



## President's Report



There has been a lot of activity on Angelman syndrome over the last few months.

The most significant of these is the formation of International Angelman Syndrome Day.

**International Angelman Syndrome Day will fall on the 15<sup>th</sup> February each year.**

23 countries were canvassed to find a common day.

The purpose of this day is to:

1. Raise awareness worldwide of the condition
2. Mobilise people to action & encourage fundraising for the individual organisation in their country
3. Remember those people with Angelman Syndrome who are no longer with us.
4. Promote research and educational resources in your country.

The Executive committee of ASA will be addressing how we can achieve some of these goals next year and in 2014, working towards an Australian event in 2015 which will be 50 years since Harry Angelman first identified the syndrome.

**A big thank you goes to Brian Mannix** for nominating Angelman Syndrome as his charity on Millionaire last month. Thanks Brian for your participation and efforts on our behalf.

**Angelman Syndrome Foundation and FAST** recently were in the USA based Chase Giving grants. If you are on Facebook you probably saw the numerous posts about voting. It's over for another year but the result was \$50,000 to FAST for research and \$20,000 for ASF for research into AS.

Australia has signed in to support a **paediatric diagnostic video** which is currently being produced by The Angelman Syndrome Foundation in the USA. When the video is completed it will be posted onto the ASF website. The video is three minutes in length and provides a concise and accurate depiction of Angelman Syndrome which will be useful for medical professionals, nurse practitioners, paediatricians and paramedical practitioners.

**Brochures:** All State contacts have now received quantities of our new brochure. Please contact your State VP (contact details available on our website) if you want some. The brochures are useful to hand to teachers, therapists, and even emergency room staff. I have a brochure attached to the inside cover of Chandra's hospital notes. The brochures can also be used when seeking support from businesses for financial or other donations.

**New Committee Member.** We are pleased to have John Hosie join the committee as State VP for Victoria. See the information on John later in the newsletter.

### **2013 Conference, Sydney**

Dates have been confirmed for October 4,5,6. Professor Bernard Dan will be attending so keep your diaries booked for this weekend. This conference is marking 20 years since the inception of Angelman Syndrome Association in Australia.

More on the Conference as it comes to hand. Preliminary intention to attend will be sent out early next year.

Separate FAST news is included in the newsletter.

*Liz Stanley*  
24<sup>th</sup> September 2012.



## Meet your committee!

### John Hosie, Victoria



My wife, Lorraine and I are retired from the workforce. I keep fit by rowing a couple of days a week and train for such events as the Rowathon on the Darling River in aid of the Flying Doctor Service and the Head of the Yarra in Melbourne. We are both interested in genealogy. I have just become the Vice President of our Supportive Families & Friends Association Eastern Metropolitan Region Inc. This group represents and provides information to assist families and friends to effectively advocate for individuals living in Shared Supported Accommodation.

Jason is 40 years old this October who is non-verbal and lives in a Supported Residential house. He shares it with four others who have various disabilities but all have epilepsy and so have staff on all night. He is happy playing with water and sand but also planning how he can escape! He is having problems at present with sleeping. He seems to be only catching three hours a night. This was the reason I was looking at the ASA and FAST sites. I am interested in Minocycline trials. He is a deletion 15.

Welcome to the committee, John. (Editor)



## ANGELMAN SYNDROME 2013 CALENDAR

Photos needed please  
by 15<sup>th</sup> October!

As a fundraiser towards the cost of the 2013 Conference and FAST we are going to produce a calendar with our Angels' photos on the page of their birth month. Email your angel's photo to Lysandra who will be co-ordinating all the photos.

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

Remember to include your angel's name and birthdate.

This project is subject to Lysandra receiving heaps of photos. Funding is being sought to assist with printing costs. Can you help?



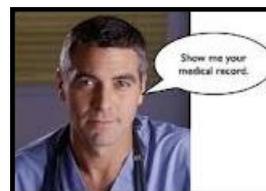
**Personally Controlled Electronic Health Records** will be introduced in Australia by the Federal Government during the next 12 months. I see this as having great benefits to angel families. As memory-poor mothers due to sleep deprivation we will no longer be worried about giving inaccurate medication or past history information to the medical practitioner. Parents of Children with Disabilities (Inc) in Western Australia have been lobbying for this for about 20 years. Provision has been made for individuals who have limited or no capacity to participate through a nominated representative of family member or carer.

**PCEHR Concept of Operations**—As part of the 2010/11 federal budget, the Government announced a \$466.7 million investment over two years for a national Personally Controlled Electronic Health Record (PCEHR) system for all Australians who choose to register online, from 2012-13.

The Concept of Operations document provides an overview of the personally controlled electronic health record (PCEHR) system and how it will work. It has been updated following public consultation on an April 2011 draft of this document, ongoing consultations with stakeholders and lessons learned from local and international efforts. This version of the Concept of Operations will set the basis for the construction of the PCEHR system.

From July 2012, all Australians who choose to can register for a PCEHR. As the PCEHR system matures, Australians who use a PCEHR will be able to see their important health information in one consolidated view. They will be able to share this information with trusted healthcare practitioners, who in turn will be able to access their patient's PCEHR to support the delivery of high qual-

ity healthcare regardless of where and when it is needed. To access the document <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-document>



### [New electronic health records for patients](#)

ACT Chief Minister and Minister for Health Katy Gallagher has launched a pilot of a new secure system for Canberrans to access their health information online. My eHealth enables patients to access personal information relating to their health care. "My eHealth is a secure, online service which improves patients' access to their health information, and helps them keep track of their appointments," the Chief Minister said. "It gives patients more control over their health records and makes using health services more convenient."

My eHealth has been designed to complement the national Personally Controlled Electronic Health Record (PCEHR) and it is intended that My eHealth will integrate with the national eHealth system. The initial launch of My eHealth includes a pilot group of consumers from the Health Care Consumers Association and a group of 40 chronic care patients. Allowing a small group of healthcare consumers to register for My eHealth means the project team can fine tune the online service before making it available more broadly.

[http://www.cmd.act.gov.au/open-government/inform/act-government-media-releases/gallagher/2012/new-electronic-health-records-for-patients?utm\\_source=e-healthcare+brief+%28Combined+List+-+Trial%29&utm\\_campaign=46b3857b39-AHHA\\_e\\_healthcare\\_brief\\_11+September&utm\\_medium=email](http://www.cmd.act.gov.au/open-government/inform/act-government-media-releases/gallagher/2012/new-electronic-health-records-for-patients?utm_source=e-healthcare+brief+%28Combined+List+-+Trial%29&utm_campaign=46b3857b39-AHHA_e_healthcare_brief_11+September&utm_medium=email)



## CLINIC CHAT with Dr Antonia Milner



The clinic has continued to see (mainly) newly diagnosed children and their families this year. We have also had phone and email contact with other carers in Sydney and across Australia. We also regularly receive requests for advice from health professionals across Australia with regard to help with diagnosis, advice on therapy and even good iPad apps for kids with AS.

Anne Funke has been a fantastic addition to our clinic, offering her unique advice to new families as a social worker and carer advocate as well as the carer of a child with AS.

I hope everyone is well and hope you have the date of the AS seminar day in your diaries: Sat 27<sup>th</sup> October. Anne Funke has been working hard to make the day an interesting and informative one and will be sending details soon.

I will be on maternity leave from 25<sup>th</sup> October to July 2013 but will return to my clinic coordination duties then. I will remain involved while I am on leave (I can't stay away) but the main coordination duties will be undertaken by Anne Funke with Dr Rani Sachdev advising her on medical matters.

The Clinic email address is:

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

I hope to see you all on Sat 27<sup>th</sup> October.  
Warm regards,  
Dr Antonia Milner

## Western Australia News



Planning is underway for a fundraising gala dinner in Nov 2013 in WA. A Mum's weekend-away booked for Oct 19 this year and a family fun day the week after. We had our AGM this week with all the roles filled. We are planning to undertake training for Family Mentors to best support new and existing members especially through transition stages of the "living with AS" family journey.

Thanks to Leticia Grant for providing this report.  
(Editor)

A new website which links all the disability resources from all Australian states and territories has been developed by Sharon Williamson. Some information about Angelman Syndrome and the ASA can be found on the link below:

[http://disabilityonline.org.au/aboutdisabilities/index.php?option=com\\_content&view=article&id=84](http://disabilityonline.org.au/aboutdisabilities/index.php?option=com_content&view=article&id=84)





## Tasmanian News

**TAKE flight presents**

# Raising our wings

## GALA BALL

Join us for the inaugural Raising Our Wings Gala Ball brought to you by Take Flight. The Gala will be hosted by Hook Line and Sinker's Nick Duigan and Andrew Hart and will include a 3 course dinner, premium Tasmanian beer and wine, live and silent auctions, and the Picasso Bros. Get your friends and family together and come along to enjoy a fantastic night supporting Angelman Syndrome.

**When:** Saturday 13 October 2012  
**Time:** 6.30pm for 7.00pm start  
**Where:** Tailrace Centre, Riverside  
**Tickets:** \$135.00 per person or buy a table of 10 for \$1,200.00  
 Tickets on sale at [www.take-flight.org](http://www.take-flight.org)  
**Dress:** Formal

For more information visit [www.take-flight.org](http://www.take-flight.org) or call 0417 510 606.

**Emma Price** from Launceston is organizing this gala ball for next month which is exciting! Some families will be meeting on the following day for a get-together

Chloe Simons who is on the FAST Australia Board reports on the human clinical trial into the use of Minocycline in AS: "We still don't have official details on a stage 3 clinical trial involving Australia, but the results from the initial study will apparently be available in November. Anecdotal evidence suggests the parents with angels in the US trial were pleased with the results over the short trial period. An easy-read write-up of how minocycline may work with AS people can be found here:  
<http://blog.friendshipcircle.org/2012/08/16/a-treatment-for-angelman-syndrome-an-interview-with-dr-edwin-weeber/>



## News from South Australia

A family day was held recently to welcome our newest Angel. A report of this event and photos will be published in the December newsletter.





8:45am – 9:00am	<b>Registration</b>
9:00am – 9:15am	<b>Welcome</b> Anne Funke   Angelman Syndrome Association NSW Vice President Dr. Robert Leitner   Director, Developmental Assessment Service and Angelman Syndrome Clinic
9:15am – 10:00am	<b>National Disability Insurance Scheme</b> Daniel Kyriacou (or representative)   New South Wales/ACT NDIS State Co-ordinator
10:00am – 10:30am	<b>Angelman Syndrome: From a Siblings Perspective</b> John Skene   Brother of Ethan (Angelman Syndrome)
10:30am – 10:50am	<b>Morning Tea</b>
10:50am – 11:30am	<b>Genetic Mechanisms and Advances in Angelman Syndrome</b> Dr. Rani Sachdev   Clinical Geneticist, Angelman Syndrome Clinic
11:30am – 12:30pm	<b>Get Connected with Technology</b> Emma Minchin   ADHC Speech Pathologist This talk will discuss how mainstream devices such as iPads and iPhones can support children with Angelman Syndrome
12:30pm – 1:15pm	<b>Lunch</b>
1:15pm – 1:45pm	<b>Human Brain Development – To Remember for Angelman Syndrome</b> Dr. Ellie Smith   Assoc Professor, Cytogenetics and Consultant, Angelman Syndrome Clinic
1:45pm – 2:30pm	<b>General Medical and Health Issues</b> Dr. Allan Sturgess   Assoc Professor and Adult Physician in Intellectual Disability, St. George Hospital
2:30pm – 2:55pm	<b>Q &amp; A: Ask the Experts – Panel Discussion</b>
2:55pm – 3:00pm	<b>Seminar Conclusion</b> Anne Funke   Angelman Syndrome Association NSW Vice President Dr. Robert Leitner   Director, Developmental Assessment Service and Angelman Syndrome Clinic
3:00pm – 3:30pm	<b>Angelman Syndrome Association AGM</b>

*\*Siblings over 16 years of age are welcome to register and attend the Seminar.*



## CHILDREN / YOUNG PERSON'S PROGRAM

*A room has been booked for siblings and/or persons with Angelman Syndrome next door to the Seminar room. Food and activities will be provided for the day at no cost.*

*It is the responsibility of the parent / carer of the person with Angelman Syndrome to co-ordinate one-to-one care for the day. Respite care for the day may be organised by contacting the Commonwealth Respite and Carelink Centre: 1800 052 222.*

*Siblings are welcome to attend and some supervision (four children: one carer pending age) will be available for siblings on the day.*

### ACTIVITIES PROGRAM

8:30am – 9:00am	Registration and Handover with respite staff
9:00am – 9:30am	Orientation
9:30am – 10:15am	Walk along Brighton Le-Sands Beach
10:30am – 10:50am	Morning Tea
11:00am – 12:30pm	Lindsay's Magic Show
12:30pm – 1:15pm	Lunch
1:15pm – 3:30pm	Arts and Craft / Video Games / Music



## CHILDREN / YOUNG PERSON'S REGISTRATION FORM

### DETAILS

	Name	Sex	D.O.B
<b>Person with Angelman Syndrome</b>		<b>Male</b>	
		<b>Female</b>	
<b>Siblings</b>		<b>Male</b>	
		<b>Female</b>	
		<b>Male</b>	
		<b>Female</b>	
<b>Parent / Carer of Person with Angelman Syndrome / Siblings</b>			
<b>Mobile Contact No.</b>			

### SUPPORT NEEDS

<b>Needs</b>	Please provide details of your person with Angelman Syndrome's needs in the following domains (i.e. wears pads, eats finger foods, mobility needs)
<b>Allergies</b>	
<b>Toileting</b>	
<b>Special Dietary Needs</b>	
<b>Feeding</b>	
<b>Communication</b>	(Please ensure your child or adult has their communication device/ book if they use one)
<b>Mobility</b>	
<b>Behaviour</b>	
<b>Medical</b>	
<b>Other Needs</b>	

**ANY MEDICATION MUST BE ADMINISTERED BY THE PARENT / CARER OF THE PERSON WITH ANGELMAN SYNDROME AND / OR THEIR SIBLINGS.**



**NSW SEMINAR**  
**Novotel Sydney, Brighton Beach | Saturday 27 October 2012**

**ANGELMAN SYNDROME CLINIC**

I would like an appointment for my child/adult with Angelman Syndrome to attend the Angelman Syndrome Clinic at Kogarah Developmental Assessment Service, St. George Hospital on Friday 26 October 2012.

YES    NO

**CARER FUNDING**

I have contacted my local Carer Support and Respite Centre    YES    NO

I will be bringing my own carer on the day    YES    NO

If yes, please provide name: \_\_\_\_\_

**CONSENT FORM**

I/We authorise and declare for: (insert name of person with Angelman Syndrome and/or sibling names)

Name: \_\_\_\_\_

Name: \_\_\_\_\_

Name: \_\_\_\_\_

Name: \_\_\_\_\_

consent to our person with Angelman Syndrome and/or siblings taking part in the day on Saturday 27 October 2012.

I give consent for the Angelman Syndrome Association to use images taken of my child / children in Angelman Syndrome Association publications and marketing materials.

YES    NO

I understand that I have the right to withdraw my consent at any time.

I acknowledge that all reasonable efforts will be made to contact me in an emergency prior to any medical, surgical or dental treatment being given, and in any event I will be notified of the treatment at the earlier possible opportunity.

Signed: \_\_\_\_\_

Name of Parent / Guardian: \_\_\_\_\_

Date: \_\_\_\_\_



## CHILDREN / YOUNG PERSON'S MENU

Name/s: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

<b>CHOOSE YOUR MORNING TEA</b>		<b>QTY.</b>
Seasonal fresh fruit and cookies		

<b>CHOOSE YOUR DISH</b>		<b>QTY.</b>
Sandwich with your choice of two fillings (please select):		
Ham Chicken Cheese Tomato	Avocado Lettuce Vegemite Peanut butter	
Cheese and tomato melt		
Pizza with ham, pineapple, cheese		
Grilled chicken fingers in a pita pocket		
Grilled boneless fish fillet with chunky chips		

*All dishes served with cherry tomatoes, carrot sticks, lettuce, broccoli*

<b>CHOOSE YOUR DESSERT</b>			<b>QTY.</b>
Frozen yoghurt			
Ice cream			
Apple Crumble			
Seasonal fresh fruit			
Plain or with	Ice Cream or	Frozen Yoghurt	

<b>CHOOSE YOUR BEVERAGE</b>		<b>QTY.</b>
Juice		
Apple	Orange	
Water		





**NSW SEMINAR**  
**Novotel Sydney, Brighton Beach | Saturday 27 October 2012**

## **SEMINAR REGISTRATION FORM**

<b>Surname</b>	
<b>First Name</b>	
<b>Address</b> (incl. post code)	
<b>Contact Number</b>	
<b>Email Address</b>	
<b>Organisation</b> (if applicable)	
<b>Relationship to Person with Angelman Syndrome</b>	<b>Parent / Carer</b> <b>Extended Family</b> <b>Professional / Other</b> (occupation)
<b>Any Special Dietary Re-</b>	
<b>Cost</b>	<b>Parents / Carer, Extended Family: FREE</b> <b>Professional / Other: \$20.00</b>
<b>Payment Options</b>	<b>Pay at the Door</b> <b>Cheque</b> <b>Please forward cheques to:</b> <b>Angelman Syndrome Association</b> <b>PO BOX 554</b> <b>SUTHERLAND NSW 1499</b>

Email completed registration forms to: [anne.asa@bigpond.com.au](mailto:anne.asa@bigpond.com.au)

Please forward any enquires to **Anne Funke**, Angelman Syndrome Association NSW on **0457 616 168**

*NOTE: Professionals in this field may register, but will be offered a place if all available places have not been filled by parents and carers at close of registration. Registration is on first come basis. Places are limited.*

**REGISTRATION CLOSES: 19 OCTOBER 2012**



## On-line payments to ASA

Quite a number of membership renewals in January/February were not identified due to lack of a reference on the payment. We therefore have a number of payments which cannot be allocated to members. If you can remember if you made an on-line payment for renewal could you please send an email to Kevin Kennedy, our Treasurer to this effect so he can apply the payment to your account.

[kevin.kennedy@angelmansyndrome.org](mailto:kevin.kennedy@angelmansyndrome.org)

Any payments you make to ASA should include your name and a reference such as the invoice number.



## 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 [kevin.kennedy@bosco.nsw.edu.au](mailto:kevin.kennedy@bosco.nsw.edu.au) requesting that your future newsletters be emailed to you. This is not only cheaper for the association but faster for our current Treasurer who volunteers his time while, like us all, juggling work, family and life with an angel

## Correspondence to President

16 Kirkcolm Way WARWICK WA 6024

## Payments to Treasurer

PO Box 554 SUTHERLAND NSW 1499

## Newsletter articles to

[sallyshackcloth@live.com.au](mailto:sallyshackcloth@live.com.au)

**Deadline** for next issue: early Dec. 2012

## ANOTHER REMINDER ABOUT THE CALENDAR!!!!

see below

## ANGELMAN SYNDROME 2013 CALENDAR

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by **15<sup>th</sup> October!**

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

Remember to include your angel's name and birthdate.

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## 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.

