

---

# Sound News

Parent Council for Deaf Education  
Autumn 2011



There's No Stopping Joel. "Meet This Country Boy With 2 Cochlear Implants" – pg 14

## Contents

Reports	2	Info for Parents of Children who are Deaf/ HoH with Additional Disabilities	11
What's On?	4	Advocating for your Child	12
Profile: Catherine Sullivan Centre	6-7	Cochlear Implants– Can they Make my Child Hear?	13
Parent Story– Jack's Journey	8-9	Cover Story	14
POD Update	10		

## President Report

This is the fiftieth year that the entity we now know as the Parent Council for Deaf Education (PCDE) has been in existence - it was founded in 1961 as the Federation of Junior Deaf Education. So we look forward to celebrating this milestone – more details to come. The anniversary year may include the re-branding of PCDE as the “**Parents of Deaf Children**”, as explained in recent Sound News editions and other communications.

The new PCDE Committee met on 30 January, but already several important things had been happening since our AGM in mid-November:

I attended the first meeting of a new PCDE subcommittee for “parents of children who are deaf / hard of hearing and have additional needs” at the home of Aileen Ryan (former PCDE Committee member) in late November. Information and articles from the Subcommittee will appear in this and subsequent editions of 'Sound News'. As I said last time, members are invited and encouraged to join this subcommittee or to help form other ‘interest group / issues based’ subcommittees.

PCDE and Deaf Children Australia (DCA) held an initial 'partnership review' meeting in mid-December. (This partnership had been formalised through a Parent Council Charter in late 2005 and signed agreement in October 2007).



President—Mark Burfield

PCDE, along with some other Deafness sector entities, signed a significant 'Memorandum of Understanding' (partnering agreement) with the Deaf Society of NSW just before Christmas.

Our Vice President, Leonie Jackson, accepted an invitation to join a committee for a fundraising event being run by the Deaf community and allied supporters. This is to raise funds for Deaf people who have experienced loss through the Queensland floods. The fundraising event is to be held on Saturday 12 March at the Santa Maria Del Monte School in Strathfield. All are invited (see details inside).

Behind the scenes, Kate Kennedy and Ann Porter have been involved in stakeholder consultations dealing with issues arising from the 'Better Start' initiative being introduced by the Federal Government where families will



receive up to \$12,000 over four years for early intervention support for their child.

On the personal front, Anita (my 11 year old daughter who is profoundly deaf) had successful surgery for a second cochlear implant for her other ear in late November. She had received her first implant at age 2, so there is a lot of 'brain training' to maximise the benefit of the second implant. This is supported by ongoing (currently weekly) habilitation sessions and occasional mapping sessions at the Sydney Cochlear Implant Centre in Gladesville.

This is the last edition of 'Sound News' to be prepared by our Administrative Assistant, Anna Iacono, for the time being as she takes a year's maternity leave. We wish Anna well, and look forward to her return in due course. Anna's position will be filled by Gloria Simunovich.

We welcome feedback on any aspect of PCDE, including ideas - and of course articles - for 'Sound News'.

Mark Burfield

President ■

## Staff Report

Staff changes at PCDE! It is with mixed emotions that we farewell our Administrative Assistant, Anna Iacono as she takes on the exciting role of mother to a new baby (due late March). We are excited for Anna, Rob and soon to be “big sister” Sarah as they wait for the next exciting addition to



their family, but we are also sad to see Anna go. Anna has brought so much energy, organization and support to PCDE, and I in particular will miss her contribution. We anticipate her return after maternity leave.

We are very pleased however to welcome Gloria Simunovich to the role in Anna's absence. We are lucky to have Gloria's skills and enthusiasm on board and I look forward to working with her as we enter this busy time ahead. Welcome Gloria.

Lots to read in this edition – we have not one, but two parent stories to share with you, both highlighting the challenges, but also the resilience, humour and positivity that parents display when faced with those challenges. We here at PCDE are always inspired by these stories and

the message of hope and shared experience that they send to other parents.

We trust you will be inspired too. If so, send us a line, we would love your feedback.

Cheers,

Kate Kennedy,

Coordinator,

Information and Advocacy.

■



## Information on Early Intervention Funding

### Better Start for Children with a Disability - Federal Funding Initiative

From the 1st July 2011, eligible children (including deaf/hearing impaired children) will be able to access government funding as part of the Better Start for Children with Disability (Better Start) initiative. Eligible children under the age of 6, will have access to funding for early intervention services and Medicare rebates under the scheme.



#### What do we know about the initiative?

- Eligible children will be able to register to access early intervention funding of up to \$12,000 with a maximum of \$6,000 per financial year.
- The funding is for therapy services such as speech pathology, audiology occupational therapy, physiotherapy and psychology.
- Audiology services provided by Australian Hearing will remain free of charge for children under 21 years.
- a Medicare rebate for the development of a treatment and management plan will be available for children under the age of 13.
- Medicare rebates will also be available for up to 4 allied health diagnostic services and for up to 20 relevant allied health treatment services per eligible children. Treatment items will be available for children up to the age of 15 provided a treatment and management plan is in place before the age of 13.
- A provision of a one off payment of \$2,000 is aimed at families living in outer regional and remote areas.
- Service providers will be approved by an expert panel and only these providers can claim for services under Better Start.
- Each time Better Start receives a statement of service from a service provider, the amount will be deducted from the funding allocated for the child. Parents will receive a statement each month outlining what services their child has received and how much funding they still have available.
- The funding provided by Better Start falls a long way short of the actual cost of providing early intervention services for children with a hearing loss. The initiative is meant to complement existing services and is not intended to replace or reduce disability support services already available.
- Early intervention services provided by State Governments will not be eligible for Better Start funding and families can continue to access these services as usual.

#### What don't we know about the initiative?

- The expert panel is yet to determine what the eligibility criteria for hearing loss will be.
- We do not yet know who will provide the gateway service. The gateway service will register children for the funding and provide parents with information about the services available to them. The gateway service will not provide case management or parent support.
- We do not know what information will be provided to families to assist them in making good decisions on the best way to effectively allocate their funding for optimal outcomes for their child.

If you are concerned about the impact of this funding and what it means for your family, feel free to contact PCDE on 9871 3049 or [pcde@bigpond.com](mailto:pcde@bigpond.com).

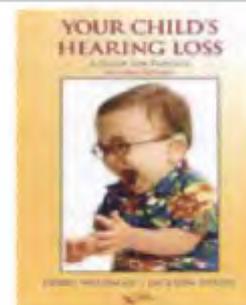
#### New Book for Parents

Your child's hearing loss: a guide for parents 2nd ed  
By Dennie Walmand and Jackson Roush, 2009

#### New DVD

Child talk: Strategies for stimulating your child's language  
Presented by Dr Charlotte Middleton 2009

An Australian DVD/workbook package that teaches caregivers how to provide their child with a powerful language rich environment.



## What's On

### Veronica James Science Challenge for Hearing Impaired Children

Saturday 9th & Sunday 10th April 2011

8.30am to 3.30pm each day

University of Sydney, School of Medicine

This is the first weekend of the school holidays)  
Numbers are limited so get your bookings in early.

Ph: 9449 5919 Helen Hammersley

Email: [vjsciencechallenge@yahoo.com.au](mailto:vjsciencechallenge@yahoo.com.au)

Age: From 7yrs (if 15 and over you could be a volunteer tutor) This challenge is not only for gifted science students. It is an opportunity for hearing impaired students of all abilities to explore and get excited about the world of science.



Cost \$35 ea student, enrol by 26th March. Each hearing impaired student must be accompanied by an adult.

Morning tea and lunch are provided for everyone each day by the Quota Club. (Please bring your own if you have special dietary needs).

For information, activities and photos from previous science challenges, see web-site [www.cfhi.med.usyd.edu.au/](http://www.cfhi.med.usyd.edu.au/)

At the Veronica James Science Challenge 2010

### Horse Riding

Sunday 13th March 2011

Glenworth Valley Horse Riding and Outdoor Adventures

Cooks Road, Glenworth Valley NSW

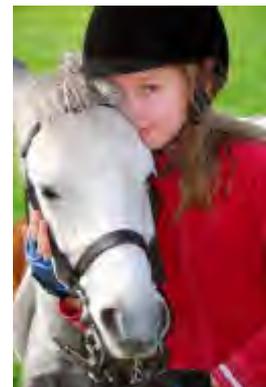
Age: 10-17 years old

Cost: \$10 per person

Time: 11.30am

RSVP: 11th March 2011 to 0408 669672 ( David)

Email: [david@ephpheta.org.au](mailto:david@ephpheta.org.au)



### Triple P Seminar: Raising Resilient Children

Thursday 23rd June 2010

10.00 am—12.30pm

Free (parents only )

Where: Castle Hill

Presented by Benjamin and Bianca Burton from Interaction Disability Services, this workshop looks at the values, skills and behaviours important to encouraging confidence in children. Children are more likely to be confident, succeed at school and get along with others when they develop certain life skills.

Contact: [tabiss@interactiondisability.com](mailto:tabiss@interactiondisability.com) or phone 1300 668 123

### Queensland Floods Deafraiser Games Night

Join the Deaf Society's fundraising entertainment and games night to support the deaf community in QLD affected by the floods.

Saturday 12th March 2011

Santa Maria Del Monte, 59 The Boulevard, Strathfield

Entrance to hall on Carrington ST

4 pm—10pm

Adult \$20, conc \$ 15, Child (5-12 yrs) \$5, Child (13-18 yrs) \$10 (sausage sizzle and soft drinks included)

Buy tickets from Deaf Society, PCDE, Ephpheta Centre, Deaf Australia (NSW) and ASLIA (NSW).

## Briefly:

### PCDE signs MoU with the Deaf Society of (NSW)



In December 2010, the Deaf Society signed separate Memoranda of Understanding with Deaf Australia (NSW), PCDE, the Ephpheta Centre and ASLIA (NSW) Inc.

The memoranda adopt strategic goals from each organisation: Some examples are:

- Actively developing the strength and capacity of the Deaf Community in NSW
- Strengthening deaf parent, youth and senior citizens support networks in NSW
- Influencing government policy in the areas of health, education and disability
- Encouraging professional solidarity of signed language interpreters in NSW

PCDE is excited by the possibilities of building on this relationship.

### Deafness Forum has new CEO

The Deafness Forum has introduced Kris Newton as their new CEO. Kris has a broad management background—in the public sector, in her own consultancy firm and for the past decade, in national not-for-profit associations. She has extensive experience in representing member-based organisations, in consultation processes, and systematic advocacy with successive Federal Governments.

### Ramp Up– the ABC’s new website



The ABC launched a new website in December 2010. Ramp Up is dedicated to everything about disability. “But not in a whingy, daggy way” says Ramp Up editor Stella Young. “This is a website with attitude”

Ramp up will feature columns from a wide range of people with disabilities that will entertain, inspire, delight and provoke. It will also have the latest news from the sector, drawn from across the ABC.

Visit the website at: [www.abc.net.au/rampup/](http://www.abc.net.au/rampup/)

### Auslan Not Included as Priority for Languages Curriculum

EVERY student will be required to study a second language for at least 300 hours before year 7, with Chinese and Italian the first to be taught under the national curriculum.

The draft shape of the national curriculum for languages, to be released today, says curriculums for 11 foreign languages will be developed to be taught in schools.

The first national language curriculums to be developed will be Chinese and Italian - chosen because they cater for the greatest range of students

This will be followed by Indonesian, Japanese and Korean, which are national priorities, French and German, which are among the most commonly taught languages in schools, and Spanish, a language of global importance.

The president of the Modern Language Teachers' Association of Victoria, Andrew Ferguson, said that while the group was pleased to see the range of languages for which curriculums will be developed, it was "most disturbed" classical languages and Auslan had been excluded.

"This is a serious oversight on the part of ACARA and an insult to the deaf community and teachers of Auslan and classical languages," he said.

Sydney Morning Herald  
February 1, 2011 •

*EDITOR'S NOTE: PCDE would like to hear from you about this issue. Send us your input to include in a parent submission on this issue.*

### Deaf and hard of hearing people can sleep safe

The NSW Government has introduced a visual smoke alarm subsidy scheme which is to be rolled out in partnership with the Deaf Society of NSW. This commitment of 2 million dollars for the visual smoke alarms is over a 3 year period.

The Deaf Society of NSW has been working closely with Fire and Rescue NSW to develop a proposal for the scheme which will see the specialised alarms subsidised for deaf and hard of hearing residents in NSW.

These specialised alarms have a flashing light or a vibrating device that will wake them in the event of a fire. The cost of these devices are approx \$450 each. A subsidy to help pay for these vital life saving devices will help families in the event of a fire.

Call PCDE if you would like further information on this scheme and eligibility.

## Profile: Catherine Sullivan Centre

A Ministry of the Dominican Sisters commencing operation in 1969.

Unique is often a word overused or incorrectly used. However, Catherine Sullivan Centre (CSC) in Strathfield is certainly unique. The Centre focuses on families and supports children with hearing loss from birth to school age. Our program sees parents as the first and most important educators of their children. We adhere to the Principles of Auditory-Verbal Therapy and see our primary role as supporting and guiding the parents of children with hearing impairment in their responsibility as educators. It's uniqueness is reflected in each facet of our program, listed below:



Each child receives a one hour **individual weekly therapy session**. These sessions involve evaluating and monitoring each child's progress, determining an Individual Education Plan in collaboration with the parent/s, and setting goals. Parents are offered sessions by a teacher from the Centre in the home until the child reaches the age of three years. These home-based sessions enable the child to learn through his/her daily routines and provides for other family members to be involved. After the child turns three, these sessions are offered in the Centre.

**Intensive Language Group** is available for children one year prior to starting 'big school'. It provides an opportunity for speech and language development in a small group. It is conducted once a week from 10.00-2.30pm by one of our teachers and without parents present. In our annual survey, parents noted that during Intensive Language Group, their child "really enjoyed news time" and it gave them an opportunity to learn "to be responsible for their own hearing aids and FM."



These children also attend their local pre-school. Our staff provides regular **visits to each child's pre school**. In this way, we can support the child and inform the pre-school staff about how to best support the children on our program.

**Playgroup** is integral to our early intervention program and provides enjoyment, new experiences and opportunities for building quality relationships. Children, together with their parents/carers, have the opportunity to learn through play while being encouraged to develop social and communicative skills. In 2010 we received a grant from Golden Stave Foundation called "Fostering a Love of Music For Life" - a music program delivered by therapists from Nordoff-Robbins Music Therapy Australia which is based in the Golden Stave Music Therapy Centre at University of Western Sydney. Our music program allowed staff and parents to engage the children in a range of musical experiences. Parents commented on the benefits their children gained through enthusiastic participation which increased confidence and brought smiles to their children's faces. One mum noted that it had helped her child to be "more expressive and joyous."

**Parental Support** is provided through opportunities to share experiences and gain encouragement from other parents and staff, through a variety of formal and informal functions. Our Parent Handbook is a unique and comprehensive resource containing a detailed range of information and resources to better prepare parents as their child's advocate. Parents frequently refer to the Handbook as it helps them deal with ongoing aspects relating to their child's development and needs.

## Profile: Catherine Sullivan Centre

CSC offer **educational workshops** for parents and extended family on a variety of topics. These informative sessions are presented by experts such as, audiologists, ENT specialists, speech therapists, child psychologists, pediatricians and music therapists.

**Individual Family Support Program (IFSP)** Meetings are held regularly with each child's parents/caregivers and CSC teacher to review the progress of each child and to set goals. IFSPs allow the family and staff to plan together and work cooperatively in all aspects of the child's development.

Our families come from diverse geographical and cultural backgrounds. As a Catholic organisation we strive to bear witness to values of joyfulness, knowledge and community.

Written by Clare Hopley

For more information email  
[admin@catherinesullivancentre.org.au](mailto:admin@catherinesullivancentre.org.au)



## Everything for the Hard of Hearing



**PRINTACALL**   
 COMMUNICATIONS TECHNOLOGY



Specialist in products for  
 the telephone, TV, radio and  
 social functions to suit hearing impaired  
 and deaf people



For more information on any of our  
 products or services, visit our website at:

**[www.printacall.com.au](http://www.printacall.com.au)**

or contact us on any of the following:



Ph: 02 9809 2392 | Fax: 02 9809 2345 | TTY: 02 9809 1283  
[sales@printacall.com.au](mailto:sales@printacall.com.au) | 2 Doig Ave, Denistone East, NSW 2112

## Jack's Journey

By Maria Fresta, Jack's mum.

*Ed's Note: We believe Maria's story highlights what many parents go through during the "roller coaster time frame" of early diagnosis and beyond. We are grateful to Maria for sharing so openly so that other parents can learn from her experiences.*

Our son Jack was born in July 2006. He was our 3<sup>rd</sup> child and brother to two older sisters. He surprised us by failing the SWISH testing in hospital and an appointment was arranged to see an audiologist.

There is no history of hearing loss in the family so we definitely didn't expect this result. We talked ourselves into believing that everything would be fine. He could hear us as he responded to banging doors, and loud clapping. The poor boy; we were constantly checking to see that he would respond to noises. At the time we thought either you could hear or you were deaf – who knew there was so much variation in between?

Four weeks later we were at the audiologist at Westmead. I remember looking at the posters, but not really reading anything as I was certain it wouldn't apply to us. We weren't particularly nervous or anxious at the time. It took a while for the audiologist to complete the testing, which started to worry me.



Finally she had the result – mild to moderate hearing loss in the left ear and moderate to moderately severe in the right. I had no idea what that meant, except that it wasn't the perfect hearing that I expected. She said that would mean hearing aids, but a cochlear implant wouldn't be necessary and he would be able to attend a mainstream school. The fact that he wouldn't need an implant and could attend school were the positive things we hung on to. We were shocked by the diagnosis, but she showed us the Frequency Chart as to what he could hear and we thought – well, it could have been much worse.

So we took all the positives we could from the situation, and then organised our next lot of appointments. The day arrived for our appointment at Australian Hearing to pick up his hearing aids. I was surprised at how upset I was. I couldn't believe that he was actually going to have to wear hearing aids – it had been ok just talking about it, but the reality of it really shook me. To be honest, I was wondering how I was going to take him out into the world with the aids on. Wouldn't people stare at him and ask me questions about them; would kids tease him? Looking back now, I can't believe I was worried about these things, but at the time, I didn't know if I was capable of handling these situations.

We settled into a routine for his early intervention, and attended firstly the

Shepherd Centre, then after a year the Catherine Sullivan Centre as it was closer to home. We got used to the hearing tests too and it seemed to be fairly stable, but always at the lower end of what we expected.

Time passed by and his hearing impairment was just another part of life. His speech developed normally and unless you saw his aids, you wouldn't know he was hearing impaired. He started pre-school and settled in well, was achieving his milestones and life was good.

At the back of our minds though was always the worry that his hearing would deteriorate and or disappear. After fairly stable results for a few years, his hearing had settled at moderate/moderately severe and mod severe/severe, but then a hearing test at 3.5 years indicated his worse ear was now severe across all frequencies. We were disappointed, but he was coping well and with his better ear, he was still hearing most of the speech range.

Earlier this year though I noticed that he was very attached to the hearing aid in his worse ear. He wouldn't mind if the other one was not on, but made a fuss for the other one. I spoke to his teacher at early intervention and to the audiologist and we decided to have another hearing test. Jack was very attached to his aids and hated taking them off, especially for hearing test. We booked in two tests a week apart so that if he was upset at the first test, then the second test would be easier as he would have the process fresh in his mind.

I was surprised how anxious I was be-

---

*“If there's one thing I've learnt over the past 4.5 years is that you need to love and accept your child for what they are, or are not, as only then they can have the confidence to go out into the world.”*

---



## Jack's Journey

fore the test; I guess I knew that something was not quite right. Jack was not in a happy mood especially when he found out where he was going. Anyway, somehow we got to do the unaided test. We started with his 'better' ear. There was no response at any frequency. I was watching him very closely and I could see that he was not playing up, he really didn't hear anything. I was pretty calm actually – obviously in denial - but I thought, well if we adjust his hearing aid, he may get enough out of it to get by. So the next week we went back for an aided test with his adjusted aids. Still nothing. He had started at birth with mild to moderate and within 4 years he was profound. Technically my child was no longer hearing impaired, he was deaf and the change was very difficult to come to terms with.

I couldn't believe how devastated I was at the loss of his hearing. I felt like we did at his initial diagnosis as a baby. The whole family was upset by the news – well, that's everyone except for Jack. He had no idea what all the fuss was about. Life carried on as normal for him. I think I cried every day for over a week. I guess I was grieving for the loss of his hearing; he had some, now even that was gone. Why did it have to go? I knew that things could be a lot worse, and considering what some families go through, this was nothing. But I guess you have to allow yourself to go through the emotions, or else you can't move on. For the sake of our son we did move on – and we moved on very quickly.

We knew the only option for him was an implant, as he couldn't get enough hearing from one aid. We also thought that if the hearing in his other ear disappears, then at least he will have the implant to provide him with hearing. Fortunately, my husband and I both agreed that this was the best option

for him, and within 3 months of his hearing test, he received his implant. . The words of the audiologist came back to me – 'no implant' – I couldn't believe that this is what we were at. It was an emotional time, but after the surgery, we all felt relieved and ready to move on with the next stage.

The day of switch on arrived, and I suddenly realised that from now on, he would have to wear the processor every day. The same feelings I had when he received his hearing aids came back to me. I was worried about people staring at him and kids teasing him at school. But that anxiety subsided much faster this time. The implant has worked so incredibly well for Jack that it's hard to believe he managed without it. He loves wearing it but it has been the increase in his confidence that has made such a huge difference to him – confidence that we didn't even realise he was missing.

He had a bad fall on Australia day; he fell from about a metre, onto a concrete driveway and landed on his head, where his implant was. It was a terrible experience – he had a small fracture no internal bleeding and no other damage. But



was his cochlear ok? We had to wait until the next day to have it tested, and thankfully it had survived. It wasn't until then that we realised how lost he would be without it, even for a short time, and how much we had all come to rely on it.

We feel very blessed that we have had such opportunities for Jack. From an early diagnosis, wonderful support from early intervention, audiologists, and now the SCIC, we can't believe how lucky we are.

If there's one thing I've learnt over the past 4.5 years is that you need to love and accept your child for what they are, or are not, as only then they can have the confidence to go out into the world with their aids, implants or whatever else they may have to wear. For Jack, these tools are part of his life and he already understands how important they are to him. I have found that kids are curious and many have asked Jack what's on his ears. He simply explains that it's his hearing aid and his cochlear and it helps him to listen. Once kids have an answer they usually move on, and that's what I have found with Jack so far.

Sometimes I see people looking at Jack then I realise that they're looking at his aid/implant, but it doesn't worry me at all, and I realise what a long way we have come.

■

## POD Information Sessions



*POD sessions have kicked off 2011 with a trip to the pub!*

What a great start to 2011 with several new parents coming along and making new connections at **POD Central Sydney**. This POD will meet every 2 months this year at several different locations in Central Sydney so make sure you are on our mailing list to keep up to date. The next POD Central Sydney meeting is the 6th April 2011.

### Other POD News/Events:

**'When I grow up I want to be.....'** A Panel Discussion for Families, Monday 28th March 2011 at RIDBC's Welwyn Centre at 7.30pm.

Come along and hear inspirational success stories from adults who happen to be deaf.

RSVP. [pcde@bigpond.com](mailto:pcde@bigpond.com) or phone 9871 3049. Free. This is the POD Northern Sydney regular meeting date for March.

**POD Mid North Coast's** next meeting is on Thursday 7th April and will be held on the first Thursday of every month at the Uniting Church Hall, 29 Albert St, Taree at 7pm. If you are interested in coming along, please let us know at [pcde@bigpond.com](mailto:pcde@bigpond.com) or phone 9871 3049.

### Parents, Why Not Join a POD Group?

POD is your local parent support group which allows you to connect with other parents of deaf and hearing impaired children and gather information and ideas on all sorts of topics. Parents are a great source of support and reassurance too.

If you are not on our email distribution list, and would like to receive regular updates on POD groups and information sessions in your area, please contact [pcde@bigpond.com](mailto:pcde@bigpond.com) or phone 02 9871 3049.



## POD North West Sydney !

### Register your interest

If you live in the North West of Sydney and would like to join a

POD group for a chat, support and information,

contact PCDE.

We need more parents to join. Please email us to register your interest at [pcde@bigpond.com](mailto:pcde@bigpond.com) with your name, suburb and available time to meet.

## Information for Parents of Children Who are Deaf / Hard of Hearing and Have Additional Needs

### New PCDE subcommittee

I would like to introduce a new segment in Sound News. It was decided at the last AGM that we would set up a subcommittee within PCDC to focus on families that have children/young adults of the deaf community who are often in need of additional help. These are children/adults who are not only deaf/hearing impaired but also have additional disabilities.

Life is difficult at the best of times but for families dealing with dual or multiple disabilities it can feel as though the problems never end. We have found that quite a number of our families have children/adults with a hearing loss and are also dealing with issues such as Autism, Down Syndrome, Cerebral Palsy, Blindness, Developmental Delay and the list goes on.

This subcommittee has been set up in the hope that we can help out as much as possible with ideas, information, following up suggestions and letting you, the parents/carer's, know what is happening.

If anyone is interesting in becoming involved in this subcommittee, please contact us PCDE office, or email Aileen, [aileen@handscantalk.com.au](mailto:aileen@handscantalk.com.au) .

This is not a committee that will be meeting up lots but more one that will get together on an irregular basis, email often and make as much information available as possible through the Sound News and the PCDE Website.

Each edition, we hope to keep you up to date with any information that we track down that we feel is worth sharing with you. Feel free to email above with questions that you need answering and any suggestions you may have for the committee.

This I hope will be the start of a long and helpful relationship.

Aileen Ryan, on behalf of the PCDE Subcommittee for parents with children who are deaf/HoH, with additional disabilities.

To read about Aileen and her daughter Aleisha's story, go to our website [www.pcde.org](http://www.pcde.org)

### Latest Information for families with additional disabilities

**New NDIS (National Disability Insurance Scheme) Campaign website launched– Every Australian Counts**  
Visit this website at: <http://everyaustraliancounts.com.au/> This website, you will find blogs from people with a disability and their stories about how the NDIS could change their lives. Blogs are also included from state campaign co-ordinators informing you of what is happening in each state and listings for news and events taking place in your area.



### STRONGER TOGETHER STAGE 2

The NSW government announced in December 2010 a further \$2 billion investment in disability services over the next five years for the second phase of the Stronger Together 2006-2016 initiative.

Under Stronger Together 2, the NSW government will:

- Set aside funding to enable each large residential centre to be closed by 2017/18;
- Create the Supported Living Fund to recognise the right of people with a disability to make choices about how and where they want to live.
- Deliver 1750 new supported accommodation places, 4500 new flexible respite places and 9380 therapy and early intervention places by 2016.
- Provide a payroll tax exemption for employers of people with disabilities. The exemption will apply to all new employees who are employed after 30 June 2011. The exemption will be provided in the form of a rebate to employers who fully pay the wages of employees with a disability.

# Advocating for your child

It is common for parents to act as advocates for their child in many situations, even though you might not recognise it as advocacy.

An advocate is someone who can support, assist or represent another person to achieve a positive outcome in a difficult situation or meeting.

## Tips for advocating for your child

- Be clear about what you want to achieve and what is an acceptable outcome.
- Find out who is responsible for the outcome you seek.
- Don't always expect conflict, as others may agree with you.
- Be firm and persistent.
- Think about what you want to say and how you will say it.
- Write down the points you want to cover.
- Think about points that others may raise and how you might respond.
- Agree on an appropriate time and place for any discussion.
- Stay focused on getting the best outcome for your child.
- Be open to other solutions that may be just as effective.
- Negotiate and be open to compromise.
- Keep some notes about what was discussed.
- Follow up on agreed actions.
- If emotions overwhelm you, ask for a few minutes to gather your thoughts.
- Try to stay calm.
- If you need support, ask a friend or advocate to help you.

## Being a parent advocate

As a parent, you have the most experience and personal knowledge about your child. If you have a strong instinct about what could improve your child's situation, be firm and persistent. Remember that you are your child's best advocate and you do not have to apologise for standing up for your child.

## How to advocate for your child

Be clear about what would be an acceptable outcome. Others will find it easier to respond if they understand your perspective and what you are trying to achieve.

Think about what you want to say and how you will say it. Write down the points you want to cover and keep a record of any meetings. Avoid being pressured into agreeing to something if you feel uncertain. It's okay to say that you need time to think things through before you respond.

Agree on an appropriate time and place for any discussion. You need to be in an environment where everyone at the meeting has time and space to actively listen without interruption. You may need to make an appointment for this to happen.

Remember to keep some notes about any discussion. This will make it easier to follow up on agreed actions. If these are not happening, or the situation changes, you can raise the issue again.

## Emotions

It is common to feel strong emotions when advocating for your child. Emotions can overwhelm you when you least want them to. Even if you are not in a situation of conflict, you may find it difficult to contribute to the conversation.

Whatever emotion you experience, you can ask for a few moments to gather your thoughts. If you have someone supporting you in a meeting, talk to them beforehand about how you would like to proceed if you become emotional.



Think about what your own coping strategies are and go with what feels right for you.

Be reassured that as a parent advocate you are doing what you believe is best for your child.

## Support and advocacy for parents

Sometimes communication issues can arise and you may want to ask a friend or advocate for support. An advocate can be a friend, family member, or a formal advocate.

You can take an advocate with you to any meeting but to comply with Student Support Guidelines the advocate must not be in receipt of a fee. You can also seek information and advice from an advocacy organisation.

Think about what you want to say and how you will say it. Write down the points you want to cover and keep a record of any meetings. Avoid being pressured into agreeing to something if you feel uncertain. It's okay to say that you need time to think things through before you respond.

Source: [www.cda.org.au](http://www.cda.org.au) . More info on advocating for your child can be found on the Aussie Deaf Kids website, [www.aussiedeafkids.org.au](http://www.aussiedeafkids.org.au) and <http://www.acdns.org.au/> ■

*If you have a strong instinct about what could improve your child's situation, be firm and persistent. Remember that you are your child's best advocate and you do not have to apologise for standing up for your child.*

## Cochlear Implants: Can they Make my Child Hear??

By Kylie Chisholm (Auditory Verbal Therapist / Speech Pathologist) and Colleen Psarros (Audiologist) at Sydney Cochlear Implant Centre, (SCIC) Sydney.

Cochlear implants are designed to provide the necessary information for a child to access sounds across the speech range – however they do not make a child understand what they hear. Hearing is a complex interaction of receiving a signal through the auditory pathway which is processed by the brain and is then “understood”.

A number of factors are needed to enable a child to **hear** with a cochlear implant:

- ideal surgical placement of the cochlear implant
- an auditory system that is capable of transmitting the information from the cochlear implant
- optimal programming of the speech processor that communicates with the cochlear implant (mapping)

In addition commitment to these factors is needed to **understand** what is heard through a cochlear implant:

- training to make sense of the sounds that are being presented through the cochlear implant
- a supportive team of parents, family and professionals who focus on communication and listening

When these factors are achieved, children can go onto develop age appropriate speech and language skills.

### My child already has a cochlear implant and they are still not hearing all that well?

Outcomes with a cochlear implant are varied. Some children can take quite a long time to adjust to the signal from the cochlear implant and to begin to use it to understand and develop spoken language. This may be frustrating for parents and other people supporting the child. However, as a lot of parents will tell you – it is

worth the perseverance.

Your cochlear implant professional will be able to advise you realistically on what intervention may be needed to help your child improve their outcome.

Some suggestions may include:

Fitting a hearing aid on the ear not implanted consider a bilateral cochlear implant make sure that you allocate some listening alone time each day during a fun activity eg playing a game, reading books, cooking, listening to music set small readily achievable goals for your child organise for a fitting of an FM system if they are having difficulties hearing at school There are some good websites that provide some good listening activities.

<http://www.manythings.org/pp/>

<http://www.manythings.org/ac/>

[http://www.ello.org/games/student\\_games.htm](http://www.ello.org/games/student_games.htm)

<http://www.esl-lab.com/>

<http://www.medel.com/int/show4/index/id/255/titel/SoundScape>

[http://www.beenleigss.qld.edu.au/requested\\_sites/audiostories/index.html](http://www.beenleigss.qld.edu.au/requested_sites/audiostories/index.html)

<http://www.findsounds.com/types.html>

<http://www.starfall.com/n/me/me/play.htm?f>

<http://www.quia.com/cb/7146.html>

[http://www.hearingjourney.com/Listening\\_Room/preview.cfm?langid=1](http://www.hearingjourney.com/Listening_Room/preview.cfm?langid=1)

### What if the cochlear implant doesn't work?

There are two ways of the cochlear implant “not working”.

Technologically the cochlear implant is man made and can break down. However



leading cochlear implant manufacturers are claiming 99.8% of survival of cochlear implants indicating that there are very few failures. If the external components of the cochlear implant stop working, SCIC can provide a loaner speech processor, and Australian Hearing can provide replacement parts once the externals are out of warranty.

Further, it is important to attend regular reviews for cochlear implant mapping and check ups of the child's listening. SCIC recommends 6 monthly reviews for children of all ages.

If a child isn't hearing as much as would be expected for that child with the cochlear implant a review of that child's communication abilities would be conducted to determine whether there were additional means of providing the input needed to communicate.

It is important to remember that the signal the cochlear implant sends to the brain along the auditory pathway is influenced by the number of nerve endings that are available to transmit the information. In turn the transferring of information throughout the auditory pathway to the brain is also dependent on good connections. Think of a train travelling along railway track from station to station. The signal from the cochlear implant is the same. If the “railway track” is buckled – it can derail a train – if the connections get switched, the train can start heading down

## Parent Story- A Bumpy Ride Doesn't Stop Joel and his Family

**Belinda, Joel's mum, shares her story and highlights the challenges that many regional families face.**

My son, Joel, was diagnosed with profound hearing loss at 18 months of age after months of speculation by specialists (one even told us that all he needed was grommets) family and friends.

Fortunately for my husband and I Joel is not our first child and as such we were aware that something was not quite right. Mind you, we thought he was an angel sleeping through constant loud noises (our eldest son was in a rock band and the four girls danced - but not to the same music!!) We first thought that he had acclimatised to noise whilst in the womb and nothing fazed him.

It was New Year Eve when I became convinced that all was not right. Joel was now 12 months old and we all went to watch the fireworks. He did not flinch or move a muscle when they were going off. I started making noise on Joel's behalf which finally led us to Professor Gibson and his first implant at age 2.

We live about 45 minutes west of Taree. We travelled to Westmead Children's hospital for the implantation and stayed in a motel the night before. The next night I stayed with Joel and Steve slept in the accommo-

modation provided by the hospital for those travelling long distance. It is a long standing debate between us as to who had the better night's sleep.

Two weeks later we travelled down to Gladesville for "switch on" which was conducted over two days. Fortunately, I have a good friend who allowed us to spend the night at her place.

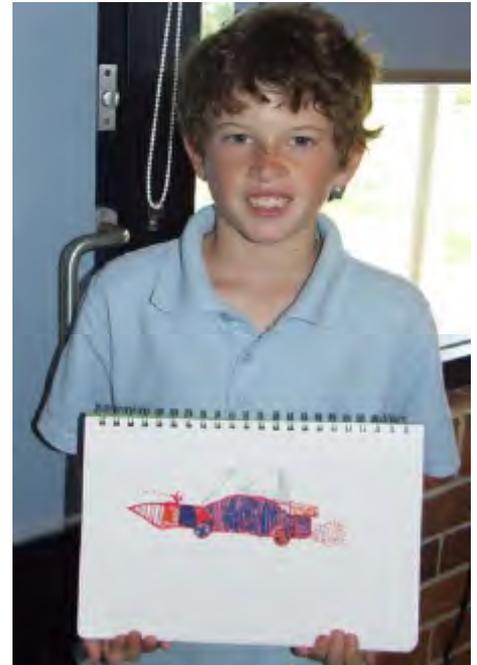
In my naivete I thought "switch on" meant he heard everything instantly and of course understood what we were saying. But it wasn't like that at all. He sat there looking like he was constipated. We travelled to Gladesville every two weeks for a two day visit for the next six months. Joel and I would drive straight through to Gladesville (around 5 hours - the Pacific Highway was only just starting its upgrade), have his appointment and then go to my friends place for the night.

The next morning we would be up and back to Gladesville for an hour appointment before heading straight home. Joel was a great traveller, I guess he had no choice, but it certainly made it easier.

Eventually, SCIC started seeing people in Newcastle which made it so much easier. Now we only have to travel two and a half hours at the most as they also come to Taree once a month and the habilitationist is based in Port Macquarie. Yee ha!!!

Times have certainly changed. When Joel was first nominated for an implant Steve and I were interviewed to ascertain whether we were suitable parents in regards to the amount of work involved, travelling etc and if we were willing and able to put in the effort.

We were very fortunate to get an itinerant teacher assigned to us that



clicked with Joel and us. We have had Robyn since Joel was first diagnosed. Due to logistics and the small number of itinerant teachers in this region this is not unusual and, therefore, it is important that the teacher, child and parents can all work together.

Robyn has followed Joel from home, to early intervention, to preschool and now primary school. Joel has a great report with Robyn and sees her as an extension of our family. She has stuck by us through all the in and outs and has been a great support and sounding board for me.

It certainly was a lot of hard work but we started to make inroads. Joel's first words were cow moo and sheep bah. One day we drove from home to Gunnedah. Do you know how many cows and sheep you pass on that trip. Millions!!

Things were going well and then they were not. Problems were occurring with the implant. After a few trips to Gladesville we were advised to have the second implant done in case the first had to be removed. This meant

---

'I thought 'switch on" meant he heard everything instantly..... But it wasn't like that at all. He sat there looking like he was constipated.'

---

## Parent Story- A Bumpy Ride Doesn't Stop Joel and his Family

another trip to Westmead and all the follow up visits in Newcastle. This time round the work was easier and Joel loved his new ear. He stopped wearing the first implant and coped at school with the new one.

Last December, Joel had his left implant replaced. What a difference a few months make! He is loving being bi lateral and there are no fights to wear either implant.

Nothing has ever stood in Joel's way. He is out going, friendly and full of life. He plays rugby league, tennis, golf and rides his motor bike. He wears his implants for all these activities. When playing football he wears a helmet. Mind you, he cant

hear much on the field but that doesn't stop me from screaming "go Joel!" from the sidelines.

He received a new motorbike helmet for his birthday but refused to wear it when riding. He continued to use his old one saying he couldn't get the new one over his ears ( we refer to his implants as 'ears'). It wasn't until I got tough and told him he will have to find a way to get it on because the old helmet was not safe anymore that he confessed he could get it on over his implants but didn't want to get his new helmet dirty. A special cloth to wipe down the helmet when he is finished riding soon solved that problem.

Living in the country does create some problems. Mainly, travelling distances to appointments. It usually is a half day or full day from school. We do not have the facilities you might find in the city but the support we do have is wonderful and with technology and road improvements it is getting easier all the time.

Nothing has ever fazed Joel. He just gets on with it and doesn't see himself different from any other kid. And, like all kids he, does know when to use his hearing loss to his advantage. "I didn't hear you tell me to clean my room." He is an inspiration to me and I am proud to be his mother.

Belinda Perrin

## Technology– Cochlear Implants: Can they Make my Child Hear??

Cont'd from pg 13

the wrong track. The same can happen to the signal from the cochlear implant. Abnormalities along the auditory pathway can cause information to become scrambled or may not get through to the brain efficiently. As a result, the child may receive a sound from the cochlear implant, however they may not be able to identify or understand what the sound is. Further the quality of the sound may be poor.

### My child already has a cochlear implant – do they need a second one?

Whilst we cannot say that every child NEEDS a bilateral implant, a second implant or a hearing aid (bimodal listening) can certainly be helpful to:

- hear when it is noisy
- locate a sound
- provide some benefits in music

There is also emerging evidence to show that having a second cochlear implant

provides the incidental listening that can lead to improvements in vocabulary and in enhancement of receptive and expressive language and speech production skills.

It can be worthwhile investigating this further. Usually this requires that a hearing aid is fitted into the ear without the implant where possible followed by an evaluation of listening function and speech and language. Currently a second cochlear implant is not funded through the public health system.

### How can I find out more information about getting a cochlear implant

SCIC is a not-for-profit organisation whose aim is to make cochlear implants services accessible for people of all ages with severe to profound hearing. SCIC has clinics in Gladesville, Newcastle, Canberra, Gosford, Lismore, Western Sydney and Port Macquarie as well as visiting



regional towns on outreach. All of the SCIC personnel have extensive experience working with hearing impaired people and will be able to answer any of your questions.

To organise an appointment to SCIC all that is needed is a doctor's referral. There is no cost involved for all people who hold a current Medicare card. CONTACT: P: 98446800 F: 98446811

E: scicadmin@scic.org.au ■



Parent Council for Deaf Education

Block D  
361-365 North Rocks Road  
North Rocks NSW 2151  
PO Box 4748  
North Rocks NSW 2151

Phone: 02 9871 3049  
TTY: 02 9871 3025  
Fax: 02 9871 3193  
E-mail: [pcde@bigpond.com](mailto:pcde@bigpond.com)  
ABN 47 618 685 904

[www.pcde.org](http://www.pcde.org)

#### Executive Committee

President *Mark Burfield*  
Vice President *Leonie Jackson*  
Treasurer *Amanda Li*  
Secretary *Vicki Cox*

#### Ordinary Committee Members

*Anna Messariti*  
*Anna Porter*  
*Leesa Cluff*

#### Advertising

Full page \$220 incl. GST  
Half page \$110 incl. GST  
Quarter page \$55 incl. GST

PCDE is endorsed as a deductible gift recipient under the Income Tax Assessment Act 1987. All donations of \$2.00 or more are tax deductible.

### Our mission:

‘To empower parents in NSW to support their children who are deaf or hearing impaired in reaching their full potential through information, support networks and representation.’

Disclaimer: Views expressed in Sound News are those of the individual contributors and do not necessarily reflect the views of Parent Council for Deaf Education.

Sound News is produced by Parent Council for Deaf Education to inform and educate families with a child who is deaf or hearing impaired.

Enquiries, comments and suggestions are welcome.

Note: We use the term ‘deaf’ to mean all types of deafness. Copyright.

Parent Council for Deaf Education is proudly supported by:



Parent Council for Deaf Education is registered under the Charitable Fundraising Act 1991 (CFN 11530) and incorporated under the Associations Incorporation Act, 1084 (Y08318-25).