

# AUTISM ASPERGERS ADVOCACY AUSTRALIA

## 2003 UPDATE 1

Dear A4 Members

Happy Australia Day to you all! Let's hope that 2003 is indeed a better year than it is shaping up to be, with the looming Iraq conflict on the world front and the drought and bush fires disasters on the national front. We need to keep our optimism alive that we can overcome these challenges – but I suspect that you have all had to do that already in one way or the other in your own family situation, as the old saying goes: "what doesn't kill us makes us stronger".

Amongst the gloom, one piece of really good news today was the recognition of West Australian Professor Fiona Stanley as Australian of the Year. It is very motivating to see a scientist and a leading child health researcher recognised in this way and hopefully it will help the profile of research in Australia, and therefore our quest for more research for ASD related conditions.

On receiving the Award, Ms Stanley says nothing is more important than Australia's young people.

"We want a kind of Australia that is going to be one that nurtures its children, it's young people, provides the kind of stimulating, wonderful environments, that will mean a future great Australia and that is what excites me, that's what drives me," she said.

Hear hear!

**Action:** Start thinking now about people in the autism community that deserve recognition – there are so many; people with ASD, their families, and those that help them reach their potential. Let's nominate some of our 'heroes' for next year's awards. Anyone can do this and the process generally takes about a year. Awards are announced on Australia Day and on the Queens Birthday weekend.

Information on how to nominate an inspirational Australian citizen for the Australian of the Year Awards and details of past winners and the selection process is available from [www.australianoftheyear.gov.au](http://www.australianoftheyear.gov.au)

This is a great way to raise the profile of ASD in our community and in the media, as well as giving public recognition to some very worthy people.

Now a brief update on some of what has been happening with A4 during January. It has been a relatively quiet month due to the school holidays and all, but things will indeed get busy again from now on.

### **Steering Committee:**

The first face to face meeting of the Steering Committee will be in Melbourne on 9<sup>th</sup> February, and the agenda is already a mile long. Issues to be discussed include: An appropriate structure for A4, a National Plan of Action for Autism, State vs Federal Advocacy, the June Walk on Parliament event/s, Promotional activities and Communication procedures.

Expect an extensive report on the meeting in our February update.

### **Website:**

During the month we contacted the A4 members who ticked the website development box on the membership form. There was a terrific response and it was amazing to see the skills in our membership base. Thank you for your contributions and we are now working on developing a new website to enhance our communication ability.

### **Policy development:**

In the same way, during February we intend to use the database and the information you have given us, to utilise the skills of members who indicated an interest in policy development. We have a number of draft papers prepared and if there is an issue that you are concerned with that relates to the Federal Government's jurisdiction, please prepare some background information for us and we may be able to use it in our deliberations and representations.

### **State vs Federal Advocacy:**

Many of our members have expressed their frustration at the lack of organised advocacy services for state related issues, particularly those related to receiving assistance for educational support. Given our current resources, it is not possible for A4 to take on every issue in the ASD area and so our priority must remain with the Federal Government at this stage. However we would certainly welcome any attempt by the various state organisations and support groups to formalise state advocacy services in close co-operation with A4. If this is of concern to you, perhaps you could take this up with your own state groups and see if we can make some progress towards a more co-ordinated approach.

### **Products and Therapies:**

We have also had approaches from our members seeking support and advocacy for particular ASD treatments, products and therapies. A4 cannot promote individual commercial products and can only advocate for therapies, which have some clear data and research to support their effectiveness. I realise that this is particularly difficult in the ASD area, as there is so much conflicting advice, so much speculation and so little research.

Personally, I try to keep a very open mind on all possible means of assistance. However A4 must establish a credible, realistic and sincere face to government if we are to be successful in our main aims and engage the key players. To do this we need to have well researched policies that can withstand any scrutiny.

### **Canberra in June:**

A4 has had approaches from South Australia, Western Australia and Queensland requesting some state based involvement in our planned activities for 2<sup>nd</sup> June. This will be discussed at our steering committee meeting, but if you are keen to proceed with something state based, you need to know that A4 cannot extend to do any of the administration or promotion. You will need to form a local committee and please continue to liaise with A4 as to details. A4 cannot support holding similar functions in the south eastern states as we feel it would detract from our numbers and our focus on Canberra on the day.

More details and an outline of the planned Canberra activities will be forthcoming in the February update, but it is definitely on!

ACT Autism will be commemorating their 25<sup>th</sup> anniversary on weekend preceding our event, and are planning a range of workshops and speakers for Saturday 31 May and Sunday 1 June. Please consider making a 'weekend' of it – with your families if necessary, I know it will be worth your while.

**NB:** This is NOT the biennial national autism conference. That is to be held in Canberra in **2004**, from Monday 27<sup>th</sup> September to Friday 1<sup>st</sup> October.

### **Federal Inquiry into Improving Childrens Health and Well Being**

Latest advice is that submissions to this Inquiry will close late March or early April. Details will be listed on the website:

[www.aph.gov.au/house/committee/fca/childwellbeing/index.htm](http://www.aph.gov.au/house/committee/fca/childwellbeing/index.htm)

A4 is working on a Submission to this Inquiry but we encourage you to do individual submissions as well. We recently received a copy of an individual submission from one of our A4 members, which is much appreciated.

### **Media File**

Following our December update, 12 Families have registered for our media file. It is not too late to do so, this will be an ongoing process. It would be great to have members to call on from every state and territory, so please consider sending us a brief outline of your family and your contact details. Remember that you can always say no later to any specific request if you do not feel comfortable following through.

## **International Update**

### **Some interesting research from the USA**

UC Davis scientists to study potential causes of autism

#### **Researchers hope to understand possible roles of environment, genetics**

UC Davis researchers have launched several major new studies to unlock the mysteries surrounding autism. They hope to answer a fundamental question: Do environmental factors combine with genetics to cause the disorder? The research, expected to break ground in an area where little is known, will take place over the next few years.

Next month, investigators from the UC Davis Center for Children's Environmental Health will begin enrolling 2,000 California children in the study. They plan to include 700 autistic children, 700 who have mental retardation or developmental delay but not autism, and 600 who have developed normally. Researchers will then analyse blood, urine and hair samples from the children and their family members to search for the presence of toxic substances.

They will compile comprehensive histories on the mother and child, looking at exposure to everything from vaccines containing a mercury preservative to pesticides, PCBs and chemicals used in industrial processes. The work will be much like fitting together the pieces of a giant jigsaw puzzle without knowing what the final picture looks like. Investigators will search for patterns of differences between the children with developmental problems and those without.

[www.bayarea.com/mld/cctimes/living/education/4834494.htm](http://www.bayarea.com/mld/cctimes/living/education/4834494.htm)

### **7<sup>th</sup> International Congress Autism Europe**

If the Melbourne Congress has whetted your appetite for international autism events (& if you have just won Tattsлото), Lisbon, Portugal is the location of the next big gathering. The dates are 14, 15 & 16<sup>th</sup> November 2003, and the theme is: *Dreams Guide Life*. Proposals for papers are being sought now

Here is the link for further information:

[www.autismeurope.arc.be/english/frame.htm](http://www.autismeurope.arc.be/english/frame.htm)

**& last but not least, the USA National Conference.**

**The 2003 ASA National Conference on Autism  
"Bridges To The Future!"  
Pittsburgh, Pennsylvania  
July 16 - 20, 2003**

More info through: [www.autism-society.org](http://www.autism-society.org)

That's all for now!

Judy Brewer Fischer  
A4 Convenor  
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