

December 2004

Issue 5

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Feature

An Audience with Autism

Promotion of Autism Awareness reached new heights this year with the first ever National Awareness Event ‘An Audience with Autism’ being staged to coincide with the Biennial Autism Conference in Canberra.

‘An Audience with Autism’ (AwA) was the brainchild of Kelley Harris, mother of Alex Harris from Traralgon Victoria. Kelley came up with the idea of AwA whilst looking through an American website called Moms on a Mission. A similar event was held in Washington DC to promote awareness of Autism, which Kelley then adapted for Australia.

A4 – Autism Aspergers Advocacy Australia staged ‘An Audience with Autism’ on the lawns of Parliament House in Canberra on Thursday 30th September 2004. The event was a major success, with over 650 members of the autism community participating by sponsoring a chair for their loved one, walking to Parliament House for the rally, or both. The event received media coverage on the local Channel Nine (WIN) news, in the Canberra Times newspaper and on radio stations across Australia that day. This was an enormous feat with the breaking news of the Paedophile Ring and the continuing coverage of the Federal Election.

Following the walk to Parliament House where a sea of 650 white chairs greeted us, Bob Buckley, Convenor of A4 welcomed everybody to the AwA event. Following Bob, we heard a taped speech from Alex Deen-Cowell. Alex is a Year 12 student who has Autism, but was unable to be with us on the day. His speech was absolutely powerful, emotional and moving. It can be downloaded from the A4 website www.a4.org.au/awarenessevent/AlexDC.mp3. We also heard from political representatives of the Liberal, Labor, Democrats and Green Parties, as well as Judy Brewer-Fischer. The crowd was then invited to visit with the ‘Audience’.

With such a successful event in mind, the Autism community needs to grab hold of AwAs shirt-tails and make the most of the awareness it has established. Now is the time to keep the ball rolling, ensuring the government and our community continues to learn about our children (young or old), their lives and their disability. Let’s remain strong in our stand to get our message heard so that when future Autism Awareness Events/Campaigns are held, Australia is behind us.

We would like to thank everyone involved in making 'An Audience with Autism' a reality. We would also like to congratulate all politicians who participated, strengthening the relationship between themselves and the Autism Community. Thank you also to Autism Victoria who donated the pins we handed out to everyone involved in the walk to Parliament House.

Lastly, AWA could not have happened without the support of our set up crew on the day and the tireless work of Kelley Harris and her committee. All involved not only succeeded in making Kelley's idea a reality, but ensuring it was a huge success. Thank you Kelley for your vision and determination in raising the level of awareness for Autism in Australia, and giving those who could not physically attend a chance to still have a voice.

Anita Harvey
Chief Editor – A4 Update

Convenor's message

Dear A4 member,

A4 now has a formal relationship in the form of a Memorandum of Understanding (see <http://a4.org.au/documents/ACA/ACAA4-MoU.png>) with the Autism Council of Australia (ACA – see www.autismaus.com.au). Hopefully, governments will recognise the ASD community speaks through both A4 and ACA with a strong and unified voice.

A new government has been elected. Though the election issues relating to people with a disability and their supporters were studiously avoided by political candidates, so few concerns about autism registered in the media. The traditional post-election restructuring is in progress. Some aspects of disability support are moving from Family and Community Services (FaCS) to the Department of Employment and Workplace Relations (DEWR). A4 has reiterated its request for a health summit on post-diagnostic treatment and early intervention. The government needs to move on this soon if the outcome is to be considered in the next Federal Budget.

Just before the election, the former Shadow Minister for Disability eventually returned my calls. She asked me repeatedly (four times during our conversation) whether the only thing that would satisfy me would be a policy specifically for autism. I explained that A4 is interested in all policies and programmes that provide equitable outcomes for people with autism/ASD. I explained that existing approaches, for example installing ramps and lifts, do not improve access to services or improve outcomes for people with autism/ASD. She did not accept my response.

Mark Latham's policy of "learning or earning — no third options" is a concern. Before the election I asked the Labor Party to explain this policy. Instead, the (former) shadow minister told me I was mad if I believed this policy applied to people with a disability. In other words, she regards me as mad for believing Mark Latham; particularly his budget reply speech on the subject of people leaving school and their post-school options. I recently met the new shadow minister: I hope she will come to understand people with autism/ASD and provide strong political support for them and their associates.

A4 must now direct its efforts towards a new government. Already, A4 met with officials in Family and Community Services. FaCS provided information showing that 572 people with autism or Asperger's syndrome were granted a Disability Support Pension during the 2003-04 Financial Year (311 or 92% of applicants with autism and 261 or 77% of applicants with Asperger's syndrome). This means the government recognises these people, many of whom have not yet completed school, are unable to work (participate economically). In that respect, the education they were provided did not succeed in preparing them for employment.

In Australia, education outcomes for a very high proportion of people with autism/ASD including Asperger's syndrome are not equitable. A challenge for A4 is to convince government that better outcomes are possible and that it should act to improve outcomes for people with autism/ASD. I expect A4 will pursue the FaCS Minister's review of recognised disabilities. We understand the Minister received recommendations but has not made those recommendations public or acted on them as yet.

Advocacy for autism/ASD at the national levels continues to be a challenge, as does advocacy at local and state levels in most parts of the country. Persistence pays off.

Regards
Bob Buckley
Convenor



Consumer, Family and Citizen Empowerment

Deborah Locke leads the People Power team for the NSW Upper House

Deborah Locke is a former Detective in the NSW Police who blew the whistle on police corruption in the 1990s, and with independent MP John Hatton, initiated the Wood Royal Commission. Her first book *Watching the Detectives* (Allen & Unwin) describes this story.

Deb also has three children, Vanessa 12, Bronte 7, and Hayes 8. Hayes has severe autism, extreme ADHD, and an intellectual disability. Through her experiences with Hayes, Deb has added disability and carer issues to her passions.

Deb has been preselected by People Power to lead its team for election to the NSW Upper House in two years time. 4% of the state-wide vote will see her elected to the Legislative Council.

<http://www.peoplepower.org.au/News.htm>

Deb herself has a diagnosis of high-functioning autism.

In 2005 Deb has a busy year including:

- A profile on Channel Nine's 60 minutes in April on police issues.
- A documentary on her life story on SBS: "The Debbie Locke Story".
- A telemovie for Channel Nine on her life story called "Watching the Detectives" featuring Bridie Carter of McLeod's Daughters as Deb.
- A second book coming out in June "Gary Lee Rogers is Dead".
- Is negotiating with film industry people for a film on her second book, including people in Hollywood.
- She is now busy as a speaker and commentator on these issues of police culture, ethics and accountability, and leads the group Whistleblowers Australia.
- She convenes the Inner West Support Group of 300 families in Sydney with a child with autism.

More information on Deb is at <http://www.peoplepower.org.au/News.htm>

You can meet Deb in North Melbourne on Tuesday 30 August at 6pm and discuss her vision and her hopes with People Power. (6pm - 7.30pm)

Please RSVP by return email if you wish to attend. Entry by gold coin donation.

Following the function, Deb will join the Victorian State Committee of People Power in planning for the next Victorian state election. If you'd like to join this Committee and participate in this campaign, please let me know by return email.

A People Power membership form is available on our website. There is no cost.

Vern Hughes
People Power
vern@peoplepower.org.au
<http://www.peoplepower.org.au>

Australian scientists uncover rare gene mutation

The Age, November 22, 2004 - 7:57AM

Australian researchers have discovered a gene mutation responsible for causing Rett Syndrome.

The mutation, in a gene known as STK9, may also contribute to other disorders including autism.

Rett Syndrome is a progressive neurological disorder that affects one in 10,000 young girls.

The girls develop normally until about six months of age, when their development stops and can even reverse.

They go on to suffer severe progressive intellectual disability, losing communication skills and mobility and developing digestive disorders, spinal curvature and epilepsy.

In 1999, researchers discovered a gene, MECP2, caused about 80 per cent of Rett Syndrome cases.

Now researchers at Sydney's Westmead and Adelaide's Women's and Children's hospitals have discovered some of the remaining cases can be attributed to a mutation in the STK9 gene.

Associate Professor Jozef Gecz (Jozef Gecz), from the Women's and Children's Hospital, said the discovery helped piece together the Rett Syndrome jigsaw.

"Once you have one cell (gene that causes Rett Syndrome), it's good. But once you start looking at the syndrome from different angles and finding different causes, you are likely to find answers," Dr Gecz said.

"That means you can start to look at treatments or prevention."

Dr Gecz said the gene mutation appeared to cause a more severe disorder than that attributed to MECP2.

"This is quite a severe form of Rett Syndrome," Dr Gecz said.

"It's associated with an early onset (of intellectual disability, and an) early start of epileptic activity."

Dr Gecz said the STK9 mutation was not responsible for all Rett Syndrome cases not attributed to MECP2 and research was still needed to determine other causes.

During the research, 11 children around the world with Rett Syndrome were diagnosed with a STK9 mutation.

"I don't want to make this (discovery of the STK9 mutation) out as something that is going to solve the problem for every Rett Syndrome family," Dr Gecz said.

"But on the other side, I want to be excited by the fact that if we are helping two or three families in Australia, or 11 families around the world, then it's something to be cheering about."

- AAP

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Building grass roots support

An important part of advocacy is building community understanding and support for people with autism. It's important because;

- It educates people about the difficulties people with autism face in their daily lives.
- It broadens the dialogue and makes government accountable to the whole community not just those directly affected.
- Politicians respond to issues if they think those issues have grass roots support.

How to build grass roots support

It can be done in a variety of ways. Some ways that have worked is to offer our services as guest speakers to branch meetings of major political parties, churches and other community groups. We have also approached churches via email and through personal contacts to ask for the prayerful support of the congregation. Big issues that started out small such as Asylum Seekers and Aboriginal Rights have used these methods.

How to start

Personal contacts and introductions are one of the easiest ways to get started. If you have contacts, use them. Otherwise some suggestions are;

Political parties

The major parties have a secretariat in each state which is listed on their web sites. Contact them by phone and follow up in writing. Ask to be put in touch with the convenor of the relevant policy committee. Eg education, health, disability. When you speak at their meeting, ask the policy committee members for a referral back to their branches.

If you already have contacts, consider which branches would be most effective to speak at. For example does the branch fall within the electorate of a government minister, parliamentary secretary or shadow? Are any key ministerial advisers involved with the branch? Do your homework, read the MP's biography on the net and Hansard for anything they have said in parliament on a related subject.

Churches

The major denominations have web sites with email contacts for individual priests or ministers. This makes it easy to contact hundreds of churches quickly and cheaply. It is a good idea to personally address your email message to the priest or minister.

You can ask for a speaking engagement (I have not personally done this) or ask for the congregation to include you, your issue etc in their prayers. Some churches operate e-mail prayer chains and hold regular prayer meetings and vigils. If you are lucky the church might respond to your request with an offer of lobbying support.

What to say

If the thought of public speaking terrifies you find a friend and share the speaking. You don't have to give a long and formal talk, plan to speak for about 5 minutes and then invite people to ask questions. Your experience is out of the ordinary so your audience will be very interested and ask lots of questions. If you feel nervous because you are not an experienced speaker remember that it is easiest to talk confidently about subjects you know really well and feel passionate about. Use notes to help you to remember everything you want to say. People like to hear about other people and their experiences so tell your story from your own perspective.

If you are talking about an autistic son/daughter/relative/friend take along some photos so that your audience can see the person you are talking about. Use his or her name often to keep the autistic person firmly in the picture.

Use some statistics and facts – the A4 web page is a good source.

Say what you would like government (local, state or federal) and the community to do. Explain why it is of long term benefit to the whole community that autistic people are given the help they need.

Depending on your audience it may or may not be appropriate to directly ask for help. You should however be prepared for offers of assistance. Be clear on what you want individuals or an organisation to do. Some suggestions are in the next paragraph.

How community groups can help us to advocate for autism

Political Parties

Referral to a ministerial staffer or minister

Referral to a policy committee

Contacts and referrals to other branches of the organisation if you want to line up another talk

Write letters to MP's and ministers. You could have a form letter ready for them to send their MP (have the name, address, email of relevant MP's and ministers as well as the key points that should be made)

A resolution to be submitted at their next state meeting or policy meeting

Community Groups

Fund raising or sponsorship

Letter writing to papers and MP's

Signing petitions

Churches

Letter writing to papers and MP's

Signing petitions

Inclusion of autism in their prayer meetings

Understanding and accommodation of people with autism at church, denominational schools, church run play groups, Sunday schools and youth groups

Even if you do not get any offers of help, remember it's never a waste of time to speak about autism. You are helping to increase community understanding and compassion. From little things, big things grow.

Letters to the Editor/A4

Dear Bob,

We decided to host a morning tea in conjunction with the Audience with Autism event. We thought we could be there in spirit if not in person. After some thought, we felt we could make it a fun time for kids as well due to it being school holidays in Qld. Then we decided to make it a fundraiser as well. We wanted to do something for the Mums as well so we organised a massage therapist to attend and she did 10 minute neck and shoulder massages for anybody willing to pay \$10.00. She then donated half of this back to the fundraiser. We had a clown and a fairy face painter there. We also ran raffles, lucky door prizes and a mini cent auction. Lexus of Brisbane donated the major prize which was a lovely gourmet pamper basket including Moet champagne, Crabtree & Evelyn products and Lindt chocolates. We had over 50 parents and kids attend and altogether raised \$711.60. We have decided to make this an inaugural event and will host this each year. We are hoping to outgrow our backyard by the third year. We are donating \$350.00 to A4 and the balance is going to Autism Qld. We would love to see any A4 members there next year.

Regards,

Laura Lewis

The following letter is in response to the Audience with Autism Report Bob sent to members

Dear Mr Buckley,

Thanks so much for taking the time to let members know that this event did indeed go ahead and that it went so well. Congratulations to you all for your dedication, commitment and sheer hard work in organising this and pulling the day off as well as you have reported! Truly proud to be an Australian and a mother of three with Aspergers! I am currently living in the U.K. but hoping to return to Australia in the next 2 years. I am a member of the National Autistic Society over here and we work pretty hard to raise awareness and funds but you are doing a wonderful job there yourselves and doing Australians with Autism and their families very proud. Excellent work!

Very Best Wishes & Thanks,
Julie

PS Loved the photo! Lived in Canberra once upon a time too, so it was lovely to see! Thanks again...

Hi my name is Belinda and I have been receiving email updates from A4. I find these updates/newsletters very informative and would like to congratulate you guys/gals for such a wonderful job. WELL DONE!

I attended the Canberra event, and was really impressed and deeply moved by it. Well done! Could you please pass on my congratulations to Alex Deen-Cowell for his amazing speech. It was absolutely fantastic, and said so many things that we all feel. Thank you Alex. I dream that one day my son will be able to express himself the way you did.

Regards,
Kelly

Hi Anita,

I read these top 5 tips in the Virgin Airlines Voyeur Magazine. The quotes belong to Simon Latchford, proprietor of a successful Yacht Charter business. These words seem very relevant.

"Simon's top 5 tips

1. Risk more than others think is safe
2. Care more than others think is wise
3. Dream more than others think is practical
4. Expect more than others think is possible
5. And never, ever give up"

Cheers,
Wendy

General Information

According to this NSW DADHC webpage, <http://www.dadhc.nsw.gov.au/idpwd/ambassadors.asp> Garry Frost is an Ambassador for the International Day of People with a Disability 2004.

Garry Frost

Songwriter and performer, Garry Frost is perhaps most acclaimed for his 1981 hit 'What about me', written during his days as guitar player with Moving Pictures.

The ballad, inspired by an experience of a boy who had autism visiting a corner shop in Annandale, recently skyrocketed to number one in Australia again when released by Australian Idol, Shannon Noll.

Expired email addresses

A few members have expired email addresses. Please let us know when you change email address otherwise we simply lose contact with you.

If you know anyone who might be an A4 member and whose email address has changed, please remind them to tell A4 about their new email address. We generally stop sending Updates when the email address is reported as invalid.

Some member's email "in boxes" are full. So their Updates don't get through.

A4 Contacts

Update team (newsletter)
edit@a4.org.au

A4 Convenor, Bob Buckley
convenor@a4.org.au

Treasurer (donations)
treasurer@a4.org.au

Profile

Our December Profile is on Kelley Harris. Kelley works part-time and is involved in a number of Autism related groups including; Steering Committee member of A4, Co-ordinator of GAAINS (Gippsland Autism Aspergers Information Network & Support), Member of GECIAN (Gippsland Early Childhood Intervention Advisory Network), REACT (Regional Autism Consultancy Team) and Alex's Kinder Committee.

NAME: Kelley Harris

BORN: 12th March, 1971

LIVES: Traralgon, Victoria

FAMILY: Husband Mic, Maddison 13, Taylor 11 & Alex 6

LIKES LISTENING: to a wide variety of music

LIKES READING: biographies

LIKES RELAXING: what's that?

LIKES EATING: yes

LIKES: faaabulous handbags & shoes

DISLIKES: ignorant people

IDEAL WEEKEND: 5 star hotel with room service (NO CHILDREN) & shopping for faaabulous shoes & handbags

LAST HOLIDAY: Canberra – Audience with Autism & Biennial Autism Conference

NEXT HOLIDAY: all legitimate offers will be considered (see Ideal Weekend)