



Australasian
Tuberous Sclerosis
Society

The Australasian Tuberous Sclerosis Society Inc.

Minutes of Committee Meeting

9 February 2008 at 33 Cherry St, Warrawee

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

Meeting opened 10:17 a.m.

Minutes of previous meeting

Leanne moved and Janiffer seconded that the minutes of the previous Committee Meeting held on 20 October 2007 be accepted as a true and accurate record of the meeting.

Business arising

Nil

Correspondence

- Christmas card from David Franz
- Letter from Sandra Cappa
- Various newsletters and pamphlets.

Reports

President-Sue Pinkerton

- Since the last Committee Meeting, ATSS held the very successful medical and family conference: “Advances in Tuberous Sclerosis: From Pathway to Therapy”. The invaluable and consistent contribution Leanne made to its success is acknowledged. She fulfilled the important role of contact person for families. Other members of the Committee, especially Janiffer, Clare, David and Belinda also contributed towards the success of the weekend. Hopefully the energy and enthusiasm of the families will continue. Leanne and Sue met over the holidays and processed reimbursement claims for those who made a claim from FaCSIA funds. Most of the tidying up is done. The decision remains about how frequently ATSS should hold medical meetings.
- Reports of the National Picnic Days are on the agenda. Narelle Kerr made a wonderful effort to increase awareness of TSC and to raise funds of over \$12 000 towards the genetic testing laboratory amongst her community in rural Victoria. She was successful in gaining publicity in both locally and in Melbourne. Her efforts should encourage all to keep on trying. Some photos are on the website.
- Sally organised a raffle with the donated prize from a friend being a weekend away. Worldwide Online Printing donated the printing of the tickets. If all 250 tickets are sold \$2500 should be profit. This will be drawn on 1 March 1.
- The CEO of Epilepsy Action, the peak epilepsy body in Australia, Carol Ireland, is joining us at this Committee Meeting. She is very impressed with how much we achieve as a small volunteer group and offered to come to a Committee meeting to discuss ways to benefit both organisations.

- Professor Michael Buckley has reported from the laboratory that they have enough samples for checking all procedures and processes and that everything is progressing to plan. Apparently ours is the model that SEALS is promoting.
- David Mowat reports that Dr Sean Kennedy, a paediatric renal specialist, has joined the team at the TSC clinic at Sydney Children's Hospital Randwick.
- At the Regional Training day held in 2005, goals were set and they have now been achieved. It is time for the 2008 Committee to set some goals to work towards: a couple of short term and a couple of long term goals so that ATSS can continue to grow in the services it provides for families. With direction and a purpose in mind funds can be sourced to make the goals achievable.

Sue moved and Leanne seconded that the report be accepted.

Treasurer- Belinda Humphrey

- Balance sheet dated February 2008 was presented. This showed Total Assets at \$69,259.63, Total Liabilities at \$0, and Total Equity at \$69,259.63.
- Profit & Loss Statement July 2007 through February 2008 was presented. This showed Total Income of \$48,975.95, Total Expenses of \$70,723.28, and a Net Loss of \$21,747.33.
- Working money at present is around \$12,000; other funds have been donated for research. Total investments are around \$32,000 after lab expenses.
- Belinda presented a projected budget for the coming year.
- Memberships, donations and interest income are roughly covering operating expenses.

Sue moved and Clare seconded that the report be accepted.

Membership Secretary-Leanne Park

For 2007/2008:

- 538 names are on database.
- 368 are considered active.
- 26 are Honorary.
- 140 financial for 2007/08 compared to 127 for 2006/07.
- Many phone calls have been received from current contacts.

Sue moved and Janiffer seconded that the report be accepted.

Information Technology-Clare Pinkerton

- Only two emails requesting information were received in the last quarter.
- There is an average of 115 visits per day to the website.
- Most people who reach the website via a search engine are through Google.
- The domain name needs to be renewed in April; this will cost \$22.
- Clare is sorting out space issues on the website.

Regional Co-ordinators

- Dianne reported on the picnic at Paradise Point on the Gold Coast. It was attended by 4 families and a lovely day was had by all.
- Janiffer had a very successful gathering in Maitland. Dr Matthew Edwards from Hunter Genetics was guest speaker. 15 people attended, including one new family. The ATSS DVD was shown.
- The picnic at Lake Parramatta in Sydney went well. 4 families attended. The children enjoyed lots of games.
- The picnic in Cairns was cancelled.

- Leanne is still chasing picnic reports.

Medical Meeting/Family Conference – November 2007

- The Sunday morning session was recorded. Sue will pick up a copy of the DVD from David Mowat.
- Some photos are on the website.
- Feedback was positive. Clare will email evaluations.

Fundraising - grants, donations

- Sue reported that we have more chance of getting money from St George Foundation for a big project. Sally and Sue will look at putting something together for hosting Seminar Days in other states.
- The Fund A Scientist campaign has raised a total of nearly \$15,000. Narelle Kerr raised a large amount of money.
- Raffle ticket sales are ongoing. The raffle will be drawn at the Pinkertons' house on 1 March 2008.

Reach Out

- David needs contributions for the May edition. He needs to receive these by the end of February.

Seminar Day and AGM 2008

- Sue will arrange for a speaker regarding epilepsy.
- Part of the ATSS Strategic Plan will be on the agenda for the day.
- Royal Institute for Deaf and Blind Children facilities are unavailable this year. Sue will talk to Meredith Wilson about using the facilities at Westmead and also investigate catering arrangements.

International Conference - September 2008, Brighton, England

- The ATS Committee agreed that accommodation and conference registration costs can be paid for by ATSS for one delegate for the September TSI conference. It was agreed that Sue Pinkerton would attend.

Policy re: Patrons, Official Regional Contacts, Medical Advisory Committee

- Belinda will write to Max Nicholls regarding him no longer being patron of ATSS.
- Non-financial members to be deleted from the list of Regional Contacts published in *Reach Out*. These former members have been given numerous reminders but remain unfinancial.

Future Plans and Projects

- There was an extensive discussion with Carol Ireland from Epilepsy Action regarding fundraising, projects, goals, paid staff, governance, and a Strategic Plan for the next 3-5 years.
- There are four aspects to the development of a Strategic Plan:
 - A: Where are we now?
 - B: Where do we want to be? (Vision and mission)
 - C: What do we need to do to get there?
 - D: Fine details of plan.
- Parts A and B of the Strategic Plan are to be completed over the next few months. Part C is to be completed at the Seminar Day in August.

General Business

- The meeting approved for Clare to spend up to \$250 per annum on web services.
- Sally will send thank you letters fro Narelle Kerr's fundraising.
- There was a discussion about the establishment of a forum on the ATSS website. It was decided that the ATSS Committee will establish a forum for a three month trial from the date of establishment under the moderation of Glenn Shields. Clare will develop a privacy policy and rules for posting to the forum.
- There was discussion about putting the ATSS DVD on the ATSS website. It was decided to put a ten minute excerpt on the website with information on how to obtain a copy of the complete DVD.
- Clare is able to include a Paypal option on the ATSS website for payment of memberships, but needs more details and will follow this up.
- Clare reported on the options for upgrading the membership database. It may be possible to apply for a small equipment grant. Actual requirements are to be looked at after development of the Strategic Plan. Clare will look for a volunteer to assist.

Next Committee Meeting

Saturday, 3 May 2008 at 33 Cherry St, Warrawee

Meeting closed 2:23 p.m.