



QUEENSLAND ANGELMAN ASSOCIATION

APRIL 2010

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Australia Day Barbie—Brisbane

All the Aussie Flags were out in force when we got together for a morning barbeque on Australia Day.

We all had a fantastic morning catching up at the Broadwater Picnic Ground for a sausage sizzle.

What more could we ask for - great weather, fantastic park for the kids to have fun, and amazing company with our beautiful angel families. A big thanks to everyone for making it a great day.



A special big thanks to Jen for her magnificent organisational skills! Our president Alison, Chefs, Mario and Steve, and photographer Michelle. With so much fun had by all there will be no doubt more social events planned for this year! Watch this space.



Would you like to organise an opportunity for angel families to catch up in your area?

Send us the details and we will promote it through our membership.

BIRTHDAY CANDLES

March

Cody

April

**Alex
Noah
Andrew**

May

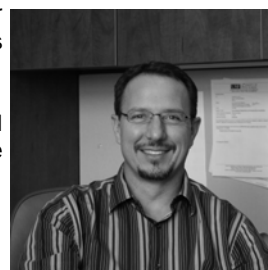
**Chelsea
Riley**

Angelman Syndrome Research Dr Edwin Weeber nominated to Hall of fame!

This year's Rare Disease Day theme was the importance of collaborations between parent groups and researchers. We thought this was the perfect opportunity to showcase our own AS researcher, Dr. Edwin Weeber and his colleagues. Their hard work and dedication is well known by Angel families around the world. Accordingly, the Queensland Angelman Association nominated Dr. Weeber to the 2010 Hall of Fame, where he is surrounded by other respected and dedicated researchers all working to aide individuals with rare diseases and disorders.

Congratulations to Dr. Weeber and colleagues - you are well deserving of this accolade, and we are thrilled to have the opportunity to publically acknowledge your research.

<http://www.rare diseaseday.org/research-hall-of-fame/nominee/dr-edwin-weeber>



Rare Disease Awareness

You don't need to be told that Angelman Syndrome is a rare condition, no doubt if you had a dollar for every person you have had to explain the syndrome to you would be a millionaire!

Australia is unlike most developed countries in that we have no National coordinated approach to Rare Disease. Alone, as parents and families of children with Angelman Syndrome we would have a hard time convincing policymakers that this is important, but combined with families of more than 8000 rare diseases we have a lot of clout.

What does this mean for us?

The European Rare Disease body EURORDIS "aims at improving the quality of life of people living with rare diseases in Europe through advocacy at the European level, support for research and drug development, networking patient groups, raising awareness and other actions designed to fight against the impact of rare diseases on the lives of patients and family."

The Australian Paediatric Surveillance Unit recently called for comment on the DRAFT National Plan for Rare Diseases for Australia, drafted by the Rare Diseases Working Group

established by the APSU last year. A copy of the Draft Plan can be found on the website: www.apsu.org.au

The objectives of the draft plan are to

1. Raise awareness of the burden of rare diseases on patients, families, health professionals and the community

2. Provide educational resources and networking opportunities for health professionals to allow them to better identify and manage rare diseases

3. Improve health care for people with rare diseases through access to diagnostic tests, new drugs and other treatments, improved primary care and specialised services

4. Promote research on rare diseases through advocacy for targeted research funds and development of national and international multidisciplinary research partnerships.

5. Increase knowledge of the epidemiology and im-

pacts of rare diseases in Australia through research

6. Develop and disseminate information to educate patients, parents, carers and the general public,

about rare diseases that is relevant in the Australian context

7. Develop an umbrella organisation to support people affected by any rare disease by linking existing organisations to facilitate the co-ordinated development of integrated peer support networks, contact among families and contact among rare diseases interest groups.

An Australian body to support Rare Conditions would mean a great deal by way of support to Angelman Syndrome families.

An online petition has been set up encouraging people to "Establish a body to support Rare conditions in Australia "

<http://www.gopetition.com/online/27998.html>



Raise awareness of the burden of rare diseases on patients, families, health professionals and the community

More Rare Coverage

Mackenzie's family from Newcastle were fantastic in sharing the story of their journey with AS, and informing the public of the lack of services or rare diseases in Australia in a February television interview with NBN.

<http://www.nbntv.com.au/index.php/2010/02/25/mackenzies-story/>

Rare Disease Day Awareness Walk—Cairns 2010

The Cross family in Cairns had their second annual awareness walk in the scorching Cairns February sun this year.

This year the goal was to get as many people aware of the plight of families affected by rare conditions with feet on the pavement!

The walk was well represented again with over 250 people walking and a range

of different rare conditions represented.

The walk was attended by the parliamentary secretary for Health and covered by local television stations Chanel seven & Win, ABC National and the local newspaper.

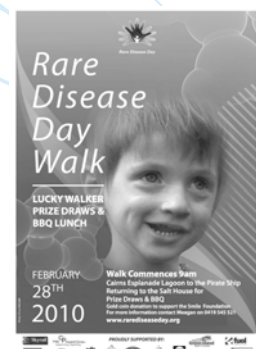
Local businesses showed their generosity by donating everything required for the day from bbq food, drinks, icypoles, venues, jumping

castles and a range of fantastic door prizes.

Although symptoms can vary immensely there are a lot of common factors that come with a rare disorder and the day provided an excellent opportunity for networking.

Footage from the Day can be found at

<http://www.mollysvoice.org/index.php?id=rdd2010>



Bad behaviour?

Prof. Chris Oliver from the University of Birmingham (Neurodevelopmental Disorders) in the United Kingdom will be in Brisbane in late September where he will host a workshop for Angelman Syndrome families on;

“Understanding and changing challenging behaviour in Angelman syndrome”

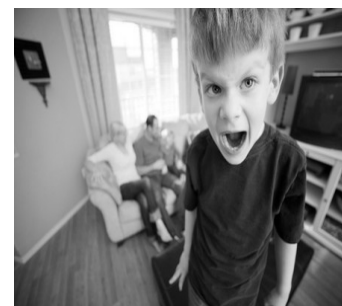
This presentation will explore the more common forms of challenging behaviour in children and adults with Angelman syndrome. There will be a description of how genetic disorder can influence behaviour and information on the forms of the behaviours and changes

with age will be followed by a description of the main causes of behaviours such as aggression to others. Methods for assessing causes will be described and a range of intervention techniques will be presented with advice on evaluating how effective different techniques are. Throughout the presentation there will be an emphasis on early intervention, the importance of consistency across environments and linking cause to intervention.

The Mater Hospital has again been very generous in providing a venue for this workshop. You may recall they provided their premises and hospitality for Dr. Wee-

ber's workshop in 2009. We hope to be able to expand upon the day to provide further information sessions for families, and an opportunity for angel families to network.

If you have any queries about the day please contact us



Workshop!

Save the date!

Sunday

September 26

Calling all Angels!

Actually...

Helping hands

In July last year we held our first workshop as a Queensland entity.

The Queensland Angelman Association is a non incorporated body—we decided we have enough red tape in our lives! By doing this we are not required to have meetings, audits or handle finances, which is great.

If we are to achieve our goals in providing a useful service there are burdens; newsletters—content and

production, event planning, web updates and liaising with families (there is also a small financial burden in hosting our website)

We really need your help!

We cant achieve this with only a few people managing the workload.

We are always looking for ideas for the website, content for newsletters and we always want to know what people are doing that works for them!

Angelman Syndrome is a complicated web of thera-

pies and medical challenges. Many families have worked so hard and are a wealth of information for families just starting out on this journey. Please share your experiences so that you can extend your hand to the new families who are looking for experience and advice

If you would like to help—in any way, no matter how large or small please

contact us!

Like to see your angels smile in

our next

newsletter?

Contact us

In Sympathy

The Queensland Angelman Syndrome Association extends our sympathy to Jess, Ash, Rhys, Riley, Rory and their families after the tragic

and sudden loss of their sister and auntie Renee Nicholls.

Renee was a world champion triathlete and a valued

member of the Australian Defence Force.

Our thoughts are with the family at the difficult time.





QUEENSLAND ANGELMAN ASSOCIATION

www.angelmansyndromeqld.org

Interesting Links

Loss of enzyme reduces neural activity in Angelman syndrome
http://www.eurekalert.org/pub_releases/2010-03/hms-loe030210.php

One protein appears to control neurons' ability to react to new experiences
<http://web.mit.edu/newsoffice/2010/brain-plasticity-0324.html>

US Drug Company, Ardane propose drug for Angelman Syndrome
<http://www.ardanetherapeutics.com/prodpipeline.html>

Angel carries Paralympic Winter Games torch
<http://www.vancouversun.com/sports/Spark+becomes+flame+torch+makes+entrance+into+Vancouver/2670039/story.html>

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.

Mad as Hell

Mad as Hell is a clever National electoral lobbying campaign designed to impact on this years Federal and State Elections.

The group is asking families and friends of people affected by Australia's inadequate disability system to pledge the following:

"We're mad as hell -

We are not going to take this anymore and there are millions of us"

"I pledge that in the next Federal and State elections, I will only vote for a political party which publically promises to transform Australia's broken, inefficient, crises-driven disability support system by:

Introducing and supporting a **national disability insurance scheme** immediately after the productivity Commission study, due July 2011.

Ensuring people with a disability and their family or nominated representative decide the best ways to use funding received to meet their individual needs."

To find out more about the innovated campaign visit their website

<http://australiansma-dashell.com.au/index.html>



Got an idea for some newsletter content?

[CONTACT US](#)

@ email address above

Interested in a Natural approach?

For those interested in exploring natural therapies, allied therapies and nutritional approaches to wellness the MINDD Foundation have a series of seminars, including the Gold Coast in June

<http://mindd.org/s/archives.php/archives.php/226-Seminar-2010-Integrative.html>