

# PROJECT HIEDI

## NEWSLETTER

For archives [click here](#)

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### In this update:

- 1) [Progress and News](#)
- 2) [Media Release National Screening Unit](#)
- 3) [New Literature](#)



## 1) PROGRESS AND NEWS

Project HIEDI members have continued their participation in both the Implementation Advisory Group and its subgroups over the past few months.

The Workforce Working Group has met a number of times since our last update, to discuss the development and training needs of the workforce. HIEDI has good representation on this group, including through our Project Leader, Professor Peter Thorne, who is Chair of this group.

Another area of particular interest for our group is monitoring and evaluation of the screening and early intervention programme. This is to be discussed at some length during the upcoming Implementation Advisory Group on the 19<sup>th</sup> of May.

HIEDI also looks forward to our continued involvement in the Group Special Education Reference Group, and its working groups, including the newly formed group focused on visual resources.

We hope you enjoy this Project HIEDI update, which includes an update regarding implementation of the national newborn hearing screening and early intervention programme. We have also included information about upcoming international conferences and a press release following Greg Leigh's visit to New Zealand for the National Screening Unit's recent symposium on screening in Wellington. As usual, we have included a selection of new literature in the last section of the update.

### Further information

Those parents or professionals wanting further information about progress towards a national newborn hearing screening and early intervention programme should visit the website of the National Screening Unit or can contact the National Programme Manager, Vickie Rydz or Mark Hutton from Group Special Education. Vickie Rydz can be reached at [vickie\\_rydz@moh.govt.nz](mailto:vickie_rydz@moh.govt.nz) and Mark Hutton at [mark.hutton@minedu.govt.nz](mailto:mark.hutton@minedu.govt.nz).

### JOINT MINISTRIES UPDATE

12 May 2008

Submitted by Vickie Rydz (Programme Manager, Ministry of Health) and Mark Hutton (Senior Advisor, Operations Policy, Group Special Education, Ministry of Education)

### Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)

Following on from the first phase of implementation in Waikato, Tairāwhiti and Hawke's Bay District Health Boards (DHB's), contract negotiations are underway with nine DHBs that have expressed interest in a 2008/2009 roll out. Contracts are expected to be in place as of 1 July 2008. The start date for screening will be dependent on DHB staff attending the Ministry of Health (the Ministry) funded newborn hearing screening training and upskilling training of audiologists working within the UNHSEIP.

Starting the end of May 2008, the Ministry will begin meeting with those DHBs that have indicated a 2009/2010 roll out. The Ministry of Education (MOE) continues to work with the Ministry of Health with respect to implementation planning to ensure early intervention services will be available to newborns detected with a hearing loss when the DHBs begin their screening programmes.

### **Workforce development**

In early March, the Ministry sought Registrations of Interest from organisations for the development and delivery of training for newborn hearing screeners and upskilling training for audiologists who will be working within the UNHSEIP. Requests for Proposals were sent to those organisations that expressed interest in providing this training. Their presentations to the UNHSEIP evaluation panel took place in early May. The Ministry anticipates that negotiations for the provision of these services will be underway by the end of May.

Following the recent survey of the Adviser on Deaf Children workforce, priorities for professional development were identified. These priorities focus on the skills and knowledge Advisers on Deaf Children need to work with babies and very young children with hearing loss, and their families. A second survey of the wider early intervention workforce (including Speech–Language Therapists and Early Intervention Teachers) will shortly take place. Following collation of the results from this survey, the MOE will develop a workforce professional development plan to address training priorities.

### **Resources**

The Ministry will be contracting Learning Media Limited (LML) to develop newborn hearing screening resources for parents, families and whānau. LML will be pre-testing these resources with parents and families/whānau. Deaf and hearing impaired parents will be included in the pre-testing groups.

A draft visual communication plan has been developed by an MOE Visual Communication Advisory Group which met in late March. The draft plan arose from the advice, information and direction given by the advisory group members comprising representatives from:

- Deaf Association of New Zealand
- The Deaf Education Centres
- New Zealand Federation for Deaf Children
- Project HIEDI
- Districts providing early intervention services to children and families following Universal Newborn Hearing Screening
- The MOE Newborn Hearing Screening Project Team.

The focus of the plan is to identify the new visual resources needed to support families to improve their children's visual development and to assist their children acquire language. The plan recognises that the visual communication strategies used by deaf parents with their deaf children offer valuable insights to hearing parents of how they can enhance the effectiveness of their communication with their children with hearing loss.

### **Programme Evaluation Measures**

The MOE Special Education has undertaken preliminary work on the issues that surround the measurement of outcomes for children who have received early intervention services following screening. An advisory group will meet in May to discuss these issues and to give some initial advice on what might be measured and how it might be measured.

A group of Advisers on Deaf Children from around the country were trained in January by Sue Lewis, the project leader for the development of the *Monitoring protocol for deaf babies and children*. This training enables them to deliver one day workshops to parents and professionals wishing to know more about the use of this monitoring tool. The MOE Special Education is currently finalising the training materials that the presenters will need when delivering their workshops.

## **BEYOND NEWBORN HEARING SCREENING: INFANT AND CHILDHOOD HEARING IN SCIENCE AND CLINICAL PRACTICE**

**19-21 June 2008, Cernobbio, Italy. Villa Erba Congress Centre  
Cernobbio (Lake Como), Italy**

The 'NHS2008' Conference will include keynote addresses as well as poster presentations, round tables and platform communications by colleagues from throughout the world, in a truly international framework. [Gary Rance](#) and [Ed Rubel](#) are the keynote speakers at the 2008 conference.

Representatives from the Ministries of Health and Education will be attending this conference along with a number of others working within this field. Project HIEDI's Manager, Janet Digby is also attending this conference and will include information about the conference in future editions of this newsletter. **Project HIEDI would like to thank GN ReSound for their generosity in providing funding to make attendance at this event possible.**

### **NCHAM Workshops**

#### **Investing in Family Support: A Workshop (October '08)**

**6pm Sunday, October 19 to 1pm Tuesday, October 21, 2008**

**Raleigh Marriott Crabtree Valley**

**4500 Marriott Drive**

**Raleigh, North Carolina 27612**

A dynamic and interactive meeting for EHDI Coordinators and other individuals interested in developing a stronger system of family support specifically directed to meeting the needs of families of children with hearing loss.

This meeting will address the following questions: How do you:

- Build a family's knowledge base and decision making skills so that they are empowered to take "next steps" and access services for their child?
- Help parents learn how to educate their pre-existing support network of family, friends, and community?
- Work in partnership with families to support their child's development?
- Expose parents and children to helpful role models, and formalized parent input/participation in the system?

#### **Diagnostic and Amplification for Children and Toddlers**

**When: August 5-8, 2008**

**Where: Arizona School of Health Sciences - Mesa, Arizona**

A.T. Still University and the National Center for Hearing Assessment and Management (NCHAM) announce an exciting opportunity for you to enhance your knowledge and skills in the assessment of hearing loss for infants and strategies to ensure appropriate amplification and intervention for infants and toddlers with hearing loss. This training combines on-line preparation with a four day session emphasizing clinical procedures and hands-on practicum.

- The course is broken into two sessions.
- There is on-line preparation for all sessions. Following completion of the chat rooms, there is an exam to measure understanding of the on-line preparation materials.
- Session I and the Full Session require a practicum following the workshop.
- Application has been made for AAA Continuing Education Credits.

## 2) MEDIA RELEASE – NATIONAL SCREENING UNIT

### **MEDIA RELEASE NATIONAL SCREENING UNIT For Immediate Use Tuesday 15 April 2008**

Newborn hearing screening transforming the lives of deaf children

The combination of newborn hearing screening and other developing technologies promises to qualitatively change life expectations for children who are born with impaired hearing, the National Screening Unit's conference was told today.

Professor Greg Leigh from the Royal Institute for Deaf and Blind Children and the University of Newcastle told delegates in Wellington that the most notable among these developments has been the increasing accessibility of cochlear implantation. Since universal screening was introduced in New South Wales, the age at which children receive a cochlear implant has been consistently falling.

"Research shows that the speech and language abilities, reading, social and emotional development, and academic attainment of children who have their hearing impairment identified early and receive effective early intervention are all much better than for those whose hearing impairments are diagnosed at an older age.

"Other studies have indicated that there is a particularly "sensitive" period for the development of language skills which extends from birth to around two years of age. If a child is to receive a cochlear implant, ensuring they receive it as early as is practicable during that sensitive period will greatly enhance their chances of age-appropriate development across a range of skills."

While welcoming the vast changes that screening and subsequent technologies like cochlear implants have brought, Professor Leigh also warned that not every deaf child will benefit from the procedure.

"We need to be very sure that in the excitement of what cochlear implants can do, we don't take our foot off the pedal in providing alternative educational options in areas such as sign language interpreting and research because we feel deafness is "fixed" by screening and implants. It is very important we don't compromise the life opportunities of deaf children by hailing newborn hearing screening and new technologies like cochlear implants as all we need to do.

"The challenge of meeting the needs of all deaf children - albeit some groups may be small - is to ensure that access to alternative models of language and social interaction continues while acknowledging the continuing potential diversity in living a life with deafness."

### **Newborn Hearing Screening in New Zealand**

Since 1986 the Ministry of Health has funded cochlear implants for over 400 people in New Zealand, about half of whom were children.

The Ministry of Health and the Ministry of Education have been working jointly to implement a free newborn hearing screening and early intervention programme. Roll out of the programme began in July 2007 with three District Health Boards (Waikato, Hawke's Bay and Tairāwhiti). The remaining 18 District Health Boards will begin their programmes over the next two years. By 2010 newborn hearing screening will be provided for all District Health Boards.

More information about the Newborn Hearing Screening Programme is available on the National Screening Unit website: [www.nsu.govt.nz](http://www.nsu.govt.nz)

### 3) NEW LITERATURE

#### **Outcomes and Efficacy of Newborn Hearing Screening: Strengths and Weaknesses (Success or Failure?)**

**Authors:** Korres S, Nikolopoulos TP, Peraki EE, Tsiakou M, Karakitsou M, Apostolopoulos N, Economides J, Balatsouras D, Ferekidis E.

**Source:** Laryngoscope. 2008 Apr 7 [Epub ahead of print]

**OBJECTIVE:** To assess the outcomes of neonatal hearing screening with regard to the final diagnosis in a very large number of newborns and investigate related strengths and weaknesses of the program. **SUBJECTS::** In this study, 76,560 newborns were assessed.

**METHOD:** All neonates were assessed using transient evoked otoacoustic emissions (TEOAEs).

**RESULTS:** From the 76,560 neonates screened, 1,564 (2%) failed the test. According to the screening protocol, all parents of failed neonates were asked to bring their children 1 month following discharge to repeat the test. Of the 541 (34.6%) newborns who repeated the test, 303 (56%) were found normal and 238 (44%) again failed TEOAE. The latter children were referred to two special public centers for full audiology evaluation. In addition, 124 neonates were also referred due to other reasons revealed in the screening process (family history, high levels of bilirubin, etc.). Of the 362 children who were referred to the two special audiology centers, 113 (31.2%) were evaluated by these two centers. In addition, 42 children who had failed initial screening and did not show up for a follow-up appointment to repeat TEOAE were also assessed in the same centers. Of the 155 children who had a special audiologic evaluation, 56 (36.1%) were found to have hearing loss (HL) and 99 (63.9%) normal hearing. In detail, 28 had bilateral sensorineural HL greater than 40 dB, 10 had unilateral sensorineural HL greater than 40 dB, and 18 had otitis media with effusion or other conductive HL.

**CONCLUSIONS:** Derived from the present study: 1) repeated testing of "failed" newborns in the maternity hospital and before discharge leads to an acceptable referral rate of 2%; 2) the 1-month follow-up of "failed" newborns further limits the false positive results but leads to high rate of newborns lost to follow-up; 3) a dedicated secretariat system should be implemented to follow-up each "failed" newborn and remind parents about their follow-up appointments; and 4) additional measures such as detailed educational material and parental friendly approach should also be implemented.

#### **Newborn hearing screening and detection of congenital cytomegalovirus infection.**

**Authors:** Stehel EK, Shoup AG, Owen KE, Jackson GL, Sendelbach DM, Boney LF, Sánchez PJ.

**Source:** Pediatrics. 2008 May;121(5):970-5

**OBJECTIVES:** The objectives were to determine the frequency of congenital cytomegalovirus infection among newborns who did not pass hearing screening tests or had confirmed hearing loss and to determine how often abnormal hearing screening results were the only manifestation of congenital cytomegalovirus infection.

**METHODS:** Retrospective chart review was performed for newborns who had abnormal hearing screening results and positive urine cytomegalovirus culture results at Parkland Memorial Hospital between September 1, 1999, and August 31, 2004. **RESULTS:** During the 5-year study period, 572 of 79047 newborns (7 of 1000 live births) did not pass hearing screening tests. Cytomegalovirus infection was identified in 24 (5%) of 483 tested infants and 16 (6%) of the 256 infants with subsequently confirmed hearing impairment. Of those 16 infants, 12 (75%) were identified as having congenital cytomegalovirus infection only because of failure to pass newborn hearing screening tests.

**CONCLUSIONS:** Congenital cytomegalovirus infection was present for 6% of newborns with confirmed hearing impairment, and the majority of those infants were identified on the basis of abnormal newborn hearing screening results.

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## **PROJECT HIEDI**

Project HIEDI is run by an independent group established in 2002 to see the introduction of a national newborn hearing screening and early intervention programme in New Zealand. It has a Steering Team of volunteers, and a part-time Project Manager. The Steering Team is: Professor Peter Thorne (Project Leader), Dr Bill Keith, Dr Dianne Webster, Oriole Wilson, Margaret Cooper and Janet Digby (Project Manager).

For further information about Project HIEDI you can contact the Project Manager for HIEDI and author of these updates, Janet Digby by phoning (09) 445 6006 or e-mailing [janet@levare.co.nz](mailto:janet@levare.co.nz). You can also visit the Project HIEDI webpage at the [National Foundation for the Deaf website](#).

## **ACKNOWLEDGEMENTS**

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