



Outgoing President's Report December 2010

It has been a pleasure to again serve in the role as National President over the past 12 months. I have served in this role since October 2003 with a year's break from October 2007 to October 2008. I have seen many developments and changes of the Angelman Syndrome Association (ASA) throughout these years and acknowledge the tireless efforts of the committee who work behind the scenes whilst juggling family life, work and other responsibilities. I thank them for their ongoing support. The national committee continue to hold internet meetings several times a year where issues are discussed and decisions are made on behalf of our members. Thank you to Sally Shackcloth from Tasmania who has been producing our newsletters - another role performed on a voluntary basis by our own members.

I would like to extend my thanks to Kevin Kennedy, our National Treasurer, for his dedication to his role which he has performed in a reliable and professional manner and is always willing to assist with any task required and often performs more duties than his role requires. Also, it is with regret that I accept the resignation of Leticia Grant as Secretary. I thank them both for their unending support which has made this role more manageable.

I wish to advise that I am resigning as National President but am happy to remain on the committee to assist where I can to continue to assist and support families where possible.

I am extremely happy that Liz Stanley from Western Australia has accepted her nomination as our new National President and I offer her my ongoing support.

I would like to thank Dr Ellie Smith for her ongoing dedication and services to people with AS and their families. I would like to also thank Dr Robert Leitner and his team at the Diagnostic and Assessment Centre for their hard work in re-establishing the Angelman Clinic services at Kogarah. Both Ellie and Robert provide us with their expertise which ensures that we have a fantastic resource available to both the Association and the individual members. I am pleased to advise that Professor Bernard Dan has gracefully accepted our offer to become International Medical Patron for the Angelman Syndrome Association of Australia.

Thank you for affording me the opportunity of being President of the ASA over the past years - I have been incredibly enriched by the experience. I hope that you and your families have had a very happy and healthy Christmas and holiday period.

Best wishes for the 2011.

Anne Funke



Western Australian News



The following article is copied (with permission) from the **Applecross Advocate No.18 2nd November 2010** published by The Rotary Club of Applecross Inc, W.A.

We had two **Guest Speakers** this week. **Leticia Grant** the State President of the **Angelman Syndrome Association** and **Giuliana Bond**, co-ordinator of the **Pater Noster Catholic Church Craft Group**. Both groups were recipients of **grants** from money raised by the **Jacaranda Festival** last year. Leticia told us about the plight of children with Angelman's Syndrome- once known as the "Puppet" Children because of the way they walked-but later renamed after the Paediatrician who 1st described the condition. These children usually have a jerky walking gait, cannot speak, laugh a lot, are hyperactive requiring little sleep and prone to seizures. They are born with a chromosomal defect (not inherited). Many problems are associated with the care of these children.

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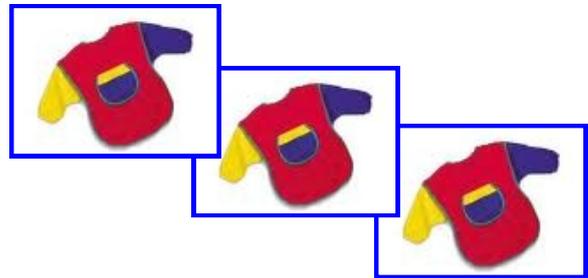
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Deadline for next issue : Early March 2011



Recently the advent of the **I Pad** has seen its use as a way these children can communicate. **Leticia** demonstrated how this and previous devices have been used to enable easier communication for the children. Our **Club's grant** has enabled the **Angelman Syndrome Association** to purchase an **I pad** for their library so parents can determine if it is suitable for their child before purchasing.

Congratulations, Leticia, and thanks for sending this article. (Ed.)



Free smocks available for children with AS. Go to smocks@cox.net. See the Angelman Syndrome Forum (www.angelmanforum.org) post 'Sophie's Smock' dated Fri Dec 17 under the heading of Eating and Drinking.

Association Committee for 2011:

Our congratulations and thanks go to the following people who have accepted the following positions for 2011:

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| National President | Liz Stanley |
| National Secretary | <i>vacant</i> |
| National Treasurer | Kevin Kennedy |
| Vice Presidents: | |

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| NSW | Anne Funke |
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| ACT | <i>vacant</i> |
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| QLD | <i>vacant</i> |
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| VIC | <i>vacant</i> |
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| TAS | Eric Smith |
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| SA | Heather James |
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| WA | Kellie Wild |
|----|-------------|

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|----------------------------|------------------|
| National Committee: | Leticia Grant |
| | Lysandra Warren |
| | John Hannaford |
| | Sally Shackcloth |
| | Kerri Monaghan |





A letter from Dr Bernard Dan

Hôpital Universitaire des Enfants Reine Fabiola

Association Hospitalière de Bruxelles – Association de droit public régie par la loi du 8 juillet 1976

Avenue J.J. Crocq 15 . 1020 Bruxelles . Tél 02/477 23 99

Brussels 25 November 2010

Dear Colleagues, Dear Parents, brothers and sisters, Dear children and grown-ups too, Dear Friends,

First of all I want to say how honoured I feel that you have offered me to serve as International Patron of the Angelman Syndrome Association of Australia.

Although I am sending this message from snowy Brussels, I still plainly feel the warmth of the welcome I received just over a year ago at the 9th Biennial Australian National Angelman Syndrome Association Conference in Perth. This was a great experience for me in many ways. It has undoubtedly contributed to refining my own practice both at the hospital, where I place more and more emphasis on interdisciplinarity and partnership between families and professionals. It has also had an encouraging effect on my research on various aspects of Angelman syndrome. But the conference was also the start of a number of cherished friendships, many wonderful discoveries and I shall never look at birds and plants again the way I used to before I had a first glance at your beautiful country – not to mention macadamia nuts and special bread recipes...

Through the ASA, I have seen how empowered you have become in your assertiveness and sense of initiative despite, or perhaps thanks to the rarity of Angelman syndrome and the complexity of issues with which the condition is associated.

Now you are leading the way again, with Aussie pragmatism and efficiency. Steam up! and there you embark again on board a specialised clinic dedicated to Angelman syndrome. I am sure you all realise this is a remarkable achievement.

The clinic will provide valuable service to improve not only health but eventually participation and quality of life of individuals with Angelman syndrome. It will be an ideal place for specifically helping persons with Angelman syndrome and those who care for them, for exchanging opinions and good practice, for building up and sharing expertise.

Having witnessed expressions of your creativity and the inventive ways in which you manage distances that defy the imagination of a mere Belgian cyclist, I can only guess how soon your clinic might start itinerating through the country...

And we might be able to help: inspired by your example, we are also starting a specialised clinic dedicated to Angelman syndrome at the Hospital for Children in Brussels. Children will be seen jointly by a paediatric neurologist, a physiotherapist/play therapist, a communication therapist, a psychologist and a social worker with easy access to other disciplines including dietician, ophthalmologist, geneticist, orthopaedic surgeon, etc. In this way, we shall grow together and will have lots to tell each other for the benefit of the people we will see here and there.

For now, let us say “Bonne chance!”

With best wishes
Prof. Bernard Dan



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 requesting that your future newsletters be emailed to you. This is not only cheaper for the association but faster for our secretary who volunteers his time while, like us all, juggling work, family and life with an angel.

Editor

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.





Ryan's birthday—what a buzz !

Let us introduce you to our little angel, Ryan Wardle (also known as Little Man).



Ryan has just had his 5th birthday, celebrating it with family and close friends on 30th May 2010. We had huge plans: to head up to Belair National Park and make the most of the great outdoors. However, bad weather saw us having to relocate back home. This made things a little 'interesting,' particularly the part where we had to move our furniture around to fit so many people into the house!

The party kicked off with a huge surprise . . . an appearance by the one and only Buzz Lightyear (don't tell anyone it was Ryan's Pop in fancy dress!). I don't know who was more excited: Ryan or his cousins.

The occasion grew even more interesting, as many of our new friends have never met Ryan's Pop. You can imagine the surprise on their face when they arrived to find a 6" tall Buzz Lightyear dancing around the house.

With the help of all the other kids at the party, Little Man got to the most important part of the day – presents!! Ryan was incredibly spoilt, getting a huge number of toys (with the Buzz Lightyear toy from Dad (Adam) and Renee

being his favorite) plus lots and lots of clothes as Ryan has grown a LOT in the last year.

Once the excitement of Pop playing Buzz Lightyear and the opening of the presents had died down, Ryan got straight into eating all the party food. Having got himself deliciously sticky, he then moved on to give everyone big cuddles followed by a sticky lolly-slobber kiss.

We brought out Ryan's Toy Story cake and all sang Happy Birthday to him. His face showed utter joy, knowing that all these people were singing for him. Instead of Ryan blowing out the candles, all the kids had a go for him. After lighting the candles a few times over, we finally got to eat. Renee's skill in feeding an Angel's child double chocolate mousse sponge cake has to be questioned, as I think more ended up on Little Man's face than in his mouth! After that, it seemed a better idea to let him feed himself. The afternoon was great fun. Ryan had the time of his life, with so many people who love him so very much. Since he's now 5, Little Man will move into the "big boys



league. Ryan has been lucky enough to be accepted into Ashford Special School. The school is wonderful and has lots of fantastic learning aids. We are hoping to see Ryan develop some new skills and enjoy his time making new friends.

The teachers have already fallen in love with our Angel Ryan.



Thanks to Adam, (Ryan's dad) for this article which is reprinted from Southern Angels, courtesy of Angelman Syndrome Association of SA Inc.



Angelman Syndrome Conference

New Zealand.



"Dancing in the Rain"

1-3 October 2010, Christchurch

It gives me great pleasure to write a short report on the AS Conference in New Zealand. These conferences, like ours, are held biannually and this was their 3rd National Conference. I attended as an invited speaker, along with Chris Oliver (UK), and many local speakers. I have attended all the NZ conferences, the first in Hamilton, then Wellington and now beautiful Christchurch. The weather was beautiful too.

While it is always difficult to get absolute final numbers, there were 70 attendees, from 14 families (many with extended relatives), 24 carers / educators / therapists and then the AS people themselves. While most were children / adolescents, there was one man there, aged 39, who had been diagnosed at age 23 - this was the first conference his mother had attended and her first exposure to other families, so you can imagine how she appreciated the happy camaraderie with the knowledge input.

The mixer on Friday night was exceptional, being held at the home of one of the Christchurch families, with amazing food and space, geared for all ages.



Saturday started with a "laughter yoga" session and then heavy science. The sessions covered current genetic research and where it might take us (Smith - Australia), behavioural management [Chris Oliver, The Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, UK], and communication - especially with the Dynavox V, with 8 GB Ipad touch, demonstrated a few times by different speakers. Chris Oliver described some aspects of behaviour in AS, which he showed were more difficult than found in other severe syndromes and that the more difficult it is for a person to communicate, the more frustrated they become and the more challenging is the behaviour. However, one's response to the behaviour also shapes future challenging behaviours, and as we know that behaviour has a learned component, it is possible to alter behaviour by your response.

On a lighter but very important vein, there were talks on special areas of recreation, which have been geared for disabled people eg horse riding "Riding for the Disabled" and swimming "Hydrotherapy, the MiniSwim Way". The children had an outing on the Saturday. Then we all met for a great dinner that night.

The Sunday morning sessions consisted of analysing the Conference, setting goals for the Society and for the next Conference.

Well done, NZ!

Clinical Assoc. Prof. Ellie Smith

Children's Hospital at Westmead, NSW.

Patron AS Australia and New Zealand.



News from

 Tasmania

Extracts from article by Mary Machen published in The Examiner, Aug. 2010...

Fingers dance across the canvas and Sheridan Hearps's face becomes a picture of happiness.

This prolific painter is hard at work in the Rocherlea "studio" she shares with some dozen or so other creative souls.

Sheridan's style is freely abstract, but her bold approach reflects a deeper reality—a willingness to participate in life, to challenge herself despite disability...

"Some (participants) are happiest working with clay and sculpture, others prefer to paint, but the program caters to individual needs and we provide the materials.

Brushes and pottery wheels, tables and easels are adapted to each person's needs so they can participate regardless of their ability.... What surprises many people is that often those with the most restricted movement can show the most freedom in their painting" explained program manager Tony Crothers.

Leading the group, which is also overseen by volunteer helpers, is Liz Scholes, the inaugural Tasmanian recipient of the Support Worker of the Year award last month....Scholes, who has a Bachelor of Arts and postgraduate degree for painting, has worked with people with disabilities since 1993.

Her inspiration is how enthusiastically participants respond to the freedom of expression that the arts offer. "It's great to receive positive recognition for their work

not only from their families and friends but also from the community at large," Scholes said.
 "Their work has won prizes at the Launceston Show, has been exhibited at the Launceston Library, and we are building up our own gallery space, because this work deserves to be shown".



Photos of Sheridan Hearps and samples of her painting.



Sheridan Hearps is happy at the Adult Day Unit art class. Pictures: SCOTT GELSTON



With thanks to Helen Hearps for providing this article. (Ed.)

