



## President's Report

*Sue Pinkerton, ATSS President, 2010/11*

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The 30th President's Report is an opportunity to reflect on the developments and success of the past year and acknowledge future challenges which will provide the vision for the activities of the ATSS.

The 30<sup>th</sup> AGM is also a timely opportunity to reflect on the beginnings of the ATSS and acknowledge the vision and determination of a small group of friends and relatives led by Mrs Lynn McKinnon (nee Wilson) in Bulli, NSW, who first met officially in 1981. With limited resources but oodles of energy and good will and supportive friends Lynn was in contact with 17 TS families. Without the advantage of today's social media, news of this support group spread throughout Australia by letter writing and stories in local newspapers. In December, 1984, I too read a news article about Tuberous Sclerosis in the local paper and made contact with Lynn, just after my 7mth old daughter Elizabeth was diagnosed with TS.

So, speaking from personal experience, and on behalf of all families who benefit from the services and support of the ATSS I express my appreciation and gratitude to Lynn Wilson, her daughter Tracey, and her family and friends who established the ATSS 30years ago.

The past year has presented a number of noteworthy achievements but also highlights the need for ATSS to respond to the ever increasing opportunities for growth.

In 2010 the Committee determined to raise \$200 000 as the major fundraising goal in order to fund a trial of a topical form of Rapamycin which would benefit all TSC affected people with facial angiofibromas. Thanks to the generosity of many people throughout Australia, with particular thanks to the ATSS Fundraising Friends, this target was reached during the 30<sup>th</sup> Anniversary Gala Dinner in May. These funds represent the interest and keenness of so many people for the development of a topical treatment instead of the current treatment with laser therapy. So, it is with great pride and gratitude that I acknowledge the generosity of all those big hearted people who donated their money, time and efforts to reach the target \$200,000 so quickly. Plans for implementation of this project at Sydney Children's Hospital, Randwick are in progress, with commencement of the trial due in February 2012.

Another 30<sup>th</sup> Anniversary of ATSS celebratory event is the “Riding the TSC Wave” Family and “Surfing the mTOR Wave” Medical Conference to be held at SCH on the weekend of 8<sup>th</sup> & 9<sup>th</sup> of October. Arrangements for these meetings are well underway with 3 international TSC experts accepting the invitation to present: Drs David Franz, Petrus DeVries and Vicky Whittemore; Along with Australian experts highlighting aspects of TSC, the programme promises an exciting weekend focussing on providing world class information, knowledge and understanding through sharing stories and expertise. Committee member, Clare Stuart is facilitating the planning and production of the conference liaising with ATSS medical advisors, Drs David Mowat and John Lawson and SCH staff. ATSS has received an educational grant of \$30 000 from Novartis and a grant from the Department of FACHSIA to provide travel assistance for families with TSC affected members to attend the conference.

In July 2011, both Clare and I attended the TS international meeting in Washington DC, followed by the 3 day Summit on Drug Discovery in TSC and Related Disorders. Travel and accommodation expenses were sponsored by Novartis for representatives from over 20 countries, including the ATSS regional contact in New Zealand, Sheryl Brasell. Australia was well represented as Clare facilitated part of the TSi meeting and I was honoured to be one of 3 people at the scientific meeting to tell their TSC story. Becoming active participants in the re invigorated TSi group is beneficial for all TSC families as resources will be shared , research can be coordinated and support for all groups worldwide is possible. We discovered in discussion with other national representatives that the issues experienced by families in Australia are common to many other countries. Meeting the needs of TSC affected families is a global issue.

A successful collaboration with Epilepsy Action resulted in a Top of Mind meeting in Brisbane last November with 25 people attending the TSC sessions. Another meeting is to be held on November 5 in Brisbane thanks to Epilepsy Action and interested Brisbane professionals including Drs Kate Riney, Stephen Malone and Professor Michael Gabbert.

During the Annual General Meeting the inaugural Elizabeth Pinkerton Memorial Award will be awarded to a professional who has made a considerable contribution to improving the lives of TSC affected people and their families. This will be an annual award presented at each Annual General Meeting.

Of course the regular activities of ATSS continue to provide information and support to families throughout Australia and New Zealand.

- Publication of Reach Out is now available online; the Committee was interested to note that few people have chosen to receive an electronic copy of this biannual preferring to receive the hard copy by mail.
- The ATSS Facebook group is proving to be a popular forum for discussion with families affected by TSC, with nearly 200 members.

- The 1300 phone service is still available as is the email contact for other enquiries.
- Regional coordinators organise social events to connect TSC families locally

Fundraising for the Topical Rapamycin Project certainly caught the interest of many families and friends throughout Australia; however, it would be remiss of me not to mention one group in particular. I refer to the Fundraising Friends of ATSS. This group of 6 people plus Deb Duffy, Hayley Hill and Sue Pinkerton organised 4 functions in the past year: a Sportsmen's Lunch, a Garage Sale, Bunnings barbeque and the very successful 30<sup>th</sup> Anniversary Dinner to raise over \$100 000 towards the ATSS research project. On behalf of all members I would like to express sincere thanks to this group of generous volunteers.

This report has mentioned a variety of activities which indicate the commitment and dedication of the volunteer ATSS Committee to improve the outcomes for people affected by TSC. I am very grateful to the Committee members who continue their involvement often in spite of personal difficulties. Special acknowledgement is due to Hayley Hill who has maintained the clerical and administration aspects of organizing the ATSS with energy and enthusiasm. Her title is Treasurer and Membership Secretary but Hayley is really the engine room of this organisation. David Matheson as editor of the journal, ReachOut continues to strive to provide articles of interest and relevance to ATSS supporters.

Unfortunately, Leanne Park, a Committee member since 2003 and Vice President since 2005 who undertook many administration duties and managed the information requests for many years is not standing for re election. I thank her and her family for their dedication and commitment to the work of ATSS.

In closing I would like to offer my sincere thanks to every ATSS Committee member who continues to serve TSC families by their voluntary work for the ATSS often despite their own personal difficulties. Appreciation is also extended to:

- The Honorary Medical Advisors, Drs David Mowat and John Lawson who are committed to working with ATSS to improve the outlook for families. Without their support the work of ATSS would be more challenging.
- The Honorary Auditor: Rachel Goddard
- The Honorary Legal Advisor: Gerard O'Donnell



The coming year brings promise and hope for the future treatment of TSC symptoms in affected people. If the giant leaps in knowledge which have occurred in the last 30 years are an indication of progress then the commitment of scientists, researchers and clinicians ensures that the future for newly diagnosed children is increasingly bright.



## Treasurer's Report

*Hayley Hill, ATSS Treasurer, 2010/11*

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During 2010-2011 I have been assisted in maintain the ATSS Accounts by our volunteer bookkeeper, Christine Cook. ATSS thanks Chris for her expertise and advice regarding the ATSS Financial Accounts.

ATSS financial accounts were audited by Rachel Goddard (ACA). ATSS would like to thank Rachel for volunteering her time once again to audit the accounts. A copy of the financial accounts follows this report.

This financial year has resulted in a profit for ATSS of \$189,414.41. This is primarily due to the amazing fundraising towards the Research & Development of the Rapamycin Topical Cream.

ATSS received many generous donations over the past year. The breakup of the donations received for this financial year 2010-2011 are:

General Donations	\$ 10,485.00
Rapamycin Topical Cream Research Fund	\$ 78,990.62

The total of the Rapamycin Topical Cream Fund including all donations from the Gala Dinner comes to a total of \$226,005.83 as at 30 June 2011.

ATSS currently holds the following term deposits:

CBA - Elizabeth Pinkerton Memorial	\$ 5,000.00
CBA Term Deposit maturing 19/8/11	\$102,937.58
CBA Term Deposit maturing 30/12/11	\$100,000.00
Macquarie Term Deposit maturing 12/10/11	\$ 28,270.66

ATSS general expenses were up this year due to increased receipting & correspondence, printing of new brochures and banners for advertising. There was also an Australia Post price increase.

ATSS financial funds could not grow without the continuous help and support from its generous members, families and friends. Thank you.

Rachel Goddard, ACA PO Box

856 Turrumurra NSW 2074

## **Auditor's Report**

### **To the Members of the Australasian Tuberous Sclerosis Society Inc**

#### **Scope**

I carried out an independent audit to enable me to express an opinion on the financial report. My audit provides reasonable assurance to members of the Australasian Tuberous Sclerosis Society Inc that the financial report is free of material misstatement.

My audit included:

- Evaluation of the accounting policies and significant accounting estimates used in preparing the financial report
- Examination of a sample of the evidence that supports the amounts and other disclosures in the financial report

My opinion does not provide assurance:

- About the future viability of the Australasian Tuberous Sclerosis Society Inc
- That they have carried out their activities effectively and economically
- About the effectiveness of their internal controls

#### **Audit independence**

The audit has been conducted independently and complies with all the applicable independence requirements of Australian ethical pronouncements.

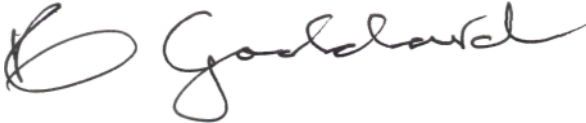
Australasian Tuberous Sclerosis Society Inc is responsible for the preparation and the presentation of the accounts and the information they contain. I have conducted an independent audit of these accounts, being the Profit & Loss Account and Balance Sheet for the year ended 30 June 2011 in order to express an opinion to the members.

The audit opinion expressed in this report has been formed on the above basis.

**Audit opinion**

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 2011 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.

A handwritten signature in black ink, appearing to read 'Rachel Goddard', written in a cursive style.

Rachel Goddard Chartered  
Accountant Turramurra

13 August 2011



## Membership Report

Hayley Hill, ATSS Membership Secretary, 2010/11

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As of 30<sup>th</sup> June 2010 the ATSS Membership Database held a total of 563 details of past & present Members. There were 21 new memberships for 2010-2011

From the details on the database **277 are Active / Financial Members**. 286 are Non-Active whereby the contact details are unknown or they have not renewed their support.

<b>Honorary Members</b>	23
<b>Organisations</b>	13
<b>Professionals</b>	85
<b>Families</b>	156*
<b>Total</b>	<b>277</b>

131 Families renewed their membership for 2010-2011. 25 did not renew  
Only Financial Members receive a copy of Reach Out, published twice a year

### The ATSS Supporter Model

During 2011, ATSS introduced three levels of annual support, replacing the single, \$25, membership fee. This new model has been introduced to both recognise and encourage donations along with membership fees. Expanding the yearly revenue of ATSS is an important way the organisation can grow.

There are 3 levels of support to choose from:

- Bronze \$25
- Silver \$50
- Gold \$100.

From each supporter level \$5 is taken as a membership and the remaining amount a donation. All donations \$2 and over are tax deductible.

As at 30<sup>th</sup> June, 42 families had already signed up as ATSS Supporters for 2011-2012. It is expected that approx 96 more are still to renew their membership under this new model.

ATSS is grateful to those members who have renewed membership by becoming supporters promptly for this year and welcomes new supporters.

ATSS now has *ReachOut* available electronically to financial Members for 2011-2012. The choice to receive *ReachOut* electronically or by post can be made when signing up or renewing as a gold, silver or bronze supporter of ATSS.

A reminder notice for ATSS Supporters for 2011-2012 will be included in the next issue of *ReachOut* in November.

### Facebook

ATSS Facebook Group – Australasian Tuberous Sclerosis Society has 161 members.

This is another communication network that ATSS uses to provide support for families affected by TSC.

The ATSS Committee hopes that you and your families find *ReachOut* and the website [www.atss.org.au](http://www.atss.org.au) very informative. Feedback and suggestions are always welcomed.



where will  
we be  
**30**  
years  
from now?

