

UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE

**Next Meeting
August 13, 2013**

May 14, 2013 meeting minutes - Approval vote taken August 13, 2013

In attendance: Jennifer Bryant (EHDI staff – first attendance), Kelly Dick, Richard Harward, Catherine Hoelscher (10:00-11:00 am), Nita Jensen, Katie Jolma, Charlene Frail-McGeever, Stephanie McVicar, Karen Munoz, Taunya Paxton, Paula Pittman, Harper Randall, Lori Ruth, Suzanne Smith, Sharon Strong, Jill Vicory, Karl White, Shannon Wnek, Erin Zinkhan (proposed NICU representative).

Excused: Krysta Badger, Susie Bohning, Albert Park, Kathleen Pitcher-Tobey, Kurt Randall, Sharon Strong, Sylvia White

WELCOME

Dr. Kelly Dick opened the meeting at 9:09 am. Members as listed above were excused from today's meeting. Introductions were made.

A motion was requested to approve the February minutes. The motion carried with all in favor and with no one abstaining.

Committee Vacancy - NICU representative

Erin Zinkham, MD, was recommended to sit on this committee as the NICU representative (per Utah Code 10-26-6). She was contacted by Dr. Albert Park and she expressed willingness for Committee service. She is in attendance today. Committee vote was opened. The following sixteen members in attendance at 9:20 voted their approval, with no one abstaining (Kelly Dick, Richard Harward, Nita Jensen, Katie Jolma, Charlene Frail-McGeever, Stephanie McVicar, Karen Munoz, Taunya Paxton, Paula Pittman, Harper Randall, Lori Ruth, Suzanne Smith, Sharon Strong, Jill Vicory, Karl White, Shannon Wnek). Majority Committee vote approved Dr Zinkham as a voting member of this Committee.

Public Comment

No comments.

Utah Early Hearing Detection and Intervention (EHDI) Updates

Stephanie McVicar stated that we are currently “on hold” in completing remote auditory brainstem response testing (ABR) with Michele Thompson, midwife, for our tele-audiology pilot. There are three tests yet to be scheduled/completed before fully evaluating the project. Ms. Thompson had recent family obligations that have delayed additional scheduling. We hope to have a few more newborns included in the pilot.

Five regional coordinator meetings were held in March 2013. Kurt Randall and Nita Jensen conducted meetings in Orem, Beaver, Moab, Ogden and Salt Lake. The HiTrack transition to Web-enabled data transfer/management was the main focus. Real-time links to State HiTrack and CHARM data were presented, and attendees were able to ask questions and see the answers with active data. Region specific issues were discussed, also. Twenty-eight of 42 facilities are now using HiTrack Web (HT Web). The two State servers

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hosting the HiTrack system need additional RAM and core added. State IT received this request the end of February, but the project is still pending. When the server update is complete, the remaining hospital systems will begin the transition to HT Web, with the goal of March 31, 2014 as the LAST date for HiTrack Windows.

Bi-annual mandated hospital Program Summaries were due May 1, 2013. There are still several hospitals/program coordinators that have not submitted a current document to State EHDI listing program oversight, equipment, protocol, processes, and referral policies. (Free-standing birth centers and Homebirth Hearing Project midwives did not have a May 1 deadline.) Kurt Randall is working with the remaining hospitals to get the required documents submitted. Karl White asked if, as a Committee, we should be concerned hospitals have not turned in their summaries by May 1st, and contact the hospital CEOs immediately if/when a deadline is not met. This should not be a “flexible” deadline. A letter from this Committee and State EHDI should be sent to delinquent programs on May 2nd with a copy going to the hospital program coordinator. Harper Randall motioned to make the May 2 “out of compliance” letter a policy. The motion was seconded by Karl White. The committee in attendance felt this was an appropriate action. A formal vote will be taken next Committee meeting. Since letters cannot go out May 2 for the current Program Summary cycle, Kurt Randall will contact CEOs/program coordinators soon about their delinquent status.

Legislation on public meetings now requires audio recordings of each of our Committee meetings be posted on the Public Notice website following each meeting. Draft minutes must be posted within 30 days, with the final, approved minutes replacing the draft following committee vote. The website is listed at the bottom of our agenda. Please register at the website to see postings of agendas and minutes for this Committee (<https://secure.utah.gov/pmn-admin/login.html>). You can now see the last 3 years of minutes. This is a new addition.

The 2011 Utah/National report of the Centers for Disease Control (CDC) Hearing Screening and Follow-Up Survey (HSFS) was distributed. (Annual HSFS summary data can be found at <http://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html> .) Utah HiTrack flowchart, the Quarterly Summary report (by facility) and a Utah program overview/report card were also distributed. Krysta Badger has been targeting loss to follow up. Positive outcomes of her efforts in getting results reported and encouraging completion of outpatient screening and diagnostic evaluation are reflected in the report. If you have specific questions on any of the reported categories, please contact Nita Jensen. In reviewing the data, Karl White is concerned that ten small facilities are not very effective in getting babies back in for outpatient screenings and evaluations. (It was noted that while Primary Children’s Hospital is shown on the data list, their efforts are not accurately reflected as their screening/diagnostic results are matched up to birth facility records.) He feels that the small centers could benefit from follow-up activities used by the very successful facilities – maybe a webinar with the efficient hospital presenting to hospitals with low return rates. Karl also queried how many babies are born at home or free-standing birth centers each year. About 1300-1400 babies a year are born outside of a hospital. Screening for that population is recorded at about 72% for 2012, while hospitals screen/report >98%. Rich Harward indicated that screening for that population went from 9% prior to the Homebirth Hearing Project began in 2008 to 72% in five years. Karl feels that population should receive extra support to reach screening/reporting at 95% or greater. Nita reported that two additional midwives have received equipment in 2013 – and midwives are selected to receive loaner equipment based on the previous year’s delivery counts from Vital Records. A list of all free-standing Birth Centers and midwives was requested. Nita will distribute the list to Committee members electronically.

Ideas to improve loss to follow-up were brain-stormed. Harper Randall would like to partner more with the Newborn Screening Program (NSP -heelstick/bloodspot program). The NSP sends out a monthly report card to the hospital pointing out where to improve. This approach has improved their incomplete/loss to follow-up rates. Lori Ruth, USDB, sees a need to re-educate audiologists who make Baby Watch Early Intervention/Parent Infant Program (PIP) referrals. The electronic PIP referral form will be resent to the audiologist/UCOPA list-serve. Taunya Paxton feels that inpatient hospital hearing screening should be more visible – or at least better reported, to parents. Parents need to be aware that hearing screening was done, what results were found, and how to get follow-up, when needed. Karl White offered to provide a conference line if hospital program education is scheduled by phone for the struggling hospitals. Diane Behl, USU, is an effective facilitator and may be willing to facilitate on this type of phone call. Kelly Dick indicated that nursery hearing screeners through his program(s) can now access the audiology office clinic schedule to schedule rescreens for babies/families prior to discharge. This should prevent delays in getting babies back for rescreen.

Utah EHDI is funded by CDC and HRSA EHDI monies. The HRSA Loss to Follow-up grant (in place since 2000) was recently cut by 20% (with a note that some monies may be re-instated during the grant year), and the CDC EHDI funding was decreased for the upcoming grant year by the amount of carryover funds from last year. This amounts to approximately one-third of previous EHDI funding. There is a small amount of money from each Heelstick Kit budgeted for Utah EHDI, but there are no other State funds directed to EHDI. Stephanie McVicar is the Project Director for both EHDI grants.

The Utah legislature did NOT fund the CSHCN building block for additional clinic funding this year. This will affect the number of CSHCN itinerant clinics for “rural” children, and possibly the clinic contracts with local health departments.

The Birth Certificate Project is still on hold due to technical issues between Vital Records and CHARM. There is no one assigned to resolve the issue, and there is no money available at this time to pay for the additional programming.

National EHDI Conference

The Annual Early Hearing Detection and Intervention for 2013 was held April 14-16, 2013 in Glendale, AZ. The 2013 Awards can be found at: http://ehdiconference.org/2013/Award_Winners.cfm?yr=2013

The State Stakeholders meeting at National EHDI Conference had a large Utah attendance. Steve Noyce, Utah Schools for the Deaf and Blind (USDB) Superintendent, was shocked at the loss to follow-up numbers. He wanted to know how USDB can help support EHDI activities to reduce the numbers of infants lost to follow-up. The USDB and the Bureau of Children with Special Health Care Needs (CSHCN) discussed rural USDB audiology services, new auditory brainstem response testing (ABR) capabilities statewide, locations, and coverage. There will be a name change to USDB Audiology Services, memo by July 1st. An MOU was developed by Stephanie McVicar to address data/health information sharing. This is a very positive collaboration as there will be more rural audiology support to families. Catherine Hoelscher, Baby Watch Early Intervention (EI), was at that state meeting to talk about collaboration with EI kids that need additional screening after failing newborn hearing and/or initial intake screening but do not qualify for EI enrollment. Follow-up will be tighter to assure that all kids seen for even one evaluation will be monitored or referred out to complete screening. Harper Randall felt that this year’s State Stakeholder’s meeting was a great “focus group”

not just a time to learn other's names and duties. We should continue this format at each year's National EHDI meeting. Steve Noyce was instrumental in securing long-term space at USDB in Ogden for regular Neo-Natal Follow-up Clinics, also. We should write a letter from the committee to thank him.

Shannon Wnek was impressed with the Arizona EDHI educational materials for physicians available at the National EHDI conference. There was some discussion on rescreens being done in primary care offices. Shannon plans activities to target physician education, including ENT providers. Harper Randall also supports efforts to improve and combine our programs with educational information. Stephanie McVicar attended a session reporting on an EHDI study on why families don't get/complete the hearing screening process for their infant(s). Money was the biggest deterrent – no insurance or insurance that does not fully cover test procedures, the high cost of appointments/travel to appointments. The presenters' state has an ENT EHDI champion – different from Utah's pediatrician champion. Physician education was also a priority: posters for "EHDI Ready" for medical offices and training visits to medical offices. Stephanie also attended a session documenting EHDI data upload directly from Vital Records, linked with HiTrack for screening results. There was some information from states that have combined hearing and newborn bloodspot screening programs. She also attended sessions re: an auditory neuropathy study presented by Al Mehl, M.D., and Pediatric Audiology Certification. Karen Munoz reported that the EHDI-PALS website and national pediatric audiologist register was highlighted at the National Conference. It is hoped that this service will be to "go-to site" nationally for all questions in researching or finding an audiologist who sees children. We need to encourage Utah audiologists to enroll. Please review (and/or enroll) at: <http://ehdipals.org/Default.aspx> .

Dr. Karl White will be honored Friday, May 17, 2013 as an Emma Eccles Jones Endowed Chair in Early Childhood Education at Utah State University. The distinction will support the continued work for children with hearing loss by providing additional "clout and credibility", and provide some funds to support research. Dr. White also serves on many national and international advisory groups, including the United States Department of Health and Human Services, March of Dimes, the American College of Medical Genetics and the American Academy of Pediatrics.

2013 Utah Legislative update

Two bills affecting EHDI programs and partners were passed in the 2013 Legislative Session. Both bills become effective July 1, 2013.

HB81, CYTOMEGALOVIRUS (CMV) PUBLIC HEALTH INITIATIVE, sponsored by Representative Ronda Rudd Menlove, mandates CMV testing prior to 21 days of age for any infant not passing the initial and follow-up newborn hearing screening. Rep. Menlove's grand-daughter was diagnosed with hearing loss as a toddler, and etiology studies identified congenital CMV as the cause. The CMV campaign will roll out July 1st and will target the public, physicians/primary care providers who provide care to pregnant women and newborns/infants, and child daycare providers including public, educational, private, and religious sites. The Utah Department of Health is charged with providing the public education for this bill. Stephanie McVicar is the lead on the project. An advisory group to oversee Rule-making, implementation, processes and education was mandated by the Bill, also. A research group is currently working on compiling CMV facts for distribution, lab codes and procedures, and State staff are working on a process. We want to make this process as easy as possible. Additional outside "experts" (possibly through the CHIP network) in the state will be asked for feedback/comments on the protocols during the development process, and protocols will be tested prior to implementation, where possible. Materials will be posted through the MedHome Portal and on the CHSCN website.

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Utah facilities' newborn hearing screening staff will also be educated on the recommended change to have inpatient and outpatient hearing screening completed prior to 21 days to facilitate a timely referral back to primary care to order the CMV lab testing. Rich indicated that a script should be available for staff speaking to families so information is consistent and will help families follow up. Karl wished there was time for parent feedback in this process prior to implementation.

This law is the first in the nation to mandate CMV screening following failed newborn hearing testing. An abstract may be submitted for consideration at the 2014 National EHDI meeting.

Link to HB 81, Utah Code 26-10-10: http://le.utah.gov/code/TITLE26/htm/26_10_001000.htm

Link to CMV educational materials: <http://www.health.utah.gov/cshcn/CHSS/CMV.html>

HB 157- CHILDREN'S HEARING AID PILOT PROGRAM, sponsored by Representative Rebecca P. Edwards, provides funding for a two year pilot ending June 30, 2015, for hearing aids for financially eligible children under three years of age. Medicaid eligible children will continue to apply for hearing aids through Medicaid, and the income/program eligibility for other applicants will be established by a mandated oversight Committee. Administrative Rules will be written to implement the project. The Utah Department of Health CSHCN Bureau will oversee the Pilot.

Link to HB 157, Utah Code 26-10-11: http://le.utah.gov/code/TITLE26/htm/26_10_001100.htm

National /NCHAM updates – Karl White

The 2013 Early Hearing Detection & Intervention Meeting held April 14-16, 2013 in Glendale, AZ, was the largest, to-date, and provided useful and current EHDI information to State EHDI program staff members, Audiologists, Physicians and other Health Care Providers, Families of children with hearing loss, Early Intervention Specialists, Speech-Language Pathologists, Advocates, Representatives from the major organizations working with EHDI programs, and Students. The Conference is co-sponsored annually by:

[AAP](#) - American Academy of Pediatrics

[CDC](#) - U.S. Department of Health and Human Services: Centers for Disease Control and Prevention

[HRSA](#) - U.S. Department of Health and Human Services: Health Resources and Services Administration

[NCHAM](#) - National Center for Hearing Assessment & Management at Utah State University

Conference information/summary can be found at: <http://ehdiconference.org/2013/>

The 2013 Awards can be found at : http://ehdiconference.org/2013/Award_Winners.cfm?yr=2013

An updated EHDI eBook: Resource Guide for Early Hearing Detection and Intervention is available at: <http://www.infanthearing.org/ehdi-ebook/index.html>.

Looking ahead: The 2014 Early Hearing Detection & Intervention Meeting is scheduled April 13-15, 2014 in Jacksonville, Florida. Updates and additional information will be published/available at:

<http://www.ehdiconference.org/>

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The Deaf-mentor project is going well. This project may have a name change, as it is really for children to use American Sign Language (ASL). This is a learning collaborative; processes and activities are shared and feedback is collected on how the project can improve. Utah PIP and Diane Behl, USU, are probable participants.

JCIH EI Supplement

This agenda item was moved to the next meeting as Kurt Randall is ill today. Kurt will coordinate with Paula Pittman and Catherine Hoelscher and prepare a summary of the recent recommendations for the Joint Committee on Infant Hearing Screening on early intervention for infants with permanent hearing loss for the August 2013 meeting.

Parent Support Groups

There are parent support collaborative efforts scheduled in the next three months. Taunya Paxton will provide an update at the next meeting.

The next meeting will be held August 13th 2013, 9-11 am, at the CSHCN building.

This meeting was adjourned by Dr. Kelly Dick at 10:43 am, vote to adjourn requested by Karl White, seconded by Charlene Frail-McGeever.

Mark your calendars for the 2013 meetings: August 13, and November 12. All meetings will be held from 9-11am at the Utah Dept of Health, CSHCN Building, 44 Mario Capecchi Dr, SLC, Conference Rooms C-D.

Meetings for 2014 have been scheduled: February 11, May 13, August 12, and November 18, 2014. Please mark your calendar now for these meeting dates. The November meeting was scheduled for the third Tuesday of the month due to the Veteran's Day holiday on the second Tuesday. All meetings will be held from 9-11am at the Utah Dept of Health, CSHCN Building, 44 Mario Capecchi Dr, SLC, Conference Rooms C-D.

FYI –You may subscribe to notices regarding this Committee on the Utah Public Notice website with instructions at <https://secure.utah.gov/pm-admin/login.html>. Agendas will also be posted on that website at least 24 hours prior to the scheduled meeting.