



## *Outgoing President's Say*

Firstly, I would like to start this report with an apology for the lack of work done by myself in 2008. Due to a serious personal illness, a major move and promotion I have not been able to give the time to the ASA as I would have liked. We, like all of you, are also experiencing some significant difficulties with our now teenager Angel, Lachlan. Sleep has not been on our agenda for months!

The 2007 conference was a tremendous success and appears that our WA friends are well on their way to organising a bigger and better conference for 2009.

I have had a few new families contact me and have put them in touch with their state's vice president. I would like to encourage all our families to keep in touch with at least one family as the support we can give each other is invaluable.

It is with regret that I tender my resignation as President. However, I would like to be considered for this position in the future when my home and work life has settled down. Good luck to our next president and I look forward to seeing you all at the WA conference in 2009.

MEGAN MOORE

## *President's Say*

It is a pleasure to return to this role again—having had a year's break. Thanks to Megan Moore our outgoing President for holding the reins over the past year—it is not easy juggling all our responsibilities at one time! I welcome our new committee members and for those that have continued I thank them for their ongoing commitment.

I also welcome any new parents and carers—Many of us have walked in your shoes so please feel free to contact your state Vice President or any of the committee members if you need to discuss anything. We recently held our AGM at the Sydney Tram Museum at Loftus and the day was a huge success. There were 70 in attendance (children included) and the tram rides were very popular and kept our Angels well occupied! 2009 promises to be an exciting year with the WA committee well underway with the plans for our first ever National Conference in that state to be held 2-4 October 2009. Also, Angelman NZ Inc will be holding their conference in March of this year.

Warm Regards, Anne Funke

## **National ASA Conference** **2 - 4 October 2009** *West Coast Angels*

The 9<sup>th</sup> Biennial ASA Conference will be held in Perth, WA on the weekend of the 2 - 3 October, 2009.

The venue is at The Esplanade River Suites, South Perth which overlooks Perth's famous Swan River. There are 101 guest room and apartments, a selection of self-contained studios and one and two bedroom apartments all with spas and feature a variety of views over the river parklands.

The website is [www.esplanaderiversuites.com.au](http://www.esplanaderiversuites.com.au)



The Conference committee report that Perth is at 85% capacity at the moment and in high demand so it is not too early for people to start booking. You need to contact the hotel by telephone and mention our conference to receive the discounted rate for accommodation. **Phone 08 9367 0300.** The accommodation is very disabled friendly and conveniently located in proximity to city and airport.

### **TOPICS ?**

If anyone has any requests for topics or sessions that they would like to be included into the conference day could they please email either:

Kellie Wild – Conference Coordinator

[ekwild@aapt.net.au](mailto:ekwild@aapt.net.au)

Liz Stanley -

[stanleyhome@bigpond.com](mailto:stanleyhome@bigpond.com)

Leticia Grant -

[maygrant@tpg.com.au](mailto:maygrant@tpg.com.au)

### *Disclaimer*

*The views expressed in this newsletter and any enclosures are not necessarily those of the Angelman Syndrome Association. Information is presented in the interest of providing a range of alternatives. Inclusions in this newsletter does not imply endorsement by the Angelman Syndrome Association.*



## *Ellie's Art Gallery*

In February 2008, I opened a small elite Art Gallery in beautiful Bundeena, NSW.

At the exhibitions, I promote Angelman syndrome, as the organisation whose needs I support.

This advocacy appears on the website of the Gallery – [www.neilstreetgallery.com.au](http://www.neilstreetgallery.com.au) which also gives the website of ASA.

The first exhibition was held in February, an exhibition of the paintings of Vojtech Kinsky, one of the artistic WW2 refugees to Australia.

At the opening, attended by over 60 people, Anne Funke came as representative of ASA and made a moving and welcoming speech. Anne brought her two children along for the afternoon – Mitchell (with AS) and Laura. Many enquiries about AS followed on (pictures enclosed).

Since then, there have been 5 more exhibitions with the final one for this year – an Art and Craft exhibition - in November.

Already for 2009, exhibitions for January, February and March have been booked.

On each occasion, I say a few words about AS, wear my Patron badge and hand out information to anyone who enquires – and ask for donations!

For anyone available to view these interesting and important exhibitions, please feel free to come along - it also helps with raising awareness to have your presence.

Dr. Ellie Smith



## *Summary of Research Findings from Andrew Moss*

The attached document provides a brief summary of a research project that was conducted in the second half of 2007 titled "Enhancing carer outcomes: Identification of predictors of quality of life, mental health and positive affect in carers of individuals with a high needs disability".

Should you wish to contact Andrew regarding any aspect of this research, he can be contacted by email at:

[mrandrewmoss@hotmail.com](mailto:mrandrewmoss@hotmail.com)

## *NZ AS Conference*

This year the NZ AS Association will be hosting their second AS Conference.

This will be held in Wellington over the weekend of the 7<sup>th</sup> – 8<sup>th</sup> March (2009).

Theme of the Conference is "BUILDING PARTNERSHIPS"

This theme aims to bring together medical, ancillary, support and research groups to interact with the AS association..



## *Association has a NEW LEASE OF LIFE*

As you are aware there has been very little activity from the Association for the last year or so. This has been for a variety of reasons. Firstly, many of the committee members have had a difficult year with family and health issues, as well as significant work commitments. This has prevented them from giving time to the Association until now – but we are all back on track. We all volunteer our time and have Angelman children just like you – and you know what this is like.

Nevertheless, I would like to apologise on behalf of the current committee to our members and those who have sought assistance or information from our association during this time and found our response somewhat sluggish. The whole committee is now hard at work and we have recently held a committee meeting via email which spanned a whole week. Many issues were discussed, especially our 9<sup>th</sup> National Conference to be held in Perth in October 2009. We have also committed ourselves to an email meeting at least once every three months. Please contact any of the committee members if you would like issues discussed at these meetings.

As a result of our inactivity, **NO MEMBERSHIP FEES** have been nor will they be collected for 2008, and all arrears have been deleted from our records. The next round of membership invoices will be sent out soon for the 2009/2010 financial year.

If there is any way in which our Association can assist you, please feel free to contact us.

Thank you for your understanding — Kevin Kennedy.



## *News from Tasmania*

Our group of Tasmanian Angelman families met up in Launceston in January for a lunchtime picnic. It was to be held in City Park but the weather looked a bit threatening so Helen and Linden Hearps were able to organise the use of the Sheridan's group home.

Altogether, there were families of six children and adults with AS (ranging in age from one year to 31 years) represented. It was exciting for one family in particular who had not met anyone else with AS. Launceston was chosen as a central spot as our families are spread far and wide across Tasmania.

Hopefully, we'll organise something similar for next Christmas holidays and we should have some more Tasmanian members attending the Conference in Perth.....

## **Angelman Syndrome and Osteoporosis**

### *Report of Chanra's visit to Professor Prince*

Professor Richard Prince is an endocrinologist whose area of expertise is Osteoporosis.

Chandra has seen him now on two occasions. A Bone Metabolic study was done by blood and urine tests. Chandra's pathology results indicated that her Vitamin D levels were down to 24 where they should be up over 50. The vitamin D level indicates that calcium and magnesium may not be metabolising properly. Chandra has been prescribed Vitamin D 1000mg plus high calcium diet, calcium and magnesium supplements.

Bone densitometry was not performed due to the difficulties in keeping her still for 20 minutes. If Chandra ever requires a CAT scan – Professor Prince would like her to have a bone scan done at the same time.

### **Professor Prince is keenly interested in Vit D / Angelman Syndrome.**

**He has suggested that all angels get their Vitamin D levels taken – when blood is taken for other reasons. He is interested in the results. He has suggested that perhaps a paper could be published – and he said he would speak at our 2009 conference. But he needs results of blood tests to determine if indeed the Vitamin D deficiency is an Angelman Syndrome phenomenon but only if there has been no supplementation of Vitamin D prior to the test.**

### **Blood Tests he requires are:**

**Parathyroid hormone  
25 hydroxy Vitamin D  
Alkaline phosphatase  
Calcium  
Magnesium**

If your doctor is agreeable – these results should be forwarded to ::

Associate Professor Richard Prince  
St. John of God Health Care Clinic  
Level 3, Suite 305  
25 McCourt Street  
Subiaco WA 6008

Your doctor should include a short note advising the results are from a patient with Angelman Syndrome, name, age and diagnosis – del+, UPD or UBE3A

*Note in six months of taking Vitamin D Chandra's levels increased from 24 to 150*

Liz Stanley

## **2008/2009 ASA Committee**

### **NATIONAL PRESIDENT:**

Anne Funke

### **VICE PRESIDENTS:**

NSW	Carla Upfill
ACT	Kerrie O'Kane
VIC	<i>Currently Vacant</i>
TAS	Sally Shackcloth
SA	Kerri Monaghan
WA	Kellie Wild
QLD	Alison Bennett-Roberts

### **NATIONAL SECRETARY:**

Kevin Kennedy

### **NATIONAL TREASURER:**

Robert Church

### **NATIONAL COMMITTEE:**

*(maximum of 5 nominees for 5 vacancies)*

Liz Stanley  
Lysandra Warren  
Leticia Grant  
John Hannaford



## Diary Dates:

ASA National Conference

2-4 October 2009



## *News from the Editor*

I would just like to say a thankyou to everyone for their contributions to the newsletter. I have really enjoyed doing it since November 2003, but due to my health, I can no longer do it.

Kerri Monaghan from South Australia has kindly taken it over for me.

Regards,  
Heather Church  
Victoria



## *Do you want your Newsletter emailed?*

If you would like your newsletter emailed to you instead of being posted (*which is cheaper and faster*), send a note to Kevin Kennedy at [kevin.kennedy@bosco.nsw.edu.au](mailto:kevin.kennedy@bosco.nsw.edu.au) requesting that your future newsletters be emailed to you.

**All Correspondence to:  
Angelman Syndrome Association  
PO BOX 554  
SUTHERLAND NSW 2232**

**Email: [kevin.kennedy@bosco.nsw.edu.au](mailto:kevin.kennedy@bosco.nsw.edu.au)**

**Newsletter articles to -  
[admin@monaghanbuilders.com.au](mailto:admin@monaghanbuilders.com.au)**

