May 9, 2018

Presented To

Advisory Committee on Heritable Disorders in Newborns and Children

Sondi Aponte | Education/Outreach Manager
Office of Newborn Screening

Sondi.aponte@azdhs.gov

“The entire NBS system process, from sample collection through transit, testing and reporting, needs to be time-effective to meet the recommendations. NBS systems can use these goals for timeliness to achieve the best outcomes for affected newborns.” ACHDNC

www.aznewborn.com
A Bit About Our State:

Our Population is Widely Dispersed

- 6th largest land/water
- 6.5 million population
- 15 counties
- 47 birth hospitals
  - 43 send samples to lab
- ~85,000 births
- One state laboratory
We Didn’t Realize The Magnitude of the Problem

“AIZONIA has one of the worst track records in the country, with 17% of all newborn screening samples arriving at the state lab five or more days after collection in 2012.”
A Plan was Established

**WHO**

- Director set as agency priority
- Collaborated with Licensing Division; sent letters
- Announced a statewide goal
- Developed an intra-agency Transit Time taskforce
- Assigned executive sponsorship

**WHY**

“NBS specimens should be received at the laboratory as soon as possible; *ideally* within 24 hours of collection.”

ACHDNC
Started with Hospitals; Identified Problems

1. Hospitals *batched* samples
2. Lack of *awareness* of urgency
3. *Courier limitations*—only ran Mon-Fri, some didn’t realize it was free
4. *Restricted lab operating hours* (Mon-Fri), no holidays
5. *Lack of knowledge* about legal requirements
6. *High turnover*; inconsistent/deficient training at sites
7. Hospital *QA/QI* systems were often inadequate
8. *Performance reports* were not routinely provided
Arizona Aimed High

“Within six months (by July 1, 2014), 95% of newborn screening bloodspots (initial screens) will be received at the Arizona Public Health Laboratory within three days of collection.” Director, Will Humble

Applied the Methods
- Identified a need or issue
- Defined the current situation
- Analyzed the problem
- Developed action plan
- Made predictions

and Reached that Goal

March Of Dimes Honors Arizona With First-Ever Newborn Screening Award
Arizona Health Director Honored for Reforms to Avoid Deadly Delays
CHANDLER, ARIZONA — Thursday, September 18, 2014
Maintained the Original Goal and Set a NEW one: 98% of Samples will be Received within 3 Days

The Science of Improvement: Spread Change

- Lab Matters article
- APHL poster and presentation
- Regional collaborative webinars
- ASTHO article
- Participated in CoIIN Training
- Applied for and received **NewSTEPS 360** grant

“All NBS tests should be completed within *seven days of life* with results reported to the healthcare provider as soon as possible.” ACHDNC
NewSTEPs 360 Partnership

Year 3 Statement of Work

Based on quality indicator (QI) data reported to the NewSTEPs repository for March, 2017 on QI5c, *Time from specimen receipt to reporting out results, 60% of normal and out-of-range results took ≥7 days to be reported out in AZ.* Data entry and verification delays are the greatest contributing factor to this deficit and therefore directly impact timeliness. By reducing these delays our goal is to improve indicators QI5c & d—*Time from birth to reporting*—of the most significant delays (>7 days) for first, subsequent and second screens by August, 2018 by 50%.

“Presumptive positive results for all other conditions should be communicated to the newborn’s healthcare provider as soon as possible but no later than seven days of life.” ACHDNC
This resource was developed by funding from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U22MC24078.

AzNewborn.com
Arizona: Variance in the time to report time critical results depend heavily on lab processes. Change of methodology in the timing of data verification resulted in a significant increase to 70% of time critical results reported within 5 days of birth and 90% within 2 days of specimen receipt.

Lesson #1

Achieving timeliness goals is directly tied to resource limitations and therefore requires innovation.
Overall Lessons Learned

- **Keep babies at the forefront**—talk to families and share their stories
- **Involve SME from each division of NBS in process improvement**
  Lab, Follow-up, QI, Education, & Demographics teams each contribute to success
- **Look for internal opportunities to improve timeliness**—
  Hemoglobinopathy testing and Demographic sight verification made a BIG difference
- **Find Quick Wins to stay motivated and Move the Needle**
- **Utilize partner resources** and learn from other states
  - NewSTEPS 360 (APHL)
  - Baby’s First Test
  - CO School of Public Health
You get what you inspect, not what you expect.
American Management Association

“The entire NBS system process, from sample collection through transit, testing and reporting, needs to be time-effective to meet the recommendations. NBS systems can use these goals for timeliness to achieve the best outcomes for affected newborns.”

ACHDNC
Questions?

THANK YOU

Sondi Aponte| Education & Quality Improvement Manager
Sondi.apontel@azdhs.gov | 602-364-1642
Azhealth.gov
@azdhs
facebook.com/azdhs

This resource was developed by funding from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U22MC24078.