Get on Board and Support the Campaign

PARENT CAMPAIGN TO STOP THE SALE OF AUSTRALIAN HEARING

In the May 2014 Budget, the Federal Government announced a scoping study into the potential privatisation of Australian Hearing. Parents of deaf children have expressed fear for their children’s future if the sale proceeds, and parent organisations including PODC, have responded to the news with a submission outlining the risks to Australian Hearing’s paediatric clients if the service is sold off.

Parents around Australia, represented by Parents of Deaf Children, Aussie Deaf Kids and the Canberra Deaf Children’s Association, say that the current hearing services model best meets the interests of deaf children and their families and the potential privatisation of Australian Hearing should not proceed.

Australian Hearing has been providing services to children since 1947, and has changed the lives of generations of deaf children. The service provides access to high quality technology and audiology to Australian children and youth, from birth to age 26. It is under threat due to a scoping study underway into the future ownership of the organisation.

According to Ann Porter, founder of Aussie Deaf Kids, the online parent support group, “The system for deaf and hard of hearing children in Australia is built around the fact that all children, regardless of location, socio-economic background or parental education levels, receive services from Australian Hearing that allow them access to high quality technology that optimises their ability to listen and, in turn, to learn. The sale of Australian Hearing will not only alter the lives of our children and families, it (cont p4) will impact on the entire health, education and disability support infrastructure that supports us. Consequently, the sale will put at risk the future outcomes for Australian children with hearing loss.”

Leonie Jackson, President of PODC, mother to a deaf child and a deaf person herself states: “It is (cont p4)
Welcome to the spring edition of Sound News. The past three months has been very busy with PODC’s first regional roadshow and a strategic planning day among other things.

I was very fortunate to be able to participate in first regional roadshow. I have met so many wonderful parents and their children during this trip. I grew up in the country and the visiting regional areas reminded me of how wonderful the community is in supporting families. I learnt a lot from those I met and I hope we will cross paths again.

PODC currently receives funding by the State Government but this will cease when (and possibly before) the NDIS is rolled out nationally. With this in mind, the PODC management committee held a strategic planning day to plan PODC’s future and how we will operate in the new world of the NDIS. The meeting was held on Saturday 23 August, 2014 and was facilitated by Alastair McEwin.

The meeting resulted in a general agreement to focus on three strategic areas, to be fine-tuned at the next Management Committee meeting in October.

The three key areas are:
1. Quality management – PODC staff and committee to work towards implementation of a quality management system that aligns with the Disability Standards to meet ADHC Funding requirements and third party verification by June 2015.
2. Supporting parents – PODC to continue to provide support to parents both in Sydney and regional NSW.
3. To be an independent and non-affiliated voice for parents in NSW – PODC to remain an independent body to advocate for parents of deaf children.

I would like to personally thank Alastair for doing such a great job facilitating on the day. One thing is clear – we have a lot of work to do to ensure that PODC has a robust future as an organisation that provides an independent voice for parents of deaf children. To survive and remain strong, we need YOU. If you have any specific skill that you would like to offer to PODC, we would love to hear from you.

Until next time, take care and give your child/children a big hug for being wonderful.

Leonie Jackson

I am writing this on the Monday of Hearing Awareness Week which takes place in August each year. On reflection, it seems that deafness is still very much misrepresented in our community, despite the best efforts of the sector to build a profile in the community. Most people now know about cochlear implants but many believe that this is a magic device that fixes hearing loss. There seems to be a perception in the public arena that hearing loss is no longer an issue. Most do not know that the majority of children with hearing loss, are in fact not eligible for a cochlear implant due to their level of hearing loss. Media does not help with misconceptions and misinformation, with stories about “switch on” and images of faces lighting up when sound is achieved.

Of course, families of deaf children know better. They know that it is a long journey - and a lot of work - from switch on or hearing aid fitting, to acquiring rich language. They know too that despite advances in technology, their children are still going to need support and services to achieve their potential.

In May this year, the federal government announced a budget decision to scope the sale of one of those valuable services for our children – Australian Hearing. This has been a blow to families who value Australian Hearing and do not want the service privatised. Three parent organisations, PODC, Aussie Deaf Kids and Canberra Deaf Children Association, have gathered parent experiences and perspectives on this proposed sale and created a submission that represents parent views. It is on our website so we encourage you to read it and then send the link onto your local Member of Parliament.

Our policy makers need to be more hearing and deaf aware, so that they can make informed decisions on behalf of our children who are the voters of the future. You can help them by writing to your local minister and let him or her know your story and experiences.

Kate Kennedy
Upcoming Events

For further information regarding upcoming events, please visit www.podc.org.au

PLAY IN THE PARK
Tues, 23 Sep 10.30 - 12.30pm
Buffalo Creek Reserve, Pittwater Rd, East Ryde.
Keep an eye out for the PODC banner. BYO morning tea, bikes, scooters etc… Cancelled if raining.

PODC AGM
Save the date for PODC’s AGM - Sun, 16 Nov

DEAF LEADERSHIP CONFERENCE FOR YOUNG PEOPLE
Fri, 7 November
University of Newcastle, Ourimbah Campus
Encourage deaf students to develop skills and confidence. Covers communication competence, social and emotional well-being, and resilience/self-advocacy. The conference will introduce deaf students to successful deaf role models who will share their personal experiences and the strategies they employed to become successful learners and ‘leaders’ in the community today. Parents are welcome to attend. For further information, please contact Rodney Adams 0422 537 105 or email: rodney.adams2@det.nsw.edu.au

NSW REGIONAL ROADSHOW
17 - 18 September
PODC will be visiting Orange (17/9) and Dubbo (18/9). Gain new skills and information to assist parenting children with hearing loss. PODC to visit Wagga Wagga, Canberra, Wollongong in November 2014. Dates TBA. Please register your interest by contacting PODC on 02 9871 3049.

NATIONAL WEEK OF DEAF PEOPLE 2014

DEAF FESTIVAL
Sat, 18 Oct 10.00am - 4.00pm
North Side of Parramatta River (between Wilde Ave & Elizabeth St)
Community celebration of the diversity of deaf, deafblind and hard of hearing people. For further information, email: deaffestival@deafsociety.com.

2014 PARLIAMENT HOUSE SCHOOLS TOUR
Mon, 20 Oct 10.00am - 12pm
Parliament House, Macquarie St, Sydney
FREE tour for deaf & HOH students. Teachers, bring your students! Hosted by Hon. Helen Westwood AM MLC. For more information please contact Kate Kennedy 9871 3049.
naive to believe that a private provider could deliver this diverse level of service to Australian children with hearing loss, given Australian Hearing’s buying power, and the high cost and low returns of providing these services especially in regional and remote locations. As parents living with and raising deaf or hard of hearing children in Australia, we believe our views need to be a major consideration in any decisions affecting our children’s lives.”

A media campaign commenced during Hearing Awareness Week, with parent organisations lobbying the government and many families of deaf parents providing support in an attempt to stop this potential sale.

Natalie Ryan from Sydney, mother to four year old Lucy, strongly opposes this potential sale. Lucy who was born profoundly deaf, now has a cochlear implant. She is one of hundreds of thousands of hearing impaired people relying upon Australian Hearing.

Nine year old Jacob Floyd from Bendigo, Victoria was also born profoundly deaf. When he was 19 months old, he received two cochlear implants, courtesy of Australian Hearing. Jacob’s mother, Andrea Floyd voiced her concerns during Hearing Awareness Week with opposition leader Bill Shorten.

Mrs Floyd is nervous and anxious about the privatisation, “If it’s sold and it’s then operated as a private business, what are they going to do? Either increase prices or reduce services.”

Now is a crucial time to let the Australian Government know why we need to save Australian Hearing.

If you value the service, we encourage you to send a letter to your federal member of parliament to highlight the risk to your child and family if the sale goes ahead. Letter templates are available at http://www.aussiedeafkids.org.au/save-our-australian-hearing-services.html#01

MP addresses can be found here http://www.aph.gov.au/Senators_and_Members/Members

A submission created by parents of three parent organisations: PODC, Aussie Deaf Kids and Canberra Deaf Children Association is available via the link below http://www.podc.org.au/parent-submission-re-potential-sale-of-australian-hearing.html

From the 2013/13 Australian Hearing Annual Report:
1. Provided a total of 463,497 hearing services.
3. Provided 4178 services to Aboriginal & TS Islanders under 26, and 1796 adults through their outreach program.
4. 10.3% of customers are under 29 years, and 85% are over 60 years of age.
5. Demand for services for children grew by 10% during the year with 255 children under 6 months fitted with hearing aids.
6. 4441 FM systems were provided to children & young adults to improve hearing in situations such as classrooms.
7. 606 speech processors were fitted through the cochlear implant upgrade program. Demand is expected to grow with the increase in children receiving bilateral cochlear implants.
8. 1141 staff, 117 hearing centres, one specialist paediatric centre, 353 visiting sites, 224 outreach sites.
Children with hearing loss have been using the services Australian Hearing provide for as long as they can remember. Documented below are individual cases on how important this service is to Australian children and families.

ISAAC

My name is Isaac. I am twelve years old and I am profoundly deaf. I wear a hearing aid and a Cochlear implant to help me listen and speak.

Being profoundly deaf, I use Australian Hearing as a service. I was diagnosed Christmas Eve 2002 and in the following March, at ten months of age, I got my first hearing aids at the Croydon Australian Hearing centre hear in Melbourne. My mum and dad were very excited to have this place to go for support and information about my hearing loss. My parents have leaned on Australian hearing for all of my twelve years and have become friends with my audiologist too.

Please don’t sell Australian Hearing because kids like me need it; parents like mine need the support to get their children the best equipment so they can live better lives.

Being able to hear brings freedom and confidence and the ability to reach our full potential. I can work when I’m older and help the country in the future. I want to be a zoologist and I think with my grades I can do that.

We need Australian Hearing. We are the best country in the world for hearing impaired people and if we loose Australian Hearing you will take away from my friends, family and myself the chance of being able to have a great life.

ANNABEL

Fortunately, we were referred to Australian Hearing at the end of our diagnosis appointment. We felt enormous relief knowing that there was a proven system in place to manage Annabel’s audiologist care; we did not feel knowledgeable enough (or indeed, emotionally ready) to investigate other audiology services. Learning about Australian Hearing was our first bit of ‘good news’ in what had been a tumultuous and emotional few weeks.

Annabel will turn 3 this September. She is a little chatterbox with age-appropriate speech and language. She demands her hearing aids before her feet hit the floor every morning and is produd to show them off. I am so grateful to Australian hearing for giving her the chance to hear. Claire - Annabel’s mum.

BAILEY

I have a twin brother, Jeremy and we are 13 years old. My brother and I are both hearing impaired with Jeremy recently getting a cochlear implant. We have been involved in AHS since we were first diagnosed at 4 years old. I have a deteriorating hearing loss and that means we sometimes go to AHS up to twice a week. We go there to get our hearing tested and out hearing aids fine tuned and adjusted depending on our loss. They also provide me with equipment to help me with my education they also provide batteries, all for free. When my hearing aids need fixing, we take it there and they fix them.

I am really worried if AHS gets sold, then children like me would not have assess (sic) to the brilliant services that they currently provide. I feel I am very lucky to have all the help through them. It makes me feel sad that we many not have the support in the future and other little children won’t have been as lucky as I have been so far. I am also scared that I will just see any audiologist, not one that actually knows me and cares.

I have attached a photo of my brother and myself for you to see that we are REAL children. I am on the right. Bailey - 13 years old.
Leah McKeown, Mum to nine year old Fraser, shares her story of Fraser’s journey and how the and his family have coped with his diagnosis of Auditory Neuropathy Spectrum Disorder.

Fraser was born on 31 March, 2005. He was, and still is, so loved and adored that sometimes I wonder whether we are ruining him with our emotions. He is just so lovable.

My boy is perfect.

The most poignant moment for me in Fraser’s youth was in childcare. One afternoon at pickup, one of the carer’s asked if I had ever had Fraser’s hearing tested. The children had been playing ‘Chinese Whispers’ earlier that day and they couldn’t seem to communicate the message to him.

This began what I can only describe as a life of appointments. We went to paediatric specialists, ear nose and throat specialists, audiologists, hospitals, you name it – we went there. I recall waiting for him to complete a hearing test at Australian Hearing in Wollongong and reading the notice board to pass the time. There was a picnic day planned for parents and carers of children with cochlear implants. I recall thinking that I felt very lucky that I wasn’t one of ‘those’ parents.

It wasn’t until Fraser was six years old when he was finally diagnosed with Auditory Neuropathy Spectrum Disorder (ANSD). We attended Westmead Children’s Hospital and an audiologist performed a bone conduction test on Fraser. Upon looking at the results, the audiologist commented, “It’s like I’m looking at the results of a deaf person”.

This was the happiest day of my life as Fraser finally had a diagnosis.

ANSD is a condition where a person’s hearing deteriorates at times or fluctuates at others. Receiving the diagnosis was a huge relief. We could read about it, ask questions and look for others with the same diagnosis. For Fraser, life carried on as normal. He is the type of child who doesn’t complain, doesn’t ask for things, he just gets on with it.

Fraser was fitted with his very first pair of bright blue hearing aids very soon after. At the time we were living on the South Coast of NSW and we found it very difficult to access anything that we needed immediately for our son. He had started school and it was evident that he was merely showing up each day with no direction.

I recall the day I found Aussie Deaf kids on the internet. I then contacted Parents of Deaf Children. It was definitely a turning point in my life and I know now that this was one of the best things that I did. I was able to express all my frustrations and concerns, and ask for much needed help.

They made me feel confident in my decisions and I highly recommend becoming acquainted with another family who has ‘been there, done that’.

My wish was for Fraser to know other children with hearing loss. He has since developed amazing relationships with children who are implanted, wear aids, sign and those who have deaf parents but are hearing. I will be forever grateful to his adorable buddy David and his equally spectacular family. They made me feel confident in my decisions and I highly recommend becoming acquainted with another family who has ‘been there, done that’.

We are now living in Moorebank in Sydney. We are close to family here and it allows us access to Fraser’s specialists. We are close to the Sydney Cochlear Implant Centre (SCIC) in Penrith and Gladesville, as well as Hearing Australia.

Fraser now attends Hammondville Public School. He excels in his learning and is involved in extension classes. He has had two of the most amazing hearing support teachers and I cannot speak highly enough of his school and his teachers. We have review meetings every six months and nothing is ever too much trouble. Every time I visit his school I feel so blessed that we chose the right place for him.

Our world spiralled once more last November when Fraser received his first cochlear implant. He was, and still is so excited to have this technology and wears it with pride. He is quite the celebrity around the playground because the student body was briefed about his transformation for when he returned to school.

There is no question that Fraser’s hearing has improved with his implant. What is the most difficult to get used to,
is other people’s perception that he might now be ‘cured’ and that his hearing will now be perfect. During a recent professional learning session with the teachers at Fraser’s school, they were shocked to realise that his understanding of conversation in a noisy environment is still very poor. He still relies on his FM system quite heavily and still lip-reads in noisy situations.

We have several more hurdles to get through in the near future. The ENT believes that Fraser needs to have both his adenoids and his tonsils removed in the future. As well as this, at our last visit to SCIC, a second cochlear implant was suggested in the future.

His switch-on was a little understated for my liking. I had watched so many on YouTube that I was expecting fireworks. The audiologist called his name and he looked at her. I said “Fraser… can you hear me?” and he gave me a nonchalant nod. Looking back I think he was a little shocked. As we drove home, my parents called and spoke through the Bluetooth in my car. Fraser had a telephone conversation for the first time in his life. There were my fireworks!

Fraser has gone ahead in leaps and bounds. We marvel at his amazing development and improvement every day. He is our miracle.
Dr Hester MacMillan is a psychologist specialising in child development and disability in childhood. She has worked in the field of hearing impairment over a number of years. She has a particular interest in the social and emotional development of children with hearing impairment. In the following article, Dr MacMillan examines the ‘capacity to think about another person’s thoughts or feelings, also known as ‘theory of mind.’

As social creatures, we are constantly developing our capacity to navigate the relational world using complex skills of which we are largely unaware. Think of any one of our everyday interactions, as simple as asking someone about how their day is going, or explaining to a friend how to do something. For interactions like these to be successful they require an awareness of the other person’s perspective, i.e., what they might be thinking or feeling, or their existing knowledge and likely attitudes. For example, giving directions requires us to ‘imagine’ what the other person may already know about their current location, or their capacity to understand the instructions we give them. This determines how we explain the directions, such as what level of detail we provide. It leads us to ask the necessary questions in order to confirm what they already know. Most of the time we do this automatically, responding with instinctive understanding of what a conversational partner needs to hear, in order to fulfil our communicative intent. When misunderstandings occur we may be forced to consider another person’s perspective more consciously, to think about what they might have been thinking, and recognise what they did or didn’t know, or understand, in order to appreciate how the misunderstanding arose. This capacity, to think about another person’s thoughts or feelings, is the foundation of successful social interactions, and is often referred to as a ‘theory of mind’ or social thinking.

As with other cognitive abilities, social thinking skills develop over time. Some people will have better skills than others. For most children, a ‘theory of mind’, is developing from a young age, starting with the emergence of awareness of one’s own self as simply being separate from others, and growing into an ever increasing appreciation of what beliefs, motivations, intentions and feelings, we, and others may hold. A watershed moment in the emergence of theory of mind is around 4-5 years of age, when children can pass what are called ‘false-belief tasks’. These tasks involve a child demonstrating, through answering questions about social scenarios that they realise why someone has misunderstood something, or held a ‘false belief’.

For some children, including those with significant hearing loss, the ability to pass these tasks can be quite delayed. This implies that their capacity to understand and negotiate social situations is compromised. Delays in developing theory of mind are found in children with neurodevelopmental conditions, including autism, and in children for whom access to fluent conversational partners and complex social interaction has been limited through hearing loss. Those with full access to a language, allowing for plenty of social interaction and conversation from birth, notably, deaf children born to deaf parents who use sign language fluently, are not delayed in developing theory of mind. Deaf children born to hearing parents often have reduced access to fluent conversation and social interaction due to the limitations of hearing devices, or their parents’ knowledge of sign language. Language development is closely linked to the development of theory of mind; as language is the means by which we represent abstract
STRATEGIES FOR ENHANCING THE THEORY OF MIND

- Clue children into the very idea of what thinking is, by ‘acting out’ that you are thinking something e.g. pointing to your head and say “I’m thinking…thinking…” perhaps when you are trying to solve a problem; talk about having an “idea in your head” or something being “in your mind”.

- Expose your child to ‘mental state language’ in the course of your interactions at home. This involves explaining explicitly what you are thinking or feeling about something, rather than just labelling objects or actions e.g. “I am dreaming about eating some chocolate”. Talk about how you know what you know, and explain misunderstandings e.g. “I think Dad will be home soon because he told me he was coming at five”.

- Talk about emotions, how you know what someone is feeling, and why they might be feeling that way. Connect facial expression and tone of voice to feelings e.g. “He looks amused”, “He sounds furious”. Draw their attention to pictures of facial expressions and postures in picture books, magazines, or on the internet and talk about how we can guess what someone is feeling by how they look. When your child shows emotions, help them to understand and express their feeling state by giving them the words e.g. “You look excited”, or “I feel very happy when I am playing with you”.

- Encourage pretend play and dress ups. This provides the opportunity to try out different social roles, imagine what other people might say or do in different situations, and take another person’s perspective. Role play helps very young children to separate what is pretend from what is real, a major stepping stone to developing a mature theory of mind.

- Read together with your child and talk about the characters in the story, their feelings, their motives and intentions. There are some stories where the plot hinges on characters who hold false beliefs; think of Little Red Riding Hood who in believing that the wolf is her grandmother, does not predict that the wolf may attack her. These stories can be used to talk about why someone is mistaken or holds a false belief, but any story can be used to help children practise making inferences. Ask questions to prompt your child to think about what characters may be planning, hoping, thinking or feeling and how that affects what they do.

- Exposure to lots of conversation and social interaction is important for developing social thinking skills. It is in the to and fro of multiple social experiences that children learn not only the language to express their ideas, but to practice thinking about what is in someone else’s mind. This requires the ability to hear clearly what people say. This becomes more difficult for children with hearing loss in noisy social situations. Children with hearing loss may also miss ‘over-hearing’ conversations, the incidental chat and the gossip that stimulates social thinking. Facilitating ‘over-hearing’ is important. The FM can be used to do this, perhaps by putting it on the kitchen bench so your child overhears family discussions, even arguments, which gets them wondering and thinking (and asking questions); watch out for children who isolate themselves socially or give up on listening in a group because it’s tiring or too hard to follow, and of course work on honing your child’s auditory skills through training them to listen in background noise (their teacher/therapist/audiologist can assist with strategies).
Usher syndrome is a relatively rare genetic disorder caused by a mutation in any one of 10 genes resulting in a combination of hearing loss and visual impairment. It is the leading cause of deafblindness. Usher syndrome is incurable at present. Vicki Cox, mother to India and Samira who both have Usher Syndrome has recently come back from the USA where she attended the International Symposium on Usher Syndrome.

I have two teenage daughters who were born profoundly deaf. They were born prior to Newborn Hearing Screening but we still managed to have them implanted fairly young; India at 21 months and then Samira at 11 months. As babies they met most of their early milestones apart from talking and walking a little late around 20 months. We were not overly concerned at the time and focused on getting their language skills up and running with their new implants. They received their second implants at 7 and 9 years old respectively and life went on as normal.

Just over 3 years ago we went on holidays to Cairns and the Daintree Rainforest. In the rainforest areas there is little or no street lighting and Samira was having difficulty getting around at night. A follow-up appointment at the optometrist indicated some retinal changes and more tests were needed including an ERG or electro retinography. These tests confirmed that she had early signs of retinitis pigmentosa (RP) and therefore had Usher syndrome. This also meant that her older sister India had the syndrome too. India also has some associated balance difficulties. I have to admit it was a devastating diagnosis and the future didn’t look too bright for our gorgeous girls!

Usher syndrome is named after Charles Usher, a British ophthalmologist who described the nature of the disease in 1914. Usher syndrome is a recessive genetic condition involving sensorineural hearing loss and retinitis pigmentosa (RP). Although considered a rare disease, it is the most frequent cause of deaf-blindness in humans and its prevalence is around 3-6 cases per 100,000.

There are at least three different forms of Usher syndrome. People with Usher syndrome type 1 (USH1) are usually born with severe to profound hearing loss and experience problems with balance. The first signs of RP — night blindness and loss of peripheral vision — usually appear in early adolescence. In type 2 (USH2), newborns have moderate to severe hearing impairment. Symptoms of RP typically start shortly after adolescence. A rarer third type of Usher syndrome (USH3) was documented in 1995. Children with USH3 are usually born with good or only mild impairment of hearing. Their hearing and vision loss is progressive, starting around puberty. Balance may also be affected.

I have recently had the opportunity to attend two conferences related to Usher syndrome. The first was the 9th National Deafblind Conference held in Sydney from 6-8 June. The conference theme was “Access to my World” and focused on advocacy, communication and accessing services including the new National Disability Insurance Scheme (NDIS). There were many inspiring deafblind adults at the conference who have been leading very successful and fulfilling lives despite the obstacles they face every day. Technological advances have made things a little easier and cochlear implants are helping to alleviate some of the isolation from the combination of vision and hearing loss in the younger generation. There were great opportunities for networking and connecting with local and international services that will support my daughters as their vision deteriorates, such as the DeafBlind Association NSW, Guide Dogs NSW/ACT, Senses Australia and Able Australia. Parents of Deaf Children (PODC) kindly sponsored my registration fee for this conference.

There was also an International Symposium on Usher Syndrome being held...
in Boston, USA in July, and thanks to some sponsorship from Quota Club International and another organisation who assisted with my airfare, I was able to attend this fantastic event that brought together researchers, professionals and families from all over the world. My head is still spinning from all the information presented at this symposium! Gene therapy, stem cell therapy, optogenetics, genetic testing, virus vectors, vestibular implants...so much to take in! It was wonderful to meet families from all over the world and particularly Mark Dunning who founded the Usher Syndrome Coalition when his daughter Bella was diagnosed with Usher Type 1.

The Usher Syndrome Coalition were my saviours during the despair of diagnosis and give families like ours hope that there is a bright future for our children. In Australia there is very limited accurate information on Usher syndrome and some families have to fight hard for the diagnosis and definitive genetic testing. The Usher Coalition provides a wealth of accurate, up to date information on the syndrome and links you with families from all over the world. They have a Facebook page, regular tele conferences to provide up to date information and organise an annual family conference in the USA and 2–3 yearly International symposiums where they bring together researchers and families affected by Usher syndrome.

So what did I learn at the Symposium? A lot!!

- Up to 10% of children with cochlear implants have Usher syndrome and 3 – 6% of people with any hearing loss will have Usher syndrome as the cause.
- In some US hospitals and in Sweden Usher Type 1 is detected in the first year as they test babies needing cochlear implants for vestibular functioning and if a problem is detected they can perform an ERG under anaesthetic during the implant surgery and arrange genetic testing.
- Researchers have produced a retina in vitro using stem cells derived from skin cells.
- There are some early stage clinical trials for gene therapy for specific types of Usher syndrome.
- The rate of visual deterioration is slower than in non-syndrome RP and most people retain some useful central vision into their 60’s and older.
- A vestibular implant is being developed as an addition to a cochlear implant
- It is very important to be on a register and know your genetic mutation to take advantage of future clinical trials.
- The Usher genes are too large for current viral vectors and researchers are working hard on this dilemma.
- Traditional mouse models are not ideal for Usher syndrome and different animal models are needed to trial gene and stem cell therapies e.g. monkeys
- Vestibular issues are a real problem for many people with type 1 Ushers
- It is better to have the diagnosis of Usher syndrome before adolescence because they are more prone to denial and don’t want to be seen as different!
- Children know and understand a lot more than we think so don’t hide the diagnosis from them
- Headaches and fatigue are common issues for people with Usher syndrome
- If you have Usher syndrome wear sunglasses and eat a diet rich in Vitamin A and Omega 3
- Move to Sweden or the UK because their health services provide a lifelong support worker from diagnosis to coordinate services. Just joking about the moving but in Australia there is very little if any coordination between Deaf and Vision services.

So where to from here?......I am setting up a closed Facebook Page called Ushering Along to connect parents who have children with Usher syndrome as this was a need we discussed at the parent forum at the symposium. There needs to be more awareness of Usher Syndrome and better diagnosis and support in Australia as many medical professionals know nothing about the syndrome or are very pessimistic about the prognosis. Get more genetic testing done as the girl’s initial test was negative and it is important to know this information! Spread the word about the Usher Syndrome Coalition and their Usher registry – the 3 other Aussie families I connected with through the coalition had issues with diagnosis and support. And finally.....start saving for the next International Symposium in 2016 in Europe!!

I would love to connect with more families affected by Usher syndrome and can be contacted by email at vicmal@optusnet.com.au.

Samira, Vicki, Mal and India Cox
**HELPING CHILDREN COPE WITH TRAGEDIES**

*When tragedies strike on a world-wide or local scale, adults can help to reduce children’s anxieties*

Sometimes on a world or local basis, something tragic happens that touches all members of the community. The following information is to help parents support their children through a tragedy. Faced with a disaster, parents will experience a range of emotions from shock to fear and anxiety. Children can be affected by their parents’ response to something like this, as well as by what they see and hear directly. The closer children and young people are to the tragedy the greater the impact is likely to be, but even distant exposure to trauma can have an impact on their emotional wellbeing. The impact can be immediate or can come sometime after the event.

**What should you say?**

How much you talk with children about an event such as this will depend on the age of the children and how closely it touches their lives. As far as possible it is usually advisable to protect very young children from things that they cannot understand and which may make them fearful. However, children can make up worse things if they know something is wrong but don’t know what it is. Simple explanations that reassure them they are safe and you are there caring for them will help. As children get older they need more explanations and time to talk.

**Very young children (preschool)**

Young children are worried by different things from adults and may not even seem to notice major traumas, however they are very affected by parents’ responses and feelings.

- Try not to show your own anxiety because children will quickly pick up your feelings and know there is something wrong. If it is close to home and children know you are upset, reassure them that it is not to do with them and that you are caring for them.
- Turn off the TV. It is very hard for young children to make sense out of what they see and hear and it can be very frightening. As children get older and into adolescence you will want to share your feelings and talk about the issues to develop their understanding.
- At all ages it is most important to listen responsively and respectfully.
- Try not to discuss what has happened in front of the children.

**Signs of stress**

Young children show worries by sleep problems, going back in their development, eg. wetting the bed again, clinging and behaviour problems. If these things happen your child will need extra reassurance. Give children more support as they need it, e.g. allow them to sleep near you for a time.

**School - age children**

- Most children of this age will have

- Keep to normal routines, which give young children a sense of safety and security.
- If your children have already heard or seen something about it:
  - Listen to their feelings calmly, give them time to talk without pressure;
  - Explain what has happened is in another country and a long way away (if this is true) and comfort them that they are still safe;
  - Give lots of physical reassurance
  - Give lots of opportunities to play, draw and paint (without guiding them). This helps children to deal with feelings and get a sense of control.
heard what has happened and will have some reactions, as they understand the reality of what has happened. They may worry that it could happen to them.

- It is still a good idea to protect them from the TV. Visual images can have a powerful impact. If they ask questions, give them information without unnecessary detail.
- You may have to answer the same questions over and over as the child tries to make sense of what has happened. Give as much information as they want but avoid unnecessary or frightening detail.
- Give opportunities to talk about their feelings and their fears. Validate their emotions as real. Let your children know they can talk to you any time they are afraid.
- Keep to routines that provide a sense of safety. Some things you can do in the time when you usually watch TV might be playing games, walking the dog, shopping, gardening, a bike ride - things that give your family a sense of togetherness.
- Try to help them with their fears by talking through the issues according to their age and understanding, e.g. ‘Sad and scary things do happen in the world but they are rare and there are lots of sensible people who are working to stop things like this happening’. Talk about the people who are helping.
- You may need to show that they are safe in whatever ways are true, e.g. that such events are rare, that where you live is different, that your home is safe etc.
- Most of all think about your own response. When things like this happen it touches our own sense of insecurity. It is really important to hold on to the sane and down to earth aspects of our daily life and this is what will make the world feel safe for your children.

Signs of stress
School age children may still show worries through behaviour as well as or instead of talking about them. They may show them by not wanting to go to school, by nightmares, behaviour problems or by physical symptoms such as headaches or tummy aches. If your children are showing worries in this way it is important to help them to talk about their fears. Bedtime is often a good listening time.

Parents
Adults also need support from each other. Talk about your feelings with friends. Remember that there are many, many people working together to make the world a better place, and there will be many heroic deeds happening during the crisis that will not be seen on TV but which attest to the sane and good forces in the world. Keep up your usual routines and things you enjoy and try not to watch too much TV!

For all children and young people, remember that you are the rock for your children. If you keep calm and caring they will usually be okay.

If necessary, seek help - if you are worried about your own or a child’s immediate or ongoing reactions, ask for help. You could call a parent helpline or your local health professional.

Doing something to help
Children and young people can be assisted by feeling there is something they can do to help. This gives some sense of control when things are overwhelming. This could be, for example:

- writing a letter of sympathy and support;
- giving toys, food or clothing;
- raising money for the victims or for organisations which support peace;
- volunteering their time in whatever way will be helpful; and
- let them see you helping as well.
How can you recognise hearing loss in babies?

It can be tricky to tell if babies are having trouble hearing because in the first two months of life they often don’t respond to the softest sounds they can hear. Rest assured this is normal and a lack of response doesn’t necessarily mean your baby can’t hear.

It can help to know what’s typical

Different levels of sound arouse various responses in babies, depending on how active they are:

- Babies react to softer sounds when they are just dozing off, but not so much when they’re awake and active.
- In early life, babies are often intrigued by voices, so they will respond to a voice at a softer level compared with their response to other noises around the home.
- They are more interested in complex sounds, such as rattles or music, than the simple sounds of beeps or whistles.
- Babies get bored, too. If a sound is repeated too much they might lose interest and stop responding (this is known as habituation).

Typical hearing and listening behaviour in babies

Age: 0 - 28 days

- Responds best to nearby sounds.
- Is startled by sounds perceived as loud.
- Widens eyes or blinks at sudden sounds and may become distressed.
- Stirs or rouses from sleep in response to sounds. Babies will generally respond to soft sounds when in a light sleep. When babies are in a heavier sleep, sounds usually need to be perceived as loud to arouse a response.
- Eye movement - newborns may corner their eyes towards a nearby, continuous sound.
- At one month, babies may move their eyes and head towards a nearby sound. Their body may tense in response to certain sounds and they may extend their limbs or fan out their fingers or toes.

Age: 1 - 4 months

- Widens or blinks eyes and may wrinkle eyebrows in response to sounds.
- Eyes may shift towards sounds.
- Quietens when sounds occur and may become tense.
- Starts turning head towards sounds by four months.

Age: 4 - 7 months

- Turns head towards sounds but can only locate the sound directly if it’s at the same level as the ear.
- Appears to listen.
- You will see the best hearing responses when it’s quiet. If the house is noisy it may be more difficult to see responses to certain sounds.

What should you do if you’re concerned?

See your doctor for advice and diagnosis. They may refer you to an ear, nose and throat specialist or to an audiologist for further advice.

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I am a photographer, I'm 27 years old and I was born with a mild to moderate hearing loss. It is perhaps a blessing and a curse that my type of hearing loss can be somewhat easy to hide. For this reason I don’t usually tell people, and up until recently I hardly wore my hearing aids. However, this means that awkward, uncomfortable and often stressful situations are the norm for me. Like when I decide I don’t want to say “pardon” again and I nod my head instead, to which the response is a blank, confused stare. Or when someone says something to me from behind and I simply walk away. I have often wondered if people think I’m rude or strange. Or if they think I’m boring because I don’t say a whole lot during group conversations or dinner parties. However, it is only this year that I feel like my life as a hard of hearing (HoH) person has really begun. I had always considered myself to be a confident person, comfortable in my own skin and without insecurities. Until I realised that awkward, uncomfortable and often stressful situations are the norm for me. Like when I decide I don’t want to say “pardon” again and I nod my head instead, to which the response is a blank, confused stare. Or when someone says something to me from behind and I simply walk away. I have often wondered if people think I’m rude or strange. Or if they think I’m boring because I don’t say a whole lot during group conversations or dinner parties. However, it is only this year that I feel like my life as a hard of hearing (HoH) person has really begun. I had always considered myself to be a confident person, comfortable in my own skin and without insecurities. Until I realised there was a part of myself that I had been ignoring. Whenever I happened to tell someone “I have a hearing problem... Oh and yeah I have hearing aids...” a part of me would tense up, my voice would shake, I would go red.

It wasn’t until I read an article earlier this year that all these thoughts and questions emerged. The article was written by a woman, also 27, who was deaf. She talked about the awkwardness of missing conversations, the embarrassment of being a teenager and telling boys about her “problem” and then she went on to explain that for her it was far more visual and that it seemed natural for her to pursue her passion as a photographer. I read it and I cried. I felt like I was reading about myself and for the first time in my life I felt a comforting feeling that perhaps these insecurities I had were not something to be ashamed of. For the first time I actually realised that having a hearing loss WAS a part of who I am, that it has made the person I am today and that I should be accepting, if not proud about it.

For 26 years I had bottled up my experience as a HoH person and suddenly thoughts and memories poured out that I didn’t even know existed. I began to think about my childhood, how I was apparently calm and quiet, yet I would dress myself it ridiculously colourful (always colour coordinated) outfits. I thought about when I first got my hearing aids and when I had to see a “special needs” teacher- this memory is painful as it was when I realised that something must have been wrong with me and I got the idea in my head that I would never be as “smart” as my friends. Despite the fact that I excelled at school, I’m ashamed to admit I could never quite shake that thought.

But I’ve also thought about how my deafness has had a positive impact on my life. I am a patient, observant, resilient and reflective person and I like to think my hearing loss has something to do with that. I have been told that I am a good listener (ironic I know) because I give people my full attention and always look at them when they speak - a quality I strongly admire in others. And of course to have the skill of lip reading and being a good sleeper are two things I wouldn’t want to live without. After I started to process these thoughts and memories I became excited to share them with people. I took photos of my hearing aids and I ‘came out’ about my hearing loss. While this was in some way a liberating experience, above all else, I wanted to make others feel the way I now did. And so the idea for the ‘Right Hear, Right Now’ project was formed - a photography based project which tells the stories and experiences of deafness. From deaf and HoH children, teens and adults, to parents of deaf children and children of deaf adults. Deafness doesn’t only effect those who experience it themselves but also family members, friends and colleagues. I don’t ever doubt my parents ability in raising me, but I now wonder if they had shared their story with others experiencing the same, the journey might have been easier for them.

The goal for ‘Right Hear, Right Now’ is to essentially provide a platform where those with any degree of hearing loss or related to someone with a hearing loss can share their stories and find a community of people who understand. It is about empowering people to accept and embrace their differences, to raise awareness and to ultimately transform negative perspectives into ones of inspiration and understanding.

I am currently talking to people about their stories and taking photographs to visually document their experiences. If you are interested in participating and sharing your story, or you would like to discuss the project further I would love to hear from you. Please get in touch by sending me an email to hi@katedisherquill.com

Kate Disher Quill, a young adult with a hearing loss, shares her story about her journey and the project that has been inspired by it.

As a child, I was far better at expressing myself visually

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I was clearly not ok with it. But why?

It wasn’t until I read an article earlier this year that all these thoughts and questions emerged. The article was written by a woman, also 27, who was deaf. She talked about the awkwardness of missing conversations, the embarrassment of being a teenager and telling boys about her “problem” and then she went on to explain that life for her was far more visual and that it seemed natural for her to pursue her passion as a photographer. I read it and I cried. I felt like I was reading about myself and for the first time in my life I felt a comforting feeling that perhaps these insecurities I had were not something to be ashamed of. For the first time I actually realised that having a hearing loss WAS a part of who I am, that it has made the person I am today and that I should be accepting, if not proud about it.

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Deaf Youth Sydney (DYS) is run by The Deaf Society of NSW and Ephpheta Centre. DYS is for deaf and hard of hearing young people aged between 12 and 17 years old. This group welcomes all levels of hearing loss and communication modes.

The purpose of the group is to establish and increase social contact between young deaf and hard of hearing people. We have social events once a month, which are a great opportunity for everyone to get together and socialise, sharing their experiences with their peers especially as a high percentage of participants are the only deaf person at their local school.

Our first event this year in February was successful with 44 young people at the FX zone in Olympic Park. The following month we had our event at Ephpheta Centre, with a deaf version of 'A minute to win it'. We have a closed Facebook group where young deaf and hard of hearing young people can join to meet other deaf and hard of hearing young people and to receive updates for every event.

https://www.facebook.com/groups/deafyouthsydney/ For parents, if you would like to receive emails every month with updates; please e-mail to youth@deafsociety.com or check out our website www.deafyouthsydney.org.au.

We also help with transport to ensure youth events are accessible to all young deaf and hard of hearing people in Sydney. To arrange transport for your child please contact Amanda Faqirzada by email youth@deafsociety.com or by sms 0423 276 079.

We have three staff working for DYS; Amanda Faqirzada, Youth Development Officer from The Deaf Society of NSW and David Parker, Community Liaison Officer and Donovan Mulligan, Community Worker from the Ephpheta Centre. At every event we will always have female and a male staff member to ensure all young people socialise in a safe environment.

REGIONAL ROADSHOW

Parents of Deaf Children is coming to Western NSW in September 2014. Our aim is to share and build the unique connection that only parents can offer to other parents. Please join us to gain new skills and information to assist you with parenting and supporting your child with hearing loss.

At each location, we will be running:

- Drop-in information sessions (get the latest info on a range of topics, including FM systems, Betterstart funding, the upcoming National Disability Insurance Scheme, School Readiness, parent mentoring, etc).
- Workshops for parents “Making Good Choices - Information is Power”.

Please register your interest by contacting Kate or Allison on 98713049

Dates: 17-19 September 2014
Location: Orange - 17 September
Dubbo - 19 September

NSW Roadshow coming to following locations in November 2014 -
Canberra, Wollongong, Wagga Wagga. Dates TBA.
The Education provider must take reasonable steps to ensure that a student is able to participate in the courses or programs provided by the educational institution and use the facilities and services provided by it on the same basis as a student without a disability and without experiencing discrimination’ from Disability Standards for Education 2005 Part 5.2 (1)

Five Areas of the Standards
1. Enrolment (Section 4 of DSE)
2. Participation (Section 5 of DSE)
3. Curriculum development, accreditation and delivery (Section 6 of DSE)
4. Student support services (Section 7 of DSE)
5. Harassment and victimisation (Section 8 of DSE)

The means by which Participation and Curriculum development, accreditation and delivery should be done include:

- Taking reasonable steps to ensure participation in courses and programs and use of facilities and services
- Consulting with the itinerant support teacher IST, and when appropriate student and parents, about the effects of the student’s disability on their ability to participate in courses and programs and use of facilities and services
- Considering information from this consultation when deciding whether an adjustment is necessary
- Making a reasonable adjustment if necessary

Repeating this process as necessary to allow for the changing needs of the learner over time.

What this means in practice:

- Curriculum is planned to meet the needs of all learners
- Curriculum is delivered in a variety of ways to meet the needs of all learners
- A range of assessment options is planned and made available
- Appropriate accreditation can be obtained

Accommodations / adjustments are categorised into four areas:

- Presentation - assessment teaching and learning may include: cue cards, alternating new learning with opportunities of practice, signing, large print, braille, captioning or providing transcripts of audio visual material, use of a sound field system or FM system, transcript to read when doing listening task which is then removed for questions, live voice rather than recorded
- Response - learners could respond in a variety of ways: verbally, by drawing, using a braille writer, by another person scribing, use of computer/ipad to write, presentation written/power point instead of oral
- Setting - assessment, teaching and learning may occur in different settings: small groups, in separate venue and/or separate supervision
- Timing - Adjustments may need to be made to the time allocation for assessment, teaching and learning activities: extended wait time to complete tasks, reduce number of tasks, allow breaks during the activity, extra exposures to listening task

WELL DESERVED RECOGNITION

PODC would like to congratulate two members of our PODC Advisory Panel:

Professor Greg Leigh was made an Officer of the Order of Australia (AO) for distinguished service to the deaf and hard of hearing community, through education, research, public policy development, and specialist services. Well known to many families in our community, Professor Leigh is Director of Royal Institute for Deaf and Blind Children (RIDBC) Renwick Centre – which operates in affiliation with the University of Newcastle – and is Conjoint Professor of Special Education and Disability Studies in the School of Education.

Anne McGrath was awarded the 2014 Premier’s IOOF Centre for Educational and Medical Research Itinerant Support Teacher (Hearing) Scholarship by the Premier, Mike Baird, and the NSW Minister for Education, Adrian Piccoli. The scholarship involves a five week national study tour and a visit to New Zealand next year, to conduct research into an area that will be of benefit to the profession and ultimately the students it serves. Anne’s research topic is ‘Building teacher capacity in the use of captioned multimedia for curriculum access’.
Being technologically savvy is not an option for parents these days, it is a necessity. Children need to be protected from online content now, more than ever before. Leonie Smith is a cyber safety educator. She educates parents, children and teachers through her presentations, workshops and publications. Her book “Keeping Kids Safe Online” provides step by step instructions for setting up safety and privacy settings to protect your family from adult content. She also provides some tips for monitoring computers and using them safely at home.

**MONITORING COMPUTERS**

**Placement**
- Keep kids PC’s and mobile devices in high traffic areas. Discourage use in child’s bedroom.
- Make agreements for mobile device use in bedrooms and time limits.
- Buy desktop PCs rather than laptops to discourage mobility. Use a laptop cable lock on laptops if you want to prevent a laptop being moved to a private room.

**Online Time Limits**
- Set time limits on computer use, stick with them as much as practical.
- Ask kids to help set time limits, if they go over time, deduct time for the next session.
- Put computer timetable on a notice board or on fridge note.
- Allow online social time including emails, Facebook, Skype, phone calls and homework.

**Monitoring**
- Limit gaming time on computers and devices during the week.
- Give rewards for times adhered to, eg. Gift cards or a special outing.
- Avoid excessive harsh punishments. Fear will make a child clamp up. Keep rewards and punishments easy and realistic - follow through.

**Get Involved**
- Find out what online words and acronyms mean and have fun with that. LOL, YOLO etc.
- Ask kids to teach YOU about what they know - guide you through a game.
- Teach children how to block and report on every program they use.
- Talk to kids about online privacy, bullying and predatory behaviour BEFORE issues arise.
- Share information about new games and updates.
- Find creative, exploratory and learning style games.
- Set boundaries around behaviour inside and outside your home. Set your expectations of what games and apps they are allowed to use.
- Give your children ideas for how they might avoid playing games or using apps they are not allowed to use.

**CYBERSAFETY RESTRICTIONS**

Just when you thought you could put off cyber safety issues until your children are teens, parents are finding out the hard way that teens aren’t the only ones with internet computer cyber-safety problems.

**Tots on Smart Phones**
The use of internet connected devices like iPads and other tablets, computers and smart phones are being used by children as young as 2 years old, and its increasing massively year by year, but parents are still thinking that cyber safety only applies to teens on computers.

Parents! You had better catch up quick! Technology is moving faster that you can adjust your mindset, and if you continue to keep thinking you don’t need to worry about cyber safety for your younger children until they are teens you and your children are sadly in for a nasty shock.

**Phones and iPads Are Computers!**
Smart phones and tablets like iPads and others are computers, and most are connected to the internet. Each of them has internet browsers like Safari and Internet Explore with access to search engines, and each have the ability to download images and adult games you would rather your child not be exposed to. Any parent that leaves one of these devices around the home unlocked or even hands this device to their child without securing it with proper filters and controls is leaving their child open to content that is beyond the child’s ability to cope with. Take your eyes away for one second and your child might see something that can’t be unseen.

When I mention to adults that I give Cyber Safety talks, they most often think “Oh For Teens”. And yes for so long that HAS been the focus of Cyber Safety. But all of that is changing so
fast and it’s taking time for parents to catch up. The are forgetting that ANY device connected to the internet makes your child vulnerable.

**Primary Schools are including Computers in their Curriculum!**

Most schools are already including computer use in their primary school curriculum, kids already know how to use Google BEFORE they get to high school, not to mention underage use of Facebook.

As a Cyber Safety Educator, I hear the same terrible story over and over again. How a parent didn’t know how to filter Google search or protect their computer, WiFi, or tablet and their child under 10 years old saw pornography or sick violence simply by looking something up on Google that was apparently entirely innocent. This absolutely horrifies me, when its so simple to protect them. Most parents I talk to just didn’t give it any forethought. I find it hard to believe that most parents don’t realise what potential dangers they are exposing their kids to when they don’t know how to filter the internet.

**Your child may not have an iPhone, but what about their friends?**

I’m also shocked how many parents don’t realise how many children under 10 years old now have iPods and smartphones that connect to the internet, and they haven’t thought how their child might be exposed to something nasty by one of these kids with such a device. Many parents don’t even have a pin password on their phone and leave them lying around the house, only to be picked up and used by their child without their supervision.

Every one of these devices has a parental controls feature and filters that you can set up to protect your child. It can be as simple as putting a pin coded phone lock on your phone or iPad so your child can’t play it without you being there to watch over them. As a parent, it is your sole responsibility to find these protections. You don’t want your child to find out about porn and horrible sick violence through the internet before you are ready to explain it to them. And most children are exposed to adult content at home NOT as school.

**Prevention is better that cure, what is seen cannot be unseen**

You should no more leave your child in a news agency and let them wander the isles of the adults only magazines that you should exposed them to the internet.

This “Teen Only” Cyber Safety awareness mindset needs to change now! And soon. My talks to parents are more important in primary schools because of these changes that have happened over the last few years. You cannot wait for high school to learn about Cyber Safety!

Please don’t leave your primary school kids unprotected with your internet devices, set the pin code locks, the filters and protections and attend your next Cyber Safety talk at your school.

If you ARE going to allow the internet in your home, protect your children from it. Let them have fund on their iPods and computers but protect them from adult content.

Reprinted with kind permission from Leonie Smith. Her website is as follows www.thecybersafetylady.com.au. Please contact Leonie at leoniesmith@thecybsafetylady.com.au to arrange a talk at your school or community group.
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.’

Executive Committee
President Leonie Jackson
Vice President Leesa Cluff
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Secretary Mark Burfield

Ordinary Committee Members
Anna Messariti
Sarah Klenbort
Julie Frendin

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Disclaimer: Views expressed in Sound News are those of the individual contributors and do not necessarily reflect the views of Parents of Deaf Children.

Sound News is produced by Parents of Deaf Children 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. Parents of Deaf Children is proudly supported by the NSW Government. Parents of Deaf Children is registered under the Charitable Fundraising Act 1991 (CFN 11530) and incorporated under the Associations Incorporation Act, 1084 (Y08318-25).

PODC is committed to ensuring that any person or organisation using our services or affected by our operations has the right to lodge a complaint or to appeal a decision of the organisation and to have their concerns addressed in ways that ensure access and equity, fairness, accountability and transparency.

We would value your feedback. Please find a feedback/complaints form on our website - www.podc.org.au