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1) PROGRESS AND NEWS

This update includes a progress report from the Ministry of Health, information about the upcoming NHS 2010 conference and abstracts from a selection of newly published articles.

If there is anything in particular you would like me to include in future updates, please don't hesitate to get in touch. I can be reached on (09) 4456006 or by e-mail: janet@levare.co.nz

UPDATE FROM THE NATIONAL SCREENING UNIT

From Vickie Rydz, Programme Leader Newborn Hearing Screening
4 December 2009

2008/2009 Phase Two Roll Out

The Phase Two implementation of the Universal Newborn Hearing Screening and Early Intervention Programme is now complete. Eleven DHBs are offering newborn hearing screening; Hawke's Bay, Tairāwhiti, Waikato, Bay of Plenty, Lakes, Whanganui, Taranaki, South Canterbury, Canterbury, Hutt Valley and Capital and Coast DHBs. This means that the parents of approximately 2,300 babies per month will be offered newborn hearing screening.

2009/2010 Phase Three Roll Out

Implementation planning continues with the remaining Phase Three DHBs who are indicating that screening will start between February and April 2010; Nelson Marlborough, West Coast, MidCentral, Waitemata, Auckland, Counties Manukau, Northland, Otago, Southland and Wairarapa.

Upskilling of Audiologists Working with Newborns

Negotiations have been completed for the provision of upskilling audiologists working with newborns. The Ministry will announce the name of the provider and details as soon as the contract is signed.

Newborn Hearing Screener Training

Screener training continues to be provided by the University of Canterbury. We anticipate another 60 to 70 screeners will be trained by 30 June 2010.

Newborn Hearing Screener Qualification

Careerforce New Zealand is finalising the unit standards for the Level Three newborn hearing screening qualification. Careerforce will manage the process for the qualification to be accepted by the New Zealand Qualifications Authority (NZQA). Careerforce estimates that all going to plan, the qualification will be registered within five months.

While the process for registering the qualification proceeds, discussions with Careerforce, the Ministry and DHBs will continue about the ongoing training, education monitoring and assessment for the qualification.

National Health Board

The National Screening Unit (NSU) sits within the Health and Disability National Services Directorate. As of 9 November 2009, the entire Health and Disability National Services Directorate (which includes the NSU) is part of the new National Health Board which sits within the Ministry of Health. The NSU and its screening programmes including UNHSEIP continue to operate business as usual.

CHANGES WITHIN THE MINISTRY OF HEALTH

As many of you will be aware there have been recent changes to the structure of the Ministry of Health following publication of the [Ministerial Review Group report](#) in July.

The Health and Disability National Services Directorate, which includes the [National Screening Unit](#) (and Disability Support Services, Clinical Training and Public and Personal Health Services) now sits under the National Health Board. We understand that the Deputy Director General will report to the head of the National Health Board and the Director General of Health.

Project HIEDI is happy that the National Screening Unit will remain intact and will continue to have responsibility for screening services within the Ministry of Health.

ANZPOD PARENT PERSPECTIVES

Australia: Coalition group provide parents with a voice on policy development

Source: <http://www.aussiedeafkids.org.au/news.html?id=57>

A coalition of parent groups has welcomed the introduction of newborn hearing screening for all Australian babies announced by the Prime Minister, Mr Rudd, this week. Parents have advocated for newborn hearing screening for many years and, as the core stakeholders in this initiative, they want to ensure that any programs within Australia, reflect world's best practice.

This coalition of parents, called ANZPOD, aims to ensure that parents of deaf and hearing impaired children have a voice in the development of policy around the introduction of newborn hearing screening. Parents have unique insights and perspectives and want to be sure that national standards meet the needs of all families whose child is diagnosed with a hearing loss.

ANZPOD has created a document titled "[Parent Perspectives and Newborn Hearing Screening](#)". Members of ANZPOD will be working with organisations and service providers to inform the debate and policy development.

HEARING SCREENING PROTOCOLS – CHILDHOOD SCREENING

New Zealand: Ministry of Health releases new protocols document for vision hearing screening done as part of the B4 School Check

Source: <http://www.moh.govt.nz/moh.nsf/indexmh/vision-and-hearing-screening-protocols-nov09>

The Ministry of Health have completed a review of the protocols for vision and hearing screening done as part of the B4 School Check. For those who are interested, pages 5-17 contain best practice for hearing screening.

This document should be read in conjunction with the appropriate National Service Specifications, which the Ministry of Health uses to purchase Vision Hearing Screening services from District Health Boards and with the [B4 School Check Handbook for Practitioners](#).

A number of groups and individuals from the hearing sector provided feedback on this document, and it is great to have an amended and updated version of these protocols available.

PRESS RELEASES: DATA AND FUNDING

Scotland: Campaign for data gathering on deaf children receives support

Source: http://www.mediplacements.com/article-18819549-campaign_for_data_gathering_on.html

A campaign to gather data on the number of deaf children in Scotland has gained the backing of a politician, it has been revealed.

In news which may be relevant to newborn hearing screeners, Hamilton South MSP Tom McCabe has announced his support for the initiative.

Although hearing tests for newborn babies were introduced in the country in 2005, there is presently no national register, the Hamilton Advertiser reports.

In support of the National Deaf Children's Society (NDCS) campaign, Mr McCabe has written to South Lanarkshire council and NHS Lanarkshire to ask how many deaf children are being supported in his local area.

"The advent of newborn hearing screening tests in 2005 was a golden opportunity to start a nationally-agreed register of deaf children which would allow us to accurately track and monitor their progress," stated NDCS Scotland director Christopher Ratcliffe.

Established in 1944, the NDCS aims to remove the barriers confronting deaf children in the UK.

AUSTRALIA: LONG WAIT FOR HEARING IMPAIRED

Source: http://www.news.com.au/adelaidenow/story/0,22606,26396868-2682,00.html?from=public_rss

CHILDREN diagnosed with deafness are waiting up to two years for treatment because funding hasn't kept up with demand, parent groups say.

The State Government introduced a comprehensive infant screening program between 2002 and 2006 to identify those with hearing problems before they developed language problems, but community carers say so many have been diagnosed the system can't cope.

The Cora Barclay Centre and Parents of Hearing Impaired South Australia, are lobbying the state and federal governments for more funding for specialists to cut waiting lists.

Cora Barclay Centre development officer Claire Harris said there should be a complete review of how demand created by the screening of infants was being met by the public health system. Private providers were also struggling.

"The system is not healthy, there are long waiting lists for hearing assessments of older children at Australia Hearing and the Women's and Children's Hospital and there is a large increase in younger children waiting because of the early diagnosis," she said.

The screening program was designed to identify children who would have problems with schooling. Parents of Hearing Impaired South Australia spokeswoman Naomi Higgs has written to the Federal Government seeking additional funding for Australia Hearing, part of the federal health department. She cites parents with infants diagnosed by the screening program waiting up to 93 weeks to be admitted to Australia Hearing.

"Clearly the benefits of any newborn screening are severely reduced if children are lost in the system for such long periods of time," she states in her letter.

Ms Harris, who has a 14-year-old son who was diagnosed late because there was no screening program before 2002, said the donations-funded Cora Barclay Centre would soon have to employ another audiologist to meet demand.

"We pushed for universal screening and it is brilliant but you can't roll it out and say, well we can't see you for eight months," she said.

One parent, Jeanette Goldy, said it took almost three months for her daughter Emily, 10, to see a doctor after she identified a hearing problem at home. "It is a really difficult situation . . . to have a child with hearing problems and it is very hard to get treatment," Ms Goldy said.

Health Minister John Hill said he had been advised that, on average, children are treated for hearing impairment in five weeks and severe cases within two weeks.

"It's disappointing that Parents of Hearing Impaired South Australia has raised these claims in this way," he said. "I met this group three weeks ago and they didn't raise this issue."

2) INFORMATION FROM CONFERENCES AND PRESENTATIONS

NHS 2010 – BEYOND NEWBORN HEARING SCREENING: INFANT AND CHILDHOOD HEARING IN SCIENCE AND CLINICAL PRACTICE

June 8-10th, Lake Como, Italy

Although it doesn't quite seem possible, the next Como Conference is not much more than 6 months away. This conference has been held every two years since 2000 and brings together attendees from many countries. The 2010 conference will include keynote addresses, special sessions, workshops, a number of satellite events, free communications and massive poster sessions.

Main topics for the 2010 conference are:

- Neuromaturation and plasticity
- Genetics of hearing loss
- Auditory Neuropathy
- Cochlear implants
- Technological improvements in diagnosis
- Development in Hearing Devices
- Family empowerment
- Intervention strategies for infants
- Changing criteria for cochlear implantation in early infancy
- Outcome measures of early intervention

Key dates:

Abstract submission: January 25, 2010

Notification of acceptance (oral or poster): March 8, 2010

Early registration: April 12, 2010

Hotel accommodation: April 12, 2010

Special events at this year's NHS 2010 include:

- a series of linked workshops on the theme of "delivering an effective screening programme" from the NHSP England; and
- a special session organised by the International Working Group on Childhood hearing on the state of implementation of EHDI programmes internationally. National and Regional representatives of EHDI Programs from all around the world will present reports on the current situation at this session.

3) NEW LITERATURE

Critical analysis of three newborn hearing screening protocols

Authors: de Freitas VS, Alvarenga Kde F, Bevilacqua MC, Martinez MA, Costa OA.

Source: Pro Fono. 2009 Jul-Sep;21(3):201-6.

BACKGROUND: Having knowledge about the validity of procedures for newborn hearing screening (NHS) is fundamental, once the purpose of these programs is to identify all newborns with hearing loss at an acceptable cost. **AIM:** to estimate the specificity and the false-positive rate of NHS protocols using transient evoked otoacoustic emissions (TEOAE) and automated auditory brainstem response (AABR).

METHOD: participants were 200 newborns who were submitted to a hearing screening test between March and July 2006. Three protocols were analyzed: protocol 1, NHS was carried out in two steps using TEOAE; protocol 2, NHS was carried out in two steps using AABR; and protocol 3, NHS was carried out in one step, using the two procedures - testing with TEOAE followed by a retest with AABR for all the newborns who did not pass the TEOAE testing.

RESULTS: although there was no statistically significant difference when comparing the referral rates to audiological diagnosis obtained in protocols using TEOAE and AABR, the protocol using TEOAE referred four times more newborns. Protocol 3 presented the highest referral rate, with a statistically significant difference when compared to protocols 1 and 2.

CONCLUSIONS: the false-positive rate and consequently specificity were better for the protocol using AABR, followed respectively by the protocol using TEOAE and using both TEOAE and AABR.

Integrating child health information systems in public health agencies

Authors: J Public Health Manag Pract. 2009 Nov-Dec;15(6):451-8.

Source: Laryngoscope. 2009 May;119(5):974-9.

Public health agencies at state and local levels are integrating information systems to improve health outcomes for children. An assessment was conducted to describe the extent to which public health agencies are currently integrating child health information systems (CHIS). Using online technology information was collected, to assess completed and planned activities related to integration of CHIS, maturity of these systems, and factors that influence decisions by public health agencies to pursue integration activities. Of the 39 public health agencies that participated, 18 (46%) reported already integrating some or all of their CHIS, and 13 (33%) reported to be planning to integrate during the next 3 years. Information systems most commonly integrated include Early Hearing Detection and Intervention (EHDI), immunization, vital records, and Newborn Dried Bloodspot Screening (NDBS). Given the high priority that has been placed on using technology to improve health status in the United States, the emphasis on expanding the capability for the electronic exchange of health information, and federal support for electronic health records by 2014, public health agencies should be encouraged and supported in their efforts to develop, implement, and maintain integrated CHIS to facilitate the electronic exchange of health information with the clinical healthcare sector.

Provision of Genetic Services for Hearing Loss: Results from a National Survey and Comparison to Insights Obtained from Previous Focus Group Discussions

Authors: Withrow KA, Tracy KA, Burton SK, Norris VW, Maes HH, Amos KS, Pandya A.

Source: J Genet Couns. 2009 Oct 2. [Epub ahead of print]

Hearing loss is a common sensory deficit and more than 50% of affected individuals have a genetic etiology. The discovery of 40 genes and more than 100 loci involved in hearing loss has made genetic testing for some of these genes widely available. Genetic services for deafness are also being sought more often due to the early identification of hearing loss through newborn screening services. The motivations for pursuing genetic testing, and how genetic services are provided to the client may differ among individuals. Additionally, information obtained through genetic testing can be perceived and used in different ways by parents of deaf children and deaf adults. This study aimed to follow up on focus group studies published earlier with a quantitative survey instrument and assess the preference of consumers for provision of genetic services. We conducted a national survey of hearing and deaf parents of children with hearing loss and of deaf adults. Data was compared and analyzed by hearing status of the participant, their community affiliation and the genetic testing status using nominal logistic regression. Consistent with our focus group results, the survey participants thought that a genetic counselor/geneticist would be the most appropriate professional to provide genetics services. Statistically significant differences were noted in the preferred choice of provider based on the genetic testing status. Parents preferred that genetic evaluation, including testing, occur either immediately at or a few months after the audiologic diagnosis of hearing loss. This data should help providers in clinical genetics keep patient preferences at the helm and provide culturally competent services.

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@leware.co.nz. You can also visit the Project HIEDI webpage on the [National Foundation for the Deaf website](#).

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