



## Newborn Hearing Screening Advisory Committee Meeting Minutes

February 11, 2015

1:00-4:00 p.m.

Amherst H. Wilder Foundation  
451 Lexington Pkwy. N  
St. Paul, MN 55104

**Facilitator:** Tina Huang

**Recorder:** Jessica Cavazos

**Attendees:**

Kathy Anderson, Nicole Brown, Kirsten Coverstone, John Gournaris, Tina Huang, Candace Lindow-Davies, Karleen Maeurer, Joscelyn Martin, Linda Murrans, Gloria Nathanson, Peggy Nelson, Sara Oberg, Emilee Scheid, Lisa Schimmenti, Geoffrey Service, Michael Severson, Kara Tempel

**Absent:**

Mary Cashman-Bakken, Dennis Ceminski, Mary Hartnett, Emily Smith-Lundberg, Rhonda Sivarajah

AGENDA ITEM	DISCUSSION POINTS/DECISIONS/NEXT STEPS
<p><b>1. Welcome and Announcements</b></p> <p>Tina Huang</p>	<ul style="list-style-type: none"> <li>• Thank you to everyone who submitted their reapplication to the committee.</li> <li>• Committee members signed Oath of Office</li> <li>• We currently have 3 open positions on the committee. Rhonda Sivarajah's position as consumer of Listening and Spoken Language, Rural Birth Hospital Rep, and Local Public Health Rep.</li> <li>• Welcome new MDH audiologist Darcia Dierking</li> <li>• Joscelyn Martin motioned to accept November meeting's minutes, Michael Severson seconded</li> </ul>
<p><b>2. EHDI Story</b></p> <p>Psychological Advantages LLC</p> <p>Nanette McDevitt</p>	<ul style="list-style-type: none"> <li>• John Gournaris introduced Nanette McDevitt, of Greater Minnesota Launch Pad, Psychological Assessments for Deaf, Hard of Hearing and DeafBlind Children.</li> <li>• GM Launch Pad is supported by a grant from DHS Deaf and Hard of Hearing Division</li> <li>• Provides specialized and culturally affirmative psychological assessments to children (birth-age 21) who have documented hearing loss, live outside the 7 county metro area, and are receiving services from a school that receive funds from MDE.</li> <li>• Presented via powerpoint and included a couple case studies that illustrate the services GM Launch Pad provides.</li> <li>• View website for additional information regarding GM Launch Pad.</li> <li>• Note: for people inside the metro who are looking for referrals, Dr. McDevitt suggested Dr. Karen Willis, Pediatric Neuropsychologist at Children's Hospitals and Clinics of MN. Volunteers of America DHH School-Based Children's Mental Health Services program can provide assessments as well.</li> </ul>

<p><b>3. MDH EHDI Updates</b></p> <p>Short-term follow-up 2014 data</p> <p>Amy Gaviglio</p>	<ul style="list-style-type: none"> <li>• Information presented via powerpoint, handout provided.</li> <li>• Please note: due to the destruction of test results data is reported by date of birth vs received date. Differences should be minimal but it can make it difficult to compare results directly.</li> <li>• 98.9% of babies born in MN in 2014 have a documented initial hearing screen (98.5% screened before 30 days). Expect this number to increase as NICU results come in on children born in late 2014.</li> <li>• Of undocumented screens, 49% come from the NICU, 27% Out-of-Hospital births (80% of the out-of-hospital births without documented hearing screen are from midwives who do not have hearing screening equipment)</li> <li>• Transfers (internal and/or external) of NICU infants is the biggest reason why NICU infants are missing hearing screens. This is going to be a communication focus between MDH and hospitals.</li> <li>• REFER rates are continuing to go down (4.2% in 2014)</li> <li>• 61.1% of REFER infants are rescreened by 1 month of age (doesn't include infants that are under 1800g)</li> <li>• 42% of REFER infants have a diagnostic evaluation by 3 months of age.</li> <li>• Audiology QA reports sent to submitting hospitals, clinics, midwives, etc. help communicate where submitters can improve their outcomes and lost to documentation cases</li> <li>• In 2014 2,869 infants REFERRED after inpatient screen of these 2,395 PASSED their rescreen or had a normal diagnosis and 313 infants were reported to have a Confirmed Hearing Loss</li> <li>• 58% of confirmed hearing losses were diagnosed &lt;90 days, 13% diagnosed 90-180 days, 29% diagnosed &gt;180 days. These do include late onset, progressive &amp; late identified.</li> <li>• 6.0% of REFERRED infants were lost to follow up – 35.5% has no audio appointment, 25.1% Primary Care Physician was unknown, 18.9% No Show, 12.0% discontinued audiological appointments. MDH uses this breakout information to determine most needed areas of focus to reduce lost to follow-up/documentation.</li> <li>• MDH Follow-up begins with 3000-4000 undocumented hearing screens and whittle it down</li> <li>• 2015 Initiatives: work with NICU facilities to make sure each infant has a documented hearing screen (if you have any ideas, please share), work on getting more infants to meet the rescreening and diagnostic timelines, to reduce lost to follow-up/documentation work with cultural programs within and external to MDH, explore MIIC &amp; WIC collaboration options (for current parental contact information)</li> <li>• MNScreen is currently being rolled out to Minnesota submitters. MNScreen is an electronic reporting tool that pulls information directly from the infant's electronic medical record. This is for every infant in Minnesota. Allows for accurate and immediate reporting of hearing screening results to MDH, including each and every hearing screen the infant receives. Will help to decrease the number of initial "missing"/undocumented cases needing MDH follow-up. Allows MDH to gather additional information regarding hearing screening (risk factors, if there are any problems with the screening protocol at the clinic, and more). Notifies screener that a follow-up appointment needs to be scheduled for REFER infants.</li> </ul>
<p><b>4. MDE EHDI Updates</b></p> <p>ECHO Training &amp; Educational EHDI Team Updates</p> <p>Kathy Anderson</p>	<ul style="list-style-type: none"> <li>• Information presented via powerpoint, handout provided.</li> <li>• The Early Childhood Hearing Outreach (ECHO) program promotes hearing screening for all children (after newborn period) because hearing status can change, children move, were missed, etc.</li> <li>• There is a federal requirement for hearing screening of children enrolled in early head start programs. This must occur within 45 days of enrollment</li> <li>• MN received ECHO train the trainer grant. 40 professionals from across the state were selected to attend train the trainer events last November. They came from all 11 educational regions of MN. Since November, these professionals have been involved in multiple activities back in their own regions to increase understanding of OAE screening in Early Head Start/Head Start Programs and school district Early Intervention/ECSE programs.</li> <li>• Educational EHDI team Annual Meeting will be in April</li> <li>• Working with Boys Town to create modules for assessment for educational professionals. The first will be posted in June.</li> </ul>

<p><b>5. Workgroup Updates</b></p> <p>NICU Guidelines – Discussion &amp; Vote</p> <p>Transient Hearing Loss- Education test</p> <p>Joscelyn Martin Linda Murrans</p>	<ul style="list-style-type: none"> <li>• NICU Guidelines – Joscelyn Martin</li> <li>• Presented via powerpoint, printed copy given.</li> <li>• NICU guidelines have an updated format to be consistent with other guidelines, updates were made to sections on equipment, clarification for readmitted infants, risk factors for hearing loss.</li> <li>• Appendixes are now included in the list of links to make it easier to update guideline information as needed</li> <li>• Linda Murrans motioned that the updated NICU guidelines be accepted by the committee, Michael Severson seconded. Voted, all approved.</li> <li>• Transient Hearing Loss – Linda Murrans</li> <li>• Presented via powerpoint.</li> <li>• Workgroup created a postcard with information for parents on Transient Hearing Loss.</li> <li>• Has been used as an appointment reminder card, audiologist writes date and time of appointment on the card.</li> <li>• Created to encourage families to return for follow-up.</li> <li>• Has been used at Children’s in St. Paul</li> <li>• Suggested to have card available in additional languages, specifically Hmong.</li> <li>• Suggestion: add a place to put an appointment time on the card.</li> <li>• Next step: testing the use of this card at audiology/ENT offices and collection data on its value.</li> <li>• Goal: family education on the importance of audiological follow-up</li> </ul>
<p><b>6. BREAK</b></p>	
<p><b>7. New Advances in Genetic Testing</b></p> <p>Lisa Schimmenti</p>	<ul style="list-style-type: none"> <li>• Advances in next generation sequencing has reduced the time and cost of genetic sequencing</li> <li>• In clinic we can now test for 119 known hearing loss genes. This allows for diagnosis before clinical signs appear.</li> <li>• Can make a genetic diagnosis for many children who are D/HH, this can be more cost effective, less invasive for the child (as opposed to several tests, diagnostic imaging, etc.), and can provide guide to other symptoms, conditions, health issues that may develop later in life along-side hearing loss.</li> <li>• Can help families decide on how to move forward with intervention</li> <li>• Example: Usher’s Syndrome. If a D/HH child is walking late, could be a balance problem that is associated with Usher’s Syndrome. Also typical to Usher’s Syndrome loss of vision at 10-20 years (retinitis pigmentosa). If families have a genetic diagnosis early on, they can decide what kind of intervention would work now and later if their child may lose their vision later in life</li> <li>• Oregon group is working on a gene therapy treatment (UshStat Treatment) for the vision loss associated with Usher’s Syndrome and has started treating a few patients with Usher’s Syndrome.</li> <li>• Dr. Schimmenti’s lab at the University of Minnesota (along with the Ekker Lab at Mayo) have created genetically modified zebrafish that model Usher’s Syndrome with similar gene deletion. Effectively, they’ve created zebrafish that are deaf. They’ve noticed that the zebra fish don’t startle to sound and swim differently than their wildtype counterparts. They are currently analyzing the effect of drugs on the Usher’s Syndrome zebrafish.</li> <li>• Insurance is more likely to cover genetic testing for hearing loss, often denials have been reversed in favor of the patient once they understood the positive impact of genetic testing.</li> <li>• Suggested reading: Orchid of the Bayou: A Deaf Woman Faces Blindness.</li> </ul>

<p><b>8. CMV</b></p> <p>General discussion / Q&amp;A</p> <p>Mark Schleiss</p>	<ul style="list-style-type: none"> <li>• Presented via powerpoint (discussion continuation of last meetings presentation)</li> <li>• Utah's 2014 bill on cCMV screening was proposed and put into law. All children who do not pass their NBHS &amp; outpatient rescreen should be tested for cCMV. Urine or saliva based testing. Bill included a strong endorsement of ganciclovir, which was criticized by AAP because there is a perception that the state is telling physicians how to practice medicine.</li> <li>• Ganciclovir requires a lot of monitoring, sometimes additional medication to treat the side-affects.</li> <li>• There is strong movement in Texas, Massachusetts, Hawaii, and Connecticut to screen for cCMV. Illinois also working on legislation.</li> <li>• Mark Schleiss suggested: point-of-care CMV screening in the nursery when an infant does not pass their hearing screen. This would allow for earlier treatment as well as greater assurance that the infection is cCMV and not CMV contracted after birth. Funding and cost issues need to be resolved for this.</li> <li>• Mark Schleiss is currently working on a point-of-care screening for cCMV for infants who do not pass NBHS, pilot study in select nurseries in Twin Cities hospitals. This is a collaborative grant with Tim Lander, MD.</li> <li>• Also collaborating with MDH on testing NBS blood spots for cCMV. Believes that blood spot testing may not be sensitive enough to pick up cCMV.</li> <li>• Universal screening for CMV doesn't meet the requirements for NBS disorder recommendation as most babies born with CMV are normal and will continue to be normal. It's premature to advocate for universal screening for all newborns. We need to learn more about "asymptomatic" CMV newborns.</li> <li>• Ganciclovir treatment shuts down the replication of the CMV virus. Early treatment can halt the progression of hearing loss because you are clearing the virus before it does more damage to the cochlea. It's unlikely that hearing loss would be restored.</li> <li>• For some reason infants have a much harder time shutting down the virus replication and have a difficult time clearing the virus. Viral replication does occur after treatment (CMV is a Herpes virus, so the child will have it forever) but there doesn't seem to be any damage to the cochlea during these episodes. It seems to be a window of time during infancy when replication affects the cochlea.</li> <li>• Some babies with cCMV pass the hearing screening, and then lose their hearing by age 2 or 3.</li> <li>• In Europe (especially Belgium, France, Germany, Northern Italy) pregnant women are screened for CMV during the prenatal period. ACOG hasn't recommended screening women during pregnancy since there is no treatment for CMV during pregnancy. ACOG prefers to teach women about precautions.</li> <li>• Note: the majority of the Utah cCMV bill was focused on education and prevention.</li> <li>• Other antiviral drugs to treat CMV are in development and seem to have less side-affects.</li> <li>• Mark Schleiss suggests that Utah's case be used a framework to begin a discussion. As we find out more about their experience we will have a better idea of how to proceed in Minnesota. Note: Utah did see an increase in timely EHDl screening &amp; follow-up, adherence to intervention timeline, education and awareness in general that coincided with the new CMV screening guidelines.</li> <li>• The medical community is still working towards CMV vaccines.</li> <li>• CMV will continue to be on the agenda at each meeting, so bring your questions.</li> </ul>
<p><b>9. Closure</b></p> <p>Tina Huang</p>	<ul style="list-style-type: none"> <li>• Next Advisory Committee Meeting: May 27, 2015 1-4pm</li> <li>• LOCATION:  Amherst H. Wilder Foundation 451 Lexington Pkwy. N Saint Paul, MN 55104</li> <li>• Notify Chair if there are any Partner Updates to put on the agenda</li> <li>• Adjournment</li> </ul>