**Arizona EHDI Connection**

**Summer 2014**

**Special points of interest:**
- New Legislation
- HiTrack & Screener's Tip
- Preparing Families
- Improving EHDI
- NCHAM
- Events & Media

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**Hearing is now part of the Newborn Screening Panel**

Big News!

**Manding Newborn Hearing Screening in Arizona, HB2491**

Arizona does a great job of completing hearing screenings! In Arizona, more than 98% of the babies born here are screened before one month of age. The original law that was passed in 2005 required that if babies were screened, the results of that screening and any subsequent testing must be reported. The problem this created was that there was no statutory authority to find or help track those children who missed the newborn screen, as there was no mandate to screen. Recently enacted legislation, HB2491, closes this gap. By adding a few words to the existing newborn screening legislation, newborn hearing screening is now mandated in Arizona. This puts newborn hearing screening on the same level as newborn blood spot screening as a mandatory part of the newborn screening panel of tests for all children born in Arizona!

For more detailed information, documents and media on this new legislation visit: www.AZNewborn.com

**NOTE:** Future newsletter publications will include all newborn screening including bloodspot information along with hearing for an all encompassing approach!
Important Tips

Screening Tip:
Should babies with a unilateral ear malformation be screened?
Randi Winston, AuD, CCC-A, Consulting Audiologist

Should babies born with a unilateral microtia or atresia (absent ear or malformed ear on one side) receive a newborn hearing screening? If a baby has one normal looking ear why wouldn’t you screen it? Given that parents/families are dealing with the reality that their baby has a malformation, knowing that one ear passed might provide a sense of comfort. The reality is that screening could do more harm than good. In the recently published ASHA (American Speech-Language Hearing Association) Newborn Hearing Screening Professional Issues statement, expert opinion suggests that these babies should not be screened in the hospital and should be referred to an audiologist for diagnostic testing within four weeks of discharge. If parents are told in the hospital that their baby has “normal” hearing in one ear, they may experience a sense of relief and a false sense of security that as long as one ear is normal, their baby will hear fine. The fact is that babies born with this condition will have some degree of hearing loss in the affected ear and will require an audiological evaluation to determine the severity. It is also critical that the “normal” ear be closely monitored for late onset and/or progressive hearing loss which could develop at any time. What is most important for parents to know, is that children need hearing in both ears in order for normal development to occur; so a referral to a pediatric audiologist is the first step and the optimal standard of care for these babies.

HiTrack Tip: The Vital Record is VITAL!
Randi Winston, AuD., CCC-A, Consulting Audiologist

The primary purpose of the vital records merge into HiTrack is to enhance the screening record and provide both comprehensive and vital demographic information for all babies. Hospitals and the newborn screening program use this critical information in their follow-up efforts. Ideally when a vital record is merged into HiTrack, it finds and combines with the screening record. However, if there is a data entry error in the screening record or the screening data has not been merged into HiTrack within one week of the birth, the records will not combine as they should and a duplicate record will be created. If you see this in your database, be sure to let ADHS know so we can combine the records. Vital records are VITAL to the success of our state EHDI follow-up program and must NEVER be deleted!
A new resource list has been distributed for Newborn Hearing Screening locations for Babies in Midwifery Care. This list serves as a great tool to help families find hearing screening and follow-up screening services.
We are really excited to offer the newborn hearing screening to our home birth families. It seems that most babies born outside of a hospital were simply missing out on this screening. They were missing out, not because they were opposed to getting the screening done, but the only place that offered it was a hospital setting. Many families didn’t see the value of screening because they notice that their baby jumped when they heard a loud noise. We provide education and screening options for families.

We have been able to screen and educate many families to the benefits of the newborn hearing screening. Many families have heard that we offer the test in our warm, friendly Midwifery office and they are happy to bring their baby in for the screening.

We have had the privilege of screening a 2 year old and a 4 year old, on separate occasions, both of whom did not pass the screening test. On both occasions the child was slower to talk than the other siblings and was never screened. The parents knew enough about the possibility that the child’s hearing might be a factor to be able to seek us out for the screen. In both situations we sent a letter to their pediatrician that the child needed follow up care by an audiologist. We were excited the family was able to provide additional attention to their child’s development now that they had more information.

We have screened dozens and dozens of babies born outside of hospitals that were not our clients. To date none of our families in our practice have ever declined the test because they received education about the importance of having a hearing screening done early. It’s a painless, non-invasive screen that is typically done in the comfort of the baby’s mom’s arms.

We appreciate the support we have received from our community to ensure babies born outside of a hospital have access to a newborn hearing screening.

Danielle Haines
Apprentice at Midwives Rising!
115 W McDowell Rd Ste 4B
Phoenix AZ 85003
602-242-4446
www.midwivesrising.com
Preparing Families for Their Diagnostic Audiology Exam

In reviewing an infant’s discharge summary or blue immunization chart, you realize that he/she did not pass their hearing screening. What are the next steps? First, refer the family to a facility that provides diagnostic audiological evaluations. The EHDI-PALS website is an excellent resource that can assist in finding a diagnostic test site. Second, prepare the family for the appointment. Inform them that testing will take between 90 and 120 minutes. The baby must sleep in order for the audiologist to obtain accurate and reliable results. Optimally, the baby should be awake upon arrival to the test site but should be tired and hungry. The audiologist will then prepare the infant for the test. Test preparation includes a light cleansing of the forehead and behind each ear as well as placement of small sticky electrodes. Once in place, the audiologist will allow the parent to feed the baby. When the baby falls asleep, the testing can begin. The audiologist will summarize the results with the family and send the primary care provider a report with results and recommendations.

Deb Flynn, AuD
Audiologist
Phoenix Children’s Hospital

EHDI-PALS

Remember:

Refer to a pediatric audiologist if the infant fails an outpatient screen or is a NICU graduate that failed the inpatient screen. Infants may need a referral from the primary care provider.

The Office of Newborn Screening refers all families and providers to EHDI-PALS!

Thank you, Partners!

In May we celebrated Better Hearing and Speech Month! Lylis Olsen (AZEHDI Coordinator and Ear Foundation of Arizona) and your AZEHDI Team sent thank you letters along with BHSM posters to all of our EHDI-PALS partners!
Quality Improvement efforts in Early Hearing Detection and Intervention (EHDI) are focused on reducing our loss to follow up. In 2012, 431 of the 833 babies that did not pass the newborn hearing screening were lost to follow up. This means that nearly half of the babies that were identified as being at risk for a hearing loss never came back to complete their diagnostic evaluation!

Our Federal EHDI grant which started in April 2014 is focused on Plan-Do-Study-Act (PDSA) cycles to try out small tests of change. A small group determines the area to work on, the specific aim and a change to try. The intent is to start small to see if it works and then make changes as needed until you know if it works or should be abandoned to try something else. Once you know you have something that really works, we spread it to others.

You may have noticed some of these terms and changes in our previous grant cycle that resulted in a 7% improvement in one year! Some of those changes included obtaining a second contact for families, making the outpatient screening appointment while still an inpatient, faxing results to the physician and following it up with a phone call and a pilot with a WIC clinic that showed promise along with many others.

One example of a new project is addressing loss to documentation. Our hard-working follow-up staff at the Department of Health spends a lot of time tracking down families only to find out that they have already seen an audiologist, but the audiologist didn’t report the results as required! We know this happens often enough to know it impacts our loss to follow-up numbers significantly.

What we are trying to accomplish with this PDSA, is to increase the number of audiology reports that are sent in and reduce those that have to be requested and/or are late. We will know a change is an improvement by tracking the data in our fax log each week. Much of the background work has already been done to look at who is reporting, the timeliness of reports and some of the barriers.

Ongoing awareness is one of the barriers that we are working on addressing through testing a mechanism to provide feedback to the audiologist about how many reports they have submitted and whether those reports were submitted timely. We met with one audiologist to Plan how to know if we received all of the reports from that facility and if our ideas made sense and were useful. We are in the middle of our first cycle of Doing the first change and will meet again in a little while to Study. We will then Act on what we learned and try it again.

Within the targeted Audiology clinic, they will be doing their own PDSA cycles to figure how to improve their reporting. One of the things they have decided to try is to send all of the results for those under the age of 24 months rather than trying to figure out who passed the newborn screen, if the newborn screen information reported by the parents is accurate or how to obtain the information. The goal is to realize better outcomes without increasing the burden on the provider. For more information on the Model for Improvement visit: www.ihi.org/resources/Pages/HowtoImprove/default.aspx.

Lylis Olsen, MS, MPH, CCC-A
AzEHDI State Coordinator, HEAR for Kids Program Manager
Are your patients hearing you? Or more importantly, are their parents hearing you? If you are a provider taking care of children with potential hearing loss, you play a crucial role in ensuring those children are diagnosed in a timely manner. In Arizona, we do a phenomenal job of screening up to 99% of all babies born annually. However, we do a very poor job of identifying those babies with true hearing loss. In Arizona, we miss out on more than 40% of those babies who fail their newborn hearing screen. These are lost children. They are the ones who slip through the cracks. Our role is imperative to communicate and ensure to those families the importance and urgency of receiving a diagnostic evaluation. So I ask again, are your patients hearing you? Are your families hearing you?

Brad Golner, MD
Arizona EHDI Chapter Champion
AZAAP

Are you reporting? Reporting hearing screening and test results timely is an important step. The intent of Universal Newborn Hearing Screening is to identify infants with a hearing loss as early as possible so that appropriate interventions can begin. Timely reporting allows ADHS follow up specialists to focus their time on helping children who need further testing get the follow up they need.

Results can be faxed to (602) 364-1495. Reporting forms are available at www.aznewborn.com or by calling (602) 364-1409.

AVERAGE DEVELOPMENTAL MILESTONES

| 0-3 Months | Quiets when hearing familiar voice  
|            | Startles to loud sounds  
|            | Makes vowel sounds like ahh, ohh |
| 3-6 Months | Looks for sounds with eyes  
|            | Uses sounds such as squeals, whimpers, chuckles  
|            | Vocalizes excitement and displeasure |
| 6-9 Months | Turns hearing toward sounds  
|            | Babbles sounds like ba-ba, ma-ma, da-da  
|            | Looks for quiet sounds made out of sight |
| 9-12 Months | Imitates speech sounds made by others  
|            | Understands no-no or bye-bye  
|            | Correctly uses ma-ma or da-da  
|            | Turns to own name |
| 12-24 Months | Conversation babbling to self and others  
|            | Follows simple directions “get your shoes”  
|            | Knows and uses more than six (6) words  
|            | Uses 2-3 word sentences |

This is not a screening tool and does not replace objective testing.
Check out the Updated EHDI E-Book!

The EHDI E-Book is an outstanding resource published by the National Center for Hearing Assessment and Management (NCHAM) at Utah State University and is available on the infanthearing.org website.

The E-Book is an online comprehensive publication consisting of a collection of 30 chapters from national experts who are actively involved in all aspects of the EHDI process and systems. Each year, as EHDI continues to evolve new chapters are added.

Anyone interested is free to download and print any or all sections: [http://goo.gl/TPkwiF](http://goo.gl/TPkwiF)

Have you been to the NCHAM website recently?

NCHAM Staff and other experts have prepared a variety of materials that can be used in making presentations about EHDI.

[Infanthearing.org](http://infanthearing.org) contains copies of various PowerPoint presentations and information about how to obtain videos that may be useful for training, conferences and public awareness activities.

Any of the PowerPoint presentations can be downloaded and used “as is” or adapted to fit your particular situation!
I was fortunate enough to be able to attend the annual EHDI conference in Jacksonville, Florida this year. Like last year, there was so much to learn in just a few days! It is always nice to be able to meet EHDI people from around the country and learn what other states are doing to reduce loss to follow up.

This year, the Arizona EHDI team had 2 poster presentations. The first was about how Arizona has transitioned from a paper resource list of audiologists to strictly using EHDI-PALS to find a qualified pediatric audiologist. Though, we did not win an award for that poster, we were asked by NCHAM to create a webinar to present nationally on our promotion of EHDI-PALS. The second poster presented was about strategies we have used for education, awareness and data sharing to decrease loss to follow up and improve our turnaround time for diagnostic evaluations. In this poster, we were able to highlight all of the data systems we currently use to locate families, ways we have increased awareness of the importance of newborn hearing screening for a developing baby as well as the partners we have collaborated with along the way.

It is encouraging, as we attended break-out sessions and met with other professionals at the poster presentations how although Arizona still has a high loss to follow up rate, we have put many progressive processes in place to reduce our rates. On the last day, we had the opportunity to receive individualized training on how to use Continuous Quality Improvement Strategies (CQI) to reduce loss to follow up. I learned a lot on how to break down an idea and create small tests of change using Plan Do Study Act (PDSA) cycles to test ideas and then revise and spread the change strategies.

Moving forward, as part of the new HRSA grant cycle, we will be establishing learning collaborative teams and implementing CQI methodology in our daily work with the end goal of being able to reduce our loss to follow up by 5% every year. The conference filled me with new ideas and renewed enthusiasm to continue making sure that all babies receive the timely screening, diagnosis and treatment they need to have the best outcome possible.

Fran Altmaier, BSW
High Risk Coordinator/Project Specialist
The Office of Newborn Screening Staff

Well Baby Follow up Team

The Well Baby Follow up Team reviews hundreds of newborn hearing cases and prioritizes these cases for management and follow up. They work closely with Hospitals, Primary Care Physicians, Audiologists, ENT’s and families to ensure every baby has been referred for an outpatient screening and/or diagnostic evaluation.

Gidget Carle is the Newborn Hearing Screening Follow up Team lead. She oversees activities performed by Hearing Follow up Specialists for well babies. She monitors progress made based on the CDC EHDI 1-3-6 goals: screening all babies by one month of age; completing a diagnostic evaluation by three months of age and verifying enrollment in Early Intervention by six months of age, with the goal to reduce lost to follow up. Gidget has more than 19 years of experience in healthcare including one and a half years as Follow-up Team lead, five years supervising clinical staff and ensuring that clinic staff provide efficient and patient-centered services, established a successful medical system that determines medical necessity long term care and 6 years as a nurse.

Amie Bobo has 10 years of experience with the Arizona Department of Health Services. She has worked 5 years with the office of newborn screening as a Follow up Specialist. Prior to working with NBS, Amie worked as an Abstractor for the Arizona Birth Defects Registry, Bureau of Public Health Statistics for 5 years. Amie loves sharing family time with her daughter and enjoys singing in her gospel group.

Erika Porras has been part of the Newborn Hearing Follow up Specialist team since September 2013. She has 11 years of experience in the medical field. Erika enjoys spending time with her husband and family in the outdoors going on adventures.

Elba Leal has worked as part of the Well-Baby Follow up Team since October 2013. Previously, she worked as a Medical Assistant with Maricopa County Public Health Department for 5 years. Elba recently welcomed her second baby.

Data Integrity Specialist

Scott Mow recently moved to Phoenix, from Michigan, after graduating with a Bachelor’s Degree from Central Michigan University with a focus in Information Technology. He is still adjusting to the 100+ degree weather from Michigan’s -10 degree temperatures. He has been working at ADHS for two months, and is focused on improving the accuracy of newborn screening data.

Marketing Specialist

Lindsay Kalbfleisch joined the ONBS team in February 2014. Before starting with ONBS she worked at Bonneville Media in radio advertising and marketing. She hopes to bring new marketing, outreach and social media ideas to the team with a focus on community outreach and education. She currently attends the Walter Cronkite School for Journalism and Mass Communications at ASU. Outside of work, Lindsay enjoys teaching dance, performing in musical theater shows, helping homeless animals and spending time with her husband, Eric and rescue pup, Dixie. A Pittsburgh native, you can often find her cheering on her Penguins, Steelers and Pirates!
Events and Media

Upcoming Events:

Arizona Hands & Voices Summer Expo
August 9, 2014
The Black Canyon Conference Center
For more information visit AZHV.org or Najwa Ghattas (602) 828-1020

Arizona Hands & Voices Retreat
September 12-14, 2014
Lions Camp Tatiyee-Lakeside, AZ

Ear Foundation of Arizona Annual Conference
Tempe Center for the Arts
October 10, 2014

Past Events:

The 2014 Annual EHDI Meeting was held April 13-15th in Jacksonville, FL. Arizona was well represented! In attendance were members from EHDI, ASDB, Providers from Pediatrix, Audiologists, an Audiologist student and even one of our parent advocates.

The 2014 Hearing Screener’s Meeting happened in March at the Phoenix Zoo with more than 40 participants. Topics included HiTrack protocols, equipment considerations, data importance, CDC survey and reports, best practices and many updates.

For the complete agenda and other related materials please visit: www.AZNewborn.com and click the Healthcare Providers Education Tab
Arizona EHDI Constant Contact Sign-Up

The Office of Newborn Screening: Early Hearing Detection and Intervention (EHDI) values your partnership and your time. In an effort to be more efficient, we are changing the system we use to communicate health-related information to you. This list will be used for newsletters, upcoming events and updates; it will not replace but will enhance the person-to-person contact you have come to expect. Registering for this email communication will allow us to keep you up to date on information that supports your efforts to improve the health of all Arizonans.

To add yourself to this list please do the following:

- Visit this page: http://visitor.constantcontact.com/email.jspm=1101362445484
- Click the box next to “Office of Newborn Screening: Early Hearing Detection and Intervention”
- Feel free to choose additional topics you would like to receive info on from ADHS
- Fill out the contact info in the column to the right so we can include you in specified correspondence as well.
- Forward to anyone you feel would benefit from specified correspondence

If you have any trouble viewing the newsletter or have difficulty signing up for Constant Contact, please give the Office of Newborn Screening at (602)364-1409.

Resources for Professionals and Families

- Arizona Hands and Voices, Guide by your Side
  http://gbys.azhv.org/
- Raising Special Kids
  www.raisingspecialkids.org/
- Arizona State Schools for the Deaf and the Blind (ASDB)
  http://www.asdb.az.gov/asdb/
- Arizona Early Intervention Program
  https://www.azdes.gov/azeip/
- EAR Foundation of Arizona
  http://earfoundationaz.org/

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Visit our website for the latest news and information on Newborn Hearing Screening!
www.AZNewborn.com