What is EHDI? EHDI (Early Hearing Detection and Intervention) was started in 2001 with the purpose of identifying newborns with hearing loss. Each state has an EHDI chapter which is comprised of multiple agencies along with an EHDI coordinator and a chapter champion.

The purpose of this quarterly newsletter is to educate and communicate with all of Arizona’s primary care providers and healthcare workers taking care of children with hearing loss.

Questions to ponder for primary care providers:

1) What is the role of the EHDI Chapter Champion?

2) What is the relevance of EHDI’s 1-3-6 goals in your practice?

Answers:

1) The EHDI Chapter Champion for Arizona helps establish best practice for our community regarding newborn hearing screening, newborn hearing loss, and identification of late-onset hearing loss in children. The chapter champion also is the liaison between the EHDI chapter participants with regards to policies/protocols and the medical home/community. Our goals for our medical community are:

- providing resources (parental support, equipment, services, etc.), appropriate referral sources and access to pertinent patient data.

2) 1-3-6 is important for the PCP to ensure that every newborn is screened for hearing loss by 1 month of age, diagnostic evaluation completed by 3 months of age, and early intervention and treatment by 6 months of age.

Our next newsletter (quarterly) will include a case study and strategies to enhance patient care, so be sure not to miss it!

Brad Golner M.D. F.A.A.P. Arizona EHDI Chapter Champion

Welcome to EHDI!

The Office for Children with Special Health Care Needs has partnered with the Office of Newborn Screening and the EAR Foundation of Arizona to improve existing training and expand access to training for those who screen children for hearing loss. We are happy to announce that eLearning enrollment will begin soon for The Newborn Hearing Screening Curriculum (NHSTC), a standardized competency-based training tool for hospital screeners.

Each hospital can register up to two screeners, and upon completion of the course, certificates will be issued. In addition, hospitals who participate will receive recognition on their Newborn Hearing Screening Scorecard. For more information, or to sign up, contact randiwinston@mac.com
Guide By Your Side - An Overview

All parents have one thing in common: children. When parents talk to other each about their children, a special bond is created. Parents talk to each other as peers. Another parent can be a source of support through shared personal experiences. Knowledge gained by one parent can be passed on to the next parent.

What do you do when you have a colicky infant; a jealous older sister; a baby who might not make it out of the NICU; no health insurance; a baby who failed newborn hearing screening? Support for the family and baby comes from dedicated medical professionals, skilled social workers, and other parents who have “been there, done that.” Parents who have been in the trenches 24/7 have a role in supporting other families.

Guide By Your Side (GBYS) is a program that selectively hires parents with children who failed newborn screening. The Parent Guides have first-hand personal knowledge. The national GBYS training curriculum broadens that knowledge and prepares Parent Guides to work with families whose babies fail newborn hearing screening. Parent Guides walk that fine line between encouraging and frightening families; between assisting and enabling; between creating trust in the system and turning parents away.

The role of GBYS is to work in concert with existing systems to ensure that families take the next step in the screening process. Arizona Hands & Voices (AZHV) is a state chapter of a national parent-driven, non-profit organization that supports families with children who are deaf and hard of hearing. GBYS is a program of AZHV that is already being used in several states. In Arizona, the Department of Health Services is partnering with AZHV to implement GBYS.

GBYS was initially piloted for 8 months at a birthing hospital. A Parent Guide worked closely with the hearing screening staff to follow up with families who failed to show up for outpatient rescreening and those whose babies referred for a diagnostic evaluation. Currently, GBYS is working with families from 13 hospitals around the state.

Acknowledging that each hospital has its own protocol for follow up, GBYS customizes to meet the unique needs of each location. GBYS is funded through ADHS in partnership with the Ear Foundation of Arizona. As such, GBYS maintains the same high level of confidentiality when working with families. GBYS is a component of ADHS’ federal Child Maternal Health grant to reduce loss to follow-up in Arizona.

Jeanne Hollabaugh
Jhallobaugh@azhv.org

A Message from the High-Risk Coordinator

The State of Arizona’s newborn hearing screening program continually strives to strengthen the follow-up process through resourceful approaches in order to continue to reduce loss to follow-up rates. This requires taking many different avenues to educate parents and providers while re-evaluating protocols and utilizing community connections.

Since 2008, our program has implemented processes to target specific nursery populations (well-babies and NICU/high-risk babies). The development of two distinct family checklists – the “Family Checklist – Infant Hearing” and the “Family Checklist for Babies at High Risk for Hearing Loss” has enabled our program to educate parents and providers after a baby fails the hearing screen.

In 2009, a supplemental grant opportunity created an impetus to seek out other creative mechanisms to continue to target vulnerable populations. Our program set three primary approaches, the first to utilize a High-Risk coordinator to provide concentrated follow-up on infants at higher risk for hearing loss, specifically those who failed hearing screens with a NICU stay of five days or greater. The second was to partner with a parent support organization, AZ Hands & Voices - Guide By Your Side (GBYS), which set the framework for parent guides to assist in connecting with families. The third was the implementation of a parent-

(continued on page 3)
High-Risk Coordinator (cont’d)

directed video “Loss & Found.”

As the High-Risk Coordinator, it is my role to monitor and follow-up with infants at higher risk for hearing loss after they fail a hearing screen. Infants in the NICU are at greater risk for neural hearing loss and are at greater risk of missing or having an incomplete newborn screen (JCIH & CLSI), this makes prompt follow-up especially important. For high-risk follow-up, our program initially focused on 12 hospitals in the state to implement the program. So far we have been working with five hospitals to monitor and follow-up with NICU infants.

Some of my other duties as the High-Risk coordinator include working as a liaison with Guide By Your Side; educating medical homes, community health centers, audiologists and other screening providers on state mandatory reporting requirements; participating in the development of a “pocket guide” to further educate medical homes on appropriate referrals for infants; and broadening collaboration efforts with other public health programs.

Valerie Odeh  
High-Risk Coordinator  
Office of Newborn Screening

The EAR Foundation of Arizona (EFAz) has a long history of collaboration with ADHS and many other partners in the arena of newborn screening, EHDI activities, and hearing screening and intervention beyond the newborn period in Arizona. These efforts have made great strides in the reduction of loss to follow-up, increased parent involvement and expanded education and training.

Some programs of the EFAz:

- HEAR for Kids - hearing aids for children
- Annual Audiology Seminar - professional training
- EHDI Statewide Coordination
- Hospital and Community based health delivery systems training and technical assistance
- Head Start ECHO initiative (Early Childhood Hearing Outreach)
- AzAAP Chapter Champion and NBS Consultants coordination in the development of professional partnerships and training opportunities

EAR Foundation of Arizona Team

- Melissa Selbst, MPH, CHES, Executive Director and Education Consultant
- Lylis Olsen, MS, MPH, EHDI State Coordinator and Consulting Audiologist
- Randi Winston, AuD, Consulting Audiologist
- MiMi Macias, PhD, Research Director
- John Macias, MD, EFAz President

Centers for Disease Control and Prevention (CDC) Launches New Website for Hearing Loss in Children

Please visit the site at [www.cdc.gov/hearingloss](http://www.cdc.gov/hearingloss) and take advantage of the wealth of resources provided.

“Infants in the NICU are at highest risk of having neural hearing loss”  
- 2007 JCIH Position Statement
Newborn Hearing Screening Scorecard

The Office of Newborn Screening implemented a screening scorecard in April 2010 that gives birthing hospitals a quarterly “score” based on the following quality indicators:

- Screening rate compared to vital records
- Refer rates
- Reporting hearing results within one week as required by statute
- % of infants returning for an outpatient screen or diagnostic evaluation
- Reporting of mother’s name and date of birth to facilitate record matching

(see next page for larger version)

In addition to the scorecard, a summary of recommended strategies for improving the score in each category is included. Issuing the scorecard resulted in a rapid and dramatic shift over the first quarter and continues to show improvement.

The table below shows overall state performance based on the results of the scorecards:

<table>
<thead>
<tr>
<th>Scorecard for</th>
<th>% of hearing results submitted</th>
<th>% outpatient return rate</th>
<th>% of records with mother’s name provided</th>
<th>% of records with mother’s DOB provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>4th Quarter 2009</td>
<td>68.23</td>
<td>65</td>
<td>73</td>
<td>71</td>
</tr>
<tr>
<td>1st Quarter 2010</td>
<td>84.77</td>
<td>71</td>
<td>88</td>
<td>87</td>
</tr>
<tr>
<td>2nd Quarter 2010</td>
<td>83</td>
<td>71</td>
<td>91</td>
<td>90</td>
</tr>
</tbody>
</table>

The most significant impact of the scorecard was a better compliance in regards to timely submission of hearing results and providing mother’s name and date of birth. The percentage of hearing results submitted timely went from 68% during the last quarter of 2009, up to 83% during the second quarter of 2010. During that same time period, the percentage of records containing mom’s name went from 73% up to 91%. Receiving hearing results on time, and being able to match records for transferred babies, improves follow-up activities by reducing delays in identifying and locating infants who need further testing.

SurveyMonkey® was used to follow-up with the 48 birth hospitals in order to assess how to further improve the scorecard. Based on the results of the survey:

- 93% of the respondents had a chance to review the scorecard and 75% shared the scorecard within their hospital (CEO, risk managers, NICU nursing staff, staff nurses, hearing screening clerk, etc).
- 62% indicated that they had implemented new procedures to improve their newborn hearing screening program such as reeducating screening staff; improving patient communication for outpatient rescreening; decreasing the number of screeners to a few experts for inpatient screening; adding notification stickers in the hearing log tracking book for transferred and deceased babies, and home births, when known; etc.
- 56% considered adding mandatory online training curriculum courses to their program.

Hearing screening teams looking for guidance in incorporating newborn hearing screening quality practices should contact Randi Winston, state audiology consultant, at (602) 284-1091 or randiwinston@mac.com.
Office of Newborn Screening
Hearing Scorecard
(April 1, 2010 - June 30, 2010)

Births in Vital Records (VR) = 943
Number of Babies Born Per HiTrack (HT) = 930
Number of Babies Screened in HT = 949
Number of Babies NOT Screened in HT = 3
Expire (w/o Screen) = 1
Missed = 0
Refused = 1
No Info = 0
Transferred Out = 1
NICU = 0
Outpatient Return
Anticipated to Return = 20
Actually Returned = 16
Your Total Score: 95.60 pts
out of 100 pts

SCREENING

Babies Documented in HiTrack vs Vital Records

- Your Facility
- Goal
- State Average

INPATIENT REFER RATE
Appropriate refer rate range is between 1% and 4%.
Your Hospital Refer Rate: 2.1%

DOCUMENTATION AND TRACKING

- % Providing Mother’s First Name
- % Providing Mother’s Correct DOB

Overall Score:

<table>
<thead>
<tr>
<th></th>
<th>Q1 2010</th>
<th>Q2 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Score</td>
<td>96.30</td>
<td>95.60</td>
</tr>
<tr>
<td>AZ Highest</td>
<td>99.83</td>
<td>99.95</td>
</tr>
<tr>
<td>AZ Average</td>
<td>82.67</td>
<td>83.42</td>
</tr>
</tbody>
</table>

Data is current as of 9/22/2010. Graph percents are rounded off to the nearest whole percent.
Hearing Screening and Diagnostic—2009 Overview

Healthy People 2010 addresses the need to increase the proportion of newborns who are screened for hearing loss by one month, have audiological evaluation by age three months and are enrolled in appropriate intervention services by age six months.

Arizona is unique in that newborn hearing screening is not mandated, yet more than 98% of all babies born are screened.

In 2009:

- 98% of newborns in Arizona were screened for hearing loss
- 2,710 newborns did not pass the newborn hearing screen.  
  * Of these, 2,390 infants returned for further evaluation  
  * Of these infants returning for further evaluation, 2,161 passed.
- 360 babies received a diagnostic evaluation:  
  * 225 were confirmed with Normal hearing  
  * 49 with Unilateral Loss  
  * 86 with Bilateral Loss  
- About 600 babies were lost to follow up

![Graph showing hearing screening results](image)

**CDC Goal: Diagnostic Evaluation Before 3 Months of age**

- 186 met ≤90 Day Goal
- 42 in 90-120 Days
- 61 in 121-180 Days
- 57 in 181-365 Days
- 13 in 366+ Days
- 1 NA

Total Confirmed Cases = 360

**2011 National EHDI Conference**

The 2011 National Early Hearing Detection and Intervention (EHDI) Conference is just around the corner.

The conference will be held February 21-22 in Atlanta, Georgia. Now in its 10th year, this conference has been successful at bringing together stakeholders, partners and participants involved in EHDI programs at both the state and federal levels. This year’s National EHDI conference will facilitate a multitude of presentations on all EHDI related topics, including networking and information sharing. Each year several members of Arizona’s state EHDI program attend and conduct presentations on the work that has been done throughout the year.

For more information on the conference, please visit: [http://ehdiconference.org/](http://ehdiconference.org/)

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“Infants who do not pass screening should have a comprehensive audiological evaluation at no later than 3 months of age”

2007 JCIH Position Statement
Arizona has a history of newborn hearing screening as the standard of care since 2000. Although hearing screening is voluntary, nearly 98 percent of babies born in Arizona are screened.

All screening results must be reported to the Office of Newborn Screening at the Arizona Department of Health Services (ADHS). ADHS is mandated by A.R.S. 36.694 to provide follow-up services to encourage the infant’s family to access evaluation services, specialty care and early intervention services if the hearing screening results indicate that the infant may have hearing loss.

The goal is to ensure that infants are screened for hearing loss before 1 month of age, receive a diagnostic evaluation before 3 months of age and are enrolled in intervention services before 6 months of age.

Last year, our office initiated follow-up activities on 2,710 cases by contacting medical homes and parents. By coordinating efforts with hospitals, discharge coordinators, pediatricians, audiologists, ENTs, parent support organizations, and families, 360 infants received a diagnostic evaluation; of those, 225 infants were confirmed with normal hearing, 49 with unilateral loss and 86 with bilateral loss.

The Office of Newborn Screening is also looking into strategies to reduce the loss to follow-up. Nearly 600* babies were lost to follow-up after failing the inpatient hearing screen in 2009. This is a significant improvement from previous years: 881 babies were lost to follow-up in 2008 and 1,104 in 2007. Strategies to reduce the loss to follow-up include fostering communications between medical homes and the Newborn Hearing Program, using supplemental grant funding for the High Risk Coordinator position, Guide By Your Side partnership, and the production of the Loss and Found DVD.

*preliminary data, as 2009 cases are still under review

HiTrack 4.5 Update

Some of you may be aware that we are in the process of updating our current HiTrack 3.5 program to HiTrack 4.5. While that may not sound all that interesting or exciting, the reality is that this is very big news for our state follow-up program, our birthing hospitals and our babies. Last year we received a grant from the Centers For Disease Control (CDC) to update our current HiTrack 3.5 Windows Desktop version to HiTrack 4.5 Web version.

This means that our state has embarked on a two year project to update HiTrack. The HiTrack state database will now reside on our secure website and all hospitals and providers will soon be able to log in and access their hospital and patient data. There are many advantages to using a web-based version, but the two biggest are:

1) The steps for data-merging and reporting will be streamlined. Hospitals will be able to securely merge their screening data directly into the HiTrack state database. Creating transfer files and emailing them to the state will be eliminated.

2) Hospitals will be able to log in and have immediate access to any follow-up information that the state has received on a baby. This will provide quicker access to follow-up results, which will provide hospitals and providers with more timely information, which hopefully, will improve the timeliness of services for babies and families.

We are very pleased to report that our state database has now been completely and successfully converted to the web version and we have begun the process of converting hospitals! Over the next several months we will be slowly updating hospitals and you will be hearing from us when it’s your turn.

Stay tuned for further updates and more information on HiTrack 4.5 Web!