



## President's Report

*Sue Pinkerton, ATSS President, 2007*

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During the past year the Australasian Tuberous Sclerosis Society has had four exciting projects underway. It has taken the commitment and energy of many people to develop these projects. The dedication and time required for this work is even more valued as so much of the work is done by voluntary members of the ATSS Committee who are living day to day struggles with their TSC affected family member.

It is with pride in our small but dedicated group that I describe the four projects:

**The National Picnic Day** held on Sunday November 26th 2006 was the first Australia wide attempt at uniting TSC families. While numbers were small, each Regional Coordinator reported a great sense of achievement in reaching out to other TSC families. Judging from the many photos taken, all who attended were pleased that they had made the connection.

The second project has come to fruition after a number of years of fundraising. The ATSS Committee has produced **a DVD of people sharing stories of the impact of TSC**. The DVD was made to support families and to increase community understanding of TSC. The DVD was produced with funds raised by Committee member Dawn Bowra and the Quota Clubs of southern NSW. The DVD will be launched later in the year.

The third project, and these are not listed in any order, is the establishment of the **only TSC genetic testing facility in Australia**. ATSS in conjunction with the South Eastern Area Laboratory Service (SEALS) at Prince of Wales Hospital, Randwick, under the direction of Dr. Michael Buckley signed the agreement in December 2006. Using funds donated over the past 25 years, plus two very large donations from TSC affected families the laboratory will be able to determine a genetic diagnosis of TSC from a sample of blood. Eventually this service will be available to any family needing it. Presently while laboratory protocols are established samples are being collected from TSC affected people in NSW. Both donors to the genetic testing laboratory requested anonymity, but needless to say the TSC community is very appreciative of their incredible generosity.

Last but definitely not least is the exciting news that **the first ever TSC Scientific meeting** is to be held at Sydney Children's Hospital, Randwick on 3rd November. Two international TSC experts, Prof. David Franz and Dr Chris Kingswood, have accepted the invitation to present with local specialists, addressing some of the many issues in "Advances in Tuberous Sclerosis from Pathway to Therapy." A concurrent Family Conference will be held over the November weekend with families from Australia and New Zealand meeting and benefiting from the opportunity to learn and share with each other and the TSC experts.

The ability to develop and conduct these major works is a testament to the spirit of the TSC community in their generosity of time, effort, money and commitment. I would particularly acknowledge Dr David Mowat, clinical geneticist and medical advisor to ATSS for his ongoing interest and advocacy on behalf of ATSS and its mission. David attended the international TSC research meeting in Rome earlier this year. He has also been instrumental in driving the establishment of the genetic testing laboratory.

David has also worked with the President of ATSS and Dr John Lawson, child neurologist and medical advisor to ATSS, to organize the Scientific Meeting in November.

Raising funds is a constant challenge and ATSS has again been successful in obtaining a grant from FaCSIA (Federal Department of Families, Community Services and Indigenous Affairs) to assist families with expenses incurred in attending the Family Conference. In the last financial year financial assistance was also received from St George Bank for last year's Family Conference. ATSS continues to rely on donations for most of its activities.

Plans for the future include:

- Distribution of the new DVD to all families on the ATSS mailing list.
- A national Picnic Day in November 2007
- The possibility of a Family Camp in 2008, depending on the success of a funding application.
- The SEALS laboratory through its testing stage and fully operational for all TSC families.
- The fundraising initiative for 2007 is a donation request to pay for an hour of a scientist's time. These requests will be distributed by the committee members and regional contacts.

ATSS Committee meetings are accessible to all committee members throughout Australia using teleconferencing to reduce the impact of distance and geographic isolation. Maintaining the business aspect of ATSS is an ongoing accomplishment and I thank all the Committee members and especially:

- the "treasury department" of Belinda Humphrey and Janiffer Reynolds,
- Leanne Park for her organizational and secretarial skills
- David Matheson for his commitment to producing Reachout, for his accurate recording of minutes and for planning and negotiating the development of the DVD.
- To Clare Pinkerton for web development and maintenance of electronic communication
- Every Committee member and Regional contact for their ideas and efforts to contribute to the work of ATSS.



This concludes the 26th Annual President's Report.



## Treasurer's Report

*Belinda Humphrey, ATSS Treasurer, 2007*

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ATSS has once again maintained a positive financial position due to the tremendous generosity and support of both families and the community. The financial support has enabled ATSS to commit to four major projects that have either been completed in the 2006/2007 financial year or are continuing into the next financial year. These projects consist of the redesign of the ATSS image, namely the logo, newsletter, fact sheets; the production of our first Australian TSC DVD; the establishment of a genetic testing laboratory for TSC in Australia; and a scientific and family conference.

As mentioned in the 2005/2006 financial report the Golden Stave Foundation generously supported the redesign of the ATSS image, it also allowed ATSS to increase its exposure within the musical community.

The production of the DVD has been totally funded by the generosity of the Quota Clubs of NSW. Funds from our CBA Cash Management Trust will be used to make payment early in the 2007/2008 financial year.

The establishment of the genetic testing laboratory has been funded by two generous donors, along with accumulated ATSS funds that have been donated over the past twenty five years. This project will be completed with monies invested in the Macquarie Cash Management Trust in the coming financial year.

Arrangements for the Australian scientific and family conference are almost complete, however some registrations and expenses incurred for brochures and dinner arrangements appear in the 2006/2007 financial year. ATSS is still seeking funding from both government and private sectors, especially where there is an association to tuberous sclerosis.

In the 2006/2007 financial year ATSS has resulted in an overall operating profit of \$13,580.

Memberships fell in 2006/2007, decreasing by 21% when compared to memberships in the previous financial year. Your 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 2006/2007 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.

During 2006/2007 ATSS received many generous donations, an increase of 28%. In addition to these donations, monies have specially

been allocated to the Genetics Laboratory and these funds are being accumulated in the Macquarie Cash Management Trust. Interest received from combined invested funds is reinvested and earning an effective rate of approximately 5.45%.

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

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 rose by about 25%. These increases were due to an increase in phone charges, postage and office supplies. Teleconferencing for each of the 4 committee meetings has increased the phone charges, but an invaluable means of connecting both interstate regional contacts and committee members. Both insurance and publication expenses fell slightly. Insurance policies have remained the same, but a change in publisher occurred during the year.

The 2006/2007 ATSS financial accounts have again been audited by our Honorary Auditor, Stefan Piechocki (MNI – Public Practising Accountant). ATSS wishes to thank Stefan for volunteering his time to audit the ATSS accounts and to provide accounting and tax assistance when necessary.

A copy of the Financial Accounts - Balance Sheet and Profit and Loss Statements, and the Qualified Auditor's Report for the 2006/2007 financial year follow this report. A Compilation Report is also included to accompany the Committee's decision to fully depreciate all assets, ie Plant and Equipment, Registered Trademark and the Wheelchair Hoist. 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.

Both completed and current projects have met with our mission statement of supporting TSC families, educating and informing both health professionals and the community. Without your continual partnership, support and interest it will be difficult to continue to meet our goals. ATSS will inevitably benefit everyone in some way affected by Tuberous Sclerosis Complex and it is up to you to ensure ATSS can continue to make this happen.





## **Membership Report**

*Leanne Park, ATSS Membership Secretary, 2006*

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These membership numbers are as at 24<sup>th</sup> July, 2007

The ATSS membership database currently holds a total of 530 records; of this, there are 359 Active members, including 27 Honorary members

Financial Members

2006/07 - 123

2007/08 - 72

There are 2 payments received in advance

Reminder notices for membership renewal will go out in November's Reach Out and we expect increase current financial member figures.

