



Australasian  
Tuberous Sclerosis  
Society

## The Australasian Tuberous Sclerosis Society Inc.

### Minutes of Committee Meeting 3 May 2008 at 33 Cherry St, Warrawee

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

**By teleconference:** Sue Williamson

**Apologies:** Dawn Bowra, Linda Cameron

**Meeting opened 10:20 a.m.**

#### Minutes of previous meeting

Clare moved and Leanne seconded that the minutes of the previous Committee Meeting held on 9 February 2008 be accepted as a true and accurate record of the meeting.

#### Business arising

- Clare wrote an email to Anchor who upgraded the space on the ATSS website by about five times for free.
- Most photos have been moved from the website to a Flickr account. Cost for a private account is \$25. David uploaded a large number of ATSS photos to Flickr.
- Letter to current Patrons has not yet been completed. Belinda to follow this up.
- The recent raffle was won by Kellie Buckley.
- An excerpt from the ATSS DVD has been placed on the website.

#### Correspondence

- Memorial card for Bruce Mills received from May Mills.
- Various newsletters and pamphlets.

#### Reports

##### *President-Sue Pinkerton*

- The SEALS ATSS Diagnostic Genetic Laboratory is only a few months away from being self supporting. The Director, Michael Buckley, is on sabbatical leave for 2 years but the head scientist, Peter Taylor, is responsible for supervision of the ATSS side of the laboratory. SEALS were successful in increasing their funding to cover the costs of ongoing testing for TSC, which ensures families will not be burdened with the costs of the tests.
- Planning for Seminar Day on Sunday, August 10 is well underway. Facilities at Westmead Hospital have been arranged with the support of Meredith Wilson.
- There have been a number of opportunities for awareness raising during the past few months. The March edition of Epilepsy Action "Epilepsy 360" carried a feature article on TSC and Lizzie Pinkerton's story. Dianne Petrie, Coordinator of AGSA, presented a paper to an international genetics conference in the Philippines using the ATSS establishment of a genetics testing facility as a model.
- World Wide Printing advertised a special deal for stand alone banners which was too good to refuse. It hasn't been delivered yet but looks good. The website address has been added under the logo.

- Clare met with Carol Ireland as a result of Carol's attendance at our last meeting. Clare has commenced the process needed to develop an effective Strategic Plan. Clare started the process with Leanne, David and Sue last weekend. ATSS is fortunate to have Clare's expertise in this area.
- David has prepared another edition of *Reach Out*, focusing on the Medical and family Conference.
- The raffle organised by Sally was drawn by the Mayor of Baulkham Hills Shire Council on March 1 and won by Kellie Buckley. Thanks for supporting this fundraiser which added \$2180 to the laboratory funds.
- There is an Autism Expo on Saturday, 10 May at the Seymour Centre in Sydney, and this would be an opportunity to have a TSC stand and raise awareness of ATSS if there is enough interest.
- It is obvious through many communications with medical professionals and other groups that ATSS is a unique and very special group. Over many years the volunteer members of the Committee have persisted and stayed committed. Achievements continue, while the basics such as phone support, *Reach Out*, provision of information and Seminar Days are maintained.
- ATSS continues to grow and create new opportunities for families with TSC despite the facts that ATSS doesn't have a regular supply of money, the Committee is entirely voluntary, and all of us are living with the vagaries of TSC.
- Sue read correspondence from Michael Buckley and David Mowat regarding management of SEALS lab while Michael is on sabbatical.

Sue moved and Clare seconded that the report be accepted.

*Treasurer- Belinda Humphrey*

- Balance sheet dated May 2008 was presented. This showed Total Assets at \$54,156.32, Total Liabilities at \$0, and Total Equity at \$54,156.32.
- Profit & Loss Statement July 2007 through May 2008 was presented. This showed Total Income of \$53,160.26, Total Expenses of \$90,101.90, and a Net Loss of \$36,860.54
- One more payment of about \$6000 is still to be made to SEALS laboratory.
- Membership income has increased by about 30%.
- Money is still to be claimed back from Sydney Children's Hospital for the conference last November.
- Belinda will follow up rates to ensure deposits are earning appropriate interest.
- Belinda will follow up the amalgamation of insurances to get a better rate.

Clare moved and Leanne seconded that the report be accepted.

*Membership Secretary-Leanne Park*

Thanks to Janiffer for her assistance.

For 2007/2008:

- 542 names are on database;
- 148 financial for 2007/08 (compared with 128 for 2006/07);
- 371 considered active;
- 5 have paid in advance for coming years.

Clare moved and Kellie seconded that the report be accepted.

*Information Technology-Clare Pinkerton*

- 20 emails have been received since last meeting; many are information requests, including DVD requests, including one from a library in Albuquerque.

- The ATSS website receives around 80-100 hits a day.
- Storage issues on the website have been resolved and the domain name has been renewed for 3 years.
- Paypal payments are still being worked on by Clare.
- Glenn Shields is happy to moderate forums and website has been upgraded to accommodate them.

### **Strategic Planning**

- Clare met with Carol Ireland from Epilepsy Action following the last Committee meeting.
- Clare discussed the planning documents.
- There was discussion of action so far and the proposed structure of the strategic planning process.
- Clare, Sue, Leanne and David met last week as part of the process.
- There will be a brainstorming workshop in June with a number of key personnel in attendance.

### **2008 AGM and Seminar Day**

- The venue will be the Doreen Dew Lecture Theatre at Westmead Hospital.
- The day will start with the AGM, followed by a genetics talk by Meredith Wilson; part of the strategic planning process; talks by Richard Webster (neurology) and Maya Chopra (genetic diagnosis); and a panel discussion. Members of the panel are yet to be conformed.
- ATSS will organise the catering.

### **Fundraising**

- No FACSIA application will be done this year.
- There are no current special appeals.

### ***Reach Out***

Editing of the May *Reach Out* has been completed and it will be sent out shortly.

### **Policy re: Patrons, Regional Contacts, Medical Advisory Committee**

- Stefan is unlikely to be available as auditor next year. Charles Humphrey's company may be able to be honorary auditors for ATSS. Belinda to follow this up.
- Belinda will send a letter to Max Nicholls regarding ATSS Patrons policy.
- The list of Regional Contacts is to be looked at for the November *Reach Out*. The role of regional Contacts also requires further discussion.
- There was discussion about asking Regional Contacts to nominate to continue in this role. They will still be appointed at the AGM.

### **General Business**

- Thanks to Narelle Kerr for her fundraising work.
- Thanks to Sally Nicholson for mailing out receipts.
- Belinda represented ATSS at the launch of *Through the Maze*.

### **Next Committee Meeting**

Saturday, 26 July 2008 at 33 Cherry St, Warrawee

**Meeting closed 12:30 p.m.**