



Australasian  
Tuberous Sclerosis  
Society

## The Australasian Tuberous Sclerosis Society Inc.

### Minutes of Committee Meeting

20 October, 2007 at 33 Cherry St, Warrawee

**In attendance:** Sue Pinkerton, Leanne Park, Belinda Humphrey, David Matheson, Janiffer Reynolds, Clare Pinkerton, Kellie Buckley, Sally Nicholson

**By teleconference:** Dianne Nitz, Narelle Kerr

**Apologies:** Dawn Bowra, Rosemary Dow

**Meeting opened 10:15 a.m.**

#### Minutes of previous meeting

Leanne moved and David seconded that the minutes of the previous Committee Meeting held on 28 July 2007 be accepted as a true and accurate record of the meeting.

#### Business arising

None

#### Correspondence

- Cheque from John Manning for \$1000 for conference dinner
- Various newsletters and pamphlets.

#### Reports

##### *President-Sue Pinkerton*

- It has been a very intense few months with many and varied aspects hopefully all coming together for the inaugural Medical Meeting and Family Conference.
- The wonderful work and support Leanne provides is acknowledged as she handles the queries and bookings for the Conference. Her assistance with all the paperwork is greatly appreciated.
- There have been numerous phone calls between David Mowat and Sue; with a couple of meetings to plan and negotiate all the details for the Conference; and too many emails between all the parties involved to count.
- The most exciting news is that her Excellency the Governor of New South Wales, Professor Marie Bashir, has accepted an invitation to open the conference!!!
- ATSS is going to be on the radar for a while after this conference.
- There was a very positive and accurate article in *Essential* magazine in the *Sydney Morning Herald* which featured Sally and her family.
- Plans for the National Picnic Days are in place. Thanks to all the Regional and Committee Members for their initiative and follow through.
- Thanks to David for his patience with some last minute changes to *Reach Out*.
- In an effort to develop connections with Epilepsy Action, Sue had a meeting with the Chief Executive Officer, Carole Ireland, recently. Sue is writing a feature article in the first 2008 edition of their journal *Epilepsy 360*. Carole expressed an interest in attending an ATSS Committee meeting.

- After discussions with David Mowat, more effort is going to be placed on developing adult renal services at the TSC Clinic.
  - 2007 has been the busiest and most productive year in Sue's 22 years of involvement with ATSS. It has been possible due to the willingness of every Committee Member to do their bit to improve outcomes for TSC affected people.
- Leanne moved and Dianne seconded that the report be accepted.

*Treasurer- Belinda Humphrey*

- Balance sheet dated October 2007 was presented. This showed Total Assets at \$74,525.43, Total Liabilities at \$0, and Total Equity at \$74,525.43.
  - Profit & Loss Statement July 2007 through October 2007 was presented. This showed Total Income of \$26,511.94, Total Expenses of \$42,993.47, and a Net Loss of \$16,481.53.
  - \$11,000 will be transferred from the cheque account into Macquarie Cash Management account for the TS diagnostic laboratory.
  - ATSS still has \$43,000 to pay for the TS diagnostic laboratory.
  - Belinda has a draft budget that will be examined at the next Committee Meeting.
- Leanne moved and Clare seconded that the report be accepted.

*Membership Secretary-Leanne Park*

- The database currently holds a total of 531; of this, there are 360 Active members.
  - 98 are financial for 2007/08; compared to 127 for 2006/07.
  - 230 letters will be sent out regarding the National Picnic Day
- Clare moved and David seconded that the report be accepted.

*Information Technology-Clare Pinkerton*

- Website hits averaged 154 per day for July.
  - There is an average of 110 per day each month, which has doubled since last year.
  - ATSS website rates highly with various search engines.
  - There has been a large increase in emails recently; the majority are requests for referrals to doctors, including from GPs.
- Clare moved and David seconded that the report be accepted.

*Regional Co-ordinators*

- Linda will assist Leanne with flyers for the National Picnic Day.
- Jannifer has arranged a guest speaker, a geneticist, for the gathering in Maitland, which will take place on Saturday, 24 November. All other picnic events will be on Sunday, 25 November.

**2007 Family Seminar Day & AGM**

- The day was low-key, but well-received.
- Kellie Buckley came for the first time and joined the Committee.

**Fundraising**

- \$2700 has been received from the Department of Families Communities and Indigenous Affairs to assist families with disabilities to attend the Conference.
- \$1000 has been received from Mannings Funerals.
- \$2385 has been received for the fund an hour of a scientist's time campaign.

### **Medical Meeting/ Family Day 3 & 4 November 2007**

- Sue is currently in paid employment part-time and is spending a large amount of time planning for the Conference.
- Families will use the main lecture theatre at Sydney Children's Hospital, Randwick. Professionals will use the conference room or another lecture theatre. There will be a combined opening.
- Registration commences at 8:15 a.m. Committee Members to arrive by 8:00 a.m. Leanne and Jannifer will take care of the registration table.
- All participants will need to be seated by 8:55 a.m. on the Saturday. Sue and David Mowat will each speak for 2 minutes at the start, then the Governor will speak for up to 10 minutes.
- The Governor needs to be initially addressed as "Your Excellency", then afterwards as "Mam" or "Governor".
- Belinda will arrange flowers as a gift for the Governor.
- Committee Members are to be ready to do any job that may arise, and also to help make people feel welcome.
- Guest speakers have been arranged by Sue.
- Clare and Leanne are working on final programming.
- Folders will be provided for all conference participants.
- Catering has been arranged.
- Various Committee Members will keep notes of different sessions for *Reach Out*; Committee Members will also thank speakers and present gifts.
- Sue will follow up on arrangements for small group workshops.
- Clare will co-ordinate a question box.
- Clare will organise thank yous for Sue and Leanne.
- Dinner has been arranged at the Bondi Icebergs club from 7:00 to 10:00 p.m. Two community buses have been organised to transport people to the dinner. Baulkham Hills Council will reimburse ATSS \$580 for the cost of the buses.
- Rotary's Ava Foundation are contributing \$15,000 for the conference. ATSS will have all of its costs covered.

### ***Reach Out***

- *Reach Out* will be out within the next week. It is being published in October rather than November because of the Conference.

### **Policy Development**

- Previous ATSS logos were trademarked; one is still valid until 2013.
- There was discussion regarding trademarking of the new logo. The following motion was proposed by Sue: "That ATSS does not trademark the current logo, but the business name is registered." The motion was passed unanimously.
- There was discussion about a Medical Advisory Committee, including renal, cardiac and dermatological specialists. It was agreed that this is a good idea for the future and will be discussed further at the next Committee Meeting. It was decided that a written policy about the Medical Advisory Committee will be developed, but the ATSS Constitution will not be changed.
- A letter will be sent to Dr Max Nicholls saying that ATSS is re-structuring its Patrons and we would like Patrons that are actively involved.
- There was discussion regarding Regional Contacts. Clare and Leanne will draft a letter to be sent to inactive/unfinancial Regional Contacts giving them opportunity

to become active and financial if they want to remain as Regional Contacts. If they do not respond they will be removed from the list published in *Reach Out*.

### **Banking and Payment Improvements**

- There was discussion regarding various electronic banking options with credit cards. Paypal appeared to be the best option. It was decided to use Paypal on a trial basis; Clare will establish this facility and it will be reviewed at the next Committee Meeting. At this stage it will only be for donations.

### **General Business**

- Clare will examine options for rebuilding the database and have information at the next Committee Meeting.
- ATSS will not be involved in the Lord Mayor's Picnic this year.

### **Next Committee Meeting**

Saturday, 9 February 2008 at Belinda Humphrey's

Other meetings in 2008:

Saturday, 3 May            Committee Meeting

Saturday, 26 July        Committee Meeting

Sunday, 10 August      Seminar Day and Annual General Meeting

Saturday, 8 November   Committee Meeting

**Meeting closed 1:30 p.m.**