

# National NoticeBoard

Newsletter of Australian Association for Families of Children with Disability (AAFCD)

## Walk A Mile in OUR Shoes

This National NoticeBoard was prepared before the Federal Budget was handed down, although some of the details had already been announced. As parents of children with disabilities, our lives are mostly consumed by the realities of the tasks we have to do to get through today, tomorrow and the next day. Federal politics often seems a long way away, and largely irrelevant to the most important things in our every-day lives.

Since taking on the job of AAFCD Co-ordinator, the political scene is now much 'closer to home', and I have been on a very steep learning curve about the way it all works (or doesn't work!).

Based on the experiences of parents involved in AAFCD, we have plenty of passion, energy and emotion about what we think the Federal Government should be doing better for families of children and young adults with disabilities. But getting them to listen and DO SOMETHING is not always as simple as we would like it to be.

I'm not sure if you were one of the 900,000 or so viewers nationwide who watched ABC Television's Four Corners program 'The Hidden Army' in late March. It was a great program and my congratulations go out to everybody who participated in it.

I had some contact with Four Corners during the program's production, including trying (unsuccessfully) to convince them to add another family profile representing parents of young children with disabilities.

Nevertheless, the carers who appeared in the program—Danny (a 14-year-old caring for his mother with depression), Felicity (two adult children with disabilities), Dorothy (husband with Alzheimer's and vascular dementia) and John (wife and daughter with muscular dystrophy)—did highlight some of the common struggles that we all face when caring for a loved one.

After the program finished, Four Corners convened an Online Forum, which I participated in. Such was the enthusiasm of parents and carers that the Forum was still going after midnight.

The transcripts of the Forum are more than 100 pages long and include some great ideas. One I'm particularly fond of is a national 'Walk a Mile in Our Shoes' day, where we could all lay a pair of our worn out shoes on the lawns of Parliament House and/or the offices of our local MPs.

If it was well organised and supported across all states and territories, and involved all types of carer situations and carer organisations, the symbolism of asking politicians and other community members to 'walk a mile in our shoes' might be very powerful. Stay tuned for more details.

Amongst the feedback on the Four Corners program, I was interested to read the comments from viewers who weren't parents or carers, which included these two responses:

*"It is so rare that I am moved by any television program but the Four Corners story tonight did so. The compassion and unadulterated devotion exhibited by the carers for their loved ones was both moving and levelling."*

*"I am a taxpayer. If only I could determine the manner in which my taxes were dispersed! People courageous and generous enough to share their extraordinary stories as those I have viewed tonight are in no way a cost to me. To contribute to their support and services could only enrich my social experience."*

We have to find a way for all politicians and community members to be exposed to the reality of our lives, to the point where they 'get it', and feel inspired to respond like these two viewers did.

Helen Johnson, AAFCD Coordinator

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Quentin McDermott, Four Corners reporter

The transcript from Quentin McDermott's report 'The Hidden Army', as well as feedback from the Online Forum, is available from the ABC web site [www.abc.net.au/4corners](http://www.abc.net.au/4corners).

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Australian Association for  
Families of Children with Disability

# Advocating for Amber

Our story is not an easy one to tell. There are four people remaining in our family group: my eldest daughter Crystal (21), my son Nathan (18), my youngest daughter Amber (6) and myself. Amber is the one who has awoken us to the issues of supporting a child with a disability.



Rick (centre) with Nathan, Crystal and Amber

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"Amber was healthy, she was strong, she was stubborn and my god, her head was big! Her original diagnosis was Congenital Hydrocephalus, determined in-utero by ultrasound. She had endured several months of a killer headache and she was grumpy, but she was beautiful, and full of spirit."

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In 1998, my wife Deb told me that we were expecting our third child. At 15 weeks into the pregnancy, our GP suggested an early ultrasound, as Deb had undergone cancer treatment two years prior. The scan showed something abnormal. After a more thorough scan at a major regional hospital the following week, we had a diagnosis that we had never imagined—our child had a major birth defect.

We were told that because we had two older children, and the defect was profound, the only sensible thing to do was to have a termination and get on with our lives. Amber was yet to be born and already we were advocating for her. We were told that she would not be capable of anything, that she was suffering, and that to continue with the pregnancy was to ignore her suffering.

The following month, Deb lost her brother in a farming accident. The month after that, we found out that her mother had a brain infection and went into a coma for about four to five weeks, and then required long-term treatment and rehabilitation. Still, if anything, this hardened our resolve to give our as yet unborn child every chance of life, and to make the best of what she presented for us.

On New Year's Day 1999, Amber was on her way, four weeks early, and again we were advocating for her. We were asked in the labour ward if our baby should be resuscitated if she did not breathe spontaneously. This is something that needs to be considered, but the question was phrased in a way that we needed it to be stated twice before we understood what they were asking. An earlier time and location would have been more appropriate. We told them to help her in whatever way was needed; but Amber knew what to do.

Amber was healthy, she was strong, she was stubborn and my god, her head was big! Her original diagnosis was Congenital Hydrocephalus, determined in-utero by ultrasound. She had endured several months of a killer headache and she was

grumpy, but she was beautiful, and full of spirit.

But we were still advocating for Amber. The hospital staff assumed that she had no feeding instinct. This turned out to be a miscalculation and led to over-feeding through her nasal tube. It was also decided that Amber had no visual sense, yet her eyes would follow the staff as they walked past. We were told to expect no hearing ability, even though she would blink if I clicked my fingers. We learned to follow our instincts and blend it with the professional advice. We learned to be suspicious of everything and to research as much as possible. We learned to challenge what we were told if it didn't seem right.

Amber was slow to reach her developmental milestones but she gradually got there. Again, the health professionals did not readily accept this and we were still advocating for her. We gave up saying what she could do, and would instead arrange 'surprises' so they could 'discover' what we already knew and had given up trying to tell them.

As a toddler, we took Amber to a kindergym and she hated it. She cried, she cried and she cried some more but we gradually got results. The people running this program were very good and they loved Amber and gave great assistance, even under duress. Amber slowly came to really enjoy the program, even if she did try every avoidance tactic known.

Amber was nearly two when her Nana died (Deb's mother), partly due to complications of treatment for the brain infection. The unforeseen side of this was that it masked the gradual decline in Deb's health. Amber was two years and three months old when Deb was diagnosed with secondary cancer, originating from her previous encounter five years earlier.

We had been here before, so we set our plans and started treatment. One week later, I revised those plans, as Deb was now

effectively bedridden. Another week later, I revised those plans again, as Deb had passed away.

I was working full-time in a high stress job, with two kids in high school (Crystal in Year 12 and Nathan at a critical adolescent age) and Amber, with her high level of need. I clung on to this role for 15 months. I would get out of bed at 5.30am, get Amber ready, take Nathan to school (thankfully Crystal could drive), do a day's work, get home, bath Amber, get dinner, do housework, prepare for the next day and fall into bed at around midnight. The next day, I would do it all again.

The combination of support from close friends, a forgiving employer, as well as my management training and process engineering experience was invaluable to me during this time. I knew how to set goals, break big tasks into smaller manageable bits, review and change them as needed and how to manage my time to best effect. This is what kept me going. But I knew it couldn't last.

In 2002, I decided that I needed to focus on Amber's development so I left my career to become a full-time carer. This also meant that I could spend more time with Nathan and Crystal as well. The benefits for Amber were enormous and she responded well, even if it took a few months for it to show. As for any carer, there are consequences of full-time caring, and these were no different for me. But I also had the added complication of being a male in a traditionally female role. My extended family is of the older generation and they did not easily come to terms with my change of role. I added my own fears and insecurities to this, as did my older kids.

However, the outcomes have been little short of amazing. Amber walked independently just before she turned five. In the beginning, she was not even expected to be able to sit up. She attended mainstream kindergarten and now goes to a mainstream school, and she is accepted in the local community. My older kids have gone on to university, with Crystal doing honours.

You will have noticed one strong theme in my story: the need to advocate effectively for your child. Not in an aggressive or disruptive way, but in a firm and persistent manner. You do not always have to accept the immediate response. I have had enormous support from people who have seen and understood my efforts, and who have helped willingly, sometimes after they had said there was nothing they could do.

But we are a long way from finished. My current efforts for Amber relate to education. While the goal of educational systems is to ensure that all children with disabilities are able to participate, they appear to stop short of ensuring that these kids can achieve. Achievement is the way to help kids such as my Amber to grow into productive adults, in work and all aspects of life. Participation is only halfway towards this goal.

I am now advocating for support for Amber at school so that she can learn how to achieve in her education. It has been a long, hard road just to get Amber to the starting line. Having got this far, I now find that she is often seen as not requiring much ongoing support because she is more functional than many others who are also in need of support. This is poor reward for all the effort we have made. It makes me wonder if the policy-makers actually think carefully about the outcomes of their strategies.

There is much discussion about helping kids reach their full potential, but to me, in the area of disability, this seems to be more PR than real intent. So far, I have managed to gain sufficient support for Amber, but the threat is ever present that it will disappear.

I am convinced that Amber will achieve the goals that are right for her because she is a very determined child. Many other people have taken an interest in her progress and find reward in her achievements. It is disappointing that we continually have to advocate for what seems so obvious, and is claimed as being provided, but at times, seems to not genuinely be there. Not without a fight.

Rick Sweetman, Port Willunga, SA

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"We learned to follow our instincts and blend it with the professional advice. We learned to be suspicious of everything and to research as much as possible. We learned to challenge what we were told if it didn't seem right."

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## Your story?

The parent/family stories are the most popular part of National NoticeBoard and we always need new stories. If you feel inspired to write, please do!

Send your story and a photo (all photos are returned) to:  
Helen Johnson  
AAFCD Co-ordinator  
590 Orrong Road  
Armadale, Vic, 3143 or email  
(helenj@aafcd.org.au).

# AAFCD Membership—Strength Together!



AAFCD Membership is FREE for families! Members receive our bi-monthly National NoticeBoard magazine. If you are not already a member of AAFCD, simply fill out the Membership Form on the AAFCD pamphlet and post it to us using our Reply Paid address (no postage stamp required). You can also join over the phone by ringing our freecall number 1800 222 660, or go online to [www.aafcd.org.au](http://www.aafcd.org.au) and complete the online Membership Form. For more information, and to be put in contact with your State/Territory representative, contact Helen Johnson, AAFCD Co-ordinator, on freecall 1800 222 660.



Katrina Clark, AAFCD NSW State Representative, with her daughter Georgia

## Introducing Katrina Clark, AAFCD NSW State Representative

I am the mother of three children: Brianna (12), Christopher (9) and Georgia (7). Georgia has severe developmental delay, with the most likely contender being Rett syndrome, but this has yet to be confirmed. Our family lives in Sydney and Georgia attends an excellent special needs school run by the Royal Institute for Deaf and Blind Children.

My husband and I were unaware that Georgia had any difficulties at all, but at three months of age she started to have seizures. Still oblivious to the implications of this, we took Georgia to our local GP. He admitted her for tests but gave us no clue of what might lie ahead of us. What followed was a flurry of doctors, medical jargon and therapists.

We had entered a brave new world that we never knew existed. I expected to see areas that needed improving, but what I did not expect, and am now confronting, is the need to fight so hard to maintain what is currently provided to people with disabilities.

Organisations like AAFCD provide one of the few avenues available for families to join forces, to be heard and to effect change. I know that between us, we have many innovative and practical ideas to improve the lives of families of children with disabilities. The challenge is deciding where to start!

Having been part of the Association for Children with a Disability in New South Wales for several years, I am very excited to now be part of the Australian Association for Families of Children with Disability.

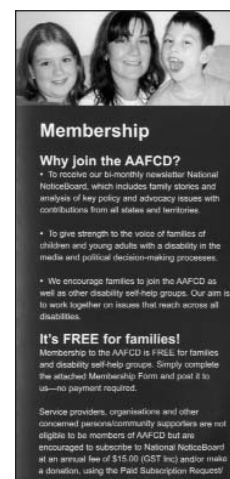
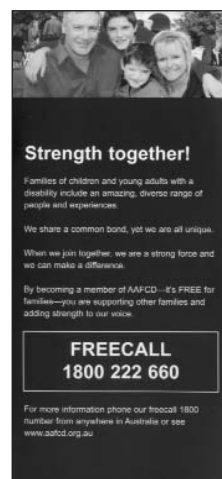
Katrina Clark, NSW

Apart from the benefits to families of getting National NoticeBoard mailed direct, the larger our membership base of families, the more powerful our message will be in Canberra and elsewhere around the country.

We encourage families to join AAFCD as well as other disability self-help groups. Our aim is to work together on issues that reach across all disabilities.

## Strength Together!

Thanks to everyone who has been actively spreading the word about AAFCD by distributing copies of our pamphlet to parents and interested professionals and organisations. We are relying on word of mouth to let people know about the benefits of AAFCD membership and getting National NoticeBoard mailed directly. It's FREE for families! To request multiple copies of the AAFCD pamphlet, contact Helen Johnson, AAFCD Co-ordinator by email [helenj@aafcd.org.au](mailto:helenj@aafcd.org.au) 1800 222 660 or Sue Crossley, Membership Officer on 03 9500 1232.



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