



Australasian
Tuberous Sclerosis
Society

The Australasian Tuberous Sclerosis Society Inc.

Minutes of Committee Meeting 26 July, 2008 at 1 Waterloo Ave, Castle Hill

In attendance: Sue Pinkerton, Leanne Park, Belinda Humphrey, David Matheson, Clare Pinkerton, Kellie Buckley
By teleconference: Sue Williamson
Apologies: Sally Nicholson, Narelle Kerr, Linda Cameron

Meeting opened 10:25 a.m.

Minutes of previous meeting

Sue moved and Leanne seconded that the minutes of the previous Committee Meeting held on 3 May 2008 be accepted as a true and accurate record of the meeting.

Business arising

- Belinda sent letter to Dr Max Nicholls on 4 June regarding his commitment to continuing as ATSS Patron; no response has been received.
- No response was received to Sue's contact regarding the Autism Expo, so there was no ATSS representation.
- Money is still to be reimbursed from Sydney Children's Hospital for the conference last November.
- Nothing has been activated regarding forums on the website.
- Letters were sent to all Regional Contacts requesting a re-commitment to the position. Responses have been received from Fiona Hiatt, Rayann Semmens, Narelle Kerr, Sue Williamson, Pat & Adrienne Coakley. Leanne will follow up by phone or email the Regional Contacts who have not responded but have had recent contact with ATSS.

Correspondence

- Information regarding the Sydney Lord Mayor's Picnic.
- Copies of *Through the Maze* booklet from Association of Children with a Disability.
- Various newsletters and pamphlets.

Reports

President-Sue Pinkerton

- The main activities since the last Committee meeting include arrangements for the Seminar Day and the strategic planning process.
- Sue has had numerous phone calls with David Mowat and Dianne Petrie.
- Sue has liaised with education centre at the Children's Hospital at Westmead and visited the venue for the Seminar Day.
- Sue stuffed envelopes with invitations to the Seminar Day for mailouts from Sydney Children's Hospital and Westmead Children's Hospital.
- Sue personally delivered invitations to the Seminar Day to the Neurology and Genetics departments at both children's hospitals.

- Sue has been helping with the Assistant Treasury role and processing of registrations for the Seminar Day as Jannifer has spent the last 6 weeks in hospital with Nathan
- Sue modified and used Sue Williamson's letter to the Regional Contacts which Leanne sent out.
- Sue, Clare, Sally, Kellie and David met with David Mowat, Maya Chopra and John Lawson at Sydney Children's Hospital as part of the strategic planning process.
- It is vital that we all participate and have ownership of the Strategic Plan as this will shape ATSS for the next 5 or so years.
- Due to the decline in Lizzie's health Sue is unlikely to attend the TSC International Conference in Brighton in September.

Leanne moved and Belinda seconded that the report be accepted.

Regional Contacts

- A report from Fiona Hiatt detailing her active recent work was tabled.

Treasurer- Belinda Humphrey

- Balance sheet dated June 2008 was presented. This showed Total Assets at \$53,991.47, Total Liabilities at \$1,625.00, and Total Equity at \$52,366.47.
- Profit & Loss Statement July 2007 through June 2008 was presented. This showed Total Income of \$60,198.09, Total Expenses of \$98,838.58, and a Net Loss of \$38,640.49.
- *Reach Out* costs have increased.
- Belinda is preparing a breakdown of the TSC genetic testing laboratory costs for the AGM.
- Memberships have increased.
- Belinda has sought quotes for insurances.
- Stefan has indicated he will not continue as ATSS auditor. ATSS to formally thank him for his work over the years.
- Belinda will do a request for a volunteer auditor through Price Waterhouse Coopers and the NSW Volunteers Centre.
- Macquarie term deposit interest is currently 8.4%.
- Belinda is planning to step down from her role as ATSS Treasurer. She will stay on for another year if required.

Clare moved and Leanne seconded that the report be accepted.

Membership Secretary-Leanne Park

Currently:

- 544 names are on database
- 373 considered active
- 147 financial for 2007/08
- 147 financial for 2008/09

Sue moved and Belinda seconded that the report be accepted.

Information Technology-Clare Pinkerton

- 9 emails have been received since the last Committee meeting from people wanting support, etc. This is in addition to many contacts from TSC organisations.
- Website received average of 244 visits a day in May. Now down to 140 a day.

- There is a possibility of receiving free or cheap software for volunteer organisations.
- Clare will examine putting the entire DVD on the website.
- Clare may be travelling for 6-7 months in 2009. Kellie Buckley has offered to help with some of the IT.

2008 AGM, Seminar Day

- Venue is Doreen Dew Lecture Theatre, Level 4, Westmead Children's Hospital.
- Date is Sunday, 10 August. Registration starts at 8:30 a.m.
- There is no child care provided.
- The last session will be a practical Q & A discussion.
- David will make signs and put up a sign at the desk of the main hospital at Westmead directing people to the Children's Hospital.
- Reports to be emailed to Clare for formatting and copying.
- Leanne to buy gifts for the speakers.
- Clare to investigate engraved glasses for future gifts.
- Belinda and Leanne to do slices for afternoon tea.
- Clare to organise sandwiches and fruit for lunch.
- Belinda to bring tea, coffee, sugar, milk, water, juice.
- Kellie to bring paddle pop sticks.
- Clare to bring name tags.
- Sue to bring banners and posters.

Strategic Planning

- Clare provided feedback on meeting at Sydney Children's Hospital on 13 June.
- Clare led an extensive discussion about ATSS's vision, mission, values and strategic priorities, and is continuing to work on the strategic planning process.

Macquarie Term Deposit Account

- The members of the ATSS Committee to operate as signatories for the Macquarie Term Deposit Account are Belinda Humphrey, Treasurer, and Sue Pinkerton, President.
- The Treasurer recommended moving \$25,000 from Macquarie cash management research account into a new Macquarie term deposit account for 12 months. The motion was passed.

General Business

- ATSS National Picnic Day is on 23 November. Sydney Picnic will be at Lake Parramatta. Leanne to contact Regional Contacts regarding picnics in other states.
- \$10,000 to be moved from cheque account into CBA cash management account.
- There was discussion about asking the Volunteer Centre for a financial manager to assist ATSS. Belinda to contact them.
- Belinda to draft a description of her current role.

Next Committee Meeting

Saturday, 8 November, 2008 at Belinda Humphrey's, 33 Cherry St, Warrawee

Meeting closed 2:50 p.m.