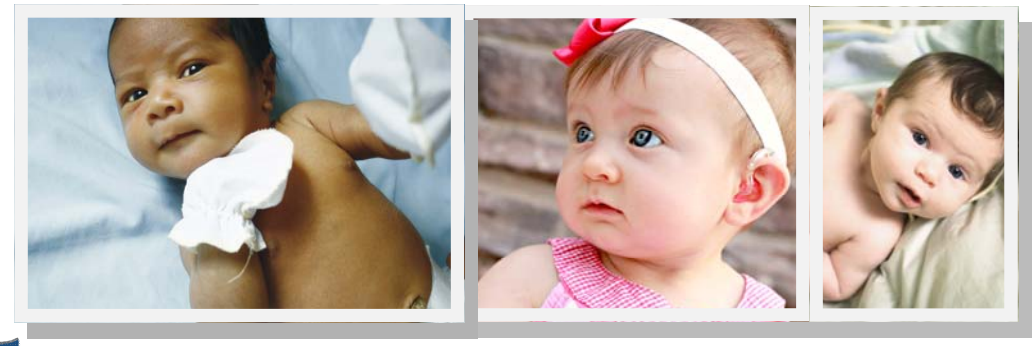
Arizona Department of Health Services

Spring 2015



Newborn Screening Connection

The Office of Newborn Screening Newsletter

AzEHDI Pages 7-12

Welcome to the Spring Edition

The Arizona Newborn Screening Transit Time Taskforce:
Sharing Our Successful Improvement Story

During the past few months the Transit Time Taskforce has actively participated in initiatives providing the team to share the success story of the transit time project on a national stage. The magnitude of the transformation has gained positive recognition creating opportunities to partner with the Association of Public Health Laboratories (APHL) and the Association of State and Territorial Health Officials (ASTHO) on three significant initiatives.

In January 2015, taskforce members Sondi Aponte and Celia Nabor welcomed the frigid temperatures during their travel to Silver Spring, Maryland to participate in NewSTEP's Collaborative Improvement and Innovation Network (CoIIN) for Timeliness in Newborn Screening. This exciting event served as a platform for Arizona to provide guidance and support to six other states that are currently working or beginning on timeliness projects in their Newborn Screening Programs. The team also had the opportunity to learn from expert facilitators and subject matter experts on developing strategies for future quality improvement initiatives focusing on the eight Quality Indicators.

Also in January 2015, the Arizona Department of Health Services (ADHS) Director Will Humble and Celia co-presented during the ASTHO webinar: Newborn Screening Quality Improvement on State Initiatives to Improve Screening Processes. During the webinar the team shared the transit time successes, challenges, and lessons learned. The team also emphasized the importance of creating transparency through the development of the transit time webpage. Another key highlight included the effectiveness of implementing a statewide courier service with capacity to provide same day pick-up and delivery services to the majority of the Arizona birth hospitals.

The taskforce is also honored to have an article published in the APHL Lab Matters winter issue, officially released on February 24, 2015. The article, "Arizona's Rapid Rise to Newborn Screening Timeliness" depicts how meaningful collaborations, efforts towards transparency, creating an encouraging organizational culture, and developing accountability through the creation of performance metrics led to positive and sustainable improvement in Arizona.

The common thread that has been a focal point for the team during these activities is the importance of collaborating with the right partners that share the same mission. This synergy will continue to positively impact newborns and families throughout the state.

Contact us:
Office of Newborn Screening 602-364-1409
www.aznewborn.com

Inside this issue:

Newborn Screening

Core Disorders on Screening Panel

Endocrine Disorders
- Congenital hypothyroidism (CH)
- Congenital adrenal hyperplasia (CAH)

Amino Acid Disorders
- Phenylketonuria (PKU)
- Maple syrup urine disease (MSUD)
- Homocystinuria (HCY)
- Citrullinemia type I (CIT-I)
- Argininosuccinic acidemia (ASA)
- Tyrosinemia type I (TYR-I)

Fatty Acid Oxidation Disorders
- Carnitine uptake defect (CUD)
- Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
- Long-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
- Trifunctional protein deficiency (TFP)

Organic Acid Disorders
- Isovaleric acidemia (IVA)
- Glutaric acidemia type I (GA-I)
- 3-Hydroxy-3-methylglutaric aciduria (HMG)
- Multiple carboxylase deficiency (MCD)
- Methylmalonic acidemia-cobalamin defect (Cbl A,B)
- Methylmalonic acidemia-mutase deficiency (MUT)
- 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
- Propionic acidemia (PROP)
- Beta-ketothiolase deficiency (BKT)

Hemoglobin Disorders
- Sickle cell anemia (Hb SS)
- S, beta-thalassemia (Hb S/ß Th)
- S, C disease (Hb S/C)

Other Disorders
- Biotinidase deficiency (BIOT)
- Galactosemia (GALT)
- Cystic Fibrosis (CF)

Disorders not detected by bloodspot screening—Point of Care
- Hearing Loss (HEAR)

Anticipated
- Critical Congenital Heart Defects (CCHD)
- Severe Combined Immunodeficiency (SCID) **

***dependent on funding*

Only use the term *PKU* when referring to the disorder below

What is PKU?

Baby's First Test- Phenylketonuria (PKU) is a condition in which the body cannot break down a specific amino acids found in proteins. PKU is considered an amino acid condition because people with PKU cannot break down the amino acid called phenylalanine. If left untreated, PKU can cause brain damage or even death. However early detection and treatment allows people with PKU to lead healthy lives.

Phenylketonuria is a condition with multiple forms, each of which have different treatments and outcomes. Classic phenylketonuria is only one form of the condition. You can read about a different form of the condition, hyperphenylalanemia, on the website. www.babysfirsttest.org

Arizona Department of Health Services Office of Newborn Screening · 250 N 17th Ave, 1st Fl · Phoenix, AZ 85007 · Phone: 602-364-1409 · Fax: 602-364-1495 · nbseducation@azdhs.gov

A Post from the Director's Blog

Arizona Public Health Laboratory Selected to Assist in Developing New Technology

In 1999 the Centers for Disease Control and Prevention (CDC) established the Laboratory Response Network (LRN). The LRN's purpose is to run a network of labs that can respond to biological threats, chemical threats, and other public health emergencies. The LRN has grown since its inception. It now includes state and local public health, veterinary, military, and international labs. Prospective reference labs must have the equipment, trained personnel, properly designed facilities, and must demonstrate testing accuracy. Our Arizona Public Health Laboratory is part of the Network, qualified to work on both biological and chemical agents.

As part of the LRN, our Public Health Lab has been involved in the testing of Anthrax, Avian Influenza, and Middle East Respiratory Syndrome. Our Public Health Lab has been selected to work with the CDC and Association of Public Health Laboratories to collaboratively develop an enhanced testing capability for toxins, which are the organism that causes botulism. As an Advanced Level Biological LRN, our Public Health Lab will work to develop new technologies for the quicker and more accurate detection of this deadly bacterium.

To follow Interim Director Corey Nelson's blog in your feed visit:
www.feeds.feedburner.com/ADHSdirectorsblog
-or-
Read it here:
www.directorsblog.health.azdhs.gov

A Message from the Medical Director

A Second Look at a Second Screen

Lisa Villarroel, MD MPH

Did you know that Arizona requires a second newborn screen?

Arizona needs your help to get the word out about the second screen – in 2014, while 98% of Arizona newborns had the first newborn screen specimen collected on time (<72h of life), only 43% of children had the second specimen collected on time (5-10 days of age). That means more than 48,000 children did not get timely, complete screening of 29 heritable disorders. There may be reasons for the confusion over the timing and necessity of the second newborn screen in this state. First, not all states require two screens – Arizona does. Second, not all states charge separately for the second screen – Arizona does. Third, not all states require the second screen to be collected at 5-10 days of age (or first outpatient visit, whichever comes first) – Arizona does.

The utility of Arizona's second screen is proven year after year: in 2014, 220 children had a *normal* first screen and an *abnormal* second screen – of which 5% were ultimately found to have a diagnosis of an heritable disorder.

So take a second to change your workflow, run a quality improvement project, inform your peers, and send that second specimen on time.

For more information, please visit the webpage at http://www.azhealth.gov/lab/aznewborn/.

Transit Time Project Update

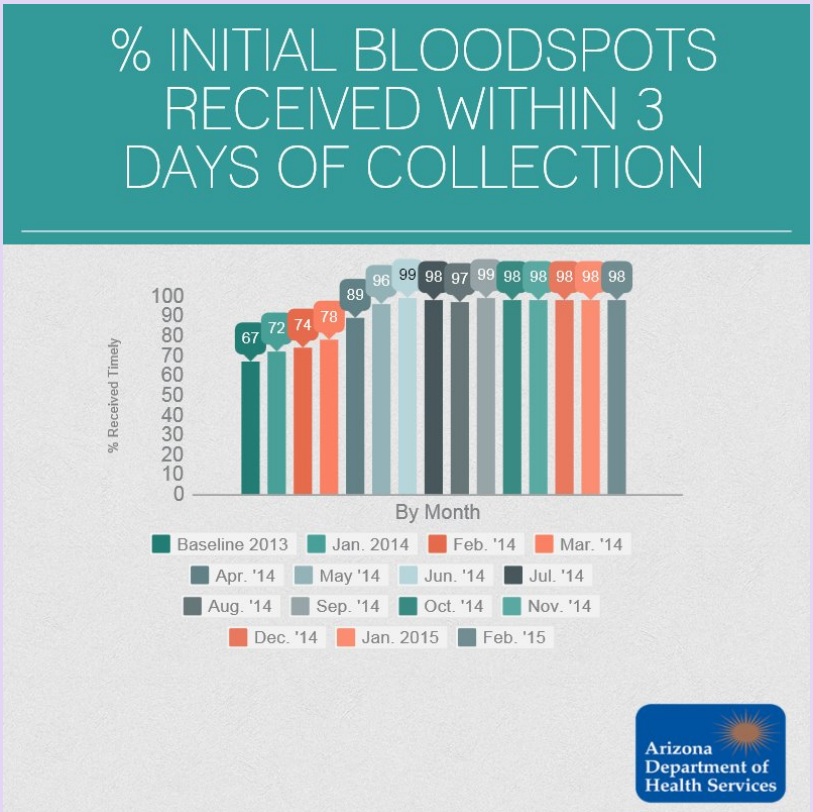
Transit Time Taskforce: Celia Nabor, Sondi Aponte, Isaac Lee

In January 2014, birth hospitals partnered with us to begin the monumental challenge of transforming the transit system. The goal was to ensure bloodspot specimens were received at the state laboratory within three days of collection. Within five months, the newborn screening transit system was successfully transformed resulting in 96% of the samples arriving within three days of collection. This success is largely attributed to all the hospitals actively partnering to ensure internal processes were operating seamlessly and the successful implementation of the courier service EZ Messenger.

In an effort to provide a constant portal of information, the Transit Time webpage will be maintained on a monthly basis providing access to your performance data. In the coming weeks you will notice the charts condensed to allow space for the cumulative performance of 2015. In addition we will continue sending specimen outlier reports via email; that provides you a timely opportunity to troubleshoot and research specimens received more than five days after collection.

In the event that your hospital would like to discuss the services provided by EZ Messenger or require assistance troubleshooting a challenge, please contact us directly at nbseducation@azdhs.gov rather than contacting the courier directly. The newborn screening team is committed to quickly resolving any issues, concerns, and/or questions.

We are proud to announce that January 2015 marks the ninth month in a row that more than 95% of the initial bloodspot specimens were received at the state laboratory within three days of collection. Congratulations to hospitals for your contribution to this statewide achievement!



NewSTEPs
A Program of The Association of Public Health Laboratories

Arizona Department of Health Services

CoIIN

Collaborative Improvement and Innovation Network for Timeliness in Newborn Screening

Learn more about quality improvement strategies being undertaken in several states to improve outcomes for newborns with heritable disorders. Improving transit time is just one of the eight quality indicators recommended from the Newborn Screening Technical assistance and Evaluation Program (NewSTEPs), a division of the The Association of Public Health Laboratories (APHL). https://www.newsteps.org/news-and-education/

FREE

Ordering Supplies

Bloodspot

Email or Fax Order Form

labreceiving@azdhs.gov

602-364-0758

Request

Specimen Collection Kits

* Linked Kits
* Supplemental Kits (single)

Pink envelopes

White Envelopes (*for mail only*)

Resources-Services

Brochures

Physician Packets

Drying Racks

Thumb Drives

Site Visits

Trainings

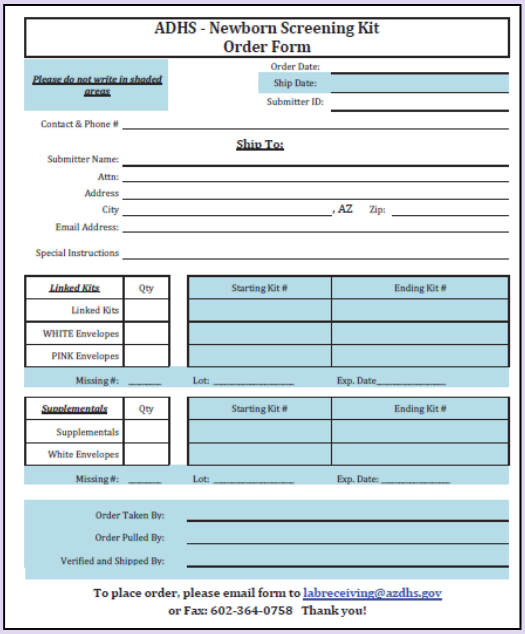
Courier-Delivery

Hospitals use local service for same day or next day pickup and delivery,
Monday—Saturday

ez messenger

High volume clinics, physician practices can use FedEx for next day service, Monday - Friday

FedEx.



ADHS - Newborn Screening Kit
Order Form

Please do not write in shaded areas

Order Date:
Ship Date:
Submitter ID:

Contact & Phone #

Ship To:

Submitter Name:
Attn:
Address
City , AZ Zip:
Email Address:

Special Instructions

Linked Kits	Qty	Starting Kit #	Ending Kit #
Linked Kits			
WHITE Envelopes			
PINK Envelopes			

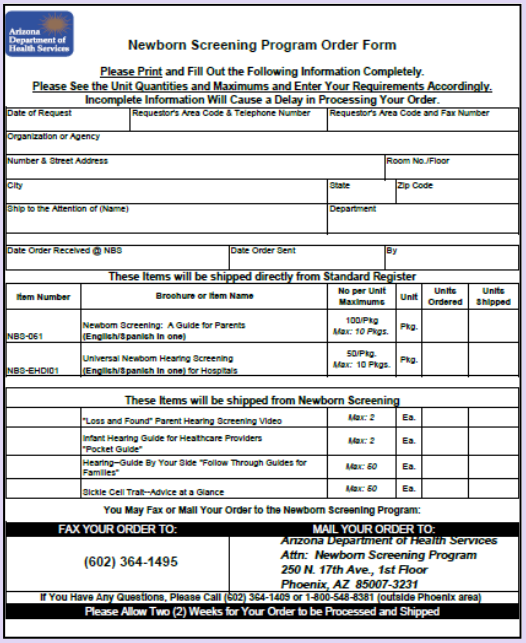
Missing #: Lot: Exp. Date

Supplementals	Qty	Starting Kit #	Ending Kit #
Supplementals			
White Envelopes			

Missing #: Lot: Exp. Date:

Order Taken By:
Order Pulled By:
Verified and Shipped By:

To place order, please email form to labreceiving@azdhs.gov
or Fax: 602-364-0758 Thank you!



Arizona Department of Health Services

Newborn Screening Program Order Form

Please Print and Fill Out the Following Information Completely.
Please See the Unit Quantities and Maximums and Enter Your Requirements Accordingly.
Incomplete Information Will Cause a Delay in Processing Your Order.

Date of Request	Requestor's Area Code & Telephone Number	Requestor's Area Code and Fax Number
Organization or Agency		
Number & Street Address		Room No./Floor
City	State	Zip Code
Ship to the Attention of (Name)	Department	
Date Order Received @ NBS	Date Order Sent	By

These Items will be shipped directly from Standard Register

Item Number	Brochure or Item Name	No per Unit Maximums	Unit	Units Ordered	Units Shipped
NBS-061	Newborn Screening: A Guide for Parents (English/Spanish in one)	100/Pkg Max: 10 Pkgs.	Pkg.		
NBS-EHDI01	Universal Newborn Hearing Screening (English/Spanish in one) for Hospitals	50/Pkg. Max: 10 Pkgs.	Pkg.		

These Items will be shipped from Newborn Screening

	"Loss and Found" Parent Hearing Screening Video	Max: 2	Ea.		
	Infant Hearing Guide for Healthcare Providers "Pocket Guide"	Max: 2	Ea.		
	Hearing–Guide By Your Side "Follow Through Guides for Families"	Max: 60	Ea.		
	Sickle Cell Trait–Advice at a Glance	Max: 60	Ea.		

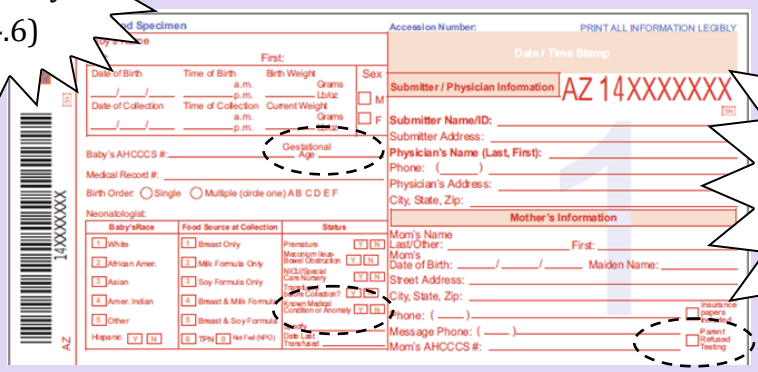
You May Fax or Mail Your Order to the Newborn Screening Program:

FAX YOUR ORDER TO:	MAIL YOUR ORDER TO:
(602) 364-1495	*Arizona Department of Health Services* *Attn: Newborn Screening Program* *250 N. 17th Ave., 1st Floor* *Phoenix, AZ 85007-3231*

If You Have Any Questions, Please Call (602) 364-1409 or 1-800-548-8381 (outside Phoenix area)
Please Allow Two (2) Weeks for Your Order to be Processed and Shipped

Tips For Completing the Card

Gestational Age:
Weeks.Days
(34.6)

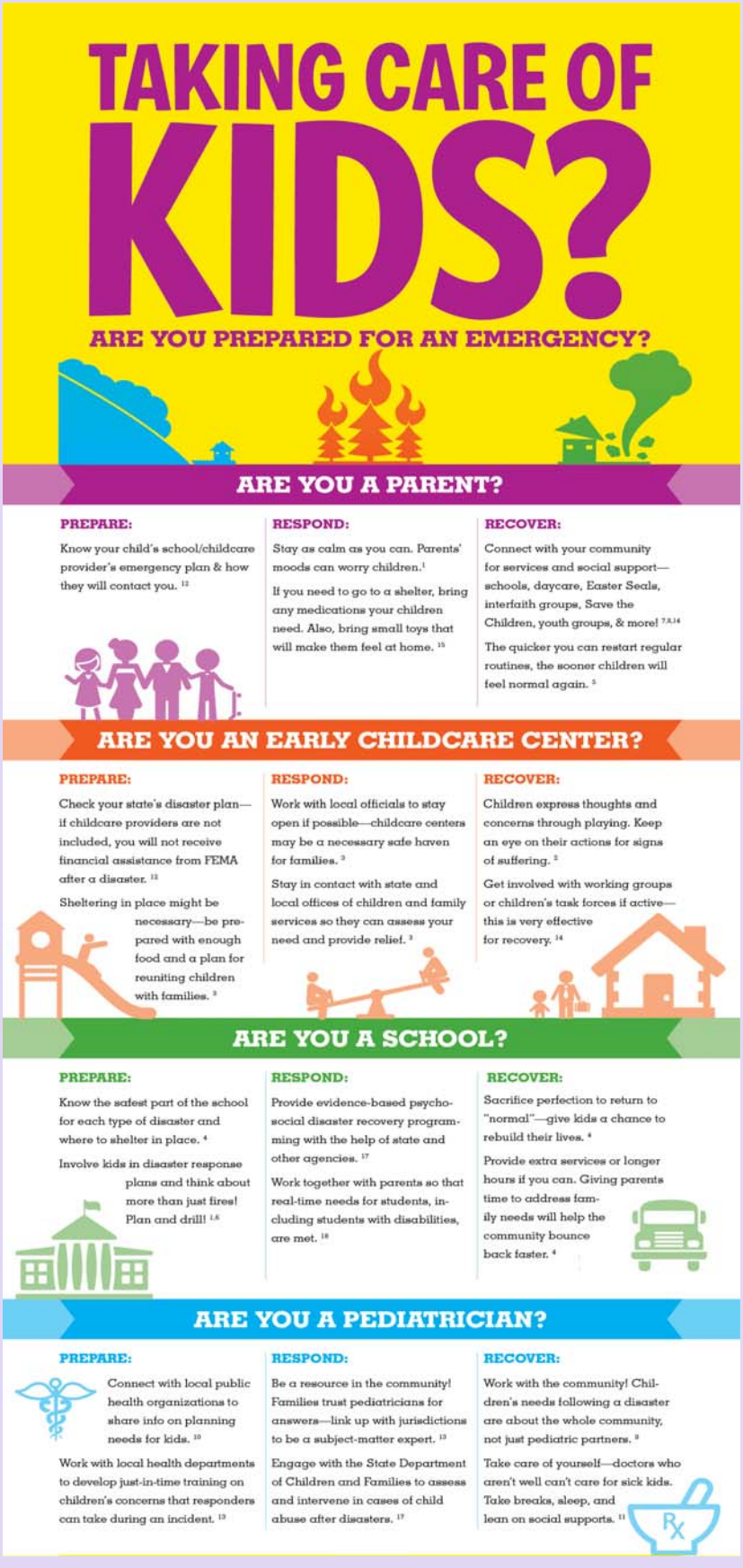


Known Anomaly:
EXAMPLES
Trisomy's
Cleft Lip
Atresia

Parent Refusal:
Complete Demographics, Mark Refusal, Return to Lab

Emergency Preparedness and Response

In the Spotlight



1 Prepare a Plan
2 Make a Kit
3 Be Informed

Resource Links

justincasearizona.com/
http://azdhs.gov/phs/emergency-preparedness/

www.bt.cdc.gov/children
www.acep.org
www.fema.gov
www.ems-c.org
www.Safeandwell.org
www.nsc.org
www.disabilitypresparedness.com

On our Website:

Emergency Preparedness Resources and Helpful Hints Flyer [Español]

CDC Emergency Social Media

azein

Arizona Emergency Information Network
https://ein.az.gov/

Preparedness Checklist for Pediatric Practices

pediatrics.aappublications.org/content/104/4/e53.full

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Severe Combined Immunodeficiency (SCID)

What is SCID?

Severe combined immunodeficiency (SCID) is an inherited condition in which the body is unable to fight off serious and life-threatening infections. Your body's immune system is made up of different parts that work together to keep the body from getting sick. In a baby with SCID, certain parts of the immune system do not work properly. This puts the baby at risk of getting many infections. Children that do not get treatment for SCID rarely live past the age of two. However, when SCID is identified and treated before the baby gets infections, those children can live longer and healthier lives.

Testing Methodology

Currently sixteen states screen for Severe Combined Immune Deficiency (SCID). The technique used to screen SCID is called T-cell receptor excision circles (TREC). The assay was first published in 2005 by Chan and Puck (J. Allergy Clin. Immunol. 2005, 115, 391) and has been adopted by all states that are screening for SCID.

TREC are circular DNA molecules formed within T-cells developing in the thymus. TREC copy number is a marker of newly-formed T cells. TREC DNA circles are measured by a technique called polymerase chain reaction (PCR). Normal newborns have one TREC per 10 T-cells. Infants with SCID, were shown to have very low to zero TRECs.

The TREC assay is the first newborn screening test to use DNA as the primary analyte. The assay is using the same newborn dried blood spot specimen that is routinely collected to test for other disorders.

Will it be included on the screening panel in Arizona?

House Bill 2491, signed by the governor on 4/23/14 says, in part "The department of health services may adopt rules regarding adding severe combined immunodeficiency testing to the newborn screening program…. The department shall seek stakeholder input, including input from health care providers, in the development of these rules."

Other added tests?

In November the Newborn Screening Advisory Committee met and recommended adding SCID to the screening panel. The Department is now going through rulemaking to Article 2 to:

* **Add a screening for severe combined immunodeficiency** to the newborn and infant blood spot test effective January 2016, *if the Arizona Legislature authorizes the Department to increase the fee for the first specimen.*

The new law also mandates hearing screening and adds critical congenital heart disease (CCHD) screening.

EHDI

Early Hearing Detection and Intervention

EHDI Coordinator Corner

Lylis Olsen, MPH, C-AAA

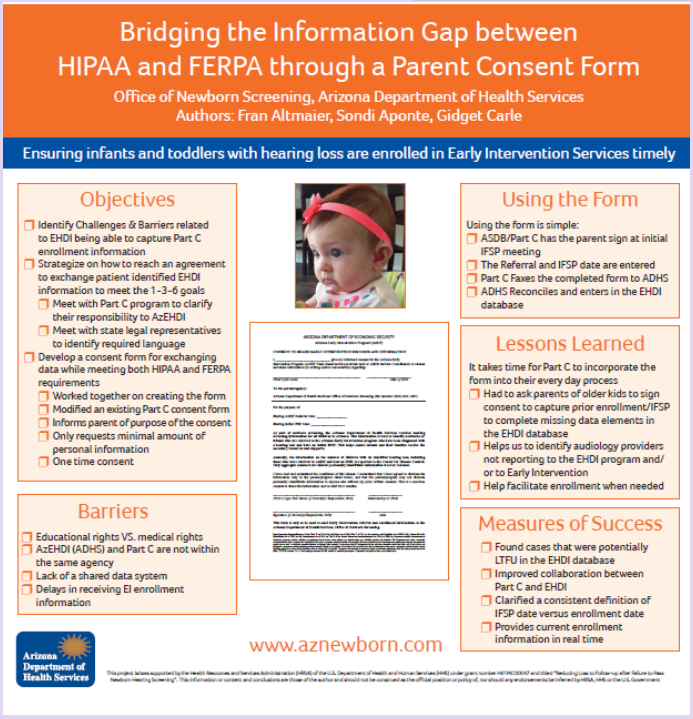
Children who are Deaf have fluid too!

One of the most common causes of delays in diagnosis for those kids who are not lost to follow up is getting caught in the medical loop because of middle ear fluid or infection. Some children who don't pass the newborn hearing screening are referred to ear specialists to rule out middle ear disorders. Often this is the cause of failing the hearing screen. Unfortunately, included in this group with fluid is a cohort of children who may have fluid AND a permanent childhood hearing loss. Identification of hearing loss can be severely delayed for these children who are being treated by specialists who have not ruled out a permanent hearing loss. Each year there are a number of children who were picked up on newborn hearing screening, whose parents followed all of the medical advice, made it to all of the appointments and still did not get a diagnosis of hearing loss and appropriate early intervention services. Everyone needs to be diligent to prevent avoidable late identification:

- Parents - ask about ruling out permanent hearing loss
- Pediatricians - make sure that hearing loss has been ruled out along with medical intervention
- Audiologists - include bone conduction measures along with other appropriate test batteries
- ENT/Otology - refer to pediatric audiologists to rule out significant permanent hearing loss

HAVE YOU RULED OUT PERMANENT HEARING LOSS?

Poster presented at the 2015 EHDI Conference



Bridging the Information Gap between HIPAA and FERPA through a Parent Consent Form

Office of Newborn Screening, Arizona Department of Health Services
Authors: Fran Altmaier, Sondi Aponte, Gidget Carle

Ensuring infants and toddlers with hearing loss are enrolled in Early Intervention Services timely

Objectives

- Identify Challenges & Barriers related to EHDI being able to capture Part C enrollment information
- Strategize on how to reach an agreement to exchange patient identified EHDI information to meet the 1-3-6 goals
  - Meet with Part C program to clarify their responsibility to AzEHDI
  - Meet with state legal representatives to identify required language
- Develop a consent form for exchanging data while meeting both HIPAA and FERPA requirements
  - Worked together on creating the form
  - Modified an existing Part C consent form
  - Informs parent of purpose of the consent
  - Only requests minimal amount of personal information
  - One time consent

Barriers

- Educational rights VS. medical rights
- AzEHDI (ADHS) and Part C are not within the same agency
- Lack of a shared data system
- Delays in receiving EI enrollment information

Using the Form

Using the form is simple:

- ASDB/Part C has the parent sign at initial IFSP meeting
- The Referral and IFSP date are entered
- Part C Faxes the completed form to ADHS
- ADHS Reconciles and enters in the EHDI database

Lessons Learned

It takes time for Part C to incorporate the form into their every day process

- Had to ask parents of older kids to sign consent to capture prior enrollment/IFSP to complete missing data elements in the EHDI database
- Helps us to identify audiology providers not reporting to the EHDI program and/or to Early Intervention
- Help facilitate enrollment when needed

Measures of Success

- Found cases that were potentially LTFU in the EHDI database
- Improved collaboration between Part C and EHDI
- Clarified a consistent definition of IFSP date versus enrollment date
- Provides current enrollment information in real time

Arizona Department of Health Services

www.aznewborn.com

Legislative Update

Newborn Hearing Screening Mandate

The Fifty-first Legislature passed HB2491 which included an amendment adding hearing disorders to the mandated panel of newborn screens. The American College of Medical Genetics (AMCG) recommended newborn hearing screening as one of the screens in the newborn screening panel. Arizona Statute 36-694 has been updated to reflect the inclusion of hearing disorders. Hearing loss is the most common condition present at birth. In 2013, 138 Arizona babies were identified with a confirmed hearing loss.

Visit www.azleg.gov for more information on House Bill 2491

Arizona Department of Health Services Office of Newborn Screening · 250 N 17th Ave, 1st Fl · Phoenix, AZ 85007 · Phone: 602-364-1409 · Fax: 602-364-1495 · nbseducation@azdhs.gov

Role of the Medical Home

Bradley Golner, M.D.
Arizona EHDI Chapter Champion

As primary care physicians (PCP), we are responsible for establishing a medical home environment for all of our patients. This is particularly important for our deaf/hard of hearing (D/HH) population. Some of the most important steps we need to take as PCPs for these patients is not only ensuring that they receive supportive services, but that they receive appropriate TIMELY REFERRALS from us.

This begins early on to establish a diagnosis (by 3 months of age) with a referral to pediatric audiology (don't forget about EHDI-PALS.org to locate the nearest center!). It is also important to follow-up/respond to any correspondence from the state newborn screening program. This includes fax-back forms and phone calls to ensure follow-up for the infant who did not pass their newborn hearing screen. Other important referrals occur after diagnosis. These include referrals to early intervention, otolaryngology, genetics, ophthalmology, and cardiology if warranted.

The absence of referrals from PCPs is often a barrier to both support services and more importantly, diagnosis. Our role as medical home providers play a critical role in the timely management of referrals and services for this population so be sure that you have systems in place for your practice to provide the best quality of care for all your patients.

Read the *Journal* Statement of Reaffirmation
http://pediatrics.aappublications.org/content/110/1/184.full

NATIONAL CENTER FOR MEDICAL HOME IMPLEMENTATION
A cooperative agreement between the Maternal and Child Health Bureau/HRSA and the American Academy of Pediatrics

Parent Resources

GUIDE BY YOUR SIDE™
FOR FAMILIES

Providing unbiased, emotional support and resources by trained Parent Guides to families with children who are deaf, hard of hearing and hearing impaired.

Arizona Hands & Voices
Guide By Your Side
P.O. Box 30163
Phoenix, AZ 85046
Toll free: 1-866-685-1050
Email: gbys@azhv.org

Order online at
http://www.azdhs.gov/lab/aznewborn/documents/forms/

Hands & Voices
Resources for Families
http://www.azhv.org/
Contacts
Najwa Ghattas,
Executive Director
Executivedirector@azhv.org

Carla Zimmerman,
Secretary
secretary@azhv.org

facebook
Name:
Arizona Hands and Voices

National Association of the Deaf www.nad.org

Growing Together, Creating Language Rich Environments.
https://www.youtube.com/watch?v=s9-ieU0vl0Q

Statewide Hearing Data

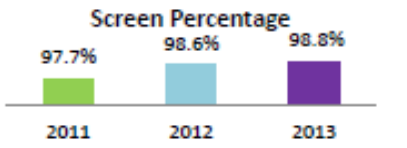
Screening

	2011	2012	2013
Total Occurrent Births	85333	87064	86498
Total Occurrent Births by Vital Records	86668	87292	86586
Not Screened			
Total Documented As Not Screened	677	1031	949
Not Screened: Infants Died	217	355	285
Not Screened: Parents/Family Declined Services	136	169	280
Not Screened: Missed	286	63	31
Transferred, no documented screen	N/A	N/A	5
Non-resident	N/A	N/A	60
Not Screened: Unknown	38	444	288
Screened			
Total Documented As Screened	84656	86033	85549
Total Pass	83836	85196	84815
Pass Before 1 Month of Age	82472	83874	83103
Pass After 1 Month but Before 3 Months of Age	1098	1087	1362
Pass After 3 Months of Age	266	235	350
NICU > 30 days pass (Not Included in Sum)	N/A	N/A	15
Pass: Age Unknown	0	0	0
Total Not Pass	820	837	734
Not Pass Before 1 Month of Age	661	684	563
Not Pass After 1 Month but Before 3 Months of Age	114	111	104
Not Pass After 3 Months of Age	45	42	67
Not Pass NICU > 30 days (Not Included in Sum)	N/A	N/A	23
Not Pass: Age Unknown	0	0	0
Fail IP Screen and Not Receive OP Screen (Not Included in Sum)	311	231	227

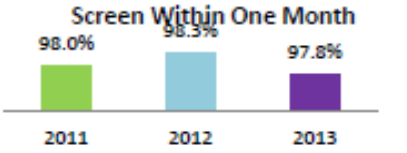
Diagnosis

	2011	2012	2013
Total Not Pass (From Screening Section)	820	837	734
Diagnosis			
Total Normal Hearing	174	244	247
Normal Hearing Before 3 Months of Age	96	155	137
Normal Hearing After 3 Months but Before 6 Months of Age	5	55	70
Normal Hearing After 6 Months of Age	23	34	40
Normal Hearing: Age Unknown	0	0	0
Total Hearing Loss	151	148	121
Hearing Loss ID Before 3 Months of Age	82	91	67
Hearing Loss ID After 3 Months but Before 6 Months of Age	33	35	36
Hearing Loss ID After 6 Months of Age	36	22	18
Hearing Loss ID: Age Unknown	0	0	0
No Diagnosis			
Total with No Diagnosis	495	445	366
Audiologic Diagnosis in Process	0	0	0
Moved Out of Jurisdiction	N/A	N/A	52
Non-resident	N/A	N/A	9
Non-resident or Moved Out of Jurisdiction	0	2	0
Infants Died	21	14	8
Parents/Family Declined Services	23	35	43
Parent / Family Contacted but Unresponsive	7	6	134
Medical Reasons	N/A	N/A	4
PCP did not refer	N/A	N/A	1
Unable to Contact	353	270	103
Unknown	91	118	12
Other Cases			
Cases of non-permanent, transient hearing loss ID	9	4	29
Cases of Hearing Loss Not Included in Total Hearing Loss	14	15	21
Hearing Loss ID Before 3 Months of Age	7	1	8
Hearing Loss ID After 3 Months but Before 6 Months of Age	1	4	1
Hearing Loss ID After 6 Months of Age	6	10	12
Hearing Loss ID: Age Unknown	0	0	0
Total Cases of Hearing Loss	151	163	142

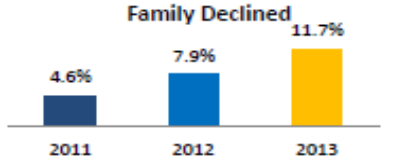
Screen Percentage	2011	2012	2013
	97.7%	98.6%	98.8%



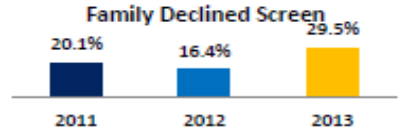
Screen Within 1 Month	2011	2012	2013
	98.0%	98.3%	97.8%



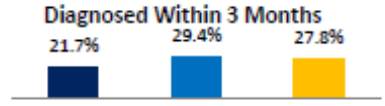
Family Declined Diagnosis	2011	2012	2013
	4.6%	7.9%	11.7%



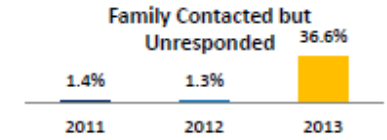
Family Declined Screen	2011	2012	2013
	20.1%	16.4%	29.5%



Diagnosed Within 3 Months	2011	2012	2013
	21.7%	29.4%	27.8%



Family Contacted but Unresponded	2011	2012	2013
	1.4%	1.3%	36.6%



Note that several categories were added for 2013 data and therefore prior years were not calculated.

Families *Contacted but Unresponsive* is now defined by the CDC as meeting one of the criteria below:

(1) A "live" conversation with the family, with the family nevertheless not going in for an outpatient screen or diagnostic evaluation (OR)

(2) A conversation with the PCP who reports that he or she has talked with the family about the need for an outpatient screen or diagnostic evaluation (depending on where the child is in the process), with the PCP reporting that the family has not followed through. (OR)

(3) A registered letter and/or email conversation with the parent. Note that if email is used, it must be a two-way email "conversation" with the parent. No reply or an automatic reply from the email account would not be considered a conversation. (OR)

(4) Confirmation that the hospital has done one of the above

Arizona Department of Health Services Office of Newborn Screening · 250 N 17th Ave, 1st Fl · Phoenix, AZ 85007 · Phone: 602-364-1409 · Fax: 602-364-1495 · nbseducation@azdhs.gov

Did You Know?

Sound of Mother's Voice in Womb May Aid Fetal Brain Growth

Feb. 23 issue of *Proceedings of the American Academy of Sciences*
http://www.nlm.nih.gov/medlineplus/news/fullstory_151104.html

MONDAY, Feb. 23, 2015 (HealthDay News) --

Babies may get a brain boost in the womb when they hear the voices and heartbeats of their mothers, a new study suggests.

Researchers studying premature babies in the hospital found that the sound centers in the babies' brains grew more quickly when they heard recordings of their mothers rather than the normal clamor of intensive care units. The recordings were manipulated to simulate sounds heard in a womb.

It's not clear what this means in the long run, "but it shows how important it is for mothers to interact with their premature babies when they visit," said study co-author Amir Lahav, an assistant professor of pediatrics at Harvard Medical School in Boston.

Babies born prematurely often suffer from hearing and language problems, Lahav explained, and the researchers wanted to know more about how they're affected by the weeks they spend in an incubator instead of in their mother's womb.

"Babies begin to hear at 25 weeks' gestation, and they're exposed to the mother's voice and heartbeat," Lahav said. "If you put them inside the incubator for five to six weeks, you're actually depriving them of these maternal exposures to the mother's voice. The incubator is seemingly a wonderful piece of equipment. But at the same time, it's like a social cage."

The study findings probably apply to all babies, one expert noted.

Previous research has shown that fetuses respond to the sound of the mother's voice. At birth, babies take notice "and say, 'Hey, that's what I was waiting for,' " said Janet Werker, a psychology professor at the University of British Columbia in Vancouver.

"There's very strong evidence that at birth, full-term babies show strong preference for the language they heard in utero and the voice of their mother over other women," she said.

But it's not clear if the mother's voice is the only important one, since exposure to other voices could be just as critical, Werker added.

For this latest study, the researchers chose a group of premature babies who were born at 25 to 32 weeks. Nineteen were randomly assigned to hear the normal noises of the hospital, while 21 heard recordings of the voices and heartbeats of their mothers. The second group listened to the recordings for three hours a day.

After a month, the study authors used ultrasound scans to measure parts of the brains of the babies. Those infants who heard the recordings had larger sound centers -- the auditory cortex -- in their brains.

"Our findings do not prove that the brains of these babies are necessarily better, and we cannot conclude that they will end up with no developmental disabilities," Lahav said. "We don't know the advantages of having a bigger auditory cortex."

It's also not clear if mothers' voices are crucial inside the womb or if the voices of other people might also make a difference.

Still, Lahav said the research suggests that parents of premature babies need to talk to them during visits in the hospital. "Hold your baby, talk to your baby, sing to your baby," he said.

Werker did caution that recordings should never be a substitute for actual visits from parents.

Important Tips

Randi Winston, AuD, CCC-A, Consulting Audiologist

Screener Tech Tip:

Timing is everything! How long should you wait to screen after well babies are born?

Why is timing so important?
When babies are born their ears have debris or vernix from the birth process, which can impact the screening outcome. In order to screen most efficiently, we want to give the ears time to dry out yet ensure there is an opportunity to provide two complete screenings, if needed, prior to discharge; therefore, timing can be tricky. Keep in mind that the earlier you screen, the higher the false positive rate will be and more babies will require a repeat screening prior to discharge.

When is the ideal time to conduct the initial screen?
If your hospital's average length of stay for well babies is 24 hours, it is a good idea to wait to do the initial screen between 12-16 hours of age. If the average length of stay is 48 hours, waiting until the baby is 24 hours old is optimal.

How long should you wait to rescreen if baby does the pass the initial screen?
If one or both ears do not pass, waiting another 4 to 6 hours to rescreen will give the ears more time to clear out, but waiting just before discharge can be risky, as there is the possibility the baby will not be in the optimal condition and the parents anxious to be discharged.

How will screening be affected if conducted immediately after birth such as when the baby is in transition?
If you are screening with OAE technology or ABR with a probe, it is not recommended to attempt screening prior to at least 12 hours after birth in order to minimize clogging with debris and damaging the probe. If you are conducting ABR screening with Ear Hugs or couplers, the only downside is that you may have more false positives, requiring that screening will need to be repeated on more babies. This may not be the most efficient strategy but the risk of passing a baby that should not pass is not increased.

If you need assistance designing and implementing the optimal screening protocol for you facility, contact **randiwinston@mac.com.**

HiTrack Tip:

The Importance of cross-referencing and filling in the gaps

Remember that all babies born at a given facility must be entered into HiTrack within one week of the screening. This includes all babies that may not have had a screen; such as missed, transferred out and refused babies. It is important to cross-reference birth logs or the hospital census to ensure all babies are accounted for and entered into HiTrack within a reporting week. In addition to entering babies that may not have had a screening, a note regarding why the screening was not conducted must also be entered in the notes section. For example, if a baby was missed because of an equipment malfunction, the inpatient result field must be populated with the "missed" status and an accompanying note must be entered with the reason why the screening could not be conducted. Providing timely and thorough information is key to timely follow-up.

Early Childhood Hearing Outreach (ECHO) Initiative

ECHO focuses on extending the benefits of periodic hearing screening to young children in a variety of health and education settings. We also serve Early Head Start programs as the National Resource Center on Early Hearing Detection and Intervention.

Featured Programs

Bureau of Women & Children's Health

Office of Children's Health

Maternal, Infant & Early Childhood Home Visiting Program

Provides home visiting programs to pregnant women and families with children under the age of five to promote improved maternal and child health, reduce child abuse and neglect, reduce domestic violence, improve family self-sufficiency, and improve school readiness for enrolled families.

Contact Jessica Stewart
602-364-1441
Jessica.stewart@azdhs.gov

High Risk Perinatal Program (HRPP)
Newborn Intensive Care Program (NICP)

Through a coordinated system of care, provides a safety net for high risk pregnant women and critically ill newborns to ensure timely access to appropriate medical care and provides support to families who have been impacted by the birth of a critically ill infant through early identification and linkage to risk appropriate services.

Contact Valerie Zbozinek
602-364-1462
Valerie.zbozinek@azdhs.gov

Children's Information Hotline
800-232-1676
Pregnancy & Breastfeeding Hotlines
800-833-4642

Office of Children with Special Health Care Needs

OCSHCN

Through contractor partnerships, OCSHCN ensured family and youth involvement in care, provides advocacy, coordinates respite and palliative care, promotes early detection of hearing loss beyond the newborn period, and overnight accommodations to families who are traveling from out of town to be near hospitalized children with special healthcare needs.

Contact Rita Aitken
602-364-1480
Rita.aitken@azdhs.gov

Office of Newborn Screening

STAR

Demographics

This team is responsible for entering all information from the collection kit into the newborn screening database where it is combined with the dried bloodspot laboratory results. It is then verified for accuracy, a report created, and mailed or faxed to the provider and submitter.

All data is hand entered!

To ensure accurate, timely reporting please:

- ✓ Complete all fields on the card—print legibly
- ✓ Enter the provider's first and last name
- ✓ Mark the sex (gender)
- ✓ Always include the date and time of birth
- ✓ Date and time of collection ensure proper testing
- ✓ Include as much information about mom as known

If you receive a call, fax, or report and have questions, please call **602-364-3190**

Media and Events

Newborn Screening Rule Making Moves Forward

The Arizona Newborn Screening Program screens more than 80,000 babies for a panel of 29 disorders annually. Although babies born with these disorders may appear to be normal at birth, with time the disorder may have a devastating or lethal effect on the infant's health and development. Early screening, detection, and quick treatment of these disorders can, in many cases, help kids avoid illness, developmental delays, and even death.

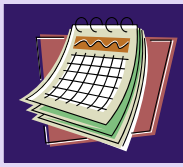
In 2014 House Bill 2491 required the Department to revise our Newborn Screening rules to include hearing tests on all newborns, add screening for critical congenital heart defects (CCHD) and consider adding a screening for severe combined immunodeficiency. On March 23, 2015, the Department received approval from the Governor's office to move forward with the rulemaking to implement these requirements.

The screening test for CCHD uses pulse-oximetry, a test that happens in the hospital. It's a device that is placed on the foot of a newborn and measures the baby's oxygen levels. A low oxygen reading can be a sign that the baby might have a heart problem. Congenital heart disease occurs in approximately eight in every 1,000 live births, and, if left undetected, children are at risk for developing of serious complications within the first few days or weeks of life. Most hospitals already do this screening, but our new rules will make the screening a requirement.

The law also requires us to take a look at adding severe combined immunodeficiency disorder (SCID) disease to our screening panel. In October 2014, our Newborn Screening Advisory Committee met and recommended that we include the screening test for SCID as part of our panel. This test would require some new equipment and increased costs, so we'd need to get the authority to increase our testing fee by $10 to pay for the testing costs before we could add it to our panel of tests. The good news is because the screening test for SCID is so reliable, we'd only need to test the first sample (taken at the hospital).

We expect to publish the draft rules for comment later this spring and then implement the updated rules July 1st.

March 26, 2015
By Cory Nelson



Mark Your Calendars! Upcoming Events

AWHONN
PROMOTING THE HEALTH OF WOMEN AND NEWBORNS

Association of Women's Health, Obstetric, and Neonatal Nurses
AZ AWHONN conference
Thursday, May 21st, 8-5pm
Black Canyon Conference Center

AzAAP, Pediatrics in the Red Rocks
June 26-28, Sedona Hilton Resort & Spa
http://www.azaap.org/
Pediatrics_in_the_Red_Rocks

PEDIATRICS ARIZONA CHAPTER

NATIONAL DOWN SYNDROME CONGRESS

National Down Syndrome Congress
Beyond All Limits
June 25-28
JW Marriott Desert Ridge

25th Annual Perinatal Trust
Perinatal Conference
August 13 & 14, 2015
Flagstaff, AZ—High Country Conference Center
https://www.azperinatal.org/

11th Annual Schuff Steel Golf Classic
benefitting *Desert Voices*
Palm Valley Golf Club Goodyear, AZ Saturday April 25, 2015
www.desert-voices.org

desert voices
WHERE DEAF CHILDREN LEARN TO SPEAK

Stay Connected

Join our constant contact list and receive updates and news delivered right to your inbox!

Simply do the following to add yourself to the list:

- Visit this page: http://visitor.constantcontact.com/email.jsp?m=1101362445484
- Click the box next to the topics you would like to receive information on from ADHS
- Be sure to choose *Office of Newborn Screening* and *AZEHDI: Early Hearing Detection and Intervention*
- Fill out the contact info in the column to the right so we can include you in specified correspondence as well
- Forward and share with a friend!

Resources for Professionals and Families

ASDB Arizona State Schools for the Deaf and the Blind
www.asdb.az.gov/asdb

The Ear Foundation of Arizona
www.earfoundationaz.webs.com

baby's first test
www.babysfirsttest.org

March of Dimes
www.marchofdimes.org

Raising Special Kids
www.raisingspecialkids.org

Mountain States Genetics Regional Collaborative
www.msgrcc.org/

Hands & Voices
www.gbys.azhv.org


www.azperinatal.org

desert voices
WHERE DEAF CHILDREN LEARN TO SPEAK
www.desert-voices.org

Pediatrics Arizona Chapter
www.azaap.org

Arizona Early Intervention Program
www.azdes.gov/azeip

Visit us on social media

Arizona Department of Health Services Office of Newborn Screening · 250 N 17th Ave, 1st Fl · Phoenix, AZ 85007 · Phone: 602-364-1409 · Fax: 602-364-1495 · nbseducation@azdhs.gov