



The Australasian Tuberous Sclerosis Society Inc.

Minutes of Committee Meeting

10 February, 2007

In attendance: Sue Pinkerton, Belinda Humphrey, Janiffer Reynolds, David Matheson

By teleconference: Linda Cameron, Rosemary Dow, Dianne Nitz (part)

Apologies: Leanne Park, Clare Pinkerton, Sue Williamson, Fiona Hiatt

Meeting opened 10:10 a.m.

Minutes of previous meeting

Belinda moved and Janiffer seconded that the minutes of the previous Committee Meeting held on 4 November 2006 be accepted as a true and accurate record of the meeting.

Business arising

- ATSS did not receive grant from Golden Stave that had been applied for; Sue has rung Marianne Knight about this.
- The FaCSIA money has been sorted out.
- Some media attention was received for the National Picnic Day
- SEALS Laboratory agreement was signed on 1 December.
- DVD planning meeting was held in November.

Correspondence

- Letter from Golden Stave declining grant.
- Several letters from Sylvia Ralston (ATSS member) sending encouragement.
- Various newsletters and pamphlets.

Reports

President-Sue Pinkerton

- Since the previous meeting last November, ATSS has attracted some media attention via publicity for the National Picnic Day; due to the efforts of Regional Representatives. The picnics did not gain large numbers but were all successful in that TSC families met together.
- On 1 December 2006, David, Belinda, Leanne and Sue met with Drs Michael Buckley, and David Mowat at Sydney Children's Hospital to sign the agreement to establish the ATSS Tuberous Sclerosis Diagnostic Testing Laboratory. This is the most important event in the history of ATSS. Michael Buckley is very excited about the venture and is using it as a model for other genetic groups to emulate. Unfortunately, the Media Relations person was unable to attract any media interest despite an official Media Release.
- Two international speakers have agreed to come to Sydney: Professor David Franz (USA) and Dr Chris Kingswood (UK). Drs David Mowat and John Lawson are planning the Medical Meeting and ATSS is planning the Family Meeting.
- Thanks to David Matheson for his ongoing work developing the DVD, Leanne for all her membership contacts re: phone, mailing etc. Also thanks to Janiffer and

Belinda for their continuous treasury duties and all the Regional Representatives who put the effort into holding the picnics.
Sue moved and Janiffer seconded that the report be accepted.

Treasurer- Belinda Humphrey

- Balance sheet dated February 2007 was presented. This showed Total Assets at \$152,386.29, Total Liabilities at \$0, and Total Equity at \$152,386.29. Total Assets includes funds for the SEALS Genetics Laboratories, currently in cash management account.
- Profit & Loss Statement July 2006 through February 2007 was presented. This showed Total Income of \$115,806.25, Total Expenses of \$40,847.24, and a Net Profit of \$74,959.01.
- ATSS will make payments to SEALS Genetics Laboratories monthly; two payments have been made so far. Total donations received for SEALS Genetics Laboratories are around \$117,000.
- Budgets need to be set for the DVD production and the medical meeting.
- ATSS has almost broken even on promotional products; the rest sold is profit.
- Telephone costs have increased because of teleconferencing.
- Postage costs have also increased.
- Several unpresented cheques remain outstanding.

Belinda moved and David seconded that the report be accepted.

Membership Secretary-Leanne Park (read by David Matheson)

As at January 2007:

- We have 524 on the database. A total of 356 are considered Active.
- Number financial for 2006-07 is 114, compared to 122 for 2005-06.
- Hopefully there are still a few who will remember to pay soon.

David moved and Janiffer seconded that the report be accepted.

Information Technology-Clare Pinkerton (read by Sue Pinkerton)

- Clare apologises for lack of updates to the website; work commitments have left her very little time to devote to it.
- Few emails have been received since the direct email contact was removed from the website; this was done because people were hacking into the website. One or two emails a month are still being received.
- Clare will be in Singapore until June or July.

Regional Co-ordinators: Summaries of Picnics

- The Sydney Picnic was held at Lake Parramatta. It was attended by some regular active members, older members renewing acquaintances, and one new family. Brad from Tabloid Sports Carnivals volunteered his time to entertain the kids.
- The speaker for the get together in Melbourne had to cancel the day before. However, the group had a good chat. Twelve people were in attendance. Rosemary is organising another get together in March. She will contact Leanne with the details.
- 15 attended the Maitland picnic. It was a great opportunity to meet other families and to share stories and information.
- Five families totalling 17 people attended the picnic in Kings Park in Perth on a 35.2 degree day. 25 years of ATSS was celebrated with a cake.

- Three families attended the picnic in the ACT. It was a great opportunity for people to get to know each other. There was face painting for the kids.
- Two families attended the picnic in Queensland. The weather was beautiful and there was good conversation all around.
- A picnic in Port Lincoln (South Australia) received publicity in the local papers.

2007 Family Seminar Day & AGM

- There was some discussion about whether to hold the Seminar Day because of the November medical Meeting and Family Day. However, the ATSS constitution indicates that an AGM must be held in August, so this day will go ahead.

Medical Meeting/Family Day: 3 & 4 November 2007

- The title for the medical meeting is *Advances in Tuberous Sclerosis: From Pathway to Therapy*.
- A draft flyer has been done, but Linda will work on updating it.
- The medical conference will be held on the Saturday and family day on the Sunday. A dinner will be held on the Saturday evening.
- International speakers are David Franz and Chris Kingswood.
- Expressions of interest for attendance to be advertised in May *Reach Out*.
- Sue will apply for funding. Rotary trust fund may be able to assist with funding.
- John Lawson is approaching drug companies regarding funding for doctors.

General Business

TSC Diagnostic Lab

- The agreement to establish the SEALS Genetics Laboratories was signed on 1 December. Michael Buckley is the Director of SEALS Genetics.
- ATSS is supporting this financially (\$50 000) and the remainder (approx. \$110 000) has been donated by two families. This lab is the first not for profit TSC genetic testing facility in the world.
- To access this service families need to contact Sue Manass, (9382 1704) genetic counsellor at Sydney Children's Hospital to organise collection of blood and completion of paper work. All are encouraged to take advantage of this and to help Michael quickly develop the testing procedures.
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DVD Production

- David reported on the planning meeting held in November and his recent meeting with Rupert and Yasmin from VNR.
- An overview was drafted at the meeting in November.
- VNR are a DVD production company. David discussed with them our aims in producing the DVD. They have a scriptwriter who is working on a first draft.
- Filming is proposed for April.
- Budget for the DVD is around \$15,000.

Next Committee Meeting

Saturday, 5 May 2007 at

Meeting closed 11:35 a.m.