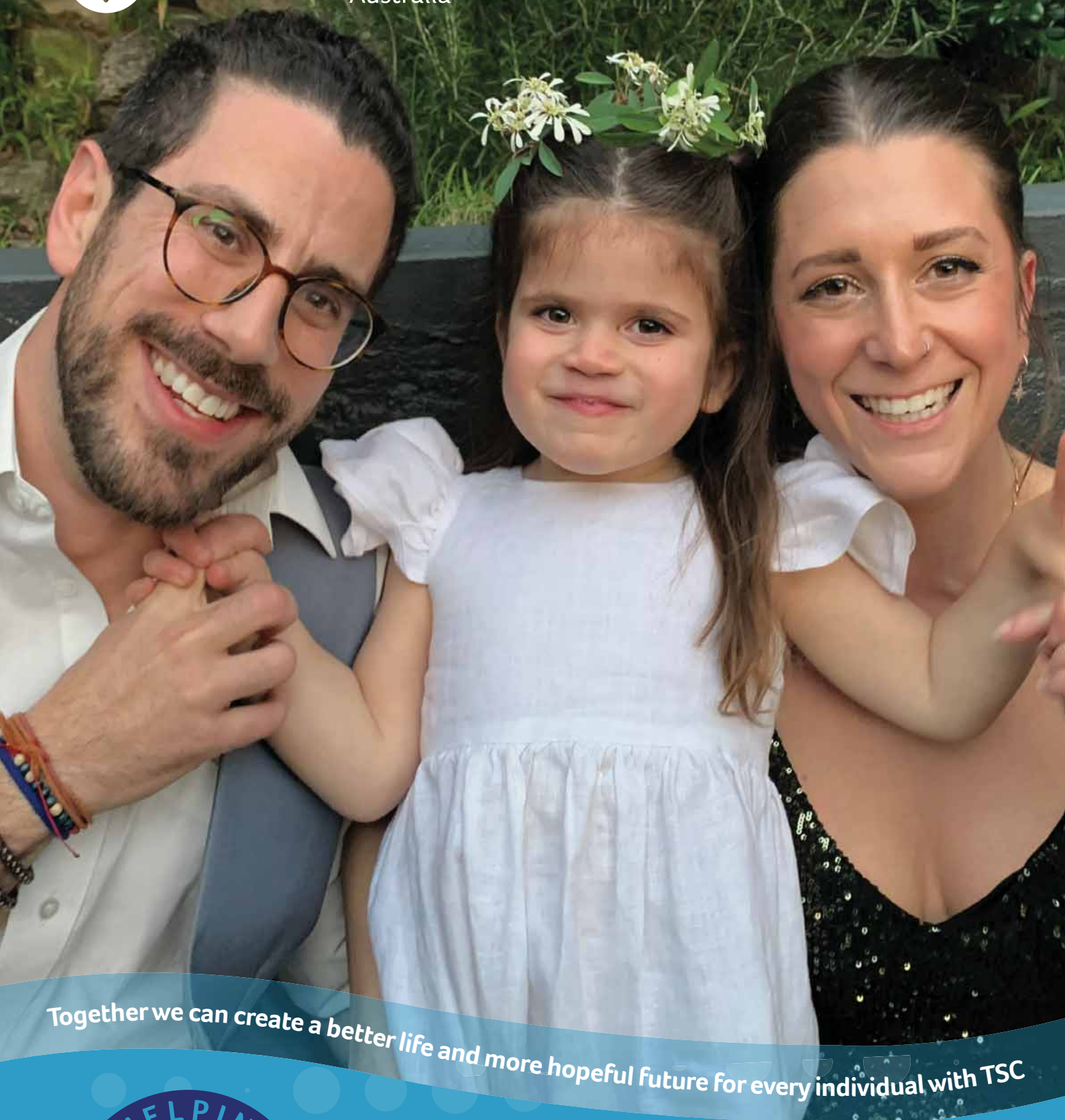




Tuberous Sclerosis
Australia



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



Annual Report 2021

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.

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.



Tuberous Sclerosis Australia (TSA)

For 40 years TSA has been informing, empowering and connecting people affected by TSC through access to the best treatment options, up to date information and support.



What we do:

- **Inform and educate**, providing accurate, balanced, up to date information about TSC, best practice management and surveillance, latest research and treatment options.
- **Empower and advocate** for people in our TSC Community to pro-actively manage their health and wellbeing. TSA provides both emotional and practical support and advice. We also raise awareness of TSC and advocate on issues such as access to health care and new treatments.
- **Connect** people living with TSC to expert health professionals and relevant services and to other people in our TSC Community facing similar challenges.

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

President's Report

What an amazing achievement to be marking 40 years. TSA has accomplished so much for individuals and families impacted by TSC in this time and it is a privilege to be part of this organisation.

Our strengths are in the teams of dedicated volunteers who have come together to shape TSA over the past 40 years, the trusted reputation we have built with health professionals and with the TSC Community, along with the high quality and diversity of the work we do.

TSA would not be the organisation it is today if it wasn't for our founder Lynn Wilson, long standing President Sue Pinkerton and first staff member, Clare Stuart. I thank them for their vision and dedication to improving the lives of people living with TSC in Australia. I would like to also thank many other people who have helped shape TSA along the way, including past committee members, volunteers, regional contacts and of course our current committee and staff team. Some of these remarkable people are featured on pages 4 and 5.

In addition to commemorating 40 years of service and the huge progress we've made, as you will see on page 7 TSA has had many reasons to celebrate over the past year. We launched our new information resources *In Safe Hands*, a guide for teachers and educators of children with TSC and an accompanying advocacy guide for parents. We held our first ever virtual TSC Community and Health Care Professionals Conference. And many families and adults living with TSC have joined us for our popular Zoom Education Events. We'll be bringing you more of these in the year ahead.

While we've had a lot to celebrate, we acknowledge this past year has been a challenging one for many of us due to COVID-19. As a small charity we depend on the generosity of our donors, fundraisers and volunteers. Even in these difficult times you have continued to support us. Thank you.

We've achieved so much together over the past 40 years. As this annual report shows, we can all feel proud of our impact and our achievements. But, as with all big challenges, we still have much more to do.

In the year ahead we hope we can count on your support with some new challenges we need to work on. We're particularly excited about the STOP2 study featured on page 10. Like Dr David Mowat and his team, we want to find out whether early intervention with mTOR inhibitors could be a game changer for babies born with TSC. And, having seen the positive impact it has had, we want to be able to continue to provide a TSA Nurse Service for our TSC Community.

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 your continuing support and for being a valued part of our TSC Community.

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

The TSA Team

- **Jackie Gambrell** General Manager
- **Kate Garrard** Fundraising and Communications Lead
- **Kim Kerin-Ayres** TSA Nurse

Our Management Committee

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

Celebrating 40 years of service to the TSC Community

TSA would never have been able to achieve all it has in its 40 years without the support of its committed, passionate and loyal TSC community. Chief among these have been the many members of this community who have generously committed their time, energy and expertise to serve on TSA's Management Committee.



'I received very little support when my daughter Tracy and I were diagnosed with TSC back in 1973. I felt like I had no-one and nowhere to turn to. I had very little information about TSC and really didn't understand it. It was a very lonely and isolating time. I was determined that others should have more support than I had and that's what led me to set up TSA (then known as the Australasian TS Society or ATSS).

I admit to being pretty astounded that TSA now has a dedicated Nurse Service, a website with online resources, education events, a magazine and enewsletters. The organisation has come a very long way indeed!

Lynn Wilson

Founder of ATSS, now TSA. Both Lynn and her daughter have TSC.

'TSA has been an integral part of TSC International. TSCI's tireless advocacy and commitment to spreading TSC information and awareness worldwide has helped build a vital support system for those living with TSC globally. This international team of passionate advocates, TSC individuals and families, medical professionals, and expert researchers has truly given us all so much hope for the future.'

Katie Smith
Director,
TSC Alliance, USA

TSCI Tuberous
Sclerosis
Complex
International
A Worldwide Organization
of Tuberous Sclerosis Complex Associations

'I've been involved with TSA for a couple of decades now and I am always impressed by the drive and professionalism of the team. It's an honour to support TSA's work to improve the outcomes for people with TSC.'

Dr David Mowat

*Clinical Geneticist,
Sydney Children's Hospital*



'It has been one of my life's highlights to turn our family's devastating TSC diagnosis into a positive for so many other families. To have played a role in improving the health trajectory of babies born with TSC through my volunteer work with TSA is very satisfying, yet humbling, and only possible with the support of my family and members of the TSA Committee.

I feel proud to have worked on establishing the original family weekends, the multidisciplinary clinic and, in conjunction with the team at Sydney Children's Hospital, the clinical trial of topical use of Rapamycin for angiofibromas, which has been life-changing in our TSC Community.

It has been a privilege to serve and support so many families affected by TSC and to provide valuable information and care during incredibly difficult times. I am delighted TSA now employs a team to carry on this important work, so that no family will ever have to face the challenges of TSC alone.'

Sue Pinkerton

Former President of TSA. Organiser of Lizzie's Lunch, a celebration of her daughter Lizzie who lived with TSC.



'I am so impressed with how far TSA has come. I first started volunteering with TSA some years after our daughter Amelia was diagnosed with TSC. I could never have anticipated the growth of our little society to the professional, impressive, trusted health organisation it is today. It's been a real privilege to work with such a passionate and dedicated group of people. The TSA Nurse is such a great addition to the services TSA now provides. It is so wonderful that everyone with TSC across Australia now has someone with expert medical knowledge to turn to for help.'

Sally Nicholson

Former TSA Committee Member and mum of Amelia who lives with TSC.

'TSA has been a big part of my life and I am excited we both get to turn 40 this year. TSA has given me connections with a community of amazing resilient families, passionate professionals and feisty advocates. It hasn't always been plain sailing. Working at TSA I often felt pain, guilt and grief linked to my sister's journey with TSC. I think many people with a personal connection to a cause experience this and this makes them all the more incredible. My wish for the future is that all people impacted by TSC can access expert health care, transformative treatments and the support they need to live extraordinary lives. TSA can play a big role in securing that future.'

Clare Stuart

Former General Manager, TSA and sister to Lizzie who had TSC.



Our achievements over 40 years

This Year

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

Presented a two-day virtual Conference for the TSC Community and Health Care Professionals.

Hosted 7 Zoom Education Events on a diverse range of TSC-related topics.

Took Comedy for a Cure online, raising funds and providing great entertainment for families during the global pandemic.

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.

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 2000s

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

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

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

The 1980s

TSA founded as the Australasian Tuberous Sclerosis Society.

First issue of *Reach Out* published.

Launched social picnics for families.

First family conference.

The 1990s

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.

TSA achieved a lot in 2021 thanks to your ongoing help and support

While 2020/21 continued to be a challenging year as we learnt to live with the continuing changes brought about by COVID-19, there were many positives for TSA and our TSC Community including:

- **Connecting and updating over 100 families** at TSA's first virtual TSC Community Conference, bringing together international and local health professional experts and our TSC Community to share new research, treatments and hope for everyone living with TSC
- **Launching *In Safe Hands*** - new online resources to support families advocating for their children with TSC in the school system and a companion guide to help teachers and school staff better understand, educate and manage children living with TSC
- **Presenting 7 successful Zoom Education Events** on a wide range of subjects, such as getting the best out of the NDIS, managing challenging behaviours, legal planning and more
- **Revamping our popular magazine, *Reach Out***. A survey of readers in April 2020 revealed that 83% of respondees read *Reach Out* from cover to cover and find the magazine interesting and useful, so will continue to provide this publication digitally and in print.
- **Securing a major grant to upgrade our web and IT systems** so that we can improve our ability to easily and readily connect and support everyone in Australia living with TSC with appropriately targeted information and resources.
- **Continuing to provide one on one support** through our TSA Nurse Service to everyone in Australia affected by TSC.

Our priority plans for the year ahead

TSA will continue to support its TSC Community in the year ahead by again providing much-needed information, support and connections. However, some of our plans for the year ahead are dependent on securing additional funding. These include:

- continuing the TSA Nurse Service (there will be no new funding from the government after June 2022)
- supporting the STOP2 mTOR inhibitors research project
- updating TSA's information resources
- hosting regular Zoom Events for individuals, families and health care professionals.



Can your network or your workplace help?

TSA needs your help to open doors, inspire new supporters and help introduce TSA to possible funders so we can continue to bring essential programs and supports to our TSC Community.

We'd love to hear from you if you think you can help.

Email info@tsa.org.au or phone us on 1300 733 435.

The impact of your support

198

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

22,661

People visited our website for information about TSC

74

TSC information pages
viewed each day

589

Members supported through our
private online TSC discussion group

718

Comments posted in our online TSC discussion group

108

Questions posted
in our online TSC
discussion group

93

Families participated
in TSA's 2 recent surveys

42

Families with a new diagnosis of TSC accessed our Parachute Packs

2

Issues of
Reach Out
published

7

Zoom
Education
Events held

1,700

Facebook followers
(82% are female)

1

National conference hosted for the TSC Community
and health professionals

116

TSC health care professionals in
our network across Australia

138

Participants in our
national conference

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

Jacob's TSC diagnosis in April 2021 came as a real blow to his dad, Joe and mum, Amira, as their first born son Frederic has a rare disease called Bartter syndrome – a disease that impacts just one in a million people! The couple can hardly believe that both their children have been diagnosed with different rare diseases.

It has been a challenging and emotional few months with many tests and medical appointments. However, Joe says they are thankful they have discovered what has been the cause of some of Jacob's odd behaviours such as when he would run around and then suddenly freeze.

Joe took a video of this to show their GP who mistakenly thought it was nothing much. Thankfully the family persisted and eventually they received a referral to a paediatrician. Initially, the specialist agreed with the GP, but then Jacob had a seizure right in front of the paediatrician. Jacob was immediately referred for an EEG, which detected abnormal brain activity and an epilepsy diagnosis was given.

Soon afterwards an MRI showed the cause of the epilepsy. There were tumours growing on Jacob's brain. It was then that the family were told that Jacob has Tuberous Sclerosis Complex.

The family wanted to get informed so they turned to Google for help and quickly found TSA's website. They downloaded the *Parachute Pack* – TSA's resource for families at the time of a new diagnosis. Then they connected with Kim, TSA's telehealth nurse. Joe says, 'Kim has been exceptionally helpful and like a counsellor in those early days.' Joe admits to asking Kim a lot of questions.

Joe and Amira have also found comfort connecting with another parent of a child with TSC. Sharing experiences and stories has helped them to feel less alone.

Five year old Jacob is social and sporty and, like his Dad, asks a lot of questions. He may have a slight developmental delay and is already receiving assistance. Thanks to the information on TSA's website Joe and Amira feel they will be able to support Jacob's development.

It is early days still for Jacob and his family and each day brings new discoveries. They feel fortunate to have access to the expert medical team at Sydney Children's Hospital and to have connected with TSA's services and information. They are remaining positive and doing everything they can to give Jacob the best future possible.



Save our Nurse!

TSA's Nurse Service provides free telehealth appointments for everyone in our TSC Community. The Nurse Service, which has provided life-changing help and support for many adults and families like Jacob's, has been made possible thanks to a pilot project funded by the federal government. Unfortunately there is no ongoing funding available to continue this vital service. Our goal for the year ahead is to secure funds so we can continue to employ a telehealth nurse. Please let us know if you can help!

What's next for health care in TSC?

Together we've helped many people impacted by TSC to access the best possible health care and new TSC treatments. But there is still much more work to do. Our biggest goal for the year ahead is to help progress a new research project with the team at Sydney Children's Hospital called STOP2, focusing on the use of mTOR inhibitors in infants under 2 years of age.

mTOR inhibitors

The mTOR inhibitor drugs - sirolimus (Rapamycin) and everolimus (Afinitor) - have had a significant impact on the lives of many people with TSC since they were introduced during the last decade. We can now treat children with TSC and severe epilepsy with this drug. Some families have found extraordinary benefits and improvements. It's reduced seizures from hundreds every day to maybe one or two a month for some families.

So, we now have a body of clinical evidence which shows that mTOR inhibitors can successfully reduce and control the size of TSC tumours or growths in many patients. They might also stop further growth. As Dr David Mowat, Clinical Geneticist and Head of the Centre for Clinical Genetics at Sydney Children's Hospital, Randwick comments: 'It would be nice if we could get rid of tumours altogether but that can't happen currently. If you stop the medicine they grow back slowly again. But, if you keep taking the medicine, everything's under control. For people with TSC, and those of us who have been working in the TSC world for a few decades, this has been a major, positive breakthrough.'

Currently, however, there is no research on the use of mTOR inhibitors in children under 2 years of age. David and the team at Sydney Children's Hospital would like to change that. They believe it could be a game changer for TSC.

The STOP2 study

Dr David Mowat says: 'As the brain is developing in utero and over the first 3 years of life, a child is forming

numerous neuronal networks in the brain under the control of the mTOR pathway. There's a growing body of thought amongst some TSC health professionals and researchers that starting an mTOR treatment at an early age, possibly at or before birth, might actually prevent the development of tumours, epilepsy and other disease manifestations associated with TSC.

We are looking to collaborate with Dr Darcy Krueger in Cincinnati, on the STOP2 study. STOP stands for Stopping TSC Onset and Progression. The plan is to explore the safety, barriers and outcomes to early treatment with mTOR inhibitors for infants. We're hoping to get funding and approval to participate in this study in Australia.

A high proportion of babies with TSC develop seizures, have intellectual disability and autism. We know in the field that we potentially have a way of changing this outcome.


And so, I think every time we don't do that, it's a missed opportunity. I have to stress, we don't know that this would be possible and there are some potential risks but, for me, it's a very important unanswered question around the use of mTOR inhibitors and TSC.

For over 20 years we've studied the safety profile of this drug and we've moved closer and closer to an age group where we're getting better and better outcomes. Now we need to find out what happens if we give this medicine at the time when it's most needed for normal brain development?'

TSA Medical Advisors

Our work is supported by a team of medical advisors who work closely with TSA to ensure the medical information we provide is accurate, up to date and balanced. Our medical advisors work with us to advance health outcomes for people with TSC. They also provide vital contributions to various TSA projects and TSC research in addition to delivering world-class clinical care to children, adults and their families impacted by TSC.

- **Dr Sean Kennedy**, Nephrologist at Sydney Children's Hospital
- **Dr John Lawson**, Paediatric Neurologist at Sydney Children's Hospital
- **Dr David Mowat**, Clinical Geneticist at Sydney Children's Hospital



Liam was diagnosed with TSC at just 6 weeks of age. He is now almost 13 years old. Liam's dad Steve says: 'Every time I hear about new research like the recent EPISTOP study or this new proposed STOP2 study, I wonder if Liam might've been spared his epilepsy and learning difficulties?'

There is a critical window of time to change the outcomes for children born with TSC to prevent these complications developing. The STOP2 study could be the "cure" the TSC Community has been waiting for. Imagine a study that could prove early and pre-emptive mTOR medications are safe to use in infants with TSC! This could prevent many of the most harmful impacts of the condition from ever developing.

Had Liam been born 10 years earlier, we might not have had access to TSC-specific treatments like vigabatrin which gave him a critical period of seizure free development from 6 months to 2 years old. We feel very blessed that we can access this medicine. However, we can't help but wonder whether it could have helped Liam's cognitive development even more, and made a big difference to all our lives, if we had started the vigabatrin even earlier?

I feel thankful for the new studies and developments for people living with TSC. Anything that can help reduce the challenges for families like ours is very welcomed. We hope this new STOP2 study gets funded so that every baby born with TSC has the best possible hope for the future.'

Steve Walker with his children, Liam and Henry.

Thank You

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

TSC Heroes raise over \$17,000



Thank you to all the TSC Heroes who raised funds and awareness for TSA by joining in these events and inspiring your family and friends to donate.

City2Surf 2020 raised over \$5,000 thanks to the team members who signed up for this virtual fun run – Yasmin Bodanca, Clements Family, Tash Kourea, Melissa Maher, Rob Rossano and Samantha Smith.

Cairns Ironman 2021

raised over \$10,900 thanks to the incredible Jeff Place who completed his first full Iron Man challenge in Cairns on 5 June. Not only did Jeff manage to swim 3.8 kms, cycle for 180.25 kms and run a marathon, he also beat his target and raised over \$10,000 for TSA.



London Vitality raised over \$1,000 thanks to Aunty Amy who was inspired to raise funds for TSA in honour of her niece Roxie who lives with TSC

#Heroes4TSC

Many families have inspired their family and friends to donate in honour of their loved ones with TSC. Thank you to #Heroes4Roxie, #Heroes4Isabel, #Heroes4Samuel, #Heroes4OskarY, #Heroes4Alana, #Heroes4Annabelle and #Heroes4Caleb. You've inspired over \$2,000 in donations. Thank you!



Special Events

Lizzie's Lunch 2021 broke a record and raised its highest amount ever – just over \$24,000. 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 event in honour of Lizzie.



Comedy for a Cure went virtual and was a huge success raising over \$21,000. Thank you to the very funny comedians and to everyone in our community who got involved to make it a fun night. Special shout out to our major sponsor Baker McKenzie for their support.



#40kfor40yearsTSCchallenge has raised over \$27,000 so far. We're halfway to our goal of raising \$40,000 to celebrate 40 years of service to the TSC Community. Heartfelt thanks to the families of Bodie, Oskar G, Kyah, Isabel and Samuel for signing up to this challenge.

In honour fundraisers were held by Lise Rossano and Pearl Blasina who inspired their loved ones to donate in lieu of birthday gifts and raised a total of \$2,545.

In memory collections were held in honour of Christine Ryan and Sarah Derrick. Thank you to their family and friends who donated almost \$1,000.

TSC Global Awareness Day

and **#Tatts4TSC** was held despite the challenges and restrictions of the coronavirus pandemic. Our dedicated TSC Community and your generous family and friends, raised over \$5,410. Shout outs to Amber Reid for organising a 'Box for Samuel' event, The Rossano Family, and Rachel Bennett, and to everyone who purchased tattoos and downloaded the Facebook Frame to help raise awareness.



TSA's Christmas and tax-time appeals raised over \$10,135 thanks to your donations and inspiring your network to donate too.

Our Volunteers and Regional Contacts

To all our wonderful volunteers around Australia, what would we do without you?! Special mention to Teresa Llewellyn-Evans our editor, Cornel Visagie our data expert, Belinda Johnstone our web developer, 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 and Fiona Crocker 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
- Nicole Stone in Western Australia

Our TSC Health Care Professionals Network

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

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

Our 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. We welcome Scentre as a new workplace giving partner.

Thanks also to the Centre for Community Driven Research, UCB Pharma, NSW Government's Social Sector Transformation Fund and the Department of Social Services for looking favourably upon our grant applications.

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 and Lanham Media.



"Jess was diagnosed with TSC at the age of 18 after three years of investigations due to a sudden decline in her health. An MRI showed she had TSC brain tubers plus two Cavernous Malformations in her brain. We have adjusted our lives to accommodate Jess' additional needs and requirements. While Jess will never hold a driver's licence and was unable to complete school, she is stable and now owns and runs her own baking business, which we set up as a way for her to be productive and have independence within the limitations of her conditions."

Cherryn, Jess's mum

Photo: Jess

Our TSC Community

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

Our Donors and Sponsors

TSC Champions

Aunt Ivy's Ironing and Laundry
Service

Belinda Allchin (*Matched by
Macquarie Bank Foundation*)

Mary Bui

Virginia Chick

Helen Clisdell

Peter Clisdell

Jennifer Cunningham

Linda Deacon

Julie Garrard

Andrew and Emily Goldstiver
(*Matched by Westpac*)

Sonia Gregson

Hayley Hill

Steve Mason

Sue Mason

Kate Norris and Steve Walker

Elaine O'Dea

Jennifer O'Donoghue

Roshan Perera

Rob Pinkerton

Sue and Ross Pinkerton

Julia Prunty

Lucy Vettom

TSC Members

Life Membership

Andrew McKinnon

Ross Pinkerton

Sue Pinkerton

Lynn Wilson

Platinum Membership

Elizabeth Cranston

Gail Cummins

Lachlan Foster

Kevin and Louise Niklaus

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Dawn and Greg Bowra

Jeffery and Kerry Bromhead

Debbie Crosby

Joanne Crosby

Kasia Durlik

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David Mowat

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Leanne Park

Steve and Judy Penniment

Maria and Giuseppe Petralito

Sam Reckwell

Daniel Strosberg

Steve Walker

Harry, Alison and Adrian Zehnworth

Silver Membership

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Melissa Matthews

Jenny May

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Ruth and Craig Schneider

Marianne Somerville

Nicole Stone

Samantha Stone

Allan and Alsa Stuart

Loren Wakeley

Geoffrey Walker

Sue and Greg Williamson

Jay Yardi

Bronze Membership

Frederick Alexander

Elizabeth and Julian Bedford

Pearl Blasina

Kirsty Boakes

Laura Boschetti

TSC Champions donate \$14,165

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.

TSC Members contribute \$19,590

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

Tania Colman
Tane Cox
Louise Cummins
Dianne Curtis
Cara Doherty
Chris and Lori Doyle
Robert and Jennifer Drury
Val Edwards
Janet Flint
Corey Fraser
Kate Garrard
Miia Groenewald
Linda Gunek
Rebecca Hayes
Marie Hell

Narelle Kerr
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Abby Marsh
Frank Martin
David Matheson
Lachlan McArthur
Rebecca McIntosh
David Meredith
May and Bruce Mills
Sarah Mitchell
Emma and Brett Morris
Gwynnydd Murphy
Rochelle Murphy
Jelle Neville

Beverley O'Reilly
Christine Phillips
Katrina and Mark Prunty
Janiffer and Ross
Reynolds
Mimi Rossano
Georgina and Scott
Schilg
Jackie and Graeme
Shaughnessy
Tracy Simpson
Holly Smith
Samantha Smith
Cynara and Matt
Stalenhoef

Donors

\$1000 and over

Baker McKenzie
Bruce and Jeannie Auty
Cory Brady
Daniel Friedgut
Dale Gordon
John Kelly
Alison McIvor
Jan Tait
Patricia Will

\$500 and over

Luyun Bai
Boris Bodanac
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Heather Deane
Kerfoot Pty Ltd
Jenni and Terry Lawry
Rachel Lawry
Dr John Lawson
Julia MacGibbon

Barbara Marneros
Litao Zheng

\$250 and over

Adrian Boschetti
Suzanne Bourchier
Michael Britton
Miriam and Curt Chalk
Roslyn and Peter Chalk
Katina and Bruce Core
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Mark Wonnacott
Scentre Limited WPG



Parker is 5 years old and has TSC. He started school this year and his mum Katherine, says he is, 'doing great.' Katherine is a member of the TSC Discussion Group on Facebook and says: 'I value the connection it brings. It's reassuring to know we are facing similar changes as other families.' She says her family feel incredibly fortunate to be linked in locally with the dedicated and knowledgeable neurology team at the Women's and Children's Hospital in Adelaide: 'we are grateful for all the teams of people that provide help and support to families like ours, including medical, allied health, other TSC families and the team at TSA, who are always there if we need them.'

Katherine, Parker's mum

Photo: Parker

We'd like to thank everyone who made a contribution to TSA this year. We are grateful for each and every gift TSA received. We have chosen to list above only donations over \$250, because there were just too many of you to include each of you by name.

Our Financial Results

TSA achieved a very good result for the financial year thanks to strong support from our TSC Community and COVID-19-related federal government assistance.

Thanks to JobKeeper support and continued grant funding under the Patient Pathways Program for our TSA nurse, we were able to retain our team of 3 dedicated, part-time paid employees for the whole period.

We had previously attracted some grant funding for the TSC conference we planned to hold in 2019 which had to be postponed due to COVID. We are thankful to our sponsors for extending the deadlines for these grants to provide funding for our first very successful virtual conference in May 2021.

Whilst community fundraising opportunities are still not back to pre-COVID-19 levels we have been extremely heartened to see continued donations and support from our TSC Community. We are also very grateful for the support shown for our major fundraising events, our first virtual Comedy for a Cure in December 2020 and Lizzie's Lunch in June 2021. We hope support for these events will continue, as they make a significant impact to our organisation.

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 returns on term deposits are now at historically low levels and so in the next financial year your committee has decided to invest some funds in low risk managed funds and exchange traded funds (ETFs) to obtain better returns. A finance subcommittee will select and manage these investments with oversight by the full TSA Committee. Investments will be made following TSA's established practice of dual authorisation for bank payments.

The accounts for the year ending 30 June 2021 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 of Liam who lives with TSC



This year we received sizeable donations from 2 pharmaceutical companies to support our conference. Our policy on working with pharmaceutical companies, which is available on our website (<https://tsa.org.au/about-us/policies/>), describes how we maintain our independence and integrity.

Financial statements

Balance Sheet as at 30 June 2021

ASSETS	30 June 2021	30 June 2020
Bank		
General Cheque Account	\$141,008	\$45,695
PayPal	\$1,842	\$4,180
Savings Accounts	\$81,359	\$81,350
Staff Debit Cards for TSA Expenses	\$3,468	\$3,431
Term Deposits	\$195,306	\$192,719
Total Bank	\$422,982	\$327,375
Current Assets		
Deposits Paid	\$600	\$0
Sundry Debtors	\$715	\$1,339
Total Current Assets	\$1,315	\$1,339
Total Assets	\$424,297	\$328,713
LIABILITIES		
Current Liabilities		
GST	\$2,460	-\$1,110
PAYG Withholding Payable	\$3,148	\$3,852
Provision for Annual Leave	\$17,921	\$15,654
Superannuation Payable	\$3,089	\$3,727
Suspense	\$40	\$0
Trade Creditors	\$1,401	\$0
Unexpended Grants	\$69,294	\$73,447
Total Current Liabilities	\$97,354	\$95,569
Non-Current Liabilities		
Provision for Long Service Leave	\$6,565	\$4,117
Total Liabilities	\$103,919	\$99,686
Net Assets	\$320,377	\$229,027
EQUITY		
Current Year Earnings	\$91,351	\$3,964
Retained Surplus	\$229,027	\$225,063
Total Equity	\$320,377	\$229,027

Financial statements

Income and Expenditure: Year Ended 30 June 2021

	30 June 2021	30 June 2020
INCOME		
Donations Received	\$89,633	\$92,132
Event Income	\$44,029	\$23,563
Grants Received	\$66,652	\$55,518
Membership Contributions and Fees	\$21,009	\$20,695
Other Income	\$ 2,204	\$4,199
Sales of Goods	\$721	\$1,154
Total Operating Income	\$224,249	\$197,260
OPERATING EXPENSES		
Accounting and Bank Fees	\$12,962	\$12,426
Advertising and Promotion	\$218	\$0
Board/Governance Expenses	\$433	\$494
Consultancy Fees	\$1,390	\$0
Educational Event Expenses	\$16,868	\$200
Fundraising and Event Expenses	\$9,157	\$5,923
Information Technology Expenses	\$11,564	\$12,295
Insurance Expense	\$2,576	\$2,746
Postage, Freight and Courier	\$1,577	\$2,279
Printing & Stationery	\$3,865	\$5,384
Publications and Information Resources	\$5,805	\$11,500
Salaries and Wages	\$153,141	\$165,953
Sundry Expenses	\$1,046	\$468
Telephone, Fax and Internet	\$570	\$601
Training & Development (Staff)	\$45	\$0
Travel & Accommodation	\$132	\$1,028
Total Operating Expenses	\$221,348	\$221,296
Operating Profit	\$2,901	-\$24,036
Non-operating Income		
Government support related to COVID-19	\$88,450	\$28,000
Deficit/Surplus	\$91,351	\$ 3,964

How TSA's funds were spent

Programs and services 44.5%

TSA's primary purpose is to provide information and support services to its TSC Community in Australia and also to the health professionals working with that community. Costs associated with program and service delivery include the TSA Nurse Service, education events such as the TSC 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*. This year it also included publishing the *In Safe Hands* resources for parents and educators of children living with TSC. Additionally, there are some costs associated with working with policy makers and advocates in health and disability to improve the care available to people living with TSC and reviewing and sharing global and local TSC research.

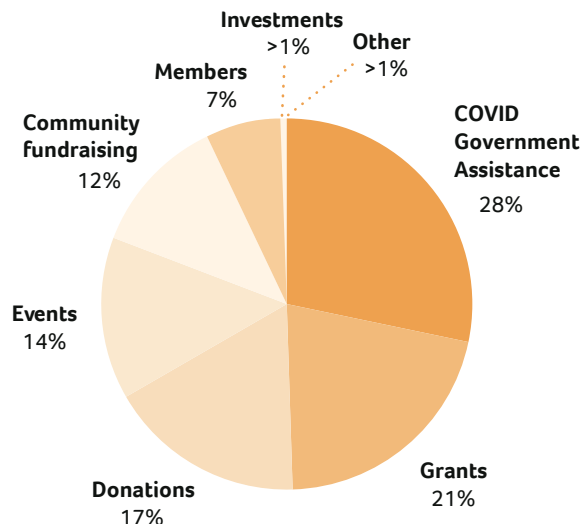
Development 20%

TSA has a deliberately diverse portfolio of fundraising activities to ensure its long-term sustainability as an organisation. The wide range of development activities includes writing grant applications, supporting community fundraising, retaining and growing TSA memberships, organising and supporting TSA fundraising events such as Comedy for a Cure and Lizzie's Lunch and developing and delivering campaigns such as Global Awareness Day.

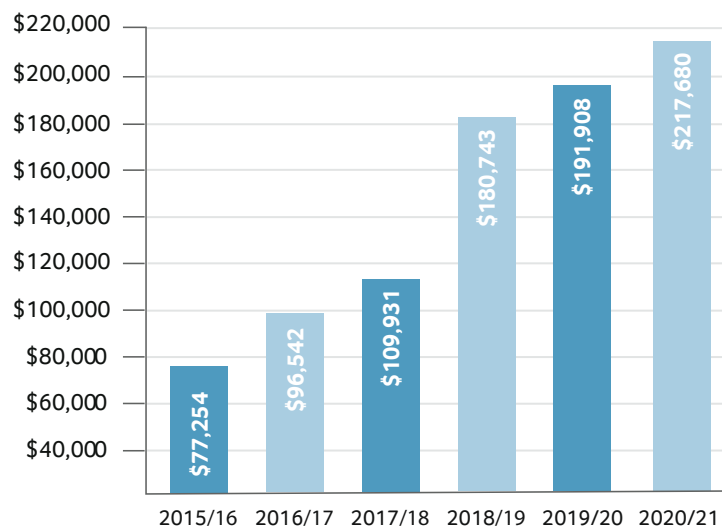
Accountability and organisation management 35.5%

Strong management and effective and transparent governance are fundamental to the success of any organisation. These are 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.

Where TSA's funds came from

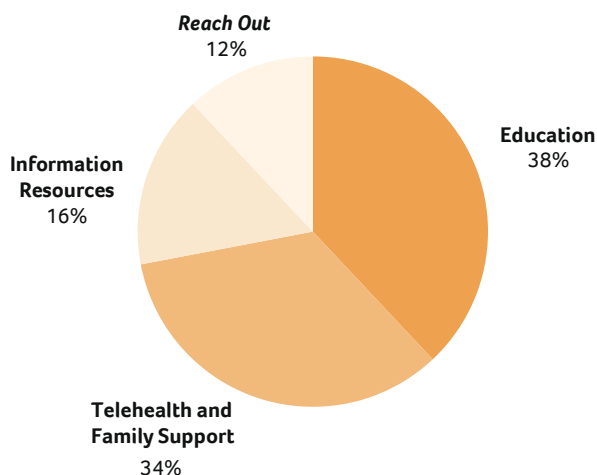


Fundraising Revenue



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

How program funds were used



There is still so much we need to do to improve the lives of people living with TSC. Together we CAN make a difference. Get involved today!

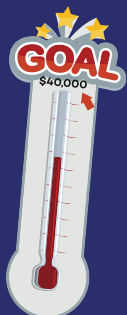
JOIN OUR #40kfor40yearsTSCchallenge

Will you help TSA celebrate 40 years of service by fundraising in honour of the person you know with TSC?

We are looking for 40 people to raise \$1,000 each over the course of 2021 so we can raise \$40k to mark 40 years of helping the TSC Community in Australia.

Your participation will help ensure TSA will be around for the next 40 years.

Join today at
<https://tsa.org.au/40kfor40years/>



Leave a gift in your will

Leaving a bequest is a wonderful way to leave a lasting legacy. Debbie has chosen to include a gift to TSA in her will and says: *'I know that giving a bequest will ensure TSA's support and information*



services can continue to make a difference for families like ours well into the future. You don't have to be wealthy to make a bequest – whatever gift large or small you choose to give will help everyone facing the challenges of life with TSC.'

Find out how to leave a gift for TSA at
<https://tsa.org.au/help/bequest/>

Can you help open doors for TSA?

TSA would love you to help make introductions to potential funders so we can expand our programs and services. It could be an introduction to your workplace or a work colleague, your local Lions or Rotary Club, a philanthropist – anyone you think might be inspired to support our work. If you open the door and make the introduction, we'll take care of the rest!

Email us at fundraising@tsa.org.au



Join or Renew your membership today

Memberships help TSA continue to provide essential free information and support services to everyone in Australia affected by TSC. If you haven't already done so, please renew or join as a TSA member today.

Join or renew at
<https://tsa.org.au/help/join/>



Tuberos Sclerosis
Australia

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CFN 13968



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A better life. A more hopeful future.