to everyone who supported this campaign and TSA.

### **Highlights of FY21/22:**

- TAND+ Conference – 100 households participated with 95% saying it improved their understanding of TSC.
- 3 Zoom Education Events.
- Development of introductory podcast on TSC for GPs and primary health care professionals
- New medical advisory panel created.
- Updated our resources to reflect the international TSC Management and Surveillance Guidelines 2021.
- Katrina joined as our new Pathways Telehealth Nurse.

### **What's coming up in the year ahead**

We all hope that one day a cure for TSC will be found and we recognise the important role that research plays in that search. TSA will continue to work with researchers with an interest in TSC and will continue to bring our TSC Community summaries of the important local and global research. In the year ahead we are excited at the prospect of working with the Sydney Children's Hospital team and other health professionals involved in the STOP2 research trial. This significant trial will investigate the impact of early intervention with mTOR inhibitors in babies and infants under 2 years of age.

We are hoping for a positive outcome for our advocacy work for abdominal MRI for TSC screening, which is

the internationally recommended screening test. If it is successful, abdominal MRIs will become more widely available and free to access for people with TSC through bulk billing services. Many thanks to all of you who completed surveys and sent letters of support. The application is still with the Medical Services Advisory Committee (MSAC) but we hope a decision will be made soon.

We have been successful in receiving a grant from the Department of Social Services through the National Disability Conference Incentive Scheme and plan to run another event connecting adults living with TSC. Look out for details to be announced soon.

One of the opportunities the expansion of our medical advisory panel in 2022 is giving us is to work in partnership with health professionals around the country to investigate and support the development of more TSC clinics or other forms of co-ordinated multidisciplinary care (whether in hospitals or virtual). This is a key priority for us in 2023.

And finally, much of 2022 has been spent preparing, planning and working on an upgrade of TSA's most

important source of information – its website. We expect to launch the new site in early 2023. We hope you will love the new look and feel and find the site easier to navigate and better to use. As always, we welcome your feedback.

#### Plans for FY22/23:

- Launch of our new TSA website with improved look, easier navigation and better usability.
- Continue to advocate for a MBS number for abdominal MRI for TSC screening.
- Work in partnership with health professionals to investigate and support the development of better models of care in Australia.
- Host an in person TSC Connect event for adults living with TSC.
- Collaborate on the STOP2 research trial investigating early intervention with mTOR inhibitors.

## There is still much work to do improving care for adults living with TSC

Georgia was born in Perth in 1995. At 2.5 months she started to have complex partial seizures and we were given the devastating news that our baby girl had TSC. Although her childhood had many difficulties with seizures, we had a lot of early intervention and support from expert doctors and therapists. Through rigorous physio, OT and speech therapy, Georgia walked at 11 months and talked at 3 years – after being told she would never walk or talk this was astonishing. Her treatment at the Children's Hospital was very holistic and each physician knew what the other was doing or treating.

However since turning 18 and transitioning to the adult health care system we've encountered many struggles. Georgia began to have kidney and lung involvement and it has been a battle every step of the way to get her the help she needs. None of the doctors we saw knew anything about TSC or the recommended treatments and we were left frustrated and unable to access the best proven treatments for her.

I reached out to the TSA nurse to help me find a doctor who could help. We now have a wonderful, very helpful private doctor on board and Georgia has started the drug Afnitor (Everolimus). We are hopeful she will have some success with this treatment.

I know I am not alone in this struggle. I have heard many similar stories. It is essential that we get more co-ordinated, holistic and collaborative care of adults living with TSC around Australia.

Today Georgia is a wonderful young lady with many friends. She's happy. She works and she leads a very productive life.

*Angela, Georgia's mum*





# Empowered Connected Families





# The impact of your support

**132**

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

**28,758**

People visited our website for information about TSC

**102**

Number of people viewing our TSC information pages each day

**639**

Members supported through our private online TSC discussion group

**667**

Comments posted in our online TSC discussion group

**182**

Individuals attended a TSA education event or conference

**1**

Podcast about TSC developed for GPs and other primary health care professionals

**59**

Families with a new diagnosis of TSC accessed our Parachute Packs

**2**

Issues of *Reach Out* published

**52**

Families downloaded the *In Safe Hands* schools resources

**115**

TSC experts in our Health Care Professionals network

**1,721**

Facebook followers  
(82% are female)





# Together we are improving TSC information and services for families like Mase's

**Doctors first suspected Maselino, affectionately known as Mase, may have TSC during an ultrasound when his mother Clarissa was 37 weeks pregnant. His diagnosis was confirmed from evidence of TSC tumours on his heart, brain and one of his eyes. Mase then suffered his first epileptic seizure at just 3 months old and quickly began having seizures lasting more than 4 minutes. Thankfully, due to his early TSC diagnosis, Mase's family understood seizures could occur in TSC and knew just what to do. They headed straight to their local hospital for immediate treatment.**

Mase's TSC diagnosis means he lives with tumours on many of his body's major organs, epilepsy, autism, global developmental delay and angiofibromas (small, red bumps on the face). Clarissa has had moments of feeling completely alone in dealing with a condition so rare that she often has to explain it to some of the doctors she sees. Ever since Clarissa connected with the medical experts at the TSC Multidisciplinary Clinic at Sydney Children's Hospital, Randwick she knew her son was in the best possible hands to get the care and treatment he needed.

And, since finding TSA's TSC Facebook Discussion Group, Clarissa says her feelings of isolation have significantly reduced, 'Having some support has helped me be stronger for him. It has helped a lot to talk to and meet other families going through the same thing and sharing stories.'

The severity of impacts in TSC vary widely in each person. Mase is often mistaken for a perfectly healthy boy as his tumours are not visible and the red marks on his face are small and not very noticeable from afar. Clarissa says she has had to explain to people that, just because he doesn't have a visible disability, he is going through a lot. 'We still haven't been able to control his seizures. Some days he has up to 6 a day and then he may not have one for 2 weeks. We don't know what triggers them.' Clarissa says she feels helpless when Mase has a seizure. He also experiences behaviour changes because of his seizure medication. 'At the moment, my son's in this phase where he is lashing out and hurting himself.'

To better help Mase understand what is happening to his body, together, Clarissa and Mase created a simple, easy-to-understand book that Mase could relate to. 'It was like a Saturday project with him. I typed up the story and he drew the pictures.' The result is their 24 page paperback book, *Did you know... I was born a TSC hero!* Clarissa explains: 'I want to help other kids and families living with rare medical conditions like TSC know they're not alone. There is someone else out there fighting the same battle and it's okay to be different and they don't need to feel left out. We are so proud of the book. You can buy a copy on Amazon.'

Meanwhile, the battles continue for Mase and his family, with Clarissa describing the most recent check-up as quite confronting. The family were advised to consider brain surgery to remove the tuber that is causing the seizure activity. While brain surgery does come with some concerning risks, it has been proven to be successful in managing unstopable epilepsy in TSC when all other options have been exhausted.

Clarissa says she feels comforted knowing she is not alone and can reach out to TSA and the TSC Community for information and support.

# Light the Way Giving Day



TSA's first Light the Way Giving Day Appeal launched in conjunction with TSC Global Awareness Day in May 2022 was a smashing success. We are thrilled our TSC Community got behind this initiative and helped inspire so many donations. The impact of this tremendous support is that TSA has the funds needed to keep our much-needed nurse and support programs and services running. TSA will continue to provide a beacon of light and hope for individuals and families when TSC comes crashing into their world making sure no-one has to face the challenges of TSC alone.

## Our Ambassadors



Iluka



Annabelle



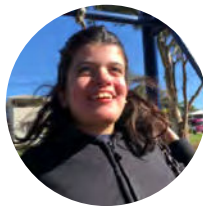
Katalina



Roxie



Isabel



Alana



Lucia



Greg



Samuel

## Our generous matching partners

**TSA Matching Circle | The Delbridge Family | The McKillop Family | Michael and Cathy Jones  
The Rossano Family | The Clisdells Group and Staff | Alison McIvor**

## What we achieved

- **\$59,000** in total was donated
- **61%** of gifts were inspired by our TSC family ambassadors and champions
- **292** people chose to make a donation
- We received our largest ever appeal donation of **\$10,000**
- The average gift size was **over \$200**
- **The impact - We did it!** We funded TSA's much-needed support programs like our nurse, information and connection services, education events and advocacy work.

Our generous Light the Way campaign sponsor

**Baker  
McKenzie.**





## Lucia

'We feel incredibly fortunate to have connected with the team at TSA through the Light the Way Giving Day. Our daughter Lucia is 2 years old and has been diagnosed with both TSC and Polycystic Kidney Disease (PKD).

Our little Lucia's diagnosis came as an enormous shock to our family. But we're trying to take it one day at a time and just focus on all the positives - like the access we have to expert treatment at Sydney Children's Hospital through the TSC Clinic and the information and support from TSA.

We wanted to get involved in the Light the Way Giving Day appeal to help shine a light on TSC. Helping to raise awareness of this unknown rare disease helped us feel like we were doing something to assist others facing similar challenges. We were totally blown away by the generosity of our family and friends who donated over \$11,000. All we had to do was share our story and the donations started flowing!

We know these gifts will help families in need access the programs and supports that make such a difference to managing our daughter's complex health conditions.'

*Lucia's parents Pep and Francesca  
from Sydney, NSW*

# Introducing our new Medical Advisory Panel

For many years Dr Sean Kennedy, Dr John Lawson and Dr David Mowat at Sydney Children's Hospital have acted as TSA's medical advisors. This small and dedicated team of doctors has helped TSA in so many ways - reviewing and writing materials for our website and new publications, facilitating introductions to other health professionals and researchers and keeping us in the loop on important medical developments. We are most appreciative of everything they have done to guide and support TSA's work.

Our network of health professionals has of course grown in the 40 years TSA has been in existence and our reach as a national organisation has also increased. We feel the time is now right to widen and deepen our medical advisory team.

We are delighted to introduce members of our new medical advisory panel who will help guide our organisation in the next phase of its development.

**Dr Denise Chan**, Paediatric Neurologist, Sydney Children's Hospital

**Dr Clara Chung**, Clinical Geneticist, Sydney Children's Hospital

**A/Prof. Nicole Isbel**, Consultant Nephrologist, Princess Alexandra Hospital, Brisbane

**Dr Sean Kennedy**, Nephrologist, Sydney Children's Hospital

**Dr John Lawson**, Neurologist and Rural, Regional and Remote Clinical Trial Enabling Program, NSW Ministry of Health

**Dr Fiona McKenzie**, Clinical Geneticist, Genetic Services of WA

**Dr David Mowat**, Clinical Geneticist, Sydney Children's Hospital

**Prof. Lakshmi Nagarajan**, Neurologist and Epileptologist, Perth Children's Hospital

**Dr Zebunnessa Rahman**, Neurologist and Epileptologist, Westmead Hospital, Sydney

**Dr Matthew Sypek**, Nephrologist, Royal Children's Hospital Melbourne and Royal Melbourne Hospital

**Welcome and thanks to all our medical advisory panel members. We look forward to working closely with you all to raise awareness and improve health care for everyone living with TSC.**

'The first 18 months after Austin's TSC diagnosis was incredibly challenging. We are so grateful for the health care he has received. Austin is now 6 and a half years old and has been seizure free for 5 years.'

*Shelley, Austin's mum*





# Winner of the Elizabeth Pinkerton Memorial Award 2022

## Congratulations to Kathryn Santamaria

**TSA is delighted to announce that the recipient of the 2022 Elizabeth Pinkerton Memorial Award is Kathryn Santamaria, Epilepsy Nurse Consultant at the Royal Children's Hospital (RCH) in Melbourne. Kathryn is the first nurse to win the award.**

The award is a wonderful way for members of our TSC Community in Australia to show their appreciation of a health professional who has gone 'above and beyond' to help them or someone in their family who is living with TSC. It is given annually by TSA to a health professional in recognition of their efforts to improve the lives of people affected by TSC.

Nominations from our TSC Community are made via the TSA website and the TSA Committee considers all the nominations to select the winner.

A member of the TSC Community in Australia nominated Kathryn saying:

*Kathryn has been a big part of our child's TSC journey from when he was just 4 months old (he is now about to turn 10). Kathryn has the most beautiful, calming, gentle and fun bedside manner. She is super organised and is always available to assist our family when required. Nothing is ever too much trouble.*

*Kathryn assists us with not only coordinating brain scans, brain surgeries etc but also assists at times with coordinating other TSC specialists. She's so reliable and makes us feel confident that if she is handling something for us, it'll get done.*

*Kathryn works closely with Dr Simon Harvey to ensure not just TSC patients, but all epilepsy patients are well taken care of.*

*There are certain medical professionals who are passionate about ensuring their patients have the best care and who advocate for them to ensure their quality of life is the best it can be. Kathryn is one of those people. She is our constant. Our son (and our whole family) adores her. Our son often won't allow any procedures to be done unless she is there with him. Kathryn has absolutely made a huge difference in our TSC journey and we would be lost without her.*



### In accepting the award, Kathryn said:

I love my job. I have been a part of the RCH team since my graduate nursing year in 2001 and I'm still here in 2022! I was so fortunate to take over the role of Epilepsy Clinical Nurse Consultant in February of 2007. It is my dream job.

Every day presents itself with new challenges. It is the relationship that we have with our families and our patients that makes it all worthwhile. This relationship is based on empathy, sorrow, happiness, trust and respect. There are smiles. There are tears. And there is friendship. The strength that our families portray (let alone find), is inspirational.

I have always thought of TSC as a journey. This journey is not always smooth. It is filled with speed bumps, roundabouts and many detours, some steps forwards and some steps back. But this journey is a partnership between patients, families and clinicians.

I am honoured to be a part of this journey and help support these amazing people. They are my inspiration. They are why I love my job. It is my privilege to support families and patients with TSC, and I am truly honoured to be the recipient of this year's Elizabeth Pinkerton Memorial Award.

**To find out more about the award please go to <https://tsa.org.au/about-us/epma/>**

# Our Supporters

It is thanks to you and your generosity once again this year that TSA has continued to have the funds needed to help and support our TSC Community. We hope you share in our sense of pride for the work we have done and will continue to do supporting anyone impacted by TSC across Australia. This work wouldn't be possible without you, our generous supporters and fundraisers.

## Light the Way Giving Day appeal

Thank you to everyone who got involved, donated, shared the appeal and joined us as a generous match giving sponsor to mark TSC Global Awareness Day in May 2022. Special mentions to a few extraordinary families who signed up to be Ambassadors and Champions: Kirsten and Boris for KATALINA, Pep and Francesca for LUCIA, Rob and Mimi for ROXIE, Iris for IULKA, Melissa Maher for SAMUEL, Michael for GREG, Samantha for ISABEL, Debbie and Anthony for ALANA, Meg for BOBBY and Rachel. Each of you helped us smash our goal and ensure TSA can keep our much-needed nurse and support programs and services running. Shout out also to Mimi Rossano who created the campaign imagery, donating her expert graphic design talents.



## TSC Heroes

Our TSC Heroes undertake physical challenges that inspire their family and friends to make donations in their honour. Thank you to all our TSC Heroes including Melissa, Amelia, Francis, Kelly, Gabby, Narelle and Ryan. We appreciate you putting your bodies on the line to raise awareness and funds for us.



## TSC Members

TSA is incredibly grateful to our new and renewing members who give so generously by taking out a TSA membership and making a valuable contribution in support of our work. Our generous members have contributed over \$19,000 in the past financial year.



## TSC Champions

Our regular givers, known as TSC Champions, make small monthly contributions to TSA. These are vital donations we can rely upon each month to carry out our work and make a big difference. Over \$13,000 has been donated thanks to our regular givers this year.



## TSC Guardians



We recognise anyone who has let us know they've left a bequest to TSA as a TSC Guardian. Thank you to the individuals who have chosen to leave TSA a bequest gift in your Will. Every legacy gift, small or large, will go directly towards improving the lives of future generations of individuals and families impacted by TSC.

## Special events

**Lizzie's Lunch 2022.** Well done and thank you to Sue and the Pinkerton family who once again inspired family and friends to come together for such a fun and memorable fundraising event in honour of Lizzie. We raised our highest amount ever - just over \$26,000. What a fantastic effort.



**A virtual Comedy for a Cure event 2021.** Thank you to the hilarious comedians and to everyone in our community who got involved in making this online event a fun night that raised \$14,700. Shout outs to our exceptional digital emcee Rob Rossano and major sponsor Baker McKenzie. And special mentions to parent speaker Amelia Tausilia and the hilarious comedians Gary Eck, Lizzie Hoo, Andrew Barnett and Eric Hutton. We hope to see you in person at the 2022 event. See the back cover for details!



**#40kfor40yearsTSCchallenge.** During 2021 we marked 40 years of TSA with a fundraising challenge. While we didn't quite reach our \$40,000 goal we did raise \$33,700 which is a fantastic effort. Special shout outs to Meg and Scott for BODIE; Narelle Kerr for LILY; Gabby for her brother MAX; Amelia in memory of ANNABELLE; Miia and Ryan for OSKAR; Amber, Yvette and Melissa for SAMUEL; the McGroder family in loving memory of KYAH; and Samantha for ISABEL.

**In honour collections.** Pearl Blasina and Francis Tausilia inspired their loved ones to donate in lieu of giving traditional birthday gifts and raised a total of \$1,550.



## TSA Partners and Funders

This year we've worked closely with our corporate partner **Baker McKenzie**. We are delighted to be working with this firm and thank them for their financial and pro bono support to improve the lives of everyone in Australia living with TSC. Thanks also to the **Centre for Community Driven Research** and the **Department of Social Services** for looking favourably upon our grant applications.

## Our TSC Health Care Professionals Network

Thank you to all the medical specialists who continue to work with us to improve health care for anyone impacted by TSC. We are thrilled to have welcomed many new TSC experts into this group this year and look forward to working with them to improve the lives of people affected by TSC.

## Our Volunteers and Regional Contacts

To all our wonderful volunteers around Australia, what would we do without you! Special mention to Teresa Llewellyn-Evans editor, Cornel Visage data expert, Dom Mercer social media specialist, Belinda Johnstone web developer, Mimi Rossano graphic designer, Vanessa Tiernan event professional and Carolyn Place.

Sincere thanks to our regional contacts who work with local families to share information and experiences. You help make sure everyone with TSC has someone they can turn to. Thank you to:

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

Special mentions to 2 long serving regional contacts Fiona Crocker in QLD and Nicole Stone in WA who have now stepped down.

## Our Collaborative Partnerships

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 TSCNZ. We advocate for people with TSC through our work with a number of partners including Genetic Alliance, National Patient Organisation Network, Consumers Health Forum of Australia and Rare Voices Australia. We are thankful for our collaborative partnerships with these organisations.

## Our Suppliers

We wish to thank our wonderful suppliers, many of whom provide free or significantly discounted goods and services to us. Special mentions to Next Print, Charli Design, MyCause and Lanham Media.



'My brother Max looks and acts like a pretty normal kid, though his TSC prevents or makes it more difficult for him to do some things. I participated in the Sydney Half Marathon in May to raise awareness and raise funds for TSA. While I'm no doctor and can't do research into finding a cure for this devastating disease or help to find new and better drugs to help manage the condition, I can do my bit in raising funds to help!' says Gabby who raised \$4,180 in honour of Max.

## Our TSC Community

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

# Our Donors and Sponsors

## TSC Champions

Belinda Allchin (*Matched by Macquarie Bank Foundation*)  
Aunty Ivy's Ironing and Laundry Service  
Mary Bui  
Virginia Chick  
Helen Clisdell  
Peter Clisdell  
Jennifer Cunningham

Linda Deacon  
Julie Garrard  
Sonia Gregson  
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Steve Mason  
Sue Mason  
Katherine Norris  
Elaine O'Dea

Jennifer O'Donoghue  
Roshan Perera  
Robert Pinkerton  
Sue Pinkerton  
Julia Prunty  
Luke Smith  
Lucy Vettom

## TSC Members

### *Life Membership*

Andrew McKinnon  
Ross Pinkerton  
Sue Pinkerton  
Lynn Wilson

### *Platinum Membership*

Gail Cummins  
Lachlan Foster  
Kevin and Louise Niklaus  
Michelle and Lee Purkiss  
Matthew Sypek

### *Gold Membership*

Frederick Alexander  
Dawn Bowra  
Jeffery and Kerry Bromhead  
Debbie Crosby  
Joanne Crosby  
Suzanne Delbridge  
Kasia Durlak-Sierra  
Alison McIvor  
Patrick Norris  
Gabriella Oliveri  
Max and Julie Osborne  
Catherine Panich  
Leanne Park  
Steve and Judy Penniment  
Daniel Raffaut  
Sam Reckwell  
Steve Walker  
Harry, Alison and Adrian Zehnworth

### *Silver Membership*

Brian Andrews  
Ray and Vicki Barassi  
Leisel Bell  
Kirsty Boakes  
Clare Boschetti  
Meg Boschetti  
Michael Catlow  
Miriam and Curt Chalk

Roslyn and Peter Chalk  
Joyce Choi Shan Chow  
Katina and Bruce Core  
Mark Costa  
Dianne Curtis  
Sandra Dear  
Jackie Gambrell  
Rob Haggett  
Natalie and Steve Hale  
Kelven and Maree Hill  
Belinda and Charles Humphrey  
Karen and Greg Jenkins  
Eileen Jerga  
Michael and Cathy Jones  
Benjamin Kamien  
Jiayi Li  
Wayne and Janet Lord  
Brigitte Mansour  
Melissa Matthews  
Jenny May  
Ryan Michael  
Emma and Brett Morris  
Marianne and David Somerville  
Nicole Stone  
Samantha Stone  
Allan and Alsa Stuart  
Loren Wakeley  
Sue Williamson  
Kay Woodcock  
Claire Young

### *Bronze Membership*

Libby Adams  
Marie Bawden  
Deb and Lee Beck  
Elizabeth and Julian Bedford  
Leslie Bishop  
Pearl Blasina  
Laura Boschetti  
Jayne Carrington  
Jacob Clements

Tania and Doug Colman  
Adam Cope  
Tane Cox  
Louise Cummins  
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Narelle Kerr  
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Jim and Lorraine Lowe  
Frank Martin  
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Lachlan McArthur  
Karen McCagh  
Bernadette McGlynn  
Faye and Kyle McLean  
May and Bruce Mills  
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Joelle Neville  
Madonna and Daniel Nielsen  
Katrina and Mark Prunty  
Joe and Amira Rahme  
Heather Renton  
Janiffer Reynolds  
Gayle Rockstroh  
Mimi Rossano  
Olivia Rowswell  
Georgina Schilg  
Jackie and Graeme Shaughnessy  
Tracy Simpson  
Samantha Smith  
Cynara and Matt Stalenhoeft  
Daphne Taylor  
Malcolm and Chris Whatmore  
Nova Young



**The impact of your donations is immense. Whether you chose to make an annual membership gift, regular monthly payments or a one off donation you can be assured your contributions are making a positive impact in the lives of individuals and families living with TSC.**

## Donors

### **\$1000 and over**

Frederick Alexander  
Bruce and Jeannie Auty  
Jeffery and Kerry Bromhead  
R Buckle  
Helen Clisdell  
Peter Clisdell  
Gail Cummins  
Heather and Kevin Deane  
Suzanne Delbridge  
Daniel Friedgut  
Dale Gordon  
Megan Gould  
Michael and Cathy Jones  
Sara Ladyman  
Brigitte Mansour  
Alison McIvor  
John McKillop  
Kevin & Louise Niklaus  
Robert Rossano  
Rachele Tari

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

Anne-Marie Allgrove  
Boris Bodanac  
Debbie Crosby  
Joanne Crosby  
Max Di Mauro  
Natalie Di Mauro  
Francesca Diamantaras  
Magdalena Durluk  
Caterina & Luigi Fantuzzi  
Miia Groenewald  
Mary Anne Hartley  
Ivy Jones

Shane Jones  
John Kelly  
Vince Labbozzetta  
Jiayi Li  
Geoff McClintock  
Francesco Morizzi  
Gina O'Keefe  
Mario Olivieri  
Vince Olivieri  
Catherine O'Malley  
Max and Julie Osborne  
Effie Savvides  
Nathan Selfs  
Domenic Sergi  
John Wilson

### **\$250 and over**

Regina Beal  
Anna Beaton  
Roslyn Beaton  
Imelda Bilato  
Michaela Blasina  
Joe Bonaccorsi  
Dawn Bowra  
Vinny Byrne  
Rachel Coppel  
Magdalena Durluk  
Michael Dusevic  
Salvatore Paolo Fantuzzi  
Rosalie Fishman  
Adam Flipp  
John Fraser  
Martin Gomez  
Robert Haggett  
Mary Anne Hartley

Mary Jerga  
Georgina Kittel  
Con and Maria Kourea  
Natasha Kourea  
Lisa Liebman  
Vanida Lim  
The Lulham Family  
Edwina Mann  
Christine Michaelopoulos  
George Nahas  
Anne Newman  
Patrick Norris  
Gabriella Oliveri  
Catherine Panich  
Leanne Park  
Priyanka Patel  
Steve and Judy Penniment  
Martin Robinson  
Daniel Strosberg  
Allan and Alsa Stuart  
Gary Sullivan  
Vince Tari  
Anne Tsang  
Philipa Wade  
Geoffrey Walker  
Steve Walker  
Claire Walsh  
Nova Young  
Alison, Harry and Adrian Zehnirith



‘My daughter Sarah received a tentative diagnosis of TSC at the age of 2 and a half. She is now 43. I think of this photo as a miracle. Generally Sarah dislikes being touched and she does not like having anything of any weight on her lap. Sarah hasn’t really shown much interest in babies but this photo captures a special moment enjoying a cuddle with her little niece. Our family is grateful to have TSA to turn to for information and advice and we appreciate all the generous donations gifted to help families like ours.’

*Lynne from  
Western Australia*

**We’d like to thank everyone who made a contribution to TSA this year. We are grateful for each and every gift TSA received. No matter how big or small it really makes a difference. We have listed donations of \$250 and over because there were just too many of you to include each of you by name but our sincere gratitude goes out to you all.**



# Our Financial Results

**I am pleased to report that TSA is in a very sound position financially and has been well managed through challenging times.**

While community fundraising opportunities are increasing they are still not back to pre-COVID-19 levels however we have been extremely heartened to see continued donations and support from our TSC Community during such uncertain times.

The huge support shown for our newest fundraising initiative, the Light the Way Giving Day, along with our Comedy for a Cure in December 2021 and Lizzie's Lunch in June 2022 has helped TSA return a small surplus. We hope support for these events will continue as they make a significant impact to our organisation's income generation and ability to deliver our programs.

The TSA Management Committee decided to broaden our investment base beyond our traditional term deposits which had record low rates to build a long-term sustainable portfolio. A finance sub-committee comprising Michael Jones, Nova Young and myself as Treasurer, was established to make investment recommendations. As a result, some initial investments totalling \$134,785 have been made into conservative market linked assets. These investments have lost value initially because of global instability, but we are confident they will provide stronger returns in the medium term. Our balance sheet shows the actual value of our assets at 30 June. The unrealised change in the value of the assets is recorded in the non-operating section of the Income and Expenditure statement.

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. Our CommBiz banking platform requires dual authorisation for any payments.

The accounts for the year ending 30 June 2022 were audited by Mark Mortimer (Registered Auditor No. 1942) of Bondy Mortimer & Co. A copy of the 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.

Whilst we continue to live in times of uncertainty, I am confident TSA is positively placed financially and is being well managed and governed to ensure its continued operational and financial sustainability.

*Patrick Norris, TSA Treasurer and grandfather to Liam, who lives with TSC*





# Financial statements

## Balance Sheet as at 30 June 2022

| ASSETS   | 30 June 2022     | 30 June 2021     |
|--|------------------|------------------|
| <b>Bank</b>  |                  |                  |
| ANZ Cash Account (Stockpot)                                    | \$1,027          | \$0              |
| General Cheque Account   | \$194,316        | \$141,008        |
| NAB Trade Accounts   | \$50,160         | \$0              |
| PayPal   | \$1,933          | \$1,842          |
| Savings Accounts   | \$32,728         | \$81,359         |
| Staff Debit Cards for TSA Expenses                             | \$2,450          | \$3,468          |
| Term Deposits  | \$11,154         | \$195,306        |
| <b>Total Bank</b>  | <b>\$293,768</b> | <b>\$422,982</b> |
| <b>Current Assets</b>  |                  |                  |
| Accounts Receivables   | \$18,500         | \$0              |
| Deposits Paid  | \$0              | \$600            |
| Refundable - Franking Credits                                  | \$415            | \$0              |
| Sundry Debtors   | \$0              | \$715            |
| <b>Total Current Assets</b>                                    | <b>\$18,915</b>  | <b>\$1,315</b>   |
| <b>Non-Current Assets</b>                                      |                  |                  |
| Add/(Less): nabtrade - Unrealised Market Value Gains/(Losses)  | (\$8,015)        | \$0              |
| Add/(Less): Stockspot - Unrealised Market Value Gains/(Losses) | (\$5,613)        | \$0              |
| nabtrade - Investments at Cost                                 | \$60,231         | \$0              |
| Stockspot - Investments at Cost                                | \$74,554         | \$0              |
| <b>Total Non-Current Assets</b>                                | <b>\$121,157</b> | <b>\$0</b>       |
| <b>Total Assets</b>  | <b>\$433,840</b> | <b>\$424,297</b> |
| <b>LIABILITIES</b>   |                  |                  |
| <b>Current Liabilities</b>                                     |                  |                  |
| GST  | (\$1,387)        | \$2,460          |
| PAYG Withholding Payable                                       | \$3,722          | \$3,148          |
| Provision for Annual Leave                                     | \$19,790         | \$17,921         |
| Superannuation Payable   | \$3,358          | \$3,089          |
| Suspense   | \$0              | \$40             |
| Trade Creditors  | \$0              | \$1,401          |
| Unexpended Grants  | \$62,377         | \$69,294         |
| <b>Total Current Liabilities</b>                               | <b>\$87,860</b>  | <b>\$97,354</b>  |
| <b>Non-Current Liabilities</b>                                 |                  |                  |
| Provision for Long Service Leave                               | \$8,049          | \$6,565          |
| <b>Total Liabilities</b>                                       | <b>\$95,909</b>  | <b>\$103,919</b> |
| <b>Net Assets</b>  | <b>\$337,931</b> | <b>\$320,377</b> |
| <b>EQUITY</b>  |                  |                  |
| Current Year Earnings  | \$17,554         | \$91,351         |
| Retained Surplus   | \$320,377        | \$229,027        |
| <b>Total Equity</b>  | <b>\$337,931</b> | <b>\$320,377</b> |

## Financial statements

# Income and Expenditure: Year Ended 30 June 2022

|  | 30 June 2022     | 30 June 2021     |
|--|------------------|------------------|
| <b>INCOME</b>                                      |                  |                  |
| Donations Received                                 | \$124,194        | \$89,633         |
| Event Income                                       | \$49,557         | \$44,029         |
| Grants Received                                    | \$43,917         | \$66,652         |
| Membership Contributions and Fees                  | \$19,505         | \$21,009         |
| Other Income                                       | \$2,392          | \$2,204          |
| Sales of Goods                                     | \$1,770          | \$721            |
| <b>Total Operating Income</b>                      | <b>\$241,335</b> | <b>\$224,249</b> |
| <b>OPERATING EXPENSES</b>                          |                  |                  |
| Accounting and Bank Fees                           | \$13,855         | \$12,771         |
| Advertising and Promotion                          | \$415            | \$218            |
| Board/Governance Expenses                          | \$0              | \$433            |
| Consultancy Fees                                   | \$0              | \$1,390          |
| Educational Event Expenses                         | \$12,048         | \$16,868         |
| Fundraising and Event Expenses                     | \$15,503         | \$9,157          |
| Information Technology Expenses                    | \$10,944         | \$11,564         |
| Insurance Expense                                  | \$2,672          | \$2,576          |
| Postage, Freight and Courier                       | \$1,660          | \$1,577          |
| Printing & Stationery                              | \$2,550          | \$3,865          |
| Publications and Information Resources             | \$3,515          | \$5,805          |
| Salaries and Wages                                 | \$145,410        | \$153,141        |
| Sundry Expenses                                    | \$625            | \$1,046          |
| Telephone, Fax and Internet                        | \$542            | \$570            |
| Training & Development (Staff) and Membership Fees | \$234            | \$235            |
| Travel & Accommodation                             | \$180            | \$132            |
| <b>Total Operating Expenses</b>                    | <b>\$210,153</b> | <b>\$221,348</b> |
| <b>Operating Deficit/Surplus</b>                   | <b>\$31,182</b>  | <b>\$2,901</b>   |
| <b>Non-operating Income</b>                        |                  |                  |
| Government Support Related to COVID-19             | \$0              | \$88,450         |
| Market Value Change of Investments                 | (\$13,628)       | \$0              |
| <b>Deficit/Surplus</b>                             | <b>\$17,554</b>  | <b>\$91,351</b>  |



## How TSA's funds were spent

### Programs and services 45%

TSA's primary purpose is to provide information and support services to the TSC Community in Australia and also to the health professionals working in this specialist area. Costs associated with program and service delivery includes costs of the TSA Nurse Service, education events such as the TAND+ Conference and regular Zoom Education Events, writing and updating our TSC information pages on the TSA website, our TSC Health Care Professionals Network and publishing *Reach Out*. Additionally, there are some costs associated with working with policy makers and advocates in health and disability to improve the care, treatments and screening available to people living with TSC and reviewing and sharing global and local TSC research.

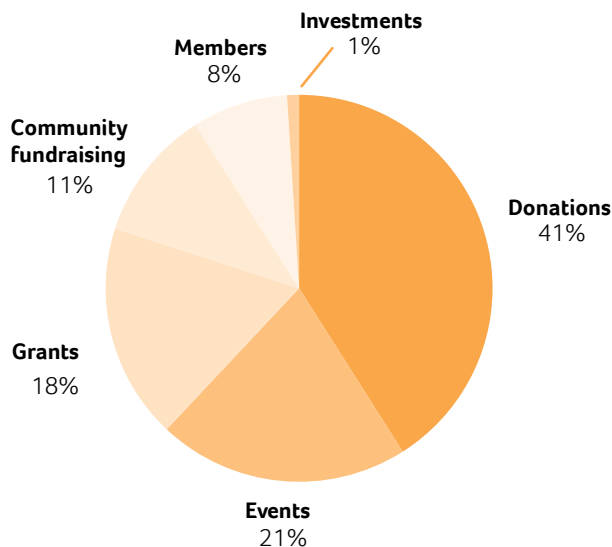
### Development 20%

TSA has a deliberately diverse portfolio of fundraising activities to ensure its long-term sustainability as an organisation. This year we held our first Light the Way Giving Day to support the continuation of our services and programs. Other development activities include writing grant applications, supporting community fundraising, retaining and growing TSA's membership program, organising and supporting TSA fundraising events such as Comedy for a Cure and Lizzie's Lunch and developing and delivering campaigns such as Christmas and Tax-time Appeals.

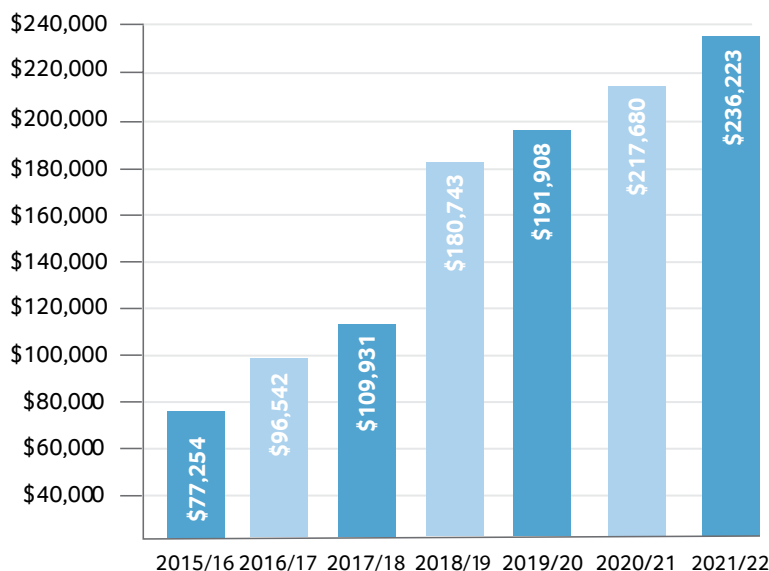
### Accountability and organisation management 35%

Strong management and effective and transparent governance are fundamental to the success of any organisation. These are necessary costs involved in running TSA and include essential activities that provide support for TSA's programs and services such as insurance premiums, compliance with regulations, accounting and auditing and IT hosting and support. Importantly it also includes reporting and governance activities related to the TSA Management Committee. TSA does not have any office-related costs as its part-time team all work from home.

## Where TSA's funds came from

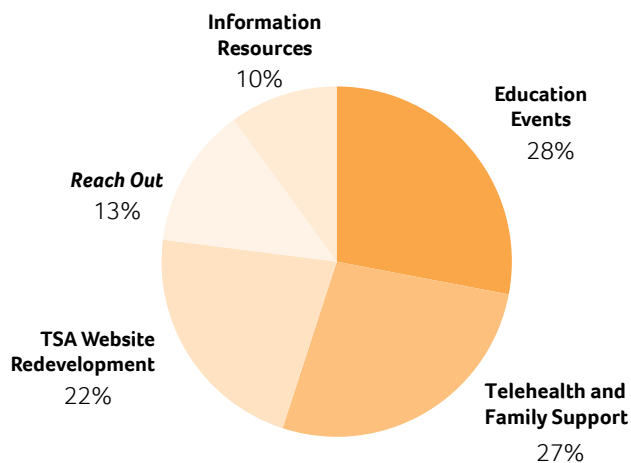


## Fundraising Revenue



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

## How program funds were used



**SATURDAY  
22 OCTOBER  
2022**



**Rob McHugh**

**COMEDY  
FUNDRAISING  
NIGHT**



**Peter Meisel**



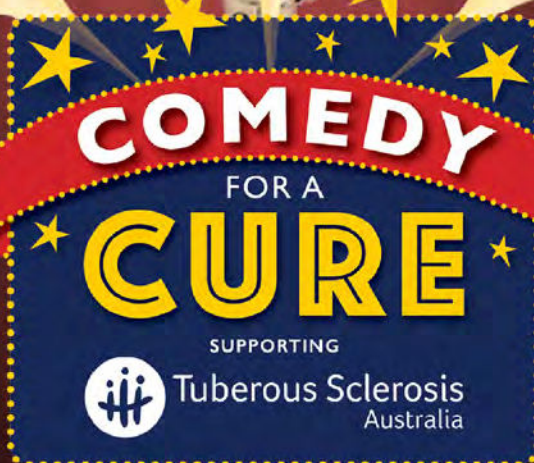
**Keith Scott**



**Andrew Goodone**



**Peter Green**



**Fiona Cox**

**Patron Sponsor**

**Baker  
McKenzie.**

**Venue Sponsor**



**GREAT PRIZES TO BE WON**

**Help harness the power of laughter to support  
families living with Tuberous Sclerosis Complex**

**GET YOUR TICKETS TODAY**

Date/Time: 22 October 2022 at 7pm  
Venue: Paddo RSL, Oxford Street, Paddington  
Cost: \$100 pp finger food and a free drink included  
Book now: [comedyforacure.org.au](http://comedyforacure.org.au)



**Tuberous Sclerosis  
Australia**

A better life. A more hopeful future.

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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)  
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