



# ANGELMAN SYNDROME ASSOCIATION

Newsletter

Charity No. CFN13843

ABN 42 169 355 488

No. 36 – December, 2004

## President's Say

### ANGELMAN SYNDROME ASSOCIATION AGM 2004 PRESIDENTS REPORT

It has been an honour and privilege to serve as the National President over the past twelve months. Whilst it has been a challenging year for me with a very steep learning curve, I have also found it to be very rewarding.

In October 2004, the National Conference held in Sydney marked the 10 year anniversary of the Association. This was a huge achievement. The Association continues to grow and there are currently over 175 on our mailing list. There have continued to be many enquiries for information by phone and email, and several new families have joined. We have even had enquiries from an overseas family intending to migrate to Australia.

We have endeavoured to increase links between the Association and the AS Clinic, and three coffee mornings were hosted by the AS Clinic in March, May and August of 2004. These were attended by both families and professionals of various backgrounds who were on hand to offer advice, information and assistance.

A Clinic survey was also undertaken by the Associa-

tion and the families that responded, highlighted the need for ongoing information, research and networking.

A small group of dedicated parents had formed a sub-committee to develop an information package to be disseminated to families and professionals. This package is in its final phase and its cover is currently being designed by a graphic artist. This will be a comprehensive resource which families and professionals can refer to for much needed information. I would like to especially thank this committee, comprising Sally Shackcloth, Heather James and Paul Webster for their efforts with this huge task.

An Internet committee meeting was held 29/8/04 – 5/9/04 in which many of the ongoing issues relating to the Association were discussed. I would like to thank the National Committee for their patience in supporting me and their ongoing assistance to the ASA. The Association would not be able to operate if it weren't for the assistance and support of many dedicated people. I wish to thank the State Vice-Presidents for their hard work over the past year. I wish to thank Dr Robert Leitner and Dr Ellie Smith for their ongoing dedication and services to people with AS and their families. Thank you to Robert Church who continues to efficiently manage his duties as Treasurer, and especially to Simone Kennedy who still continues to have an active role as Secretary despite ongoing health issues. This support and assistance to me over the past twelve months has been very much appreciated.

Thank you to all the families, carers and friends of the ASA for their willingness to communicate and share

*Continued on Page 2*

### From the Editor -

Firstly, I must apologise for not getting the last newsletter out in time. We had a lot of trouble with our computer, and I lost a lot of data. So this issue is a bumper issue.

Please send any stories, jokes, photo's, info. to me at emailrobhedge@ozemail.com.au (please mark it "Newsletter").

Thank you. "Merry Christmas". Heather Church (Vic.)



**All Correspondence to:**  
**Angelman Syndrome Association**  
**PO BOX 554**  
**SUTHERLAND NSW 2232**  
**Email: kevink@angelmansyndrome.org**

### Diary Dates:

**The 7th National Conference**  
Friday September 30 - Sunday 2nd  
October, 2005



their experiences, despite the challenges of coping with the care of our angels.

With 2005 approaching, we look forward to the next National Conference to be held in October 2005 in SA and already the committee there have the planning of the conference well under way. Thank you to them for undertaking this task in such a well organised fashion.

Thank you for affording me the opportunity of being President of the ASA and I look forward to another challenging and productive year if re-elected.

Anne Funke



Hello all, again and welcome to this Christmas edition of the newsletter.

At our recent AGM I was re-elected to serve as President of the ASA for another year. (Report on page 1). Thank you to all the other office bearers for their ongoing commitment and to the new office bearers for their assistance.

There are a few vacant positions, so for those in the States without a vice president, please consider this as an option of having a voice and for helping other families. I wish to advise that Heather Church (VIC Vice-president) has decided to step down after 11 years service in that State. Thank you Heather for all your efforts over the years - I am sure the families in VIC have appreciated your dedication and we wish you well for your "semi-retirement". Heather continues to assist us with the editing and formatting of the newsletter.

I wish you and your families a happy festive season and best wishes for the New Year. Warm regards,

Anne Funke

### ***New Committee for 2005***

President - *Anne Funke*  
Secretary - *Simone Kennedy*  
Treasurer - *Robert Church*

### ***National Committee***

*Mary Bills*     *Carla Upfill*     *Annie Cole*  
*Keith Bradley*     *John Hannaford*

### ***State Vice-Presidents***

New South Wales - *Cathy Bayliss*  
Victoria - *Raye Hearn*  
South Australia - *Heather James*  
Tasmania - *Sally Shackcloth*  
Western Australia - *Vacant*  
Queensland - *Vacant*  
A.C.T. - *Kerrie O'Kane*

*Congratulations to the new Committee. If you would like to fill in the vacant positions, please contact the Association on (02) 9520 5857*

### **PLANNING FOR A RESPITE HOME OUR EXPERIENCES**

Our daughter, Hannah, is now 15 years old. She currently lives at home from Monday to Monday one week and at a respite home the second week ( i.e. 50% respite). It has taken a **long, long** time for us to get to this happy stage! I thought other parents may be interested to hear how the respite home project was developed.

It all started in early 2001 when a group of like-minded parents and a Family Services worker (representing 6 or 7 children) got together to discuss their future respite needs. All of the parents were dissatisfied with the availability of their current respite situation. They were extremely anxious about the future situation too, envisaging a much higher demand for respite as they, (both parents and children) got older. Everyone was interested in *part-time* regular respite as a transitional step to full-time care. At this stage we had the idea of four children in respite for four days then they would swap with the second group for four days.

We followed a confusing path dealing with the bureaucracy involving quite a few contradictions and delays. Initially, we thought we would have to apply to the Housing Department to build a house as well as to individually apply for funding under the Individual Options Program (a Commonwealth-funded program). Apparently it was important to 'get into the system' by applying for the I.O.P. funding. In Hannah's case I applied for 2 weekends/month respite plus individual support hours for weekly swimming lessons.

Our next task as a group was to visit individual 'service providers' and find out basic information as well as philosophies behind the organizations. We wanted to find out how the organization was formed, its strategic plans, grievance policies, types of accommodation available, training of support workers and emphasis on skill development, etc. As a group we were unanimous in not wanting to incorporate *ourselves* as a service provider. We were wanting to reduce our work-loads, not increase them! Visiting currently-operating group homes run by various groups was an interesting learning experience for us. Most, of course, catered for older people with disabilities.

In August, 2001, we had a meeting with representatives from Disability Services (State Government department), two service providers, seven parents and a family advocate from Association for Children with Disability (Tas.)

*Continued on Page 7*





Angelman Syndrome Association  
*7th National Conference*  
30 September to 2 October 2004

## ***Angels in Adelaide***

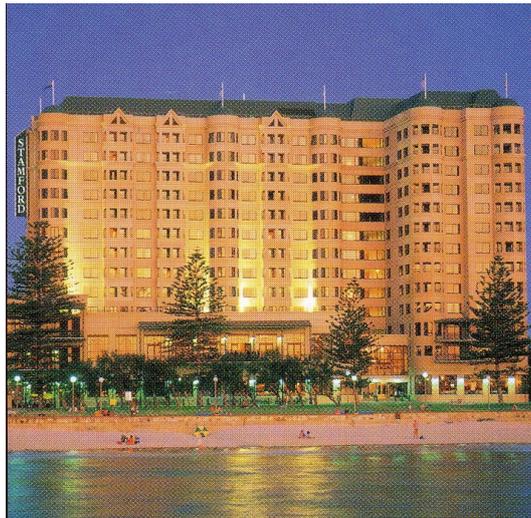
Details to date:

### **The Event:**

The 7<sup>th</sup> biennial National Conference of the Angelman Syndrome Association. This conference also celebrates the fortieth anniversary of the discovery of the Angelman syndrome by Dr Harry Angelman in 1965.

### **The Place:**

The Friday pre conference drinks and the Saturday Conference seminars are to be held at the **Stamford Grand, Moseley Square, Glenelg, South Australia**. The conference dinner is to be held also at the Stamford Grand.



The Stamford Grand is a four and a half star hotel, situated on the beach front at Glenelg. Glenelg is a popular tourist destination and is just a short tram ride to the city centre.

### **The Time:**

Welcome drinks will be on Friday evening, 30 September 2005. Conference registration will be also be available at this time.

The seminars will be held on Saturday, 1 October 2004 from approx. 9.00am to 5.00pm in the Ballroom 2 with registrations from 8.15 am.



**Accommodation:**

There are several accommodation options ranging in price and location to suit all budgets. (see attached information sheet). Most accommodation options are walking distance to the conference venue. Conference attendees should make their own accommodation arrangements according to individual needs and requirements.

**The Child Care:**

Child care will be provided for AS children and their siblings from approx. 8.30am to 5.30 pm and from 6.30 pm to 10.30 pm on Saturday 1 October 2005. Outings with carers will be planned to various Adelaide entertainment venues.

**The Program:**

The programme is currently being developed. Topics will be based on the need expressed in the Conference Questionnaires.

**The Dinner:**

The Conference dinner will be held at the Stamford Grand (Ballroom 1). Cost to be advised. We also plan to hold an auction on the night.

**The Politics:**

The Annual General Meeting of the Angelman Syndrome Association will be held at St Ann's Special School, 37 Finniss Street, Marion (times to be advised). All welcome.

**The Sunday Picnic:**

The Sunday family/picnic lunch will be held in the fenced grounds of St Ann's Special School, 37 Finniss Street. The picnic will be a fully catered.

**The Cost:**

Costs will be kept to a minimum. Further details to be advised.

***More detailed information and registration sheets will be posted as soon as details are finalised. Stay tuned.***



## Accommodation Options

**Glenelg:** Glenelg is located on the delightful Adelaide coastline about 12 km from the city centre and about 3 km from the airport. As it's a popular holiday destination a range of accommodation (most within walking distance of the conference venue) is available at Glenelg, from 5 star hotel, medium range hotels, holiday cottages, through to cabins etc at the nearby West Beach Caravan park. There are over 60 licensed restaurants and café's in the area.

### **Stamford Grand Accommodation:**

Moseley Square, Glenelg

Phone: (08) 3875 0632

Website: [www.stamford.co.au](http://www.stamford.co.au)

Attendees can contact the Groups & Tours Coordinator at the directly on **(08) 8375 0632** and quote the booking number **16151** or mention that they are a part of the Angelman Syndrome Conference and they will be able to access the special rate.

The special rate per night for a city view room is \$165.00 and an ocean view room \$205.

### **Best Western Ensenada Motor Inn:**

13 Colley Terrace, Glenelg

Phone: (08) 8294 5822

Website: [www.ensenada.com.au](http://www.ensenada.com.au)

The Best Western Ensenada Motor Inn is a four star motel overlooking picturesque Colley Reserve opposite Glenelg beach and only one minute walk to the Stamford Grand. All rooms and suites are non-smoking. Prices range as follows:

Executive rooms	- Single & Double	\$120
Delux rooms	- Single & Double	\$135
Extra \$15 per person		

**Note:** No ground floor rooms, all rooms on second floor – stairs only.

### **Taft Motor Inn:**

18 Moseley Street, Glenelg

Phone: (08) 8376 1233

Website: [www.taftmotorinn.citysearch.com.au](http://www.taftmotorinn.citysearch.com.au)

The Taft Motor Inn is a four star motel and only two minutes walk to the Stamford Grand. All rooms are on the ground floor. Prices range as follows:

Single rooms	\$ 98
Twin rooms	\$105
Apartments – 1 bedroom	\$117
Apartments – 2 bedroom	\$137



These one and two bedroom self-contained apartments are an ideal home-away from home. Each has a fully equipped kitchen with a fridge, stove and cooking/eating utensils if you choose to prepare your own meals.

**Glenelg Beachside Apartments:**

Colley Terrace, Glenelg

Phone: 0421 478 922 (Martin Mack)

There are a boutique of 14 apartments, at the middle of Colley Terrace, Glenelg and only a two minute walk to the Stamford Grand. All apartments are near new, fully furnishes, self contained, main bedroom with ensuite, private balcony, spa, kitchen, laundry with all linen and towels included.

Prices start for a 2 bedroom apartment is \$129 per night (three night minimum, less by negotiation).

**Adelaide Shores Caravan Resort:**

Military Road, West Beach

Phone: (08) 8355 7320

Website: [www.adelaideshores.com.au](http://www.adelaideshores.com.au)

The Caravan Resort has lawned sites for tents through to luxury cabins, while the Holiday Village has 93 self contained family units. The resort is rated 4 and a half stars and only 10 minutes drive to the Stamford Grand. Cabins range from:

Deluxe 6 berth cabin (int. ensuite)	\$103
Executive 4 berth cabin (int. ensuite)	\$ 92
2, 4 or 5 berth cabin (int. ensuite)	\$ 87
6 berth cabin (ext. ensuite)	\$ 72
Standard 6 berth cabin	\$ 65
6 berth onsite van	\$ 49

**Note: All accommodation (excluding Stamford Grand) may be subject to price changes.**

*Look forward to seeing you there.*



*Continued from Page 2*

Discussion involved: the difficulty of funding the model with part-time clients; problems of finding flat land for a purpose-built house; questions of what happens when needs change and the client might need full-time care; the need to specifically identify the eight clients which may affect the suitability of the house; possible disputes e.g. over holiday times; physical access to day-support etc. We were told that ... "We are generally supportive of the model..."

A week later we had a meeting with a representative from St. Giles with whom we were most impressed. St. Giles has a long history of caring for children with disabilities. It was initially set up during the polio epidemic of the 1930's in Launceston. As well, St. Giles has recently built a children's respite house. As a group we were invited to visit this house as well as the therapy centre. We signed a "memorandum of understanding" with St. Giles. From this point the C.E.O. of St. Giles, Michael Sertori, would represent us in funding submissions.

From his first meeting with Disability Services, Michael found that normally service providers have to tender for a new proposal but we as a group had decided on the service provider. At this time we agreed to pay the St. Giles standard rate of \$12/night

board (up to 16 y.o.) and \$20 (16 y.o.+). The staff client ratio would be 1:2 and 1:4 (night) with a wake-shift. Quite a few of the children have epilepsy and/or disturbed sleep patterns and the parents had agreed this was essential, at least at the start.

Later that year Michael Sertori met with Disability Services representatives with a lot of the discussion centred around the Commonwealth States and Territories Disability Agreement (CSTDA) which had not been signed. (Oct. 2002) The new State Minister of Health, David Llewellyn, did not want to set up a service that may become unfunded. In other words, they didn't want to commit themselves until they had the dollars. The Minister would include it as an unmet needs project in the State Commonwealth negotiations. At this stage the parents had a meeting with the Minister to re-affirm the government's commitment to the project.

This signalled the start of an intensive and political letter-writing campaign with Michael Sertori and St. Giles in general working hard on our behalf. We had more meetings with the Minister and one with the Shadow Minister for Health. Finally by the end of July 2003 we had some good news at last. The state government had approved recurrent funding of \$350,000/annum for staffing but there was no capital funding to actually build the house. Michael Sertori was convinced that the political pressure had worked. The next question was "How to fund the house?"

We now had the fun of looking at possible rental properties and advertising for the position of Co-ordinator. In January 2004, St.Giles signed the lease on a large four-bedroomed house in Kingston (only 15 minutes drive from our home!). Another parent and I attended the interviews for the Co-ordinator position along with the Human Resource Manager and the Co-ordinator of Client Services. Following this appointment, Support Workers (six permanent part-time, two casual) were hired. The St. Giles Board approved 'set-up' funding to purchase furniture and vehicles. Anything purchased would be used in the new house when it is built. We had some delay as we had to put in a planning application to council. There were further steps to take before moving in. The parents signed a "release of information" from Disability Services so that any relevant information dealing with the child in respite could be passed on to the St. Giles staff. As well, the Co-ordinator visited each family to go through the Personal Profiles. This covered feeding, sleeping, mobility, communicating, dressing, medication, education, self-care, physiotherapy, speech and O.T. issues, etc. At long last Hannah had her first visit to her new respite home on Monday 26 April 2004. Our 40<sup>th</sup> meeting (of the parent group) was a celebration in May.

### AN UPDATE!

St. Giles are hoping to build 'our' respite house from a fund-raising project whereby a very generous building firm (with a lot of donations and goodwill) will build an executive-type house (sounds like Hyacinth Bucket!) and then sell it. The profit will be used to fully or partly build our house on land already purchased in Kingston.

On a more personal note, Hannah has settled into her new routine very well. Apparently during the first two or three visits she was terrible at school. She hadn't gone to sleep until 2 or 3 am and then of course was falling asleep at school and being cranky. Since then she has seemed quite used to her new life. I show her photos of the staff and the house on the Monday morning to let her know where she's going and she always looks quite happy about it! The rest of us in the family are equally thrilled!

Please contact me if you'd like any more details: Sally Shackcloth (ph. 03 62 672025) or email: [smshackcloth@tasmail.com](mailto:smshackcloth@tasmail.com)

Sally Shackcloth





## *An Uplifting Moment for one of our “Angel” families -*

Nina and Chris Hensley, who are the parents of “Angel” Ivy 5 years, Adam 3 and Tio eight months, were presented with a wonderful gift from The Bush Bashing Variety Club of Queensland when they attended the Solferino Woolshed Dance. The Hensley’s were presented with a new buggy for Ivy and a further \$10,000 to help with Ivy’s ongoing needs. Isn’t that great!!!!

Below is an extract of the speech that Nina gave to The Variety Club -

- If you think you know what joy is, *you’ve never blown up a balloon for Ivy*
- If you think you know how to have a good time, *you’ve never had a water fight with Ivy*
- If you think teaching a cat tricks would be a challenge, *you’ve never tried to teach Ivy something new*
- If you think catching a fish with your bare hands would be a slippery job, *you’ve never given Ivy a bath*
- If you think putting an octopus in a straight-jacket would be impossible, *you’ve never tried to dress Ivy*
- If you think a goat would cause chaos in a foodmart, *you’ve never been shopping with Ivy*
- If you think you’ve been touched by an Angel, *you must have experienced an Ivy moment.*

The following poem was written by Kay Mifsud and is titled “Ivy’s Angels”

The Variety Club is coming, to a Woolshed in the bush,  
*There’s a purpose for their visit, and a cause they want to push,*  
 Young Ivy Hensley is her name and she’s only 5 years old,  
*She lives outside of Clermont,; she’s excitable and bold.*

When Ivy was born back in ‘99, she never, ever cried,  
*Placid yet hyperactive, she could “flip” from side to side,*  
 Mother Nina loved her on sight, though breastfeeding seemed a chore,  
*Ivy’s breathing was peculiar; her attention span was poor.*

So finally at 9 months of age, they found a specialist who’d listen,  
*He trusted a ‘mother’s instinct’; found a chromosome branch was missing,*  
 At last a diagnosis, it was ANGELMAN SYNDROME,  
*Her parents searched for information, feeling over-whelmed – alone.*

A.S. Children are compulsive, they’re obsessed with water and food,  
*There are seizures to contend with and some unexplainable moods,*  
 Ivy’s temperature’s erratic, there’s no speech for communication,  
*She scratches and bites her brothers, as she acts out her frustration.*

Ivy’s life must be organised, she thrives on a set routine,  
*With play dough and paints for mornings and a sleep every day in between,*  
 She has a special Zip Up Bed, and just loves to watch TV,  
*There’s the outdoor time in the afternoon, with a fence to contain Ivy.*

Ivy lives on a cattle property and her parents work as a team,  
*If there’s work to be done in the cattle yards, they say goodbye to routine,*  
 She’s a part of the Hensley family, with brothers Adam and Tio, her chums,  
*A hardworking Daddy who loves her, and an overworked marvelous Mum.*

But as she grows, so do her needs, and her family travels far,  
*To Emerald Special Ed Classes, they’re off and in the car,*  
 She gets to take swimming lessons, though these days are quite rare,  
*And sometimes even a sleepover, a break in respite care.*

Even when Ivy is tipping, washing powder or rocks, down the loo,  
*Or if she’s found the conditioner and sometimes Mummy’s shampoo,*  
 When she’s trying to bounce on the baby, or being sent to her room for ‘time out’,  
*Not a day goes past when her antics, don’t have them laughing and falling about.*

The Hensley’s love family outings, though sometimes this is a chore,  
*Taking Ivy out is a problem, without constraints she’d cause an uproar,*  
 The Variety Club is donating a pram; they love to help meet children’s needs,  
*A Special Needs Pram, just for Ivy, it’s just one of many good deeds.*

Little Ivy Just loves people, and she always has a smile,  
*And I know that she would want us, to enjoy the Woolshed Dance a while,*  
 So thanks to “Ivy’s Angels”, the Bush Bashing Variety Club,  
*There’s a brand new buggy for Ivy, donated with lots of LOVE!!!!*

