



# National NoticeBoard

Newsletter of the Australian Association for Families of Children with Disability

8 Grubissa Court, Benalla, Victoria, 3672 ~ Phone: 1800 222 660 ~ Fax: (03) 5762 7000 ~ E-mail: barbara@cnl.com.au

Auspiced by the Association for Children with a Disability

**Edition 5**

**January 2003**

## Funding Boost!

In December 2002, the success of our first year was recognised through being awarded a Telstra Foundation grant of \$25,000 per year for the next two years. This is a very exciting development! With your help, our Association will grow even bigger and stronger in 2003 and beyond. The focus of the Telstra Foundation grant is to link parents to information and support as early as possible, including local and regional parent support groups. See page 3 for more details.

For those of you who were part of our Association and National NoticeBoard in 2002, you'll know that we asked you to send us an answer to the following question:

If you had the key politicians/government decision-makers in your lounge room and they wanted to know the top 3 things the Federal Government could do to better assist your family and other families of children with a disability, you'd tell them...?

For those of you who found the time and inspiration to send us your thoughts, a very big thank-you! We received 562 replies, written with passion and emotion - where all the best policy begins - from the heart.

In National NoticeBoard No. 3 (Sept 2002) and No. 4 (Dec 2002) we reported on the priorities to emerge from this input, including: Respite and Accommodation; Education; Financial issues and Centrelink; Child care/Vacation care and the Special Needs Subsidy Scheme; Vehicle Modifications and other Aids and Equipment.

One of our most important tasks for 2003 is to translate this 'real-life' information about

family issues into policy proposals that government department staff and politicians can adopt as part of their world. Sometimes it seems there is an enormous gulf between the real world and the world of policy and budgets that flows in and around that big building in Canberra.

From my experience on various committees and meetings with politicians, it is possible for us to crash through the bureaucratic barriers of 'policy speak', but it is hard work!

There is power in numbers and in 2003 we need to continue to build both our membership base and the number of contributors to our 'real-life' research on family issues.

If you haven't yet formally registered as a member of our Association, please do so using the Membership/Registration form on page 4 or by phone (freecall 1800 222 660), e-mail: barbara@cnl.com.au or fax 03 5762 7000. There is no cost. Benefits of formally registering include having National NoticeBoard mailed directly to you.

Meanwhile, if you didn't find the time last year to provide your 'Top 3' issues/policy suggestions for the politicians, it's not too late. I'd love to hear from you!

You might also like to consider writing your story for National NoticeBoard. It can be as long or as short as you like, your whole life story or just a part of it. In each and every one of our stories, there is something of benefit for other parents and families.

Barbara Alexander AO  
AAFCD Convenor



South Australian parent Mary-Ann Murphy and family. See page 3.

### State/Territory Networks

In addition to a focus on Federal Government policy priorities, our Association is active in assisting State/Territory based networks of families of children with a disability. See pages 3 and 4 for details.

### Inside this Edition...

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### Quicknote:

Do you know who your local Federal MP is? Your Senators? You should! They might need you to educate them about the key issues for families.

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)

# Vehicle Gymnastics

We are parents of four children: Connor, aged 9; Eamon, aged 7 and his identical twin, Kieran, stillborn, and Neve, aged 3. Eamon has severe multiple disabilities as a complication of twin-to-twin transfusion syndrome and requires a wheelchair. When Eamon, aged four, 'graduated' from a buggy and insert to a wheelchair and insert we knew that the time had come for us to find a more suitable family vehicle. We had met too many parents who said they wished that somehow they had found the money for a modified vehicle sooner; it had made all the difference to their lifestyle and their child's participation in the community, even if it was too late to save their backs and necks.

I already had a chronic neck/back problem that was exacerbated by transferring Eamon frequently throughout the day, and I was expecting another baby. I talked to many parents, health care professionals and others to learn what types of vehicles would be most suitable for our family situation and to see how we could possibly find the funds to get a wheelchair accessible van and hoist.

There had been a lease scheme operating in WA, but that was no longer available. The Cerebral Palsy Association of WA sold off their vehicles by public tender, but they were not planning to do so that year, or in the near future, due to 'restructuring' of their funding from the Disability Services Commission. A scheme operated by one of the car dealers was only available for new vehicle purchases that would ultimately cost us more. We did not need a new vehicle anyway. However, we did prefer a vehicle a few years old, because reliability was such an important factor and it would cost over \$500 to transfer any hoist from one vehicle to another.

The quest for a van continued. We were living on one income; the demands of caring for Eamon prevented me from working outside the home, especially with the constant sleep deprivation. We only had one vehicle: a Corolla sedan which was definitely not going to cope with a wheelchair and insert. I spent many hours talking with one of the employees of a local firm which fits and maintains hoists. She provided lots of practical support, but the problem was always where were we going to find the money for what our family needed?

One of the mothers in my son's class called the radio and listeners donated enough money for a second hand van, but we just couldn't do that. We were very glad that the public responded generously to this family's need, but saddened that this parent had to 'go public'. We already felt that everyone



Eamon and Neve Guilfoile

(therapists, health care providers, educators and others) already knew so much of our private life. We felt that we couldn't tell the world how desperate we were to fund a van. Today, we open the local weekend newspaper to see another mother appealing for funds for a 1992 Hi-Ace van to transport her severely disabled son. Three years on, it doesn't look like anything has changed. The path we eventually took to fund our van was to accept loans from each of our parents. We preferred not to do this, but at the same time were most appreciative of their help.

Finally, after many months of attending vehicle auctions, and filled with both fear and determination, I successfully bid for an ex-Disability Services Commission Hi-Ace van that would meet our needs. Luckily, it had an appropriate floor with the necessary tracking. The wheelchair hoist had been removed, and there were no wheelchair restraints, plus most of the seats had been removed. We needed to purchase second hand seats which we did at a later date. We were relieved that we now had a van, but we still faced a problem that we didn't know how to overcome. The Lotteries Commission was willing to fund a hoist for us but we had to have the vehicle first, and then the time lag between application and funding was up to three months. The Commission knew that we were only going to purchase one particular kind of van, but it didn't matter, they were very strict about this rule.

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"With me now 8 and a half months pregnant, and in the rising heat of Perth in December, we had a van; but ironically, no way to transport Eamon anywhere. There was no way we could lift the wheelchair and insert that high off the ground."

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## Your story in the next National NoticeBoard?

We always need more parent stories for National NoticeBoard. You might want to write about a particular issue or experience or just share your thoughts.

Send your story and a photo to  
Barbara Alexander,  
8 Grubissa Court, Benalla,  
Victoria, 3672 or e-mail  
barbaraa@cni.com.au

With me now 8 and a half months pregnant, and in the rising heat of Perth in December, we had a van; but ironically, no way to transport Eamon anywhere. There was no way we could lift the wheelchair and insert that high off the ground.

I was prepared for a 3 month wait and wondered how I could possibly get through the school vacation unable to take Eamon out in our own vehicle and with a new baby to cope with as well. Miraculously, we were given a three-year-old hoist from a man who found it a little small for his use, and another family gave us their spare wheelchair restraints. We just had to find an extra \$500 to fit it - which wasn't easy, but we did it. Our Christmas had come a week early!

We were overjoyed, and not long after I delivered our daughter with the reassurance that at least now we could transport Eamon.

Other families we meet say how lucky we are to have a van and hoist: we ARE, but only because two other families with disabled members and our parents helped us, not because our governments supported us. (Ironically, if Eamon was our foster child we would have been supplied with a van with a

hoist.) Any family needing a van with a hoist has enough additional stresses on their family unit. Our children didn't do anything to cause their disabilities; neither did their families. In a society that is willing to spend millions on keeping our children alive, please support us by providing them with the necessities, which includes transportation. Families requiring a hoist so that they can function as a family and include their family member with disability in the community need government support to enable them to do so. We shouldn't have to beg!

Unfortunately, though the van and hoist are a BIG improvement on how things used to be, it's not all 'plain sailing' with our van. For example, we still pay more for car insurance, tyres and maintenance, and we can't access some multi-story car parks because the van roof is too high. We have yet another appointment and bill to service the hoist and the van won't fit in our carport. Safely positioning Eamon in his wheelchair, insert and van takes at least 16 points of positioning, but as families with a disabled child/ren this won't be a surprise to you!

Jim and Julie Guilfoile  
North Lake, WA

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"In a society that is willing to spend millions on keeping our children alive, please support us by providing them with the necessities, which includes transportation."

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## Are South Australian families meeting the challenge?

The work of the new national association, including the distribution of National NoticeBoard throughout Australia, has demonstrated just what can be achieved in a short space of time, despite the impediments of distance and a severe lack of money!

Now South Australian parents are grasping the opportunity to develop a united statewide voice for families. In many parents' minds a parent/family driven organisation that has key objectives of representing the interests of children and young adults with all types of disability is long overdue. We all know it's not easy for parents to take on extra tasks but South Australian parents are managing to do just that.

Our Working Party has shown energy and drive with preparations now well in hand for incorporation this year. We were particularly encouraged by the attendance and interest at a public forum held in Adelaide last October. Also many disability organisations have since shown a strong interest as they too see the need for families to have better representation and for families to play a part in suggesting solutions to problems. Many SA parents/carers are indeed meeting the challenge. If you would like to share the journey or just register your interest, please phone or e-mail us at the addresses below.

Mary-Ann Murphy and Cale Dalton,  
SA Working Party members

### **South Australian Working Party**

Sarah Rischmeuller, Chair of Working Party  
E-mail: [scml@chariot.net.au](mailto:scml@chariot.net.au) Fax/Phone: 08 8281 5550  
Postal: c/- PO Box 598, Salisbury, SA, 5108

Note: For contact details in other States/Territories, phone Barbara on 1800 222 660.

### **Parent/Family Support Groups Database**

Following a generous grant from the Telstra Foundation, our Association will have extra time to expand and maintain our database of local and regional parent/family support groups. Wherever possible we aim to link parents to support from other parents in their local area. To ensure your support group is listed on our database, please send the details to Barbara at the AAFCD office at 8 Grubissa Court, Benalla, Victoria, 3672 or e-mail [barbaraa@cni.com.au](mailto:barbaraa@cni.com.au).



# Australian Association for Families of Children with Disability

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Barbara Alexander, AO,  
AAFCD Convenor

## Why join the AAFCD?

Our Association is a 'grass roots' organisation, run by parents/families for parents/families. Our Association includes all types of disability. By becoming a member of the AAFCD you will receive 6 copies National NoticeBoard a year. Membership is free.

## Our Purpose

The formally defined purpose of the Australian Association for Families of Children with a Disability 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."*

## Voting Membership

Voting membership is only available to parents/families of children with a disability. Professionals, organisations and government department staff are welcome to join the subscription list for National NoticeBoard and other information, but they are not eligible to become voting members.

To join as a member, simply fill out the Membership Registration Form below and send it in to the address at the bottom of this page. You can also join on the Internet via the Association for Children with a Disability (Vic) web site [www.acd.org.au](http://www.acd.org.au).



## Australian Association for Families of Children with Disability Membership Registration Form

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

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: .....

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Send this completed form to:

Australian Association for Families of Children with Disability  
8 Grubissa Court, Benalla, Victoria, 3672 or  
Fax to (03) 5762 7000

## AAFCD

### Committee Members

#### Australian Capital Territory

Karen Connaughton  
Cheryl Patrick

#### New South Wales

Lisa Brown  
Julie Brunson  
Sue Griffin

#### Northern Territory

Bruce Young-Smith

#### Queensland

Melinda Ewin  
Leonie McKnight  
Lisa O'Donnell

#### South Australia

Mary-Ann Murphy  
Cale Dalton

#### Tasmania

Cheryl Shuttleworth  
Gail Smith

#### Victoria

Barbara Alexander AO  
Jan De Witte  
Lyn Kemperman

#### Western Australia

Clara Harris  
Cherie Shaw

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