

How Early is too Early ?

The outcomes of Cochlear Implantation in infants
under 6 months, 7-9 months and 10-12 months

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Australasian Newborn Hearing Screening Conference 2013
SUPPORTING FAMILIES PART I



The Shepherd Centre is a proud member of First Voice, a national alliance of member organisations whose primary focus is the provision of listening and spoken language for children who are deaf or hearing impaired



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The First Sounds Implant Program

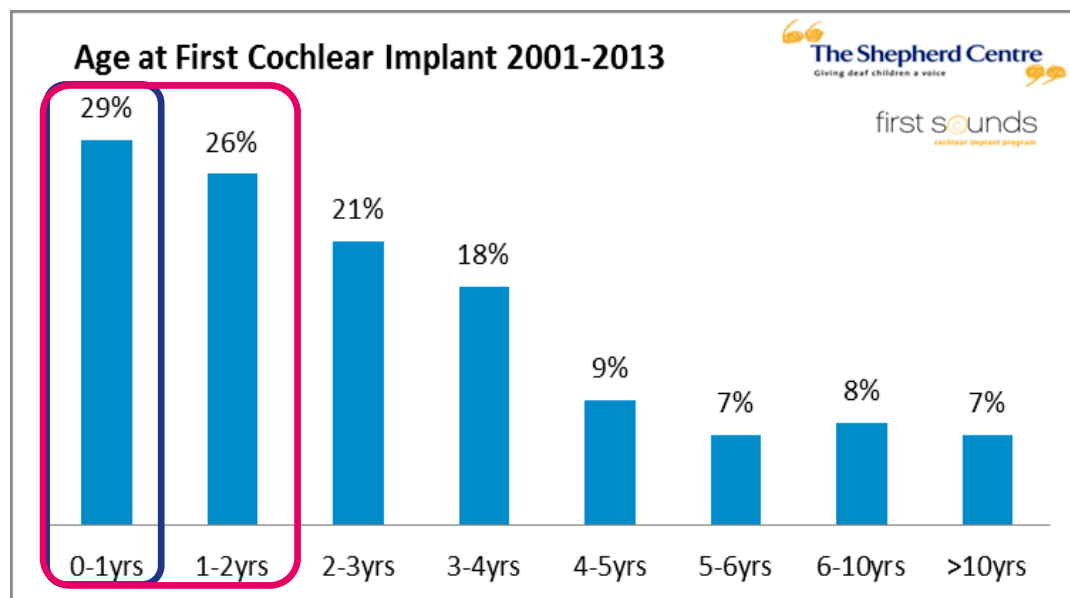
- Joint initiative: **The Shepherd Centre** and **Sydney Children's Hospital**
- Over 10 years experience in providing **integrated medical, audiological, therapy and counselling services**
- **Evidence based program** publishing outcomes and guiding quality improvement
- **100% children diagnosed through UNHS** and thresholds clearly in CI category implanted by 9mths



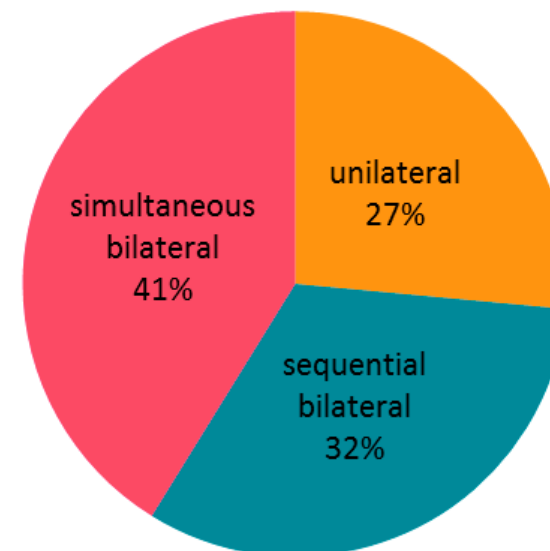
Cochlear implant surgeons:
Phillip Chang & Thomas Kertesz



The First Sounds Implant Program



TSC surgeries Apr2012-Apr2013



73% of children in program have bilateral CI

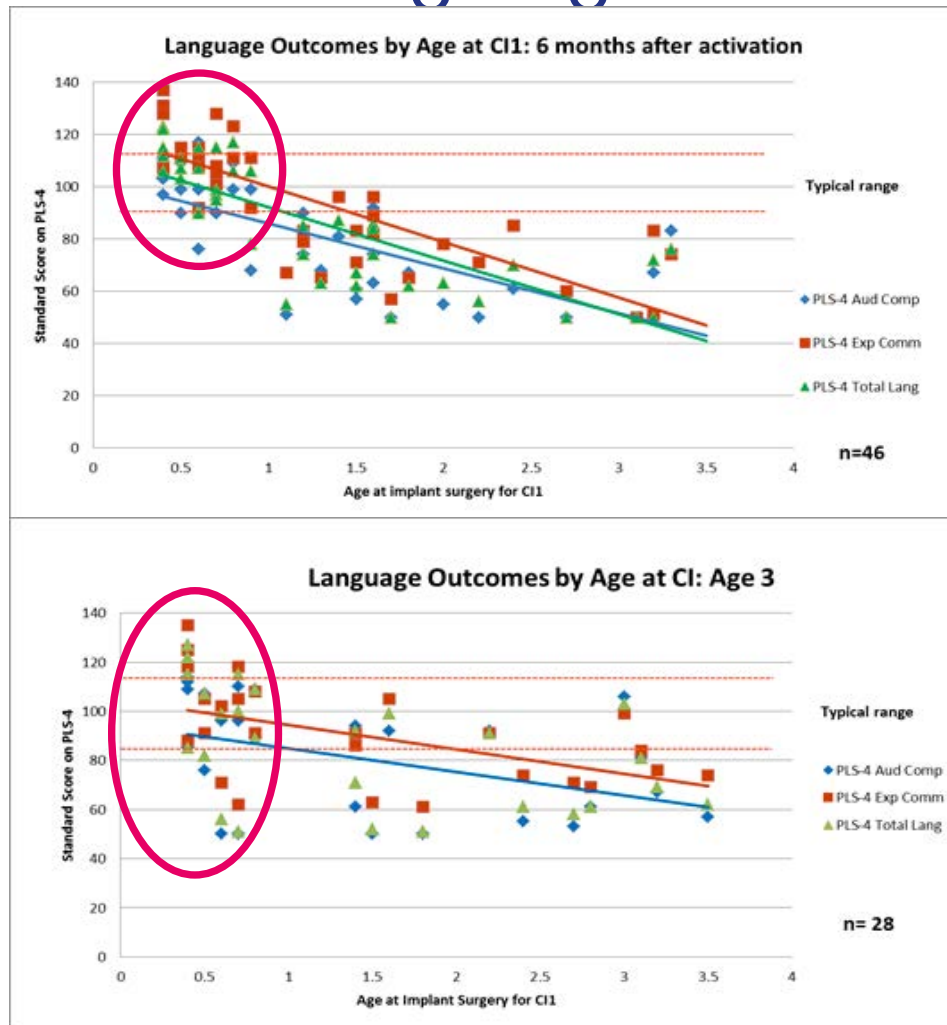


Why offer early implantation?

- Use the opportunity provided by UNHS
- Limit auditory deprivation
- Utilise the benefits of early access to sound for speech and language, including neural plasticity
Kral et al 2002, Sharma & Dorman 2006, Sharma et al 2002, Giraud et al 2001
- Increased evidence at a clinical level
CI<12 months for past 9 years, CI<6 months for past 8 years
- Increase the likelihood of seeing language develop like that of typical hearing children
Colletti et al 2011; Ching et al 2009; Tait et al, 2007; Dettman et al, 2007; Tomblin et al, 2005; Colletti, 2009



Language Outcomes for early CI



Clinical outcomes for children at The Shepherd Centre suggest that the best chance of language results in the typical range is with earlier age at implantation



Clinical Question in 2013



- Benefit of early implantation clear, but is earliest always best?
- Is the outcome similar if implantation occurs before 6 months or if it occurs a few months later?
- What other benefits should be considered with implantation in this age range?
- What are the characteristics of families that are ready to consider CI?



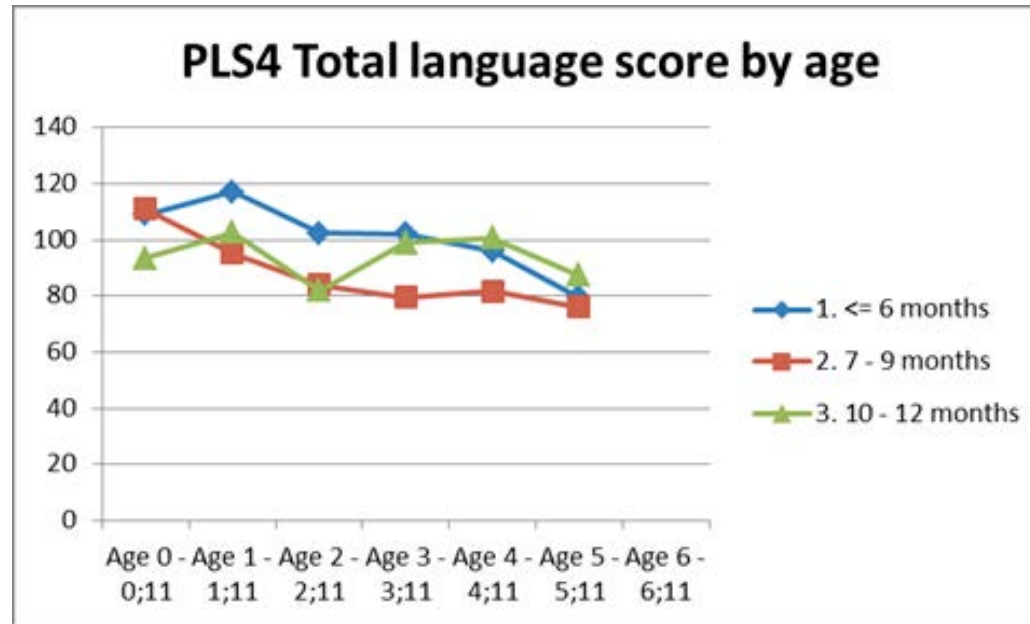
What else do we know about children who receive CI under 12 months?

n=42 children, 59 implants

	GROUP 1: CI<6 mths	GROUP 2: CI 7-9 mths	GROUP 3: 10-12 mths
Total children	13	17	12
Total implants	20	27	12
Mean age at CI1	5 months	7 months	11 months
UNHS diagnosis	90%	100%	100%
Implant configuration	6 unilateral (CI1) 7 sim. Bilateral (CI1+2)	7 unilateral (CI1) 11 sim. Bilateral (CI1+2)	8 unilateral (CI1) 4 unilateral (CI2)
Traditional CI candidacy	90% 1 meningitis	88% 1 ANSD, 1 borderline HL	83% 2 borderline HL



Outcomes for CI under 12 months



For children implanted under 12 months,
there are minimal differences in long term outcomes



Detailed file review

Implant around 6 months-----9 months-----Implant around 12 months

Family has accepted the diagnosis-----Family need confirmation/seeking understanding

Family lead the decision making-----Family more influenced by professionals

Family have clear goals for their child-----Family less certain about impact of HL

Family are well supported-----Family may have less strong support around or conflict

Family engagement very high-----Family engagement more challenging

Fast to gain hearing aid compliance-----Slower to gain hearing aid compliance

Little or no functional response to sound-----More functional responses to sound

50% will have an older sibling-----78% will be a first/only child

Profound/severe-profound SNHL----- Severe SNHL, complex audiology

COMMON ACROSS THE WHOLE GROUP

Early diagnosis of HL (UNHS)

Early intervention at a young age (8 weeks)

Early hearing aid fitting (8-12 weeks)

Good language models within the family (not always English)

Both parents* strong involvement in decision making & follow up



Detailed Interview for families $n=11$

Questions devised by interdisciplinary team at TSC

Surgery

- Impact on the family
- Decision making for very young child

Age at Implant?

- How do you feel about the age at which your child received CI/s?

Earlier?

- How would you have felt about CI at a younger age?

Later?

- How would you have felt about CI at an older age?

Confidence?

- In the test results? Would you have done more?
- In the guidance you received?



Families we interviewed $n=11$

- Access to Child and Family Counsellor (in case questions raised any concerns)
- Mothers interviewed via phone
- 5 male, 6 female
- Current age between 1- 11 years
- Range of cultural & SES backgrounds
- Not all “star performers”
- 2 Bilateral CI by 6 months
- 4 CI1 6 months, CI2 11-15 months
- 5 CI1 12 months, CI2 16-31 months



Impact of age at surgery

- Children implanted most recently reported less impact on the family overall

"We wanted him to have the best possible chance of hearing so we took the chance."

"It was nerve wracking but exciting because we knew he would be able hear."

"As a parent you are always worried when your child needs to have an anaesthetic."

"Because she was so tiny I was worried about the risks."

"This was huge at the time, very distressing especially as you don't know the outcome. I feel that I was more attached and protective of her and this is still the same."



Impact of age at initial activation

- Early bilateral positive, Early CI1 positive but would like to have had CI2 earlier, later simultaneous/sequential would have liked both earlier

"The second operation was harder when he was older."

"Having one and a shorter surgery time made the decision easier."

"Looking back we would have had both at the same if we could to save all the anxiety the second time around."

"I don't know that I could have done both together it was such a huge decision that even now I am not sure I would do this if I had the option."

"it was one surgery and one anaesthetic which was less strain for him and less stress for us as a family."



Earlier or later at age of implant?

- Most said they'd have considered earlier CI if it was available, and were concerned that later CI would have had a negative impact on their child's outcomes & their relationship with their child

"Having a baby we were dealing with lots of normal baby issues — I think we wouldn't have been able to do it any earlier."

"I'd have been ok with this as he was healthy baby, we'd have definitely gone earlier."

"If we'd had to wait we would have done everything that we could have to change it."

"I wouldn't hesitate earlier would have been better not sure how early I think I would have been ok with 6 months."



Confidence about having CI?

- All said they were confident at the time of surgery, but that this developed over time sourcing information from other families and professionals

"99% sure this was best option but a small bit of doubt. But more testing would not have changed the 1%."

"We were really confident and happy with the amount of testing, we had no doubts at all."

"Very confident no reservations at all, she had nothing to lose."

"If we'd waited, we would have needed more therapy. It would have been so hard — the first 6mths was so hard enough."

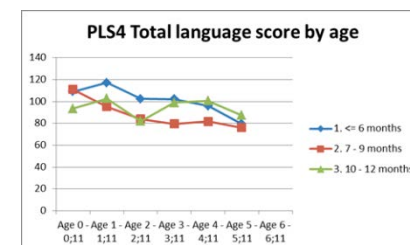
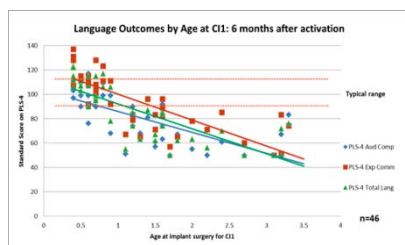


Feeding into clinical practice

- Increased attention to family-centred service
- Consciously taking more time to listen to families
- Increased Child & Family Counselling staff: 3.6FTE
- Introduced tools to monitor family characteristics in a consistent way
 - Moeller Family Participation Scale (Moeller, 2000)
 - McMaster Family Assessment Device: The General Functioning Scale (1983)
 - Karitane Parent Confidence Scale (Crncec, R., Barnett, B., & Matthey, S. (2008)

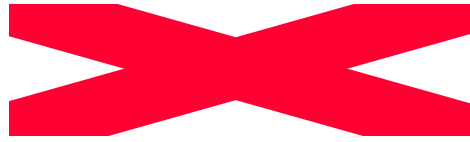


So with early CI, are language scores all that matter?



- Family feedback that assessment scores are important (Goal 6 JCIH update 2013: Pediatrics 2013;131:e1324)
- Child and family well-being is important to address (JCIH update 2013)
 - can be challenging to measure
 - Growing body of research showing it can be pivotal to overall outcomes
- TSC outcomes measures will include measures related to the family
- Early implantation can yield age appropriate outcomes, earliest implantation (where appropriate) appears to have a positive impact on the family- more data required
- **Is it factors related to the family that yield best outcomes for children?**





“ Thank you this much!”

