



# National NoticeBoard

Newsletter of the Australian Association for Families of Children with Disability

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Auspiced by the Association for Children with a Disability

**Edition 4**

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## Parent Power

Well, we're up to Newsletter No. 4 and it's obvious we're going to be around for a long time to come. The enthusiastic response from parents all over Australia has been fantastic.

In addition to lobbying the Federal Government about better policies to assist families of children with a disability (see page 4) many parents and parent groups have asked for advice and support in setting up new State/Territory based parent networks along the lines of our Victorian Association for Children with a Disability.

I was guest speaker at the Association for Children with Disability (Tas) Inc. where I learned of the giant steps they have taken over the last five years. They now have government funding, a part-time family advocacy worker and administration person who also has extensive experience dealing with families of children with disabilities. This has come from small beginnings and still has a long way to go, but I am sure with their enthusiasm, this group will be of great assistance to families in Tasmania.

The South Australian representatives of our National Group called a meeting of interested parents in their State. I was invited to speak about what is possible and it was wonderful to see and hear their commitment to providing support to parents and families.

In the Northern Territory there are also moves afoot to form a new Territory-wide group to represent families of children with disabilities.

In NSW, a group of parents has established a new Association for Children with a Disability. Their first newsletter was published in



Barbara Alexander AO

September and they've already got a first draft of a NSW version of a 'Through the Maze' guide to services. Negotiations are continuing with various trusts and government funding bodies, including the John Symond Foundation (of Aussie Home Loan fame) to provide funding to complete and publish the Through the Maze booklet.

To find out more about the initiatives in your State/Territory, give me a call on 1800 222 660 and I'll put you in touch with key parent contacts. See list on page 4.

My involvement in parent support groups goes back more than 20 years to when I was first involved in a local group as a young mother with two children with severe disabilities. I never cease to be amazed at the power of what we can achieve when we work together and support each other.

Barbara Alexander AO

Back copies of National NoticeBoard are posted on the 'National Network' section of our Internet site [www.acd.org.au](http://www.acd.org.au). For more hard copies, contact me on 1800 222 660 or the Victorian Association for Children with a Disability on 1800 654 013.

### Vehicle Modifications New Action Research Project

Arising directly from your 'Top 3' Policy Priorities input, we've initiated a new Action Research Project to convince Federal and State/Territory governments and the car industry, to provide better support for families of children with a disability who require a modified vehicle.

We need more examples from each State/Territory to demonstrate the financial realities families face. Contact Barbara on 1800 222 660 or [barbara@cni.com.au](mailto:barbara@cni.com.au) with your story and/or ideas on the vehicle modifications issue.

### Inside this Edition...

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### Quicknote:

At the time of writing, negotiations were still continuing between Federal and State governments on a new Commonwealth State/Territory Disability Agreement (the CSTDA).

The Australian Association for Families of Children with Disability (AAFCD) is auspiced by the Association for Children with a Disability. For updates and more information see [www.acd.org.au](http://www.acd.org.au)

# Hannah

As the 5th birthday of our daughter Hannah gets closer, it is a reminder to us of the events of 5 years ago. We already had 3 gorgeous boys, Sam (10), Adam (8) and Alexander who was about to turn 6. Although the pregnancy was not 'planned' we were still thrilled and looked forward to the addition to our family of Oliver. (We were positive that we were having another boy - what else did we produce!)

Early in the pregnancy I experienced some slight spotting and high blood pressure, but the rest of the pregnancy ran smoothly. My gynaecologist decided on an induction a few days earlier than the due date so on August 29, after being in mild labour for most of the day, Hannah made a very swift entry into the world. Both my husband Grahame and the doctor missed the birth, as did the second midwife who was merely 2 rooms away.

Hannah was very tiny, just 2,295g (5lb oz). Compared to her brothers who weighed in at 8lb 5oz, 8lb 6oz and 7lb 5oz, she seemed even tinier. Grahame and I were marvelling at how like Alexander she was, meanwhile the doctor and the midwives were attending to her with oxygen and expressing some concerns as she was extremely hypotonic (low muscle tone). The paediatrician was called and we were settled into another room.

Grahame and I were just elated that we had a 'pink one'. We were in a state of absolute amazement. A close friend who is also a midwife arrived for her shift and, like us, she was also thrilled and thought that Hannah looked like a tiny version of Alexander. Meanwhile, words like 'Down syndrome' were being bandied around by many of the staff.

Over the next 9 days, many problems were found with Hannah. She did not have Down syndrome, but she did have a heart murmur and a cleft palette of the soft palette, which meant that she was unable to breastfeed. I was determined to give her breast milk; I had basically been a cow with the boys so knew that I could. She was tube fed for the first 8 days, but on day 9 she drank from a small cone shaped medicine cup, which was not only great but also very cute.

The midwives were great, although each day someone commented on a different one of Hannah's features as being odd - like her eyes being wide apart, her ears too low set and other such comments. We were trying to enjoy our little girl and sometimes these comments were hard to hear. Comments like 'You and Grahame are coping so well, I admire you.' We didn't know we were being



Hannah with her brothers

admirable and coping, we were just enjoying our baby even though she appeared to have some problems.

Her big brothers were thrilled and every visit they would cuddle her. We had many visitors, lots of family and friends and our room was full of flowers (mostly pink), cards (all pink), teddies (again pink) and a big banner announcing 'Welcome to your baby girl'. Even though these days were filled partly with apprehension and a niggling feeling of something not right, we were not prepared for the diagnosis on day 9.

Blood tests were carried out on day 5 or 6 and when the results came back our paediatrician called and suggested that Grahame meet us at the maternity unit. He arrived with a very bleak look on his face and an extremely bleak looking photocopy from a medical textbook. Hannah was diagnosed with Wolf Hirschhorn Syndrome. Never heard of it? Well, neither had the doctor. It is a rare chromosomal disorder, a deletion on the short arm of the 4th chromosome. He told us that it would have been better had the diagnosis been one of Down syndrome. He then told us that we would probably like to go home, rather than stay in the maternity unit.

We were very keen to get out of there and home to our boys, who were with my sister-in-law, Denise and her 2 girls, Kate (8) and Claire (6). As Hannah had begun drinking from a cup we were able to take her home without a tube for feeding. We left the hospital with very heavy hearts, an intense feeling of nausea, an electric pump from Nursing Mothers and that wretched photocopy!

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That night was one of many mixed emotions for Grahame, Denise and myself. We all held ourselves together for dinner and getting the kids to bed, who were obviously very excited to have Hannah home. They went to sleep blissfully unaware of how our lives had just changed. We spent the night phoning family and friends and trying to come to grips with what little we knew. We also cried, had a few scotches, cried some more, talked, raged and generally went to bed exhausted. One of the issues that we spent a long time on was how and what do we tell the children? We literally agonised over it for many hours that night and the next day.

We decided that we had to be honest, but not brutally so. We got the 5 of them together and basically gave them the simple facts that something had gone wrong when Hannah was growing inside me and that she had a disability called Wolf Hirschhorn Syndrome. We gave them a little bit of information about the syndrome and also explained that people would be upset and that if they had any questions then they were to ask them, they weren't to keep it to themselves.

Adam's comment will stick with us forever. In his gorgeous 8-year-old matter-of-fact voice he said, 'But we'll love her anyway, that was my marble Sam gimme it back!' The children took it in their stride. As we watched Sam and Adam rumble over a marble and Kate, Claire and Alexander roll around in laughter we simply looked at each other and shrugged.

Over the following week we were all kept pretty busy. Apart from the usual everyday things that had to be done for the 5 kids, we also had to cope with what we were going through. Grahame took a month off work and made himself very busy with things around the house and running the children everywhere. Denise took on the role of mother to all of us, while also managing to spend a lot of time at the local library researching Wolf Hirschhorn Syndrome and finding out all she could. I seemed to spend my time attached to the breast pump or feeding Hannah from her cup, and pedantically recording every mill she drank!

Denise eventually had to return to Sydney and we managed to get into a routine. We had some services such as Homecare coming in to help once a week, and apart from the feeding problem, Hannah was a

delightful baby - placid, happy and loved being cuddled, which was just as well.

It is only now as I have been looking at videos of Hannah when she was first born that I really remember those early weeks. We travelled everywhere as a united family - Grahame, Sam, Adam, Alexander, Hannah, the electric pump and myself! We had fantastic support from family and friends and Hannah spent many hours happily being cuddled and passed from one person to another; sometimes it was a battle for visitors to wrench her from her brothers' arms. Looking back at people holding her and all the family that visited from Sydney (and they all came up quickly) I can only see the love, fear and questions in their eyes that at the time I was unable to see.

Over the last 5 years we have become a strong family (although I have to say that maybe there should be a support group for parents of children with a teenage disposition) and Hannah has become quite a character. She is such a delight and as I sit and write this, I can hear her in the boys' room where Alexander and his mate Haydn are playing. She is talking to them in her own way, getting in the way, thoroughly enjoying being there and if perchance they were to take her to the living room she would roll back there as fast as she could. Hannah loves her brothers, and rightly so, they are all fantastic with her, each of them is special to her in their own right. She is such a people person, her very favourite occupation is to be with children, not on her own or even with adults; she loves the company of kids, particularly boys.

How to sum up the last 5 years? This story could fill a book, and one day I will do that. For now, some words come to mind - busy, tiring, like a roller-coaster, rewarding, long, too short, amazing, full of cuddles (and not only from Hannah), new experiences, anger, new friends, tears, I could go on.

I would not swap my girl for anything in the world, nor could I ask for a better dad for her or better brothers. If there were just 2 things that I could change, they would be that neither Hannah nor us and the boys had to go through the ordeal of seizures and that she could speak!

Anne Chafey, NSW

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### Your Story?

Have Anne, Grahame, Hannah, Sam and Adam inspired you to write your story?

It can be your whole story or just part of it. For our thousands of parent readers, there is inspiration in every parent story.

Send your story and a photo to Barbara Alexander, 8 Grubissa Court, Benalla, 3672 or email [barbaraa@cnl.com.au](mailto:barbaraa@cnl.com.au)



Sue with son, Scott

## Sue Griffin (NSW)

My husband and I have three gorgeous sons, Luke (14), Mark (11) and Scott (7). However, life is not easy for two of them. Luke started having seizures when he was 4 and over the years has developed a permanent tremor (cause unknown). Scott was born with Wolf-Hirschhorn Syndrome, which involves the deletion of part of a chromosome. As a result, he has seizures, can't walk or talk, and is fed via a gastrostomy button. (Our 'healthy' son Mark wondered for many years when he would start having seizures and why he was the only one who didn't get to see doctors regularly.) Whilst Scott's condition is much more severe than Luke's, emotionally, we often find it is Luke's condition that causes us the most heartache. Watching the pain he experiences when other children make fun of the way he 'shakes' while doing everyday things is very difficult. Scott, on the other hand is physically tiring but blissfully unaware of other people's reactions. He believes everyone is there for his entertainment.

One of the things I would like to see changed is the way people view anyone who is 'different'. I'm also keen to see parents getting the information and support that they need to cope with the many stresses that having a child with a disability brings. For this reason, in August this year, a group of like-minded parents started the Association for Children with a Disability NSW. It's been wonderful talking to parents from many different places around the state, building links and sharing our stories. As we work together, both in NSW and at a national level, we can have a voice loud enough to be heard and the opportunity to put real support networks in place. As I've watched my sons find ways to overcome the obstacles they face I realised how heroic our children really are.

NSW Association for Children with a Disability

To contact the NSW Association and get on the mailing list for NSW NoticeBoard, contact Sue Griffin on (02) 9688 3383 or (03) 9890 8631.

## Federal Policy Priorities/2003 Federal Budget Advocacy

Based on your input to the 'Top 3 Priorities Input' form distributed with the first, second and third editions of National NoticeBoard, we've completed a draft Federal Policy Priorities document that will form the basis of our lobbying to the Federal Government in the lead-up to the 2003 Federal Budget in May.

We recently had a visit from Andrew Kirk, Senior Adviser to the Minister for Family and Community Services, Amanda Vanstone. After listening to our Victorian parent members talk about their lives and the need for improved Federal policies, Andrew reiterated how much he (and the Minister) appreciated hearing directly from 'real people', ie. families. In our experience, real-life stories told directly to politicians are often much more effective than long written reports.

We will be seeking another audience with Andrew and Minister Vanstone early in the new year, where parent/family reps will ask her to respond to our policy suggestions. Our style with governments is brutal and honest - 'telling it like it is' - but also we're about being realistic and constructive, always seeking to suggest and discuss solutions.

Governments aren't to blame for everything and they shouldn't be seen as the only source of solutions, but they do have a role in providing a basic level of support to all families of children with a disability. At the Federal and State/Territory level, all our governments still have a long way to go!

### Top 5 Policy Issues

1. Respite and Long Term Accommodation Support
2. Education
3. Financial Issues and Centrelink
4. Child Care, After Hours and Vacation Care - the Special Needs Subsidy Scheme
5. Vehicle Modifications and other Aids and Equipment

We're still interested in your thoughts and ideas about these priorities and the next list of 6-10. Have we missed any crucial issues?

Please phone/fax or email Barbara on 1800 222 660, fax (03) 5762 7000 or email barbara@cni.com.au

## Australian Association for Families of Children with Disability

### Committee Members

#### ACT

Cheryl Patrick  
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#### NSW

Sue Griffin  
Lisa Brown  
Julie Brunson

#### Western Australia

Clare Masolin  
Clara Harris

To be put in contact with your State/Territory representatives, phone Barbara on freecall 1800 222 660.