



## 2003 UPDATE 2

Hello again A4 members.

Like the logo? After much debate we now have settled on this as our special signature and we hope that it will become familiar to you and to all Australians as we continue to strive to bring the needs of the ASD community into the public eye. It will be on our promotional material, our website, our community service announcements, on our media releases, and if anyone would like to put it onto T Shirts, hats, bags, folders, balloons or tattoos or anything else, don't hesitate to get in touch.

& so to February.....

### **STEERING COMMITTEE MEETING 9/2/03 MELBOURNE**

The steering committee of A4 finally came together face to face for a day long meeting to review where the organisation was after the first three months of operation, and to continue to work on developing an effective structure and modus operandi for the future. 19 members of the 22 member committee made the huge effort of getting to Melbourne, which was a wonderful demonstration of the commitment and enthusiasm there is for our aims.

In brief some of the decisions taken were:

- The adoption of a statement of purpose for A4:

**Autism Aspergers Advocacy Australia (A4)** is a national organisation comprising and directly representing people with an Autism Spectrum Disorder (ASD), their families and associates. **A4** benefits its constituents through:

- a) developing and promoting appropriate national policy;
- b) influencing relevant decisions; and
- c) monitoring and reporting on outcomes.

- The appointment of an honorary treasurer and (pro bono) accounting advisor to look after our finances. The account is now open and accepting cheques – kicked off by a \$1500 donation. A4 does not have tax deductibility or charity status as we are primarily an advocacy group, but a modest amount of ongoing finance will be needed to fund our operation and promotional expenses.
- Commencement of work on incorporation and on framing a Constitution for A4. For practical and for legal reasons we need to formalise our unique structure that allows for minimum bureaucracy and maximum involvement of the grassroots membership.
- Reports were given on various promotional projects including the promotional video/s and community service announcements being created, the planned evolution and renaming of our website, and fundraising and marketing ideas.
- Consideration was given to the form that our National ASD Plan of Action should take. This is to be a concise public document, designed for mass distribution, that states clearly what the problem is and what is needed. It will highlight the lack of planning and fragmentation of ASD services across the country and call for a consistent national approach. We hope to make it a centrepiece of our Canberra Advocacy Event in June.
- A long discussion was held regarding the relationship and obvious overlap between State and Federal ASD advocacy issues. It was agreed that A4 would continue to focus on issues of national policy and direction as well as specific issues under the jurisdiction of the Federal Government. However it was recognised that most of the day to day issues faced by ASD families, such as health and education, are often more directly the responsibility of state authorities. So this is what we have proposed:

**THE FORMATION AND RE-ENERGISING OF SPECIFIC ASD STATE ADVOCACY GROUPS IN EVERY STATE, TO LIAISE WITH A4.**

A4 is committed to national policy renewal and raising the profile of ASD issues to the government and to the community. We formed to fill the void that existed at the national level and to become the advocacy arm of the Autism Council of Australia. We do not want to duplicate the work of the state autism and aspergers organisations who have state advocacy as part of their charter. However the degree to which the state organisations take on advocacy work clearly varies from state to state depending largely on their focus, structure and resourcing.

Every day, A4 is approached by families in need of support and help with accessing services. In many cases there is no one to refer them to, so they have to work alone to convince the authorities of their need. We need a mechanism to bring these people together, to stop making every family 'reinvent the wheel' with every approach to government. Imagine if we could

have a Federation of state advocacy groups, linked into the existing autism and aspergers organisations, but feeding in to the national policy agenda. We would really be a force to be reckoned with. We would then be able to gather information on every issue and decision made, and use the information to influence policy change and improve service provision.

A4 encourages you to find out what is happening in your own state and what organisations you have that do advocacy work for the ASD community. Perhaps you can push for a meeting in your state or region to bring together all the parties concerned and to develop some co-ordinated strategies.

### **'WALK WITH PARLIAMENT' CANBERRA 2 JUNE 2003**

Our main focus for the next few months will be planning and marketing our first major public ASD advocacy event. Reflecting A4's commitment to forming constructive relationships with governments and parliamentarians of all persuasions, we have decided to call this day the 'Walk WITH Parliament' as a sign of our willingness to work together with our elected representatives to ensure a better future for our ASD community.

We cannot give you the exact details of the day as yet, due to new security arrangements at Parliament House that involve more layers of paperwork and rubber stamping than you can believe. But as soon as we have the appropriate approvals, you will be emailed a detailed program, a registration form, and a flyer to distribute as widely as possible.

What I can tell you is that it will a very special day for us all. A chance to come together en masse to raise the profile of ASD to the national media, a chance to see some of the inner workings of the Federal Parliament, a chance to meet with some of the MPs and Senators, and a chance to see our new promotional material launched in the national capital.

& a chance to attend the activities associated with:

## **Autism ACT 25<sup>th</sup> Anniversary Conference**

**Partnerships for success: Parents, Professional and Services - Working together for people with Autism**

**Preceding the A4 Walk With Parliament**

**Key themes of the conference will include:**

- fostering positive relationships between parents, professionals and service providers
- enhancing skills in the family and for professionals
- hands-on guide to educational opportunities, support groups etc
- discussion of key issues confronting families with Autistic children in the ACT
- information sharing and network building across parents
- navigating the system and asking the right questions

**Saturday May 31 & Sunday June 01 2003**

**National Convention Centre, Canberra**

**Cost and program to be advised soon**

**A 25<sup>th</sup> Anniversary dinner will also be held on Saturday 31 May at the Chifley Hotel on Northbourne Avenue to celebrate 25 years of the Autism Association of the ACT.**

To register your interest please email details to [autism2004@dpm.com.au](mailto:autism2004@dpm.com.au)

## **STATE MARCHES ON JUNE 2**

A number of people have enquired about organising events in individual States to coincide with the Canberra Walk With Parliament (WWP). While A4 clearly does not have the authority to stop anyone or any organisation carrying out an activity in the name of autism promotion, A4 has decided not to endorse any associated state activities on the same day as the WWP.

There are compelling reasons for this. As this is our first national advocacy event, we need to maximise numbers in Canberra on the day. We need to keep the focus on Federal Parliament and on the need for a national policy approach. Associating activities and issues with state and Federal Parliaments could confuse the community and the media. Our key message may be lost. While it is great to feel the empathy of our families around Australia who cannot attend in Canberra, particularly those from furthest away, there are other opportunities for state activities at other times and we urge you to help us ensure that the WWP is a success.

It is important to reinforce that this is not a 'protest' activity. In fact it is not a March or a Rally, it is a peaceful and positive 'walk', modelled on the success of the ASA in their annual 'Walk on Washington' event. However, if we are not supported by our Parliamentary representatives, well then, who knows what might develop in future years? But for this Inaugural Event, and for all promotional material it is a "walk"!

## **FEDERAL PARLIAMENTARY INQUIRIES**

Thanks to those A4 members who have made contributions or submissions to the current Federal Parliamentary Inquiry into Improving Children's Health and Well Being, as discussed in previous updates.

Now it is time to get out your pens and keyboards again and start work on this one:

## **Public Inquiry into the Disability Discrimination Act 1992**

**Reference: <http://www.pc.gov.au/inquiry/dda/index.html>**

**The Commission has commenced a public inquiry into the Disability Discrimination Act 1992. Further details are available in the press statement of the Parliamentary Secretary to the Treasurer and the terms of reference.**

**The inquiry will examine the social impacts of the legislation on people with disabilities and on the community as a whole. Among other things, the Commission is required to assess the costs and benefits of the DDA and its effectiveness in achieving its objectives, which in summary are to:**

- eliminate as far as possible discrimination on the grounds of disability**
  - ensure equality of people with disabilities before the law**
  - promote recognition and acceptance of the rights of people with disabilities.**
- The inquiry is particularly relevant for people with disabilities, their associates and representatives, service providers, businesses and those involved in overcoming disability discrimination.**

**The Commission will publish an issues paper shortly and will be holding public hearings in May. A draft report is planned for September 2003. The Commission is required to report to the Government by 5 February 2004. Further details are available in the detailed terms of reference.**

**Key Inquiry Dates :**

**Receipt of terms of reference 5 February 2003**  
**Due date for initial submissions mid-April 2003**  
**First Round Public Hearings May 2003**  
**Draft Report early September 2003**  
**Final Report to Government 5 February 2004**

## **INTERNATIONAL AUTISM NEWS**

Here are some interesting statistics from the US of A.

### ***DID YOU KNOW?***

***Over 1.5 million Americans are affected by autism.***

***U.S. rate of growth over the last decade:***

***Population: 13%***

***Non-autism-related disabilities: 16%***

***Autism: 173%***

***Today 50 families in America will find out that their child has autism***

Does anyone want to have a go at compiling Australia's comparative figures?  
It is certainly an effective way to start a letter.

## **& an interesting snippet of news from the UK**

### **Medical Research Council Review of Autism Research: Epidemiology and Causes**

The Medical Research Council (MRC) was commissioned by the Department of Health to review the current autism research base and make recommendations for priority areas of future research. The NAS was represented on the lay group and the steering group for the Review, which identified an estimated prevalence for autism spectrum disorders of 60 per 10,000 children under eight. This is the greatest public recognition of the scale of the challenge posed by autism to date; as the report states, 'These estimates make autism spectrum disorders far more common than was previously generally recognised.' The Review makes specific recommendations on research areas where knowledge is lacking, including refining case definition and developing hypotheses around abnormal physiology, such as gut disorders. At the Autism Awareness Year Conference held in London on February 14th, Jacqui Smith MP, Minister of State at the Department of Health, announced £2.5 million in funding to the MRC to begin implementing the research agenda established by the Review.

Copies of the MRC Review of Autism are available from the MRC website at [www.mrc.ac.uk](http://www.mrc.ac.uk)

### **CONGRATULATIONS.**

Finally, congratulations to A4 member Bruce Mitchell on winning an international Award for the Speech-Language Pathology Site of the Month for his excellent website! If you haven't checked it out before, do so now.

Asperger Syndrome Australian Information Centre  
<http://members.ozemail.com.au/~rbmitch/Asperger.htm>

Here is an extract from the citation. Great to see that A4 gets a mention too!

Site of the Month 2003  
REVIEWS OF THE VERY BEST  
Speech-Language Pathology related sites

MARCH 2003 If it's about Asperger Syndrome and it has relevance in Australia, parent-advocate Bruce Mitchell will have included it in his Asperger Syndrome Australian Information Centre web site. A stickler for acknowledging his sources and contributors, Bruce has included a good description of Asperger Syndrome, practical advice for parents, and an article about fitting in at high school. The home page is here and all the goodies are listed here (among them links, groups, guests and a Yahoo! group). You don't have to be Australian to appreciate, or benefit from, all the work that has gone into this. VERY nice. Oh, and if you still think A4 is a piece of paper, look here.

REVIEW About this review  
Asperger Syndrome Australian Information Centre [home]  
Resource description: Education Professional Student Consumer  
Resource evaluation: Quality+++ Usability ++ Authority+++ Design+  
Level of prerequisite knowledge: Non-technical Link hand-checked February 26, 2003

On that happy note, I will sign off for this month.

Kindest regards  
Judy Brewer Fischer  
February 2003