



TSA

Tuberous
Sclerosis
Australia



Impact Report 2023

We are stronger together

About TSC (Tuberous Sclerosis Complex)

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 an individual will be affected but with appropriate support most people with TSC can live fulfilling lives.

About TSA (Tuberous Sclerosis Australia)

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 information, 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.

The TSA Team 2022/23

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

Our Management Committee

- **Debbie Crosby** President
- **Michael Jones** Vice President
- **Nova Young** Treasurer
- **Alison McIvor** Secretary
- **Rob Rossano** Committee Member
- **Sze-Ann Woon** Committee Member

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 by providing 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



President's Report

I am so proud of what TSA (Tuberous Sclerosis Australia) has been able to achieve over the past year for everyone in Australia living with TSC (Tuberous Sclerosis Complex). There have been many great accomplishments to celebrate, and this impact report highlights the amazing work of our TSA staff, volunteers and our TSC Community.

I feel incredibly fortunate to be a part of TSA and have valued volunteering on the management committee for the past 13 years. This year will be my last year serving on the committee, and I feel both sadness and hope. I will miss being part of this amazing organisation that has supported the TSC Community for over 40 years. I will miss the incredible group of people who work and volunteer for TSA and who care so much for our TSC Community. But I also feel optimistic knowing that TSA will continue to prosper and serve the needs of the TSC Community in Australia. I will continue to be an advocate for anyone living with TSC and will still be a volunteer Regional Contact for individuals and families in NSW.

TSA has changed so much over the years. When I first joined the committee, the organisation was run solely by volunteers who would meet and chat around the kitchen table in someone's home. I would like to thank all past and current committee members who have given TSA their time, experience and support. Without these committee members TSA would not be where it is today. TSA now has 3 part-time staff around Australia who regularly connect using new online meeting rooms like Zoom. I'd like to thank Jackie Gambrell, Kate Garrard and Katrina Watt, who do so much with such limited time and resources. Their

commitment, persistence and compassion ensure TSA's success in providing information, support and connection to people living with TSC.

Behind the scenes it takes many hands to run our small but mighty organisation. I would like to thank all the volunteers who have assisted us with events, campaigns, fundraising and administrative support. The great privilege of being part of this organisation has been meeting so many wonderful people from our TSC Community and connecting with you. This Community has, not only supported myself and my family, they have also supported TSA for over 40 years. Thank you to everyone who has generously donated, shared their story, raised awareness, connected with and supported other families, and inspired family and friends to support TSA. Thank you all for your ongoing and generous support and being part of such an inspiring Community.

We have achieved so much together, and I wish TSA and the TSC Community all the very best in the future. I am confident that working together, TSA will continue to achieve its purpose to help create a better life and a more hopeful future for everyone in Australia affected by TSC.

Debbie Crosby, TSA President

Pictured: Debbie and her husband Anthony, parents of Alana who lives with TSC

Our Focus

TSA strives to create a better life and more hopeful future for anyone in Australia living with TSC

During the 2022/23 financial year, the TSA Management Committee and team developed a new strategic plan to focus our future direction and actions. The priorities were carefully selected after surveying you, our TSC Community, to identify where you think we should concentrate our efforts and limited resources. We are delighted by the progress we have made against the strategy so far this year and will keep working to achieve our goals. None of this work would be possible without your support and we sincerely thank you for your collaboration.

Strategic Goals for 2023 - 2025

GOAL 1: Work to support the development of models of coordinated, multidisciplinary care for people living with TSC in Australia.

Outcomes for Goal 1 in 2022/23

- TSA held 2 information events, one digital and one face to face, focused on identifying and understanding some of the key issues in provision of health care for adults living with TSC. These great events provided insights from families and health care professionals and helped increase TSA's knowledge of what is needed and how improvements can be made.
- An in-depth survey on health care for people living in Australia was completed by 92 people from the TSC Community and demonstrated strong support for improved multidisciplinary and coordinated care across the country.
- We have started working closely with a number of health care professionals in NSW, VIC and WA to look at options for developing better models of coordinated, multidisciplinary care.

GOAL 2: Ensure everyone living with or caring for someone with TSC is aware of TSA and can find us and the help they need.

Outcomes for Goal 2 in 2022/23

- TSA's upgraded and redesigned website was launched in May 2023 with an improved look, easier navigation, better usability and improved ability for people to more easily find the site in searches and locate the right information once on the website.
- We successfully advocated for abdominal MRIs to be funded under the Medical Benefits Scheme (MBS) making them free through bulk billing services for anyone living with TSC. MRIs are the recommended form of screening in the international guidelines for TSC. This reduction of out of pocket costs will make it easier for our Community to access the screening they need.

GOAL 3: Collaborate on the TSC-STEPS research into early use of mTOR inhibitors, promote research trial opportunities in Australia and make our Community aware of global TSC research.

Outcomes for Goal 3 in 2022/23

- TSA has committed to funding transport and accommodation costs to encourage participation and increase access to the TSC-STEPS research trial investigating early intervention with mTOR inhibitors for families across Australia.
- We updated the TSC Community on relevant new research across the world through the publication of 6 summaries on various TSC research topics.
- TSA informed the TSC Community about a number of relevant research trials and how to participate both in Australia and overseas.

Thank you to TSA's Medical Advisory Panel who have helped to guide and support our organisation over the past year. Thanks also to our network of Health Care Professionals who work with us to improve care and treatment for anyone impacted by TSC. A special thanks to Rare Voices Australia, Dr Matt Sypek and A/Prof Kathy Nicholls for their work to help get abdominal MRIs funded under the Medical Benefits Scheme (MBS).

Thanks also to the Social Sector Transformation Fund grant which made redevelopment of our website possible this year.

Our Achievements

This Year

Successfully advocated for abdominal MRIs to be funded under the Medical Benefits Scheme (MBS) for patients living with TSC in Australia. This will make abdominal MRIs free to access through bulk billing services.

Launched new TSA website featuring updated information and supports for the TSC Community.

Saved the TSA nurse, thanks to donations supporting TSA's Light the Way Giving Day.

Hosted an in-person Community Connect event in Melbourne and online education events.

The 2020s

Hosted several education events and conferences both in person and on Zoom on a diverse range of TSC-related topics.

Updated TSA's medical information website pages with the new international TSC Surveillance and Management Guidelines.

Recorded and distributed the first podcast on TSC for General Practitioners (GPs).

Welcomed our TSA Nurse Katrina Watt who provided one-on-one support to our TSC Community through our telehealth nurse service.

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.

Produced *In Safe Hands* - new educational resources for parents and teachers of school-age children living with TSC.

The 2000s

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 1980s

TSA founded as the Australasian Tuberous Sclerosis Society.

First issue of *Reach Out* published.

Launched social picnics for families.

First family conference.

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 researchers and patients in Australia 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 1990s

Leaders in the establishment of TSC International.

Successfully advocated for 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.

3 educational events held around Australia.

How new research is hoping to delay seizure progression in infants with TSC

TSC-STEPS is an exciting new research trial happening now in Australia

TSA is delighted to be working with the team at Sydney Children's Hospital (SCH), Randwick which has now started recruiting for the TSC-STEPS research trial. The trial is aptly named as it could be an important step to finding a cure for TSC.

Sirolimus is an effective treatment in reducing tumour size and improving seizure control for many people living with TSC. The purpose of this ground-breaking research is to learn more about the safety and efficacy of early Sirolimus treatment.

This is a global study and the team in Sydney is working in partnership with Dr Darcy Krueger and the team at Cincinnati Children's Hospital in the USA. Dr Krueger says: 'In tuberous sclerosis we have such a high rate of epilepsy that occurs. Unfortunately, all of our available treatments, particularly our medical treatments, fail to fully control seizures in nearly half of our patients. This has created a challenge for us medically, as it has major impacts for long-term learning and development, and of course, quality of life and opportunities.'

The hope of this study is to test if Sirolimus treatment can aid in the prevention of epilepsy before seizure onset.

The trial is open to infants 0 to 6 months old who are diagnosed with TSC and have no history of seizures. It is open to families across Australia.

TSA is proud to collaborate with the team on this research and we don't want cost to be a barrier for anyone who is eligible and wants to participate. Some financial assistance is available for families wishing to participate to help with travel and accommodation costs.



The Sydney children's
Hospitals Network

If you would like to find out more about the trial and possible eligibility, please visit clinicaltrials.gov (identifier NCT05104983) or contact Dr Denise Chan at SCH on denise.chan@health.nsw.gov.au
For any information regarding financial assistance please contact TSA at info@tsa.org.au

The impact of your support

139

Consultations with our TSA nurse for individuals and families living with TSC and the health care professionals caring for them ensuring anyone impacted by TSC has someone to turn to

1,954

Facebook followers who are informed and updated on all things TSC related

2

TSA Education and Connect Events connecting and empowering the TSC Community

77

TSC information pages viewed each day on TSA's website highlighting the TSC Community can be self-sufficient in finding the information they need

680

Members supported through TSA's private online TSC discussion group which provides the vital peer support and connections needed to reduce the isolation a rare disease diagnosis can bring

1

New website launched which is helping to keep the TSC Community informed with up-to-date medical information on TSC and stories from the TSC Community

73

Individuals attended a TSA Education Event in person or online. 93% will take action based on knowledge gained at the event

51

Families with a new diagnosis of TSC accessed the Parachute Packs which provide vital information on how to access help and support in navigating life with TSC

67

Families downloaded the In Safe Hands resources so they can access help and support for their school-age children

114

TSC experts in our Health Care Professionals network who together are helping to improve care and treatments in TSC

92

Individuals participated in TSA's 2023 Health Care Survey confirming support for TSA's services and priorities

28,384

People visited TSA's website for information about TSC helping anyone impacted by TSC to be informed, empowered and connected



Together we can continue to improve the information and supports available for families like Olivia's

'If only we had known about TSA and had their support at the time of our TSC diagnosis, we could have been spared so much energy worrying about all the frightening possibilities that we came across online. We could have focused on being present and showing our daughter that the only thing that matters is that we will do it together no matter what lies ahead. We are sharing our story to highlight that there is a huge spectrum of severity with TSC. Our daughter Olivia is living a very normal healthy life. She hasn't let her diagnosis stop her from doing all the things she loves, like playing basketball, riding motorbikes, hanging out with her friends and playing with her dog, Jeff the chocolate Labrador.' Says Olivia's dad Chris.

Olivia, fondly known as Livy, is 11 years old and lives in Newcastle NSW. Olivia is in Year 6 and was recently diagnosed with TSC (Tuberous Sclerosis Complex).

About 2 years ago Olivia noticed some unusual bumps on her face which made her feel quite self-conscious. The local family GP didn't know what they were and referred her to a dermatologist for further investigations. Right away, the dermatologist knew that the lumps on Olivia's face were angiofibromas and told Chris that it was very likely Olivia had a rare genetic disease called TSC.

This news came as such a shock to Chris as Olivia had always been so healthy and happy. Also, Chris had worked in health care as an emergency intensive care nurse and paramedic for nearly 20 years but had never heard of TSC.

Chris says the diagnosis was a terrible process: 'The dermatologist shared this shattering news in such a matter-of-fact way, without providing any information on the disease, what it meant for Livy or what would happen next. I was just told to go and get a special cream that would help with the bumps and referred back to our GP. There was no good case scenario here. All the information provided was doom and gloom and we were left to read the worst case scenarios online. If only we had been introduced to TSA at that time, the new diagnosis parachute pack resource would have helped so much. I now know where to go for balanced information on TSC and I wish we had been given this information that day at the dermatologists. I was left feeling helpless as a parent because I didn't know what to do for my child. It was dreadful being on the other side. I was used to taking care of patients and now I didn't know what I was supposed to do to take care of my own daughter.'

When the family returned to visit their GP, they found their doctor had never heard of TSC either. What followed was a series of specialist appointments and tests, none of which were easy to access. 'I had just been told our daughter had a very complex rare disease but we were going to have to wait 8 to 12 months for an MRI or to

see an expert in TSC to know for sure. It was a frustrating experience not being able to easily access the tests I knew my daughter urgently needed.'

Chris became Olivia's very vocal advocate and used his experience working in health and hospitals to 'make some noise'. It worked and within 8 weeks Olivia had a brain MRI, kidney CT scans, genetic blood tests and an appointment with the experts at Sydney Children's Hospital (SCH) in Randwick.

'Once we were seen by the multidisciplinary TSC clinic team at SCH, we knew we were in the right place to get the care we needed. We were finally given the right dose of the miracle cream Sirolimus and, thankfully, Livy's facial angiofibromas have now virtually disappeared.'

Genetic testing showed that Olivia has mosaic TSC and neither Chris nor Livy's mum Melissa has the disease. The scans showed that Olivia has TSC tumours on her brain and kidneys, although right now they are not causing any significant health issues. 'We are incredibly thankful that it looks as though Livy is mildly impacted by TSC at the moment, although she does have some learning difficulties which we now know are likely due to the jellybean-sized tumour in her brain. We will keep a close eye on her brain and kidney tumours with annual check-ups and surveillance.'

Just recently Olivia needed an urgent review. Thanks to the team at the TSC Clinic in Sydney and in particular the Clinical Nurse Specialists, Josie and Eleanor, this has now taken place. Chris says that, as a parent and a health care professional, he understands the frustration of dealing with a rare disease and navigating the health care system. He encourages other parents to do what he has done and keep loudly and proudly advocating for their child.

Light the Way Giving Day



We did it! Thanks to the incredible support we received from our devoted TSC Community we saved our TSA nurse service.

Our second Light the Way Giving Day was held on 15 May 2023 to mark TSC Global Awareness Day. We are delighted our TSC Community again got behind this initiative to help shine a light on TSC. The impact of this tremendous support is that TSA now has the funds needed to keep our vital telehealth nurse service running for another year. TSA can continue to be 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.

Thank you to our Ambassadors and Champions



Robert



Iluka



Dante



Katalina



Roxie



Asta



Karamo



Isabel



Lucia



Greg



Tilly



Holly

Our generous match giving partners

The following match givers made a generous matching gift so every donation to Light the Way was doubled.

Double the donations = double the impact!

**Frederick Alexander | Anonymous | Sara Ladyman
John McKillop | John Wilson | Alison McIvor
Doyles Carpet Court Five Dock**

Getting involved in TSA's Light the Way Giving Day was a really positive experience for our family. The specially designed ambassador page created for our girls looked great and made it so easy to help shine a light on TSC. Both our daughters, Holly and Tilly, have recently been diagnosed with TSC and when we shared our story we were taken aback by the amazing generosity of our friends and family. The girls have had so many lovely messages of support from their friends, it has given them a real boost. They also courageously spoke at their school assembly where no-one had heard of TSC before. We look forward to getting involved again next year and I encourage you to join in too!

Tish Perry, Holly and Tilly's mum from Victoria

What we achieved

- \$62,192 in total was donated
- 370 people chose to make a donation
- The average gift size was over \$168
- Over 30 buildings around the country lit up with blue lights on 15 May
- 75% of gifts were inspired by our TSC family ambassadors and champions
- **The impact - We did it! We saved our nurse service.**

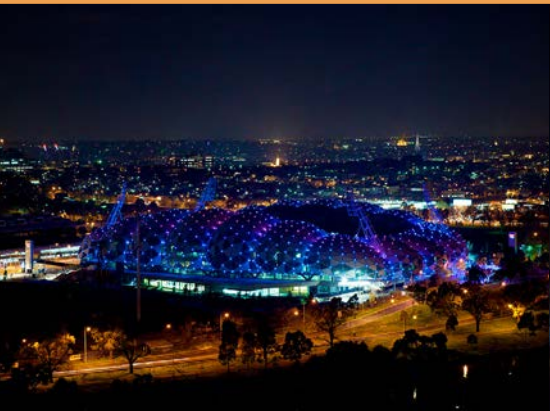


Shining a light on TSC

Landmarks across Australia lit up with blue lights to shine a light on TSC on 15 May raising vital awareness for this rare disease. Iconic buildings including, Sydney Olympic Park, Melbourne's AAMI Park, Perth's Trafalgar Bridge, Brisbane's Victoria Bridge and ACT's Black Mountain Tower all went blue for TSC.

Special thanks to Indi Hall who lives with TSC and as part of her Duke of Edinburgh Award volunteered with TSA. Indi together with her mum Michelle (pictured) successfully inspired over 30 buildings and landmarks to light up blue to raise awareness for TSC. Thank you to Indi, Michelle and to everyone who visited the sites and shared photos with us.

Indi says: 'Volunteering with TSA was a really good experience. I was thrilled by all the positive and supportive responses I received when I reached out to ask for support. It was great to feel like I could do something to help shine a light on this rare disease. I hope to get involved again next year and get even more buildings to go blue for TSC.'



Our Supporters

Yet again the TSC Community has blown us away by their generosity and continued support of TSA's work. This loyal support funds our programs and services for anyone impacted by TSC. We hope you share in our sense of pride for the work we have done and will continue to do supporting children, adults and families living with TSC. Thank you to our TSC Community for choosing to support TSA and for inspiring your family and friends to also get involved. We couldn't do it without you!

Light the Way Giving Day Appeal

Huge thanks to everyone who got involved in our second Light the Way Giving Day to mark TSC Global Awareness Day on 15 May 2023. So many people came together to raise awareness and vital funds. We are grateful for each of your contributions whether you made a donation, shared the appeal or your TSC story or joined us as a generous match giving sponsor. Special mentions to a few extraordinary families who signed up to be Ambassadors and Champions who raised \$46,644: Tish for Holly and Tilly, Heidi for Asta, Sze-Ann for Karamo, CJ and Leiden for Dante, Pep and Francesca for Lucia, Meg for Robert, Rob and Mimi for Roxie, Iris for Iluka, Samantha for Isabel, Michael for Greg and Kirsten and Boris for Katalina. Each of you helped us smash our goal and ensure TSA can keep running our much-needed nurse service.



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 Melanie Mak, Ryan Groenewald for Oskar and Amelia and team for Annabelle. We truly appreciate you putting your bodies on the line to raise awareness and funds for TSA.



TSC Members

TSA is incredibly grateful to all 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 \$14,000 in the past financial year.



TSC Champions

Our regular givers, known as TSC Champions, make monthly contributions to TSA. These are vital donations we can rely upon to carry out our work. Over \$13,499 has been donated thanks to our TSC Champions this year.



Special events

Lizzie's Lunch 2023

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 \$22,300. What a fantastic effort.



Comedy for a Cure 2022

Thank you to the hilarious comedians and to everyone in our Community who got involved to help make this event a fun night that raised over \$25,000. Special mentions to Oskar's mum, our parent speaker Miia Groenewald, and the hilarious comedian Rob McHugh who inspired so much support for the event. We hope to see you in person on 28 October 2023. See the back cover for details!



Community events include Anita Parker's Jersey Day for her grandson Bentley which was generously matched by her workplace QBE Foundation, Matthew for Abigail, Samantha's garden raffle in honour of Isabel, Albany Creek State School in honour of Samuel, Windaroo State School, Brew Ha Ha Coffee Roasters, Melissa Maher with her Scarves for Samuel and Central Hockey Club ACT Fundraiser.

In honour collections were held by Megan for Harrison and Shelly for Austin who inspired their loved ones to donate. Megan collected donations in celebration of her birthday and Shelly for Austin being 5 years' seizure free. Thank you for raising over \$750.

TSC Guardians

We recognise anyone who has let us know that 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 life for future generations of individuals and families impacted by TSC.



Our Collaborative Partnerships

TSA works closely with many organisations to ensure people 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 (NPON) and Rare Voices Australia (RVA). We are thankful for our collaborative partnerships with these organisations.

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, Mimi Rossano and Jackie Schmidt graphic designers 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:

- Claire Young in South Australia
- Robert Best in Western Australia
- 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

TSA's Medical Advisory Panel have helped to guide and support our organisation.

Special thanks to:

- **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, 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 Melbourne Hospital



TSC Hero Melanie

Melanie was diagnosed with TSC as a young adult in 2009. Since then, she has been through 12 years of IVF to prevent passing on this genetic condition to her baby. Melanie is now the proud mother of a healthy happy son, Logan. While recent testing has revealed Melanie has several tumours that need to be monitored, and will possibly need removing, she is living well with TSC and runs her own conveyancing consultancy firm in Sydney. After discovering TSA, Melanie was moved by the stories of children and families also impacted by TSC on our website. When she discovered donations are needed to support TSA's work helping people on their TSC journey Melanie and her son signed up to become TSC Heroes and completed a walking challenge raising \$3,400.

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

The impact of your donations is immense. Whether you chose to make an annual membership gift, regular monthly contributions 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.

TSC Champions

Belinda Allchin (*Matched by Macquarie Group Foundation*)
Aunty Ivy's Ironing and Laundry Service
Mary Bui
Virginia Chick

Helen Clisdell
Peter Clisdell
Elliott Cunnew
Jennifer Cunningham
Linda Deacon
Julie Garrard

Vikki Gilchrist
Sonia Gregson
Jenni and Terry Lawry
Steve Mason
Katherine Norris
Robert and Catherine Pinkerton

Sue and Ross Pinkerton
Julia Prunty
Lucy Vettom

TSC Members

Life Membership

Andrew McKinnon
Sue and Ross Pinkerton
Lynn Wilson

Platinum Membership

Gail Cummins
Lachlan Foster
Kevin and Louise Niklaus
Dr Matthew Sypek

Gold Membership

Andrew Benstead
Dawn Bowra
Jeffery and Kerry Bromhead
Debbie Crosby
Joanne Crosby
Suzanne Delbridge
Kasia Durluk-Sierra
Lisa Liebman
Alison Mclvor
Patrick Norris
Max and Julie Osborne
Catherine Panich
Leanne Park
Steve and Judy Penniment
Daniel Strosberg
Geoffrey Walker
Steve Walker
Dr Harry, Alison and Adrian Zehnirith

Silver Membership

Brian Andrews
Ray and Vicki Barassi
Leslie Bishop
Clare Boschetti
Meg Boschetti
Miriam and Curt Chalk
Roslyn and Peter Chalk
Joyce Choi Shan Chow
Katina and Bruce Core
Dianne Curtis
Jackie Gambrell
Robert Haggett
Kelven and Maree Hill
Evelyn Howard
Karen and Greg Jenkins
Eileen Jerga
Michael and Cathy Jones
Dr Benjamin Kamien
Jenni and Terry Lawry
Nele Leenders
Wayne and Janet Lord
Brigitte Mansour
Jenny May
Ryan Michael
Joelle Neville
Daniel Raffaut
Georgina Schilg
Marianne and David Somerville
Nicole and Darryn Stone

Samantha Stone
Allan and Alsa Stuart
Malcolm and Chris Whatmore
Sue Williamson
Jay Yardi
Claire Young

Bronze Membership

Libby Adams
Frederick Alexander
Elizabeth and Julian Bedford
Pearl Blasina
Kirsty Boakes
Laura Boschetti
Jayne Carrington
Michael Catlow
Tania and Doug Colman
Louise Cummins
Sandra Dear
Cara Doherty
Patricia Donaldson
Robert and Jennifer Drury
Deb Duffy
Miia Groenewald
Marie and Jeffrey Hell
Mary Jerga
Narelle Kerr
Jim and Lorraine Lowe
Melanie Mak
David Matheson

Lachlan McArthur
Karen McCagh
Bernadette McGlynn
McKillop Family
Faye and Kyle McLean
May Mills
Gwynnydd Murphy
Katrina and Mark Prunty
Joe and Amira Rahme
Janiffer Reynolds
Gayle Rockstroh
Mimi Rossano
Robert Rossano
Olivia Rowswell
Jackie and Graeme Shaughnessy
Tracy Simpson
Suzie Tan
Sharmaine Whitley
Matt Wickstead
Kay Woodcock
Bek and Jason Yarnold
Nova Young

Donors

\$1000 and over

Bruce and Jeannie Auty
Baker McKenzie
Boris Bodanac
Doyles Carpet Court Five Dock
Simon Dunstan
Prof. Magdalena Durluk

Francesca and Lucia Fantuzzi
Daniel Friedgut
Rick Gould
Michelle Hertz
John Kelly
Sara Ladyman
Macquarie Group Foundation

Edwina Mann
Alison Mclvor
McKillop Family
QBE Foundation
Kynan Scarr
Nina Sorrenti
Gary Sullivan

Gary Symons
Gabriele Trento
Amanda West
Patricia Will
David Wolf
Sze Ann Woon

\$500 and over

Frederick Alexander
Maree Brattan
Ditmar Brauer
Brisbuild Group
Jeffery and Kerry Bromhead
Suzanne Delbridge
Denis Dordevic
Caterina and Luigi Fantuzzi
Peppino Fantuzzi
Courtney Flint
Mulga Road Bookshop
Mario Olivieri
Max and Julie Osborne
Amy Rockstroh
Andrew and Christina Savvides
Jacqui-lyn Saw
Stradbroke School
Your Accounting Team
John Wilson

\$250 and over

Marcus Asokendaran
Anna Beaton
Andrew Benstead
Matt Biddle
Joe and Janelle Bonaccorsi

Robert Bozinovski
Julie Brennan
Simon Carpenter
Ashleigh Chance
Debbie Crosby
Nicole Denny
Francesca Diamantaras
Paul Fantuzzi
Salvatore Paolo Fantuzzi
Andrew Goldstiver
Pam Goode
Mary Anne Hartley
Belinda and Charles Humphrey
Judith Johnston
Vikki Kennelly
Kerfoot Pty Ltd
Aimee King
Goodstart Kingston
Lulham Family
David Mak
Daniel McCluskey
Hamish Montague
Roy Morizzi
Anne Moussa
Anne Newman
Alannah and Keith Ogilvie

Alora Lauretta Olivieri
Vince and Isabel Olivieri
Wendy Paech
Catherine Panich
Vince Parris
Dom Pelle
Jason Perry
Concettina Polimeni
Susan Rennie
Robert Rossano
Gary Scarr
Tania Seary
Joseph Sergi
Madelyn Siwady
Kaye South
Allan and Alsa Stuart
Rasiah Sureshkumar
Vince Tari
Srivathsan Thiruvengadam
Anne Tsang
Olga Vanzidler
Cheryl Vernon
Kess Wearne
Tim Whitmore
Matthew Whyte



My daughter Lilly is 10 years old and lives with TSC. Watching her having seizures every day and often multiple times a day is incredibly distressing. While I know we are fortunate to have access to amazing doctors caring for and treating Lilly, it breaks my heart that we've been unable to stop her having seizures. Living with such a challenging condition like TSC really is a scary and isolating experience. This journey would be so much more difficult without the TSC Community to connect with during tough times. It's really encouraging for our family to see all the support for TSA's work and I hope one day there will be a cure for all children born with this devastating disease.

Lilly's mum Erin

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.

TSA Partners and Funders

This year we've again worked closely with our corporate partner **Baker McKenzie** during the final year of our partnership. We have enjoyed working with this firm and thank them for their financial and pro bono support. Thanks also to the **Social Sector Transformation Fund** and the **Department of Social Services** for looking favourably upon our grant applications.

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 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 and Charli Design.



Our Financial Results

I took over as Treasurer in October 2022. The change of Treasurer provides an opportunity to review TSA's financial processes and I thank my predecessor, Patrick Norris, for handing over TSA in a robust financial condition. My goal is to ensure that TSA's funds continue to be managed appropriately with strong controls in cash management, banking and meeting our financial reporting obligations for TSA's financial sustainability.

TSA's total income for 2022/23 was \$264,953 versus \$238,993 in the prior year. The increase was mainly due to grant funding for the web redevelopment project. Donations remain TSA's main source of income with a total of \$121,418 received. This was a pleasing outcome given economic pressures and was reinforced by strong support for fundraising campaigns and events. Operating deficit came in at a loss of \$30,996 due mainly to additional investment and spend on the web redevelopment project that were not covered by the grant for this project and increased salary spend for additional project work for the TSA nurse.

TSA's balance sheet remains solid with net assets of \$321,842 as at 30 June 2023. Gross assets of \$362,473 were comprised of 46% cash and high interest cash accounts and 54% balanced investment portfolios. During the year, funds were deposited in high interest at call cash accounts, taking advantage of rising interest rates, whilst

providing adequate liquidity to support ongoing programs and services.

At year end, the value of TSA's investments was \$166,780 compared to \$121,157 in the prior year. The increase was due to additional investments, income received and improved market value. TSA's Investment sub-committee regularly monitors these investments. Despite the potential for short term fluctuations, the investment objective is to hold these assets for long term capital growth and diversification of TSA's income. Additionally, these assets are highly liquid, should TSA ever need access to these funds.

Liabilities declined significantly in the year as all grants received were fully expended during the year.

Looking to the year ahead, we expect further cost pressure from rising inflationary costs. The team continue to work tirelessly on funding initiatives and managing expenditure, whilst providing critical services to the TSC Community.

I thank our Community, sponsors, members and volunteers for their ongoing support during 2023 and look forward to this continuing into 2024.

Nova Young, TSA Treasurer

Pictured: Nova and Alison McIvor, TSA Secretary at the TSC Community Connect event in Melbourne

Financial statements

Balance Sheet as at 30 June 2023

ASSETS	30 June 2023	30 June 2022
Bank		
General Cheque Account	\$56,297	\$194,316
Savings and Other Accounts	\$122,807	\$85,848
Other Expense Accounts	\$4,502	\$2,450
Term Deposits	\$11,210	\$11,154
Total Bank	\$194,816	\$293,768
Current Assets		
Accounts Receivable	\$0	\$18,500
Sundry Debtors	\$877	\$415
Total Current Assets	\$877	\$18,915
Non-Current Assets		
Add/(Less) - Unrealised Market Value Gains/(Losses)	(\$6,323)	(\$13,628)
Investments at Cost	\$173,102	\$134,785
Total Non-Current Assets	\$166,780	\$121,157
Total Assets	\$362,473	\$433,840
LIABILITIES		
Current Liabilities		
GST	(\$4,182)	(\$1,387)
PAYG Withholding Payable	\$3,186	\$3,722
Provision for Annual Leave	\$21,671	\$19,790
Superannuation Payable	\$0	\$3,358
Trade Creditors	\$9,252	\$0
Unexpended Grants	\$0	\$62,377
Total Current Liabilities	\$29,927	\$87,860
Non-Current Liabilities		
Provision for Long Service Leave	\$10,704	\$8,049
Total Liabilities	\$40,631	\$95,909
Net Assets	\$321,842	\$337,931
EQUITY		
Current Year Earnings	(\$16,089)	\$17,554
Retained Surplus	\$337,931	\$320,377
Total Equity	\$321,842	\$337,931

Financial statements

Income and Expenditure: Year Ended 30 June 2023

	30 June 2023	30 June 2022
INCOME		
Donations Received	\$121,418	\$124,194
Event Income	\$56,843	\$49,557
Grants Received	\$72,377	\$43,917
Membership Contributions and Fees	\$14,056	\$19,505
Other Income	\$259	\$1,820
Total Operating Income	\$264,953	\$238,993
OPERATING EXPENSES		
Accounting and Bank Fees	\$16,156	\$13,855
Advertising and Promotion	\$49	\$415
Board/Governance Expenses	\$0	\$0
Consultancy Fees	\$2,072	\$0
Educational Event Expenses	\$8,738	\$12,048
Fundraising and Event Expenses	\$19,713	\$15,503
Information Technology Expenses	\$79,447	\$10,944
Insurance Expense	\$2,701	\$2,672
Postage, Freight and Courier	\$546	\$1,660
Printing and Stationery	1,584	\$2,550
Publications and Information Resources	\$2,430	\$3,515
Salaries and Wages	\$155,074	\$145,410
Sundry Expenses	\$286	\$625
Telephone, Fax and Internet	\$552	\$542
Training and Development (Staff) and Membership Fees	\$430	\$234
Travel and Accommodation	\$6,171	\$180
Total Operating Expenses	\$295,949	\$210,153
Operating Deficit/Surplus	(\$30,996)	\$28,840
Non-operating Income		
Investments: Income and Change in Value	\$14,908	(\$11,286)
Deficit/Surplus	(\$16,089)	\$17,554

How TSA's funds were spent

Programs and services 45%

TSA delivers on its purpose by providing information and support to empower and connect the TSC Community in Australia. Program and service delivery costs include: running the TSA Telehealth Nurse Service; hosting education events such as TSC Community Connect and Zoom Education Events; writing and updating information on our TSA website; managing our many TSC-related networks including working with policy makers and advocates in health and disability to try to improve the care, treatments and screening available to people living with TSC; reviewing and sharing global TSC research.

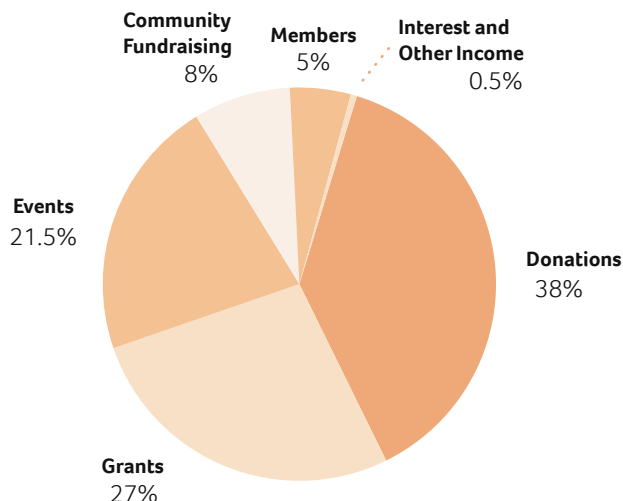
Development 20%

TSA has a deliberately diverse portfolio of fundraising activities to ensure its long-term sustainability. Our flagship campaign is our Light the Way Giving Day each May which supports the continuation of our services and programs. Other development activities include: writing grant and sponsorship applications; supporting our community fundraisers; retaining and growing TSA's membership program; organising and supporting TSA fundraising events such as Comedy for a Cure; Christmas and Tax-time appeals; identifying new funding opportunities and developing new initiatives.

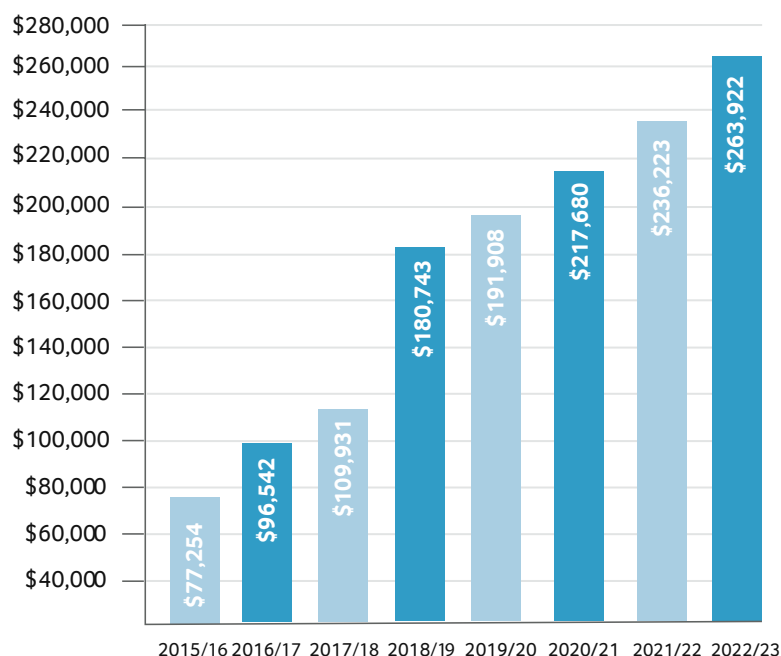
Accountability and organisation management 35%

Strong management and effective and transparent governance are fundamental to the success of any for purpose organisation. Costs involved in running TSA include: insurance premiums; regulatory compliance costs; accounting and auditing fees; website hosting and IT support costs. Every effort is made to minimise running costs and increase the impact of the donations and contributions that we receive. All TSA staff work from home and all Management Committee members are unpaid volunteers. We use pro bono and discounted services and volunteers to help us in our work whenever possible.

Where TSA's funds came from 2022/23

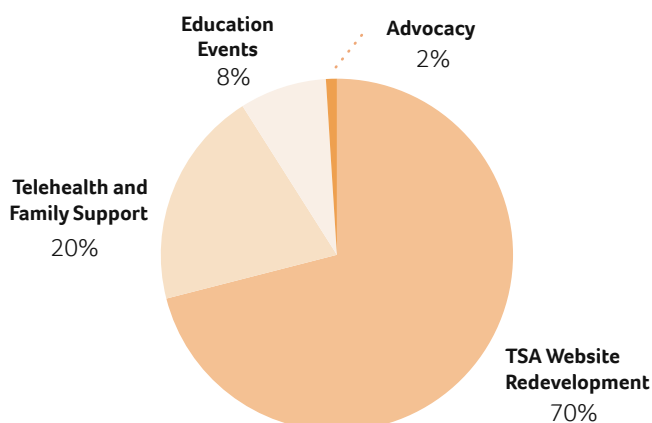


Fundraising revenue



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

How program funds were used 2022/23





In collaboration with:



Venue Sponsor



Catering Sponsor



Cam Knight

- Just for Laughs Festival at Sydney Opera House
- ABC's 'Soul Mates', 'Stand Up Australia'
- Triple M's 'Merrickville' / 'The Weekenders' with Dan Ginnane

"*** Will have you in stitches from the first minute until the last" - The Advertiser**

"*** The master of all masters... one of the best of the fest" - The Last Laugh**



David Smiedt

- Sydney & Melbourne International Comedy Festivals
- Opening act Joan Rivers & Martin Short
- 'The Today Show', 'Standup Australia'
- Acclaimed author & Editor of GQ Magazine

"A living, breathing joke machine" - Adam Hills



Bruce Griffiths

- Triple J Comic of the Year Winner
- Triple-M, Live At Jongleurs (UK)
- Aria Award winning writer for 'Good News Week' & 'The Glasshouse'
- Gold Medal in the New York Festival Film & TV Awards

"The best one-liner comic in the business"



Brett Nichols

- Sydney Comedy Festival
- Green Faces National Champion
- Finalist in the U.S Network NBC's 'Last Comic Standing'
- 'The Footy Show', 'Stand Up Australia'

"He had me in tears of laughter"



Tuberous
Sclerosis
Australia

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

Saturday 28th October 2023

Doors: 7pm / Showtime: 8pm (15+ Only)

Venue: Paddo RSL - 220 Oxford Street, Sydney

General Admission: \$100 / Book table of 10 (get 1 ticket free): \$900

Ticket includes a free drink on arrival and finger food.

BOOK at comedyforacure.org.au



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