



The Australasian Tuberous Sclerosis Society Inc.

Minutes of Committee Meeting

4 November, 2006

In attendance: Sue Pinkerton, Leanne Park, Belinda Humphrey, Janiffer Reynolds, David Matheson, Sally Nicholson (part meeting)

By teleconference: Fiona Hiatt

Apologies: Rosemary Dow, Linda Cameron, Dianne Nitz, Clare Pinkerton, Dawn Bowra

Meeting opened 10:23 a.m.

Minutes of previous meeting

Leanne moved and Janiffer seconded that the minutes of the previous Committee Meeting held on 24 June 2006 be accepted as a true and accurate record of the meeting.

Business arising

- * Hats were purchased as promotional products instead of shirts.
- * St George Foundation gave a grant to ATSS.
- * Creature Feature at the Family Conference was a success.
- * Diagnostic testing laboratory cost is now \$150,000.
- * A cheque was received from Quota.
- * Interstate Family Conference participants were reimbursed 50% of their costs.

Correspondence

- Various newsletters and pamphlets.

Reports

President – Sue Pinkerton

- * These past few months could be characterised as opportunities: opportunities for awareness raising, education and fundraising.
- * Sue gave a presentation to 18 postgraduates studying Genetic Counselling through Charles Sturt University in September.
- * Leanne prepared invitations to all the Picnic Days. On behalf of the Committee, thank you Leanne. She has arranged a professional sportsperson to organise games for the kids at the Sydney picnic.
- * John Lawson requested a flyer to advertise the Medical Meeting next year. Linda Cameron very quickly responded and there is now an advance notice flyer advertising the Medical Meeting.
- * Vince Booker, a Rotary fellow, is trying to get Government funding for the Medical meeting. Sue developed the program for professionals and families, costed it and prepared a budget.
- * A funding application to Golden Stave Foundation was submitted requesting \$50,000 towards the cost of the genetic testing facility.
- * \$1255.00 was finally received from the FaCSIA in mid October. The delay and error was theirs. We are waiting on clarification of the correct amount.
- * Katina Core advised that they have raised \$2000 towards the genetic testing facility.

- * Contact was made with the *Sun-Herald* Health reporter, Louise Hall who was interested in the genetic testing developments.
- * Cumberland Newspapers may publish a TSC piece in the next week or two.
- * Peter Fitzsimons, journalist and 2UE presenter, may give us a mention.
- * National Picnic Day is advertised in the November issue of *Sydney's Child*.
- * Channel 7 *Sunrise* may also assist with awareness raising.
- * David sent a sneak preview of *Reach Out*. What a new look it is! Well done David.
- * The agreement with SEALS is not yet signed; this will happen shortly. Letters have been written to the two major donors for this project.

Leanne moved and Janiffer seconded that the report be accepted.

Treasurer- Belinda Humphrey

Balance sheet dated November 2006 was presented. This showed Total Assets at \$91,296.59, Total Liabilities at \$0, and Total Equity at \$91,296.59.

Profit & Loss Statement July 2006 through November 2006 was presented. This showed Total Income of \$24,150.54, Total Expenses of \$10,281.23, and a Net Profit of \$13,869.31.

- * Thanks to Janiffer for assistance with Treasurer's role.
- * Insurance has been paid.
- * Leanne is following up on two unrepresented cheques.
- * Memberships income is around 15% less than last year.
- * Telephone costs have increased due to teleconferencing.
- * Cost for office supplies increased because of brochure production.

Sue moved and Leanne seconded that the report be accepted.

\$10,000 to be moved from cheque account into cash management account.

Membership Secretary-Leanne Park

For 2006/2007:

- * 107 members have paid.
- * There are 40 honorary members of which 2 have paid.

Sue moved and Janiffer seconded that the report be accepted.

Information Technology-Clare Pinkerton

- * ATSS website has been updated.
- * The website was down for a while, but is fine now.

Regional Co-ordinators

- * Fiona Hiatt has sent information regarding the picnic in Cairns to various people, media and other organisations in the local areas.
- * Rosemary Dow has had ten acceptances to the Melbourne gathering.
- * A picnic has been organised in Port Lincoln, South Australia.
- * Janiffer has advertised in newsletters in Newcastle.
- * Sue will order 200 ATSS balloons for use at regional picnics.

2006 Family Conference Weekend

- * The Family Conference was very successful.

2007 Seminar Day

- * Date has been set for Sunday, 12 August 2007.
- * Speakers will be David Gracey (kidney specialist) and Michael Buckley (TS genetic testing laboratory)

General Business

TS genetic testing laboratory

- * A ceremonial launch will be held.
- * Two major donors have committed to support the establishment of the laboratory.
- * ATSS is to commit up to \$50,000.

November 2006 Reach Out

- * David emailed a sneak preview of the new look to some Committee Members.
- * It will be out soon.

Medical Meeting 2007

- * David Franz will be the keynote speaker.
- * ATSS will need to pay for an audio-visual person to operate the equipment.
- * ATSS will require some secretarial support.
- * While the medical meeting is occurring on the Saturday there will be social activities for families.
- * The Sunday will be a Family Day.
- * On Saturday evening there will be a conference dinner for all with a guest speaker.
- * Drug companies will fund some of the conference.

DVD Production

- * There has been little recent progress due to other commitments.
- * David volunteered to take on a co-ordinating role and maintain contact with Dawn.
- * DVD meeting will be held at Sue Pinkerton's on Friday, 17 November at 7:00 p.m.
- * David will email some ideas to Committee Members before the DVD meeting.

2007 Meetings

- * Committee meetings:
 - Saturday, 10 February 2007
 - Saturday, 5 May 2007
 - Saturday, 28 July 2007
 - Saturday, 27 October 2007
- * Seminar Day:
 - Saturday, 12 August 2007
- * Medical Conference
 - 3-4 November 2007
- * National Picnic Day:
 - Sunday, 25 November 2007

Next Committee Meeting

Saturday, 10 February, 2006 at

Meeting closed 12:02 p.m.