

UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE

**Next Meeting
November 12, 2013**

August 13, meeting minutes FINAL - Approval vote November 12, 2013 – no changes. (NRJ)

In attendance: Susie Bohning, Jennifer Bryant (CHSS staff), Kelly Dick, Richard Harward, Catherine Hoelscher, Nita Jensen, Katie Jolma, Karen Munoz, Albert Park, Kathleen Pitcher-Tobey, Paula Pittman, Harper Randall, Kurt Randall, Lori Ruth, Suzanne Smith, Sharon Strong, Karl White, Sylvia White, Russell Frandsen (guest - UDOH Budget Officer).

Excused: Krysta Badger, Charlene Frail-McGeever, Stephanie McVicar, Taunya Paxton, Jill Vicory, Erin Zinkhan

WELCOME

Dr. Kelly Dick opened the meeting at 9:08 am. Members as listed above were excused from today's meeting. Introductions were made.

Harper Randall requested a change to the May draft minutes. A paragraph near the end of the section, **Utah Early Hearing Detection and Intervention (EHDI) Updates**, regarding budget cuts was amended to read, "The Utah legislature did NOT fund the CSHCN building block request 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." No other changes were requested. A motion was requested to approve the May minutes. The motion carried with all in favor and with no one abstaining.

Public Comment

No comments.

2013 Utah Legislative update

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

Link to HB 81, Utah Code 26-10-10: **Cytomegalovirus (CMV) public education and testing**

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>

Link to HB 157, Utah Code 26-10-11: **Children's Hearing Aid Pilot Program**

http://le.utah.gov/code/TITLE26/htm/26_10_001100.htm

There have been tremendous efforts through the Utah Department of Health's Children's Hearing and Speech Services Program (CHSS) to develop educational materials, brochures, presentations to implement Utah Code 26-10-10 CMV by July 1, 2013. Stephanie McVicar is the lead for this project and represents the Utah Department of Health on the Advisory Committee for this mandate. Mass email distribution of materials and educational brochures was arranged by Dr. McVicar through partnerships with family physician, pediatrician, OB-GYN/Fetal medicine physician associations, day care licensing and religious groups that offer child care. Webinars and group presentations have also helped educate women, families, and providers of CMV risks to unborn babies and the new state requirements for CMV screening of newborns. Rich Harward stated that there are two parts to this legislation – an educational component and then referral/notice to a primary care provider

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for CMV PCR orders prior to 21 days of life when an infant fails a second hearing screening. Albert Park said that he has noticed that more infants/families seen at the PCMC Hearing Loss Clinic have already completed the CMV testing prior to their appointment with him. Harper Randall indicated that there has been quite a bit of national interest in the new CMV mandate. Karl White stated that the law has also generated interest nationally on the current tests available to screen for CMV. Katie Jolma asked if the CMV testing could be done on the bloodspot screening that is required for all newborns. Harper indicated that is only about 30% accurate. Rich noted that PCMC/Hearing Loss Clinic are requesting bloodspots to be pulled/tested when an infant has a positive CMV test by saliva or urine PCR. Documentation of the referral, testing, and outcomes are currently being requested by fax, but Stephanie will be contacting HiTrack developers to see if a CMV module could be written and added to the HiTrack database.

The Children's Hearing Aid Pilot Program is a two- year pilot project to provide hearing aids and audiology follow-up to eligible Utah-resident children from birth up to three years of age, with \$100,000 appropriated each of those years. The project will be administered through the Utah Department of Health's Children's Hearing and Speech Services Program (CHSS), Stephanie B. McVicar, Manager. An Advisory Committee formed by the mandate is actively completing the Administrative Rule to implement the law. Lori Ruth was thanked for her help in finding a parent/family representative for the advisory committee. There is one more meeting prior to the Rule's final draft. The Rule will then be posted for a 30 day public comment process. Application forms and processes will be in place by the time the Rule is effective. The CHSS is already receiving calls and application requests from families and audiologists. Information and forms will be distributed to all Utah-licensed audiologists, as soon as the Rule is in place and funds are released for the Project. Audiologists requesting funds through the mandate must follow all Utah Pediatric Hearing-Aid Fitting Guidelines. Parents can find eligible Utah providers through the EHDI-PALS on-line directory (www.ehdipals.org). Katie Jolma wondered if information about this mandate can be published in the AAP-Utah Chapter newsletter so medical home providers are aware of services now available to their patients with hearing loss. Harper Randall and Katie will make an inquiry to Cathy Oyler, AAP-Utah.

Utah Early Hearing Detection and Intervention (EHDI) Updates

Of 43 birthing hospitals, 42 have updated and submitted the bi-annual Program Summary required by Utah Code 26-10-6. Kurt has been in contact with the delinquent Program Coordinator, but without success. The Program Summaries are available for review by committee member request through Kurt Randall. There is a webinar scheduled with State EHDI and hospital EHDI programs August 28. There will be a review of the implementation of hospital EHDI referral for CMV-PCR testing, reporting and educational materials. A new re-submission date of October 1, 2013 will then be assigned to add CMV protocols and processes to the EHDI Program Summaries.

The tele-audiology project has not yet reached the goal of completing ten "remote" ABRs. Of the seven completed, it has been shown the testing is accurate, it is the internet that is unreliable. One attempted last Friday was unsuccessful after multiple tries. We are now looking in to using an internet hotspot to continue/complete this project. Since the rural areas are the locations with the most need, and we cannot assure in advance that the internet connection will be stable, we will again contact Daniel Ladner at NCHAM for additional help and training. Karl White approved this support by NCHAM without additional billing.

The Annual Utah EHDI Conference is planned for September 27th, "Ask me About CMV". Both Dr. Park and Dr. Jolma have been asked to present. Dr. Park has a previous commitment to speak out of state, so his

question and answer presentation will be filmed. Rep. Ronda Menlove and family will also be presenting to hospital newborn hearing screening coordinators and supervising audiologists, providing background on how and why the legislation was initiated.

The HiTrack database and web servers have now been upgraded. The delay was attributed to multiple staff changes at State IT and the work order not being re-assigned. There are still reports from users that individual records take a long time to update. Thirty sites are now using HiTrack Web. The confidentiality form will be updated and approved, and the remaining sites will then be strongly encouraged to move to HiTrack Web. It is hoped that all sites will be able to do this by March 31, 2014 before the end of the next hospital/HiTrack contract renewal with NCHAM. 95% of sites are reporting weekly. Cleaning and de-duplicating data is an issue as the data has many missing fields when uploaded directly from the screening equipment. There was also a staffing challenge with Krysta Badger out on FMLA.

Federal funding has been cut for both the CDC EHDI and HRSA Loss to Follow-up grants for Utah EHDI. Recent budget and Progress report were submitted to the CDC –funds not expended during the last fiscal year were not available as carryover this year, but included in the current year’s funding for a total of \$154,000. The HRSA grant was cut by 20% the previous fiscal year and expires March 31, 2013. It is anticipated that a new grant will be open for application; More information will be available at the November meeting. Rich noted that all newborn hearing activities are funded with federal grant monies, there is no state money budgeted for newborn hearing screening.

The audiology agreement with the Utah Schools for the Deaf and Blind discussed at the May committee meeting has not yet been signed/finalized. Paula Pittman announced that Joel Coleman is the new Superintendent of USDB and he is now being oriented to the audiology proposal, and this proposal may again be reviewed with him.

Karl White was reviewing HiTrack reports and opened discussion/brainstorming on hospitals with poor rescreen data for the first two quarters of 2013. Approximately three infants per hundred do not return for rescreen. Shouldn’t there be quicker response/better return rate? There are ten birthing hospitals that are dragging our numbers down. Homebirth screening and reporting should also be much higher – rescreens, too. Nita Jensen stated that follow-up letters and calls from State EHDI have been greatly reduced while Krysta has been on maternity leave. We did have staff assigned to send homebirth letters and follow-up letters but calls were not completed on a regular basis and it has had a detrimental effect on completion of first and second screenings. A recommendation was made to contact these CEOs or screening coordinators in a supportive way. Some hospitals achieve 95%, others not even close. Kurt stated that completed screening should improve July through the end of 2013 with the screening deadlines enacted by the new CMV mandate. Karl then recommended that Kurt, Stephanie, and Nita call these places to get improvement activities in place. This isn’t new information and we shouldn’t wait for the CMV mandate to see if the data improves. We have not been rattling enough chains so to speak in a professional way. Karl made a motion to have someone in State EHDI make phone calls to the screening coordinator for any hospitals 60% or under in the second quarter 2013 regardless of the facility size to ask why the numbers are so low – could it be documentation? Rich Harward suggested that this recommendation be discussed with Stephanie McVicar, State EHDI Director, to initiate additional activities. Harper Randall indicated that Newborn Heelstick has received effective responses to their hospital reports cards, and if the Newborn Hearing report card is distributed soon, it could initiate “rattling the chains” for Newborn Hearing Screening improvement.

Sylvia White asked the status of the Birth Certificate Project. Rich said he had recently spoken with Christine Perfili, CHARM Manager, and she indicated that the program is still not running, but that contact with Vital Records and Jeff Duncan, Health Data, indicates that a test of the production system will be done in the next week, and when that is complete, the alert letters will begin generating at the SLC Cannon Building Birth Certificate office.

Karl made a second motion to closely review homebirths and analyze what can be done to improve screening percentages for those infants. Kurt supervises the Homebirth Hearing Project, so it was recommended that he be assigned to further review the data. Suzanne Smith, the committee midwife representative said she would be willing to work with Kurt on this. This motion was made again, seconded by Sylvia and passed with all in favor with no objections.

JCIH EI Supplement

Early Intervention referral/Eligibility

Catherine Hoelscher presented information on eligibility and services provided through Utah's Baby Watch Early Intervention Services. All infants and children with hearing loss receiving intervention services through the Parent Infant Program (PIP) are part of Baby Watch enrollment, also. If a child in the Baby Watch evaluation/enrollment process fails two OAE screenings, that child is referred to PIP for monitoring until a hearing diagnosis is complete. Most referrals to early intervention come from professional recommendation due to delays. Many services are not therapy services, but educational and parent coaching services. Rural area referrals usually come from primary care providers – sometimes referrals are delayed by “watch and wait” in these areas. There is currently a big national push to inform communities of early intervention programs. More information can be found at: <http://www.utahbabywatch.org/>

National /NCHAM updates – Karl White

The 2014 Early Hearing Detection & Intervention Meeting is scheduled April 13-15, 2014 in Jacksonville, Florida. Pre-sessions begin on Sunday. Updates and additional information will be published/available at: <http://www.ehdconference.org/>. The conference hotel is filling up quickly; rooms should be reserved soon.

The tele-intervention project through NCHAM/Sound Beginnings is being evaluated. If tele-intervention is used for a child only once per month, the costs are higher than a face-to-face visit would cost. However, if there are multiple visits per months, the costs are equitable or lower than face-to-face visits. The take home message: there is no disadvantage to using tele-intervention, and sometimes allows a child more visits. Rich wondered if funding would be on-going for this project. Karl indicated that funding is not guaranteed, but hopes that funding will not be lowered or dropped. NCHAM/the National Technical Assistance Center is also developing a training program for Deaf Mentors, and is currently identifying six-eight states for this project.

Karen Munoz discussed a pilot project with Utah and Indiana regarding hearing aid use for infants and toddlers. There was a 70% response rate for Utah parents who received the survey. Most responses came from families who had a year or more “experience” with a child wearing hearing aids – most respondents were parents of two-year olds. Karen noted that it took 5-9 months to get fitted, and that most responses indicated that these toddlers were not wearing their hearing aids the amount of time recommended by their audiologist or interventionist. Dr. Park would be interested to look at hearing aid usage over a 24 hour period. Rich thought that information reported a few years ago reported a four month fit time; now it is 5 months? Sylvia is working with a Spanish-speaking family now through early intervention that has experienced delay in hearing aid fitting. Harper thought information from this pilot could be very useful for the Children's Hearing Aid Pilot Project advisory

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committee. Karen said the information could be requested. Dr. Park said he would ask other states he is working with if they have information on the timeline between confirmed diagnosis and hearing aid fitting for the 0-3 population. Paula said that USDB/Parent Infant Program protocol has changed to support early hearing aid fitting and use so that babies are not missed and fitting is not delayed. Karen will update the committee throughout the project.

Parent Support Groups

There are parent support collaborative efforts scheduled in the next three months, and will be reviewed in November. Taunya Paxton is not in attendance today. Here is an emailed update to the Committee from Taunya received August 12 at the State EHDI office. *"I will not be at the meeting tomorrow. I am still working on parent support and will be attending a Hands and Voices Meeting and A.G. Bell Meeting in the coming months. I was not able to attend the Hands and Voices meeting in July due to scheduling conflicts. Steve Noyce is taking over as president of A.G. Bell and I am sure he will bring some great things to the table.*

Would you please let everyone at the meeting know that I will work with Paula Pittman and have more information at the next meeting for us to discuss. We were supposed to have more information to share tomorrow but due to summer vacations and schedules, we have not been able to give due diligence like we wanted."

Adjourn

This meeting was adjourned by Dr. Kelly Dick at 10:58 am, vote to adjourn requested by Karl White, seconded by Sylvia White.

The next meeting will be held November 12, 2013, 9-11 am, at the CSHCN building.

Mark your calendars for the 2013 meetings: 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.