



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 ~ ABN 39 835 407 788 ~ www.acd.org.au

Spreading the Word!

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Hi, I'm Lyn Kemperman, the President of the Victorian Association for Children with a Disability (ACD) and one of the Committee members of the Australian Association for Families of Children with Disability (AAFCD).

My daughter Claire is 11 years of age and has an intellectual disability. Claire's passions include art, cooking, music, dancing and the 'In the Box' TV show. Claire's brother Todd is aged 7 and he's a good little brother, most of the time!

For those of us involved in the inner circle of the AAFCD, we were disgusted at the lack of attention paid to disability during the federal election (to put it mildly!). It has made us more determined than ever to do whatever it takes to put disability issues on the radar at the federal level.

Helen Johnson, whose story appeared in the July 2004 National NoticeBoard, is now the new AAFCD Co-ordinator, taking over from Barbara Alexander (see page 4). Helen's energy and enthusiasm is infectious and together with the rest of the AAFCD committee and our membership base, we are looking to harness every bit of spare parent/family energy to increase our visibility and influence on the federal political scene.

If you have any spare energy (and I know it is always a big if!) give Helen a call on 1800 222 660 (freecall from anywhere in Australia) or helenj@aafcd.org.au and discuss any ideas you have for how you could help out. There are all sorts of contributions you might be able to make. In short, we need whatever

mix of time, energy, networks and skills you have available!

One key task is to increase our membership. We need you to encourage every parent/family you know to sign up as a member—which is FREE for families!—so they can receive National NoticeBoard. You can photocopy and use the form on page 4, or you can request multiple copies of the new AAFCD pamphlet/membership form.

Meanwhile, Treasurer Costello has already started work on the next federal Budget to be delivered in May 2005. Between now and then, we will be telling him and his team about the priorities for families of children and young adults with a disability—beginning with the rate of payment of Carer Allowance and the Contingence Aids and Assistance Scheme (CAAS).

I'm looking forward to being part of the AAFCD's development over the next few years and achieving real, positive results for families. Together with other organisations, I see the AAFCD as a crucial part of a growing alliance of people and families that will one day (by the 2007 election?) see disability issues for families given the prominence that we, and our children, deserve in the political decision-making process.

Lyn Kemperman,
ACD President and AAFCD Committee member

- To request copies of the new AAFCD pamphlet and/or to contribute ideas to our policy priorities contact Helen Johnson, AAFCD Co-ordinator on freecall 1800 222 660 or helenj@aafcd.org.au.

AAFCD Membership— it's FREE for families

In addition to AAFCD membership, we actively encourage all parents/families to be members of relevant disability specific support groups (such as A4 for autism, Down syndrome and cerebral palsy associations, etc.). Our aim is to work together with these organisations on issues that reach across all disabilities.

We are committed to keeping AAFCD membership free for families in the hope that parents/families will become members of AAFCD in addition to their disability specific group and/or other key support groups.

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*The Australian Association
for Families of Children
with Disability is auspiced
by the Association for
Children with a Disability
(www.acd.org.au).*



Our Little Miracle

At the end of 1997, my husband and I thought we would start our family, which of course was going to have two children — a boy and a girl. With me always having problems in that area (I suffer from endometriosis) I told my husband that I didn't expect to fall pregnant within the first 12 months. If I hadn't fallen pregnant within 12–18 months, I would seek medical advice. Eight weeks later, I was pregnant. I couldn't believe it! And the story begins.

At five weeks gestation I had some abdominal bleeding. I was sent for an ultrasound and was told that I had miscarried. Devastated, I went home and told my husband the news.

About a month later, still showing signs of being pregnant (all day nausea!) I went back to the GP only to find out I hadn't miscarried at all. I was still pregnant! During the first trimester, I lost 6 kilograms in three weeks.

At 24 weeks, I was diagnosed with gestational diabetes and was now considered high risk. My baby was in the breech position and I had high blood pressure.

At 36 weeks, it was decided to try and turn my baby, as she was still breech. My blood pressure skyrocketed and it was considered too dangerous to try and turn the baby, instead, I was admitted for total rest. We found out after she was born that they would have killed her if they had tried to move her.

The next day, I started to go into labour, which was to last 52 hours! I was then taken for an emergency Caesarean. When they cut me open they couldn't get the baby out - she was stuck! They ended up having to cut the umbilical cord while she was still inside me. They were then able to get her out and found that she wasn't breathing. You could have heard a pin drop. They finally got her breathing and told me it was a miracle she survived her birth. She was already our little miracle considering they thought I had miscarried her. We named her Caitlyn Ashleigh.

Caitlyn was a nightmare baby—she wouldn't breastfeed, she screamed from 6am–9pm and then slept in half-hour blocks. She would take 40 mills of formula and then throw it up. She was losing weight and was classed as 'failure to thrive'.

At eight weeks, she was admitted to Princess Margaret Hospital for Children (PMH) and was diagnosed with chronic



Caitlyn

reflux and put on medication. At 12 weeks, she was readmitted for the same problem and taken off all medication and placed on thickened feeds. At three-and-a-half months she was placed on solid food. Nothing really helped.

At five-and-a-half months, Caitlyn came down with chronic diarrhoea. For ten days I took her to and from the GP's with each visit ending in 'bring her back in two days if she hasn't stopped'. On day 11, I had made up my mind to take her into PMH, when she stopped (sigh of relief).

Six weeks later, she started again (oh no!). On day five I took her to PMH and she was admitted immediately. (Mental note: three visits to PMH, three admissions—stay away from PMH!) Caitlyn was doing eleven soiled nappies a day; she was being fed through a nasogastric tube into her stomach.

She had another 17 days of diarrhoea and blisters all over her bottom from so many soiled nappies. My poor baby. She was in

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hospital for three weeks. To this day, they still can't explain what the cause of the diarrhoea was.

Just when I thought I had jumped the last hurdle for a while, I couldn't have been more wrong. On the day before she was to be discharged, her paediatrician thought she was floppy for her age. While doing a blood test to do with the diarrhoea, he thought he would test her CK level (creatin kinase). When your muscles are wasting, they send out an enzyme called CK. For a normal person, the CK levels are 200 or under; hers were 4,060. She was immediately referred to a neurologist and put under general anaesthetic and had a muscle biopsy.

At eight months, Caitlyn was diagnosed with congenital muscular dystrophy. We were told that this is a rare condition with a one-in-a-million chance. We were to have more chance of winning First Division Lotto than having a child with this condition. We were told we would be lucky if Caitlyn made it to one year, and if she did, she would be lucky to see the age of five.

We were devastated. At genetic counselling we were told that we were both carriers of the faulty gene and that if we had met and married anyone else it wouldn't have happened. I guess we are just too perfectly matched.

We have a one-in-four chance of having another child with this same condition and as they don't know what gene causes it yet, they can't test in-utero. The decision was made that we wouldn't have any more children, though it breaks our hearts.

Just before her third birthday, Caitlyn started deteriorating for no apparent reason. I was told by her neurologist to go home and discuss with my husband whether we wanted Caitlyn to have quality of life or quantity. If we wanted quality, we would leave her as she is. If we wanted quantity, we would put her on a breathing machine. We were told that either way, not to expect her to make her third birthday. We chose quality.

She had her third birthday and was placed on steroids for a while, this seemed to boost her up and she started to get better again. No one can explain what happened. Not long

after this episode, Caitlyn started to get migraines. This is apparently unrelated to the muscular dystrophy.

Caitlyn is now five. She has also been diagnosed with asthma (again, not related to the muscular dystrophy). Just lucky, I guess. She is also allergic to blue food colouring, not red like most kids. Strange child!

When she was four she had both feet operated on to straighten them. This was a success. We have just found out she needs an operation on her hips where they have to break both hip bones and place them in the sockets properly, which I am not looking forward to.

Aside from all this, Caitlyn has been in an electric wheelchair since she was three-and-a-half. Otherwise she is a normal five-year-old. Everyone who meets her says she has been here before. She is an old soul and knows way too much for her years.

Wherever she goes people are drawn to her, and she can talk the hind leg off a horse! I used to say that the only peace I got was when she was asleep, but now she talks in her sleep too!

Every time I take her to Rocky Bay where she has her therapies, they ask me if I want them to make her wheelchair faster. My response is that my nerves aren't ready for faster yet!

We live one day at a time. I figure that the future will get to us in time and it gets too scary to look too far ahead.

Karen Day, Hocking, WA

"Every time I take her to Rocky Bay where she has her therapies, they ask me if I want them to make her wheelchair faster. My response is that my nerves aren't ready for faster yet!"

"We live one day at a time. I figure that the future will get to us in time and it gets too scary to look too far ahead."

Your story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories. Whether it's your whole life story—or just part of it—if you feel inspired to write, send your story and a photo to Fiona Gullifer, The Editor, National NoticeBoard, AAFCD, 590 Orrong Road, Armadale, Vic, 3143 or email (fionag@aafcd.org.au).



AAFCO Personnel Changes



Barbara Alexander AO

Ever since we began as a national Association, Barbara Alexander AO has been at the forefront of our work as AAFCO Convenor and the voice at the end of our 1800 number for families. Barb's contribution to the AAFCO has been amazing—juggling the time and travel requirements of various Canberra based committees as an AAFCO rep, the demands of her other 'day job' as Executive Officer of the Tomorrow: Today Foundation, as well as other voluntary commitments in her Victorian home town of Benalla.

With the time requirements for the AAFCO continuing to grow, Barb made the difficult decision to step down as Convenor. Barb will be staying on the AAFCO Committee and we look forward to her continuing contribution.



Helen Johnson and family. Helen's story appeared in the July 2004 National NoticeBoard.

Helen Johnson lives in rural Victoria (Gippsland) and is employed 15 hours per week as the AAFCO Co-ordinator, which she spreads across various days. She is already run off her feet (as Barb was) and it is obvious that somehow we are going to have to find some extra funding to increase her hours. If you get the dreaded answering machine message when you ring Helen on the 1800 number, please leave your details and she will get back to you as soon as possible.

What is the AAFCO?

Our Association is a 'grass roots' organisation, run by parents/families for parents/families. Our Association includes all types of disability. Our formally defined purpose is:

'To provide information, support and advocacy to families of children aged 25 and under with disability in all States and Territories of Australia. The advocacy role includes provision of information to the Federal Government about family needs and issues and advocacy for changes required to Federal policies and programs to address these needs and issues.'

AAFCO Committee Members

Australian Capital Territory

Cheryl Patrick

New South Wales

Kylie Ramstadius

Northern Territory

Bruce Young-Smith

Queensland

Leonie McKnight

South Australia

Cale Dalton

Tasmania

Diane Fugslang

Victoria

Lyn Kemperman

Barbara Alexander AO

Jan De Witte

Western Australia

Clara Harris

Contact Helen Johnson on 1800 222 660 to be put in contact with your state/territory representative.

Australian Association for Families of Children with Disability National NoticeBoard Membership/Subscription Form

If you're not already on our mailing list to receive National NoticeBoard, you need to register as a member/subscriber by sending this completed form to the address below or join online at www.aafcd.org.au. It's free for families and service providers.

I would like to be put on the (free) membership/subscription list for information from the Australian Association for Families of Children with Disability, including National NoticeBoard.

I am a: Parent/Carer A young person with a disability
 Service Provider Family friend/Concerned person Other

Name:

Organisation & Title:

Postal Address:

Town/Suburb: Postcode:

Phone: () Mobile:

E-mail:

(Optional) If parent/young person, child's name/your name, DOB and disability:

Send this completed form to:

Australian Association for Families of Children with Disability
590 Orrong Road, Armadale, Victoria, 3143 or Fax to 1800 222 660