



## President's Report

International Angelman Day was celebrated on 15<sup>th</sup> February with family events organised. I am happy with the response considering the short lead in time we had. Next year we will be a lot more organised and will endeavour to get some media coverage.

**The Better Start programme** for Angelman families has commenced. Eligible families can register with Carers Australia for their early intervention benefits for children under seven years of age, and for families with children under 13, having registered a health care plan for Medicare benefits. If you require more information, the fact sheet is available to download from our website:

[www.angelmansyndrome.org](http://www.angelmansyndrome.org). Children with Angelman syndrome are eligible regardless of sub-type - deletion, UPD, UBE3A and mutations, and if your child has a clinical diagnosis without laboratory confirmation, a letter from a geneticist, or clinical paediatrician will be required to confirm diagnosis.

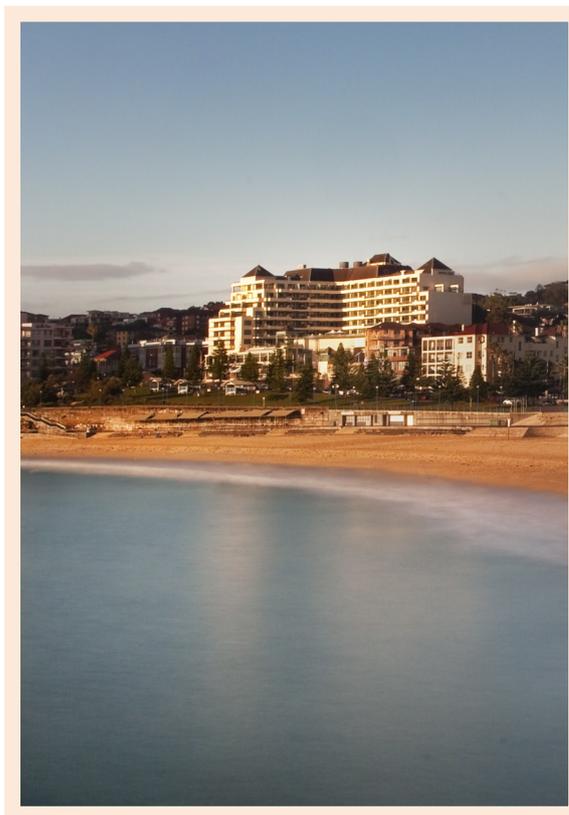
A list of registered therapists in each State can be found on [www.fahcsia.gov.au/betterstart](http://www.fahcsia.gov.au/betterstart)

**The 2013 Conference** will be held in Sydney on **Friday 4<sup>th</sup>, 5<sup>th</sup> and 6<sup>th</sup> October**. Professor Bernard Dan and Professor Edwin Weeber have both indicated they will attend. It will be great to have Bernard back downunder for our conference. Those of you who attended the Perth Conference will remember his fantastic presentation and the easy way he interacted with families. Professor Weeber will be talking about the clinical trials underway in America. Details of the conference will be sent to registered members shortly.

The Management Committee met in April. We have set up a Links and Resources page on the website which will give members easy to find websites on epilepsy, Government disability sites and general disability information.

Liz Stanley  
President  
19th April 2013

# Angelman Syndrome Conference 2013



## Date

October 4th to 6th, 2013

## Venue

Crowne Plaza, Coogee Beach, Sydney, NSW, Australia

## Invitation

On behalf of the organising committee, it is our pleasure to invite you to the

### **International Angelman Syndrome Conference, 2013**

### **"20 Years Of Angelman Syndrome in Australia, Looking Back and Moving Forward"**

to be held in Sydney on October 4-6, 2013.

The Conference is being organised as a collaborative venture between the Angelman Syndrome Association , Australia and the Angelman Clinic in Kogarah, South East Sydney Local Health District.

The conference aims to enhance the understanding of this rare syndrome to improve the health and well being of people diagnosed with Angelman Syndrome through the sharing of information related to research , clinical practice, service models and best practice. This will provide an ideal learning and networking opportunity for parents and carers, medical practitioners, allied health staff and disability workers and consumers.

On behalf of the organising committee, we look forward to meeting you in Sydney.

Dr Robert Leitner , Director of Developmental Assessment Service & Angelman Clinic Co-ordinator

Anne Funke , Social Worker- Disability Carer Advocate & NSW Vice President Angelman Syndrome Association.



## Apps help smiling Allara communicate

26/Feb/2013 Melville Times Community News



ALLARA May is a 12-year-old girl with a rare condition hiding behind an infectious smile. That infectious smile was out in full force last week when she joined dozens of others to celebrate the inaugural International Angelman Syndrome Day with a trip to Maylands Waterland. "It was an opportunity to get all the families together for a picnic to celebrate the first IAD," her mum Leticia Grant, of Applecross, said.

In WA, about 84 people are living with the syndrome. It is a genetic condition affecting the 15th chromosome it's not inherited, but rather a random occurrence at the time of conception.

Ms Grant is the President of the Angelman Syndrome Association of WA.

She said the aim of the association and the international day was to support, inform, educate, network and advocate families with a child with Angelman syndrome.

"We hope the day will help to raise awareness so we can find and support the many not yet diagnosed with AS."

Ms Grant said the ever-improving technology was helping Allara, who has been unable to speak, communicate.

"She is learning to use the Ipad, and a 'talking' app, which has been life changing for her to be able to communicate."

The day has just passed but already Ms Grant is planning the next fundraising event, which will be held in East Fremantle in November.



## Victoria



International Angelman Syndrome Day  
News from Victoria

Jo Davis organized a picnic in the Royal Botanical Gardens which was attended by about ten families.

Posted on youtube.  
<http://youtu.be/TTVySQwTGik>  
 Hope to be bigger next year!

John Hosie, VP (Vic).

## ANGELMAN SYNDROME CALENDAR 2014

We are intending to produce a **2014 calendar** to have ready for sale at the October conference. Please participate! The more the merrier! Send a photo of your child or adult by **the end of June** (with their name and date of birth included) to:

Lysandra Warren  
[warren.lysandra@gmail.com](mailto:warren.lysandra@gmail.com)



**Newsletter by email**

If you would like your newsletter emailed (PDF format) to you instead of being posted send a note to Kevin Kennedy at [kev-in.kennedy@angelmansyndrome.org](mailto:kev-in.kennedy@angelmansyndrome.org) requesting that your future newsletters be emailed to you. This is not only cheaper for the association but faster for our Treasurer who volunteers his time while, like us all, juggling work, family and life with an angel.

**Correspondence to President**  
 16 Kirkcolme Way WARWICK WA 6024  
**Payments to Treasurer**  
 PO Box 554 SUTHERLAND NSW 2232  
**Newsletter articles to**  
[sallyshackcloth@live.com.au](mailto:sallyshackcloth@live.com.au)  
**Deadline for next issue: early July, 2013**



Continued from page 6

And lastly, a friend of mine has her own business on facebook called Emnicjans selling homewares and different sorts of things. She offered to have a special \$15 sale on her wall decal quotes and donate \$5 for each one sold. Once again I was plastering all over facebook what was going on. The response was better than I expected and raised \$465. So after I originally hoped to raise about \$2500 for F.A.S.T. in recognition of International Angelman Day, along with some awareness in my local community now that Jesse is starting to get older and interact with a wider range of people, I was overwhelmed by the support that we received. Our total figure was **\$6,483.05**. I was so excited and grateful to everyone that helped out, and already looking forward to next year. I hope if things don't turn out for me, my community will get behind my family and help Adam carry on what I have started as an annual thing. I keep telling him every time I put tomatoes in the freezer they are for the relish for next year's stall, alongside the raspberries and strawberries for jam, and to make sure he is ready to bake, bake, bake.



Thank you Anne for that inspiring report! Scottsdale has really got behind you and your family and the Angelman cause! Best wishes, Sally.

**Angelman Syndrome Association  
National Conference**

4<sup>th</sup>, 5<sup>th</sup> 6<sup>th</sup> October 2013

Sydney

**Keynote Speakers**  
Professor Bernard Dan (Belgium)  
Professor Edwin Weeber (Florida USA)

Save the Date

More information next issue

For more details on the conference go to page 9 of this newsletter.

## CLINIC CHAT with Dr Madhura Bakshi

Hi all,

Here at the Angelman Clinic, the focus over the next few months is planning the AS conference coming up in October this year. Hope to see many of you at the conference!

I am putting some time into reviewing the clinical data from the information collected via clinic over the years, with a view to presenting it at the AS conference. In particular, I will be looking at the data to try and address some of the specific questions raised at the AS Seminar held in Sydney in 2012 for example, behavioural differences and bone health in AS.

I would be interested in feedback from association members if there are other aspects that might worth looking into based on the clinical information we have collected over the years.

Emails can be directed to the AS Clinic , [AngelmanClinic@SEZIAHS.health.nsw.gov.au](mailto:AngelmanClinic@SEZIAHS.health.nsw.gov.au).

Best wishes,

Madhura Bakshi



Madhura Bakshi is a Clinical Geneticist by training with a paediatric background.

## Essential Medical Equipment Payment

The **Essential Medical Equipment Payment** is an annual \$140 payment to people who experience additional increases in home energy costs from the use of essential medical equipment to manage their disability or medical condition. Payments will start from 1 July 2012.

For more details look up:



Chronic Illness Alliance

[www.chronicillness.org.au](http://www.chronicillness.org.au) Click on the section, **What's new at CIA**

People eligible for the payment must hold or is included on: Health Care Card, Pensioner Concession Card, Commonwealth Seniors Health Card or Department of Veterans' Affairs (DVA) Gold or White Card; and provide proof that the specified essential medical equipment or medically required heating/cooling is required as a result of a specified medical condition.

(NOTE: This is not the same 18% concession payment that some may be already receiving from the State government.)

## Some more news from Western Australia! Please support this worthwhile fund-raiser!

Join us for  
a night for the angels



Charity dinner and Auction  
raising funds and awareness for:

**Date:** Saturday 16th November 2013  
**Location:** East Fremantle Football Club, Perth  
**Dress:** Cocktail  
**Tickets:** \$135 includes 3 course meal & drinks  
Tickets available and donations welcome through the website.  
[www.nightfortheangels.org](http://www.nightfortheangels.org)

General Enquiries and Admin Co-ordinator

Danneal Jez  
0407 470 581



I've just been reading the **Assert** Newsletter 51, Autumn 2012 and found an interesting article reporting a study into 'Stress in parents of children and adults with Angelman syndrome. It was interesting that the study found four specific factors influencing the level of parental stress including: self-injurious behaviour; conduct problems; impulsive and repetitive behaviour and the level of support parents received. The study was conducted by the Cerebra Centre for Neurodevelopmental Disorders and one of the researchers is **Prof. Chris Oliver**. You can find the newsletter on the Assert website:

<http://www.angelmanuk.org/>

(Editor)



Families may be interested in a South Australian business designing clothes for children with disabilities. The website is:

[www.inspiredbylaceyshea.com.au](http://www.inspiredbylaceyshea.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.



## NSW Vice President report May 2013

Hi all - Planning is well underway in preparation for the big conference in October 2013 and it is most exciting that we have our two international speakers confirmed! Expressions of interest will be sent out shortly and a webpage is being developed, so please spread the word amongst all your family, friends, treating professionals, care workers etc.

### Conference Title:

**"20 Years of Angelman Syndrome In Australia: Looking Back and Moving Forward"**

**Friday October 4 - Sunday October 6**

Friday Oct 4 - Scientific Conference; Welcome to Families PM

Saturday Oct 5 - Family Conference; Conference Dinner PM

Sunday Oct 6 - AGM; Conference Picnic

### Venue:

Crowne Plaza Coogee Beach  
Cnr Arden & Carr Streets (PO Box 558)  
Coogee NSW 2034  
<http://www.crowneplazacoogee.com.au/>

### Accommodation:

The online booking site for Accommodation:  
<https://resweb.passkey.com/go/angelsyndrome>

Accessible rooms are available by request and the contact person is Christie Hollis  
E: [christie.hollis@ihg.com](mailto:christie.hollis@ihg.com) T: +61 2 9315 9115 F: +61 2 9315 8113

If you are intending to attend it would be advisable to book your room online as soon as possible. Alternative Accommodation options are being investigated and will be sent out shortly.

To register your interest to attend the conference, you can email the committee on:

[AngelmanClinic@sesiahs.health.nsw.gov.au](mailto:AngelmanClinic@sesiahs.health.nsw.gov.au)

The children and young adults with Angelman Syndrome and their siblings will be provided with an activities program to enable families to attend and fully participate in the conference. This will be forwarded shortly once finalised.

We have applied for national funding to assist those travelling from interstate and regional and remote areas to attend. Additional funds will be allocated from Angelman Syndrome NSW, to also assist families. We will provide a form for people to complete and submit with the registration forms to the committee if they would like assistance to attend. We would encourage as many of you to attend to celebrate this significant achievement of 20 years of the Angelman Association and establishment of the Angelman Clinic.

We are seeking input from interested people wishing to assist on a conference sub-committee to help organise a theme and activities for the Saturday night conference dinner as well as some input into the topics for the Saturday conference. If you are interested, please email me directly on [anne.asa@bigpond](mailto:anne.asa@bigpond) or alternatively call me on Mob: 0457 616168 to discuss what is required

Look forward to seeing you at the conference!

Regards Anne Funke

