



## 29th Annual General Meeting

22nd August, 2010

### Agenda

1. Opening remarks and Welcome
2. Apologies
3. Minutes of 28th Annual General Meeting, August 9, 2009
4. Business arising from minutes
5. Reports
  - President
  - Treasurer
  - Membership Secretary
6. Election of Office-bearers for 2010/2011
  - All positions declared vacant and appointment of returning officer- Ross Pinkerton
  - Election of officers
7. General business
  - Acceptance of revised ATSS Constitution
  - Appointment of Medical Advisors and Honorary positions.
  - Appointment of Auditor
  - Appointment of Public Officer
  - Appointment of Regional contacts
8. Close of meeting



## President's Report

*Sue Pinkerton, ATSS President, 2009/10*

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The following report is the Annual President's Report for the 29th Annual General Meeting of the Australasian Tuberous Sclerosis Society Inc.

The ATSS Mission drives the activities of this organization:

- To provide access to current information and resources
- To help TSC families build relationships and support networks
- To connect Australia and New Zealand with worldwide resources.

Consequently the range of activities is broad.

To prepare for the 30th Anniversary of the ATSS the Committee has conducted a review of the Articles of Association to align this document with the requirements of the NSW Department of Fair Trading. This has been a lengthy process and the new Constitution will be presented to the 29th AGM for acceptance. On behalf of all ATSS members I thank Hayley Hill for preparing the document.

During the past year, activities which have supported TSC affected families have been held.

In August, the annual Seminar Day was held at Sydney Children's Hospital, Randwick. This attracted a number of newly diagnosed families who have benefitted from services developed in collaboration with the ATSS medical advisors, Drs David Mowat and John Lawson.

In November, TSC families in Western Australia had the opportunity to attend the Top of Mind conference which was held in collaboration with Epilepsy Action in Perth. Information sessions covering neurological, genetics and renal issues in TSC were very popular. A major benefit from this meeting was the opportunity for parents and affected family members to meet each other and develop connections in their own city. ATSS is grateful to the presenters who provided information and guidance to the families who attended. ATSS is collaborating with Epilepsy Action to hold a Top of Mind conference in Brisbane in November 2010 in the ongoing efforts to meet the needs of TSC affected families in Queensland.

The annual ATSS Family Event day was held in May in various venues throughout Australia. These days are organized by the ATSS regional representatives in their local areas. The Sydney gathering was held at a Ten Pin Bowling complex which was a change from the regular picnic.

The Committee is aiming to provide the November issue of Reachout on line for all interested people to access. This is a major breakaway from the long term stance of only financial members receiving a copy of Reachout. The ATSS website now also has facilities for direct donations to be made for specific activities. It is hoped that the ease of donating will encourage many to provide financial support.

As President of ATSS I have attended a number of professional events during the year. These are opportunities to raise the profile of ATSS and also raise the level of awareness of Tuberous Sclerosis Complex. During Genetic Disorders Awareness Week last September I was interviewed for Sky News, this led to another interview during a Business program on Sky, raising awareness of TSC and of course the profile of the Australasian Tuberous Sclerosis Society. Collaborating with Epilepsy Action to develop the Perth Top of Mind Conference was another opportunity to cement relations with other professional groups. In January I presented an information session at the Orientation Day for new Genetic Fellows at Randwick. This was a great opportunity to develop relationships with professionals who will be working with TSC affected families.

Committee member, Clare Pinkerton attended the TSC Research Conference "From DNA to Human Therapies" in Chicago in September 2009 with Gayathri Parasivam, the Genetic Counselor from Sydney Children's Hospital and Coordinator of the TSC Clinic. This was a learning experience for them both as they realized the potential for research into a wider range of areas due to the current knowledge of TSC; thus raising the level of interest and financial support into TSC related research throughout the world. Their presence on the international scene also added weight to the existence of ATSS.

In August I attended the SEISMIC Symposium in Sydney, a meeting for neurologists and representatives of consumer groups throughout Australia to develop policy guidelines for governments to improve outcomes for people with epilepsy.

In Sydney and now Brisbane TSC affected families have the option of receiving care and management through the multidisciplinary teams at the TSC clinics. ATSS thanks Dr Kate Riney for her initiative in providing this model of care for some Queensland families. ATSS continues to appreciate the team of professionals who conduct the TSC Clinic at Sydney Children's Hospital, Randwick. Dr Lawson instigated the Australian participation in the worldwide trials of everolimus (rapamycin) in June 2010.

To continue with the ATSS commitment to research, a fundraising project was undertaken this year. The goal is to raise \$200 000 to fund the research and development of a topical form of the drug rapamycin to be available to treat facial angiofibromas. It is hoped the successful trials will eliminate the need for ongoing painful laser treatment. The trials will be undertaken at the Sydney Children's Hospital with the support of Drs Mowat and Lawson. This project would not be possible without the support of a great number of people. ATSS is grateful to all who have donated to this cause, to the ATSS members throughout Australia who have organized email appeals, held functions and supported this project. In particular, I would like to acknowledge a group of people who have formed the Fundraising Friends of ATSS and are working tirelessly to organize fundraising events in Sydney. A Gala Dinner for 300 next March will also celebrate the 30th Anniversary of the foundation of ATSS.

Staying active for 30 years is a major achievement for a small, not for profit, non government organization relying on a voluntary workforce. In 2011 the other organized event to mark the 30th anniversary will be a Medical and Family Conference in collaboration with the team from Sydney Children's Hospital.

This report has mentioned a variety of activities which indicate the commitment and dedication of the 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.

Of course living with TSC is never smooth sailing, as all of you know. My family and I experienced our own tragedy this year with the death of our daughter and sister Lizzie, who has always been the inspiration for the family involvement in ATSS. I would like to thank our friends in ATSS who expressed sympathy and passed on their condolences at our terrible loss.



AS ATSS approaches the fourth decade since its foundation I envisage tremendous growth in the knowledge and management of TSC. Due to the advocacy of ATSS medical advisors Drs David Mowat and John Lawson, Australian medical professionals are becoming more aware of the need to provide comprehensive services for TSC affected families. The beneficiaries of this interest and involvement are the TSC affected families throughout Australia.

This concludes the 29th President's report.



## Treasurer's Report

*Hayley Hill, ATSS Treasurer, 2009/10*

ATSS Accounts have been maintained by our volunteer bookkeeper, Christine Cook and the Treasurer Hayley Hill. ATSS thanks Chris for her expertise and advice regarding the 2009-2010 ATSS Financial Accounts.

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

This financial year has resulted in a profit for ATSS of \$86,551 due to the major fundraising project launched in January 2010.

ATSS received many generous donations over the past year. The breakup of the donations received as at 30th June 2010 are:

Rapamycin Topical Cream Research Fund                      \$74,363

Memorial Donations In Memory of Kenneth Marriot              \$1,725

The family of Kenneth Marriott have requested that this amount be donated to the Rapamycin Topical Cream Research Fund. This will be accounted for in the next financial year accounts.

Memorial Donations In Memory of Elizabeth Pinkerton      \$5,071

A Term Deposit was established in May 2010 for 12 months \$5,000 @ 6.0%. As discussed at the May Committee Meeting an annual award will be made in Memory of Lizzie Pinkerton to a professional who contributes to an improvement in services and outcomes for TSC affected families.

As at 30th June ATSS held 2 other Term Deposits.

Macquarie Bank has \$26,835 @ 5.35% maturing October 2010.

Commonwealth Bank has \$25,000 @ 6.3% maturing in October 2010.

ATSS general expenses for postage and office supplies increased this financial year due to the increase in receipting donations and correspondence. Insurance costs were reduced due to renewing with the one Insurance Company- AON.

ATSS funds grew over the last financial year. This growth would not have been possible without the continuous help and support of members and friends.





## Membership Report

*Hayley Hill, ATSS Membership Secretary, 2009/10*

As of 30th June 2010 the ATSS Membership Database held a total of 564 details of past & present Members. There were 14 new memberships for 2009-2010.

From the details on the database 393 are Active/Financial Members. 171 are Non-Active whereby the contact details are unknown.

Honararies	23
Organisations	14
Professionals	90
Families	266
<b>Total</b>	<b>393</b>

135 Families renewed their membership for 2009-2010. 131 did not renew. Only Financial Members receive a copy of Reach Out, published twice a year

As at 30th June, 59 Families had prepaid their Membership for 2010-2011. It is expected that approx. 80 more are still to renew.

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

ATSS is aiming to have ReachOut available electronically to financial Members for 2011-2012. More details on this in the next issues of ReachOut.

A reminder notice for ATSS Membership Renewal for 2010-2011 will be included in the next issue of ReachOut in November. Members will be asked to update their details with their email address also opting to receive the ReachOut journal either by email or post. This will help reduce the printing and postage costs for ATSS.



In 2010 ATSS created a Facebook Group - Australasian Tuberous Sclerosis Society. This has 141 members. This is another avenue 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.