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7th Australasian Newborn Hearing Screening Conference

17-18 May 2013

Auckland, New Zealand

Handbook and Book of Abstracts

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Hear now. And always

Mā te rongo, ka mōhio;
Mā te mōhio, ka mārama;
Mā te mārama, ka mātau;
Mā te mātau, ka ora.

Through feeling comes awareness;
through awareness comes understanding;
through understanding comes knowledge;
through knowledge comes life and well-being.

Acknowledgements

The Australasian Newborn Hearing Screening 2013 Committee would like to thank the following organisations for their generous contributions and support

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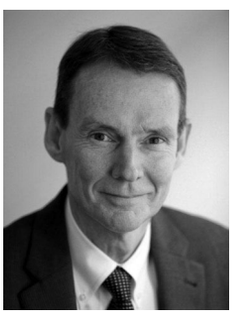
7th Australasian Newborn Hearing Screening Conference
17-18 May 2013
Auckland, New Zealand

Welcome to the ANHS Conference



As the Chairman of the Australasian Newborn Hearing Screening Committee (ANHSC), it is my pleasure to welcome you to the 7th Australasian Newborn Hearing Screening Conference. This is the first time that this conference will venture 'across the ditch' and we are looking forward to convening the conference in the vibrant city of Auckland, New Zealand.

Since the establishment of the ANHSC in 2001, great progress has been made in establishing screening programmes in both Australia and New Zealand. It must be acknowledged, however, that further work is needed to ensure that standards of delivery are maintained and that there continues to be a focus on programmes improvement and development. With this in mind, the theme of this conference is about nurturing, growing, and enriching newborn hearing screening programmes.

The programme for the conference includes a mix of plenary and concurrent sessions, and the topics covered include:

- cultural issues in screening
- parental experiences at point of identification
- cross collaboration and multidisciplinary team approaches to newborn screening
- maintaining motivation and quality in established screening programmes
- effective evidence based ways of delivering early intervention programmes

There is strong representation by presenters and delegates from both Australia and New Zealand, as well as attendees from outside of Australasia. We welcome this opportunity to share ideas with and learn from colleagues internationally.

The conference brings together a wide range of professionals and perspectives involved in newborn hearing screening and early intervention, including medicine, audiology, education, therapy, and parents. This meeting aims to provide a comprehensive selection of practical presentations to meet the needs and interests of this diverse group.

We hope you find the conference an exciting and stimulating environment to develop new skills and knowledge, interact with colleagues, and make new friends or renew old acquaintances.

Professor Greg Leigh
Chairman
ANHS Committee

Welcome to the 7th Australasian Newborn Hearing Conference here in Auckland. The Ministry of Health and Ministry of Education are excited to be hosting this conference for the first time in New Zealand. Thank you for your support of this conference. This is a valuable opportunity for us all through the learnings that will be gained from the wide spectrum of presentations and the workshops to consider how we can develop and strengthen our newborn hearing screening programmes. It is acknowledged that the New Zealand hearing screening programme has had challenges over the last year however from a National Screening Unit perspective we strongly endorse the theme of the conference "nurture, grow, enrich" as an opportunity to learn together, share and continue to develop the screening programme and make a difference to the babies we screen.

Jane McEntee
Group Manager
National Screening Unit
Ministry of Health

Conference Organising Committee

Greg Leigh (NSW)
Zeffie Poulakis (VIC)
Kirsty Gardner-Berry (NSW)
Alison King (VIC)
Ann Porter (VIC)
Rachel Beswick (Qld)
Moira Mcleod (NZ)
Damien Mansfield (SA)

The Organising Committee thanks the New Zealand organising and logistics committee which includes members from the Ministry of Health and Ministry of Education.

Conference Managers

Conference Innovators Ltd
PO Box 28084
Remuera
Auckland 1541
Tel: +64 9 525 2464
Fax: +64 9 525 2465
E: wendy@conference.co.nz

The Australasian Newborn Hearing Screening Committee

The Australasian Newborn Hearing Screening Committee aims to foster the establishment, maintenance and evaluation of

- high quality screening programs for the early detection of permanent childhood hearing impairment throughout Australia and New Zealand;
- accessible and appropriate assessment and intervention for children identified with such hearing losses;
- accessibility to information and support for parents and of children identified with permanent childhood hearing loss; and
- a national database of newborn hearing screening.

The Committee also aims to facilitate discussion and sharing of experience among professionals and parents involved in programmes aimed at the early diagnosis of permanent childhood hearing loss in Australia, as well as promoting research into the delivery of and outcomes from these programmes. This Conference is a key activity undertaken by the Committee to achieve these aims.

The Committee advocates at both National and State levels for progress and innovation in policy and resourcing for the area of early detection and intervention for children with a hearing loss.

The Committee consists of members from every state and territory in Australia, as well as representatives from New Zealand. Committee members cover a number of elements of early detection process including programme administration and management, parents, audiology, paediatrics, otorhinolaryngology, habilitation, and early intervention/education.

Website: www.newbornhearingscreening.com.au
E-mail: committee@newbornhearingscreening.com.au

Committee Members

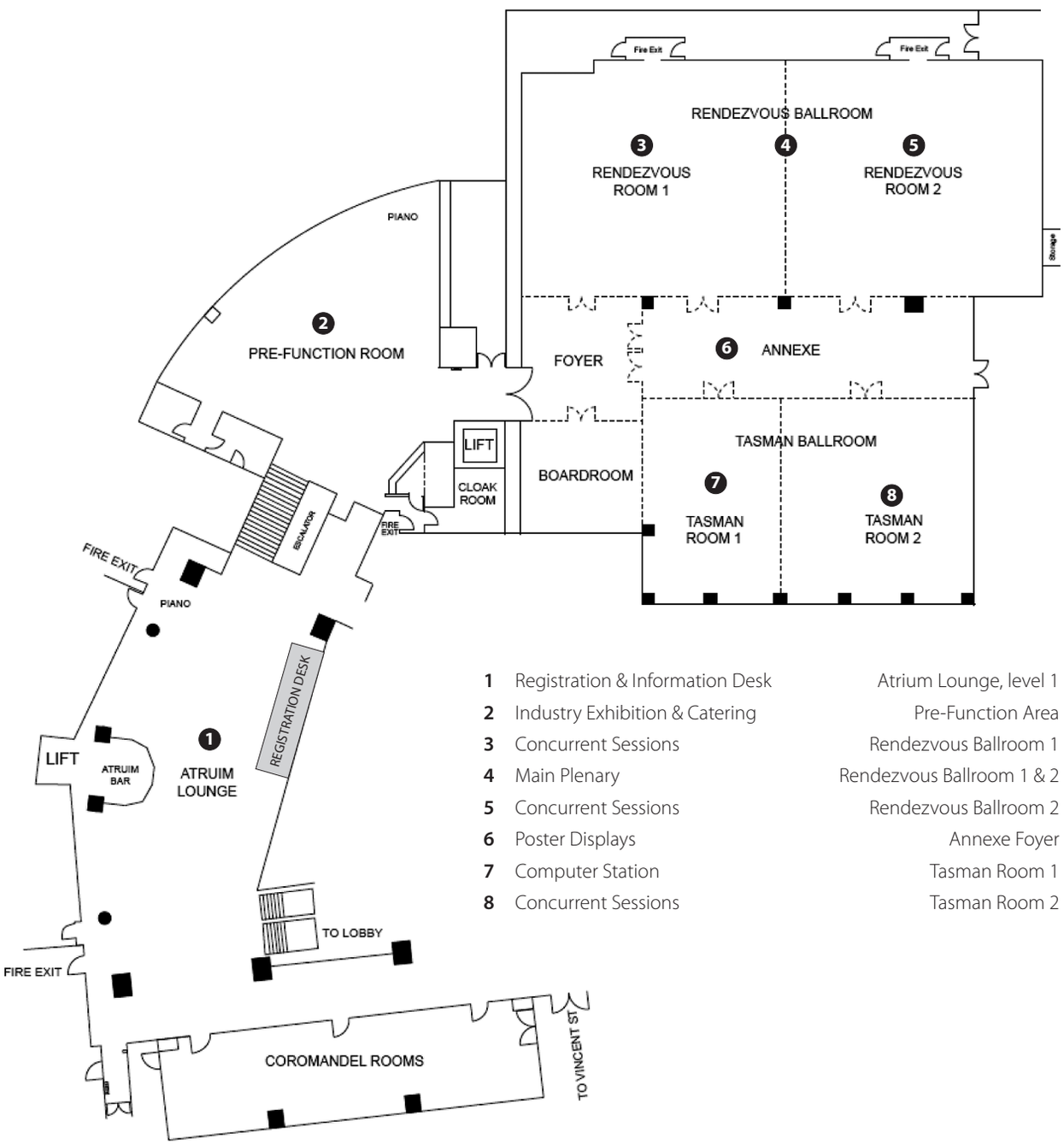
Chair:	Greg Leigh
Committee Secretary:	Zeffie Poulakis

Members:

Australian Hearing:	Alison King (Vic)
Parent Representatives:	Jo Quayle (Vic), Grant Vesper (Qld), Ann Porter (NSW)
Education:	Greg Leigh (NSW)
Deafness Forum:	Vacant
Audiology:	Kirsty Gardner-Berry (NSW), Tegan Keogh (Qld), Lee Kethel (Tas), Lara Shur (WA)
Otolaryngology:	Fiona Panizza (Qld), Stephen Rodrigues (WA),
Paediatrics/Child Health:	Damien Mansfield (SA), Melissa Wake (Vic)
Population Health:	Vacant
State Program Representatives:	Rachel Beswick (Qld); Zeffie Poulakis (Vic), Lisa Dawson (NT),Sharon Price (SA), Isobel Bishop (NSW), Judy Mathews (WA), Lara Shur (WA), Lee Kethel (Tas); Jennifer Bursell (ACT)
NZ UNHSEIP Representative:	Moira McLeod (NZ)
Project HEIDI Representative:	Vacant
Correspondence:	c/- RIDBC Renwick Centre, Private Bag 29, Parramatta, NSW, 2124, Australia.

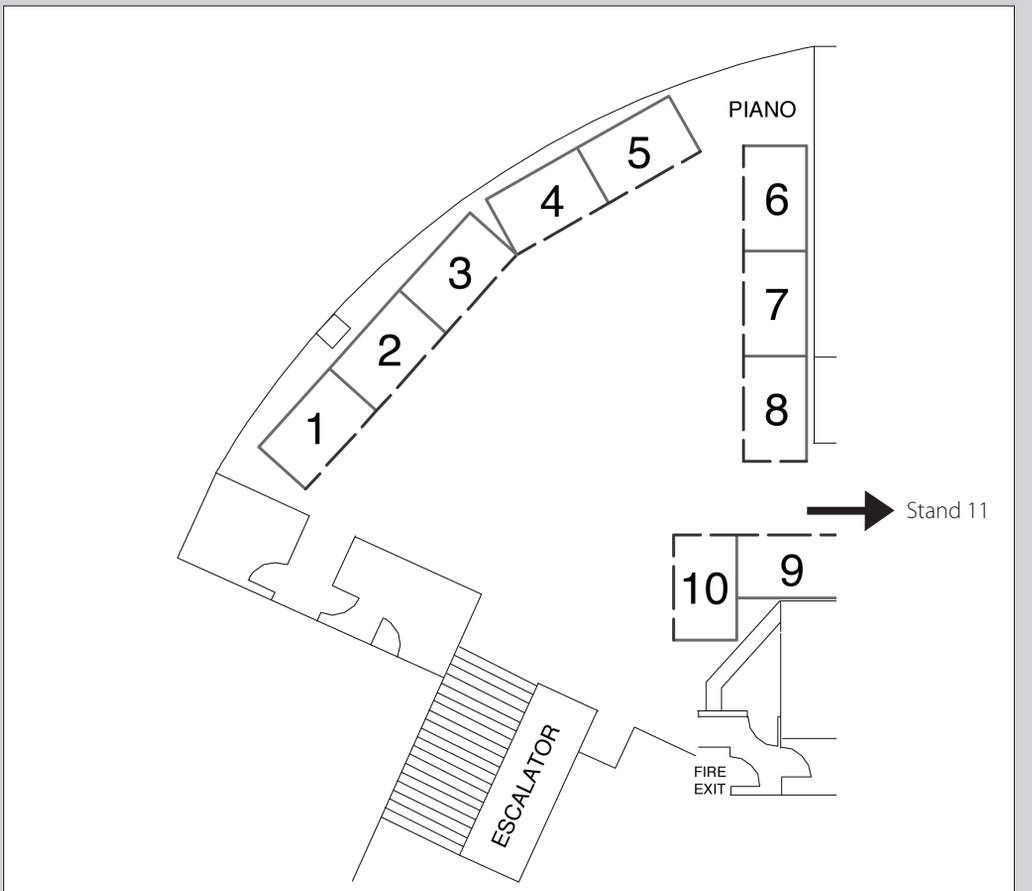
Venue Directory

Rendezvous Grand Hotel, Level 1



1	Registration & Information Desk	Atrium Lounge, level 1
2	Industry Exhibition & Catering	Pre-Function Area
3	Concurrent Sessions	Rendezvous Ballroom 1
4	Main Plenary	Rendezvous Ballroom 1 & 2
5	Concurrent Sessions	Rendezvous Ballroom 2
6	Poster Displays	Annexe Foyer
7	Computer Station	Tasman Room 1
8	Concurrent Sessions	Tasman Room 2

Exhibition



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Exhibitor Directory

Company (alphabetical order) **Booth**

Cochlear Limited 10

1 University Avenue Macquarie University, North Ryde NSW 2109, Australia
C: Linda Ballam-Davies
E: customerservice@cochlear.com
T: 1800 620 929 (Aust) 0800 444 819 (NZ)
W: www.cochlear.com/au

Hear now. And Always with Cochlear. Our mission is to help people hear and be heard, empowering them to connect with others. We will help change the way people understand and treat hearing loss and provide an innovative range of implantable hearing solutions, delivering a lifetime of hearing outcomes.

GN Otometrics 9

4 Fred Thomas Drive, Takapuna, Auckland 0750
C: Chris Webber
E: cwebber@gnotometrics.com.au
T: +612 9743 9707 | +61 406 096 472
W: www.otometrics.com

Otometrics is the world's leading manufacturer of hearing and balance instrumentation and software. Over the last 50 years, we have provided solutions ranging from newborn hearing screening applications and audiologic diagnostics to comprehensive hearing instrument fitting and balance testing.

Interacoustics / Oticon 8

AU: Suite 4, Level 4, Building B, 11 Talavera, Road North Ryde NSW 2113, Aus
NZ: 142 Lambton Quay, Wellington 6141, New Zealand
W: www.interacoustics.com / www.oticon.com

With more than 45 years experience, Interacoustics is dedicated to supplying its customers with the best possible diagnostic solutions for their professional needs.
Oticon Paediatrics: offering dedicated hearing solutions and services to enable hearing professionals help hearing impaired children achieve their full potential

MED-EL Implant Systems Australasia Pty Ltd 5

38 Ricketty Street, Mascot NSW 2020, Australia
C: Rosanne Fava
E: Rosanne.Fava@medel.com
T: +61 421 754 898
W: www.medel.com

MED-EL offers the broadest portfolio of hearing implant solutions available to meet the needs of candidates with varying types and degrees of hearing loss. Our products are supported by a comprehensive range of rehabilitation materials and a dedicated clinical support team.

Ministry of Education 11

National Office, Pipitea Street, Wellington
C: Mark Douglas
E: mark.douglas@minedu.govt.nz
T: +64 27 284 5526
W: www.minedu.govt.nz

The Ministry of Education provides support for children and young people with developmental needs, behaviour challenges, and disability including children/students who are deaf and hearing impaired. A significant part of the support is for the families/whānau and educators who support the children and young people. The Ministry also works closely with Health and Social Service providers.

Ministry of Health 11

PO Box 5013, Wellington 6145
C: Moira McLeod
E: info@health.govt.nz or moira_mcleod@moh.govt.nz
W: www.health.govt.nz

The Ministry of Health leads New Zealand's health and disability system, and has overall responsibility for the management and development of that system. Through its whole-of-sector leadership of the health and disability system, the Ministry helps ensure New Zealanders live longer, healthier and more independent lives, while delivering on the government's priorities. The Ministry advises the Minister of Health, and government as a whole, on health issues, and has a role as a funder, purchaser and regulator of health and disability services.

OZ Systems 7

USA, Australia, Switzerland, Mexico

C: Steve Montgomery

E: montgomery@oz-systems.com

W: www.ozsystems.com

OZ Systems develops and implements the world's smartest technology platforms, bridging crucial information gaps and helping children thrive through improved data accountability, performance measurement, quality certification, and analytics. OZ's platforms have advanced electronic information exchange, standards, data integrity, metrics, accountability and interoperability around the globe. It all starts here.

Phonak New Zealand Limited 2

Level 1, 159 Hurstmere Road, Takapuna, Auckland 0622

C: Brent Tustin

E: brent.tustin@phonak.com

T: 0508 746 625

W: www.phonakpro.co.nz

Phonak has played a key role in developing and supplying hearing solutions for children for 40 years. Innovations include SoundRecover, a non-linear frequency compression algorithm that enhances audibility of crucial high-frequency speech sounds and recently the introduction of Roger, a new standard in wireless communication which will deliver unparalleled speech in noise performance.

Scanmedics 1

Unit 6, 15-17 Gibbes St, Chatswood NSW 2067 Australia

C: Margo Woods

E: scanmedics@bigpond.com

T: +61 2 9882 2088

W: scanmedics.com

Scanmedics represents NATUS Medical in Australia & New Zealand specialising in solutions for the newborn, including newborn hearing screening devices, Natal LX Incubators, Phototherapy, Cerebral Brain Function monitoring and brain cooling. In particular Scanmedics offers a range of NATUS AABR® ALGO technology offering screening of the entire hearing pathway in one simple step. NATUS Echoscreen compliments hearing screening choices with OAE and ABR for additional forms of hearing testing.

Siemens Hearing Instruments 6

55 Hugo Johnston Drive, Penrose Auckland 1061

C: Bonyta Watson

E: audiologist.nz@siemens.com

T: 0800 66 66 71

W: www.siemens.co.nz/hearing

For over 130 years now, Siemens has been developing and making hearing instruments. Our innovations constantly set new technological benchmarks in the market. Siemens caters to its younger clientele by offering a full selection of hearing instruments and streaming accessories.

Sonic Innovations 3

PO Box 301 872, Albany, Auckland 0752

C: Michael Stockhammer

E: michaels@sonici.co.nz

T: +64 21 445 712

W: www.sonici.co.nz

Sonic has been manufacturing and distributing high quality hearing instruments since 1980 and is proud that its success has been based on advanced technology, superior product quality, professionalism and impeccable customer service. Sonic is also one of the largest and most versatile distributors of audiological equipment in Australia and New Zealand. Sonic distributes products of some of the most popular and reputed manufacturers from all over the world.

Widex NZ Ltd 4

22 Williamson Ave, Ponsonby, Auckland

C: Sam Jeffs

E: sam@widex.co.nz

T: 021542510

W: www.widex.co.nz

Widex is the leading supplier of high quality and reliable hearing aids in New Zealand. Widex continues to support the New Zealand hearing profession through our trademark high quality service and support nationwide.

Keynote Speakers

Gwen Carr

Gwen Carr is Deputy Director of the NHS Newborn Hearing Screening (NHSP) and the NHS Newborn Infant and Physical Examination (NIPE) Programmes in England. She is also Deputy Director of the MRC Hearing and Communication Group, which hosts the two NHS Programmes, based at the Royal Free Hospital NHS Trust in London and Hon. Senior Research Associate at the UCL Ear Institute.

Gwen's early career was in educational audiology and deaf education, specialising in the early development of language and communication and in supporting very young deaf children and their families. Following wide experience supporting deaf children in early years, specialist schools and mainstream settings, she spent 10 years as Head of Sensory Support Services in a Metropolitan Authority during which time she was responsible for partnership working with the Health Authority and worked jointly in clinical settings in Paediatric Audiology and ENT. In 2001, she led the implementation of Newborn Hearing Screening in her area, as one of the first wave pilot sites in England and subsequently became a consultant to the national programme, leading on the development of early intervention services and multi-disciplinary teams. Before joining the MRC Hearing and Communication Group in 2006 she spent 4 years as Director of UK Services at the National Deaf Children's Society (NDCS) where she was responsible for all the Society's direct work with families and the professionals who work with them across the UK.

Together with Professor Adrian Davis, Gwen is responsible for the strategic direction of the NHSP and NIPE Programmes' work and specifically leads on the Quality Assurance and Improvement, Services Development, and Early Intervention agendas. Her particular interests are in the promotion of Informed Choice, the development of family friendly services, outcomes for children and families, multi-professional teamwork and family support and sharing the news of the diagnosis of deafness with families. She also plays a lead role in the cross screening programme work within the UK National Screening Committee's wider agenda for development and integration of non-cancer screening programmes and works closely with Screening Leads and Regional Newborn and Ante-Natal Screening Co-ordinators across the country to ensure programme maintenance and improvement at local and regional levels.

As a consultant to the Government's 'Early Support' programme in England, Gwen contributed to the production of the Early Support Services Audit Tool and the Monitoring Protocol for Deaf Babies, and edited the Deafness Information booklet for Parents. She subsequently co-led the UK government funded research and development study 'Informed Choice, Families and Deaf Children' leading to the production of national guidance for professionals and a comprehensive handbook for parents. She was also part of the research team at the University of Manchester which undertook the 'Positive Support' study on the impact of early identification on child and family outcomes in collaboration with University College London and Deafness Research UK. She is the author of the NDCS booklet for parents entitled 'Communicating with your deaf child', based on Informed Choice principles, and continues to support parents of deaf and hearing impaired children in relation to communication development through involvement with the charity's network of residential support weekends for families of newly identified children.

Gwen sits on several working groups in relation to Childhood Deafness, Newborn Hearing Screening and Early Intervention at home and abroad, and has presented extensively both in the UK and overseas on all areas of her specialist interests and work. She also undertakes training and service development work nationally and internationally to support the implementation and development of EHDI systems and the enhancement of professional practice and collaborative multi-agency teamwork.

Dr Capi Wever

Capi Wever is an otolaryngologist and facial plastic surgeon whose involvement in the detection and treatment of moderate and severe hearing loss extends beyond surgical and technical skills. For over 15 years he has explored the decision-making issues and ethical dilemmas of the field and offers a consensus building approach to bring together the various stakeholders and disciplines involved.

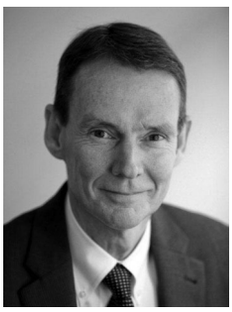
He has studied, worked and taught in The Netherlands, Belgium, the United States and the Caribbean.

Dr Wever has been involved in the Developmental Evaluation of Children: Impact and Benefits of Early hearing screening strategies Leiden (DECIBEL) collaborative study. The study involved children born in the Netherlands over a 3 year period assessing the verbal skills and other developmental markers in those who received newborn hearing screening compared with distraction hearing screening at 9 months of age.

Dr Wever has extensively explored the issues relating to paediatric cochlear implants. As a surgeon he values the role of the parent and family, a topic he explored in a narrative-ethical analysis as part of his Ph.D. dissertation.

He is an auditor for the hospital accreditation process in the Netherlands and sits on quality improvement committees where he incorporates his grounded approach to patient-centred care. He is based in the Leiden area of the Netherlands.

Opening Speakers



Greg Leigh

Greg Leigh is Director of Renwick Centre for Professional Education and Research at the Royal Institute for Deaf and Blind Children (RIDBC) in Sydney, Australia. He is conjointly Professor and Deputy Director of the Centre for Special Education and Disability Studies at the University of Newcastle. He has previously held academic appointments at Deakin University and as an International Visiting Scholar at the National Technical Institute for the Deaf in Rochester, New York.

Professor Leigh holds degrees in Education and Special Education from Griffith University; a Master of Science (Speech and Hearing) degree from Washington University; and a PhD in Special Education from Monash University. He is a Fellow of the Australian College of Educators.

Professor Leigh serves on the editorial boards of Deafness and Education International and Phonetics and Speech Sciences and on various government committees related to deafness—both state and federal. Notably, since 2005, he has been Chair of the Australasian Newborn Hearing Screening Committee. Through that position he has played a significant role in advocacy for, and implementation of, neonatal hearing screening in Australia. He is a former National President of the Education Commission for the World Congress of the World Federation of the Deaf and is Chair of the International Steering Committees of both the Asia-Pacific Congress on Deafness and the International Congress on Education of the Deaf.

Pat Tuohy

Dr Pat Tuohy took up the position of Chief Advisor Child Health in December 1997. Later in 1998 Pat's role expanded to include youth health. His responsibilities include coordination and leadership of child and youth health with respect to the Ministry of Health, district health boards and child and youth health professionals and organisations.

Pat is a specialist paediatrician with a particular interest in community child health. After studying medicine at the Otago Medical School, and qualifying in 1979, Pat undertook postgraduate training in Paediatrics in Wellington, Melbourne and Nottingham. For three years he worked as a General Paediatrician in New Plymouth and joined the Plunket Society in 1991 as its Regional Paediatrician based in Wellington. Pat was later appointed to the position National Paediatrician for Plunket at the head office in Dunedin, until his move to the Ministry in 1997.

Currently Pat has a number of roles within the Ministry. He has been the National Immunisation Coverage champion for six years, and is a member of a number of national advisory committees including the National Screening Unit Governance Group, Child and Youth Mortality Committee, Paediatric Clinical network Steering group, and represents the Ministry on a number of cross agency work groups including the Children's Commissioner's COMPASS group, and the development of the Children's Action plan.

Pat's particular interests are in the areas of developmental and behavioural paediatrics, SUDI, immunisation and child protection.

Pat is passionate about Well Child initiatives, and continues to be a strong advocate for newborn hearing screening in New Zealand,

Brian Coffey

Brian is the Group Manager for Special Education Strategy at the Ministry of Education. He came to this position three years ago and has previously worked as a manager in Special Education, an educational psychologist, and a teacher.

He is of Te Atiawa descent and is now back home living in the Hutt Valley but has worked in education on the East Coast, Gisborne, Nelson, Auckland, Hutt Valley, Christchurch and now back in Wellington. Brian is married with four kids and an increasing number of moko puna.

Some of the key work programmes in which Brian is, has been, involved or led:

- The develop of the Special Education Service
- The merger of the Special Education Service with the Ministry of Education
- The review of severe behaviour services
- The development and implementation of Positive Behaviour for Learning (2009)
- The Review of Special Education (2009) and "Success for All- Every School. Every Child"
- The Resource Teacher: Learning and Behaviour (RTLB) transformation and merger of the Supplementary Learning Support (SLS) service
- The Review of Residential Special Schools and the establishment of the Intensive Wraparound Service
- The merger of the van Asch and Kelston Deaf Education Centre Boards and aggregating of resources for the deaf education centres and Blind and Low Vision Education Network New Zealand (BLENNZ)
- A number of key across government initiatives

Brain remains committed to a fair go for all New Zealand kids, the opportunities available for all through education and learning and a schooling system and society that continue to enable full presence, participation and achievement of students with special education needs.

Panel Speakers

Jane O'Hallahan

Dr O'Hallahan is a Public Health Medicine Specialist with 25 years' experience working in the New Zealand health system, working at District Health Board, Ministry of Health and non-government organisation levels. Highlights of her career to date include: Leading the development and implementation of a national strategy for the high risk roll out of the Meningococcal B Immunisation Programme. The programme was delivered within the $200m budget over a period of 5 years, Leading the establishment of a comprehensive safety surveillance system to monitor new vaccine that has been recognised as 'world class' by international experts, National Director of the Public Health Training Programme and Acting CEO College of General Practitioners.

Jane is the Clinical Leader for the National Screening Unit.

Jane McEntee

Jane McEntee took on the role of Group Manager, National Screening Unit in July 2012. Jane has worked for the National Screening Unit, and its predecessor, since December 1998 and over this time has worked across the five screening programmes and one quality improvement initiative that the Unit is responsible for leading. Initially her role was National Screening Coordinator for both the breast and cervical screening programmes. Jane was then the Manager, NCSP from 2002 – 2008. From 2008 - 2012 Jane was Manager, Antenatal and Newborn Screening overseeing the Antenatal HIV Screening Programme, Antenatal screening for Down syndrome and other conditions, Newborn Metabolic Screening Programme and Universal Newborn Hearing Screening and Early Intervention Programme.

Jane initially trained as a Registered Nurse and previously worked for the Auckland Cancer Society for 8 years. She also has a BA in Nursing and Education and a Graduate Diploma in Health Science (Health Management).

Moira McLeod

Moira McLeod is the Programme Leader for the national Universal Newborn Hearing Screening and Early Intervention Programme. Based at the Ministry of Health Auckland office in Penrose as part of the Antenatal & Newborn team, Moira has been in the role since July 2012. Prior to working at the Ministry of Health in New Zealand, Moira was the BreastScreen Aotearoa Programme Manager at BreastScreen Waitemata Northland for seven years and was also Programme Manager for the Bowel Cancer Screening Programme pilot at Waitemata DHB.

Moira has a background in nursing management and a special interest in community based primary health care initiatives and collaboration.

Zeffie Poulakis

Zeffie Poulakis has been with the Victorian Infant Hearing Screening Program (VIHSP) since its inception in 1992. Her research career has focused on early identification of congenital hearing loss and promotion of optimal outcomes amongst children with hearing loss. Zeffie currently practises as a senior clinical psychologist, and VIHSP co-director.

Kylie Bolland

Kylie is currently working at Hutt Valley District Health Board as Head Audiologist and UNHSEIP coordinator. She has been working at Hutt Hospital for the past five years predominantly working in paediatric Audiology.

Prior to this Kylie spent four years at the Nuffield Hearing and Speech Centre, RNTNE hospital in London. Here Kylie was introduced to the challenges of newborn hearing screening as the programme had recently been rolled out across the UK.

With a large catchment area she saw large numbers of babies referred from the screening programmes and worked within a multidisciplinary team to provide accurate diagnostic assessments and management.

Andrew Keenan

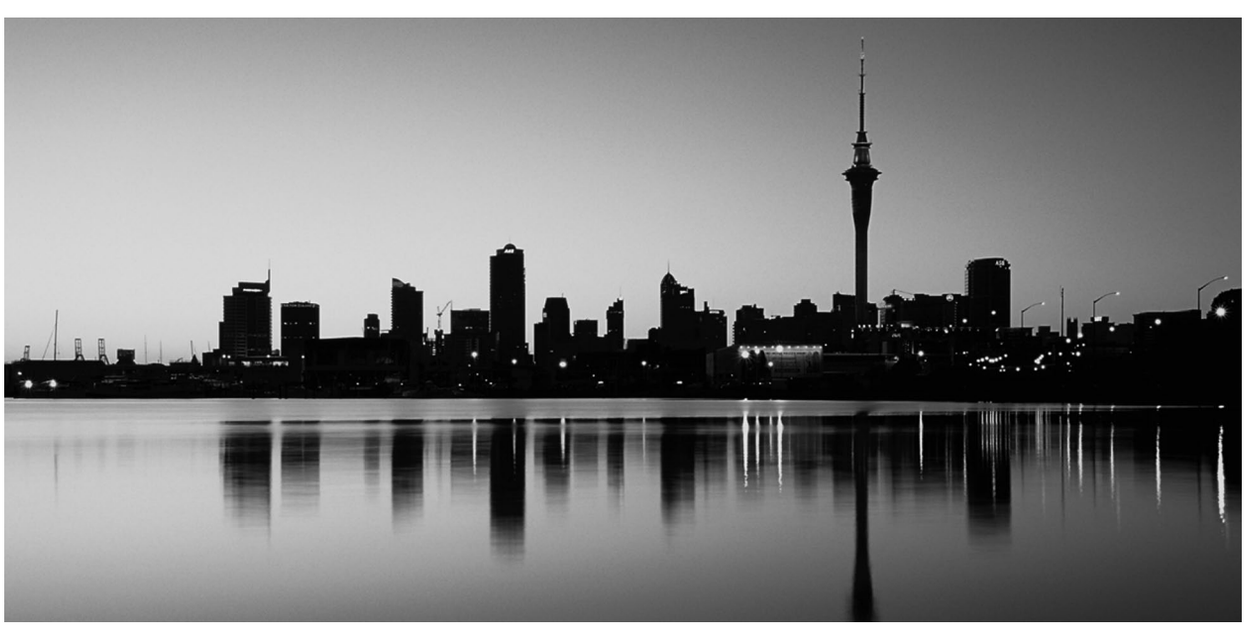
Andrew is the Group Manager for Quality and Clinical Safety at Auckland District Health Board. This role includes the consumer experience portfolio, National Project director for hand hygiene and surgical site infection projects.

Andrew is also a privacy officer and protected disclosure officer for ADHB and is a practising advanced care paramedic.

PROGRAMME

Friday 17 May 2013

0800-1800	Registration desk open	Rendezvous Atrium Lounge
0945	Gathering for Powhiri	
1000-1030	**Powhiri** Piripi Davis, *Ngati Whatua*	Rendezvous Ballroom 1 & 2
1030-1100	**Welcome and conference opening** Hon Jo Goodhew, *Associate Minister of Health* Professor Greg Leigh, *Chairman ANHS Committee*	
1100-1130	**New Zealand Newborn Hearing Screening and Early Intervention Programme** Dr Pat Tuohy, *Chief Advisor, Child & Youth, Ministry of Health* Brian Coffey, *General Manager, Special Education, Ministry of Education*	
1130-1215	**Keynote Address** **Dr Capi Wever** The idea of "saving deaf children" – the role of family centered counselling and informed choice	
1215-1300	Lunch amongst the industry exhibition	



	Rendezvous Ballroom 1	Rendezvous Ballroom 2
	Concurrent 1A – Supporting families (Part I) Chair: Kathy Bendikson & Sue Primrose	**Concurrent 1B – Maintaining motivation and quality assurance in newborn hearing screening programme (Part I)** Chair: Greg Leigh & Sarah Greensmith
1300-1315	**Nic Mahler** Family-centred early intervention for children with a permanent hearing loss: insights from parental consultation	**Angela Deken** Natural disasters and a newborn hearing screening programme: maintaining services, quality and sanity
1315-1330	**Elfriede Rohrs** Caregivers' experiences with the diagnosis of hearing loss	**Rachael Beswick** Implementation of an early hearing detection management and information system to improve quality and standardisation in Queensland
1330-1345	**Yetta Abrahams** "How early is too early?" – The outcomes of cochlear implantation in infants under 6 months, 7-9 months and 10-12 months	**Loren Catherine** Reflections on an investigation into reported changes in rates of referral from screening to diagnostic assessment
1345-1400	**Lydia O'Connor** Adapting a coordinated early intervention service to best support the families of babies screened under UNHS – a New Zealand perspective	**Gabrielle Kavanagh** Screening infants who are young and too young: an analysis of gestational age at screening in Victoria
1400-1415	**Maree McTaggart** Bilateral cochlear implantation in children identified in newborn hearing screening: why the rush?	**Bronwyn Craig** How a hearing screening programme database can result in both quality improvements and cost savings.
1415-1430	**Janeen Jardine** Journey to a cochlear implant following a hearing loss	**Rosemary Douglas** When a unilateral refer reveals a bilateral loss on diagnosis: cause for concern?
1430-1445	**Yetta Abrahams** "No discipline is an island": working together to support families who need it the most	**Zeffie Poulakis** VicCHILD: establishment of the world's first population-based childhood hearing impairment longitudinal databank
1445-1500	**Carolyn Cottier** Newborn hearing screening facilitates early diagnosis of congenital CMV infection	**Andrea Kelly** Screening anomalies in newborn hearing screening programmes in NZ

Tasman Room 2
Concurrent 1C
DHB Newborn Hearing Screening Workshop

1215-1230 Lunch (in workshop room)

1230-1400 Role play in everyday situations:
-Screening under pressure
-Giving results
-Working with other health professionals

1400-1415 Short break

1415-1515 Getting it right from the start: the role of screeners in contributing to positive outcomes for children and families
-Screening in the UK
-Videos of real-life experiences

1500-1530	Afternoon tea amongst the exhibitors	
1530-1630	**Plenary / Panel session** **Expect the unexpected: managing incidents and improving quality in screening programmes** Chair: Dr Jane O'Hallahan **Panel** Jane McEntee, *Group Manager, National Screening Unit, Ministry of Health, New Zealand* Moira McLeod, *UNHSEIP Programme Leader, National Screening Unit, Ministry of Health, New Zealand* Andrew Keenan, *Quality and Safety, Auckland District Health Board, New Zealand* Dr Zeffie Poulakis, Director, *Victorian Infant Hearing Screening Program, Australia* Kylie Bolland, *Hutt Valley District Health Board, New Zealand*	Rendezvous Ballroom 1 & 2
1630-1730	**Keynote Address** **Gwen Carr** Not everything that counts can be counted and not everything that can be counted counts: Perceptions of quality in newborn hearing screening programmes	
1730	**Close of day** Jill Lane, Director, *National Services Purchasing, Ministry of Health, New Zealand*	
1900	**Conference Dinner** At the Grand Tearoom, Heritage Hotel, refer to page 20	

Saturday 18 May 2013

0800-1530	Registration desk open		Rendezvous Foyer, Atrium Lounge
0830-0900	**Welcome day two**		
	Rendezvous Ballroom 1 **Concurrent 2A – Effective evidence-based ways of delivering early intervention programmes** Chair: Mark Douglas & Jo Davies	Rendezvous Ballroom 2 **Concurrent 2B – Maintaining motivation and quality assurance in newborn hearing screening programme (Part II)** Chair: Zeffie Poulakis & Juthika Badkar	**Tasman Room 2** **Concurrent 2C** **Paediatric Audiology Professional Development Workshop**
0900-0915	**Kirsten Smiler** Nga Kohungahunga Turi: envisioning a whanau-centred approach to early intervention	**Moira McLeod** The pieces of the jigsaw puzzle: The range of tools and resources required to deliver a quality newborn hearing screening programme in New Zealand	**0830-0850** Introduction and update on changes including LittleEars, issues with the UNHS programme
0915-0930	**Melissa McCarthy** Developing a blended service model to deliver family-centred early intervention	**Felicity Hood** Identifying ethically important scenarios in newborn hearing screening	**0850-0935** Update on UK programme and measures put in place for areas of weakness e.g ABR
0930-0945	**Helen-Louise Usher** Barriers to early intervention service delivery for children with hearing loss – the Queensland experience	**Aishwarya Nallamuthu** Overcoming challenges of delivering a newborn hearing screening program in a tertiary care hospital in India	**0935-0955** Management issues for complex populations e.g Down Syndrome, cleft palate and draft of a national protocol for audiological assessment
0945-1000	**Valerie Green** "Learning to listen to a baby who cannot hear"	**Jill Clarke** Are we screening the correct baby?	**0955-1105** Case examples and development of national protocols
1000-1015	**Kirsty Gardner-Berry** Impact of the presence of auditory neuropathy spectrum disorder on outcomes at 3 years of age	**Melinda Barker** Rescreening infants in Victoria 2011-2012	**1105-1110** Wrap up
1015-1030	**Felicity Hodgson** Responding to the needs of families of children with unaidable mild and borderline hearing losses	**Donna Barker** Cultural issues in hearing screening	**1110-1130** Morning tea
1030-1045	**Jackie Brown** Tele-Practice: delivering early intervention and audiology services to families in rural and remote areas	**Jenny Woodward** Maintaining and retaining a competent screener workforce	
1045-1100	**Melissa McCarthy** A home based model of cochlear implantation: the role of telepractice	**Sian Burgess** Holding onto the tail of the tiger: education and training of the newborn screening workforce in New Zealand	

1100-1130	Morning tea amongst the industry exhibition		
1130-1230	**Keynote** **Dr Capi Wever** NHS – Why did we start it, what are we achieving and where do we want to go		Rendezvous Ballroom 1 & 2
1230-1300	Lunch amongst the industry exhibition		
	Rendezvous Ballroom 1 **Concurrent 3A – Mixed sessions. Targeted surveillance, late onset hearing loss and cochlear implantation** Chair: Kirsty Gardner-Berry & Moira McLeod	Tasman Room 2 **Concurrent 3B – Supporting families (Part II)** Chair: Sian Burgess & Hedwig van Asten	Rendezvous Ballroom 2 **Concurrent 3C** **Early intervention workshop**
1300-1315	**Rachael Beswick** Recommendations for monitoring hearing in children using a risk factor registry	**Sharon Ewing** Parents and deaf and hard of hearing adults: supporting families in screening programs	**1300-1500** The philosophical framework of informed choice: from theory into practice in Early Intervention and support for families. *For more information refer to page 79.*
1315-1330	**Andrea Kelly** Success of risk indicators for detecting late onset and progressive hearing loss – an analysis of the New Zealand protocol	**Liz Ray** The experiences of hearing siblings when there is a deaf child in the family	
1330-1345	**Suzanne Harris** Weaving the tapestry	**Julie Gillespie** The Victorian infant hearing screening program early support service	
1345-1400	**Zeffie Poulakis** Universal, risk factor and opportunistic screening for congenital hearing loss: 5-6 year old population outcomes	**Kym Adamson** Coordinated tertiary care: childhood hearing clinics, Queensland	
1400-1415	**Pat Tuohy** Sequential cochlear implantation in children – does age at second implant matter	**Suzanne Harris** Cultural issues in screening	
1415-1430	**Beth Atkinson** Pathways to cochlear implantation following identification of hearing loss from newborn hearing screening	**Karin Van Der Merwe** The evaluation of a 2000hz auditory steady state response newborn hearing screening protocol	
1430-1445	**Suzanne Harris** Creating a baseline	**Sargunam Sivaraj** Workshops for parents of children with unilateral/mild hearing loss identified through UNHSEIP programme	
1500-1530	**Conference Close** Jane McEntee Prof Greg Leigh		Rendezvous Ballroom 1 & 2

Social Programme

The Conference Gala Dinner will be held at the Grand Tearoom in the Heritage Hotel and promises to be a delightful evening where conference delegates can socialise over a delicious meal in beautiful surroundings.

Location: Heritage Hotel, 35 Hobson Street, Auckland
Date: Friday 17th May 2013
Time: 1900 – 2230
Cost: $80.00 per person
Dress code: Smart Casual

Cash bar facilities available

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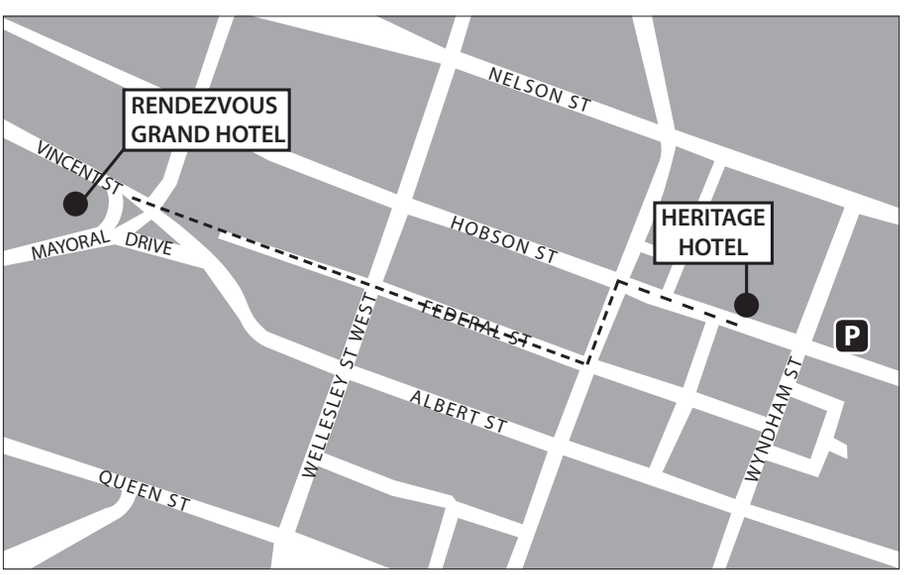
Getting there:

Driving: A public pay & display car park building is located on the corner of Hobson Street and Wyndham Street.

Walking: Walk straight from Rendezvous Grand Hotel onto Federal Street, turn left onto Victoria Street West and right onto Hobson Street. The walk will take you approximately 10 minutes.

Taxi: The Rendezvous Grand Hotel concierge can organise a taxi for you at your own expense.



Friday 17 May, 1100-1130

New Zealand newborn hearing screening and early intervention programme

Pat Tuohy, *Chief Advisor, Child & Youth, Ministry of Health*

Brian Coffey, *General Manager, Special Education, Ministry of Education*

NOTES

Keynote Address
Friday 17 May, 1130-1215

The idea of "saving deaf children" – the role of family centered counseling & informed choice

Wever, C

Wever Facial Plastics, Wassenaar, The Netherlands

Social policy-making by definition requires a moral guideline or "worldview" to lead its actions, how to design the "ideal" society so to say. Two central themes that have evolved in time and that can be rather diametrical are Freedom and Rationalism.

The Enlightment marked the beginning of a high belief in "rationalism", of "value-free thought", of thought freed from religion and other superstition, that could hence lead – but also legitimize – politicians and social thinkers towards their ultimate goal of creating the "ideal society" while vexing accusations of idiosyncrasy, subjectivism, classism, or even state despotism. Freed from the surveillance of religion, early Enlightment thinkers believed that a better, more true and honest world could be found through rationality, and that mankind – or some of us at least – were able to actually think in such terms. The underlying Enlightment theme is – much of it unknowingly – that science in itself somehow allows an "objective" analysis of things and consequently can lead to solving "all of human's problems". Emotion, superstition, stupidity, and prejudice are the classic adversaries of rationality, sometimes clustered around a hierarchical notion of mankind, society and culture.

Today, this view continues, through an increasingly intense alliance between science and Public Health. Yet many have criticized these basic assumptions, by repudiating the underlying similarity between the study of the natural world of math and physics and that of mankind, culture, ethics and values. In "Birth of the clinic" French philosopher Michel Foucault focuses on the most natural of human sciences, namely medicine, and reveals how it too is inseparable from the panoptic system, and hence functions as a normalizing agency in defining normal from deviant. Preventive medicine and its political analogue Public Health – skyrocketing in popularity and influence – now defines "deviant" based on assumed "future" health issues. Life style issues such as eating, smoking, breastfeeding, sexual promiscuity in relation to HIV, iPod use, and TV consumption are just a few contemporary examples. Typical of all "panoptic" systems is that they constructs a bridge "between fact and value", extracting "identity" from "individual behavior" (Vaz & Bruno). In Obesity, for example, in spite of the complex plethora of causes it is particularly the assumed frailty in individual self-control stands out.

The abysmal idea of silence, of the lack of language, the lack of a means to cognitive, social and emotional development – to humanity really – has strongly driven deaf educators and scientists since the earliest of times. That language is to be perceived as a primer of humanity appears a rather universal value, but not so the degree to which language is allowed to monolithically overrun other meaningful arguments. As a consequence, emotions of urgency – of the need of savior – have dominated the field since earliest writings. Approaches to solve the assumed problem in absolute terms to gain "total control" have been twofold from the get-go, alternating between spoken language and sign language paradigms with their consequent narratives and values. Yet arguments have been largely theoretical driven – across the divide – and strongly value based as well – complying largely with the panoptic perspective described previously. Even modern studies on neurological biomarkers of cognition do not change this perspective categorically.

A complicating factor is involved when dealing with deafness – namely the "problem" of parents. Pediatrics is a good example of where things can lead when parents are involved: as a profession they tend to perceive themselves as responsible for the sake of children, parents are almost by definition distrusted and approached skeptically, and literature is full of explorations of parental competence. In the earlier days, deafness was institutionalized, and parents naturally abandoned their parental role and rights around the time of diagnosis. Since the 1950's all institutions of authority – including institutions for the disabled – have been on a steep decline throughout the Western world. Parents of disabled children have since become more educated, more verbal and have reclaimed their role of guardians. In this context, informed choice is not just a formal strategy. It is the only appropriate attitude in proxy decisions from the position of Liberalism: it ought to be the starting point of all professionals that deal with childhood deafness. The values of the French revolution more closely represent the values of Freedom: Liberty & Equality, Autonomy, Fraternity (the latter was added at a later time). Liberty is being defined as "being able to do anything that does not harm others". In this lecture these topics will form the backdraft of a view on family centered counseling parents of deaf children.

NOTES

Plenary/Panel session
Friday 17 May, 1530-1630

Expect the unexpected: managing incidents and improving quality in screening programmes

Chair: Jane O'Hallahan

Panel

Jane McEntee, *Group Manager, National Screening Unit, Ministry of Health, New Zealand*
Moira McLeod, *UNHSEIP Programme Leader, National Screening Unit, Ministry of Health, New Zealand*
Andrew Keenan, *Quality and Safety, Auckland District Health Board, New Zealand*
Zeffie Poulakis, *Director, Victorian Infant Hearing Screening Program, Australia*
Kylie Bolland, *Hutt Valley District Health Board, New Zealand*

NOTES

Keynote Address
Friday 17 May, 1630-1730

Not everything that counts can be counted and not everything that can be counted counts: perceptions of quality in newborn hearing screening programmes

Carr, G

A fundamental aim of universal newborn hearing screening programmes is to enable all children born with hearing loss to achieve their optimal language, communication, socio-emotional and educational outcomes through early identification followed by timely, accurate assessment and effective early intervention and family support. Professionals in policy, strategy and practice in both healthcare and education strive collaboratively to provide equitable and integrated services in pursuit of this goal, and develop quality standards, protocols and best practice guidelines to underpin programme delivery.

As we seek to 'nurture, grow and enrich' programmes, it is of course vital to ensure on going monitoring and evaluation of programme performance to enable continuing improvement and development and to quality assure services. Collection of routine data - and regular analysis to inform understanding - plays a critical part in that process, and mature programmes are now data-rich. Keeping in mind Plato's assertion that good decisions are 'based on knowledge not numbers' however, how can we be sure that the data we collect are the 'right' data, used in the most meaningful way, to positively impact on desired outcomes and take forward the quality agenda? What else, perhaps less amenable to routine data collection, really counts when it comes to measuring quality in service planning, delivery and evolution? Key stakeholders may have different perceptions of what constitutes quality in newborn hearing screening programmes, depending on their roles, responsibilities, accountabilities and experiences within the system. What 'quality' looks like and feels like to one constituency may differ from what it means to another, and judgments of quality from different perspectives can be usefully explored and combined to give added value to existing data. How can we make sure that a shared vision reflects a multi-faceted understanding of what really counts in the assessment of quality and that everything that really matters gets counted?

NOTES

Keynote Address
Saturday 18 May, 1130-1230

NHS – why did we start it, what are we achieving and where do we want to go?

Wever, C

Wever Facial Plastics, Wassenaar, The Netherlands

Explains deafness and its interventions as a narrow-margin condition. This implies that screening and interventions only work effectively if things are set right in place, and even under these conditions healthy modesty is called for. The underlying premises of NHS have been silently ideological as well as political. Ideologically it appears to be silently assumed – or so it seems – that "early" is the newest weapon in the persistent belief that science can indeed solve "all" of deafness problems. Mediocre results in cochlear implantation – for example – are often disallowed based on the assumption that modern day technology and earlier intervention makes for a different world. Politically it appears that the age-old dichotomy between sign and spoken language based interventions is categorically shunned. Much has been said about the benefits of NHS, but as a surgeon I am skeptic as I have seen eureka been called and abandoned over more than a single surgical procedure. Certainly it is much better to avoid late diagnostics such as witnessed under the Ewing era, but I have not seen unambiguous empirical evidence that arguments go beyond this – up close things always look impressive of course. NHS also implies that we are – at least theoretically – lowering the threshold for cochlear implantation, which has it own set of benefits and liabilities. Parents are much less knowledgeable about deafness under the age of 12 months, and much more prone to yield to the route of normalcy that is set out. Finally I will explore what this may imply for the position of minorities, which represents a significant proportion of newly diagnosed deaf children in New Zealand.

NOTES

Concurrent Session 1A: Supporting families – Part I
1300-1315

Family-centred early intervention for children with a permanent hearing loss: Insights from parental consultation

Mahler, N [1,2] and Buckley, C [3] and Chessels, J [1]

1. *Hearing-Impaired Children's Therapies Inc, Brisbane, Queensland, Australia*
2. *Griffith University, Gold Coast, Queensland, Australia*
3. *Yeerongpilly Early Childhood Development Program, Brisbane, Queensland, Australia*
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To realise the benefit of early identification of hearing loss, concomitant quality early intervention is paramount (Kumar et al., 2009). In synchrony with research evidence and expert opinion, a consultative and flexible family-centred approach which engages families by incorporating their needs, values and choices, builds the foundation for best practice in early intervention (ASHA, 2001). Parents of children with permanent hearing loss play a key role in their children's habilitation. Although a range of studies have provided evidence of this inter-relationship across various child outcome measures, the direct correlations between parental input and child outcomes remain poorly understood (for a summary, see Kumar et al., 2009). The primary aim of the current project was to inform practices and service delivery options through parent consultation in order to better meet families' needs and secure optimal outcomes for children with permanent hearing loss.

The Parent Consultation Questionnaire (PCQ) was developed to inform the consultation process. This survey included both open questions such as "What helped to build your confidence in learning to meet your child's needs?" and closed questions investigating targeted areas. The questionnaire was comprised of three sections: About your child, About your family and About the service. The PCQ was distributed to all families whose children attended the service in 2012 (N=96), with a return rate of 34%. Service evaluation was rated on both importance and satisfaction of targeted areas, with parents rating all areas examined between important (2) and very important (3) (Range= 2.18, 2.91). Despite satisfaction consistently being reported between satisfied (2) and very satisfied (3) (Range= 2.0, 2.91), importance and satisfaction ratings were significantly different, $t(17)=4.52$, $p<.05$, with a mean difference score of 0.16 (SD=0.04, N=18). Discussion will focus on the areas of primary importance and need identified by parents and subsequent changes in service delivery.

NOTES

Concurrent Session 1A: Supporting families – Part I
1315-1330

Caregivers' experiences with the diagnosis of hearing loss

Röhrs, E and Kathard, H and Taljaard, D

University of Cape Town, Cape Town, Western Cape, South Africa

Knowledge of the impact on caregivers with children with a hearing loss and their relationships with professionals involved in their lives, emotional, social as well as the perceptual impact of the news on the caregivers, especially in South Africa, is inadequate or lacking. The purpose of this study is knowledge generation based on the experiences and perceptions of caregivers. A qualitative, retrospective, narrative inquiry research design was used consisting of two phases. In the first phase participants were interviewed using a semi-structured interview schedule and in the second phase a responsive interviewing approach will be used. Participants for the first phase were purposefully selected consisting of one couple and 12 caregivers.

Five themes emerged from the first phase's data:

1) Time: a sense of urgency often drove parents to obtain help, but also to express a need for earlier identification. They often also expressed a need to have more time to let the news sink in after diagnosis.
2) The most significant emotions present from before, at and after diagnosis included denial, shock, worry, and hope.
3) Communication: expressing the need to obtain information at diagnosis which was often lacking or denied and expressing the need for gentle yet honest language use by the professional at diagnosis.
4) Resources: all participants expressed gratitude and a sense of hope when integrated into a school system. Families and communities that labelled their child or didn't support or understand their chosen communication mode was voiced as challenging.
5) Inherent and learnt attitudes and beliefs: The meaning of the news was perceived differently under different circumstances. Increased professional insight should generate more refined counselling strategies and should become an integral part of diagnosis of hearing loss in children so as to better serve families that are coming to terms with it.

NOTES

Concurrent Session 1A: Supporting families – Part I
1330-1345

"How early is too early?"
The outcomes of cochlear implantation in infants under 6 months, 7-9 months and 10-12 months

Davis, A [1, 2] and Abrahams, Y.[1]

1. *The Shepherd Centre, Sydney, NSW, Australia*
2. *Macquarie University, Sydney, NSW, Australia*

This ongoing study aims to determine if there are significant differences in the audition, receptive and expressive language skills of children who received at least one cochlear implant at 6 months of age or younger, compared with those implanted between 7-9 months of age, and those implanted between 10 and 12 months of age. The typical profile for children in each group is also reviewed.

A range of auditory tools including the Categories of Auditory Performance-Revised, Auditory hierarchy and functional access to the Ling 6 sounds were used to assess the listening skills and the Preschool Language Scales were used to assess the receptive and expressive language abilities of 30 children who received at least one cochlear implant prior to 12 months of age. Children were allocated to one of three groups: Group 1 (first CI 6 months of age or younger), Group 2 (first CI between 7 and 9 months of age) and Group 3 (first CI between 10 and 12 months of age). Other factors including parental attitudes, family engagement levels, device usage and medical and audiological factors were examined.

No significant issues were seen for any children receiving CI as young infants. With a combination of objective and behavioural MAPping techniques they were able to access sounds across the speech range. By 3 years of age the performance of the cochlear implant users who received their first cochlear implant before 12 months outperformed those who received their first cochlear implant after 12 months and was comparable to their hearing peers. For infants, those who were implanted at the earliest ages showed better performance than those implanted between 7-12 months.

Outcomes for children implanted 6 months of age and under indicate that with full-time device use and engagement in an Auditory-Verbal Therapy early intervention program age appropriate vocabulary and language can be reached by 3 years of age. A variety of factors influence age of implant and also influence longer-term outcomes.

NOTES

Concurrent Session 1A: Supporting families – Part I
1345-1400

Adapting a coordinated early intervention service to best support the families of babies screened under UNHS – a New Zealand perspective.

O'Connor, L and Lin, R

The Hearing House, Provider to the Northern Cochlear Implant Programme, Auckland, New Zealand

The Hearing House is the provider to the Northern Cochlear Implant Programme, providing audiology services from 0-19 years, and habilitation services from 0-6 years. Habilitation is also provided for a few children who use hearing aids, on a case by case basis.

Since UNHS was rolled out across New Zealand, we have seen the age of children enrolling on The Hearing House programme lower from an average age of 1 year, 10 months to 6 months. This has presented the team with some interesting challenges, and as a result we have had to adapt our audiology and habilitation programmes to best meet the needs of these young babies and their parents. This presentation will discuss how audiology and therapy sessions have been adapted, and the development of a pilot two day workshop for these families. Professionals have been upskilled to meet the unique dynamics of working with babies under one. The role of the habilitationist, while always including a counselling role, has shifted even more towards this role, as we encounter these new parents who are grieving for their baby's hearing loss. From an audiological perspective the challenges have involved testing the babies and amplifying them appropriately. There have also been discussions around determining cochlear implant candidacy and the optimal age for implanting these young babies. We have found that meeting other parents in similar situations plays a significant factor to families' commitment and participation to the programme, and this is facilitated through the various initiatives, in particular the two day workshop.

NOTES

Concurrent Session 1A: Supporting families – Part I
1400-1415

Bilateral cochlear implantation in children identified in newborn hearing screening: Why the rush?

McTaggart, M and Chisholm, K

Sydney Cochlear Implant Centre, Australia
Maree.Mctaggert@scic.org.au

This paper explores the outcomes of three groups of children identified as cochlear implant candidates soon after newborn hearing screening.

We aim to identify the impact on receptive and expressive language as well as functional and perceptual listening abilities when receiving just one or two cochlear implants and, if two, the impact of simultaneous or sequential bilateral cochlear implantation.

Method:
Speech, language, perceptual and functional measures at 6, 12 and then 2 years post cochlear implantation and then again at 5 years of age, were measured.
Group 1. bilateral simultaneous cochlear implants
Group 2. bilateral sequential cochlear implants (second CI before 2yrs)
Group 3. unilateral cochlear implant (with hearing aid use in their contralateral ear - bimodal)
Data was analysed for 45 children grouped according to the interval and number of cochlear implants:

Results:
There was no significant difference between outcomes of the three groups in the first two years following cochlear implantation. Results for the following data interval was more variable.

However a trend was observed in the data that demonstrated the influence of parental support and engagement on outcomes.

Conclusion:
These findings demonstrate good outcomes can be attained if the child is implanted within the first 12 months of life, albeit bilateral or unilateral. The importance of parent involvement in defining the outcome of their child will be addressed.

NOTES

Concurrent Session 1A: Supporting families – Part I
1415-1430

Journey to a cochlear implant following a hearing loss

Jardine, J

Mater Cochlear Implant Clinic ,Brisbane QLD ,Australia

Following a birth in Queensland since 2004 it has become routine to have a hearing screen. These screens are mostly carried out prior to leaving hospital. Medical technology has allowed the early identification of detection of hearing loss in newborns. It has become accepted that early detection and intervention enhances the child's ability to achieve better outcomes with communication. Yoshinaga-Itano and colleagues recognised those infants whose hearing loss was identified before the age of 6 months had stronger expressive language than later discovery.

What does this mean for the family? How early are these families entering a medical model where they embark on a journey of intervention and management of hearing loss? A lot of choices may be predetermined by the process removing the decision making from the parents. There are many individuals involved in the process making the journey smooth for some, but still complicated for many. What does it feel like for those children and their families that have slipped through the gaps or were late diagnosis, have a progressive hearing loss with little or no follow up?

The aim of this presentation is to tell the story of a few of the children that have been referred to the Mater Cochlear Implant Clinic. For some of these families they have been diagnosed within 4- 6 weeks and start the journey of appointments and an acceptance that a Cochlear Implant is the best choice. For others it is a period of anxiety trying to navigate the myriad of appointments and decisions. In addition to this equation into the mix comes different languages, cultural opinions, social problems, making the decision making very difficult. Each family needs to be treated individually and all aspects taken into consideration to help this family reach a decision that will allow the child to reach their potential.

This journey involves many professionals along the route.

NOTES

Concurrent Session 1A: Supporting families – Part I
1430-1445

'No discipline is an island':
Working together to support families who need it the most

Davis, A [1, 2] and Beresford, S [1] and Southgate, M [1] and Abrahams, Y [1]

1. *The Shepherd Centre, Sydney, NSW, Australia*
2. *Macquarie University, Sydney, NSW, Australia*

One of the frequently reported challenges from both program and staff levels in services providing support to families of children with hearing loss is addressing how to ensure that vulnerable children and families with minimal support networks are not excluded from follow up programs, but rather actively engaged in them to gain their true benefits. There is a growing body of research to support that it is these parents, particularly without informal supports, who potentially have the most to gain from follow up services and are the least likely to actually access them (Katz et al, 2007).

This paper will explore how barriers to inclusion and engagement in early childhood intervention services can be overcome for such families after identification of a hearing loss through the framework of interdisciplinary teams and building inclusive communities and support structures.

The journey towards this framework will be discussed through the experiences of a large not-for-profit early intervention service in Australia as it works towards a system of integrated services and community inclusion, drawing from the experiences of families and network service providers. Case studies will be used to examine how this can result in enhanced outcomes for families, reduced disincentives for families to access services and creative service delivery models which can be adapted for providers at all points along the hearing diagnosis pathway. Challenges to this model of cross collaborative service for organisations and families and will be identified and discussed.

NOTES

Concurrent Session 1A: Supporting families – Part I
1445-1500

Newborn hearing screening facilitates early diagnosis of congenital CMV infection

Cottier, C [1,3] and Wilkinson, M [1,4] and Hall, B [2] and Rawlinson, W [2,3] and Palasanthiran, P [1,3]

1. *S ydney Children's Hospital, Randwick, N.S.W., Australia*
2. *Virology Research, Department of Microbiology, SEALS, Randwick, N.S.W., Australia*
3. *University of NSW, Kensington, N.S.W., Australia*
4. *Macquarie University, North Ryde, N.S.W., Australia*

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Introduction

Congenital CMV (cCMV) is an aetiological factor in up to 20% of cases of significant sensorineural hearing loss (SNHL). Two thirds of babies with cCMV will have SNHL as a sole manifestation of the infection Timely treatment of cCMV with intravenous ganciclovir and possibly oral valganciclovir in the neonatal period may prevent hearing deterioration. Routine testing for cCMV is not currently standard practice in N.S.W.

Method

In 2009, an algorithm for testing urine for CMV PCR was introduced in the Audiology Department at Sydney Children's Hospital (SCH) for babies with a confirmed SNHL. Saliva swab CMV PCR was added in 2011. A factsheet was given to parents/carers at the time of testing. All babies with CMV PCR positive urine and/or saliva were referred to the Department of Infectious Diseases for an urgent assessment for congenital CMV status and consideration of treatment. All babies were followed up with Audiology and the Hearing Support Service.

Results

Of the 224 babies referred from SWISH in whom a diagnosis of hearing loss was confirmed, seven definite and one probable cCMV infants were identified. Mean age of testing was 4 weeks (range 2-6 weeks). One family proceeded with oral valganciclovir treatment.

Conclusion

Newborn Hearing Screening with CMV testing provides a unique opportunity to make an early diagnosis of cCMV, allowing families to access timely treatment and monitoring.

NOTES

Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1300-1315

Natural disasters and a newborn hearing screening programme: maintaining services, quality and sanity

Deken, A

Canterbury District Health Board, Christchurch, New Zealand

The Canterbury region experienced two natural disasters over a six month period with the most significant being on February 22nd 2011 an earthquake of significant strength. It was akin to a natural disaster of the scale only read about or seen on the world news. As individuals within New Zealand we are encouraged to prepare for a natural disaster within the home and work environment. This earthquake has given the opportunity for the Canterbury District Health Board to "test" its policies around disasters'. Employees including newborn hearing screeners are guided by their employer to meet certain obligations during events such as these.

This presentation describes the impact of the earthquake on the screening staff and programme outcomes. It will include a description of the immediate impact, the events as the disaster unfolded and the ongoing effect that has followed for staff and families.

The presentation will also focus on the supports that were made available to assist with coping through a disaster, initiatives established, practical application and an outline of key documents and polices that guide a screeners practice when faced with a natural disaster.

NOTES

Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1315-1330

Implementation of an early hearing detection management and information system to improve quality and standardisation in Queensland

Beswick, R

Health Services Support Agency, Queensland Health, Queensland Government, Queensland, Australia

Newborn hearing screening programs have become standard practice in most developed nations, with an abundance of literature available on the benefits of these programs. Programs require that infants are screened early and accurately in order to achieve timely identification of the hearing loss, streamlined referrals, and appropriate intervention. A breakdown at any point in this process may cause significant long-term negative effects on the child. Large population screening with crucial time limits imposes many challenges on hearing screening programs including (1) management of mass data, (2) delivering a high quality of service, and (3) ensuring consistency is maintained across all parts of the program. In addition, there is an increasing demand to provide standards-based reporting on all aspects of newborn hearing screening programs at both a state and federal level. To overcome these challenges, Queensland Health's Healthy Hearing Program developed a new clinical, management, and information system: QChild. This system incorporates detailed information from birth, newborn hearing screening, audiology, early intervention, family support, and medical appointments. The system includes automatic processes such as daily import of all hospital births statewide, population of team screening lists, infant and screening result matching and error detection, and referrals to audiology. The open-ended nature of the data structure in the system allows for incorporation of future modules to expand beyond hearing screening. Linkages or interfaces with other data sources will also be possible. As misinterpretation of audiology reports may be as high as 29.2% in children with abnormal outcomes (Ramachandran et al., 2011), audiograms and diagnostic letters are generated within the system to help standardise audiology reporting across sites. This presentation will demonstrate the generation of audiograms and letters, as well as detailed management and quality assurance on all aspects of the continuum of care that is a part of the Healthy Hearing Program.

Ramachandran, V., Lewis, J. D., Mosstaghimi-Tehrani, M., Stach, B. A., & Yaremchuk, K. L. (2011). Communication outcomes in audiologic reporting. J Am Acad Audiol, 22(4), 231-241.

NOTES

Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1330-1345

Reflections on an investigation into reported changes in rates of referral from screening to diagnostic assessment

Catherine, L and Fizzell, J and Murphy, E

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The NSW Statewide Infant Screening- Hearing (SWISH) Program was established in December 2002. The Program consistently performs at a level superior to the international newborn screening benchmarks, including screening more than 99% of live births using Automated Auditory Brainstem Response (AABR) technology.

A review of the recent SWISH Program activity data was undertaken by NSW Health in 2012 to investigate reported changes in rates of referral from SWISH universal newborn hearing screening to diagnostic audiology assessment.

The limitations of the existing SWISH Data Collection (which consists of monthly aggregated reports prepared manually and corrected over a 6 month period) presented various data and resource related challenges to the epidemiologists and policy officers involved in the review.

Various factors which may potentially impact on referral rates were identified including equipment type and modification as well as changes in staffing, birth rate and referral pathways.

Detailed activity data was sought from Local Health Districts for the period from July 2011 to April 2012, during which more than 72,000 babies were screened.

Analysis of this data was completed to substantiate any change in rates of referral and diagnosis, and to enable consideration of the above factors. The findings of the review related to both recent and historical trends in SWISH Program activity and supported the value of early observations made by SWISH clinicians.

A range of additional quality-focused SWISH projects were initiated in response to the findings including the development of a Quality Framework.

The results of the review and initiatives undertaken since will be discussed.

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Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1345-1400

Screening infants who are young and too young: An analysis of gestational age at screening in Victoria

Kavanagh, G and Poulakis, Z and Barker, M and Clarke, J

Royal Children's Hospital, Melbourne, Victoria, Australia

Screening programs such as the Victorian Infant Hearing Screening Program (VIHSP) must be regularly monitored and reviewed to ensure data are of a high quality, patients are not tested unnecessarily, staff are working to acceptable standards and participants are receiving the best possible service.

Gestational age at screening data from the financial year 1 July 2011 – 30 June 2012 were examined, with a particular focus on infants screened young – prior to 36 weeks corrected gestational age (CGA), and those screened too young - prior to the eligibility of 34 weeks CGA.

Data indicated that 0.08% of infants screened were screened before they were 34 weeks CGA, and 2.85% of infants were screened with CGA below 36 weeks.

Records of infants screened before 34 GCA indicated that the majority of these infants were screened at 33 weeks and 5 days or 33 weeks and 6 days. The method used by the VIHSP database to ascertain CGA, and readiness to screen, rounds CGA at two points, which resulted in infants appearing to have reached 34 weeks of age a few days early. For infants screened between 34 and 36 weeks CGA, investigations revealed possible causes to be very short stays and Special Care Nursery infants being discharged within hours of completion of treatment. Not screening these infants when the opportunity arises, and waiting until these infants are greater than 34 weeks CGA may result in them missing their screen while inpatients.

An enhancement to the VIHSP database is due to be implemented to remove both points where the gestational age is rounded. VIHSP is confident that this database change will ensure that staff do not inadvertently screen infants who are too young to screen. Further monitoring of CGA at screening will continue.

NOTES

Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1400-1415

How a hearing screening programme database can result in both quality improvements and cost savings.

Deken, A and Craig, B and Anthony, J and Wilson, J

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Offering a newborn hearing screening programme in a large District Health Board (DHB) in New Zealand for up to 7000 babies per year without electronic support leads to inherent quality and process risks from the screening offer to audiology referrals. There was no national database in 2009 when the Canterbury DHB (CDHB) commenced the Universal Newborn Hearing Screening Programme. As the programme rolled out the need for a database was clear, so the CDHB created a customised database. This database has significantly improved the quality of the screening service by facilitating identification and tracking of babies, screens and outcomes. It also saves screener and coordinator time, resulting in annual DHB savings of $48,000. The National Screening Unit (NSU) also saves costs in reduced data entry time.

Every CDHB hospital birth is automatically populated into the database daily. The database collates screening and audiology information which is electronically accessible to DHB clinicians and local GPs. It sends electronic data for screening and audiology outcomes to the NSU and flags data entry errors. It also has an appointment tracking system. Monthly and quarterly reports are generated, which support analysis of the service and enable the instigation of quality initiatives. Screener performance for yearly appraisals is also reported from the database.

The next database development proposed is for babies who are diagnosed with hearing loss and will include their full clinical details and developmental milestones, to enable assessment of intervention effectiveness. We are also currently exploring the option of a direct daily download of screening data, to improve screening quality auditing facility and to save time.

The development of this database has significantly improved the quality of the service and mitigated many of its risks to optimise patient safety and the programme's efficacy.

NOTES

Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1415-1430

When a unilateral refer reveals a bilateral loss on diagnosis: cause for concern?

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Children's Hospital at Westmead ,NSW, Australia

It has been reported that in many newborn hearing screening programs more attention has been placed on infants who refer bilaterally than those who refer unilaterally. In fact some programs only report bilateral refers (Chang,KW et al 2009).At the same time, the trade-offs most programs make on screening signal characteristics to maintain specificity mean that unilateral refers can sometimes result in bilateral loss at diagnosis.

Over the last decade, the Audiology Clinic at Children's Hospital Westmead has assessed more than 2,000 infants via the State Wide Infant Screening Hearing (SWISH) program. Over 600 of these were unilateral refers and of those,121 were diagnosed with hearing loss in both the referring and pass ear : close to 1 in 5.Of further concern, close to one quarter of this latter group had bilateral sensori-neural hearing loss.

This paper will examine both the type and degree of hearing loss detected, as well as report relevant risk-factors, including the possible bias in our sample. A case study will then examine the potential psycho-social effects resulting from these unexpected cases.

Future opportunities will then be explored for fine-tuning the support our program provides, to ensure these infants receive optimum quality care.

Chang,KW,et al.J Med Screen 2009;16:17-21

NOTES

Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1430-1445

VicCHILD: establishment of the world's first population-based childhood hearing impairment longitudinal databank

Wake, M [1,2,3] and Poulakis, Z [1,2] and McMillan, L [1] and Hampton, A [1] and Tobin S [1] and Mueller, K [1] and Burt, R [1] and Stevens, L [1] and Halliday, J [1]

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2. *Royal Children's Hospital, Melbourne, VIC, Australia*
3. *The University of Melbourne, Melbourne, VIC, Australia*

Context:
In an era of better life chances than ever before for deaf children, congenital hearing losses continue to exert major impacts on speech and language, incurring lifelong social, educational and economic costs.

Objective:
(1) To establish the world's first population-based longitudinal databank for children with congenital hearing loss and (2) facilitate collaborative population-based research to: (i) describe secular trends in outcomes; (ii) support population-based quality improvement activities; (iii) identify and quantify factors that predict outcomes; and (iv) facilitate randomised controlled trials of interventions.

Design:
Established in late 2011 to prospectively recruit children indefinitely and follow them from soon after birth through adulthood, VicCHILD combines (1) questionnaire and assessment data collected approximately 5-yearly from VicCHILD families and children; (2) linkage to deafness-specific and generic population-based health and educational databases; and (3) salivary samples for genetic, epigenetic and viral studies.

Setting:
Currently the state of Victoria, Australia, but with capacity for future national/international federated membership.

Participants:
189 children as of January 2013, prospectively targeting all children born in the state of Victoria since 2011 with bilateral or unilateral congenital hearing impairment, identified through the Victorian Infant Hearing Screening program (VIHSP), plus one-off retrospective re-recruitment from two population-based studies and children born during VIHSP's roll-out (2005-10).

Main outcome measures:
The REDCap web-based server can be tailored to researcher access requirements. Data include: hearing diagnosis (type, degree, age at diagnosis); birth and family history data; demographics; child outcomes (eg language, academic achievement, mental health, HRQoL); parent outcomes (eg mental health, HRQoL); treatment; service utilisation, including lifetime Medicare data; buccal samples extracted and stored.

Implications:
VicCHILD responds to a clearly-identified international need for new approaches to coordinated, collaborative, population-based research. As the VicCHILD repository grows, we hope it will stimulate and support novel local and international collaborations and capacity in congenital hearing impairment research.

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Concurrent Session 1B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part I
1445-1500

Screening anomalies in newborn hearing screening programmes in NZ

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Recently, revelations of deviations from the national screening protocol by individual new born hearing screeners have made media headlines in New Zealand. This presentation will discuss the identification of the anomalies in the data and contrast data from two very different heath boards in New Zealand. One health board is based in the largest metropolitan area of NZ and employs the largest number of screeners in the country and the second is small urban health board that has one of smallest screening workforces in the country.

Data will be presented to show the pattern and types of anomalies identified, the techniques developed to analyse data for prompt data screening, and measures put in place to attempt to prevent future occurrences. Causal factors identified by the two screening programmes will be discussed.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
0900-0915

Nga Kohungahunga Turi: envisioning a whanau-centred approach to early intervention

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This presentation will report on a study that investigated the early intervention experiences of whanau (family) of Maori deaf children. Based on five case studies, the research aimed to document Maori perspectives on interaction with early intervention services and to explore what other information and ideas shaped their perception of deafness and influenced their decisions around communication, language, and parenting. The features of a whanau-centred model of intervention are explored between the researcher and whanau participants in order to provide an understanding of how early intervention services could be more effective from Maori perspectives.

Whanau in the study reported that their initial encounters with professionals focused on medical perspectives and responses to hearing loss. As the child entered developmental stages whereby language acquisition and social acculturation process began however, whanau needed more social and linguistic support to ensure participation in home and educational contexts. Early intervention services were seen by some participants to constrain, or to conflict with, their social-cultural aspirations for the child, by a focus on acquiring spoken English and participation in mainstream educational contexts. Whanau expressed frustration at the compromise they felt and wished for a model of support that engaged with whanau aspirations and relational styles more effectively. Potential features of a whanau-centred model of early intervention were identified between the researcher and whanau during a wananga (forum) held as a part of the research.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
0915-0930

Developing a blended service model to deliver family-centred early intervention

McCarthy, M

Royal Institute for Deaf and Blind Children, Sydney, New South Wales, Australia

The implementation of Universal Newborn Hearing Screening has resulted in earlier identification of hearing loss for many children and their families. While this is a significant achievement, the full potential of screening programmes is only realised when those programmes are complemented by early amplification, ongoing audiological management and early intervention services.

The Royal Institute for Deaf and Blind Children (RIDBC) furthers the objectives of screening programmes by providing audiological management and early intervention services to families throughout Australia. RIDBC uses a family-centred approach focusing on coaching and guiding families to be the primary facilitator of their child's language and communication development. In metropolitan areas, individual and group early intervention services are delivered 'in-person' through home-based or centre-based sessions. Families in regional and remote areas access similar early intervention services through home-based or centre-based 'telepractice' sessions using videoconferencing technology.

Data is regularly collected from families regarding their satisfaction with both types of service delivery. Feedback from families indicates that both in-person and telepractice sessions are valued and each adds a different component to the families' early intervention experience. In response to this feedback, RIDBC has developed a blended approach to service delivery, which incorporates the benefits of both types of sessions. The blended model uses a combination of in-person sessions, telepractice sessions, and asynchronous web-based learning to address the individual needs of each family.

This presentation will examine the development of a blended service model to deliver family-centred early intervention and the rationale for implementing a blended approach in metropolitan areas as well as remote areas. Case studies will be presented to explicate the blended service model and the ways in which technology can be used to foster a family-centred approach.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
0930-0945

Barriers to early intervention service delivery for children with hearing loss – the Queensland experience

Usher, H

Health Services Support Agency, Queensland Health, Queensland Government, Queensland, Australia

Since its inception in 2004, the Queensland Health Healthy Hearing Program has established a high quality screening program. In addition to early identification of a hearing loss, it is widely acknowledged that children need timely engagement in appropriate early intervention programs to realise their best outcomes.

Feedback from parents and early intervention providers have indicated that parents of children with a hearing loss find access to appropriate early intervention services to be problematic in some areas of Queensland. Between October 2010 and December 2011 the Healthy Hearing program conducted a project aiming to 1) identify and describe the range and location of major early intervention services for Queensland children, aged 0 to 5 years with a permanent hearing loss and 2) suggest practical strategies to improve access to early intervention services for these children.

A series of interviews was conducted with staff across Queensland and in New South Wales with consultations revealing a number of barriers to service delivery. These were classified under the following headings: (1) access to specialised hearing loss services, (2) proximity to services, (3) inequity of services for children with hearing loss, (4) referral pathways and case management, (5) information gaps and (6) family issues.

To overcome the barriers, this project developed some practical strategies to target the limitations in current service delivery including (1) the formation of an Early Intervention Working Group to develop standard early intervention guidelines and promote professional development opportunities; (2) promoting the increased use of video teleconference services where appropriate; and (3) the development of an early intervention module in the new Early Hearing Detection Management and Information System, which can facilitate better communication across agencies, store clinical and medical information and monitor children's engagement and progress in early intervention services.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
0945-1000

"Learning to listen to a baby who cannot hear" infant hearing loss and attachment

Green, V

Queensland Hearing Loss Family Support Service, Queensland Health, Australia

The Queensland Hearing Loss Family Support Service was established in 2007, as a part of the Healthy Hearing Program (which conducts newborn hearing screening, as well as surveillance screening of older children).

This statewide team of family support facilitators provides family-centred counselling and support to families of children diagnosed with a permanent hearing loss.

This includes emotional support and counselling where required, with regard to parental adjustment to diagnosis, as well as ensuring families gain information about their child's hearing loss and the full range of habilitation options available to support their child's communication, development and health needs. Advocacy on behalf of children with a permanent hearing loss (PHL) and their families, within relevant services and systems, and contributing to the development of research and best practice in this field are additional focal points for our service.

This presentation will focus on the effect of the diagnosis of infant hearing loss on early Parent-Child interaction, and how the therapeutic relationship, as well as provision of information and advocacy, can ameliorate this impact and maintain parental capacity to meet the child's needs, both emotionally and with regard to early communication and educational needs.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
1000-1015

Impact of the presence of auditory neuropathy spectrum disorder on outcomes at 3 years of age

Ching, TYC [1,2] and Day, J [1,2] and Dillon H [1,2] and Gardner-Berry, K [1,2] and Hou S [1,2] and Seeto M [1,2] and Wong A [1,2] and Zhang, V [1,2]

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2. *The Hearing CRC, Melbourne Australia*
3. *Australian Hearing, Sydney Australia*

There is limited literature on speech and language development in children with auditory neuropathy spectrum disorder (ANSD), with the majority of publications restricted to measures of speech perception and functional auditory behaviour. There is also considerable controversy about the most appropriate early intervention to recommend for this group, and the increased need for cochlear implants regardless of the degree of the hearing loss. The aim of this study was to investigate the impact of the presence of ANSD on speech, language and psycho-social development of children at 3 years of age, and to compare these outcomes to children without ANSD.

Methods: Forty seven children with ANSD who participated in the Longitudinal Outcomes of Hearing Impairment (LOCHI) study were assessed using standardized measures of speech production, receptive language and expressive language. Performance was compared to that of children without ANSD in the LOCHI study.

Results: Sixty-four percent have hearing sensitivity loss ranging from mild to severe degrees, and the remaining had profound hearing loss. At 3 years, 27 children used hearing aids, 19 used cochlear implants and one child did not use any hearing device. Thirty percent of children have disabilities in addition to hearing loss. On average, there were no significant differences in performance level between children with and without ANSD on speech production or language development. Also, the variability of scores was not significantly different between those with and without ANSD.

Conclusions: There was no significant difference in performance levels or variability between children with and without ANSD. There was also no difference between children who use hearing aids, and those using cochlear implants.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
1015-1030

Responding to the needs of families of children with unaidable mild and borderline hearing losses

Britton, L and Gold, T and Hodgson, F and Ter-Horst, K

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Universal Neonatal Hearing Screening identifies hearing losses across a wide range, from borderline to profound. While intervention pathways for children with significant bilateral aidable hearing losses are typically well established, the pathways for children with milder losses are less well defined. Nevertheless, the need for families to receive support and information in regard to the consequences of hearing losses, which are unlikely to benefit from the fitting of hearing aids, remains evident.

This paper reports on the development and implementation of a family-centred early intervention program for the families of children identified with mild hearing loss. The program developed by the Royal Institute for Deaf and Blind Children offers individually and group-delivered information sessions, as well as audiological monitoring and speech/language assessment. Families are encouraged to take an active interest in their child's language development and, where delays became apparent, the services of speech therapists and teachers of the deaf are made available. The rationale for the program as well as an overview of the content of the information component of the program will be presented, together with feedback from participating families. Implications for screening programs more broadly will be discussed.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
1030-1045

Tele-practice: delivering early intervention and audiology services to families in rural and remote areas

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Advances in technology are changing the way health and educational practitioners are able to provide quality services to children with hearing loss. In order to benefit from the early diagnosis of hearing loss, professionals need to seek innovative ways of providing effective Audiology and Auditory-Verbal Therapy for all children, regardless of geographical location.

Tele-Practice is providing professionals with exciting and rewarding opportunities to disseminate their services to all clients, wherever they may be throughout the world. It is changing the face of how professionals at Hear and Say interact with children with hearing loss and their families.

This presentation will describe two aspects of the Hear and Say eMPOWER model of Tele-Practice: early intervention using Auditory-Verbal Therapy (eAVT) and remote MAPping (programming) of cochlear implants using videoconferencing (eAudiology). Video footage will be used to demonstrate these two programs.

Research outcomes will be tabled from

- A validation study of the eAudiology program, conducted with 40 children
- A survey of parent and professional satisfaction with the eAVT program
- A pilot study, showing the feasibility of the eAVT program, comparing a group of seven children in the eAVT program matched with seven children in the face-to-face program. This is the first comparison study of its kind world wide.

NOTES

Concurrent Session 2A: Effective evidence based ways of delivering early intervention programmes
1045-1100

A home based model of cochlear implantation: the role of telepractice

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The nature of support for cochlear implant (CI) recipients is rapidly evolving due primarily to the exponential growth of the CI population and technological advances. Expanding selection criteria, bilateral cochlear implantation and the increasing evidence of the efficacy of early implantation for children identified through newborn hearing screening have been a strong impetus for the growth in the population of CI recipients. As a result, CI clinics must reconsider their traditional service models to ensure that they meet the needs of a diverse and growing client base, whilst preserving a high standard of service delivery.
Further, a high proportion of cochlear implant recipients reside outside of their metropolitan area, hence access to services can be difficult.

Remote mapping of cochlear implants through the use of teleaudiology was first documented by Frank, Pengelly and Zerfoss in 2006. Following recent studies by the Hearing CRC the feasibility and the validity of this procedure has been established (Psarros, van Wanrooy, & Rushbrooke 2012). In over 70 cochlear implant maps that were performed, all but 3 were found to achieve all essential criteria for a "successful" mapping session. Questionnaire data revealed that parent and recipient satisfaction was high.

The methodology and feasibility of implementing remote management of cochlear implants using telecommunications for audiology and habilitation will be reported in this paper. Further, a case study will be presented whereby the entire cochlear implant process has been managed using telecommunications. The multidisciplinary teams engagement of the family in this process has ensured minimal disruption to the families routine and inclusion of local professionals to maximize outcomes in ongoing management.

Plans and procedures for future development of this home based model in keeping with technological advances and family needs will be discussed with particular reference to the needs of children and families identified through newborn hearing screening.

References:

Frank, K., Pengelly, M., & Zerfoss, S. (2006). Telemedicine offers remote cochlear implant programming. Voices, 13(1), 16 – 19. Psarros, C., Van Wanrooy, E., & Rushbrooke, E. (2012). Telemedicine in Audiology: Cochlear Implant Mapping. Workshop presented at Audiology Australia Conference, Adelaide.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes - Part II
0900-0915

The pieces of the jigsaw puzzle: a range of tools and resources required to deliver a quality newborn hearing screening programme in New Zealand

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Wikipedia describes a jigsaw as a *"tiling puzzle that requires the assembly of numerous small, often oddly shaped, interlocking pieces. Each piece usually has a small part of a picture on it; when complete, a jigsaw puzzle produces a complete picture".*

The Universal Newborn Hearing Screening and Early Intervention Programme can be likened to a jigsaw puzzle with many interlocking components required to build a quality screening programme.

Evaluation and monitoring activities in screening programmes aim to generate the information needed to confirm whether or not a programme is safe and effective. The National Screening Unit draws on a suite of resources and tools to provide newborn hearing screening service providers with the tools to assist with high quality service provision. The pieces of the puzzle that build a complete picture of a quality newborn hearing screening programme include National Policy & Quality Standards (NPQS); the screener competency framework; consumer resources and provider audits.

The three-year audits have a quality/performance improvement focus and assess the service provider procedures and operations relating to the newborn hearing screening programme against the NPQS and contract requirements. The audits have identified areas of partial or non-compliance and also potential opportunities to improve provision of the newborn hearing screening programme.

This presentation will include recommendations from the audits that contribute towards producing a complete jigsaw puzzle picture of a high quality sustainable newborn hearing screening programme in New Zealand.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
0915-0930

Identifying ethically important scenarios in newborn hearing screening

Kavanagh, G [(1)] and Delany, C [(1,2)] and Poulakis, Z [(1)] and Barker, M [(1)] and Hood, F [(1)] and Clarke, J [(1)]

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The Victorian Infant Hearing Screening Program (VIHSP) aims to promote early identification of permanent congenital hearing loss through a high quality newborn hearing screening program. VIHSP staff work as primary health practitioners to:

- Inform families about the screening program and engage them in the screening steps
- Competently conduct screening
- Inform families and other health professionals of screen results
- Create a relationship of trust with families of a newborn when positive screening results arise to ensure appropriate support for outcomes
- Follow up families who require ongoing assessment, support and management.

The effectiveness of universal newborn hearing screening (UNHS) in promoting early identification is well established. However, individual families or family members may not always agree with or wish to participate in screening programs and/or attend further consultations. In these types of situations, the roles of VIHSP staff to obtain consent for screening, to educate, motivate, support and monitor families become ethically complex. How much information should be given to families? What is the best way to present screening results? Are there limits to following up families who are unwilling to attend future appointments for their child?

These questions raise specific and unique ethical issues that have received little attention in health ethics literature. Specific case studies and narratives about hearing screening practice were used in a series of clinical ethics workshops to facilitate discussion, debate and education about ethical issues arising in and from our screening program. Through supported ethics analysis and reflection, staff gained an increased understanding of the dimensions of ethical issues in screening programs. This presentation will share a clinical ethics education approach and provide insight into the ethical guidelines developed by VIHSP to assist others involved in UNHS to analyze and reflect on their practice.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
0930-0945

Overcoming challenges of delivering a newborn hearing screening program in a tertiary care hospital in India

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One of the challenges of Newborn Hearing Screening (NHS) program is lost to follow up (LFU) at various stages of the program. New strategies need to be adopted to know the hearing status of the babies who LFU. This study documents how challenges were overcome in delivering NHS program. In this retrospective study, data of 1135 babies born between September 2011 and August 2012 were extracted and percentage analysis was done.

First screening was done before 1 month of age and for babies with NICU stay before 1 month of discharge. OAE Screening was done for all except for babies with NICU stay (>4 days) and hyperbilirubemenia for whom ABR screening was done. Second screening was recommended for babies who got referred in first screening. When babies are referred in second screening, immediate first detailed evaluation was done. Based on the results, follow up evaluation after three months (for maturational delay) or intervention (if diagnosed hearing loss) was recommended. For babies who lost to follow-up (LFU) in screening or diagnostic evaluation, telephone follow-up (TFU) was done. Reasons for LFU were documented and hearing screening checklist (Northern & Downs, 2002) was administered to know the hearing status of babies.

Using two step screening, the referral rate was 2.2%. Immediate diagnostic evaluation reduced the requirement for follow-up. Babies who LFU where contacted telephonically. Two parents showed concern and were urged to come back. On exploring the reasons for LFU, 57% of parents were convinced that child can hear and 13% reported that child's hearing was screened elsewhere. The remaining 30% expressed their inability to bring the child because of distance problem, preoccupied work & personal issues. This indicates that NHS protocol should be fine tuned and adapted to cultural needs.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
0945-1000

Are we screening the correct baby?

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Royal Children's Hospital, Victoria, Australia

The Australian National Safety and Quality Health Service Standards mandates that all patients be identified by at least three approved patient identifiers prior to undergoing any procedure. Babies are not able to verbally identify themselves and reliance on a cot card is not sufficient, as babies have been placed into the wrong cots. There are known instances of the incorrect newborn undergoing a procedure. Newborn hearing screening services are vulnerable to the same challenges – relying on checking a cot card alone has resulted in the incorrect baby being screened. Additionally, the hearing screen may have been undertaken without the parent or guardian providing informed consent.

Analysis of data from the Victorian Infant Hearing Screening Program (VIHSP) identified that there are occasions when a hearing screen has been performed on an incorrectly identified baby, or an incorrectly identified twin. There are significant implications when this occurs including unnecessary stress and anxiety for parents, the correct infant not undergoing screening (while their record erroneously indicates they have), requirements for call-back of infants for screening, and reduction in stakeholder and public confidence in the screening process.

Following a trial of mandatory checking of three approved identifiers prior to completing a hearing screen, VIHSP has now amended the screening procedure making it mandatory that all in-patients have their identification band checked for full name, date of birth and address before completing a hearing screen.

Compliance with the amended procedure has been validated through observational audits. Manually uploaded screening result data has also been reviewed to verify the results belong to the correct baby.

The VIHSP hearing screening procedure is now compliant with the ACSQHC (Australian Commission for Safety and Quality in Healthcare) National Standards for patient identification which is a requirement for hospital accreditation under the ACHS (Australian Council on Healthcare Standards).

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
1000-1015

Rescreening infants in Victoria 2011-2012

Kavanagh, G and Barker, M and Poulakis, Z and Clarke, J

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Screening programs must be regularly monitored and reviewed to ensure reportable data is of a high quality, patients are not being unnecessarily referred for further testing, staff involved are working to acceptable standards and participants are well informed and receiving the best possible service.

The Victorian Infant Hearing Screening Program (VIHSP) recently undertook a review of data from the financial year 1 July 2011 – 30 June 2012 to investigate the rate of re-screening of newborns. Rates of re-screening are important considerations in the quality of screening provided, minimising false negative results, and resourcing of screening services.

Analysis of data from this period indicated that the VIHSP rescreen rate is approximately 10%. While data were being analysed, a number of interesting subsets of information came to the attention of the monitoring team. VIHSP then undertook an in-depth review of particular sets of this data, focusing primarily on rescreens indicated to have been undertaken within twenty minutes of the previous screen. This revealed some errors and screening practices specific to some screening sites that were not consistent with the majority of VIHSP services. Practices such as rescreening inpatients immediately following a refer result and data entry errors often related to the screening of multiple birth infants.

Through this analysis VIHSP has been able to create and implement a guideline for rescreening infants. It has also undertaken an education program for all staff delivering screening across Victoria to raise awareness to the importance of following procedures and attending to detail.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
1015-1030

Cultural issues in hearing screening

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Osborne Park Hospital provides care for the highest number of CALD women (per total births) in Western Australia. Cultural issues are a reality in today's society and one that also needs to be addressed and evaluated within the newborn hearing screening program. One main issue that has been observed in a small WA hospital located in a large multicultural area is the language barrier and how information in relation to the newborn hearing program is being disseminated to these families.

Although consent forms are signed at their initial clinic appointment, the hearing screener is often faced with the fact that these families are still unsure of what the hearing screener is doing, therefore raising the questions, are they understanding what they are signing in the first place and how is this programme initially explained to them, so they are able to comprehend what will happen in the test?

With the majority of migrants speaking little or no English and the use of Interpreters an expensive exercise and unfortunately aren't always available at the time of the screen, can at times, be difficult to ascertain the information required in relation to family history, or explaining results of a hearing test, especially when it's a referred result can pose problems.

So how do we overcome these barriers to continue to improve the standards of delivering a hearing programme that enriches the lives of all infants?

Bearing in mind that the English language is a difficult one to understand, we need to learn to simplify our sentences to enable migrants to try and understand, so one suggestion is a trial of small cue cards translated into a variety of languages with a very simple question and answer type card. By trialling something as simple as this card may in fact, assist with the language barrier and help to continue improving the Hearing Screening Program.

Osborne Park Hospital Newborn Hearing Program has developed a set of cue cards both written and pictorial to improve the collection of newborn hearing family history and informed consent from CALD women.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
1030-1045

Maintaining and retaining a competent screener workforce

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For New Zealand and internationally part of the initial development and implementation of a Newborn Hearing screening programme has been to monitor the success or failure of a programme performance on the 1-3-6 goals. Given the recent incidents within both the UK and NZ screening programmes it is evident that there is a need for closer scrutinizing of individual screener performance and at a much lower level of screening protocol, this will help to identify any anomalies of either low or high performance that are out of internationally recognised levels. However there also needs to be increased efforts to improve staff engagement to the ideals of the programme.

To achieve this we needed to look at some of tools available internationally in both the health and corporate sectors for maintaining and retaining a quality workforce. Supporting evidence proves that by developing feasible, cost effective tools to assess individual competency, ensuring a programme of regular and detailed internal and external audit tools and ensuring that they are efficiently and consistently managed can improve effectiveness, productivity and service quality.

The additional expansion of an accessible and achievable career structure for screeners, include education packages for coaching and mentorship programmes, Lead screener and Coordinator training and Trainer development would assist in the future proofing of the programme. The benefit of this is to create an interactive and self-supporting screening community. If all of these improvements are applied together the aim would be to increase the retention rate of good staff, thereby increasing service quality and reducing staff turnover. For New Zealand government available data substantiates that this would bring considerable cost savings to both the recruitment and training of new staff.

NOTES

Concurrent Session 2B: Maintaining motivation and quality assurance in newborn hearing screening programmes – Part II
1045-1100

Holding onto the tail of the tiger: education and training of the newborn screening workforce in New Zealand

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In 2007 New Zealand introduced universal newborn hearing screening to improve the outcome for babies born with permanent congenital hearing loss. The implementation of a high quality programme presented a workforce development challenge as it required a new screening workforce to be created.

As there was no national qualification or training programme for newborn hearing screeners, the National Screening Unit (NSU) undertook the development of competencies, a training programme and qualification for newborn hearing screeners.

Two trainers, an audiologist and a midwife who had skills in adult learning and assessment, delivered a programme based on international models to about 110 people. It consisted of technical and practical sessions and hands-on experience followed by an onsite visit for further assessment and sign-off.

In 2010 the NSU developed the National Certificate in Health, Disability and Aged Support (Newborn Hearing Screening) which is on National Qualifications Framework. The original cohort of screeners was given an opportunity to complete the qualification through a Recognition of Current Competency (RCC) process. For screeners joining the programme later, the NSU expects that all will complete the qualification within a year of commencing employment. To date, 52 screeners have gained the qualification and 38 screeners are actively working toward completion, both RCC and screeners trained by the DHB. To address the issues of replenishing the screener workforce after training the initial cohort, the NSU developed a train the trainer model. Expert screeners were trained as trainers; to deliver the foundation training, and to date 33 new screeners have been trained. An evaluation of the training will be presented, which found that there were both benefits for the trainee and trainer.

The presentation will include the competency framework that has been developed alongside an online tool to support the on-going competency of screeners on an annual basis once they have completed the NZQA qualification.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation
1300-1315

Recommendations for monitoring hearing in children using a risk factor registry

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The Joint Committee on Infant Hearing (JCIH) recommend targeted surveillance of at-risk infants using a risk factor registry, in conjunction with parent and/or professional monitoring to detect hearing loss that develops post newborn hearing screening. However, criticisms of these recommendations are emerging as targeted surveillance programs are costly, resource intensive, have poor follow-up rates, and lack evidence of best practice. The purpose of this presentation is to provide recommendations for risk factor registries incorporated within targeted surveillance programs. These recommendations were developd by combining the results of previous research including a systematic review of the literature and a comprehensive evaluation of a targeted surveillance program in Queensland. Recommendations are as follows. Children with the risk factors of family history or craniofacial anomalies should have their hearing monitored, whereas, children with the risk factor of low birth weight should not. Children with the risk factors of syndrome or prolonged ventilation should potentially have their hearing monitored, however, the evidence was not definitive. Equally, children with bacterial meningitis, hyperbilirubinemia, or professional concern as a risk factor may potentially not need their hearing monitored but again, the evidence was not definitive. For the risk factors of severe asphyxia and congenital infection, the evidence was inconclusive and/or conflicting so no recommendations were able to be made. More research is needed to further inform evidence-based clinical policy recommendations for hearing loss detection in early childhood.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation 1315-1330

Success of risk indicators for detecting late onset and progressive hearing loss: an analysis of the New Zealand protocol

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It is widely recognised that a universal new born hearing screening programme will only detect a proportion of childhood hearing loss. The remaining hearing losses will be diagnosed predominantly in the preschool years. The importance of early intervention is also acknowledged as integral to new born hearing screening programmes to enable infants and young children access to sound and the opportunity to develop language.

Techniques used to detect hearing losses that are not identified in new born infants typically consist of a combination of approaches including the identification of risk indicators for late onset or progressive hearing loss that were present as a new born infant and the recall and testing of these children at some older age and the use of a further universal hearing screening programme for older children. Both approaches can be costly and the efficacy of each approach can be difficult to monitor due to incomplete coverage and difficulties with maintaining accurate databases over time.

New Zealand uses both approaches by recalling children identified by the universal new born hearing screening programme with risk indictors for hearing loss and a universal hearing screening programme at age four to five years (B4 School Check). An analysis of the data that has been collected by a large metropolitan district health board using the unique New Zealand risk indicators will be presented and contrasted to risk indicators that are used internationally. Additionally data will be presented on the efficacy of the B4 School check in identifying late onset and progressive hearing losses and contrasted to the use of monitoring by risk indicators.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation
1330-1345

Weaving the tapestry: working with geographic and cultural diversity

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The Queensland Hearing Loss Family Support Service (QHLFSS) provides services to families identified with a permanent hearing loss through Universal Newborn Hearing Screening. Queensland is a geographically diverse state – nearly 1.7 million square kilometres. Population centres are concentrated in the south east corner and along the coastline.

Providing specialist hearing loss services to this diverse area brings many challenges including coordination and collaboration between services. With geographic diversity there is an added demographic of cultural diversity -to the north of the state a high proportion of families are of indigenous origins, while in other areas refugee and immigrant families bring cultural and religious complexities to service provision.

With limited clinical resources, extensive geographic areas and cultural diversity to weave into the tapestry the QHLFSS has developed unique ways of working. At a community level an extensive community development approach to building sector capacity and at a family clinical level - a case management approach to service delivery for complex family situations.

This presentation will describe the journey for 3 families from new born hearing screening to Early Intervention. The studies will identify pathways and roadblocks, and highlight the importance of working closely with our families and sector partners to achieve good outcomes.

The concept of "good outcomes" will be explored to generate thoughts on what is desired, what is ideal and what are agreed goals for families based on the principles of family centred care.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation 1345-1400

Universal, risk factor and opportunistic screening for congenital hearing loss: 5-6 year old population outcomes

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Objective:

To compare population outcomes of universal newborn and risk factor screening with opportunistic detection a decade earlier.

Design, Interventions and Setting:

Population-based follow-up of (1) 5-6 year olds born 2003-5 in New South Wales (NSW) and Victoria (VIC), when NSW offered universal newborn and VIC risk factor screening (neonatal intensive care screening + universal risk factor referral), with both offering similar educational and post-diagnostic services; and (2) 7-8 year olds born 1991-3, when detection was largely opportunistic.

Participants:

Children in the national register with bilateral congenital HL >25 dB HL in the better ear, aided by 4 years; the 1991-3 cohort excluded children with intellectual disability.

Main Outcome Measures:

Age of diagnosis; directly-assessed language, receptive vocabulary and letter knowledge; and parent-reported behaviour and health-related quality of life, compared between states using adjusted linear regression.

Results:

69 children born NSW and 65 born Victoria 2003-5; 86 born Victoria 1991-3. For all children, UNHS showed trends towards better language, receptive vocabulary and letter knowledge compared to risk factor screening. Among children without intellectual disability, outcomes improved incrementally from opportunistic to risk factor to universal screening for age of diagnosis (22.5 vs. 16.2 vs. 8.1 months, $p<0.001$), receptive language (81.8 vs. 83.0 vs. 88.9, $p=0.05$), expressive language (74.9 vs. 80.7 vs. 89.3, $p<0.001$) and receptive vocabulary (79.4 vs. 83.8 vs. 91.5, $p<0.001$); nonetheless, all remained well below population means. Benefits of universal screening were maximal in the mild-moderate range for letter knowledge, severe range for receptive vocabulary, and profound range for receptive language. Behaviour and parent and child health-related quality of life were largely independent of both severity and screening program.

Conclusions:

UNHS improves outcomes, but realising its full benefit will require rigorous optimization of early pathways, plus research to advance the science of intervention, amplification and hearing restoration.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation
1400-1415

Sequential cochlear implantation in children – does age at second implant matter

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A sensitive period for the normal development of hearing exists in humans, although the exact length of this period is unclear. A significant body of research suggests that the auditory cortex of children with severe/profound Sensorineural Hearing loss (SNHL) is poorly responsive to auditory stimulation by the age of seven to eight years if adequate auditory function is not developed by this age.

The recognition of this critical period for the acquisition of hearing in the early years has led to worldwide implementation of newborn hearing screening programmes, which aim to screen, diagnose and treat congenitally deaf children by the age of 6 months. There is considerable evidence that these programmes provide better speech and language outcomes for children with severe and profound SNHL, and the earlier children receive cochlear implants (CI) the more rapidly and closely the implanted children approach the speech and language capabilities of their normally hearing peers.

There is ongoing pressure to provide bilateral CIs in children with congenital SNHL, and most Australian states have adopted this approach. In New Zealand the Ministry of Health funds bilateral electrode insertion for eligible children with profound post-meningitic deafness. This was justified as an insurance policy for these children, because in the presence of a contralateral ossified cochlea, a unilateral electrode failure is likely to mean that no further surgical therapeutic options are available. However the Ministry does not fund provision of the external processor or mapping and habilitation for the contralateral ear.

This policy led the author to review the medical literature to determine the maximum safe waiting period after the first CI and contralateral electrode is inserted until a child with bilateral severe profound SNHL should be offered a second processor? The results of this review are presented and discussed.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation
1415-1430

Pathways to cochlear implantation following identification of hearing loss from newborn hearing screening

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The introduction of Universal Newborn Hearing Screening has resulted in an increased number of families accessing early intervention services with their very young children. This presentation will describe the multidisciplinary team involved in the care of these children. Case studies of children identified through screening will be discussed. We will look at the pathway to cochlear implantation for these children and their parents and professionals involved in their care. These include a baby who received simultaneous bilateral cochlear implantation at 8 months of age and unilateral implantation in a toddler with auditory dys-synchrony. Video clips will be used during the presentation to demonstrate the progress these children have made following a developmental approach to their speech and language development in an Auditory-Verbal therapy Early Intervention Program.

NOTES

Concurrent Session 3A: Mixed session. Targeted surveillance, late-onset hearing loss and cochlear implantation
1430-1445

Creating a baseline

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The Queensland Hearing Loss Family Support Service (QHLFSS) provides services to families identified with a permanent hearing loss through Universal Newborn Hearing Screening. The QHLFSS commenced service in 2008 with a vision to "support families to optimize the quality of life and potential of children with a permanent hearing loss."

Developing a quality service in a sector rich with varied and sensitive cultural and communication norms has not been without its challenges. A specialised service has emerged that is seen as the unique in providing support services to families whose children have a permanent hearing loss.

With the following founding principles in the QHLFSS Mission statement to -
"Work in partnership with families and professionals. Facilitate access and engagement to services which will promote health and well being for children and. Utilise a family centred philosophy based on the delivery of comprehensive, unbiased access to objective information".

While also providing high quality services to families, the QHLFSS has engaged in a rigorous process of service development and quality management.

In 2011 the QHLFSS Service Model was created to articulate the model of care and lay a foundation for future goals of the service. The Service Model has created a template against which the service can be measured and evaluated, enabling an informed approach to service development.

A quality Clinical Audit was carried out in 2012 to measure the service against set criteria as described by Australian Health Care standards, the QHLFSS Model of Service and proposed National Newborn Hearing Screening Standards. The audit also identified service components relating to consumer/family engagement.

This presentation describes this Clinical Audit process and identifies emerging issues and strategies for the future development of the service and its clinical practice.

NOTES

Concurrent Session 3B: Supporting families – Part II
1300-1315

Parents and deaf and hard of hearing adults: supporting families in screening programs

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Two recently established programs are providing families with newly diagnosed children valuable support from both parents who have experience raising a child with a hearing loss, and adults who have grown up with a hearing loss. These programs are helping families broaden their understanding of deafness while gaining support, inspiration and encouragement from those with lived experience. Families are able to talk to parents who have an older child with a hearing loss, as well as meet adults who have had a hearing loss since childhood and are now living fulfilling lives, working, travelling, studying, or raising families of their own. These adults come from different walks of life, and use different technologies and communication methods including speech, sign language, or a combination of both.

The feedback from participants in both programs has been overwhelmingly positive, with families reporting such impacts as feeling more reassured and confident about their child's future, feeling that they have a better understanding of deafness and what their child might go through, feeling inspired by meeting such positive people, and feeling less alone. Whilst still in their early days, both programs are proving to be valuable and worthwhile complements to the professional services newly diagnosed families receive.

NOTES

Concurrent Session 3B: Supporting families – Part II
1315-1330

The experiences of hearing siblings when there is a deaf child in the family

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When a child is identified as deaf, intervention services typically focus on parents and the deaf child. In New Zealand and internationally little has been written about the experiences of hearing siblings when there is a deaf child in the family. Marschark (1997) suggests that we know very little about how sibling relationships might be affected when one child is deaf. It is still unclear whether hearing siblings experience negative affects when there is a deaf child in the family or whether relationships with deaf siblings are warm and close with a special understanding.

This presentation will describe a current New Zealand study investigating the experiences of hearing siblings of deaf children. Preliminary findings to be presented include: Information on specific approaches and strategies parents use to ensure sibling experiences are typical and affirming. Understanding the experiences of deaf and hearing siblings will better inform the services that professionals provide to hearing siblings and families when a child is identified as deaf.

NOTES

Concurrent Session 3B: Supporting families – Part II
1330-1345

The Victorian infant hearing screening program early support service

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The Victorian Infant Hearing Screening Program (VIHSP) Early Support Service provides support and information to families whose child was referred for further hearing testing following a refer result on the VIHSP hearing screen. Ongoing support is provided to families whose baby has a subsequent diagnosis of hearing loss. The philosophy of the service is to provide independent, unbiased, family-centred and child-focussed support and assistance. Facilitating families to make informed and timely decisions that provide for optimum communication outcomes for their child is a priority of the service.

An independent evaluation was carried out to assess the performance of the service in the first year of operation (September 2010-August 2011). Data was collected from three main sources: stakeholder feedback collected by online questionnaire; family feedback collected by mail questionnaire; and service database audit. As part of the evaluation, families described the role the Early Support Service played in navigating the pathway from screen to diagnosis, through to engaging early intervention services (for whom those services were applicable).

While the feedback from families was largely positive, families were able to offer recommendations for improving the service. Additional recommendations were also made as a result of stakeholder feedback, and the service database audit, many of which have now been implemented. Common themes including the influence of the family's cultural perspective, readiness to engage with services, and the importance of cross collaboration with stakeholders, will be explored.

NOTES

Concurrent Session 3B: Supporting families – Part II
1345-1400

Coordinated tertiary care: childhood hearing clinics Queensland

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In Queensland approximately 120 children are diagnosed each year with a permanent hearing loss through the Healthy Hearing Program (UNHS). The degree of hearing loss is not the single factor in determining functional outcomes for these children. Access to early intervention when the child is very young is ideal so the child can utilise the brain's sensitivity to auditory input. With a focus on early intervention the establishment of the Childhood Hearing Clinics (CHC) in Queensland in August 2011 has enabled the parent early access to a multitude of health professionals. Currently three multidisciplinary CHC clinics exist with two in Brisbane at the Royal Children's Hospital and Mater Children's Hospital and one in far North Queensland in Townsville. The clinics provide the initial medical investigations and consultations, developmental assessment, early amplification and opportunities for early intervention from allied health and other external agencies as well as referral to other Specialists as required. These services are provided in a series of three to four sessions for infants less than 12 months of age. Benefits of the clinic include: reductions in the appointment attendance required of families; streamlined care; consistent information for families; and enhancing the parent's capabilities to address their child's emerging needs in a holistic timely manner. Waiting list for admission to CHC is minimal with appointment times achieved within 2 to 4 weeks from point of diagnosis confirmation and referral. The majority of children first access the clinic at 2 to 4 months of age with most referrals seen by 6 months of age. With over 140 families through the Brisbane clinics alone since clinic inception, the coordinated Tertiary care in a multifaceted approach is proving to be both valued and popular. Multidisciplinary clinics can provide a model of care that is best practice in providing optimal quality care for children with a permanent hearing loss.

NOTES

Concurrent Session 3B: Supporting families – Part II
1400-1415

Cultural issues in hearing screening

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Australian Indigenous children, both Aboriginal and Torres Strait Islander, who are between birth and three years of age have an incidence of hearing loss that is three times greater than that of non-Indigenous children.

The Queensland Hearing Loss Family Support Service (QHLFSS) since its inception in 2008 has played an active role in regional areas developing sustainable community networks across the hearing loss sector in particular for services linked with Indigenous families. Through the collaboration and work one such community network - the Northern Partnership Group the need for an Indigenous Community Development worker was identified and a business case was put forward for its establishment.

In 2011 the QHLFSS successfully engaged an Indigenous Community Development Worker (ICDW). The purpose of the role to effectively engage Aboriginal and Torres Strait Islander hearing-impaired children and their families in a timely manner to mitigate the impacts of hearing loss on speech and language development, school readiness, educational achievement, social inclusion, mental health and subsequent whole of life outcomes.

This presentation will highlight the work of the ICDW through the Community Development Framework. This Framework is described through the community development work currently being undertaken by the ICDW with the commitment of Lockhart River Aboriginal Community. Lockhart River is located 535km north of Cairns, Queensland, Australia. Providing specialist hearing loss services, to this remote area brings many challenges including coordination and collaboration between services against a background of cultural values, traditions and sensitivity in a remote location.

NOTES

Concurrent Session 3B: Supporting families – Part II
1415-1430

The evaluation of a 2000Hz auditory steady state response newborn hearing screening protocol

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Achieving the recommended referral rate of <4% in newborn hearing screening programmes, current screening techniques, namely AABR and Screening OAE (sOAE), have attained 100% sensitivity and 95% specificity rates in hearing loss detection (JCIH, 2007). However, current techniques remain to present with limitations, such as failing to detect single frequency hearing losses and markers for progressive hearing losses, implying that the identification of congenital hearing losses can still be improved (Leigh, Schmulian-Taljaard & Poulakis, 2009; Norton et al., 2000).

Over the last decade, clinical findings have validated the potential application of Auditory Steady State Responses (ASSRs) in newborn hearing screening (Rance, 2008; Perez-Abalo et al., 2001). Due to the technique's objective, frequency specific and rapid hearing threshold detection abilities (JCIH, 2007), the purpose of the study was to generate knowledge on a 2000Hz ASSR screening protocol's sensitivity, specificity and screening time by following a quantitative, comparative-descriptive research design.

The performance characteristics of a 2000Hz ASSR protocol presented at 30dB nHL, 40dB nHL, 50dB nHL and 60dB nHL were compared to that of AABR and sOAE when all three methods were performed on healthy neonates between 2-28 days of age (n=52 ears). Results concluded that all four ASSR intensity levels achieved 100% sensitivity and 25%, 55%, 88% and 94% specificity rates, respectively. AABR presented with 100% sensitivity and 80% specificity rates, whereas sOAE presented with 100% sensitivity and 65% specificity rates in hearing loss identification. Additionally, ASSR obtained the lowest median test time of 1:05 minutes, followed by sOAE's 1:24 minutes and AABR's 2:32 minutes.

Although ASSR presented with the lowest median test times, early results conclude that its sensitivity and specificity values were comparable to those of AABR and sOAE when presented at 50dB nHL and 60dB nHL. It therefore compares equivalent to the current techniques, as it is not able to reliably detect mild hearing losses in the newborn population.

NOTES

Concurrent Session 3B: Supporting families – Part II
1430-1445

Workshops for parents of children with unilateral/mild hearing loss identified through UNHSEIP programme

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2. *Ministry of Education, Wellington, New Zealand*
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The levels of incidence for hearing loss in new born children range from 0.36 to 1.30 per 1,000 for mid bilateral hearing loss and 0.8 to 2.7 per 1,000 for unilateral hearing loss. (Dalzell, et al., 2000; Johnson et al., 2005; Watkin and Baldwin, 1999; White et al., 1994).

Many children with unilateral and mild hearing losses are identified few months after birth through Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP). There are number of compelling evidences to show that early identification and intervention of hearing loss results in very favourable outcomes and with the introduction of UNHSEIP, we have an opportunity to intervene earlier for children with Unilateral Hearing Loss (UHL) and mild hearing loss(MHL) and alleviate/reduce the impact on speech and language development, learning and psychosocial issues.

This workshop was held on 26 Feb 2012 in order to educate and support the parents of infants/children with unilateral and mild hearing loss in the Capital and Coast District Health board(C&C DHB) region, by making them aware of the risks and the difficulties associated with unilaterial and mild hearing losses. The parents of 7 affected children attended the workshop. The information was presented by the Audiologist, Advisor on deaf children, Speech and Language therapist and an Acoustician. This information was also shared with hearing screeners highlighting their role in identification of hearing loss and facilitating better outcome.

This workshop covered various topics on difficulties experienced by the children with unilateral and mild hearing loss, effects of child's hearing loss on speech-language development, bilingualism, and potential learning issues. The information was also provided on facilitating better learning at home, crèche /preschool, including strategies to enable a more "listening friendly" environment. The available treatment options such as conventional hearing aids, Frequency Modulating (FM) System, Osseo integrated Auditory Device, Contralateral Routing of Signal (CROS) aid were discussed. The parents were also provided with information pack consisting of speech and hearing checklist, glue ear and prevention, speech and language stimulation at home and methods of making home a "listening friendly" environment. After the workshop, the parents would like to have a support group for children with unilateral/ mild hearing loss in this region.

NOTES

Are we on track? An effective early intervention programme by using a trans-disciplinary approach to universal newborn hearing screening and early intervention programme (UNBHSEIP)

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Introduction:
The UNHSEIP aims to identify newborns with hearing loss early so they can access to appropriate assistance as soon as possible, leading to better outcomes for these children as well as their families/whānau and society. The age at when children begin to have access to language and communication and the characteristics of the intervention are the primary cause of better outcomes. Screening is the avenue through which access to quality intervention is made available. [Yoshinaga-Itano (2004)]. There are number of compelling scientific evidences show that age of identification of hearing loss is reduced, that age of intervention initiation is lowered, and that the outcomes of intervention are better because of the establishment of a New-born hearing screening and Early Intervention programmes

Aim:
The aim of this data analysis is to analyse the effectiveness of hearing screening and early identification programme in CCDHB region.

Methods:
The study would involve the collection of data from Capital Coast District Health and The Ministry of Education on the number of babies born between July 2009 and July 2012, number of babies screened, number of babies not screened, the number of babies identified with SNHL/AN, the time between screening and identification and the time between identification and intervention from an AODC. Comparative analysis was also performed on a similar size region.

Results:
1) It is important to have a coordinated team approach to hearing screening, diagnosis and early intervention strategies to produce better outcomes for all children. 2) Highlights the importance of the role of Advisor on deaf children (ADOC) and the speech and language therapist in translating audiology into auditory approach for the children and the parents of the children identified with hearing loss.

Conclusion:
A well-coordinated trans-disciplinary approach is necessary for better outcomes for all children identified with hearing loss through UNBHSEIP.

NOTES

Association of high risk factor for hearing loss and initial hearing screening result in a tertiary care hospital at South India

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Refer result in first screening often heightens the anxiety in parents. It has been reported by Pereira et al (2007) that specific risk factors are more likely to be associated with 'Refer' result in initial Newborn Hearing Screening (NHS). However, the association of risk factor varies with different countries and available medical technology. Hence, it is important to study this association at a tertiary care hospital where large proportions of babies are from NICU referrals.

The current study analyses the association of high risk factors with the initial results of NHS in a tertiary care hospital. Data from 1653 babies screened from April 2011- August 2012 were extracted from the medical records. Initial hearing screening was done between 10 days and 1 month of age. Information on risk factors was collected as a part of the protocol. DPOAE was the primary screening tool to screen all babies. BERA screening was done only for babies with hyperbilirubinemia (>13 mg/dl) and NICU stay for >5 days.

Among 1653 babies screened, 753 are with risk factors and 900 babies are without risk factors. 147 babies obtained 'Refer' result of which 85 had risk factors for hearing loss. On analysis, the presence of one or more risk factors have significant association with 'Refer' results (OR of 2;CI=1.12,1.51;p=0.002). Risk factors such as craniofacial anomalies, preterm birth, LBW and NICU stay were the significant factors related to the possibility of 'Refer' result. Combination of preterm and LBW has two times more chances of obtaining 'Refer' result. Results of the current study can be used to sensitize the medical professionals and parents about the high possibility of 'Refer' results and therefore prepare parent adequately for follow up if necessary.

NOTES

It all starts with screening: Long term audiological, speech, language and pragmatics outcomes after early intervention

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2. *Macquarie University, Sydney, NSW, Australia*

Ongoing research on the longitudinal educational and social outcomes of children with hearing loss in school systems is necessary for professionals working with children in these settings to determine the optimal type and amount of support required. Empirical data on performance by this population also provides an evidence base to guide government lobbying and policy development and facilitates continuous quality improvement in early intervention programs.

A group of over 150 children between the ages of birth and twelve years of age were assessed on a range of standardized speech, language and pragmatic development tools measures over a 10 year period. All of the group attended the same Auditory-Verbal Early Intervention Program in Sydney, Australia before transitioning to mainstream school.

The outcomes indicate the long-term listening, speech, language and pragmatics skills for children transitioning to school are varied. Individual trajectories of children's rate of progress showed that for children entering the main stream schooling environment with above average scores in language continued to do well, however as a group, children with standard scores of under the typical mean struggled to maintain age appropriate levels. A range of factors were investigated and their complex interaction, impact and possible influence on this group will be discussed. In addition, the pragmatic levels of a group of 30 children with hearing loss graduating from early intervention in 2012 will be discussed. Review of these outcomes and variances provides the evidence base for focussing and planning effective support services for children with hearing loss in the long term.

Attendees will gain an understanding of the long term outcomes for children with hearing loss developing spoken language in Australia and an understanding of the factors that impact on these outcomes, so as to be able to apply this in the development of support systems that facilitate optimal educational outcomes for children identified with a hearing loss.

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Concurrent 1C: The DHB Newborn Hearing Screening workshop
Friday 17 May

1215-1230	Lunch in Workshop Room
1230-1400	Role play in everyday situations: • Screening under pressure • Giving results • Working with other health professionals
1400-1415	Short break
1415-1515	Getting it right from the start: the role of screeners in contributing to positive outcomes for children and families • Screening in the UK • Videos of real-life experiences
1515-1530	Afternoon tea

NOTES

Concurrent 2C: Paediatric Audiology Professional Development Workshop
Saturday 18 May

0830-0850	Introduction and update on changes including LittleEars, issues with the UNHS programme
0850-0935	Update on UK programme and measures put in place for areas of weakness e.g ABR
0935-0955	Management issues for complex populations e.g down syndrome, cleft palate and draft of a national protocol for audiological assessment
0955-1105	Case examples and development of national protocols
1105-1110	Wrap up
1110-1130	Morning tea

NOTES

Concurrent 3C: Early Intervention Workshop
Saturday 18 May

1300-1500 The philosophical framework of Informed Choice: from theory into practice in Early Intervention

This session will explore the theoretical framework and principles of informed choice and the challenges of translating philosophy into practice in early intervention and support for families.

Decision making has been remarked upon as an enduring experience of parenting a deaf child (Des Georges 2003) and with the advent of newborn hearing screening, choice and decision making have become part of parents' earliest experiences with their deaf child. The compressed time frame now encountered by parents from screening through to diagnostics, medical investigations and on to early intervention means that families meet an array of professionals from a variety of different disciplines and in a range of contexts, sometimes with polarised or potentially conflicting advice to give. How can professionals ensure that their practice facilitates and supports families in making informed choices for their child and for themselves?

Drawing on the wider research on informed choice and decision making, and the findings of a two year research and development project funded by the English Government which culminated in published guidance for professionals and a comprehensive handbook for parents, the session will discuss and interactively explore the underpinning elements of Informed Choice to focus on how early intervention professionals can work to make Informed Choice a reality for families of deaf children.

NOTES

General Information

Accommodation
Delegates who have booked accommodation via the Conference Managers (Conference Innovators) should ensure your account is settled in full prior to your departure.

Airport Transfers
There are a number of companies that provide transport to the airport. Should you wish to pre-book, contact one of the companies listed in the telephone directory or see the staff at the registration desk who will be pleased to assist.

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Central city banks are open Monday to Friday 0900-1700. The nearest ATM to the Rendezvous Grand Hotel is ASB Bank Limited, 68 Victoria Street West, Auckland Central 1010.

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Please note all car parking is subject to availability.

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2-3 hours $15	4-5 hours $24
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Morning tea, lunch and afternoon tea is included in delegates' registration fees. All catering breaks will be held amongst the industry exhibition. If you have advised the Conference Innovators regarding special dietary requirements you will receive special instructions in your registration pack.

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Individual hearing loop units are available from the AV technician desk located in the ballroom. These are available for keynote sessions only. Please see the technician for assistance.

Live captioning will be provided for keynote sessions. Captioning can be viewed on the large screens or can be streamed directly to iPads and tablets.

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Please wear your name badge at all conference sessions and at the social function. Tickets are required for entry to the conference dinner.

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Interpreters will be signing the plenary and concurrent sessions throughout the conference. Please note workshops will not be signed.

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Telephone: 021 223 3575

The desk will be open at the following times:

Friday 17 May	0800-1800
Saturday 18 May	0800-1530

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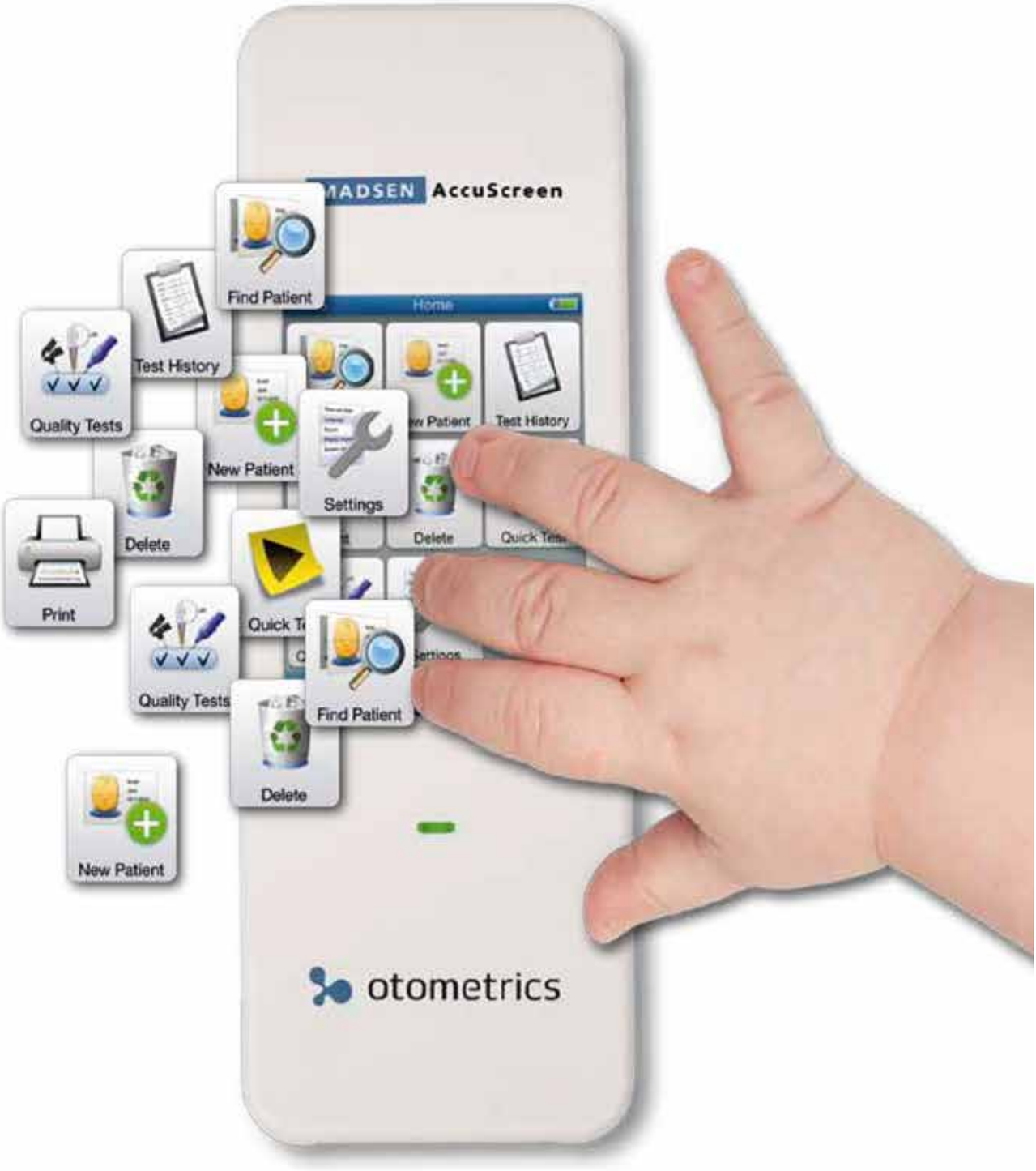
Newborn Hearing Screening gets a "touch" more intuitive



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