



ANGELMAN SYNDROME ASSOCIATION

Newsletter

Charity No. CFN13843

ABN 42 169 355 488

No. 37 – March, 2005

President's Say

Hi all and welcome to any new parents/caregivers. The year is already speeding by and Easter is almost upon us.

Preparations are well under way by the Conference Committee for the 2005 ASA Conference to be held in South Australia in September/October.

This will be a fantastic opportunity to meet and network with other families and learn some new information to assist us all in living and working with our angels.

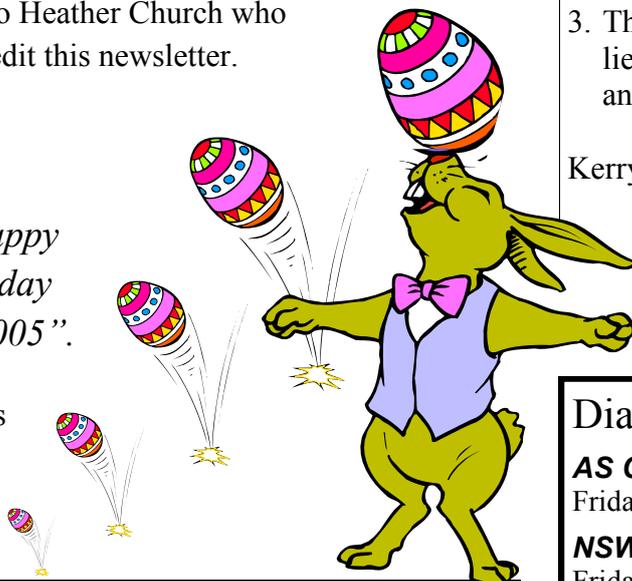
Thanks again to this hardworking committee for all their efforts.

They have included a couple of advertisements on page 2 of this Newsletter.

Thanks also to Heather Church who continues to edit this newsletter.

"I wish you all a very safe and Happy Easter Holiday break for 2005".

Warm regards
Anne Funke



From the Editor -

Hi, I hope everyone enjoyed their Christmas. How did all your 'Angels' like their presents? Or were they more interested in the wrapping paper?

I hope you all had a safe and happy holiday break, but isn't it good to get the children back to school.....

Write in and tell us what your 'Angels' got up to – or in to! How about some other family stories?

Please send any stories, jokes, photo's, info. to me at email-robhedge@ozemail.com.au (please mark it "Newsletter") or send to 18 Baker St, Lilydale Vic. 3140

Thank you. Take care. Heather Church (Vic.)

A message from the A.C.T.

Thought some members may be interested in the Standing Committee on Family and Human Services' current inquiry into balancing work and family:

<http://www.aph.gov.au/house/committee/fhs/workandfamily/index.htm>

Terms of Reference

The Committee shall inquire into and report on how the Australian Government can better help families balance their work and family responsibilities. The Committee is particularly interested in:

1. The financial, career and social disincentives to starting families;
2. Making it easier for parents who so wish to return to the paid workforce; and
3. The impact of taxation and other matters on families in the choices they make in balancing work and family life.

Kerry O'Kane – A.C.T.



Diary Dates:

AS Committee Internet Meeting 2005

Friday 1st April – Tuesday 5th April

NSW Family Coffee Morning

Friday 8th April, 2005 @ 10.30 am at Bayliss residence, 4 Wardington Rise, Bella Vista Estate, Baulkham Hills.
RSVP ph: (02) 9634 7032

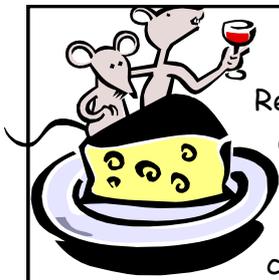
AS Clinic Coffee Morning

Friday 27th May 2005
Old Post Office Building, Kogarah

The 7th National conference

Friday September 30 - Sunday 2nd October, 2005 at the Stamford Grand, Moseley Square, Glenelg, South Australia.





TOOTH MOUSSE

Recently Hannah's dentist told me about a new product, **Tooth Mousse**, which could be useful in protecting her teeth against decay and making them stronger. Even though we clean her teeth with an electric toothbrush, it is quite hard to clean them properly. Not very long ago she had to have four fillings under general anaesthetic and we want to avoid that if possible.

To quote from the brochure:

..."It contains calcium and phosphate, the major minerals teeth are made from. Because these minerals are carried in a special milk-derived protein...they are available in a soluble form. This means Tooth Mousse can protect the teeth like saliva and replace minerals lost by regular acid attack after eating and drinking..."

Tooth Mousse can be obtained from your dentist.

Sally Shackcloth
Tasmania

News from Victoria

Hello, my name is Raye Hearn, I have taken over the role of State Vice President for Victoria from Heather Church.

My family moved back from Queensland 5 years ago, where I was the Angelman Vice President for a couple of years. Some families may remember my family and son Gus from that time. Gussy is now 14 years old.

I would like to thank Heather and her family for her 11 years of work for the Association and wish her well for the future.

We are having our annual 'Angels' picnic, family get together on the 20th march and I look forward to getting to know the Victorian families then.

I am honoured to be elected vice president for Victoria, and I am happy to be contacted for any queries or support enquiries anytime, my email address is -

rayemondehearn@optusnet.com.au

I would like to wish all A.S. families well and hope you all have a lovely restful Easter break.

Kind regards Raye Hearn.

Messages from the Conference Committee

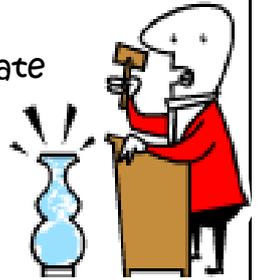
To All Families

Auction for Conference Saturday, 1 October 2005

During the Saturday night dinner, we plan to hold an auction. Tiffany Jellicoe is organising this section of the conference and is already in the process of asking for a number of items for this.

Do you know anyone famous that may be able to assist us with a sellable item???
Or, do know anyone in the retail industry that may be able to donate goods to the auction???

If you do, we would appreciate any assistance that you may be able to give with donations for the auction.



To All Families

Photo Display National Conference Saturday, 1 October 2005

We plan to have a power point presentation of our 'Angel's to run during the conference dinner.

We would like as many photos as possible for this. If you would like your 'Angel' included in this presentation you can forward your photo to me in the following formats:

Email to: monbuild@iprimus.com.au
JPG (JPEG) images are preferred

Post to : Kerri Monaghan
PO Box 202
Woodcroft Town Centre SA 5162

All photo's will be returned if needed, so please include your return address.

Thank You

Conference Committee



"Angelman" Rule City Farm in New South Wales

Hello to you all,



On the 23rd of January (an ex-President's Birthday) we organised a picnic at Fairfield City Farm.

About 60 families said they would love to come. A few families asked what to do if it rained, I reassured them that we had spoken to the right person above and all would be great considering it was January and usually stinking hot.

The night before the picnic a huge storm hit with lots of rain, lightening and thunder. Still being positive I hoped it would pass, but early Sunday morning more thunder and lightening and buckets of rain. Oh well I still got up and made a picnic basket to take.

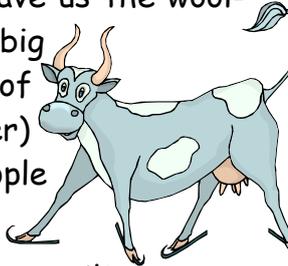


After a few phone calls and cancellations we decided to go to the picnic and take our rain coats and wet weather gear.



Well!!! What an adventure.

After unloading our children and bags we got some good news, the farm organisers gave us the woolshed (which was big and had plenty of seats and under cover) because not many other people would turn up in the storm.



The day was fantastic, we were spoilt rotten by the staff, we had private tours of the nursery, bottle fed sheep, goats and pigs, we had as many turns of milking the cow as we wanted, a dog show, a sheep shearing show in the woolshed, the koalas were brought to us to pat and take photos of. And there was



also a brilliant whip cracking show.

We got plenty of time to catch up with all the families and mingle with some new Angelman families.

I must thank all the families that turned up and especially the families from Newcastle way and Central coast, it was great to see you.

For the families that couldn't make it, don't worry, we are organising more get togethers for us all.

Hope you all have a Wonderful Easter and that the Easter Bunny makes it worth while.



Until next time, be good and take care.

Cathy Bayliss



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Telephone: +61 8 8161 6737
Facsimilie: +61 8 8161 7032
Email: info@siblingsaustralia.org.au
www.siblingsaustralia.org.au

Parents supporting siblings

If you are able to support your children, the whole family is likely to function more positively. Also your children are more likely to develop strength and resilience, compassion and tolerance, responsibility. Look after yourself too, explore your own feelings, don't be afraid to ask for help.

What can parents do?

- ◆ Provide siblings with information about the disability
- ◆ Acknowledge a sibling's feelings – LISTEN
- ◆ Recognise and discuss their losses
- ◆ Encourage open communication
- ◆ Include siblings in family discussions
- ◆ Spend 'one on one' time with siblings

These are just a few things of what parents can do. For more information, please visit the above website, or send an email to the above address.



more News from N.S.W.

Our "angel" Sarah has had her 19th birthday, (11th November - oh what a birthing memory!!) and last year was the first after finishing school.

The last six years prior to that were spent at Kingsdene Residential School - a fantastic environment with dedicated carers and teachers. After much publicity and constant lobbying by parents the school will keep its doors open for at least another 12 months.

This school should be a role model for many others around Australia. When Sarah started at Kingsdene (1998) there were three other Angelman students, 3 have since left after turning 18, and 3 other "angel" students now attend).

With leaving school came concerns as to what respite services were available.

On Friday 22nd October, I attended the Annual Fundraising Dinner for the Estia Foundation, Master of Ceremonies being Ray Martin. This was held at Doltone House, Jones Bay Wharf, Pyrmont, Sydney, and what a fabulous night!

Estia (which means "hearth" or "warmth") is an initiative of the Greek Orthodox Archdiocese of Australia which is dedicated to helping young adults who have a disability, physical and/or intellectual, by providing respite in one of two houses.

It was at this dinner I caught up with Jenny Chippindale (mother of Sascha - nearly 22 yrs), who was one of the founding members of our association and the first President.

Ray Martin had the Angelman Syndrome story on his Midday Show some 10 years ago. He introduced Jenny who spoke of Angelman Syndrome, but mainly of the respite house, the dedicated and caring staff and the great feeling that our charges are being looked after "as if they were family".

The evening was, I'm sure a great success for the organising committee, (and financially I'm sure) as well as bringing people together and enlightening those to the needs of people with disabilities. (Maybe we could get Jen back on board to help organise something similar!)

PS: One little reminder for Easter - our angel's arms magically extend an extra foot, AND their noses become super super sensitive to chocolate and other lollies!! Who knows what I mean - I hear you giggling about past experiences you've had. Oh, God Bless our chocolate faced Angels -Amen!

Annie Cole

Enjoy today for who knows what tomorrow may bring



Our "angel" Sarah.

This pickie was taken in Sept/Oct last year at Sylvanvale when the ARL Cronulla "Sharks" visited and put on a BBQ.
Annie Cole

Don't You Hate It When

- The car park is full and you have to park 1km away.
- You discover that someone has turned up the volume on your stereo to "full" - after you turned it on.
- You accidently tear your new jeans.
- People throw their McDonalds pickles on the ceiling.
- People throw their McDonalds pickles on the ceiling and it falls off while you're sitting underneath.
- The best 3 T.V. shows are all on at the same time.
- Your VCR breaks down.



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Newsletter articles to -
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