

UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE

*Next Meeting
May 14, 2013*

February 12, 2013 meeting minutes – APPROVED by Committee Vote - MAY 14 – All in favor, no one abstained.

In attendance: Krysta Badger, Susie Bohning, Kelly Dick, Catherine Hoelscher, Nita Jensen, Katie Jolma, Charlene Frail-McGeever, Karen Munoz, Albert Park, Taunya Paxton, Kathleen Pitcher-Tobey, Paula Pittman, Kurt Randall, Lori Ruth, Suzanne Smith, Sharon Strong, Karl White, Sylvia White

Excused: Richard Harward, Stephanie McVicar, Harper Randall, Jill Vicory, Shannon Wnek

WELCOME

Dr. Kelly Dick opened the meeting at 9:05. Members as listed above were excused from today's meeting. Introductions were made.

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

Dr. Harper Randall made some inquiries to find a new NICU representative for this committee but has not received any positive feedback. If anyone knows of a candidate please let us know. This can be a physician, nurse, neonatologist; but it does need to be a representative from a NICU nursery. The previous representative, Susan Fox was the Director of the NICU at PCMC. Dr. Albert Park will speak with The neonatologists he works with and see if he can find anyone that would be interested.

Public Comment

No comments.

Utah EHDI Updates

HiTrack was updated last week to Version 4.5.6. This updates all HTWeb users to the new version, too. Twenty-two birthing hospitals are now using HiTrack Web. This has been a learning experience in how incomplete the data is that is coming directly from the screening equipment. NCHAM's programmers have cleaned up the statewide physician's list so hospitals are no longer seeing duplicate physicians with incorrect codes (State HiTrack physicians list was archived for all records prior to 2011 births). The physicians list will now be synchronized statewide. CDC recommendations of reporting categories are now reflected in the HiTrack Most Conclusive Results calculations and HiTrack Flowchart and CDC reports. Infants previously calculated as PASSED when only one ear was screened as outpatient, now are included as "recommended for evaluation".

A few hospitals have new coordinators. Lakeview's contract changed hands in December, the contract is now held by Mountain West ENT and will be overseen by Niki Barwick, AuD. Kane County's coordinator, Rosalie Esplin, has retired and Charlene Kelly, R.N., is now over the program. Salt Lake Regional Medical Center, Jordan Valley Hospital, and Pioneer Valley Hospital are all under contract through mid-2013 with Rex Scott, Audiology Associates. Due to family issues Rex has asked Tina Osborne to be a co-contractor and have

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oversight of those programs. Tina is now overseeing seven hospitals in Utah, five of those are using the HiTrack Web application.

The State EHDI team is doing site visits to all Utah hospital newborn hearing screening programs. Twenty visits are completed (20 site visits out of 42 hospital programs). They will also be holding annual regional Coordinator meetings in March (Orem, Beaver, Moab, Salt Lake and Ogden), with the main focus on HiTrack updates and training. Dr. Stephanie McVicar and Kurt Randall have been invited to present on Newborn Hearing Screening at the annual Utah Speech-Language and Hearing Association's meeting to be held March 7th in Park City. Kurt and Stephanie have also been accepted to present on Utah's Tele-audiology project at the National EHDI Conference in April. Jay Hall, PhD, is scheduled to lead a two-day workshop on electrophysiology testing on infants and small children. This will be held at the Children with Special Health Care Needs office in Salt Lake. The conference is open to all pediatric audiologists (in the state), but requires pre-registration through the State EHDI office.

Nita Jensen updated the committee on the Birth Certificate Project and its history. When the birth certificate files changed in 2009, the connection was no longer available with CHARM, putting this project on hold. During the last month Vital Records and the CHARM team have been working out the bugs and each local health department who distributes birth certificates will soon be on-line and trained to distribute alert letters. Due to grant funding, all training must be complete and printers must be placed by the end of March.

Kurt Randall reviewed the Tele-audiology project. We currently have one piece of equipment placed with a midwife in Mt. Pleasant who has been trained to set up ABRs. We have completed 7 ABRs via Tele-audiology and have proven that the weak link is not the capability of the system but the functionality of the internet service. Otherwise the process works. Dr. McVicar is currently at the AMCHP Conference to present this project and she and Kurt will be presenting at the National EHDI conference.

USDB Parent Infant Program

Paula Pittman is now the Director of Utah Schools for the Deaf and Blind's (USDB) Deaf Parent Infant Program (PIP). She has been with PIP for 25 years and has also worked at Utah State University's SKI-HI Institute. USDB has had a lot of staff changes recently and some disorganization in the program that they are trying to correct. The first issue is the orientation process. Four years ago they created a process in which two deaf adults would be the 1st point of contact. They have had struggles with the system and it was taking too long to get an IFSP written and get children into the system. Parents felt like they weren't getting support. They have changed this so that once a referral is received, the child is assigned to a staff member, the family/child goes through orientation with this staff member and then the team services are introduced. They begin by working with the parent on early foundation education: understanding audiograms, what hearing aids do, what cochlear implants do; things parents need to know to begin making decisions. PIP staff are working hard to get amplification on the children and help parents to understand the importance of consistent use of amplification. Paula noted that they receive a lot of feedback from audiologists about getting kids to wear their hearing aids regardless of the communication method they have chosen. Once an orientation team goes in and speaks with the family, the family gets a chance to meet someone from the deaf community, but is not forced to make a decision on communication methodology immediately. PIP wants families to get bonding and communication going first. Once orientation is complete, the family can choose their method and they will be connected with the best professional for that expertise (LSL-listening and spoken language or ASL English-literacy skills). This is a big change in the program and seems to be working well, but will take 2-3 years to get the program back on track. Feedback from families has been positive so far.

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The biggest change since August is that PIP will now be providing more services to children with unilateral and conductive hearing loss. In the past, these children were only seen once a month for 3 years. Now, they will serve these families weekly for 6-8 months. The primary issue with conductive hearing loss is usually not the hearing loss. EI services are often still available to these families after PIP steps away; if EI requests more help with these children, PIP will step back in. PIP staff plan to focus on more intensive services for a shorter period of time. They will look at these families by situation/need and decide what to do; they want to give them the support they need. This also includes children with unilateral permanent hearing loss.

Another change that has occurred is the referral process. Previously, they were getting referrals in too many formats/sources. They are now tightening the process and will have one main contact point for referrals. Hospitals can still send secure email referrals, but all others must be faxed to a secure fax line (801-629-4777). Kurt Randall will distribute this information, as well as the referral form to the UCOPA list-serv. The referral form can also be found on-line at <http://www.usdb.org/pip/deafpip/Deaf%20%20HH%20PIP%20Documents/Referral%20Form%20Updated%209-12-12.pdf>. They have had a huge increase in the number of children receiving services and Paula has requested two more staff members to serve this increase. There are now 18 PIP advisors. They are also bringing back the Deaf Mentor Program since its elimination 2 years ago (due to funding). They have hired two Deaf mentors and are working to get them funded in hard money (not soft money). Deaf mentors will see the families who opt for an ASL English approach. Every family who chooses that approach has access to the Deaf Mentor Program. PIP also serves children with severe hearing loss whose families request ASL English as a “supplement” to Listening-Spoken Language services. Once PIP sees that the system is working they will provide a deaf mentor to the family, but only those who choose the ASL English approach will have mentors permanently assigned.

A new PIP secretary, Susan Westergard, has been hired. Susan was previously with USDB Blind services. She will start in two weeks. The phone number will remain the same 801-629-4768. Dr. Susie Bohning asked about receipt of confirmation when a referral has been faxed. They have not been doing that yet, but once Susan starts they will begin sending confirmation to the referring audiologist to notify them of which PIP provider the family was assigned. PIP would like to maintain the audiologist/family relationship. Right now the current staff doesn't have time to see all of the PIP families, but they are trying to increase staff so this won't be a problem. PIP still refers to Early Intervention (EI), with staff members attending EI meetings to let them know when they have a child they are sending for PIP hearing services. This seems to be working well. Right now there are some EI agencies that have 4 staff members serving families, but they are going to try and move that to 1-2 staff members per region. This will take 2-3 years to re-configure. Nita Jensen noted that the USDB audiologists serving rural areas are very good to contact us and see if we have children that need follow-up for NBHS, and we appreciate USDB staff's willingness to collaborate. Since PIP is part of the EI CHARM data sharing agreement, we can share information on these children. Lori Ruth also keeps Paula on track to make sure all children with confirmed loss through the EHDI system are getting services.

Sylvia White has been in contact with a pediatrician who would like to start screening five year olds at the People's Health Clinic in Park City, and would like to know who the contact would be for those kids. PIP is only up to age three, but Paula Pittman will give Sylvia a contact for older children. We do have some school districts who report after age 3, but that reporting is not mandated.

Dr. Albert Park would like copies of the Pediatric Audiologist booklet as well as the one page referral sheets (send to Paula Pittman as well).

Parent Support Groups

Taunya Paxton was asked to contact other states to inquire what they do for family to family support. It seems, to her, that most states only provide services up to age three and it is all about funding. She has been in contact with Colorado, Indiana, and Wisconsin and is waiting to hear back from Minnesota. All three of these states use the Hands and Voices Guide by Your Side (GBYS) program. The USDB PIP Program is similar to GBYS in that they contact the family at first diagnosis and get them into the system. There is a difference in how the programs are funded; most of these states use portions of their EHDI grants for funding, and GBYS uses parent outreach, not professional. In Utah, we use EHDI funding for other things. Wisconsin cobbles together funding so that if one thing is cut they can still run GBYS. They use federal grants through outreach services and money in coordination with the Wisconsin School for the Deaf. Indiana's GBYS program is fully funded by the state. Wisconsin used their EHDI grant funds to cover the first year and then it is on a sliding fee scale for the parent. Indiana has two part-time parents to fill one full time position as well as 13 parent guides. Wisconsin has 17-24 parent guides; since they are more rural they are trying to feel out if it is better to have less guides and pay for them to drive to different locations or have local guides that are always there. Karl noted that the difference, and similarities, between GBYS and USDB in these states is that families have early contact, but they are getting contacted by GBYS parents as well as the professional contact through the School for the Deaf. Without GBYS, like Utah, families are only being contacted by an EI provider and they are not receiving that parent to parent contact until the families are enrolled and have networking opportunities. In these states, the programs are working together, in parallel. In Indiana they have very close coordination between GBYS and EI. The GBYS program is employed by the state agency that runs PIP. This way, they can share information so the professional and the parent can both be in contact with the family and the parent guide has a paid position. The guide is designated a few hours at diagnosis and a few hours at transition to see these children. Of these three states, none are funded through the legislature. Minnesota, however, does have some legislative funding. Some states use the funding they get from the Newborn Screening kits to help fund GBYS (some get \$30 out of the \$80 charged for the screen). Dr. Kelly Dick asked if one program seemed to be more effective than another. From the State Directors that Taunya spoke with, they were all very upbeat about their programs and they have ways to give Hands and Voices funding. They all sounded pretty creative. Wisconsin employs one parent guide through the Department of Health and one through outreach so that they can provide benefits to the parent guide. Other states didn't offer benefits to parent guides, but all seemed to have similar structures. There will be presentations on GBYS at the upcoming National EHDI conference. In Dr. Karl White's opinion, the programs that Taunya has spoken with are some of the most developed in the country, but it does circulate around available funding. Having parent to parent contact is a great thing. Minnesota worked for a few years with legislators to get money appropriated. Indiana is also largely legislatively appropriated and their whole system is changing to combine EHDI, the School for the Deaf, Medicaid and "under 5" services into one central office. Dr. White thinks that in order for us to move forward with anything like GBYS we will have to go to the legislature for funding. The HRSA/EHDI grant will be sustaining a 5-8% cut this year so there will be no extra money there. We can demonstrate the benefits of parent to parent support and we should be thinking about working with USDB to put together some sort of common proposal (whether administered through USDB or somehow that we can share information). Some states have set it up so parent to parent support programs have to be contacted by the family (less beneficial) and other states have made it part of the system so that they can outreach to these families. Some years there is a little bit of money left in the legislature to put towards new things, and some years they are cutting budgets. This year we don't know. For this to be successful, we need to start this summer, and we need to have good advocates (Reps. Ronda Menlove and Becky Edwards were mentioned as possible advocates). Taunya is concerned that legislators will think they are already funding this because USDB receives so much funding.

Paula noted that they are working on getting a Hands & Voices chapter reinstated in Utah. They started last year and it is slowly growing. She would be glad to work with them to generate some funds and will see if there are PIP funds available for planning and improvement of the program. Doing a pilot with Hands & Voices could be beneficial. In some states, the Vice President of Hands & Voices has helped with this. Sylvia asked how the process works; if families choose to have other families contact them when they register for the program. The current approach taken by GBYS is that they want to make sure that the families providing the support are trained and sensitive to issues that may come up. The social networking approach has pros and cons, sometimes well-meaning families can give bad information. Coordination of GBYS through USDB has a lot of advantages. While the legislature does already give USDB funding, that funding is budgeted and this would be a new component. It would be nice to point to the states that are doing this and could provide good data on the effects and outcomes. We could also coordinate and run this with Baby Watch, although it makes more sense to go through USDB. It takes finding a representative with strong feelings to help. Rep. Ronda Menlove has been leading the CMV bill and had strong feelings on how it should be written and enacted (and that was different than what Dr. White would have suggested). You have to take your lead from the legislator who is willing to help. Charlene noted that Medicaid received one-time funding to do care coordination in rural areas, but needed to prove that it could be effective. It might be beneficial to approach this as a pilot; get one time funding and show this collaboration as effective with commitment and accountability and then go back to champion the program and ask for permanent funding. Parent support needs to be comprehensive, objective data provided every step of the way so parents can make choices that are respected, but also allow a change in direction when needed. They need high quality comprehensive support for the choices they are making. You will always find, no matter the choice, a divergence of opinion. That is just the way it is.

Do we want to pursue this for the next legislative session? Taunya has been carrying this all by herself; if so, are there others interested in working on this proposal? Paula and USDB need to be involved if this is going to be effective. Dr. White does not see any chance that funding will come from existing EHDI money, but legislatively, there is always hope that next year will be a good year. Taunya will contact Mary Hartnett of Minnesota, to see if she can obtain language from the proposal they used. Mary is part of the council for the Deaf and Hard of Hearing in Minnesota and worked with Part C to lead their efforts. Our next Advisory meeting is May 14th; Dr. Dick would like to have this information put together before that meeting so we can begin contacting sponsors. Dr. White believes there are a number of people in the legislature with an interest in hearing loss issues. This will be a process. Dr. Park would like to know if there are measures showing the cost effectiveness or improved patient outcomes in these states. We need to be able to have some outcome measures to support this to move forward; validated surveys, etc. Charlene would also suggest selling it as how WE would do it and how WE would measure it. Taunya knows there are some statistics out there; she thinks Dr. Clough Shelton with the Cochlear Implant Team has some studies on amounts that EI services save over time in regards to education and special education. Dr. Park is referring to outcomes with one-on-one parent support. It was noted that Mel Brown is the head of the appropriations committee and has a soft spot for EI; Sylvia thinks we could tap into him. Paula and Taunya will work on this for further discussion in May.

National EHDI

The National EHDI Conference will be held April 14-16 in Phoenix, AZ. The hotel is booking quickly so reservations should be made soon if you are planning to attend. Last year there were 1000 attendees and given the hotel reservations thus far, there will be at least that or more this year. If you are going, please be sure to support the State Stake Holders Meeting. This is a good chance to meet everyone from Utah, to work together and set goals.

The American Academy of Pediatrics (AAP) has been working on a position statement and guidelines for screening hearing in physician's offices. They plan to release this formally at the National EHDI meeting. This will help to give guidelines and enable providers interested in providing screening to do it well. The Academy is concerned it could be done and done poorly. Terry Foust recently authored a paper (that was accepted to be published in a Pediatrics journal) that outlined a study where 600 babies were screened at the Federal Qualified Health Center (FHC) of Utah and identified three with hearing loss. This shows that screenings can be done successfully at a physician's office. Nita is not aware if the data from this study has been reported to us. She will contact Terry Foust. Charlene also knows the director of the FHC if we want that contact information. The take home is that more screenings are being done in early childhood settings, and they are documenting as many kids with hearing loss as we find through Newborn Hearing Screening. Some of these are kids who failed NBHS with no follow-up, but many are late onset hearing loss. The age group in the study was children under 3. It would be appropriate for Nita to email Terry and let him know we heard about the paper and ask if those kids were reported to State EHDI.

EHDI Pals

Karen Munoz presented on EHDI-Pediatric Audiology Links to Services (PALS), a "web-based system to help parents, hospital personnel, and physicians find pediatric audiology facilities that will meet an individual's needs". For more details see the attached PowerPoint presentation. The EHDI Coordinator of each state will have access to all of their state's listed audiology resources and can interact with the providers who choose to "self-report" in this system. Dr. White also envisions a link for 'User Feedback', where providers can be rated. If providers do not fill out their application to meet specific requirements, they will not be listed on the website. They must know "Best Practices" in order to be listed. This release is the first step for EHDI-Pals.

Legislative Update

Representative Ronda Menlove has been leading a proposal on CMV legislation (House Bill 0081). Her granddaughter was recently diagnosed with a CMV related hearing loss. Rep. Menlove has proposed legislation that would include intensive education campaigns to educate providers in places such as nurseries, licensed child care facilities, etc., as well as required CMV testing for children who fail the 2nd newborn hearing screen. We estimate 250 children per year will need to be screened for CMV through this bill. The screen would be paid for by insurance or Medicaid, if eligible, and the test costs about \$100. Dr. Park was one of the primary testifiers at the committee hearing. The key to this bill is the education component. There is a lot of literature posted and most health care providers are not aware of the effects of CMV, even though it is common. Utah has had input on this from Dr. Cannon (with CDC), and this could be a stepping stone for a national effort. The mandate proposed for CMV screening is not perfect; the process is still somewhat questionable AND it would be labor intensive at a high cost. CMV testing should be done before 3 weeks of age, after that we would have to rely on metabolic testing and dry blood spot - there are concerns with sensitivity testing the dried blood. Education and screening are included in this proposed bill. It did pass unanimously through the Committee and is headed to the House. CMV can be devastating to an otherwise normal child in more ways than possible hearing loss. There are some concerns among some of the medical community that the legislature is telling them how to practice medicine. Dr. White is confident that the education part of this bill will pass, but he is not sure about the section on CMV testing. Nita will email a link to the committee.

<http://le.utah.gov/~2013/bills/static/HB0081.html>

Another Bill from this legislative session concerning this Committee was proposed by Becky Edwards, Representative of North Salt Lake, with involvement from Rep. Ronda Menlove. If enrolled and passed, this Bill would provide hearing aid funding for children under the age of three identified with hearing loss. This was proposed as an insurance mandate last year, but did not get a committee hearing. Rep. Menlove's idea is that, in the big scheme of things, it would be about \$250,000 to make hearing aids available to these children and provide new hearing aids at 3-year intervals. This would be recommended as a restricted fund; money would be allocated through legislation and any child who met the criteria (hearing loss) would be eligible. This bill has not been filed and has no bill number yet, but Dr. White spoke with Rep. Edwards last week and she was moving forward. There will be an advisory committee and she will be getting input from local experts. The draft bill states that this would be administered through the Department of Health; this is NOT as payor of last resort. It is not clear yet if this Bill will be enrolled, and it could change a lot as it progresses. Dr. Park asked if it would be helpful to know which legislators have supported this and who your representative is. He, himself, spoke with his representative about the CMV bill. This committee cannot vote on something like this, but as private citizens, if you have feelings about H.B.0081, you should contact your representative. Taunya thinks it helps if financial eligibility is NOT attached. Karen Munoz mentioned that ABC World News is looking at hearing aid access for children and finding that those who are the hardest hit are those that "can afford" it. Most middle class families don't qualify for anything. The idea of not having it financially "needs based" would help reach more kids. In this state, an insurance mandate is dead on arrival. Taunya tried to go through insurance for Chance's hearing aids, but they denied (and still do decline) their coverage. Most states that have insurance mandates also have many loopholes. The draft of the bill Dr. White saw allocated \$2000 per hearing aid, \$4000 per pair. This could change by the time the bill is done. In the states where hearing aid bills have passed, it is often a \$500 credit, but varies for each state. Links to every state's legislation can be found at www.infanthearing.org. If this bill is enrolled and passed, it would be the best one in the country, per Dr. White, and a huge step forward. Dr. Sharon Strong asked if there was any mechanism to get this information out to the health care field. Dr. White will talk to Rep. Menlove and see if she has a preferred press release that could be distributed to Utah Pediatric Association and the Academy of Family Physician members. There was an article in the Tribune that Dr. Park will forward to Dr. Strong. The best way would be to contact someone in the organization (UPA) who can distribute the information to all members. Dr. White will speak with Rep. Menlove, get the current status of bill, and put together information that can be sent out to the committee.

The CMV bill is going to vote within the next three days. Dr. White thinks it will get through the House, but is unsure of Senate support. Contacting House members would be helpful, but contacting State Senators should be the big push. Dr. Park is going to notify all his patients with hearing loss and let them know about the bill. Nita will send the committee a link to the recent news article. Taunya noted that some hospitals (American Fork, Utah Valley) host events like "pancakes and politicians" where you can meet with local politicians to discuss issues. Sharon Strong will contact the Utah Academy of Family Physicians and Utah Medical Association (although she lost her contact at UMA). It would be helpful to contact the Utah Hospital Association as well. The UMA has concerns about the legislature telling their members how to practice medicine and has risen a bit of a fuss. Dr. Katie Jolma will also send this information to Cathy Oyler to distribute to the Utah AAP branch. Dr. White will put something together once the Hearing Aid bill gets a number. Dr. Park noted that getting patients to the hearing is very powerful. If families with a vested interest are involved (AG Bell) it will send more of a message. USDB could also let parents know.

Next meeting will be held May 14th 2013.

Adjourned by Dr. Dick at 10:50, vote to adjourn Karl White, Sylvia White.

Newborn Hearing Screening Committee

Mark your calendars for the 2013 meetings: May 14, 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.

FYI—You may subscribe to notices regarding this Committee on the Utah Public Notice website with instructions at <http://pmn.utah.gov> . Agendas will also be posted on that website at least 24 hours prior to the scheduled meeting.