



Australasian  
Tuberous Sclerosis  
Society

## The Australasian Tuberous Sclerosis Society Inc.

### Minutes of Committee Meeting

1 November, 2008 at 33 Cherry St, Warrawee

**In attendance:** Sue Pinkerton, Belinda Humphrey, David Matheson, Clare Pinkerton, Sally Nicholson, Chris Cook

**By teleconference:** Sue Williamson, Fiona Hiatt, Dianne Nitz, Karen Jenkins

**Apologies:** Leanne Park, Dawn Bowra, Janiffer Reynolds, Kellie Buckley, Hayley Hill, Narelle Kerr, Linda Cameron

**Meeting opened 10:30 a.m.**

#### Minutes of previous meeting

Clare moved and Sue seconded that the minutes of the previous Committee Meeting held on 26 July 2008 be accepted as a true and accurate record of the meeting.

#### Business arising

- No response has been received from Max Nicholls regarding him continuing as Patron of ATSS.
- Money has been received back from Sydney Children's Hospital for the Conference last November.

#### Correspondence.

- Various newsletters and pamphlets.

#### Reports

*President-Sue Pinkerton*

- Welcome to the 2008/09 committee and particular welcome to the new Committee Members Hayley Hill and Karen Jenkins.
- An email was received from Libby Mercer in Tasmania. Her first line was: "The report from Tasmania is that nothing is happening." She described the minimal contact she has had with three families over the past few years, proving that there is some activity however small. This is similar to developments in ATSS.
- Apologies to Belinda for not acknowledging and thanking her for her 10 years as Treasurer at the AGM. Sue had assumed she'd be in there for one more year and wasn't ready to follow the procedures established. A presentation was made to Belinda at the meeting.
- Clare has prepared a final draft of the Strategic Plan including input from participants at the Seminar Day at Westmead. She has also solved the problems with establishing a workable system with Paypal. Donations can now be made online.
- Sue couldn't attend the TSC conference in England, but by all accounts it was a marvellous opportunity for our three medical representatives, David Mowat, Meredith Wilson and Professor Ernie Somerville, to develop greater knowledge and enthusiasm for their work in Australia. David is keen to visit other major cities in Australia as a combined Medical and Family Weekend. ATSS needs to source funds.
- Sue attended the launch and 20<sup>th</sup> birthday celebrations of Genetic Disorders Week on 30 October. This was an opportunity to re-ignite her enthusiasm to continue with the ATSS goals. Quite a number of genetic counsellors took a copy of the ATSS

DVD. It was exciting to meet younger ones who are already aware of TSC. ATSS is recognised for our professional standing and expertise among the genetics profession.

- Sue welcomed a volunteer, Chris Cook, to the committee meeting. Chris responded to the ATSS need for a bookkeeper. Due to the Constitution requirements: “That an Executive committee must be a member for 3 years”, Sue suggested that Dawn Bowra is Treasurer, and that Chris fulfils the role of Financial Manager responsible to the Committee. At the AGM, after Belinda announced her intention to stand down, Dawn Bowra nominated to be Treasurer on the understanding it was until a skilled volunteer could be found. Leanne has discussed these changes with Dawn and Dawn is aware that Chris is able to commit to this role. Welcome Chris.
- There doesn't appear to be much action on National Picnic Day. Many have experienced difficulties during the past few months. There will always be next year.
- David has prepared another issue of *Reach Out*, with our thanks and appreciation for reliable and consistent commitment to this publication.
- There will be no ATSS display space at the Epilepsy Action Conference as no one volunteered.
- More copies of the brochure need to be printed and DrMaya Chopra has agreed to edit the information about genetic testing.

Clare moved and Belinda seconded that the report be accepted.

#### *Regional Contacts*

- Sue Williamson has had contact with a new family who have two children with TSC.
- Sue Williamson suggested moving the National Picnic Day to earlier in the year. There was general agreement about this and the last Sunday in May was proposed. The 2009 picnic will be on 31 May.
- Fiona has distributed information about TSC to medical professionals in Far North Queensland.
- Dianne will contact some Brisbane families about a picnic in Brisbane.
- Fiona is organising a picnic in Cairns.

#### *Treasurer- Belinda Humphrey*

- Balance sheet dated June 2008 was presented. This showed Total Assets at \$58,019.48, Total Liabilities at \$0, and Total Equity at \$58,019.48.
- Profit & Loss Statement July 2008 through October 2008 was presented. This showed Total Income of \$8,838.65, Total Expenses of \$3,185.64, and a Net Profit of \$5,653.01.
- There has been a 10% increase in membership renewals.
- All insurances are now due on 31 October and are held with AON.
- The bank balance is currently around \$18,000. \$10,000 is still to be moved out of the cheque account.
- \$1,500 from Sydney Children's Hospital is still to be banked.

Belinda moved and David seconded that the report be accepted.

#### *Membership Secretary*

No report.

### *Information Technology-Clare Pinkerton*

- 11 emails have been received since the last Committee meeting from people asking questions, wanting support, etc.
- Website received an average of around 100 visits a day.
- Paypal can now be used for donations. There is a link on the ATSS website. The process for paying memberships online should be ready by next year.

### **Review of 2008 AGM and Seminar Day**

- Positive feedback was received.
- The day was generally targeted towards families with a new diagnosis.
- There is a need for clinical guidelines about follow up testing to be more widely followed by doctors.
- Sally offered to adapt the published clinical guidelines for ATSS and these will later be put on the website.
- In 2009 there will either be a Family Conference on 8-9 August or a Seminar Day and AGM on 9 August. Which of these is yet to be decided.

### **Strategic Planning**

- Hayley Hill has offered to moderate a Facebook group; it has already been created.
- Clare is planning to approach Glenn Shields about taking over the website when she is overseas next year. Kellie Buckley will be taking over responding to emails.
- Sally has offered to take over the 1300 number if necessary.
- Hayley Hill has offered to update the membership list.
- Karen Jenkins offered to revamp some publications as information sheets.
- Belinda offered to co-ordinate the redevelopment of the membership database. A volunteer with IT expertise will be sought to work on this with Belinda as the contact person.
- Chris Cook is happy to take on hands on things related to the bookkeeping and accounts, but not so much the financial planning role.
- Clare will write an article for the May edition of *Reach Out* about the Strategic Plan.
- Sue moved and Clare seconded that the Strategic Plan dated 1 November 2008, which has been developed for the next three years, be accepted by the ATSS Committee. The motion was passed unanimously.
- From next year the Mission Statement on the front of *Reach Out* will be replaced with the ATSS Vision.

### **Volunteers**

- Sue and Clare put together two job descriptions and listed them with Volunteering NSW. The positions were a Bookkeeper and a Financial Manager.
- Sue later approached Chris Cook, who will take on the role of Bookkeeper.
- A number of responses for both roles were received. The Financial Manager position was listed in the *Sydney Morning Herald* through Volunteering NSW.
- Clare will say no thanks to the applicants for the Bookkeeper position as Chris Cook will take this on. She will also contact the applicants for the Financial Manager position.

- Belinda asked Charles Humphrey to pass on a request for a volunteer auditor, but this requires follow-up. If no response is received, a request will be put through Volunteering NSW.
- Clare will contact a friend about re-developing the database.

### **General Business**

- There was discussion about wristbands as a fundraiser.
- Karen Jenkins will make enquiries about the procedures for establishing a National TSC Day or Week.
- Sue discussed Bunnings barbecues as a fundraiser. Committee members to contact their local Bunnings to find out about the process.
- Leanne has asked Dawn to investigate sourcing funding grants.
- Sue Williamson will follow-up on a grant application book she became aware of.
- Sue Pinkerton to investigate changing the ATSS Constitution regarding trustees.
- Committee Meeting dates in 2009: 7 February, 2 May, 25 July, 7 November.

### **Next Committee Meeting**

Saturday, 7 February, 2009 at Belinda Humphrey's, 33 Cherry St, Warrawee

**Meeting closed 2:15 p.m.**