



Families in CHARGE

C coloboma of the eye

H heart anomalies

A atresia of the choanae

R retardation of growth

G genitourinary system anomalies

E ear anomalies and hearing loss

Feel free to contact us for brochures, handbooks, videos, literature, parent support or to make a donation.

CHARGE Syndrome Association of Australasia Ltd is a registered charity with DGR status and all donations are tax deductible.

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Families in CHARGE Newsletter

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Please send newsletter article contributions to Tricia or Paul.

President's report

Dear families....

Welcome to the August issue of the CHARGE Newsletter for 2011

Since our May newsletter life for the President has been busy! I thought the stresses of February were well behind us and things were settling down but then there were the aftershocks of June 13! This brought more turmoil and unrest to our lives. This was a reminder to our Canterbury families that the earth was still moving and we need to ensure our children and families are prepared for the unexpected. On September 4th it will be the one year anniversary of the first big shake, a day many of us would like to forget.

However my family and I we were lucky enough to get away from the shaking for a while and escaped to America also missing the first big snowfall. The purpose of our trip was to attend the American CHARGE Conference in Orlando. Thank you to all the people who supported us and assisted with funding. The conference in Orlando was amazing. It was a fantastic opportunity to meet with families from around the world including families from Germany, Spain and Norway along with catching up with our very own Rob Last, Sharon Barry Grassick, Belinda Arnell and Ellen

Howe. The conference was attended by over 850 people.

Thank you to Marie Patterson who nominated my daughter Aimee for "Win a Wish" with the Kristies Foundation in America. Aimee was fortunate enough to be accepted and as part of the Win a Wish Aimee visited, Knottsberry Farm, Disneyland and Universal Studios in Los Angeles. Watch for the next newsletter where Aimee's story will appear!

"Why I am Me" – After some last minute amendments I am pleased to advise the book is now with the printer. Once the book is printed a formal launch will be arranged. Should you wish to assist arranging the book launch or have any ideas on marketing of the book please feel free to make contact with me as soon as possible. Having had a sneak peek of the book I am really excited about the publication of this book. It is a fantastic, informative book with an engaging story.

Hopefully winter is now behind us and spring will roll on smoothly into summer.

Annette Stocker

President

CHARGE Syndrome Association of Australasia Ltd 2010/2011 Officers

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You can find contact details on our website:
www.chargesyndrome.org.au.

Families in CHARGE

10th International CHARGE Syndrome Conference,

July 2011, Orlando, Florida, USA

Orlando, Florida is an ideal location for a family conference it being the home of Disneyworld, Epcot, Animal World, SeaWorld, Universal Studios, Harry Potter World and many more.

The conference was well attended with 850 parents, children with CHARGE, siblings, grandparents, extended family, carers and professionals.

The Australian and New Zealand delegates were Annette and Tony Stocker and their children, Matthew and Aimee from New Zealand and from Australia, Belinda Arnell, Ellen Howe and her cousin, Ruby Curan Stevens, Sharon Barrey Grassick and Rob Last.

Presentations were provided by Ellen, who was a participant in the Young Adults Panel, which was held on the final morning of the conference.

Sharon Barrey Grassick provided a poster presentation of her 'Neurophysiology Benefits of Tai Chi' and her 'Sign Chi' project. Sharon also presented this at the Fremantle Conference in 2010.

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'Why I an ME', written by Marie Patterson and Carry Ward with Illustrations by Penny Levett. They were provided with pre-order forms and advised that the Australian website would provide all the relevant details.

Presenters from our Australian and New Zealand Conferences were there, Tim and Nancy Harts-horne, Kasee Stratton, David Brown, Jeremy Kirk, Kim Blake and Conny van Ravenswaaij-Arts.

The conference proceedings were provided on a

USB stick, Sharon and Rob have one if anyone wishes to borrow one, however we were advised the conference proceedings will be available on the American website within a couple of months at www.chargesyndrome.org

If anyone would like to view photos from the conference go to www.majorsphotography.com then select Galleries from the menu and then CHARGE 2011.

A number of families expressed interest in the Australasian 2012 Conference in the Sydney/Penrith area in NSW.

The 11th International CHARGE Syndrome Conference is to be held in Scottsdale, Arizona. Scottsdale is a suburb of Phoenix. The venue is The Fairmont Scottsdale Princess. Check it out on www.fairmont.com/scottsdale

So another impressive and memorable conference concluded. Whether in America, Australia or New Zealand they are always a memorable experience to savour.

Winter 2011

Ellen Howe's Presentation for the Adults Panel at the 10th International CHARGE Syndrome Conference, Orlando, Florida, July 2011.

My name is Ellen Howe. It is so great to meet all of you in person at long last after being on the list serve. A lot of you know all about me but for those who don't I have Coloboma of the eyes, hearing loss, tummy probs, hormonal probs and few other bits. Magic happens here is the theme of this year's conference well that's what it says on the conference page on the foundation site and to me this is perfect usually people could attribute it to Disney World close by but to us in Charge Land it can be just being here seeing all these great people shine hearing about the miracles that come and with those thoughts to me that is magical.

I am 25 years old and I live in Sydney Australia. I live at home with Mum and Dad and my brother when he's around. I have six over sixty vision with bilateral colobomas. I have conductive and sensory neural hearing loss and am in the process of getting a Baha. I have the cleft lip and palate which was repaired as a young girl, I also have the growth and hormonal problems. I have had osteoporosis which was improved with yearly infusions of Zymeta and oestrogen. I also have had scoliosis which was improved by Osteopathy. The hormonal probs were one of my big problems. I have no to little reproductive and growth hormones. I have had oestrogen and provera but these made uncontrolled bleeding so we stopped this. My biggest problem is my gut and digestion problems I have been tube fed my whole life. Spent a lot of my life on and off hospital including five hospital years. I have had the tube central line and tube removal of my gall bladder just before my 18th birthday greatly improved these attacks which we all know as CVS or abdo migraines. Acupuncture also helped this to. I haven't had a big attack since my gallbladder removal and I

am able to be on tube feeds. I do eat a bit by mouth I like cheese tofu and smoked salmon a kind of Australian fish. I will also eat hummus and try other things on occasion.

So as you can see I have had a very full and hard medical life but I don't let this stop me. I completed high school by doing both main school and lifeskills. I now attend a day programme through the Northcott disability services four days a week. I have many supportive carers who try and help me to reach new and better goals. I also work in a sheltered workshop one day a week and volunteer at my old school one morning a week. I lead a busy social life so often I will hang out with friends as often as I can. I am known for getting on Facebook way too much during times when I should be doing my programmes. Many of my friends call me a loudmouth. My hobbies and interests are reading swimming going out with friends going on Facebook and being with family. I am a very positive and happy person and many people know me for that I am a good friend to many people and I always want to help out. As you can see for this I have the treasure of Charge a lot of families on the Charge list and on Facebook will know I delight in the successes of the other Chargers and I feel for the losses and I know some have said they can feel my positive outlook in my posts I sure hope you can feel it now as well. Coming over here is something people 25 years ago people thought I would never do even ten years ago people thought I wouldn't be here tomorrow. Well here I am after many infections and operations later after many tough times and with the help of many people I made it and I will also go to Harry Potter Land which is my dream. I have always loved the Harry Potter books and I have always wanted to get into Harry-

Potter Land so here where magic happens I will get into the magical world of Hogwarts. Hogwarts is like Charge Land it is magical and it is the best place for magic to happen just like here our hospital times are like the dark times but the magical times are the spells. It is always hard to achieve dreams sometimes but when you believe you will so I say believe and you will. Remember the magic every day and remember to stay positive and you can always add on Facebook through the many Charge pages and groups we have on there. Half my Facebook friends are the Charge families. People who have helped me to stay positive are my friends and my family I have a big extended and supportive family and lots of great friends who will always help me when I need it. My Mum's parents are the strongest and most loving grandparents I could ever have. They have shown me how to be positive and love me every step of the way. Mum and Dad have also been there every step of the way helped me fight the battles in early life and still support me to do things by my self even now. My CPP carers are always helping me to be independent even if it's just making me push my self just a bit more or go across a road oh they have such trouble there. But with patience and practice we get there. All my friends help me to be me and listen to me and they're taking me to Harry Potter world to because we all wanted to go.

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Speak up, speak clearly, don't give in and don't give up! They are worth it!!! a quote from Michelle one of my Charge parents

Ellen Howe 2011

Families in CHARGE

Ellen Howe's first experience travelling overseas and attending an International CHARGE Syndrome Conference.

This report was written by Ellen for the American CHARGE Syndrome Newsletter.

Ellen has agreed for her original version, and this version, which has some alterations, to be published in the Australian and New Zealand newsletter.

Hey all, my name is Ellen Howe from Australia and I want to share my experiences of travelling to America for the first time and attending the CHARGE Conference. Well let me say this doesn't happen without months of planning, but no good thing does, does it.

On Friday the 22nd of July I went with my friend Sev and her family and my cousin, to the airport to fly to LA. Going through Sydney airport was a breeze. I have to say I think Sydney is just a bit too relaxed about my food formula but a doctor's letter is always good to have on hand. Well our flight was good but of course, being us, we breezed through customs in America, where my Aunt and Uncle and also one of my cousins had said we'd have problems because of my feeding pump, well they couldn't have been more wrong.

We landed after a long flight, got straight through even with my Uncle Phil's warning of no jokes or winks.

Well getting to the hotel was another story. I am never going to complain about a taxi taking a long time again. We were waiting for ages with the shuttle lady saying we should be have rung ahead, 'Um, hello woman', we have just got off a plane and when we did ring no one answered.

Well we did get a van and ended up at our hotel, which at first was only one room for six people, 'Um, no thanks'. The Ramada Inn in LA was OK but was a bit odd and breakfast ran out quickly, not that that mattered to me.

Well anyway we went to Disneyland. I have to say that it was a great rides

parade and all. Also a stroll down Hollywood Boulevard was interesting. I saw 'Winnie the Pooh' and I thought he belonged to Disney. Also a trip to Leggo Land was very interesting. Everyone was very nice and helpful.

Then we took the shuttle to Las Vegas, which was OK. The hotel was good and we walked around and went to the MGM Grand and saw 'Cirque de Soleil' and a few other things.

Well then it was on to Orlando. On arrival we had three shuttle busses not want to take me, 'Um, we can fold my chair thanks'. We didn't get in till three am, then slept.

In the morning we wandered down to the lobby, I chatted to lots of people and registered for the conference. I also had a swim. The Meet and Greet was great fun and I saw many families I had met on Facebook and the CHARGE Syndrome list.

Friday was the official start of the conference. I wandered into a technology session, very interesting. Then I went to the 103 session for new families, which was good. I also went to a few other bits and then watched CHARGE Idol in the evening. It was amazing. I am planning on helping make this happen at our next Australian and New Zealand Conference. I believe it brings out the talents in our Chargers and doesn't focus on their medical problems for a while. So if anyone is interested in being in the CHARGE Australian/New Zealand Idol, please feel free to contact me. Highlights for me from American Idol were Kennedy Weir, she is amazing, Rachel Allen, who was great and won the award, as were many others.

Saturday I went to the general session and listened to the CHARGE awards and the information about the next CHARGE Conference, then I went to a session on transition, which I thought would be good for me but it was mostly about younger kids. Then I went to an Endocrinol-

ogy session, there is always something to learn in CHARGE, although I knew most of it. It was Jeremy Kirk's talk about 'Puberty in CHARGE' and how it relates to smell. That was very interesting for me as I have had hormonal problems and I am not really sure about what I can smell. Some things I can, some things I can't, like if Mum's cooking a really yummy meal, I smell it, but if someone has poohed, I don't necessarily smell it.

I also went Rob Last's DVD session 'Children with CHARGE', which I'm in, that was good.

The Saturday night carnival was great fun. I spent most of the time with Crystal and Eva and their family and I also sat with a few others. It was great fun dancing around and looking at all the Silent Auction stuff.

Sunday was the Adult Panel, where I was one of the speakers. Everyone loved me.

David Brown did the best closing speech ever I think. I might make a suggestion for him to do our Australian/New Zealand Conference closing.

I hope to see everyone at the next International Conference in Arizona.

After the conference I went to Harry Potter World. A note to people, if you don't get the disability pass at the ticket gate, which the lady refused to give us, then go through where you hand your tickets in, tell them there and they will point you to a special place where they will make one for your group. We were able to get into most of the stuff in Harry Potter World, which is what I always wanted. I loved it there.

Then we went back to LA, had a layover, which was OK. Then I slept all the way home.

It was a great holiday.

Ellen Howe 2011

Winter 2011

Original Version

Hey all My name is ellen howe from australia and i want to share my experiences of traveling to america for the frist time and the charge confrence to. Well let me say this didnt happen with out months of planning but no good thing does does it. On Friday the 22nd of July I went with my friend sev n her fam and my cous to the airport to fly to LA. Going through sydney airport was a breeze. I have to say i think sydney is just a bit to relaxed about my formula but a drs letter is allwasy good to have on hand. Qell flight was good but of course being us we breezed through customs in america where my aunty and uncle and also one of myu cousins has said wed have problems because of the pump well they couldnt be more wrong. We landed after a long flight got straight through even with myu uncle phils warning of no jokes winks i have to say they did make one or two pooey to him. Well getting to the otel was another story i am never going to complain about a taxi taking long here again we were waiting for ages with the suttle lady saying we should of rung um hello woman we have jsut got off a plane and when we did no answers. Well we did get a van ended up at our hotel wich at first we only got one room to six people um no thanks. The remada in la was ok but was a bit odd breakfast ran out quick not that mattered to me well anyway we went to disney i have to say that was great rides parade and all. Also a stroll down hollywood inter-

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Ellen Howe 2011

Families in CHARGE

Lets give them the reins



On the morning of June 12 2011 we woke at 6.30am to a foggy freezing Sunday morning. David was riding in his first combined training day at Wyena Pony Club. He had participated in horse trials back in March and has done some small shows but this was a significant event for him. He was competing in grade 5, with children as old as 15 competing against him. David had no special consideration and the judges didn't know that David had CHARGE Syndrome or that he was profoundly deaf. They also didn't know that in true CHARGE fashion, his left ear was discharging, his nose was running, and he was feeling "unwell", but we couldn't stop him from competing. There were 19 riders in his group and he had learned his two dressage tests perfectly. He also had to compete in a show jumping round that consisted of 13 jumps, 45cm high. David completed his two dressage tests as family and friends supported him.



He did a beautiful job, but there were 18 other competitors and we weren't expecting any placings. As we waited for the results to come in David was shivering and the early morning start was taking its toll. David said he didn't want to compete in the show jumping so I withdrew him. Half an hour later the results were posted and we so excited and proud to see that David had placed 5th and would be presented with a ribbon. Fifth out of nineteen for his first dressage completion was outstanding. Our club DC came over to us and asked if David would reconsider doing the jumping because he had a real chance of winning the whole competition if he completed a clear round. In true CHARGE style he said "yes".

We had people racing to saddle the horse, I was dressing David in his jumping gear and then Emily ran him down to walk the course and hopefully memorize it in the small amount of time he had. My heart was racing as the flag waved and David took off in a canter to tackle the jumps. I have never felt so proud but sooooo scared. He was on his own; I couldn't yell, "sit back" or instruct him where to go. He started beautifully, jumping each jump and knowing exactly where to go, unlike me who lost track after the 3rd jump. Unfortunately, he had three refusals towards

the last few jumps, which eliminated him from the jumping part of the competition. Eleven of the other competitors in his group were also eliminated, so he was not alone. David was angry with himself but we couldn't have been more proud. He was presented with his dressage ribbon and he also won the "Best Grade 5 Rider" for Wyena Pony Club as he placed above his teammates. We never thought he would achieve competing in the "normal world", but he can, he has and he will continue to do so. Maybe it was beginners luck or maybe he has found his niche in life, as horses will always be an important part of his life. Our little Chargers can achieve, so lets give them the reins and allow them to achieve because as you and I know, they have determination and courage, skills that are essential in life.



Winter 2011

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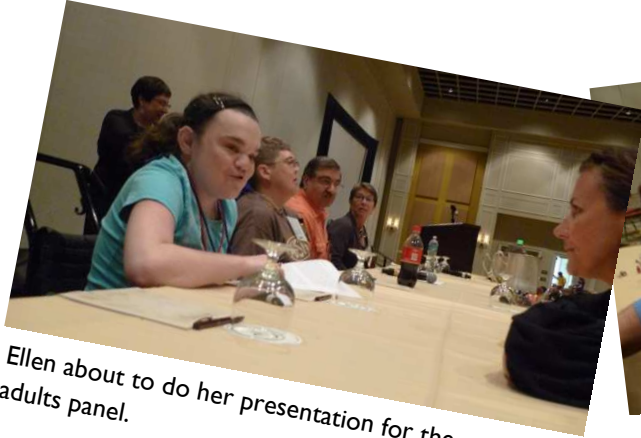
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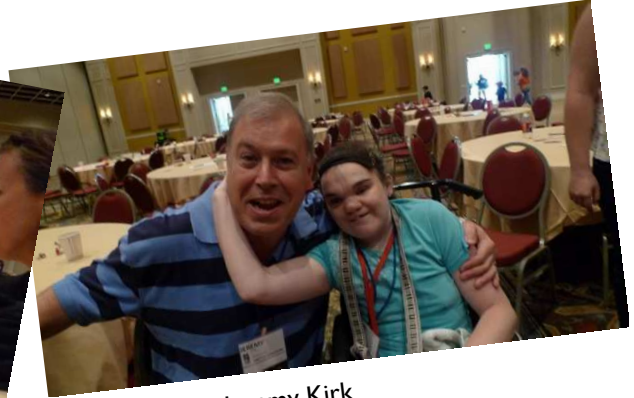
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Families in CHARGE

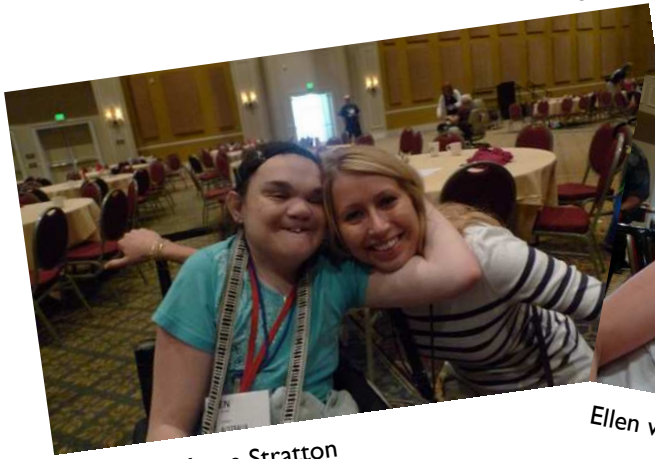
Conference America



Ellen about to do her presentation for the young adults panel.



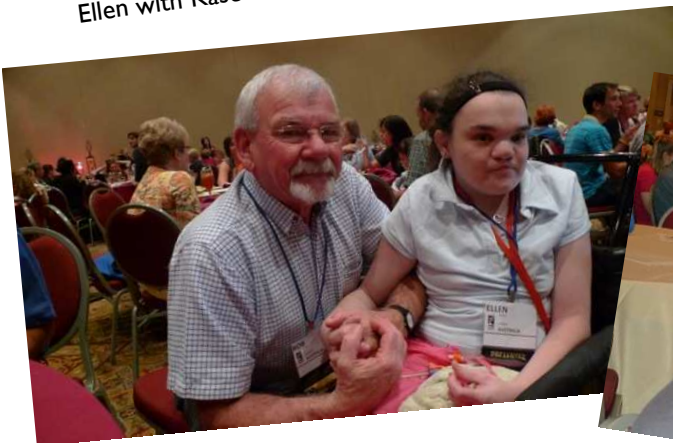
Ellen with Jeremy Kirk



Ellen with Kasee Stratton



Ellen with David Brown

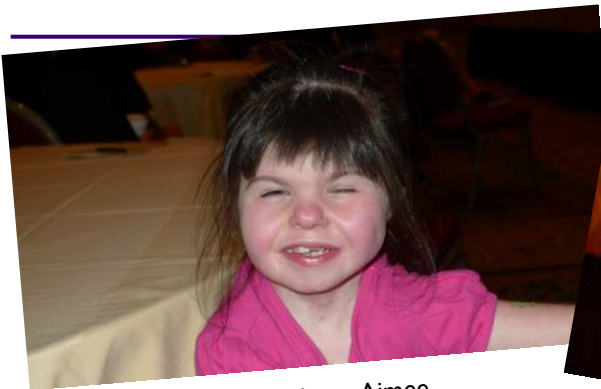


Ellen with Rob Last



Tony Stocker and our esteemed President Annette Stocker. As you can see Annette is very busy and involved with important business!

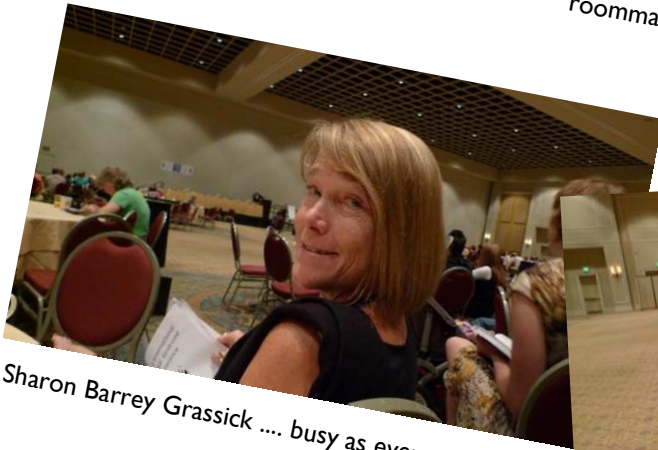
Winter 2011



Annette and Tony's daughter, Aimee



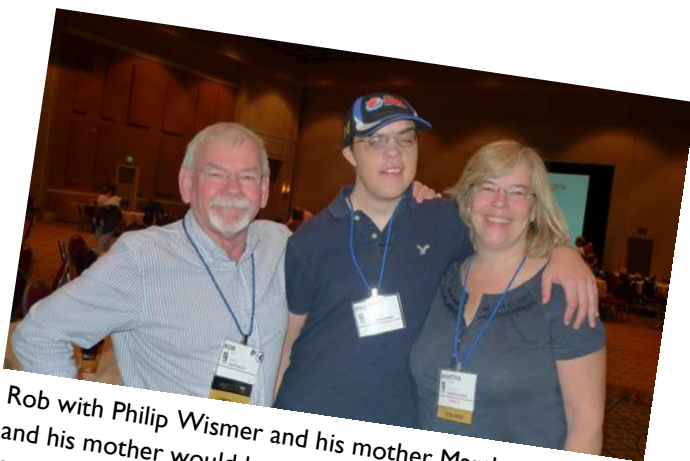
Belinda Arnell and her American friend and conference roommate Karlee Ludwig.



Sharon Barrey Grassick busy as ever.



The Hartshorne Family with Gail from the SENSE Organisation in the UK and Jacob with his carer Carolyn. Aaron, Tim, Seth, Gail Deuce, Nancy and in front Carolyn Soule with Jacob. Gail is in the job that David Brown once was in when he was with SENSE UK. Carolyn used to be Jacob's carer and remains close to him and the Hartshorne family. She volunteered to come to the conference to assist with Jacob.



Rob with Philip Wismer and his mother Martha. Philip and his mother would love to come to our 2014 conference. I think Philip would be a great Keynote speaker and he would be very happy to do that.

Improving the quality of life for children and adults with CHARGE Syndrome

Thank you to all our recent donors.

The CHARGE Syndrome Association of Australasia is a not-for-profit organisation committed to improving the health and welfare of children and adults with CHARGE Syndrome. The Association supports families in Australia and New Zealand to enable children and adults with CHARGE Syndrome to reach their full potential.

Since the formation of the parent support group in Australia, 1994, conferences have been held every 2 years. A newsletter is produced, fundraising activities occur and planning for future needs of these children and young adults is a major consideration.

Families of newly diagnosed children with CHARGE are provided with an information package on request, and parent and professional representatives are available to discuss CHARGE with any interested persons.

Interested medical and educational professionals have involved themselves in gaining data about children in Australia and New Zealand. Such professionals also keep abreast with current developments locally and internationally.

\$12,000 over four years for eligible children with a hearing loss

The Federal Government is providing \$12,000 over four years for eligible children with a hearing loss. A child is eligible if he/she has a hearing loss of 40 decibels or greater in the better ear, across four frequencies (including children with permanent conductive hearing loss and auditory neuropathy). The assessment can be face-to-face, via telephone on 1800 242 636, webcam, email or a video link and you will need the following documents:

Child's birth certificate or passport

Proof of address

Written confirmation of diagnosis including thresholds

Child's Centrelink customer reference number.

Visit: www.betterstart.net.au for more information. Sydney Families will find that it is likely that their private early intervention provider (like the Shepherd Centre or RIDBC) will take most of this funding over the time the family is with the service. Families need to question what type of service they will get for their funding. Some questions to help them are below. Regional NSW families need to know that NSW Department of Education and Training services (early intervention is often provided by Itinerant Teachers of the Deaf from diagnosis onwards in regional NSW) will not attract this funding, and that service will continue to be available.

Regional families can still access Better Start funding for other services, such as RIDBC Teleschool or local speech pathology services. Some questions that families can ask their provider or service:

1. What is early intervention? What can you do for our child? What services do you provide?
2. Does your service have staff trained to work with young babies and toddlers with a hearing loss?
3. How will we know if the service you provide is working for our child? What changes should we expect to see?
4. How will our child's progress be measured? Will you send progress reports to our GP and us? How often will this happen?
5. How much will the early intervention service cost?
6. What will happen when we have used all our Better Start funding?

If you have any parents that need help navigating this new funding and what it means for them, you can refer them to me. Kate Kennedy, Coordinator of Information and Advocacy Parent Council for Deaf Education (PCDE) PH: 02 9871 3049 (M, T, W) F 02 9871 3193 MOBILE: 0419628829 EMAIL:

kate@pcde.org WEB: www.pcde.org