



President's Report

Sue Pinkerton, ATSS President, 2008

The 2007/08 term has been marked with a number of outstanding achievements for ATSS.

The major event was the Scientific and Family conference held at Sydney Children's Hospital, Randwick in November 2007 titled "From Pathways to Therapy". This event resulted from collaboration between the medical advisors of ATSS, Drs. David Mowat and John Lawson, Sue Pinkerton and the Committee of ATSS. The Governor of NSW, Marie Bashir, herself a doctor, opened the Conference and commended both the organisers and the families who live with TSC for their commitment and dedication.

The ATSS DVD "You are Not Alone", funded by Quota and produced under the direction of Committee member David Matheson, was launched at the Conference. This is an excellent resource and is available on request from ATSS. An excerpt placed on YouTube website has been seen nearly 1000 times and been given a 5 star rating.

The ATSS national Picnic Day was held in several locations in November and again provided opportunities for TSC affected families to meet others in similar situations.

The ATSS Diagnostic Genetic Laboratory based at the Prince of Wales hospital, Randwick, Sydney completed its final collection and sampling in June 2008. Australia now has a TSC genetic testing facility thanks to:

- The vision of Dr. David Mowat and the ATSS Committee
- The generous donors who made this possible
- The Director and staff of South East Area Laboratory Services

The ATSS committee maintained its commitment to provide opportunities to support families by holding a Seminar Day at last August. The 2008 Seminar Day is at Westmead Children's Hospital and families from Westmead and Sydney Children's Hospital Randwick were invited to attend. This was achieved with the cooperation of the Neurology and Genetics departments from both Children's Hospitals for which ATSS is grateful. An important part of the mission of ATSS is to provide information and opportunities to meet others with TSC.

During the past 8 months, the Committee has participated in Strategic Planning under the direction of Clare Pinkerton with the assistance of Carol Ireland CEO from Epilepsy Action. This is an essential process in order for ATSS to evaluate the effectiveness of its work and make plans for future directions to meet the needs of TSC affected families throughout Australia. A process of reassessing the Regional Contact role also took place. The people willing to actively contribute to the work of ATSS in supporting families throughout this huge land will be appointed at the AGM.

While the ATSS Committee is a completely voluntary group, it prides itself on the variety and number of activities achieved. Every member of the Committee should feel very proud of the consistent and excellent standard of ATSS activities.

On behalf of every TSC family who has benefited from contact with ATSS I would like to thank the members of the ATSS Committee. I would especially like to thank,

- Leanne Park who is the voice at the other end of the 1300 phone number for all her energy and work for TSC affected families who require information, a listening ear or an empathetic response. She also does an excellent job maintaining registrations for any ATSS activities.
- Clare Pinkerton has directed the Strategic Planning process with professional expertise which can only benefit the future growth of ATSS. She has had numerous meetings with key stakeholders, collated all the data and produced a document to guide ATSS for the next 3-5 years.
- David Matheson for producing Reach Out, the ATSS biannual journal; David is also a meticulous keeper of the meeting minutes and is always ready to offer his services wherever they are needed.
- The treasury team of Belinda Humphrey and Janiffer Reynolds- the ATSS financial documents are scrupulously maintained.
- The Committee members, Narelle Kerr and Sally Nicholson who initiated Fundraising projects.

What does the future hold for ATSS? The Strategic Planning experience has highlighted the need to attract other volunteers with specific skills to join the ATSS committee. It has also highlighted the value of the work undertaken by ATSS. The strategic plan is the topic of one of the sessions at the 2008 Seminar Day.

I hope that during the coming year opportunities to develop connections with professionals in other states and capital cities will be pursued as ATSS strives to meet the needs of all families affected by TSC throughout Australasia.

This concludes the 27th President's Report.





Treasurer's Report

Belinda Humphrey, ATSS Treasurer, 2008

Over the past twelve months ATSS has been able to successfully fund and complete three main projects, namely the:

- Production and distribution of the ATSS DVD
- Australian TSC Medical and Family Conference in November 2007
- Establishment of the ATSS Genetic Diagnostic Laboratory (SEALS), completed in June 2008

Each of these major projects would not have been possible without the financial assistance and tremendous generosity of members, supporters, government and private sectors.

The 2007/2008 Financial Accounts reflect these expenses. Refer to the accounts for Research Lab Costs, Aust Medical Conference and Educational Products. The 2007/2008 financial year for ATSS has resulted in an overall operating loss of \$38,640

The loss reflected in this financial year as the funds for many of these projects were collected during the previous financial year. Funding for the TSC DVD and the establishment of the ATSS Genetic Diagnostic Laboratory (SEALS) was supported by donations accumulated in the CBA Cash Management account and the Macquarie Bank Research Cash management accounts. A Financial Summary Report on the ATSS Genetic Diagnostic Laboratory (SEALS) is to be delivered at the AGM.

Memberships have increased by 30% over the past twelve months. Membership fees provide assistance to publish and print our journal, Reach Out, distributed twice a year and to the general running costs of the society. Thank you to all those current members who did renew their membership for 2007/2008 and to past members rejoining, as well as new members contacting and joining ATSS for the first time. Please check your membership status for this next financial year as non financial members will not receive Reach Out due to substantial production costs. Membership renewals can be made at any time during the year and our Membership secretary can assist regarding your status.

ATSS received many generous donations and were allocated to the nominated project/s. Interest received from combined invested funds is reinvested and earning an effective rate of approximately 6.9%.

Each year ATSS submits proposals to various foundations to provide financial assistance for our Family Conference Weekend or Family Seminar Day. ATSS was successful and a grant was received from the Federal Department of FACS. ATSS wishes to thank the federal government for this generous grant and ongoing support to the Society.

ATSS continues to raise funds during the year from our promotional products. Support in the past from members, friends and families is well received and ATSS hopes that you can again contribute.

ATSS general expenses for phone (including teleconferencing), postage and office supplies decreased over the last financial year. Insurance costs for Business, Public Liability and Voluntary Workers remains fairly static. These policies are currently being reviewed to bring each of the three under one insurer, namely AON, to streamline renewals and to possibility reduce premiums.

Reach Out publication and printing expenses increased over the last twelve months due to an increase in copies printed and additional inserts in the last issue. A review has been noted at the last committee to examine cheaper ways to reduce these costs.

The 2007/2008 ATSS financial accounts have again been audited by our Honorary Auditor, Stefan Piechocki (MNIA – Public Practising Accountant). ATSS wishes to thank Stefan for volunteering his time to audit the ATSS accounts and to provide accounting assistance when necessary. This will be Stefan's last audit for ATSS as he is retiring from business. Requests for an auditor for 2008/2009 are under way. Any assistance or contacts then please contact the Society.

A copy of the Financial Accounts - Balance Sheet and Profit and Loss Statements, and the Qualified Auditor's Report for the 2007/2008 Financial Year follow this report. Please take a moment to read through the Financial Reports and trust you are pleased with our progress.

The ATSS treasury role has again been supported by Janiffer Reynolds, completing both the banking and receipting of all monies received by ATSS. Janiffer's efficiency and support is greatly appreciated.

At our last committee meeting I have indicated that I will step down from my role as treasurer and will assist in transitioning a new treasurer over the next 12 months. I have overseen the accounts for the past ten years and feel it is time to handover to another member or volunteer.

The great progress that ATSS has made to meet specified goals would not have been possible without your continual partnership, support and interest. ATSS is continuing to look for new ways to support different areas to those living with Tuberous Sclerosis Complex.





Membership Report

Leanne Park, ATSS Membership Secretary, 2007

As of 6th August 2008 the ATSS Membership Database holds a total 545 Members.

This can be broken up as:

- 370 Active – meaning that contact details are correct
- 26 Honorary Members
- Financial members for 2007/8 totaled 147
- Financial members to date for 2008/9: 96. I expect that 60 -70 members are still to renew their membership for 08/09.

Renewal notices were sent with Reach Out in May and apologies are given for a printing error stating that it was a Reminder. A reminder notice will be forwarded in the next edition of Reach Out due November 2008.

I would like to send a warm thanks to those of you who renewed your membership so promptly and welcome our new Members – some of whom I have had the pleasure of talking to on the phone. The ATSS Committee hopes that you find Reach Out and the website (www.atss.org.au) informative and beneficial and remind you that your feedback and/or suggestions are always welcomed.





SEALS Genetic Testing Laboratory Project Financial Summary Report

Funds Received

Funds Received for Laboratory Project	\$110 895.26
<i>Total of all donations and fundraising activities</i>	
Interest Received on Funds	\$ 6 643.32
<i>Macquarie Cash Management Account</i>	
ATSS Contribution	\$ 28 547.32
<i>From funds raised prior to this project's inception</i>	
Total	\$146 086.00

Costs

Scientist Salary 1	\$ 83 304.00
Counsellor Salary 2	\$ 29 592.00
Consumables	\$ 33 190.00
Total	\$146 086.00

Balance of funds in Research Account (Macquarie Cash Management)
as at 30/6/2008: **\$30 608.24**

