



Fall 2014



Newborn Screening Connection

The Office of Newborn Screening Newsletter featuring Arizona EHDI

Welcome to our readers!

Welcome to the first issue of the Newborn Screening Connection! We are very excited to collaborate with AZEHDI to bring you our new educational and informative newsletter. We look forward to continuing to serve the community and provide material that our partners and providers can use for Arizona babies. As you may know there have been some big, positive changes this year for newborn screening. With more coming we want to be sure our outreach is expansive and successful. Each issue will feature the latest in bloodspot and hearing news, along with media and upcoming events.

We are always looking for collaboration from you, our valued and trusted healthcare professionals. If there is anything you would like us to feature in an upcoming issue or a special story you would like to share, we want to hear from you!

Contact us:

Office of Newborn Screening e-mail: nbseducation@azdhs.gov

Thank you for reading!



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Newborn Screening



Pursuant to law, DHS established a newborn screening program to ensure that the testing for congenital heart disorders and the reporting of hearing test results that are required to be ordered by a physician attending a birth or a person required to make a report of a birth, are conducted in an effective and efficient manner. DHS specifies in rule the disorders to be tested, the process for collecting specimens and reporting requirements for test results. The U.S. Department of Health and Human Services recommends a panel of 31 screened disorders. Currently, Arizona has adopted 29 of the 31 recommended disorders to screen. Current statute requires the Director to designate the state laboratory as the only testing facility for the NSP.

House Bill 2491 Facts

1. Requires, by July 1, 2015, DHS to adopt rules adding critical congenital heart defect screening using pulse oximetry to the panel of tests required to be ordered for every newborn delivered.
2. Adds hearing disorders to the panel of tests required to be ordered on each birth by the attending physician or person required to report on the birth.
3. Allows DHS to designate laboratory testing facilities, other than the state laboratory, for conditions or tests added to the NSP on or after the effective date of this act and requires the facility to follow all of the privacy and sample destruction timeframes required of the state laboratory.
4. Allows DHS to consider rules adding severe combined immunodeficiency testing and Krabbe disease testing to the NSP test panel. It requires DHS to perform and consider a cost benefit analysis and seek stakeholder input from health care providers in the development of these rules.

This information is from the H.B. 2491 Fact Sheet located on www.azleg.gov. Please visit the website for more information.

What is CCHD?

Baby's First Test- Critical congenital heart disease (CCHD) represents a group of heart defects that cause serious, life-threatening symptoms and requires intervention within the first days or first year of life. CCHD is often treatable if detected early. It can encompass abnormalities in the rhythm of the heart, as well as a wide array of structural heart problems. These problems can range from mild (never requiring cardiac surgery) to severe (requiring multiple different stages of open heart surgeries). CCHD can involve abnormal or absent chambers, holes in the heart, abnormal connections in the heart, and abnormalities in the function or squeeze of the heart. Most congenital heart conditions affect patients from childhood through adulthood.

Some babies affected with CCHD can look and act healthy at first, but within hours or days after birth they can have serious complications. Pulse oximetry newborn screening is a non-invasive test that measures how much oxygen is in the blood and can help to identify babies that may be affected with CCHD before they leave the newborn nursery. If detected early, infants affected with CCHD can often be treated and lead longer, healthier lives.



www.babysfirsttest.org

A Post from the Director's Blog

Newborn Screening Advisory Committee Recommendation: Add SCID



Newborn Screening consists of critical laboratory and bedside tests done on newborns to see if they have certain inherited diseases. Early detection for these specific diseases is critical for the babies, doctors and parents, because delays in treatment can result in irreversible developmental delays, sickness and even death. With the passage of HB 2491 last year, the legislature asked the ADHS to consider adding Severe Combined Immunodeficiency (SCID) and Krabbe Disease to our newborn screening panel (we currently test for 28 disorders).

Wednesday October 1st, our Newborn Screening Advisory Committee met to consider the costs and benefits of screening for SCID and Krabbe. The Committee recommended that we change our rules and begin testing for SCID. If I decide to proceed with their recommendation, we'd also need to get the authority to increase our testing fee by \$10 so we can pay for the testing costs. Because the screening test for SCID is so reliable, we'd only need to test the first sample (taken at the hospital). We wouldn't need a second follow-up sample like we do for the other 28 disorders. The committee didn't make a recommendation one way or the other about Krabbe Disease.

We're currently working on a rule revision to require hospital testing for heart defects (critical congenital heart defects) to our testing requirements. Some babies born with a heart defect look healthy at first but have complications later. Newborn screening (by pulse oximetry) estimates the amount of oxygen in a baby's blood, and can identify some of these babies early so they can get quicker care and treatment.



Over the next couple of weeks I'll examine the data, evidence, and the Advisory Committee's recommendation. We'll include any decision to add SCID and/or Krabbe in the draft rules already underway to add critical congenital heart defects.

DRAFT RULES HAVE BEEN PUBLISHED AND ARE OPEN FOR PUBLIC COMMENT

www.AZNewborn.com

(look for link in the callout box on the main page of our website)



To follow Director Will Humble's blog in your feed visit:

www.feeds.feedburner.com/ADHSdirectorsblog

-or-

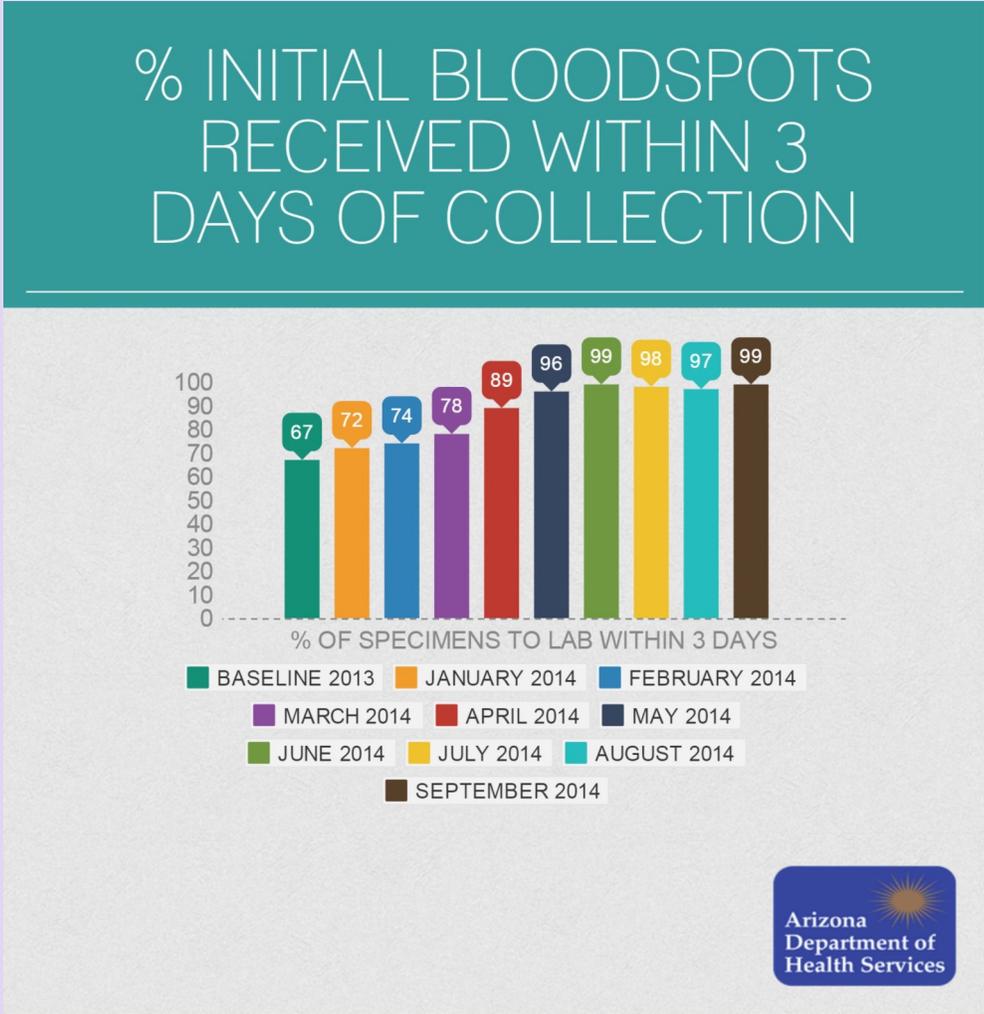
Read it here:

www.directorsblog.health.azdhs.gov

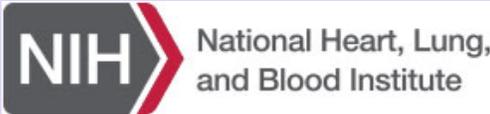
Transit Time Project

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

In an effort to improve services to newborns and families, ADHS developed an internal taskforce to lead newborn screening transit time initiatives. The taskforce is committed to transparency, accountability, and increased partnership as stakeholder's progress towards meeting this new statewide goal. The goal was set to be completed by July 1, 2014 with 95% of all newborn screening bloodspots (initial screens) being received at the Arizona State Public Health Laboratory within three (3) days of collection. The infographic below displays the progress that has been made statewide since the project began in January 2014, including the baseline for 2013.



Guidelines Update



New guidelines from the National Heart, Lung and Blood Institute for management of Sickle Cell Disease are now published.

Visit: <http://www.nhlbi.nih.gov/health-pro/guidelines/sickle-cell-disease-guidelines/index.htm> to learn more

What is the Office of Newborn Screening?



The Office of Newborn Screening Program

Education and Quality Assurance Team

provides marketing, outreach and solutions to care providers and families



Case Management Team

ensures proper follow-up, diagnosis, and care plan to families and providers

Laboratory Staff

provides screening and timely results of newborn screening bloodspot specimens



Demographics Team

ensures proper data management of testing and follow-up

www.AZNewborn.com

NBS Collection Kit Update

As some of you know the State Lab has been reducing the total number of linked kits, white and pink envelopes being shipped with your order. Supplemental kit orders have not been effected. A delay in receiving the newly designed linked kits *resulted in reduced quantities being shipped to all hospitals* but should be available within the next two weeks. Small quantities are still available to your hospital. As soon as our shipment arrives, routine orders for a 3-month supply will be filled.

Since the successful launch of the Ez Messenger courier service, which includes preaddressed 8.5x11 envelopes at no cost to you, *the old business size white envelopes will no longer be used for bloodspot samples transported from hospitals*. Once samples have been dried and the flap closed to protect the sample, please insert kits directly in the EZ Messenger envelope and place in the green bin.

Pink envelopes for parents have also been redesigned but also delayed. As soon as they are received to the State Lab, orders for them will be filled—expect them in two weeks. If you are completely out of envelopes for parents, simply give them the second part of the linked kit and ask that they keep it with their immunization card, protected if possible.

Updated Bloodspot Card



Please contact the Office of Newborn Screening or the Receiving Team if you have any questions
www.azdhs.gov/lab/shipping-receiving.htm

Updated Pink Envelope



Newborn Screening Program
 ARIZONA DEPARTMENT OF HEALTH SERVICES

Parents: Do not open envelope to protect filter paper kit.
 Padres: Por favor de no abrir el sobre puede causar daños al filtro.

Newborn Screening Bloodspot Collection Kit
 Take this envelope with the kit inside to your baby's medical provider at the 1st visit. Get the blood test for your baby between 5-10 days of age.

Equipo (Kit) de recolección gota de sangre del recién nacido para la Evaluación del Recien Nacido

En La primera visita lleve este sobre con el equipo (kit) dentro al proveedor medico del bebe. Obtenga la prueba de sangre para su bebé entre 5-10 días de edad.



EHDI

Early Hearing Detection and Intervention

Call to Action!

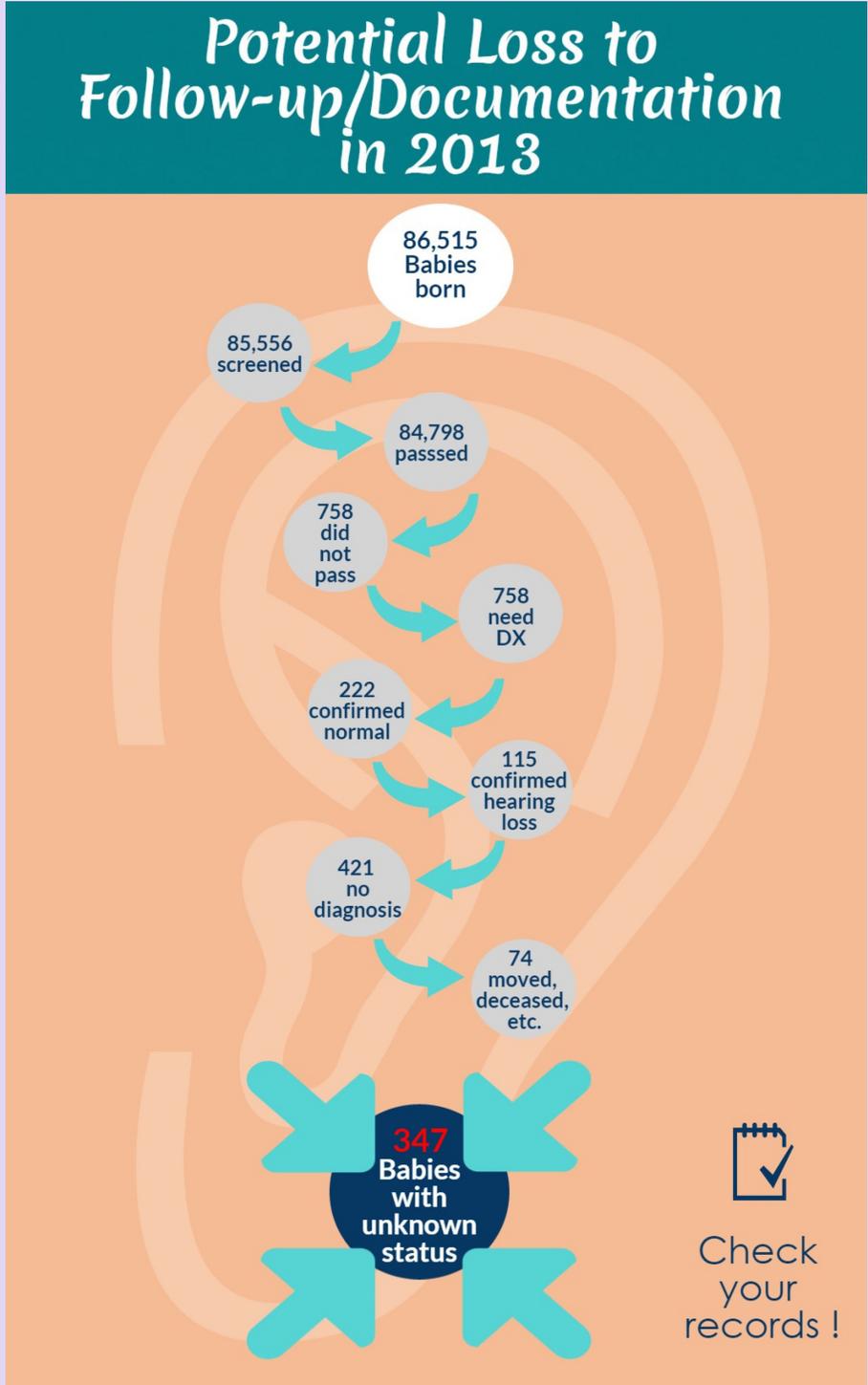
Of the 86,515 babies born last year who failed a final hearing screen, more than 300 have no documented diagnosis. Are these infants really falling through the cracks by not receiving a diagnosis, or is the Department of Health Services simply missing the results?



Call to Action for Audiologists:

- ⇒ Please check your records for all babies born in 2013 who were screened or diagnosed and fax the reports to 602-364-1495.
- ⇒ All results are important, even the passed repeat screens. Help us to reduce loss to follow-up/documentation in Arizona, and remember reporting is required by law.

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



Check your records!

Loss to Follow-Up
Bradley Golner, M.D.
Arizona EHDI Chapter Champion

Have you or your office been plagued by LTFU? Or have you helped LTFU? What is LTFU?! LTFU, or Lost To Follow-Up, is really what is plaguing EHDI. LTFU represents all those newborns that did not pass a hearing screen but never had any follow up testing or diagnostic evaluations. This has become EHDI's #1 problem. EHDI's goal is to identify all newborns with hearing loss or children who develop late onset hearing loss. This is not only an Arizona problem but also a national problem. When an infant is not accounted for after referring on a hearing screen, the potential for disaster ensues. If these babies are born with hearing loss...but do not receive any diagnostic evaluations by 3 months of age, or any intervention by 6 months of age, the window of opportunity for the brain to learn and develop language and speech begins to close and expressive language will never fully develop. So how do we reduce LTFU? The medical home needs to follow-up on all patients who have not passed their newborn hearing screen. This involves ensuring adequate referrals for diagnostic testing and/or Early Intervention services. This also involves emphasizing the importance to parents to follow through on these referrals in a timely manner. Finally, the Medical Home needs to report any hearing screening results to the state EHDI program. Everyone needs to improve our lost to follow-up. Don't let LTFU plague you!



A Message from the High Risk Coordinator
Fran Altmaier, BSW

Beginnings and endings..... This is my last update as the High Risk Coordinator. Over the past 2 ½ years as High Risk Coordinator, I have been able to make a substantial impact on reducing LTFU for babies who spend >5 days in the NICU. I have been able to identify and provide close follow up to babies at high risk for hearing loss who might have been late identified or missed. One difficulty that still remains is related to those babies that are lost to documentation.

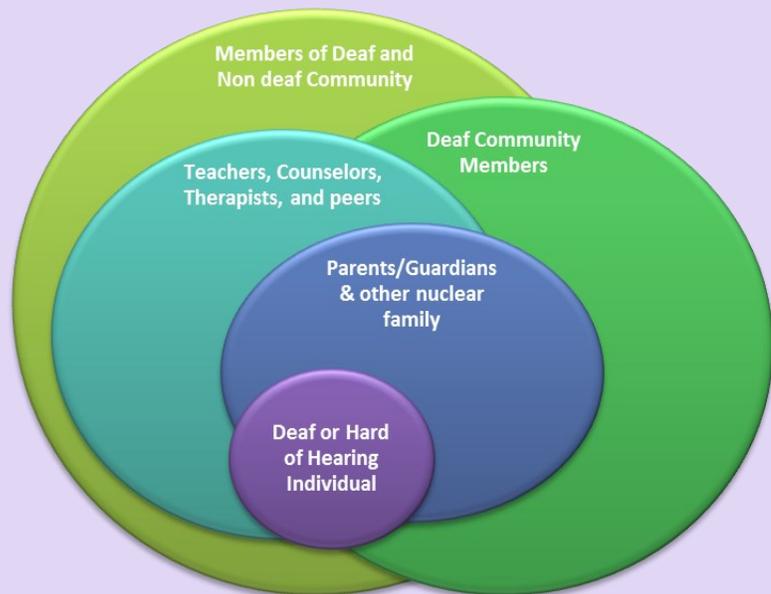
The newborn screening follow up team and I spend countless hours hunting down results for babies that were not reported. Recent CQI work has started to identify trends related to why results are not reported to ADHS. One tendency seems to be related to lack of clarity on who to report results for. Statute requires that results for any baby who receives a screening or diagnostic test under the age of 2 years old must be reported to the Office of Newborn Screening within 7 days. So, as a new beginning, I am asking that anyone who provides a hearing screening or diagnostic test on a baby who is less than 2 years old, report the result to ADHS. I challenge you to find a way to make it a part of your everyday work. If you are not sure who or when to report, please contact us and we will help with identifying strategies to make it as easy of a process as possible.

As I end my role as High Risk Coordinator, I begin my new role as Case Management Coordinator. I will still be here in the Office of Newborn Screening, providing oversight to the whole follow up program for both hearing and bloodspot. Together, we can continue to reduce our rate of those babies who are lost to follow up and lost to documentation.



Did You Know?

Individuals born with a different hearing level or those that have experienced a change in hearing status later may choose to identify as “Deaf.” Noted linguist and scholar, James Gee of Arizona State University, calls this a sort of *affinity identity* (2000); whereas a person feels simpatico or closeness with others based on shared experiences or practices. Those individuals that identify as Deaf are often also members of a larger Deaf Community. In this community, there are a myriad of people, with varied levels of hearing that may share a commonality of these experiences – as deaf individuals themselves, or as non-deaf family members and/or close friends. This community can also be likened to the *ecological framework* that surrounds individuals with differing hearing status’ (Bronfenbrenner, 2009). This foundational surrounding could provide layers of support for the individual. At times, some of the concentric circles will change proximity to the center as the deaf or hard of hearing individual develops and matures.



References:

- Bronfenbrenner, U. (2009). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Gee, J. P. (2000). Identity as an analytic lens for research in education. *Review of research in education*, 25, 99-125.



Jennifer Hensley & Beca Bailey

Arizona Commission for the Deaf and the Hard of Hearing
for the deaf and the hard of hearing

Jennifer Hensley is the Family & Youth Resource Specialist for the Arizona Commission for the Deaf and the Hard of Hearing, providing families of Arizona support and resources focusing on those with deaf and/or hard of hearing children, and also parents whom are deaf and/or hard of hearing seeking familial support. In addition, Jennifer is a doctoral candidate at the University of Georgia in Early Childhood Education, specifically studying deaf education. She is personally familiar with the families she supports, as a hearing child of deaf parents.

Beca Bailey has been a Deaf Specialist with the agency since 2004. She provides information and referral, resources, outreach, education and training to Arizonans. A Deaf person herself, she understands the challenges the Deaf face on an everyday basis and continues to be an advocate for equal access for the Deaf community for the past 18 years. Beca graduated from Rochester Institute of Technology with a B.S. in Social Work in 1996 and holds an Arizona General Deaf Interpreter license.



Important Tips

Randi Winston, AuD, CCC-A, Consulting Audiologist



Screener Tech Tip: *Don't wake a sleeping baby!*

How often do you attempt to prepare a soundly sleeping baby for an ABR screen, just to disturb them, wake them up and cause them to wiggle and cry? Running the screen while the baby is sleeping is the key to an accurate measure, will save you test time, eliminate the need to rescreen and minimize your false positive rate.

Here is a tip that may help.....

Conduct the skin prep and electrode placement earlier; for example if baby is in the room with Mom and feeding, get the baby ready and then leave to continue other tasks. Ask Mom to call you or check back in to see if baby is sleeping. Once asleep, all you have to do is hook up the electrodes and run the test. If you are using ear muffins or couplers to deliver the sound, you can try to place those earlier too. If you are using a probe, attempt to place it in the ear with the gentlest touch. Very often this can be accomplished without disturbing the baby and lead to a happy baby, happy screener and happy Mom!



HiTrack Tip: *Note the significance of NOTES!*

For a newborn that has a screening status other than a passing result, the timeliness of follow up is of the essence. Families have numerous circumstances that can interfere and delay the process of early identification. Unfortunately, more often than not, the follow-up team at the Arizona Department of Health Services is faced with the challenge of trying to piece together the puzzle of identifying the whereabouts of a family, who their PCP is and where they are in the identification process. Information provided by the screening site in the notes section of HiTrack can provide the missing piece of the puzzle and make the difference in the success of follow-up efforts. PLEASE take the time to add a note with any information you have.

To add a note in HiTrack:

1. Make sure the record you want to add a note to is selected or highlighted on the Baby List.
2. Click on "Demographics" from the yellow card. This baby's Demographics screen is shown.
3. Click on the "Notes" section. The baby's note history is shown. If no notes are present, a "New Entry" field is selected and the cursor is set for you to type.
4. Type in your note. Your name, the date and time are automatically stored with each note entry.
5. Click the "Save" button at the bottom of the screen.

Demographics for Test, Baby Girl

Medical ID: 55556677
Birth Date: 6/14/2011
Action: Need Inpatient Screening
Status: Deceased

Record Overview
Tracking Options
Demographics
Screening
Risk Indicators
Diagnostics
Hearing Disposition
Amplification
EI Services
Letters
Transfer
Recommended Actions: Manage

Messages:
Milestones: -/-
This baby is marked as deceased.

Demographics for Test, Baby Girl

Demographics | Contacts | Notes

Baby

Medical ID: 55556677 Birth Date: 6/14/2011 Birth Facility: ARROWHEAD COMMUNITY
Name-Last: Test Time: 00:00 Nursery: [blank]
First: Baby Girl Order: Single Location: [blank]
Middle: [blank] Weight: [blank] g Gender: -Blank-
Insurance: [blank] Gest. Age: [blank] Physician: [blank]
Race: [blank] ICU Days: [blank] Att. ID: [blank]
Deceased: 6/14/2011 Notes: [Click here to enter notes]

Primary Contact

Name-Last: TEST Address: [blank] Phone: [blank]
First: [blank] Ph 2: [blank]
Middle: [blank] Email: [blank]
Medical ID: [blank] City/State/Zip: [blank] County: [blank]
Birth Mother: Birth Date: [blank] Language: [blank]
Title/Suffix: [blank] Race: [blank] Gender: -Blank-
Education: [blank] Ethnicity: [blank] Deceased:

Change Date: 6/14/2011 11:38:46 AM

Save



Lisa Villarroel, M.D., MPH

Dr. Lisa Villarroel serves as the fulltime Medical Director for the Bureau of Epidemiology and Disease Control and part-time for the Office of Newborn Screening for ADHS. Originally from Indiana, she received her Bachelor's from Princeton University and went on to achieve her Masters in Public Health in South America and her Doctorate from Northwestern. Dr. Villarroel is a believer in newborn screening and even spends her spare time thinking about public health! When she is not sharing her knowledge and expertise with us, she is playing the role of mom to her two darling boys.

Kostas Petritis, Ph.D.

Dr. Petritis is a bioanalytical chemist by training. He has more than 40 peer-reviewed publications related to newborn screening, bioanalytical method development, proteomics, biomarker development, automation and bioinformatics. In addition, he has more than 100 conference communications and four patents. He was the first to demonstrate that amino acids can be analyzed by electrospray mass spectrometry without the need of derivatization and that the approach can be applied in newborn screening.



Fran Altmaier, BSW

Fran Altmaier was recently promoted to be the new Case Management Coordinator providing oversight to the Newborn Screening Follow up team, for both hearing and bloodspot. Fran brings more than 20 years of experience in pediatric Social Work specifically with babies 0-3 years old. She has an extensive background in the medical and developmental needs of infants and toddler as well as a high level of knowledge related to early intervention (IDEA Part C and Part B). She has spent the past 2 ½ years as the High Risk Coordinator for hearing follow up. She is looking forward to her new role and the challenges it will bring. In her free time, Fran enjoys playing cheerleader and chauffer to her 4 kids and their busy sports schedules.



Media and Events

March Of Dimes Honors Arizona With First-Ever Newborn Screening Award



September 18, 2014- The March of Dimes today announced a new award, the Newborn Screening Quality Award, and gave it to the Arizona Department of Health Services for outstanding changes in the newborn screening process. The March of Dimes cited the Department's ability to turn around such a critical program in months and creating a transparent system that other states can copy as the reasons for the new award.

"Our staff and hospitals across the state embraced the issue knowing that the sooner we could test the newborn blood spots for life-changing or -ending disease, the better it would be for the babies," said Will Humble, director of the Arizona Department of Health Services. "This intense group effort to make sure the babies' tests quickly made it to lab shows what can happen when you identify a situation, set goals and work together to overcome obstacles." Blood spots are taken from babies within the first few hours of birth and sent to the Arizona Public Health Laboratory for evaluation. At the lab, 28 tests check for diseases that can alert physicians to digestive or developmental issues; quick intervention for babies with those diseases will make a significant difference in their lives.

In December 2013, 67 percent of the samples were making it to the state laboratory within three days; others were taking more than five. By July 2014, 98 percent were checked into the lab within three days and none took five days. The department's transit time task force worked with hospitals to identify issues including the courier service, when the state lab was open and clear processes in hospitals to make sure everyone from the delivery room to the mailroom knew the importance of the tests. The monthly reports are available online for anyone to see.

The March of Dimes established the new awards in honor of Dr. Robert Guthrie, known as "the father of newborn screening" for developing the first mass screening test for babies 51 years ago. The awards recognize leadership in establishing culture of safety as a way to avoid those deadly delays in states' newborn screening process.



For more information on the March of Dimes, please contact [Elizabeth Lynch](#), (914) 997-4286. Locally, contact [Terri Spitz](#), (602) 321-7989.



For more media coverage on this topic please visit the news and publications section on www.AZNewborn.com

Media and Events

Arizona Hospitals honored for excellence in Newborn Screening Transit Time Project

On August, 7th, a ceremony and celebration was held for the Arizona hospitals that met our statewide goal of getting 95% of blood spot samples to the State Lab within 72 hours. The hospitals were given a special plaque to display highlighting their accomplishments.



State Lab Bureau Chief Victor Waddell and Director Will Humble address the hospital representatives



Attendees eagerly await the start of the ceremony



EZ Messenger Courier Service is awarded for its efforts in reducing transit time of bloodspot samples to the state lab



Members of the Department of Health Services with the Transit Time Task Force

Media and Events

The 9th Annual EFAz Seminar was held on October 10, 2014 at the Tempe Center for the Arts. Over 90 audiologists, audiology students, early intervention staff and educators from around the state attended the informative and enjoyable seminar. Presentations by Dr. Hunter, Dr. Jacob and Allen Gjersvig are available on the EFAz website. The next seminar will be held in 2016.



**Mark Your Calendars!
Upcoming Events**



The 2015 EHDI Annual Meeting will be held March 8-10 in Louisville, KY
www.ehdimeeting.org



**AZAAP SPEAK UP FOR KIDS
Holiday Soirée**
Monday, December 8, 2014
6:15 p.m. to 9:00 p.m.
ASU Karsten Golf Course
Trophy Room Restaurant
www.azaap.org



Hand and Voices Family Picnic Potluck

Sunday December 7, 2014, 12p-3p
Reid Park, 900 S. Randolph Way Tucson, AZ 85716
For more information contact: executivedirector@azhv.org

Save the Date!

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>
- Click the box next to the topics you would like to receive information on from ADHS
- Be sure to chose *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



www.earfoundationaz.webs.com



www.babysfirsttest.org



www.marchofdimes.org



www.raisingpecialkids.org



www.msgrcc.org/



HANDS & VOICES

www.gbys.azhv.org



THE AMERICAN ACADEMY OF PEDIATRICS ARIZONA CHAPTER

www.azaap.org



www.desert-voices.org



www.azperinatal.org

Arizona Early Intervention Program

www.azdes.gov/azeip

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