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

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**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**

### Baby’s First Test - Phenylketonuria (PKU)

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](http://www.babysfirsttest.org)
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 Second Look at a Second Screen
Lisa Villarroel, MD MPH

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/.
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!

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/
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

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

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**

**TAKING CARE OF KIDS? ARE YOU PREPARED FOR AN EMERGENCY?**

**ARE YOU A PARENT?**

**PREPARE:**
- Know your child’s school/childcare provider’s emergency plan and how they will contact you. 11
- If you need to go to a shelter, bring any medications your children need. Also, bring small toys that will make them feel at home. 11

**RESPOND:**
- Stay as calm as you can. Parents’ mood can worry children. 11
- If you need to go to a shelter, bring any medications your children need. Also, bring small toys that will make them feel at home. 11

**RECOVER:**
- Connect with your community for services and social support—schools, daycares, Easter Seals, internships, groups. Save the Children, youth groups, & more. 11
- The quicker you can restart regular routines, the sooner children will feel normal again. 11

**ARE YOU AN EARLY CHILDRENCARE CENTER?**

**PREPARE:**
- Check your state’s disaster plan—if childcare providers are not included, you will not receive financial assistance from FEMA after a disaster. 11
- Sheltering in place might be necessary—be prepared with enough food and a plan for evacuating children with families. 11

**RESPOND:**
- Work with local officials to stay open if possible—childcare centers must have a business plan prepared for families. 12
- Stay in contact with state and local offices of children and family services so they can assess your need and provide relief. 12

**RECOVER:**
- Children express thoughts and concerns through play. Keep an eye on their actions for signs of stress. 11
- Get involved with working groups or children’s task forces if active—this is very effective for recovery. 11

**ARE YOU A SCHOOL?**

**PREPARE:**
- Know the safest part of the school for each type of disaster and where to shelter in place. 11
- Involve kids in disaster response plans and think about more than just food. Plan and drill! 12

**RESPOND:**
- Provide evidence-based psycho-social disaster recovery programming with the help of state and other agencies. 11
- Work together with parents so that medication needs for students, including students with disabilities, are met. 12

**RECOVER:**
- Sacrifice perfection to return to “normal”—give kids a chance to rebuild their lives. 12
- Provide extra services or longer hours if you can. Giving parents time to address family needs will help the community bounce back faster. 12

**ARE YOU A PEDIATRICIAN?**

**PREPARE:**
- Connect with local public health departments to share info on planning needs for kids. 11
- Work with local health departments to develop and increase training on children’s needs that responders can take during an incident. 11

**RESPOND:**
- Be a resource in the community—Families trust pediatricians for answers—link up with jurisdictions to be a subject matter expert. 11
- Engage with the State Department of Children and Families to assess and intervene in cases of child abuse after disasters. 12

**RECOVER:**
- Work with the community—Children’s needs following a disaster are about the whole community, not just pediatric patients. 11
- Take care of yourself—doctors who aren’t well can’t care for sick kids. Take breaks, sleep, and lean on social supports. 11

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**Preparedness Checklist for Pediatric Practices**

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

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**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.disabilitypreparedness.com

On our Website:

Emergency Preparedness Resources and Helpful Hints Flyer [Español]

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

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.
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?

Legislative Update

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
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

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

National Association of the Deaf www.nad.org
Growing Together, Creating Language
Rich Environments.
https://www.youtube.com/watch?v=s9-ieU0vl0Q
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

Note that several categories were added for 2013 data and therefore prior years were not calculated.
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.
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 your 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.
Bureau of Women & 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

Office of Newborn Screening 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

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

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

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
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](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

- [www.asdb.az.gov/asdb](http://www.asdb.az.gov/asdb)
- [www.earfoundationaz.webs.com](http://www.earfoundationaz.webs.com)
- [www.babysfirsttest.org](http://www.babysfirsttest.org)
- [www.marchofdimes.org](http://www.marchofdimes.org)
- [www.gbys.azhv.org](http://www.gbys.azhv.org)
- [www.raising.specialkids.org](http://www.raising.specialkids.org)
- [www.desert-voices.org](http://www.desert-voices.org)
- [www.azperinatal.org](http://www.azperinatal.org)
- [www.azaap.org](http://www.azaap.org)
- [www.azdes.gov/azeip](http://www.azdes.gov/azeip)

Visit us on social media:

![Social Media Icons]