

# President's Report

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Sue Pinkerton, ATSS  
President, 2006

It is with great pleasure and pride that I present the 25th Annual President's Report of the Australasian Tuberous Sclerosis Society.

This past year has been a major period of growth for ATSS. Growth in services provided to families, growth in support from medical professionals, growth in recognition and above all growth in the strength of the ATSS Committee.

Remembering that the ATSS Committee is composed entirely of volunteers, without any paid staff, the achievements of this past year are outstanding.

Communication with members and TSC affected families continues through Reachout and the informative and popular ATSS website. The national phone number is used regularly by people needing to make personal contact.

I would particularly like to acknowledge the contribution of David Matheson, Editor of Reachout, and Clare Pinkerton, Manager of the ATSS website and email communications, and Leanne Park who receives and processes the information requests via the phone.

Following the Regional Training Day held in August last year, the regional contacts have been more focused and have accessed the Committee meetings via teleconferencing. It is hoped that Regional picnic days will be organized for the National TS Day, November 26.

Growth in support from the medical fraternity has come via the work and commitment of Drs. David Mowat and John Lawson. Both of these men have actively promoted TSC throughout their profession by addressing their colleagues on TSC issues. Dr. Mowat arranged for an international TSC expert, Dr. David Franz to address a group of specialists at Sydney Children's Hospital. Information about the drug, Rapamycin, and its ability to reduce angiomyolipomas in the kidneys and lungs is causing excitement amongst geneticists.

Major developments include:

- The national TSC Medical Meeting to be held in Sydney in November 2007 with a number of overseas experts sharing their knowledge with, we hope a good number of Australian specialists.
- The first ever Australian TSC Clinic for families was established this year at Sydney Children's Hospital. This clinic is held on the first Tuesday of every month. It is hoped that this will be a model for other Centres to follow. A member of the ATSS committee also attends the TSC Clinic to be available for families.
- A TSC information afternoon was held in June for families in the South East, Illawarra Area health region of NSW. This event was attended by a number of TSC families, many of whom had not made previous contact with ATSS. Dr Meredith Wilson is organising a similar event for families in Sydney West area towards the end of this year.



- It was during this information session that the possibility of establishing a TSC Genetic Testing Laboratory in Sydney was first mooted. While discussions are still being held, the financial commitment required from ATSS is considerable and supporting this exciting development will be a major stage in the life of ATSS.

Both Drs. Mowat and Lawson have been proactive in supporting TSC families, particularly in the South East, Illawarra Area health region of NSW.

Growth in recognition has been achieved from a number of ways:

- Addressing community groups and raising awareness of TSC has been facilitated by Committee members Dawn Bowra and Leanne Park and myself. Mrs. May Mills, a grandmother of a TSC grandchild also addressed a community group. Dawn has been tireless in her fundraising efforts through the Quota Clubs of NSW, successfully raising \$12 000. Leanne has supported Dawn in these endeavours and has addressed community groups in Sydney herself.
- These funds are for the production of an Australian TSC information DVD for families and GPs. I was pleased to receive the cheque at the Quota Club Conference where I gave a presentation on TSC.
- I was a guest speaker at the launch of Genetic Disorders Awareness Week in July which raised the profile of TSC.
- Earlier in the year a short DVD was produced featuring some Committee members and their families as a means of attracting funds and raising awareness. The DVD production was donated by a friend of Clare Pinkerton's, Aleks Rzadkowski.

To celebrate the 25th year of ATSS and to enhance awareness of ATSS, a graphic designer was commissioned to create a new symbol and image for ATSS. This new image was launched at the 2006 Family Conference. The new look extends to our website, corporate caps, brochures, banners, posters and information folders.

During 2006, ATSS also successfully applied for a number of grants available through the corporate and Government sectors. These funds increase the support offered to families, in particular those attending the Family Conference.

Grants have been received from:

- Lend Lease
- St. George Foundation
- Department of Families, Community Services and Indigenous Affairs.

This report wouldn't be complete without acknowledging the efforts of the committee members who complete their roles consistently and reliably. Each and every member of the committee is living with TSC. Despite some very challenging domestic situations the commitment and generous use of their skills and time continues unabated.

In particular, Leanne Park has made a great contribution to the organization of the Family Conference. She has provided all the secretarial support and has been the contact for all bookings and much of the catering.

Organising the Family Conference is a combined effort of all the Committee members, and on behalf of all ATSS members I thank them for their willingness to contribute their time and talents.

Once again, I would like to acknowledge my family and thank them for their patience, understanding and support offered to me.

I would also like to acknowledge the support, collegiality and friendship of Dr. David Mowat, honorary Genetics Advisor to ATSS.

Looking to the future, ATSS is holding a National TSC Picnic Day on November 26, 2006. Professionally, the TSC Medical Meeting in November 2007 will increase the knowledge of TSC amongst the medical community, and even more exciting is the proposal to establish a genetic testing facility in Sydney to serve all of Australia.

The future for TSC families and ATSS is certainly looking bright.

## Treasurer's Report

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*Belinda Humphrey,  
ATSS Treasurer,  
2006*

ATSS has maintained a steady and positive financial position over the last twelve months, progress that would not have been possible without the tremendous support and generosity of family members and friends, caring professionals and other private and public organisations, who have joined to support our mission.

In the 2005/2006 financial year ATSS has resulted in an overall operating profit of \$9,645.14.

The financial activities of ATSS for 2005/2006 have revolved around supporting and maintaining memberships, the production of the Reach Out newsletters, a Training Day for Interstate Representatives, and a Family Seminar day.

The generous donation from the Golden Stave Foundation has allowed ATSS to begin to update its TSC Brochures and Fact Sheets, generate a new logo, stationary, and banner. ATSS was able to produce a promotional DVD that was used to raise funds to allow us to begin production of an Australian video of TSC in this coming financial year.

During 2005/2006 ATSS received about 56% of its income from donations. Income from Memberships provides 15% of the income, with Memberships increasing by 21% when compared to memberships in 2004/2005.

Thank you to all those current members who did renew their membership for 2005/2006 and to past members rejoining, as well as new members contacting and joining ATSS for the first time. Your membership fees provide assistance to publish and print our journal, Reach Out, distributed twice a year. Memberships are carefully checked by our Membership secretary and non financial members will not receive Reach Out due to substantial production costs. Check your membership status and membership renewals can be made at any time during the year.

Donations towards research and development in TSC are being accumulated in the Society's cash management trusts, namely CBA and Macquarie Cash Management Trusts, with invested funds totalling \$77,779.28. Interest received from invested funds makes up about 11% of the income, and is reinvested and earning an effective rate of approximately 4.8%.

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 Community Grant from Lend Lease and a Family Conference Grant from the Federal Department of FACS. ATSS wishes to thank Lend Lease for this generous grant and ongoing support to the Society and to the federal government.

ATSS has acquired promotional products and has begun to raise funds during the financial year from these sales. Support in the past from members, friends and families was well received and ATSS hopes that you can again contribute.

ATSS expenses rose by about 6% due to an increase in operating



costs such as phone charges, postage and office supplies. Both insurance and publication costs remained steady.

The 2005/2006 ATSS financial accounts have again been audited again 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 and tax assistance when necessary.

A copy of the Financial Accounts (ie Balance Sheet, Profit and Loss, and Depreciation Schedule) and the Qualified Auditor's Report for the 2005/2006 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 this year by Janiffer Reynolds, completing both the banking and receipting of all monies received by ATSS. Janiffer's efficiency and support is greatly appreciated.

We hope that you will maintain your partnership with ATSS as we continue to achieve our mission statement of supporting TSC families, educating and informing both health professionals and the community. As we strive to increase our public awareness and family support, ATSS will inevitably benefit everyone affected by Tuberous Sclerosis Complex.



*Sue Pinkerton receiving the donation from the 35<sup>th</sup> District of the Quota Club International*

# Membership Report

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*Leanne Park, ATSS  
Vice-President, 2006*

We currently have **357** active members on our database.

237 of our active members are sufferers of TS or families of TS sufferers. The remaining 120 are Professionals or Organisational bodies.

As at 9th August, 82 members have paid their '06/'07 membership. The '05/'06 financial members totalled 121 so I happily assume another 30 or more will pay for current membership shortly.

I encourage you all to continue your involvement with ATSS via membership and donations as without your vital support the ATSS Committee cannot maintain the mission statement it works hard to meet each and every day.



*Shireen Doyle and her team after  
Kayaking the Murray River to raise funds for ATSS*

