



ATSS's vision is that:

TSC families are empowered, through access to information and support.

Tuberous Sclerosis Complex (TSC) affects more than 3000 individuals in Australia and New Zealand and thousands more carers, families and friends who live with the impact of the disease.

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

President's Message

It has been a very rewarding first year as President of ATSS. I have had the opportunity to talk and meet with many people and families affected by TSC and it is a privilege to represent ATSS as President. There have been many achievements and highlights which have supported our vision that TSC families are empowered, through access to information and support.

Our focus on online communication has been very successful with the new website, monthly newsletters and regular news posts. The ATSS Facebook group has grown and connecting with others and sharing our thoughts and stories on a more regularly basis is an important part of feeling supported and getting the latest information on TSC.

Another major achievement was the commencement of the Topical Rapamycin clinical trial at the Sydney Children's Hospital. It is great to see the trial up and running and ATSS has been able to fund an 18 month extension of the trial with the generous support of our donors. Further, in October 2012, ATSS and individual families made submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) who considered listing Everolimus on the Pharmaceutical Benefits Scheme (PBS). I am very happy to report that Everolimus was recommended for listing and having this medication subsidised through the PBS will improve access to this treatment. I would like to thank the families who made personal submissions to the PBAC.



Providing information and support to families throughout Australasia is our major goal and this was the focus of the ATSS Family Conference in Perth. The conference was very informative and it was great to see people share their stories, ideas and connect with one another. I would like to thank everyone from Perth who helped us in making the conference a success. Another highlight of our year was TSC Global Awareness Day on 15th May. There were many activities and events around the world to raise awareness of TSC and here in Australia picnics were held in each state and it was wonderful to see so many people coming together.

The work of ATSS in supporting individuals and their families affected by Tuberous Sclerosis is made possible by our donors, volunteers and staff. I would like to thank our project manager Clare Stuart for her outstanding work and many of our achievements can be attributed to her commitment and hard work. I would also like to thank the committee and regional contacts who give their precious time and commitment to ATSS. Most importantly, thank you to those who made a financial contribution to ATSS this year. We look forward to your continued support in 2014 to further grow the information, support and advocacy work we do to improve the lives of families living with Tuberous Sclerosis.

Debbie Crosby, President

“ The work of ATSS in supporting individuals and their families affected by Tuberous Sclerosis is made possible by our donors, volunteers and staff. ”



Committee

Debbie Crosby, President
Hayley Hill, Treasurer and Membership Secretary
David Matheson, Minutes Secretary
Mary Beijerinck-Gooley
Kate Green
Narelle Kerr
Sally Nicholson
Kate Norris
Jannifer Reynolds

Staff

Clare Stuart, Project Manager

Regional Contacts

A vital part of the ATSS volunteer team, the regional contacts live throughout Australia and New Zealand and work with local families to share information and experiences.

NSW: Janiffer Reynolds
WA: Nicole Stone & Sue Williamson
QLD: Fiona Hiatt
VIC: Narelle Kerr
TAS: Georgina Schilg
NZ: Sheryll Brasell

Medical Advisors

Dr David Mowat, Clinical Geneticist
Dr John Lawson, Paediatric Neurologist

Measuring our impact

Awareness

Our website provides information about TSC to more than **200** visitors each week, including **12** personal stories illustrating life with TSC.

Our Facebook page is followed by more than **200** people. **55** posts were made, each seen by up to **488** Facebook users.

Information

We sent **204** copies of Reach Out in May, **243** in November.

Our website offers **10** TSC information pages reviewed by Australian medical professionals along with other articles and videos.

We sent **10** email newsletters to more than **200** subscribers.



Research & Advocacy

We brought back research news from **2** international conferences.

ATSS and TSC family submissions led to recommendation to list **1** new TSC medicine on the PBS.

We've provided more than **\$200,000** to an innovative clinical trial, including new **18** month extension phase.

Support

We helped more than **60** families helped through our phone and email support services.

We hosted **8** family picnics held around Australia and New Zealand.

Our Facebook support group has over **200** members and had **400** discussion topics during the year.



Australasian

Tuberosclerosis
Society

Our sights are set ...

help us provide the first TSC Advisor in Australia and New Zealand

With your help we will provide a new vital service to families living with TSC.

The TSC Advisor will:

- Be there for parents when their child is diagnosed or individuals diagnosed as adults;
- Offer some immediate support and reassurance;
- Have accurate and up to date information about Tuberous Sclerosis;
- Be able to connect the family with other support services they need.

“ When I make a new diagnosis of Tuberous Sclerosis, we sit with the families for an hour or so, and then they go home. To have someone who they can call and who can fill in all those details for the family and provide support would be an enormous benefit for them. ”

**John Lawson – Paediatric Neurologist at The Sydney Children’s Hospital
and Medical Advisor to ATSS**

ATSS is a registered charity and we receive no ongoing government funding.

We rely on your donations to provide support to families affected by TSC.

Consider becoming a Gold, Silver or Bronze Supporter of ATSS, or be a Champion and donate monthly.

Every bit of assistance helps us improve the lives of families affected by TSC.

www.atss.org.au/help



Information and support services

The core of ATSS's work continues to be providing information and support to individuals with TSC and their families. Online communications and social media continue to play a large role in ATSS's ability to reach a wide audience. Facebook, monthly email newsletters and our website were popular sources of the latest news on TSC research, available treatments and local resources to help TSC families. In particular, the Discussions of ATSS facebook group continues to provide a positive peer support network for many families with more than 200 members.

The twice-yearly magazine, *Reach Out*, offers families, health professionals and donors TSC news and information along with personal stories from families living with TSC.

Our dedicated volunteers continued their work this year answering phone calls and emails from families around Australia and New Zealand. Families reach out to ATSS often after a new diagnosis or in times of crisis. Our next major goal is to grow this direct support service through the employment of a TSC Advisor.



Our advocacy work contributes to PBS listing recommendation

The first treatment specifically for TSC was recommended for listing on the Australian pharmaceutical benefits scheme (PBS) in April 2013. The committee's understanding of TSC was enriched by submissions from TSC affected individuals and their families and the submission made by ATSS.

Up until the approval of Everolimus by the Therapeutic Goods Administration (TGA) in early 2012, brain surgery was the only treatment option for large SEGAs, a potentially life-threatening symptom of TSC. Listing of Everolimus on the PBS will make this much needed second option affordable for those patients and their families that require this treatment.



Research into topical cream for skin tumours

This clinical trial is part of a world-wide study to demonstrate the effectiveness of a topical cream to treat facial angiofibromas, a disfiguring skin condition experienced by the majority of individuals with TSC. This non-invasive treatment shows promise as an alternative to painful laser surgery. The Treatment trial commenced in 2012 at Sydney Children's Hospital - fully supported by funds contributed by ATSS's generous donors. Initially running for 6 months, ATSS recently provided funding for an 18 month extension phase.

While the trial is taking place ATSS is helping families who are interested in this experimental treatment. ATSS has connected with dermatologists throughout Australia and New Zealand as well as the compounding pharmacists who are manufacturing the cream. This work has led to improved access and reduced costs for many families.



ATSS Family Conference, Perth

More than 50 people attended this two day event, the first major TSC event ever held in Western Australia. The keynote speaker for the weekend was Professor Petrus de Vries. Petrus is an experienced neuropsychiatrist and a leading researcher into the behavioural, intellectual, learning and mental health challenges experienced by people with Tuberous Sclerosis. In addition to speaking at the Family Conference, Prof de Vries spoke to a professional audience of neurologists and psychiatrists, raising awareness of these aspects of Tuberous Sclerosis and the developments in research and new treatments for TSC.

The family conference included a variety of talented speakers covering topics such as neurology, genetics, autism, the kidneys and the skin. Several speakers outlined the services available to individuals and families living with TSC offered by organisations such as Kalparrin, the Neurological Council of WA and Epilepsy Action Australia. All speakers donated their weekend time willingly and ATSS are very grateful for their support. The conference was made possible by the hard work of several ATSS volunteers in Perth: Sue Williamson, Nicole Stone, Karen McCagh, Samantha Stone and Joelle and Peter Neville.



“ I just wanted to say it again: thank you. Without your help over the last 6 years I would have been so lost. ” - An attendee at the conference

Profit and Loss: Year ended June 2013

	June 2013	June 2012
Income		
Donations	\$32,590.76	\$29,932.52
Donation - Rapamycin	\$435.00	\$3,358.00
Gold Supporter	\$100.00	\$290.00
Silver Supporter	\$45.00	\$115.00
Bronze Supporter	\$130.00	\$330.00
2012-2013 Gold Supp Advance	\$0.00	\$145.00
2012-2013 Silver Supp Advance	\$0.00	\$105.00
2012-2013 Bronze Supp Advance	\$0.00	\$165.00
Committee Sitting Fees	\$345.00	\$0.00
Interest Income	\$10,706.90	\$15,015.19
Grants Received	\$44,584.00	\$50,760.00
Other Income	\$0.00	\$782.97
Promotional Products	\$150.00	\$1,530.00
2011 Family Conference Registration	\$0.00	\$7,350.00
2011 Family Conference Book & DVD	\$20.00	\$280.52
2011 Family Conference Dinner	\$0.00	\$4,110.00
2012 Melbourne Conference Registration	\$0.00	\$2,695.00
2012 Brisbane Seminar	\$161.00	\$330.00
2013 WA Conference Registration	\$2,715.00	\$0.00
2013 WA Conference Dinner	\$1,980.00	\$0.00
Seminar Day Registration	\$420.00	\$630.00
Total Income	\$94,382.66	\$117,924.20
Expenses		
NSW Fair Trading Fees	\$51.00	\$48.00
QLD ACNCS Fee	\$500.00	\$0.00
Fees to other Membership Comp	\$50.00	\$132.00
Everyday Hero Fee	\$411.84	\$0.00
2011 Family Conference October	\$0.00	\$16,029.78
2011 Family Conference - Travel Reimbursement	\$0.00	\$12,426.95
2011 Family Conference Gifts	\$0.00	\$892.31
Conference Registrations	\$0.00	\$525.00
ATSS Anniversary Gala Dinner	\$0.00	\$95.91
2012 Melbourne Conference Cost	\$0.00	\$2,209.37
2012 Brisbane Conference Costs	\$0.00	\$483.00
2013 WA Conference Expenses	\$9,183.11	\$0.00
2103 Conference Travel/Accommodation Reimbursement	\$7,870.81	\$0.00
2013 WA Conference Catering Expense	\$2,486.50	\$0.00
Seminar Day Expenses	\$323.15	\$298.42
Rapamycin Trial Costs	\$65,913.20	\$96,916.37
Bank Charges	\$989.92	\$687.73
Eway Web Active Fees	\$40.20	\$0.00
Insurances	\$2,030.93	\$2,569.41
PayPal Charges	\$2.74	\$285.70
Postage	\$414.75	\$753.10

Profit and Loss: Year ended June 2013 cont.

Expenses cont.	June 2013	June 2012
Printing	\$663.58	\$560.64
Office Supplies	\$484.30	\$932.21
Computer Programs	\$40.70	\$339.60
IT System Maintenance	\$11,297.25	\$0.00
Telephone	\$815.39	\$808.72
Other Expenses	\$160.00	\$46.62
Travel & Accommodation	\$8,732.54	\$5,246.03
Gifts & Awards	\$709.45	\$1,073.95
Educational Products	\$0.00	\$2,498.50
Resource Directory Project	\$0.00	\$6,315.20
Wages & Salaries	\$15,252.64	\$11,723.48
Superannuation	\$1,581.42	\$601.25
Workers Compensation	\$175.00	\$199.86
Publishing & Printing ReachOut	\$5,176.38	\$4,915.82
Postage for ReachOut	\$705.80	\$0.00
Total Expenses	\$136,062.60	\$169,614.93
Operating Profit/(Loss)	(\$41,679.94)	(\$51,690.73)
Other Income	\$0.00	\$0.00
Net Profit/(Loss)	(\$41,679.94)	(\$51,690.73)

Balance Sheet as at 30 June 2013

Assets	
General Cheque Account	\$34,045.19
PayPal Account	\$19.48
Investments	
Macquarie Cash Management Account	\$7,882.74
Macquarie Term Deposit - Matures 8/10/2013	\$32,370.71
CBA Cash Investment Account	\$49,705.19
Term Deposit - E Pinkerton Matures 19/5	\$5,000.00
CBA Term Deposit Matures 19/8/13	\$114,169.18
Total Assets	\$243,153.53
Liabilities	
Current Liabilities	
Gold Supporters in Advance	\$125.00
Silver Supporter in Advance	\$45.00
Bronze Supporter in Advance	\$120.00
Total Liabilities	\$290.00
Net Assets	\$242,863.53
Equity	
Retained Earnings	\$284,543.47
Current Earnings	(\$41,679.94)
Total Equity	\$242,863.53

Audit opinion (The full audit report can be viewed on the ATSS website or provided on request.)

In my opinion:

1. The accounts of the Australasian Tuberous Sclerosis Society Inc are properly drawn up so as to provide a true and fair view of the state of affairs as at 30 June 2013 and present fairly the results for the year ended on that date.
2. The Australasian Tuberous Sclerosis Society Inc has maintained proper accounting records and books during the period covered by the audit.



Rachel Goddard
Chartered Accountant
Turramurra

9 August 2013

Financials - key messages

- This year's operating loss of \$41,679.94 was due to more than \$60,000 of accumulated funds being provided to continue funding of the topical rapamycin clinical trial. Excluding this payment, ATSS made a surplus of over \$20,000 towards our future activities.
- ATSS has approximately \$170,000 as true reserves, ensuring that the organisation can survive a downturn in grants and donations. These reserves form a portion of our retained equity, the remaining consisting of:
 - :: \$5,000 set aside to fund the perpetual Elizabeth Pinkerton memorial award
 - :: Approximately \$60,000 still to be paid for the topical rapamycin clinical trial
 - :: Approximately \$8,000 budgeted for future website maintenance as remaining funds from original project grant
- The following grants were received during the year:
 - :: \$450 – received from Novartis on International Rare Disease Day
 - :: \$8,000 – received as an educational grant from Novartis used to fund the 2012 conferences in Brisbane and Melbourne
 - :: \$1,380 – volunteers grant from the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) used to cover expenses incurred by ATSS volunteers
 - :: \$11,380 – received from FaHCSIA under the National Disability Conference Initiative and used to fund travel grants and audio visual costs at the 2013 ATSS Family Conference in Perth.
 - :: \$8,374 – received from LotteryWest to fund the 2013 ATSS Family Conference in Perth
 - :: \$15,000 - received as an educational grant from Novartis used to fund the 2013 ATSS Family Conference in Perth

Community fundraising

Our work is made possible by the support of our donors and fundraisers. Major fundraising efforts during this year included:

- ⌘ Riversdale Golf Club in Victoria raised more than \$6,900 through the efforts particularly of Caroline Cox and Catherine Catlow
- ⌘ Genesis Gym Blacktown raised more than \$2,500 through the efforts of their personal trainers and Hayley Hill
- ⌘ Elliott Cunnew raised \$1,100 from friends and family by running in the Foster Triathlon in honour of his daughter Amelia who has TSC
- ⌘ Coles 'Click for Community' campaign on Facebook raised \$1,000



Our work with pharmaceutical companies

During this year, ATSS has collaborated with Novartis Pharmaceuticals in a number of ways:

- A total of \$23,450 received in grants towards ATSS educational events held in Brisbane and Melbourne in 2012 and Perth in 2013
- Clare Stuart's travel to conferences in Naples, Italy and Washington, DC, USA was sponsored by TSC International from a grant from Novartis
- ATSS is a member of the steering committee for the review of the Working Together Guide for patient organisations and pharmaceutical companies. This guide is a joint project of Consumers' Health Forum and Medicines Australia (a pharmaceutical industry group) and Clare Stuart receives a modest sitting fee for this work
- Clare Stuart volunteered her time as a member of the steering committee for the Health Consumer Advocacy group. Events held by this group are financially supported by Novartis and Pfizer.

ATSS representatives meet regularly with staff from Novartis to keep up to date on their work with new medicines for TSC. The ATSS Policy on Working with Pharmaceutical Companies describes how ATSS maintains its independence and integrity. This policy can be viewed on the ATSS website or provided on request.

NetApp's Operation Lend a Hand

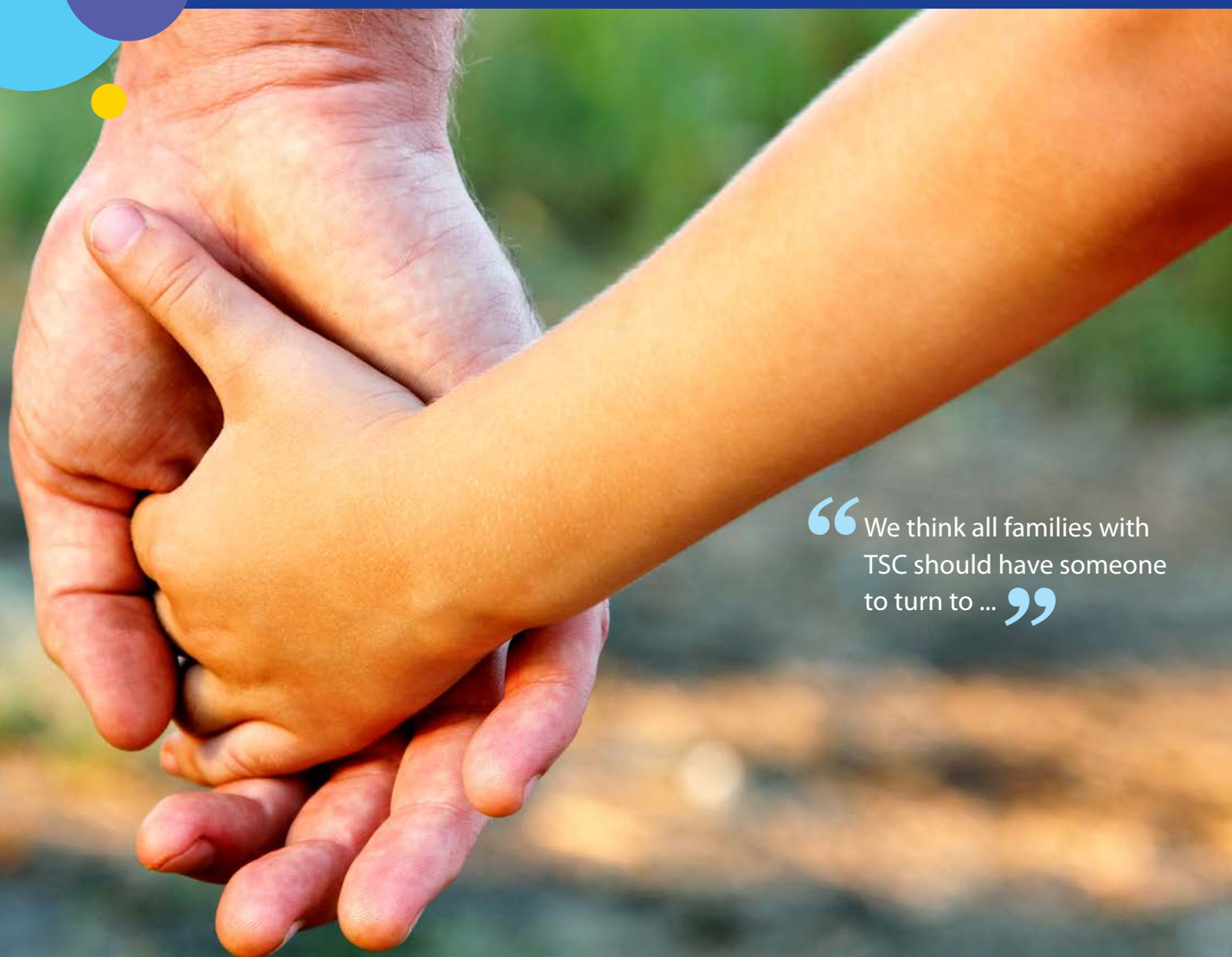
ATSS was proud to nominate Leanne Park, whose son Luke has TSC, to be the beneficiary of NetApp's Operation Lend a Hand. Leanne's house received a makeover from NetApp's staff using their volunteer leave. The project was the brain child of NetApp staff member Elliott Cunnew, father to Amelia, who has TSC.





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Incorporation no. Y 07116-42
Registered Charity CC25313
CFN 13968

Donations of \$2 and over
are tax deductible



“ We think all families with
TSC should have someone
to turn to ... ”