



ISSUE 7

QUEENSLAND ANGELMAN ASSOCIATION

OCTOBER 2011

INSIDE THIS ISSUE:

RESEARCH	1
RESPITE	2
A FEW FAVOUR- ITE THINGS	3
A NIGHT FOR ANGELS—GALA 2012	3
INTERESTING LINKS	4

BIRTHDAY CANDLES

April
Alex
Noah
Andrew

May
Genieve
Chelsea
Riley
Jasmine

July
Molly
Tara

August
Grace

September
Lucy

October
Finn

Remembering Lachlan Brock Jones

Our close knit community lost the gorgeous Lachlan Jones recently; saddening everyone who had the privilege of meeting him. Beautiful Lachy passed away in September due to seizure related complications. Lachlan's life was full of adventure, living in the jungles of Papua and travelling the world with his parents, Mel and Peter and sister, Imogen. Lachy's short life was filled with adventures and travels that most of us only dream of. Lachy often came to Australia and was friends to many Angels in Queensland and Western Australia. His gorgeous blonde curls, cheeky smile and adventurous spirit will be missed friends all over the world.



Lachy's family are constantly in our thoughts during this difficult time. We hope they are comforted by the knowledge that Lachy brought a shining light and endless joy during his time in this world, and that he will never ever be forgotten.

Research Updates

In the last couple of months there have been some very exciting achievements in the search for a therapeutic for Angelman syndrome. The [Foundation for Angelman Syndrome Therapeutics \(US\)](#) will soon be commencing clinical trials for an FDA approved drug which has proven to alleviate some of the AS symptoms within the mouse model, specifically motor co-ordination and brain function. We will be interested to see the results of the upcoming clinical trials.

Furthermore at the recent [Angelman Syndrome Foundation Conference & Symposium](#) in the States, it was announced that the laboratories of Drs. Ben Philpot, Mark Zylka, and Bryan Roth have teamed up to identify molecules that can unsilence the paternal Ube3a allele in a mouse model. Their discoveries and ongoing research are expected to lead towards rationale clinical trials in AS. There are exciting times ahead!

Respite

We all know how important planned and regularly scheduled respite is for our families. It provides carers an opportunity to take a break and regroup.

There are a large range of respite agencies available throughout Queensland. Most have geographic boundaries and some have limitations on their services based on the care needed. Like most services within the disability sector they are also stretched in terms of the funding available.

The experience of some of our families is that it can take approximately six months or longer in some



instances to find an agency with respite hours available for your family. It is a laborious task contacting agencies, but once you have the right respite fit for your family it is an integral part of your support.

Listed below are a number of contacts to assist in finding respite for your family.

Click on the headings to visit the websites.

***“If Mama
ain't Happy,
ain't No One
Happy”***

[Commonwealth Respite and Carelink Services](#)

Commonwealth Respite and Carelink Centres are information centres for people with disabilities and those who provide care and services. You can contact your nearest Centre by phoning a national telephone number freecall 1800 052 222 or visit the website to search for Respite agencies. Once registered with this service you can also access emergency respite when needed.

[QFinder-Queensland Director of Health & Community Services](#)

Search engine of Queensland community services, enter your required service “respite” and location.

[Lifeline Community Directory \(Brisbane\)](#)

Provides up to date information on Disability Respite and Activity Centres in Brisbane.

Some of the agencies used by some of our families are listed below. As you would know each agency has their own geographical and funding boundaries, please contact to see if you are eligible.

- [Xavier's Children's Support Network](#)—Provides support to families whose children are between 0-6 and have complex support needs.
- [Mamre](#)—Provides flexible family support to families of an individual with a disability who wish to friendships, natural networks and opportunities.
- [ALARA Association](#)—Respite in the Ipswich area.

[Movement Solutions](#)—Physiotherapy Brisbane

The Physiotherapists at Movement Solutions come very highly recommended by some of our Angelman Syndrome families! The dedicated team at Movement Solutions all have a special interest in pediatrics and are passionate about providing excellent services to our children. For more information, please visit their website <http://www.movementsolutions.com.au/>



Finn's Toy Review

My name is Finn Roberts and I just turned nine. After months of letting the mums do the talking, I thought it was about time that I let you in on some of my favourite things... toys! I have had loads of experience to pass onto my younger angel friends. So here are a few of my favourite things, Oprah eat your heart out. Click on the headings to go to the website.

[Gyrocar](#)
This is a great little ride on car that moves forward based on the side to side movement of the handle. No pedals and no batteries. Works best on flat ground.



[Vibrating Pillow](#)

I love this one so much that mum has had to buy me a few of them. This one is special as it has a gentle pressure switch, once I take my hands off it the vibrating stops! Mum

likes it because the batteries are safely tucked away and it has a removable washable cover. Always helpful when I couldn't sleep, I would fall asleep and it just turned off.



[Ladybug Light](#)

This is a cool toy when I just want to lay back and chill. It shines stars all over my sleeping—sweet! It has a timer as well, makes mum happy.



[Vibrating Turtle](#)

Okay, so I don't actually have this one yet, but I have my eye on it. It vibrates when

you cuddle it—how cool is that! Friends, let me know if you get one before I do.



[Clothes](#)

So mum reckons that all in one pjamas are pretty important? Not sure why, but I know these are hard to get out of during the night.



Thanks for reading!
Finn

"It is fun to have fun, but you have to know how" Dr. Seuss

A Night for Angels—Save the Date

Angelman families will be able to enjoy their very own Gala next year in Sydney on the 23rd March. A Night for Angels is being organised by the family and friends of Angelman Syndrome mum, Michaela Townsend, with all proceeds going to FAST Australia. All details of the Gala, including ticket sales, are on the website <http://www.anightfortheangels.org/>

or follow updates on Facebook <https://www.facebook.com/#!/anightfortheangels>

It is going to be an amazing night for Angelman families to wine, dine, dance and enjoy themselves. We hope to see you there!





QUEENSLAND ANGELMAN ASSOCIATION

www.angelmansyndromeqld.org
enquiries@angelmansyndromeqld.org

Interesting Links

[Children with a Disability—Australia](#)

[\\$500,000 Funding boost for children with a disability](#)

[New Advisory Group on School Students with a Disability](#)

[Baby Bridges—New Early Intervention Program 0-5 years](#)

[Inclusive Learning Technologies Conference](#)

[Fragile X Research](#)

[Productivity Commissions Final Report into Disability Care and Support](#)

[Angelman Sucks—Funny new blog written by Angel Dad](#)

Queensland Angelman Association is an unincorporated group of parents & carers focused on providing support & information to Queensland families who have been touched by Angelman Syndrome.

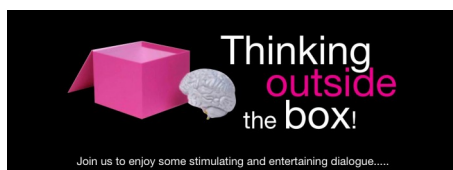
Through our experiences we have discovered the comfort in being surrounded by a loving & compassionate Angelman Syndrome community. For whatever challenges that may be faced during this journey, there will be others to support & provide advice. It is our goal to open a channel of communication between Queensland families.

We believe that information is power. It is important that our Angelman Syndrome families are provided the most up to date information on research, studies & the achievements of our angels around the world.

[Epilepsy Queensland 2011 Symposium](#)

Epilepsy Queensland is holding their 2011 Symposium, Thinking out side the Box, on the 2nd and 4th of November at Griffith University, South Bank Campus. For registrations and full details on the speakers please visit the [Epilepsy Queensland Website](#). Some of the topics include:

- Complementary Therapies in Epilepsy
- Epilepsy Research and Local Service Developments
- The Private Life of the Brain
- The Future of Epilepsy
- Specific Gene Testing



Controversies in epilepsy

Wednesday 2 November
9:00am - 1:00pm

The future of epilepsy

Friday 4 November
1:00pm - 5:00pm



[Conductive Education Queensland](#)

Conductive Education Queensland has just recently commenced it's programs at Coopers Plains. CEQ is a registered charity providing Conductive Education programs for babies, children and young adults with cerebral palsy and other neurological disabilities.

CEQ provides a valuable option for families who seek programs that address individual needs in a group setting. High expectations and the expertise to facilitate success

has seen CEQ grow very quickly in a few months of operation.

For more information on Conductive Education, and the programs available please visit their website. <http://www.ceq.org.au/index.html>

